



Horridge, K, Harvey, C, McGarry, Kenneth, Williams, J, Whitlingum, G, Busk, M, Fox, S and Rahman, F (2016) A proposed disability complexity scale to describe the multi-facted needs of disabled children and young people. In: International Conference on Cerebal Palsy and other childhood-onset disabilities, 1 - 4 Jun 2016, Stockholm, Sweden.

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## Abstract book

### **International Conference on Cerebral Palsy and other Childhood-onset Disabilities Stockholm 1–4 June 2016**

Bookmarks can be used to navigate between the session types.

The abstracts are organized in session types, and within each group in alphabetical order of the first author's last name.

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## Keynotes

## **Human rights of children with disability: reality or fantasy?**

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Human rights are those rights that every individual, including children with disability, should enjoy – simply because he/she is human. Accessible basic education is an example of such a right, as are access to health care, having an effective, affordable communication system available that would allow for freedom of expression and access to information as well as such things as food, shelter, a non-threatening physical environment and freedom from abuse.

However, human rights should be seen as much more than only freedom, but also as basic requirements for the maintenance of human dignity and the opportunity to thrive.

The United Nations Convention on the Rights of Persons with Disability (CRPD) states that persons with disability should have “full enjoyment of all human rights and fundamental freedoms on an equal basis with others” thereby underscoring the fact that these individuals should be seen as rights-bearers rather than as recipients of pity and charity. The CRPD thus marks the migration of disability issues into the human rights arena. However, human rights concerns tend to be salient for the most vulnerable individuals in a population.

Individuals with disabilities and specifically children in low and middle income countries are arguably the most vulnerable because their impairments make them dependent on others. Furthermore, they often live in dismal poverty at the mercy of charity. Underdeveloped rural areas frequently do not have clean water, electricity, and indoor plumbing, resulting in exclusion, marginalization and serious human rights infringements.

In this presentation, the rights of children with intellectual disability to basic education is explored in relation to various human rights as set out in Article 24 (Education) of the CRPD. Six studies conducted with a large cohort (n=220) children with intellectual disabilities and their primary caregivers regarding these children’s human rights, will be discussed.

## **In Praise of Imperfection**

Richard Ellenson<sup>1</sup>

<sup>1</sup>CEO, Cerebral Palsy Foundation, NEW YORK, United States

We are all here in Sweden to help move forward the world of cerebral palsy. But what is the correct speed at which this should happen? What are the trade-offs implicit in our decisions as we pursue improved outcomes? How do we focus on the needs of a person with disabilities while also addressing the less obvious needs of families, caregivers, and medical professionals, as well as those of casual acquaintances?

Ultimately, while we look towards a better future, how do we best navigate and embrace the world in which we live? As we search for answers that lie ahead, this talk celebrates the imperfection of today.

## **Go Baby Go; creating technology and training that lets a kid act like a kid**

Cole Galloway<sup>1</sup>

<sup>1</sup>Department Of Physical Therapy , University Of Delaware, Newark, USA

Effective community mobility at home, work and play is a human right.

As such social mobility impacts all major aspects of the life of the individual, their family and our broader society. Assistive and Rehabilitative Technologies (A/RTs) for mobility and the therapy, industry and research professionals that promote, manufacture and study them are in serious trouble. In this presentation, we will briefly discuss the causes and consequences of the lack of high impact A/RTs. We will also discuss how this situation is placing neurorehabilitation and rehab research at risk for becoming passe' if not laughable to the larger world outside of academic and medical settings.

Relax! All may not be lost!

We will also discuss specific steps that I believe allow the tech industry, neurorehab and rehab researchers to take over the free world in a way rarely discussed. These steps require individuals, groups and institutions to exhibit honest and sustained self assessment, courage and a mind shift in which professionals, users, caregivers and the broader community collaborate openly towards a radical yet feasible reality: where A/RT is user designed, community based and supports social mobility of every type, by everyone, with everyone, everywhere, all the time. The first generation of such technology is available right now.

## **The Challenge of Manpower Development for Child Development Centres in Major Hospitals in Bangladesh: Making them Sustainable and Replicable**

Naila Z Khan<sup>1</sup>

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**Background:** Rising rates of neurodevelopmental disorders (NDDs) in low income countries requires expertise to address the wide range of disorders from ages 0-18 years presented; and sensitivity of the services towards the family. Child Development Centres (CDCs) established in public, non-profit and private hospitals across Bangladesh are providing quality services to these vulnerable children.

**Objective:** To describe a training module for a multidisciplinary team of professionals, and administrative staff, to competently run CDCs independently.

**Methods:** A three months training is provided to a multidisciplinary team of professionals; and a week-long training to administrative staff. Evidences of replicability of the training and sustainability of quality services will be presented.

**Results:** A structured training format will be described which emphasizes evidence-based best clinical practices, teamwork, and an empathetic parent-professional partnership. Evidence of the success of the 22 CDCs established till date in government, autonomous and private hospitals will be presented.

**Conclusion:** Bangladesh has taken the challenge of expert manpower development to provide quality services to children with a range of NDDs in the health sector. The service is being considered exemplary for the region and beyond.



## **Engagement of Children, Youth, and Families in Therapy**

Gillian King<sup>1</sup>

<sup>1</sup>Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto, Canada

The engagement of children, youth, and their family members in pediatric rehabilitation interventions has long been considered to be critical to the success of these therapies. A fully engaged client is actively invested and involved in the intervention, receptive to what is happening, shares thoughts and experiences, and participates in activities. This talk presents initial findings from an international program of research on client engagement, which is exploring engagement using both qualitative and quantitative methods. In this research program, engagement is considered to be both a process and a changing state influenced by client, service provider, and intervention characteristics. The talk will consider the nature of engagement from the perspectives of parents of younger children, youth themselves, and service providers, and will also identify strategies to foster engagement. The team is also developing and validating a series of measures of engagement, which will allow evaluation of client, service provider, and intervention characteristics that optimize engagement, and permit examination of the predictive power of engagement on outcomes. This practice-based research will inform and potentially change service providers' perspectives and practice with respect to understanding, measuring, and optimizing engagement in rehabilitation-related interventions.

## **Working memory training as a clinical tool to improve WM capacity and attention in everyday life**

Torkel Klingberg<sup>1</sup>

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Working memory (WM) is the ability to temporary store and manipulate information. The neural mechanisms of visuo-spatial WM are to a large extent identical to those of controlled, or top-down, attention. The similarities between WM and attention is also evident from behavioral studies. In particular are the inattentive symptoms of ADHD associated with deficits in WM capacity. It is also these inattentive symptoms and WM deficits that are the strongest predictors of academic failure in children and adolescents with ADHD.

It was previously assumed that WM capacity was a fixed characteristic of the individual. However, research first carried out by Klingberg and collaborators have shown that intensive training on WM tasks over several weeks can enhance performance also on non-trained WM tasks. This training is also associated with improvement in attention as measured by standard neuropsychological tasks, but also ecologically more relevant tasks, such as tests of the ability to remember and carry out instructions. This suggests that improved WM capacity is in itself relevant to functions in daily life.

The neural basis of training is presumably related to the plasticity of prefrontal and parietal cortex and the basal ganglia. Studies with positron emission tomography, as well as genetic studies, has implicated dopaminergic transmission as a key factor in this plasticity.

Improvement in attention has been measured with neuropsychological tests, as well as questionnaires of attention in everyday life, such as ratings of inattention according to the diagnostic criteria of DSM, Conner's rating scales, The Cognitive Failure Questionnaire, and direct observer ratings. The studies, conducted by several independent research groups, include typically developing children and adults, children with ADHD, children born prematurely and children with cognitive deficits as a results of cancer treatment. There are now five, randomized, controlled trials showing improvement of attention after working memory training. A recent meta-analysis of 12 studies using the Cogmed WM training method showed that, across different population, inattentive symptoms decrease with an effect size of around 0.4, although effects differ among different child populations.

WM training is an experimental paradigm to study cognitive plasticity, but is also clinically useful in order to improve WM and attention in everyday life of individuals with impaired WM and inattention.

## **The genomic landscape of cerebral palsy**

Michael C Kruer<sup>1</sup>

<sup>1</sup>Phoenix Children's Hospital, Barrow Neurological Institute, Phoenix, USA

Although prematurity and hypoxic-ischemic injury are well-recognized contributors to the pathogenesis of cerebral palsy (CP), as many as 1/3 of children may lack traditional risk factors. For many of these children, a genetic basis to their condition is suspected. Recent findings have implicated copy number variants and mutations in single genes in a subset of children with CP. Interestingly, most identified "CP genes" do not mediate inflammation or thrombosis. Instead, several genes map to intersecting pathways controlling neurodevelopment and neuronal connectivity. Analogous to other neurodevelopmental disorders such as autism and intellectual disability, the genomic architecture of CP is likely to be highly complex. Although we are likely just 'scratching the surface of the iceberg,' new genetic insights are anticipated to serve as a unique window into CP neurobiology and suggest new targets for intervention.

## **Deep Brain Stimulation Neuromodulation in Childhood Dystonias**

Jean-Pierre Sao Ming Lin<sup>1</sup>

<sup>1</sup>Complex Motor Disorders Service Children's Neurosciences, Gu's And St Thomas' NHS Foundation Trust, London, UK

Children living with dystonia face an uncomfortable future of disability, deformity & a reduced capacity for activity & participation. Medication is often poorly tolerated or ineffective & conventional orthotic, physical therapy or orthopaedic interventions have a limited capacity to provide comfort or promote function. Dystonia can be considered as a pathological re-emergence of the co-contracting postures & movements of early childhood due to an imbalance between cerebral plasticity, crucial to learning new skills, & motor surround inhibition, which allows us to perfect movements through repetition & practice. In dystonia there is an excess 'plasticity' but not enough 'surround inhibition'. Typically developing children & healthy elderly people commonly 'over-recruit' when performing actions compared to young adults : they exhibit a lack of surround inhibition, leading to overflow co-contraction, so common in children with cerebral palsy. Over-recruitment, overflow & co-contraction present at rest & exacerbated by action, are hallmarks of dystonia. The dystonic child is unable to progress from 'goal-directed' a 'habitual' movement patterns, which interferes with motor learning. In dystonia & parkinsonism, slow oscillations within the basal ganglia appear to underpin the movement disorder. Deep brain stimulation (DBS) neuromodulation restores the balance between cerebral plasticity & surround inhibition by promoting higher-frequency basal-ganglia oscillations with dramatic results in monogenetic isolated dystonias. Effects of DBS are more modest in secondary dystonias in childhood, of which the cerebral palsies are the largest group. Improved case stratification based on diagnosis, age at onset, proportion of life lived with dystonia, dystonia severity, existing motor abilities or skill-set & goal-setting are essential to achieving an appropriate personalised prognosis for DBS outcome in childhood to help manage expectations.

## **Harnessing experience and neuronal activity to promote plasticity in the developing corticospinal system after unilateral brain injury**

John H Martin<sup>1</sup>

<sup>1</sup>Department Of Physiology, Pharmacology, And Neuroscience, City University Of New York School Of Medicine At City College, New York, USA

The corticospinal (CS) system is the principal motor system for skilled movements. Damage of the CS system during development produces a loss of motor function, including weakness and paresis, and incoordination. Injury also leads to a gain of aberrant and debilitating functions that are key motor impairments in cerebral palsy (CP), including hyperreflexia and spasticity. Whereas weakness is due primarily to the loss of the direct projections of the corticospinal tract (CST) from motor cortex (M1) to spinal cord motor circuits, the other impairments are less well understood and likely reflect many additional factors. Our research uses animal models to examine how altering the function of the developing CS system impacts not only its own development but the development of key spinal motor networks and other components of the motor system.

I will discuss how unilateral M1 injury impacts development of the CST originating from both the intact and injured hemispheres. In addition, I will examine how the same kind of M1 injury can also lead to aberrant development of muscle sensory fiber connections in the spinal cord and impaired development of spinal interneurons. Finally, I will discuss how postnatal M1 injury produces long-lasting changes in the function of another motor control pathway, the rubrospinal system.

Our animal models show that these myriad impairments in motor system development can be explained by a neural activity-dependent mechanism and that the same mechanism that can disrupt development when it goes awry, can be harnessed through behavioral manipulation and M1 electrical stimulation to help restore CST connections and movement control in an animal model. Design of experiments correlating neural and behavioral changes may inform the clinical decision making process of which connections to promote and which connections to impede with therapy after injury

## **Using a Framework of Priorities & Goals to Define Outcomes that Matter: A Tale of Two Measures**

Unni G. Narayanan<sup>1</sup>

<sup>1</sup>Departments Of Surgery & Child Health Evaluative Sciences, The Hospital For Sick Children, University Of Toronto, Toronto, Canada

Cerebral Palsy (CP) is the most common cause of chronic physical disability in children. The impact is lifelong and affects not only the child with CP, but also their parents or carers, and the family at large. The life experiences of children with CP, and of their parents who care for them, influence their priorities (concerns, needs, expectations) and goals. These children are subjected to numerous kinds of interventions to address these goals. The effectiveness of these interventions (outcomes) must be evaluated based on whether they have achieved the goals for which they were intended. Outcome measures are most meaningful when they reflect the priorities and goals of the recipients of these interventions. Understanding patient priorities is essential for the development of patient/parent-reported outcome measures to make credible judgments about the value of interventions.

This talk will present two such outcome measures, the CPCHILD<sup>®</sup> and the GOAL<sup>®</sup> questionnaires, that used a framework of patient priorities for their development and validation; and discuss their utility for clinical decision making as well as their role as primary outcomes measures in clinical trials and cohort studies for this population.

## Early Intervention 2.0

Iona Novak<sup>1</sup>

<sup>1</sup>Cerebral Palsy Alliance, University Of Sydney, Sydney, Australia

“What it is to be a child?...It is to be so little that the elves can reach to whisper in your ear; it is to turn pumpkins into coaches, and mice into horses, lowliness into loftiness, and nothing into everything.” (Francis Thompson Shelley). Early intervention aims to help enable children develop the skills to participate in the activities of their daily and magical lives – whether that is to sprinkle fairy dust with friends, ride a skateboard independently, or eat dinner with family. Despite universal beliefs about the benefits of early intervention for children with cerebral palsy, systematic reviews suggest that traditional intervention for infants is limited. Early Intervention 1.0 is limited because: (1) late diagnosis is the norm, which means that intervention is late not early, limiting neuroplasticity after brain injury; and (2) when intervention eventually starts it involves traditional passive approaches, which have been proven ineffective. Current best available evidence from pre-clinical studies, systematic reviews and randomised controlled trials will be critically appraised. For example, neuroscience pre-clinical data strongly supports early training as an intervention for improving brain structure reorganization and functional outcomes after early brain damage. Based upon best available evidence, an analysis of current intervention trends and future directions for Early Intervention 2.0 will also be provided. The aim is to assist professionals make evidence-informed decisions, which help children, fulfil their dreams, and turn “nothing into everything”.

## **ADHD and Stimulant Drug Treatments: Moral Experiences of Children**

Ilina Singh<sup>1</sup>

<sup>1</sup>Psychiatry And Philosophy, University Of Oxford, Oxford, United Kingdom

Does stimulant drug treatment turn young people into docile zombies? Does Ritalin encourage children to 'blame the brain' rather than to take responsibility for their behaviour? This talk presents findings from the Wellcome Trust-funded VOICES study (Voices on Identity, Childhood, Ethics & Stimulants), which involved interviews with over 150 young people in the United States and the United Kingdom. Findings from the study suggest that many children view stimulant drug treatment as promoting, rather than hindering moral functioning in key areas. However, significant concerns were articulated by children around access and experiences of clinical services, awareness and availability of non-drug treatments for ADHD, and peer dynamics. The talk will provide insights on how benefits of ADHD diagnosis and stimulant drug treatment can be maximised, and how potential harms can be monitored and addressed through child-centred clinical practice.



## **Risk and protective factors in the etiology of ASD; a missed translational opportunity**

Peter Szatmari<sup>1</sup>

<sup>1</sup>,, University Of Toronto, Toronto, Canada

The objective of this presentation is to highlight examples of the interaction between risk and protective factors in the etiology of autism spectrum disorder (ASD). There is unfortunately little discussion in the literature on protective factors but such factors do play a role in explaining sex differences, the reduced penetrance and variable expression of risk genes, and the prevalence of “resilient” outcomes in follow up studies. A focus in the research community on risk as opposed to protective factors has limited the translational opportunities that might accrue from a study of basic mechanisms. Uncovering the nature of these protective factors might lead to new ‘strengths-based’ interventions.

## **Achieving "disruptive innovation" for cerebral palsy**

Patrice (Tamar) L. Weiss<sup>1</sup>

<sup>1</sup>Occupational Therapy, University Of Haifa, Haifa, Israel

“Disruptive innovation” leads to technologies that invigorate an existing paradigm in a way that completely shifts current consensus and practice. There are many examples of disruptive innovations that have changed society and individual behavior including steam engines, motor vehicles, airplanes, computers and, more recently, the Internet, mobile phones and social media. Disruptive innovations in rehabilitation have been more elusive to achieve with many advances (e.g., robotics, virtual reality and tablets) not yet reaching Gladwell’s “tipping point” wherein a series of small changes or incidents becomes significant enough to cause a larger, more important transformation of practice. This presentation will explore the factors that promote and impede disruptive innovation for assessment and intervention for children with cerebral palsy.

## **Legislation supporting persons with disability; a Swedish experience.**

Bengt Westerberg<sup>1</sup>

<sup>1</sup> -, -, Stockholm, Sweden

In 1993 Sweden carried through the biggest reform ever for persons with disabilities. A new law – The Act Concerning Support and Service for Certain Persons with Functional Impairments – was decided in order to support persons with major and permanent physical or mental impairments which cause considerable difficulties in daily life and, consequently, imply extensive needs for support and service.

The goal of the Act is as follows: "The activities pursuant to this Act shall promote equality in living conditions and full participation in community life for those (with significant and permanent impairments). The objective is to make it possible for the individuals in question to live as others do. ... The support concerned shall be based on respect for the individual's right to self-determination and privacy."

The law preceded the UN Convention on Rights of Persons with Disabilities, but is still to a great extent in accordance with the Convention.

The most important proposal in the new Act was the right to personal assistance. "Personal" in this context stands for individualization and empowerment. The beneficiary shall have a great influence on the services provided to him or her. It also means that there is not a universal solution, not a one-size-fits-all model designed by others, but an individual and custom-made solution made by the user for his or her unique needs, circumstances and priorities.

Now Sweden has 20 years of experience of the law. It has been very well received by the persons concerned and their relatives. Many of those who get personal assistance, in all about 20 000 people, claim that it is extremely important for their quality of life. But the reform has been more expensive than expected and the Swedish Government has recently announced that it wants a tightening of the application.

I will account for different perspectives on the personal assistance and for certain lessons that can be learned from the Swedish experience of it.



## **Mini-Symposium – Panel discussions - Controversies**

## **Finding The Way: Overcoming Sociocultural Barriers That Impact Well Being of Children With Disabilities.**

Robert W Armstrong<sup>1</sup>, Juan Bornman<sup>2</sup>, Angelina Kakooza-Mwesige<sup>3</sup> and Naila Z Khan<sup>4</sup>

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The World Health Organization estimates that approximately 15% of the world's population lives with some form of disability. The world over, children with disabilities face an uphill battle to achieve the potential they are born with. Cultural beliefs and norms and the presence of limited resources drives a level of neglect and sense of helplessness that leaves families struggling to simply cope. By any measure there is a long and challenging road ahead for children with disabilities if they are to achieve a valued and respected position in the societies within which they live. The two Conventions, that virtually all governments have signed onto (Rights of the Child and Rights of Persons with Disabilities), are powerful advocacy tools in the hands of parent and professional groups that can impact national policies and community practices. For example, policies in Bangladesh are becoming operational through national disability forums, strong parent advocacy groups, political commitment and through scaling up government services. Strategies for working with parents of children with disabilities, governments, nongovernmental organizations, professionals and building community engagement can reduce cultural biases and taboos. At the same time evidence-based, community-adapted interventions developed at the grass roots offer therapeutic options that can be implemented in low-resource settings. There is need to prioritize the research areas that builds the knowledge base on sociocultural barriers that impact children with atypical pathways of development and the application of this knowledge to services and interventions that improve opportunity. Increased focus on south-south partnerships can improve transfer of skills and technology and promote increased sharing of experiences that capture both achievements and challenges. This workshop will identify the key sociocultural, government, and donor agency barriers that impede progress and propose strategies for intervention drawing on experience from collaborative international partnerships in differing cultural settings.

## **Translating local research into global recommendations and back to local context**

Ilona SK Autti-Rämö<sup>1</sup> and Iona Novak<sup>2</sup>

<sup>1</sup>Health Department, The Social Insurance Institution, Helsinki, Finland

<sup>2</sup>Research Institute Cerebral Palsy Alliance School Of Medicine , University Of Notre Dame , Frenchs Forest , Australia

**BACKGROUND:** Not all children and adults with cerebral palsy receive evidence based care. Clinical guidelines are an effective tool for translating research into clinical practice; however, international guidelines for cerebral palsy do not yet exist. In 2014, agreement was reached between the European Academy of Childhood Disabilities (EACD), the American Academy of Cerebral Palsy and Developmental Medicine (AACPD), and the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) to collaborate to develop international guidelines for cerebral palsy. The project will be a joint partnership under the banner of the newly formed International Alliance.

**AIM:** The aim of this mini-symposium is to describe the pathway that guideline writers use to translate ideas from original research into systematic reviews and further into evidence-based recommendations that are applicable both globally and locally. The possible obstacles on the way and how to facilitate the process will be discussed.

**METHOD:** Research into the effectiveness of clinical guidelines for bridging research-practice gaps suggests that they must be clear and unambiguous, based on systematic reviews, and state clear recommendations for clinical practice including: who benefits; how to do it; when to do it; and how much of it to do. Recommendations must also include a continuum of options to cater for different implementation contexts. The AGREE II tool delineates all of the necessary components for good guideline development and features that authors ought to consider so that the guideline is likely to be used. In order to reach effectiveness in real life additional knowledge translation requirements are needed: knowledge, training and benchmarking.

**CONCLUSION:** The mini symposium covers each step from identifying the need for evidence to implementing evidence based guidelines in local context.

**The Visual Function Classification System: a new classification system for visual function in children with Cerebral Palsy**

Giovanni Baranello<sup>1</sup>, Peter Rosenbaum<sup>2</sup>, Belinda Deramore Denver<sup>3</sup> and Leena Haataja<sup>4</sup>

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It is reported that about half of the children with cerebral palsy (CP) have some degree of visual impairment, which can be either secondary to the brain damage itself (Central Visual Impairment), or associated to the involvement of peripheral visual structures. This is also clearly stated by the new definition of CP, which suggested that visual-perceptual disorders, together with the motor disorder, are an integral part of the clinical picture of CP. The WHO International Classification of Functioning, Disability and Health (ICF) highlighted the importance of evaluating the functional consequences of all health states. Over the past 20 years the need for classifying how the disorder underlying CP affects activity and participation has become obvious, and new classification systems for gross motor, manipulative and communicative functions have been developed. To date, no similar classification system for visual function in children with CP is available. In the last three years a task force of professionals and experts in the field of CP and visual disorders has been constituted, to develop and validate, with the contribution of parents and patients with CP, a new classification system for visual function in children with CP: the Visual Function Classification System (VFCS). The purposes of the present mini-symposium are: i) to describe the conceptual framework of classification systems in children with CP; ii) to present a systematic review on measurements of functional visual ability in children with CP; iii) to present the VFCS, including the procedures of its development and validation; and iv) to discuss the usefulness and applicability of the VFCS in clinical and research settings.

## **Cerebral palsy – the invisible aspects of the disability**

Louise Boettcher<sup>1</sup>, Seth Warschausky<sup>2</sup>, Kristine Stadskleiv<sup>3</sup>, Jacqueline Kaufman<sup>2</sup>, Silja Pirilä<sup>4</sup>, Tamar Silberg<sup>5</sup>, Jaana Ahonniska-Assa<sup>6</sup> and Elina Hakkarainen<sup>7</sup>

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Using a data-blitz approach, presenters in this symposium will present brief compelling sets of findings which describe different invisible aspects of CP as a childhood disability including: (1) Cognitive impairments, as opposed to more salient physical aspects. (2) Violations of test preconditions in cognitive assessment, and (3) challenges for children and families with CP leading their lives in contexts designed for typically-developing children.

The first part will present new research on cognitive impairments in CP. Elina Hakkarainen, and Silja Pirilä will describe error detection and learning in children with CP, and Jacqueline Kaufman, PhD, will report on working memory, ADHD symptoms and quality of sleep in children with CP.

The second part addresses methodological problems associated with assessing cognition in children with CP. Seth Warschausky, PhD will present a study examining psychometric properties of a standard vocabulary test administered using a noninvasive brain-computer interface. Kristine Stadskleiv, Neuropsychologist, addresses how executive functioning in children with CP with severe speech and movement impairments can be investigated by adapted neuropsychological assessment and behavioral tasks.

The third part consists of three studies of psychosocial and academic aspects of living with CP. Tamar Silberg, PhD in psychology and Jaana Ahonniska-Assa present a study on levels of agreement between parents and teachers reports of children's emotional and behavioral states and whether differences are related to various child characteristics. Silja Pirilä, PhD , will describe whether mothers or fathers of children with CP differ in their perceptions of available social support. Louise Bøttcher, PhD , will present a qualitative study examining the translation of cognitive assessment into useful support of children with CP in mainstream schools.



**When training executive functions makes a difference: for whom, when, how (and why)**

Paola Brovedani<sup>1</sup>, Samuele Cortese<sup>2</sup>, Torkel Klingberg<sup>3</sup>, Peter J Anderson<sup>4</sup> and Chiara Pecini<sup>5</sup>

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Children with complex and heterogeneous neurodevelopmental disabilities, as ADHD, cerebral palsy, and autism spectrum disorder, are particularly at risk of developing deficits in executive functions (EFs) ( Kasper et al., 2012; Bodimeade et al., 2013; Di Lieto et al., submitted, Brovedani and Cioni, 2014; Pellicano, 2012). Prematurity and extremely low-birth weight per se are significant risk factors for executive function deficits, aside from poor cognitive outcome (Burnett et al., 2015). Cognitive intervention on executive dysfunction is thus crucial as EFs may mediate the causal risk pathways to neurodevelopmental disorders and increase plasticity of brain circuitries ( as for e.g., fronto-parietal networks) underpinning, at least in part, such neurodevelopmental disorders when viewed within a modern developmental cognitive neuroscience framework. Currently, the level of empirical evidence, in terms of availability of randomized controlled trials (and meta-analyses pooling them ) is a “hot” topic of research, highly debated and discussed in the scientific community.

Debates have arisen in terms of when EF training is effective, for whom it is indicated, how to treat EF deficits and why EF training works (or does not) (Abikoff et al., 2014; Darki and Klingberg, 2014; Cortese et al., 2015; Dunning et al., 2013; Harrison et al., 2013; Jolles et al., 2013; Pascoe et al., 2013; Pugin et al., 2015; Rueda et al., 2012; Thorell et al., 2009; Wass et al., 2015).

For clinicians, answers to these questions are crucial in terms of possible positive impact on the quality of life of children with neurodevelopmental disabilities. Knowing which treatments work for which patients, the limits that a specific training has, and how to measure change after training, will allow the clinician to make informed decisions on treatment options that are ethical, cost-effective and evidence-based.

**Autism spectrum disorder: unraveling complexity, early detection, disability assessment, social skills training, and support in adulthood**

Sven Bölte<sup>1</sup>, Tatja Hirvikoski<sup>1</sup>, Kristiina Tammimies<sup>1</sup>, Soheil Mahdi<sup>1</sup> and Terje Falck-Ytter<sup>1</sup>

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Prevalence estimates for autism spectrum disorder (ASD) in school-aged children are ~1-2.5%. Evidence suggests largely genetic fundamentals in ASD, but the influence of bioenvironmental factors acting as triggers or “second hits” has probably been underestimated. Neurobiologically, ASDs are likely to be conditions of altered neuronal-cortical organization and connectivity. The precise mechanisms driving ASD phenotypes remain poorly understood. Sufficiently sensitive or specific genetic or neurobiological markers are not yet available to establish an organic diagnosis of ASD, which would be particularly important for early detection and intervention. Moreover, no cure or effective biologically based treatments for core ASD symptoms are available. Although much is known about the characteristics of the psychosocial environment (family, school) and behavioral interventions that affect adaptive functioning in everyday life, sparse knowledge about the (heterogeneous) nature of ASD currently limit the potential impact of individualized psychopedagogical interventions. In this symposium we present novel evidence from twin studies on complex causal pathways, early detection, standardized international (dis-)ability assessment, social skills group training, and support in adulthood. We present new data from several areas of preclinical and applied ASD research: (1) multilevel studies of biological alterations in twins discordant for ASD phenotypes (RATSS study) (2) the observation of early trajectories and identification of biomarkers for ASD by high-risk siblings studies (EASE study), (3) the development of WHO ICF core sets for ASD (4) case management and psychopedagogical models to help young adults with ASD, (5) a larger RCT multicenter study of social skills group training effects in clinical and community (school) settings.

**Acquired brain injury in developing children: perspectives on neurological and neuropsychological disorders and their rehabilitation**

Enrico Castelli<sup>1</sup>, Catherine A Jonsson<sup>2</sup>, Carol Hawley<sup>3</sup>, Eli Gunnarson<sup>4</sup> and Ingela Kristiansen<sup>5</sup>

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<sup>5</sup>Department Of Pediatric Neurology, Uppsala University Children's Hospital, Uppsala, Sweden

Acquired brain injury (ABI) in developing children contributes significantly to childhood disability and challenges independence and quality of life in adulthood. Beside traumatic brain injury (TBI), stroke and CNS infections, anoxic events and brain tumors are common causes of ABI in childhood. Brain injuries during development disrupt the progressive maturation of anatomical loops and structural differentiation on which cognitive development rely. Thus, a brain injury will have different consequences depending on age at injury.

The symposium will present implications of diffuse and focal TBI in childhood.

A process-oriented model for interventions will be presented, along with evaluations guided by the recovery of the child, focusing on early potential during the recovery stage versus long-term remaining deficits. Common cognitive deficits and their relation to school performance will be addressed. Short and long-term rehabilitation needs of children and adolescents with brain injuries will be discussed, with account taken to the developing brain. Effective strategies to compensate for deficits, ranging from multi-disciplinary rehabilitation techniques to specific memory training aids will be presented.

A school-based neurorehabilitation program for children and adolescents with acquired brain injuries, currently applied in Stockholm, will be presented. It offers 20 weeks of complementary training, cognitive and educational rehabilitation as well as detailed planning of the children's return to school after ABI.

Finally, a review of mild TBI with an emphasis on sport injuries will be presented, describing differences in injuries in the developing brain in children compared with adults. Short- and long term sequelae and recommendations for follow-up as well as international examples of return-to-play guidelines will be provided.

## **The End Organ: Muscle in Cerebral Palsy**

Henry G. Chambers<sup>1</sup>, Richard L Lieber<sup>2</sup>, Martin Gough<sup>3</sup>, Adam Shortland<sup>4</sup> and Lee Barber<sup>5</sup>

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<sup>5</sup>Cerebral Palsy And Rehabilitation Research Center, University Of Queensland, Brisbane, Australia

Although it is well known that the cause of cerebral palsy is injury to the developing brain, many of the end effects of the movement disorders occur in skeletal muscle. This symposium will address the state-of-the-art knowledge on the basic science and clinical work on muscle in children and adults with cerebral palsy

The cerebral palsies are the result of an insult to the the developing brain. There are many manifestations of this injury including cognitive, visual, speech, hearing, epilepsy, etc, but many of the problems are caused by the movement disorders. Spasticity, dystonia, athetosis, and ataxia all manifest themselves differently in the musculoskeletal system. What is happening at the muscle level with severe spasticity or dystonia? Why do children with spasticity develop contractures? How is this syndrome different from other diseases which cause muscle contractures? This symposium will unite leading basic science and clinical experts in the fields of muscle physiology, biochemistry, genetics, imaging, and the effects of therapies and surgery on muscle. Each of the members of the panel have contributed much to the world's literature and they will provide a journey from the bench to the bedside with insights into effects of movement disorders to the effects of surgery and medication on muscle. Discussion of invasive and noninvasive (biopsy and ultrasound) will be highlighted.

. The symposium will be divided into sessions describing the clinical consequences of movement disorders on muscle; the physiology and genetics of muscle from patients with cerebral palsy compared to typically developing children; our understanding of the three dimensional architecture of muscle; in vivo techniques for evaluating muscle and tendon problems such as ultrasound, EMG, and motion analysis; and finally, the effect of various treatment modalities such as physical therapy, oral medication, chemodenervation and surgery.

### **Selective Dorsal Rhizotomy in CP: Beneficial or harmful?**

Hank Chambers<sup>1</sup>, Graham Fieggen<sup>2</sup>, Jules Becher<sup>3</sup>, Freeman M Miller<sup>4</sup> and Kristina Tedroff<sup>5</sup>

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Selective dorsal rhizotomy (SDR) is a neurosurgical procedure aimed at reducing spasticity in patients with bilateral spastic diplegia. It reduces muscle tone by partially interrupting the afferent pathway of the exaggerated myotonic stretch reflex that induces spasticity. A number of clinical studies and systematic reviews on the short term outcome demonstrate reduced muscle tone and increased range of motion, together with improved gait and motor function. However, there is still a lack of consensus concerning the long term outcomes, with inconsistent results across the few available follow-up studies. There remains controversy on the indications for this surgery and the criteria for patient selection. In addition, the operation may be accompanied by adverse effects such as increased muscle weakness, progression of spinal deformity and loss of bladder control. To reduce adverse effects and improve the results, modern SDR operations include less invasive procedures and stricter selection of patients, but controversy remains concerning the role SDR in the arsenal of measures to reduce spasticity and improve function.

The panel consists of four clinicians with extensive clinical and research experience of patients with spastic CP and those undergoing SDR, but have come to different conclusions regarding the benefit of SDR in the management of spasticity in children with CP.

**Action-Observation Training: a new approach for rehabilitation of motor disorders in children**

Giovanni Cioni<sup>1</sup>, Bert Steenbergen<sup>2</sup>, Giuseppina Sgandurra<sup>3</sup>, Anna Basu<sup>4</sup> and Stefano Vicari<sup>5</sup>

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Recent discovery of Mirror Neuron System (MNS) whose core regions are ventral premotor and inferior parietal cortex, activated both when individuals perform goal-directed motor acts and when they observe or imagine someone else performing the same or a similar motor act, has provided interesting neurophysiological evidences on observational learning. The application of these findings to neurorehabilitation has fostered the development of rehabilitation protocols based on the observation of meaningful actions followed by their execution. This approach, often labelled Action Observation Training (AOT) has been used with promising results in adults with stroke and other neurological and non-neurological diseases. In the last years, AOT has been used also in children with neurodevelopmental disabilities (NDDs), such as cerebral palsy (CP) and complex genetic NDDs with interesting results. The interest in this field could be very large, because AOT can be easily downloaded, reproduced and generalised to broader population of children with different types of NDDs. During the minisymposium a general neurophysiological overview of AOT will be shortly presented by Giovanni Cioni (Pisa, IT). Bert Steenbergen (Nijmegen, NL) will discuss the wide-ranging rehabilitative approaches having MNS as main neurophysiological background, such as motor imagery and AOT. Giuseppina Sgandurra (Pisa, IT) will present the available evidences, by neurophysiological and brain-imaging studies, of brain activation associated with AO in typically developing and in children with congenital brain disorders. Anna Basu (Newcastle, UK) will present the results of a RCT where AOT was delivered by parents on upper limb function in children with unilateral CP. Finally Stefano Vicari (Rome, IT) will conclude the presentations with results around the use of AOT in children with some genetic syndromes, as Williams and Prader-Willi syndromes.

## **Neural Precursor "Stem Cells"- The Hope and the Hype: Are We Ready?**

Darcy Fehlings MD Msc<sup>1</sup>, Iona Novak OT PhD<sup>2</sup> and Michael Fehlings MD PhD<sup>3</sup>

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<sup>2</sup>Medicine, University Of Notre Dame, Research Institute, Cerebral Palsy Alliance, Sydney, Australia

<sup>3</sup>Surgery, University Of Toronto, University Health Network, Toronto, Canada

Background: Interest exists in the role of stem cells for neural repair in cerebral palsy (CP). Two approaches include mesenchymal and neural precursor cells (NPCs). Trials with mesenchymal stem cells are underway. However, given that NPCs are the developmental “building blocks” of the brain, interest exists in how to translate this technology into the clinic. Questions exist around the following:

Should we do endogenous or exogenous NPC approaches?

What are the best sources of NPCs?

How do we balance exploring mechanisms in pre-clinical research with the need to move a clinical research plan forward?

How can we engage a “stakeholder voice”?

What are the long-term side effects of NPCs?

Learning Objectives: To understand the state of evidence and opportunities for NPCs in CP

Audience Targeted: All

Format

Setting the “Debate” Stage (10 minutes (m)): Professor D.Fehlings leads two large Canadian CP focused translational neuroscience networks which include CP stem cell discovery. She will provide an overview of the necessary background to understand the premise of the debate.

Neural Precursor Cells – We are ready in CP – Lets Go! (10 m): Professor I.Novak has established “Xcellerate” a research network for rapidly translating stem cell science from bench to bedside. She will present a logical approach to moving clinical NPC trials forward!

Neural Precursor Cells – We are not ready for clinical trials of NPCs in CP –Stop! (10 m): Professor M.Fehlings is a neurosurgeon and neuroscientist, with a research focus in NPCs. He will present a logical approach to what is required in the pre-clinical and ethical/stakeholder world before clinical trials in NPCs move forward.

The Middle Ground (15 m): Profs M Fehlings and I Novak will present a combined perspective.

Audience Participation (15 m): Professor D.Goldowitz (Scientific Director of NeuroDevNet) will lead a discussion on missing steps and the “popular” audience vote on the sequencing of events.

## **From Basic Science to Clinical Application: Translational Neuroscience and Potential Treatment Implications for Cerebral Palsy**

Andrew M Gordon<sup>1</sup>, John H Martin<sup>2</sup>, Hans Forssberg<sup>3</sup>, Bernadette T Gillick<sup>4</sup> and Kathleen M Friel<sup>5</sup>

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<sup>5</sup>Medical Research Institute, Burke-Cornell, White Plains, USA

### **Background**

Recent advances in knowledge about the normal development of the CNS and underlying pathology of cerebral palsy have important implications for potential clinical application to CP. These include an understanding of the normal and pathological development of corticospinal development, chemical and activity-based guidance of cortico-spinal circuits and the circuitry and neurochemical basis for skill learning. These provide exciting possibilities of pharmacological and brain stimulation techniques to re-mediate development after early CNS injury and to enhance skill learning approaches to rehabilitation pharmacologically or with non-invasive brain stimulation to prevent or minimize the impact of subsequent movement disorders.

### **Plan of the symposium ( 2 hours)**

1.General Introduction of theme and speakers (5 min) Andrew M. Gordon (New York, USA)

#### **Speakers:**

2.1) Role of motor-cortical activity and chemical mediators in the development of corticospinal connectivity and motor skills- 20 min- (John Martin, New York, USA)

2.2) Optimizing neuroplasticity in skill-based treatment approaches-20 min-(Kathleen Friel, New York, USA)

2.3) Pharmacological enhancement of motor/cognitive training– 20 min (Hans Forssberg, Stockholm, Sweden)

2.4) Non-invasive brain stimulation to enhance skill-learning- 20 min (Bernadette Gillick, Minneapolis, USA)

2.5) Summary-10 min (Andrew Gordon)

3. General Discussion -30 min- (John Martin, Kathleen Friel, Hans Forssberg, Bernadette Gillick)



**“Involving children with long term health conditions and disabilities as participants in longitudinal studies”**

Mats Granlund<sup>1</sup>, Alecia Samuels<sup>1</sup>, Berit Björkman<sup>1</sup>, Maria Björk<sup>1</sup> and Margareta Adolfsson<sup>1</sup>

<sup>1</sup>CHILD, Jönköping University, Jönköping, Sweden

Some of the relations between phenomena in cross sectional studies are not related to change. Children with long term health conditions or impairments change with time just like all other children. These changes occur both in terms of development, as traditionally measured with developmental tests, but also in terms of everyday functioning, as measured with instruments focusing on everyday functioning and participation. What can be considered as functioning ‘well’ varies with context. Children’s natural contexts change with time at a faster pace than for adults. The fast and sometimes different patterns of change in children with long term health conditions or impairments make it necessary to assess change over time. As of today, few longitudinal studies of everyday functioning in children with long term health conditions or impairments exist. Most longitudinal studies to date have a focus on body function rather than functioning in everyday activities and/or are based almost exclusively on ratings made by professionals, teachers or parents. This mini symposium will discuss methodological issues in longitudinal studies of everyday functioning in children with long term health conditions and/or impairments. A special focus will be children’s self-ratings or children acting as informants in qualitative interviews in such studies. The presentations are based on the results of a systematic review of how change is conceptualized and measured in longitudinal studies of everyday functioning in children with long term health conditions or impairments and experiences from ongoing longitudinal studies of this group of children. After introduction the session will focus on how change is conceptualized (Alecia Samuels), children as informants (Berit Björkman), young children as informants in longitudinal studies (Maria Björk), using ICF-CY qualifiers and codes to illustrate change (Margareta Adolfsson). The session will end with a general discussion

## **Early intervention: promising perspectives of recent trials**

Mijna Hadders-Algra<sup>1</sup>, Ann Christin Eliasson<sup>2</sup>, Andrea Guzzetta<sup>3</sup> and Aleid Van Wassenauer-Leemhuis<sup>4</sup>

<sup>1</sup>Paediatrics, University Medical Center Groningen, Groningen, The Netherlands

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<sup>3</sup>Dept. Of Developmental Neuroscience, Stella Maris Scientific Institute, Pisa, Italy

<sup>4</sup>Dept Of Neonatology, Amsterdam Medical Center, Amsterdam, The Netherlands

**Background and relevance:** Two in every 1000 newborn infants is later diagnosed with cerebral palsy (CP). CP is caused by a lesion of the brain during early development. Current early diagnostics allow for the detection of a large proportion of these infants at early age. This offers the opportunity for intervention at an age that is characterized by high plasticity of the young nervous system.

Most knowledge on early intervention is based on studies in high risk infants without a lesion of the brain, i.e., without CP. In these infants early intervention programs promote cognitive development until preschool age; motor development profits less. Up until recently little was known about the effect of early intervention in infants later diagnosed with CP. Recently completed trials started to close this gap in our knowledge.

**Aim:** critical presentation of the current state of the art on early intervention in infants at very high risk for CP. Special attention is paid to a) specific types of infant practice, and b) family empowerment as means to promote better function of the child and family.

**Description of session:** Four renowned experts in the field of early intervention present and critically discuss their novel results and ideas. 1) Ann-Christin Eliasson presents the baby variant of Constraint Induced Movement Therapy, a concept to promote increased hand use for infants below the age of 12 months with clinical signs of unilateral CP; 2) Andrea Guzzetta summarizes the implications of action observation for early intervention in infants at risk for cerebral palsy; 3) Aleid van Wassenauer-Leemhuis reports the results of the Infant Behavioral Assessment and Intervention Program; and 4) Mijna Hadders-Algra discusses the COPCA-program for high risk infants, including family empowerment, as a means to promote child and family function. The session concludes with a panel discussion (15 minutes) focusing on future perspectives.

## **Gait Analysis : clinical sense or nonsense ?**

Adam Shortland<sup>1,5</sup>, Jaap Harlaar<sup>2</sup>, Annemieke Buizer<sup>2</sup>, Eva Broström<sup>3</sup>, Michael Schwartz<sup>4</sup> and Adam Shortland<sup>5</sup>

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In paediatric disability, especially in Cerebral Palsy, the development and preservation of mobility during growth is a major treatment objective. Walking involves a complex interaction of many functions of the neuro-musculoskeletal system. Hence clinical decisions on treatments that aim to promote walking ability are far from obvious.

The promising role of gait analysis to enhance clinical decision-making took off a few decades ago. Technical innovations including motion capture technology enabled to design specific clinical gait laboratories. A gait analysis yields a description of walking in terms of biomechanical variables, representing skeletal functions (joint-kinematics), the net muscular function (joint-kinetics) and neurological control (EMG). Recognizing aberrant functions, and deducting them to the cause of the walking problems, provides a rationale to identify the aetiology to be targeted by a specific therapy. These include orthopaedic surgery (bony or soft tissue), selective dorsal rhizotomy, muscle denervation (botulinum toxin) or ankle-foot-orthotics. Currently, clinical gait analysis is implemented in a large number of clinical practises, supported by advanced information technology and an active scientific community (ESMAC, GCMAS, Gait&Posture).

This panel discussion will discuss the current state of the art, i.e. how the biophysical approach of analysing the gait patterns has been shown to improve clinical decision making in the treatment of mobility problems in cerebral palsy and other pathologies. What have we learned from retrospective analyses? Should clinical gait analysis be implemented as standard diagnostics? Should gait analysis characterize patients to match successful cases instead of reasoning ? What are expected future developments (big data/ musculoskeletal modelling) ?

The panel consists of experts from world leading centres that apply clinical gait analysis as part of their practises, who will express their critical appraisal.

**Epidemiology, risk factors and neuroimaging in cerebral palsy – current knowledge and news.  
Can we predict the future?**

Kate Himmelmann<sup>1</sup>, Eve Blair<sup>2</sup>, Elodie Sellier<sup>3</sup>, Veronka Horber<sup>4</sup> and Sarah McIntyre<sup>5</sup>

<sup>1</sup>Pediatrics, Clinical Sciences, University Of Gothenburg, Göteborg, Sweden

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<sup>3</sup>TIMC/Themas-RHEOP, Grenoble University Hospital, Grenoble, France

<sup>4</sup>Pediatrics, University Of Tübingen, Tübingen, Germany

<sup>5</sup>Cerebral Palsy Alliance, University Of Notre Dame, Darlinghurst, New South Wales, Australia

The panorama of cerebral palsy is constantly changing, affected by advances in medicine and changes in society. For example, over the last two decades the prevalence of cerebral palsy has decreased in most preterm groups. There is conflicting evidence regarding the prevalence trend in the extremely preterm born children, whose survival is still increasing. The epidemiology of cerebral palsy (CP) is relevant to obstetric and neonatal care, child neurology rehabilitation services for both adults and children, and to society.

New interventions may change prevalence by increasing the survival of vulnerable infants or by decreasing the incidence or severity of brain damage. Such interventions alter the contributions of specific risk factors or combinations of risk factors. For example, cooling after asphyxia may reduce prevalence and severity of cerebral palsy in the term-born child following to intrapartum hypoxia. At the same time changes in reproductive behavior, lifestyle and immigration patterns may alter the contributions of old risk factors or introduce new ones. Carefully monitoring these changes, searching for causal pathways and establishing the corresponding neuroimaging patterns will increase our understanding of cerebral palsy and assist in devising more effective neuroprotective interventions and provide a better foundation for evidence-based advice and decision-making regarding early interventions.

The purpose of this symposium is to present the latest news and recent trends in epidemiological research in cerebral palsy, including an overview of current risk factor research. The classification of pathogenetic patterns in neuroimaging will be discussed. The clinical profiles associated with different neuroimaging patterns in CP will be presented, based on data from the large database of Surveillance of Cerebral Palsy in Europe.

## **An overview/update of evaluation & management of pain in people with Cerebral Palsy**

Joshua E Hyman<sup>1</sup>, Hiroko Matsumoto<sup>2</sup> and Darcy Fehlings<sup>3</sup>

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<sup>3</sup>Pediatrics, University Of Toronto Bloorview Research Institute, Toronto, Canada

**Background/Content:** ~20-60% of people with Cerebral Palsy (CP) have daily pain. Nearly 70% of adults with CP report chronic pain: 33% of these patients are discontent with their pain management. Given its subjective nature, pain evaluation & management is challenging. Many patients with CP have difficulty expressing their pain, adding an extra layer of complexity. As a result, treatment may be inadequate or delayed, leading to an increased burden of care for families, caregivers and the health system. Thus, there is a need for investigation & improvement in the evaluation and treatment of pain in people with CP.

### **Aims:**

To describe the current understanding of the physiologic and biochemical effects of pain in patients with CP

To discuss the current state of pain assessment in verbal and non-verbal patients, and describe ongoing research in improving pain evaluation

To understand current modalities of operative, non-operative & pharmacologic management of pain for pediatric and adult patients with CP

To describe optimized management of pain in people with CP

**Methods:** Six 15-minute lectures & two 15-minute Q&A sessions given by leaders in the field of pain management and CP

### **Results: Speakers & Topics**

Joshua E. Hyman, MD: Moderator

Heakyung Kim, MD: Symptoms, signs, management of pain in CP

Hiroko Matsumoto, MA: Assessment tools & quality of life measures

Chantel Barney, PhD: Basic science approach to pain and physiologic markers

M. Wade Shrader, MD: Clinical aspects of pain assessment in pediatric patients with CP

Joseph P. Dutkowsky, MD: Clinical aspects of pain management in adults with CP

Darcy L. Fehlings, MD, MSc, FRCP(C): ADOPT (Assessment, Demystification, Optimize, Promote, Treat)

**Conclusions:** Evaluation & management of pain in patients with CP is constantly changing; novel therapeutic approaches lead to improved understanding and outcomes.

## Spasticity: Good or Bad?

Gunnar Hägglund<sup>1</sup>, Reinald Brunner<sup>2</sup>, Diane L. Damiano<sup>3</sup>, Martin Gough<sup>4</sup> and Freeman Miller<sup>5</sup>

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Children with cerebral palsy often have increased muscle tone, muscle weakness and joint contractures. Spasticity, weakness and contracture interact. Conventional wisdom suggests that muscle weakness can sometimes be compensated by spasticity or contracture as shown in other basic diseases such as Duchenne muscle dystrophy.

Spasticity may changes with age. Muscular strength often increases with age, but must be viewed in relation to the increasing demand due to increasing body weight and height. In this view muscular strength related to body weight is often reduced with age.

One of the central questions we will address here is whether spasticity should always be treated just because it is present. The degree of spasticity, the importance of spasticity to function and hence the indication to treat spasticity may vary across children and during the growth period. For the family, patient, therapist and physician there is often a sense that the major problem with functional movement is due to the spasticity which is easy to feel but may not be the cause of what we see when the child is moving.

In this symposium the following questions will be discussed.

- What do we mean by spasticity?
- What is the role of spasticity in contracture development?
- What is the importance of spasticity and strength with respect to gait and mobility?
- How do spasticity and strength develop with age?
- What is the effect of strength training on spasticity and function?

Studies and case examples showing the long-term development of spasticity and strength and the consequences of spasticity treatment will be presented. One of the ideal methods to further evaluate this difficulty is by modulating the spasticity mainly by reducing it using intrathecal baclofen. Using case examples we will show how this can work to help the patient make their best evidence-informed decision.

**To splint or not to splint ... that is the question.**

Christine Imms<sup>1</sup>, Margaret Wallen<sup>2</sup>, Brian Hoare<sup>3</sup>, Melinda Randall<sup>1</sup> and Susan Greaves<sup>4</sup>

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Background: Little published evidence supports prescription of rigid wrist hand orthoses (splints) for children with cerebral palsy (CP): indeed best available evidence suggests we probably should not. Yet, orthoses continue to be prescribed. In an era of evidence-based healthcare why is this? Should we continue to use unproven interventions? Tension between the four pillars of evidence based practice (EBP) - research evidence, clinical expertise, client preferences and clinical resources - is at the heart of this question. An additional tension is improbability of a body structure intervention influencing activity or participation. The risks of making the wrong decision (to splint or not) however, may be costly to children, families and health-care.

**Learning objectives**

Participants will: Review variation in prescription, aims and manufacture of hand orthoses; Update knowledge of current evidence for and against orthoses prescription and consider why the research provides little direction; and Consider how to apply the evidence in practice and future research.

Target Audience: OTs, PTs and those interested in EBP

Format: This will be a debate between five occupational therapist-researchers with expertise in upper limb outcomes for children with CP. Debaters will: 1) review current evidence evaluating orthoses, concluding that prescription should cease; 2) refute these conclusions by applying EBM's Six Dangerous Words and the EBP pillars; 3) discuss the inconsistent rationale for orthoses use, present research supporting underlying theoretical premises, and argue that practice is diverse because there are no agreed principles; 4) argue against orthoses prescription as it is unlikely that a body structure and function intervention will impact activity and participation outcomes. The debate will conclude with suggestions for using EBP principles to guide orthoses practice, and engage audience and speakers in proposing research to answer: To splint or not to splint?

**Optimizing movement exploration and mobility in infants at risk for developmental delays or Cerebral Palsy: Timing, content, and dosing.**

Thubi Hlapang A Kolobe<sup>1</sup>, Jill Healthcock<sup>2</sup>, Beth Smith<sup>3</sup> and Barbara Sargent<sup>3</sup>

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<sup>3</sup>Biokinesiology And Physical Therapy, University Of Southern California, Los Angeles, USA

Movement exploration and independent mobility are critical to functional independence, yet children with developmental delays and disabilities (DD), particularly cerebral palsy (CP), rarely experience mobility or efficient movement strategies during the first year of life. Though it is now widely accepted that many of the mobility constraints observed later during childhood and adulthood emerge early during infancy, new effective interventions have not been forthcoming. The period of infancy is associated with dramatic changes in development and high synaptic connections in the brain. Therefore, understanding characteristics of movement learning patterns that are likely to impact learning and skill acquisition in infants with or at risk for delays is paramount in designing appropriate interventions. The challenge for pediatric rehabilitation worldwide has not only been that of identifying high risk infants early, but also determining interventions that are effective (content) and that can be provided during the first year of life (timing). In this mini-symposium we will present recent and novel research approaches and findings that focus on content and timing of targeted interventions to promote improved mobility and exploration during infancy. We will focus on the use of instrumentation and robotic technology to: a) identify and measure outcomes for infants that are at risk for delays, coordination disorders, or CP early; b) engage the infants in self-initiated movement exploration and learning; and c) examine neural correlates to changes in movement learning. We will also discuss evidence for the timing of intervention and implications for dosing.



## **Homage to Bengt and Gudrun Hagberg - teachers, tutors, friends**

Marten Kyllerman<sup>1</sup>, Kate Himmelmann<sup>2</sup>, Ola Skjeldal<sup>3</sup> and Tomas Sjodin<sup>4</sup>

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Bengt and Gudrun's recent deaths present an opportunity to pay tribute to the enormous contribution they both made to our knowledge and understanding of the world of disability, in particular Cerebral Palsy and Rett Syndrome. Parents and professionals alike were touched by their knowledge, humbleness and enthusiasm and it seemed fitting that this Homage should take place in Sweden.

The International Cerebral Palsy Society has therefore invited four speakers to come and talk about the work they shared with Bengt and Gudrun Hagberg.

Marten Kyllerman will chart a journey of discovery and inspiration with Bengt and Gudrun. Marten worked very closely with Bengt in the paediatric clinic. Marten describes Bengt as an exceptional physician and clinical scientist and a remarkable human in all aspects of life, about which he will tell us.

Kate Himmelmann will describe how the Hagbergs set up the Cerebral Palsy CP Register in Western Sweden collecting data from the birth year of 1954 onwards. To date this Register has produced 11 reports of the prevalence and origin of CP.

By continuing to work on this Register, Kate is ensuring that Bengt and Gudrun's important work in CP is carried on.

Ola Skjeldal was for many years taught by Bengt. He will give a brief history of Rett Syndrome, especially the role Bengt played in the development and our knowledge of it. He will explain how today we consider the spectrum of phenotypes in Rett Syndrome and will try to give some perspective of the status considering the clinical research in the field.

Tomas Sjodin will speak about the setting up of 'Anonymous', a parent organisation whose children have disabilities of unknown origin.

Tomas and his wife had two children, both had disabilities. They went on a journey to discover what was wrong with their children, but at every turn they met a brick wall - that is until they met 'Father Bengt' who supported them and together they set up 'Anonymous'. Tomas will tell us his story.

## **CEREBRAL PALSY: NEW EVIDENCE OF GENETIC CAUSATION: FUTURE DIRECTIONS**

Alastair H MacLennan<sup>1</sup>, Mark Corbett<sup>1</sup>, Jozef Gecz<sup>1</sup>, Clare L Van Eyk<sup>1</sup> and Michael Kruer<sup>2</sup>

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Cerebral palsy (CP) is heterogeneous with different clinical types, co-morbidities, brain imaging patterns, causes and now heterogeneous genetic aetiology. Few cases are solely due to severe hypoxia or ischemia at birth. CP rates have remained the same for 50 years despite a sixfold increase in caesarean birth. Epidemiological studies show that the origin of most CP precedes labour. Increased risk is associated with preterm delivery, congenital malformations, intrauterine infection, fetal growth restriction, multiple pregnancy and placental pathology.

Until recently 1-2% of CP (mostly familial) had been linked to genetic mutations. Recent DNA sequencing studies of sporadic CP cases show that 14% of cases have likely causative single gene mutations and up to 31% have clinically relevant copy number variations. Multiple genetic variants have been identified and require follow-up functional investigations to demonstrate causation. Large scale sequencing of CP cohorts with application of complementary genomic investigations, e.g. whole genome sequencing and transcriptome profiling, will extend the percentage of CP cases with a genetic pathology. Clinical risk factors may act as triggers for CP genetic susceptibility. Stratification of genetic and non-genetic CPs will help assign aetiology. CP pathogenesis overlaps that of other neurodevelopmental disorders, e.g. autism, intellectual disability and epilepsy where new genomic technologies have demonstrated a considerable role of genetic variation. To understand genetic and non-genetic contributions to CP causation, there is a need for the establishment of an International CP Genetic and Clinical Database. We propose an International CP Collaborative Alliance. Such partnerships, databases and biobanks will reshape research into CP causation. Many other benefits including pre-conception or pre-implantation testing and targeted therapies based on an improved understanding of the molecular basis of specific CPs will follow.

## Healthy living through leisure participation

Annette Majnemer<sup>1</sup>, Keiko Shikako-Thomas<sup>1</sup>, Darcy Fehlings<sup>2</sup> and Desiree B. Maltais<sup>3</sup>

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Participation in leisure activities is vital to the health and well-being of children with disabilities. This symposium highlights the importance of engaging in leisure activities as part of promoting a healthy lifestyle, and emphasizes the challenges experienced by children and youth with cerebral palsy (CP). A solutions-based approach is offered, with exciting new directions in health promotion for this population.

This symposium defines leisure participation and updates the participants on the current state of knowledge on research conducted on children with CP. Potential solutions to the obstacles that children and families face when trying to engage in preferred leisure activities are proposed. First, the relationships between leisure participation and quality of life will be clarified. An overview of the profile of participation in leisure activities in children and youth with CP will be provided and will be compared to children from other disability groups. Key determinants will be highlighted. A summary of existing evidence on rehabilitation interventions that enhance leisure participation will follow. Knowledge translation efforts in Canada have resulted in the creation of CHILD LeisureNet, a new network of stakeholders that are working collaboratively to promote leisure participation in children with disabilities. As part of these efforts, a new App called JOOAY was developed, to help families locate local leisure opportunities that welcome children with disabilities and offer adapted programs. An overview of the state of the evidence on interventions designed to improve and maintain health-related physical fitness for children with CP will be provided. In particular, advances in virtual reality and exergames that have been developed to foster fitness will be presented. These technologic innovations are meant to complement real life experiences, by developing skill competencies and fitness, while also having fun.

## **Success of a Multidisciplinary Approach in a Resource Constrained Country – An Experience**

Shazia Maqbool<sup>1</sup>, Aisha Farid<sup>1</sup> and Wajeeha Zahra<sup>1</sup>

<sup>1</sup>Developmental & Behavioural Paediatrics, The Children's Hospital & Institute Of Child Health, Lahore, Pakistan

Childhood disability prevalence includes 10% of the paediatric population and in developing countries like Pakistan this figure is even higher. These include Jamaica 15%, Pakistan 15%, and Bangladesh 8%. Our aim is to share the successful outcome of a multidisciplinary team approach in our country where people are deprived of basic medical facilities due to lack of resources and awareness.

Department of Developmental and Behavioral Paediatrics established in 1998 is one of the unique setup in a public (government) sector providing multidisciplinary services to children with special needs under one roof. It houses Developmental Paediatricians, Clinical Psychologists, Speech therapists, Occupational therapists, Special needs educationists, Sensory therapists, Developmental therapists and Disability Technicians.

### **Autism Spectrum Disorder: Services in a Resource Constrained Country**

Prof Dr Shazia Maqbool (MD Paeds, FRCPCH) will do introduction and share the holistic and eclectic approach in managing children with Autism. She has set up the department and has played a pivotal role in starting second Fellowship and MD with 5 fellows working in the speciality. She has a special interest in Autism Spectrum Disorder (ASD) and Early Child Development (ECD). She will convene discussion at the end.

### **Opportunistic Developmental Screening: Is it useful?**

Dr Aisha Farid (FCPS Paediatric Medicine) is a Senior Registrar doing a 2nd fellowship in Developmental and Behavioural Paediatrics. She will share the experience of screening children for developmental problems and discuss results of a research that led to construction of a developmental inventory for the indigenous population.

### **Learning Centre: An Experience in a Hospital Setting**

Wajeeha Zahra (MSc & ADCP) is a Senior Clinical Psychologist with 15 years experience. She will share the working of a Learning Center in a hospital setting which is a unique concept introduced for the first time in Pakistan to encourage inclusion.

## **Changing the environment to enable children and young people's participation: are we all talk and no action?**

Jennifer Mcanuff<sup>1</sup>, Diane Kay<sup>2</sup>, Andreas Seidel<sup>3</sup> and Niina Kolehmainen<sup>1</sup>

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Participation, i.e. 'involvement in life situations',<sup>1</sup> is a fundamentally important health outcome for all children and young people and a major contributor to their longer-term health, well-being and quality of life. In comparison to their peers in the general population, children and young people with disabilities experience restrictions to their participation across many life domains.

Participation is influenced by environmental factors, e.g. physical accessibility, assistive technology, social support, peer attitudes, and availability of services. The importance of environmental pathways to participation is frequently highlighted in research conclusions. The session theme is captured in one key question: in our existing interventions for children and young people with disabilities, are we doing enough to change the environment to enable their participation?

Learning objectives:

(1) To critically discuss evidence and experiences related to two opposing perspectives on the place of environmental factors within existing interventions: (i) interventions recognise the importance of, and actively target, environmental pathways to participation; and (ii) interventions rarely explicitly target environmental pathways and, when they do, they focus narrowly on the physical environment and caregiver knowledge and skills, with limited efforts directed at wider social-environmental factors.

(2) To critically reflect on these different perspectives, and to answer whether current interventions are doing enough to change the environment to enable children and young people's participation.

The session is targeted at parents and carers, service providers, researchers, students and funders. The format will be interactive, visual presentations and open discussion between the facilitators and the audience.

<sup>1</sup>World Health Organization. International classification of functioning, disability and health - children and youth version. ICF-CY. 1st ed. World Health Organisation, 2007

## **Dyskinetic Cerebral Palsy: from better understanding towards a targeted management**

Elegast Monbaliu<sup>1</sup>, Laura Bonouvrie<sup>2</sup>, Jean-Pierre Lin<sup>3</sup>, Daniel Lumsden<sup>3</sup>, Els Ortibus<sup>4</sup> and Kate Himmelmann<sup>5</sup>

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**Aim:** to improve insights in background, neuroimaging, the clinical presentation of secondary dystonia and choreoathetosis, functional profile and medical management in dyskinetic CP

**Background:** Dyskinetic Cerebral Palsy (CP) is the second largest group of children with CP but, to date it has not received the same level of attention as spastic CP. The aetiology, neuroimaging findings and functional profile in individuals with dyskinetic CP differ from those in spastic CP. The complexity of dystonia and choreoathetosis in dyskinetic CP and the difficulty of measuring these particular motor disorders is a challenge. However, better evaluation and understanding of dystonia and choreoathetosis is vital if medical interventions and rehabilitation are to be better targeted. Also in addition to changes in dystonia and choreoathetosis improvements in daily life activities are increasingly recognized as important goals for these patients.

During this session, definitions and classification of dyskinetic CP will be presented, as well as background, neuroimaging insights and functional profile in motor function with special attention for the discrimination between dystonia and choreoathetosis. Pathological signs will be reviewed and clinical patterns of dystonia and choreoathetosis will be described. Management and effects on daily life activities will be discussed, with special attention for Deep Brain Stimulation and Intrathecal Baclofen interventions

**Learning objectives:**

1. to clarify the currently definition and classification of dyskinetic CP
2. to gain insight in the background, neuroimaging, functional profile according to the ICF model
3. to clarify the clinical patterns of secondary dystonia and choreoathetosis in dyskinetic CP
4. to improve insights in medical management of dystonia and choreoathetosis in dyskinetic CP

**Target Audience:** most paediatric health care professionals interested in the management of dystonia and choreoathetosis in dyskinetic CP.

## **International Clinical Guidelines for Early Detection and Early Neurorehabilitation of infants with CP – evidence and opportunities**

Catherine Morgan<sup>1</sup>, Andrea Guzzetta<sup>2</sup>, Alicia Spittle<sup>3</sup>, Domenico Romeo<sup>4</sup> and Iona Novak<sup>5</sup>

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**Background:** Early detection and early intervention are essential for children with cerebral palsy (CP) and their families. In previous years researchers and clinicians believed that children with CP could not be identified until the second year of life. With improvements in neuroimaging and the introduction of sensitive assessment tools, the so called “silent period” for CP is now considered over. Furthermore recent neuroscience research supports intensive, repetitive, task-specific intervention for CP that should start early while the brain is most plastic, yet the average age for diagnosis is 17 months.

**Aim:** The aim of this workshop is to outline the content of a new international clinical guideline on early detection and early neurorehabilitation in infants with CP

**Method:** An international summit was convened of 40 multidisciplinary experts to develop AGREE-II compliant clinical guidelines on early detection and early intervention in cerebral palsy. Included studies were: Systematic reviews, or clinical guidelines that reviewed accurate early detection of CP; assessments of infants with/at high risk of CP; CP early intervention across the domains of motor function, vision, cognition, communication, feeding and sleep. Where no such publication existed, a systematic review was conducted.

**Results:** Multiple recommendations were made. For example: High-level evidence recommends early detection of “high risk of CP”, before 5-months of age, using robust tools measuring quality of movement (General Movements) and neuroanatomy (MRI). Decision-making trees were developed based on best available evidence.

**Conclusion:** The development of this clinical guideline will provide clinicians with the most up to date scientific information to promote the earlier detection of CP, guide decision making for early intervention. Major knowledge gaps exist on non-motor cognitive assessment, plus proven effective early interventions for cognition, feeding and vision for infants with CP.

**Partnership in Knowledge Exchange to translation - engaging in possibilities opportunities, and challenges**

Eva Nordmark<sup>1</sup>, Jan William Gorter<sup>2</sup>, Dianne Russell<sup>3</sup>, Marjolijn Ketelaar<sup>4</sup>, Margaret Wallen<sup>5</sup>, Christine Imms<sup>6</sup> and Ann Alriksson-Schmidt<sup>7</sup>

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Partnership in knowledge generation and translation - engaging in possibilities, opportunities, and challenges

People with disabilities and their families have the right to direct their own decision-making about their health and wellbeing, to make choices about services. The "partnership paradigm" is proposed as the ideal constellation to facilitate cooperation between professionals and users for healthcare delivery. The same principles of engagement apply to developing research and generating knowledge which is accessible, meaningful and transferable to healthcare practice. Research which is conceived and implemented in a partnership between people with disabilities and researchers is mutually beneficial. The overall goal is to embed the partnership paradigm into the entire research process from identifying research priorities through to ensuring the appropriate implementation of research outcomes into real life. The research program is strengthened and the benefits are maximized for people with disabilities, their families, clinicians, service providers, researchers, administrative and/or policy decision makers by proactively working together. There is much to be learned together about how to develop a successful partnership paradigm. What are the best ways to ensure people with disabilities have an integrated, legitimate and respected voice in the design and implementation of research, follow up programs and registers? How can we collaboratively interpret the results of research and meaningfully exchange the knowledge generated? We address some of these questions and share experiences of meaningful partnerships in different parts of the world and diverse settings. In this interactive panel discussion we will start with brief presentations by professionals and family faculty members. Participants will be encouraged to share their experiences and create the take home messages.



## **Pediatric Rehabilitation Services: Expanding Horizons**

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Providing evidence informed rehabilitation services for children with cerebral palsy and other developmental disabilities is a complex and challenging process. This is largely due to the uniqueness of children and families, how services are regulated, the focus of intervention, and research evidence that is often difficult to apply to individual children. Despite or because of so much uncertainty, several factors are transforming rehabilitation services for children and youth with disabilities. These include enablement frameworks such as the International Classification of Functioning, Disability, and Health, a greater understanding of priorities and life experiences of individuals with disabilities and families, and evidence on prognosis, service delivery, and determinants of intervention outcomes. This transformation raises a number of questions on how services should be provided, what the focus of interventions should be, and what are the desired outcomes. This symposium will present a holistic framework for pediatric rehabilitation service delivery. Supported by theory, research, practice knowledge, and client perspectives, we will propose recommendations for individualized, collaborative service delivery including identification of outcomes that are meaningful to children and families, key elements of intervention, and the knowledge and skills needed by professionals to support children and their families. Themes include: a) services that build child, family, and community capacity, b) strength-based and solution-focused interventions that support real world life experiences, and c) future planning and anticipatory guidance. This mini-symposium will motivate practitioners, educators, and researchers to reflect on their current practices, challenge boundaries, and provide innovative evidence informed interventions that optimize rehabilitation outcomes.

## **Motor speech disorders in childhood: diagnosis, assessment and management**

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Motor speech disorders (dysarthria and childhood apraxia of speech [CAS]) are common in neurodisability and strongly associated with reductions in participation levels and lower quality of life for children. This mini-symposium will present an overview of the genetic and neural bases of childhood motor speech disorders and provide evidence-based frameworks for their assessment and management. At the end of the session, participants will be able to identify and treat dysarthria and CAS.

**Origins of motor speech disorders:** We will discuss how magnetic resonance imaging has transformed our ability to study brain and speech behaviour relationships, causing us to question existing motor speech classification systems. We will also discuss how advances in genetic analysis are transforming our knowledge of the neurobiological or aetiological bases of motor speech disorders.

**Dysarthria:** Discussions on dysarthria assessment will cover three domains: impairment of voice and speech function; speech activity limitations; and communicative participation restrictions. We will provide an overview of research on the effects of treatment for dysarthria on children's speech characteristics, intelligibility, communication, and social participation, and place specific emphasis on systems-based and single-target treatment approaches. We will describe how to integrate motor learning principles into speech treatment and provide suggestions for games and activities for promoting intelligibility.

**CAS:** A focus on the motor planning and programming deficits unique to CAS will be presented, including comparison with dysarthria and linguistic speech impairments. Four CAS treatments with current best evidence will be discussed; determining which aspects of CAS they treat and emphasizing key ingredients for practice.

**Improving saliva control – a multidisciplinary approach to assessment and management from the Australian and Dutch teams**

Dinah S Reddihough<sup>1</sup>, Louise Baker<sup>2</sup>, Peter Jongerius<sup>3</sup>, Karen Van Hulst<sup>4</sup>, Susan M Reid<sup>5</sup> and Jan Van Der Burg<sup>6</sup>

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Poor saliva control (drooling) is a significant problem for young people with cerebral palsy and other neurological impairments. The secretions damage clothing, books and computer equipment. Drooling impedes successful integration into home, school and community life. Successful management results in improved self-esteem and peer acceptance. Assessment and treatment requires a multidisciplinary team.

The purpose of this symposium is to educate participants about the options that are available for the management of saliva control along with the scientific evidence for each treatment. The teams from Australia and the Netherlands have adopted a hierarchical approach from the least to the most invasive treatment. Optimal methods of assessment and the scales to evaluate change will be discussed. Areas covered will include behavioural approaches, medication, Botulinum toxin injections and surgery. The symposium will highlight research directions that are being pursued in the Netherlands and Australia. By the conclusion of the symposium, participants will have an improved understanding of strategies to approach this challenging problem.

Karen van Hulst, a speech pathologist, will discuss the Drooling in Infants and Preschoolers-Survey (DRIP-s) and multidisciplinary assessment. Speech pathology approaches will be described.

Sue Reid, a senior research officer, will give details of how the Drooling Impact Scale was developed and how it is now being used in day to day management.

Jan van der Burg, a psychologist who has undertaken research regarding the use of intense behavioural approaches, will describe how this work can be implemented in practice.

Louise Baker, a paediatrician, will provide an overview of the use of medication.

Peter Jongerius, a rehabilitation specialist, will provide an overview of the use of Botulinum toxin along with research in this area.

Dinah Reddihough, a paediatrician, will discuss saliva control surgery.

## **Creation of a National CP Registry & Its Use as a Platform for Discovery**

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**Background:** Traditionally registries focus on incidence, prevalence, and identification of risk factors. **Aim:** This symposium shows how the Canadian CP Registry is also used to define the CP phenotype and to enable clinical research to include the genetics of CP. **Method:** Creation of the registry was not a linear process. Policy and funding imperatives shaped its character, content and magnitude. A network based on trust was forged by answering basic questions and needs consensually and addressing pragmatic challenges to implementation. **Result:** Registry data are defining the national phenotype of CP, its regional variations and associated socio-demographic and economic factors and providing clues to explain the observed patterns. Understanding these associations in the etiology of CP will influence prevention policy efforts. The registry's data collection is a framework for ongoing collaborations among centers and a platform for population-based clinical research projects. Thus, knowing the age of referral diagnosis in current practice and reasons for delays will inform evidence-based knowledge translation efforts promoting early diagnosis and more timely rehabilitation interventions. An environmental scan of rehabilitation service utilization will examine child and environmental factors mediating access to services. Registry data, by defining the CP phenotype, also enable the application of emerging technologies to begin to unravel the genetics of CP, support case-ascertainment in an unbiased manner and facilitate subject recruitment for genetic testing. Collaborations among clinical, basic and epidemiologic researchers insure a robust and contextual interpretation of the data. **Conclusion:** Registries are powerful tools that can function as scaffolds, enablers or catalysts of innovative research projects, not envisaged at the outset, that improve our understanding of the pathogenesis of CP, lead to more timely diagnosis, better interventions and clues to prevention.

## **Augmented mobility and participation for children with cerebral palsy**

Elisabet Rodby Bousquet<sup>1</sup>, Ginny Paleg<sup>2</sup>, Roslyn Livingstone<sup>3</sup> and Debbie Field<sup>3</sup>

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There is a relationship between independent mobility, overall development and participation in everyday life for children with disabilities. Children need to move independently in order to play and explore their environment; prime childhood behaviors that facilitate growth and learning. Infants and toddlers with motor impairments, as well as children with intellectual impairment, benefit from independent mobility experience to enhance overall development, while older children and adolescents need efficient mobility to enhance their participation in meaningful activities at home, at school and out in the community. With all available research on the benefits of enhancing early mobility and the growing evidence that manual wheelchairs are not always the solution for children who wish to attain independent wheeled mobility, power mobility should be an option, along with other methods, to augment mobility.

This mini-symposium will present research supporting the use of power mobility in children with disabilities; describe the use of manual and power wheelchairs in children with cerebral palsy, risk factors for not attaining independent wheeled mobility; and assessment tools for power mobility use and participation in daily life. Four clinicians and researchers from different countries will present best evidence-based practice and discuss physical, social and environmental factors influencing the acquisition and learning of power mobility skills in children.

Roslyn Livingstone, OT (CAN) - Best practice considerations for power mobility and its impact on children's development.

Debbie Field, OT (CAN) – Measuring participation in daily life for those who use power mobility.

Elisabet Rodby Bousquet, PT (SWE) - Use of manual and power mobility, and risk factors influencing wheeled mobility.

Ginny Paleg, PT, (USA) - Case stories demonstrating use of power mobility devices and gait trainers in different settings.

Discussion and questions.

**Beyond borders. Best practices to promote self-management and life skills of emerging adults with childhood onset disability**

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**Background**

In their transition to adulthood young people with disabilities may experience problems in building their own lives and taking responsibility for their health. A key element for young people with a disability is to learn how to self-manage life. Using this element, Dutch and Canadian Rehabilitation Institutes developed a series of interventions for emerging adults to discover and strengthen their self-management and life skills. We aim to share these best practices internationally, to facilitate broad implementation of transition programs.

**Content**

Four interventions for young adults with disabilities will be presented by speakers of Rehabilitation Institutes that are innovative in transition and lifespan care and research. With the use of practical examples and discussion on feasibility and preliminary effectiveness of the interventions we encourage interaction with participants of the symposium.

Gorter: Self-management promotion in a Teen-Transition clinic setting. He will demonstrate the use of the Youth KIT, individualized self-management goals and the TRANSITION-Q.

van der Slot: Intervention 'Manage Your Life' in a young adult rehabilitation clinic. This is a group intervention aiming to promote self-management and autonomy of young adults with disabilities.

King: Residential Immersive Life Skills Programs. Away-from-home programs for youth with disabilities, which take place in university or college residences. Participants acquire new insights, self-realizations, and positive yet realistic views of the future.

Roebroek: Intervention At Work?!, converging rehabilitation and vocational services in one program. The intervention supports young adults with disabilities to find and keep suitable work.

**Learning objective**

To gain knowledge on implementing interventions to promote autonomy and self-management of young adults with childhood onset disabilities.

**Audience targeted**

Clinicians and researchers in pediatric and adult care.

## **WHAT ABOUT US? FINDING SOLUTIONS TO THE CHALLENGES OF PROVIDING THERAPY SERVICES TO CHILDREN WITH CEREBRAL PALSY LIVING IN UNDERSERVED AFRICAN SETTINGS**

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Sub-saharan Africa makes up 11% of the world's population, accounts for 24% of the global disease burden, is home to just 3% of the global health workforce but commands less than 1% of global health expenditure. Health care delivery infrastructure is inadequate with skilled health care workers and essential medicines in short supply. With diseases such as malaria, TB and HIV dominating the health agenda, it not surprising that children with cerebral palsy (CP) enjoy little attention. Therapists specialized in working with children with CP are scarce and the majority of children go untreated whilst families remain uninformed and unaware of simple measures which could make a meaningful difference.

Most therapy interventions described in the literature have little relevance to children with CP in Africa. Where services are available, the mainstay of therapy is passive movements combined with massage and little if any emphasis on activity or participation. Yet, in these settings, the need for creative, innovative and resource-efficient strategies is paramount.

Despite the fact that the evidence base of interventions that work in underserved settings is limited and research to establish effectiveness of therapeutic strategies viewed as an unaffordable luxury, many models of good practice have emerged. Key elements of these models include (i) training and (ii) an embedded community based rehabilitation approach.

Panel members will describe how intervention services in underserved African settings were transformed through the incorporation of these key elements. The purpose of discussion is to illustrate how the challenges of providing therapy for children with CP in the absence of clinical specialists can be overcome; and how traditional impairment based strategies can be transformed. It is envisaged that anyone from resource-constrained settings, whether urban or rural, within or outside the African continent will benefit from the panel's collective experience.

## **ICF Core Sets for children and youth with CP: Embracing functional abilities and cultural differences**

Veronica Schiariti<sup>1</sup>, Anjan Bhattacharya<sup>2</sup>, Shahnaz H. Ibrahim<sup>3</sup> and Maria Krol<sup>4</sup>

<sup>1</sup>Pediatrics, University Of British Columbia, Vancouver, Canada

<sup>2</sup>Pediatrics, Apollo Gleneagles Hospital, Kolkata, India

<sup>3</sup>Pediatrics, Aga Khan University, Karachi, Pakistan

<sup>4</sup>Pediatrics, The Step By Step Association For Help To Disabled Children In Zamosc, Zamosc, Poland

This mini-symposium will be of interest to clinicians, researchers, and educators. The ICF Core Sets are ICF-based tools that serve as an overarching framework, systematically outlining critical information for assessment, management, and evaluation. This important information can guide deliver appropriate interventions for children with CP.

Purpose: 1) To demonstrate the clinical applications of the new ICF Core Sets for children and youth with CP; and 2) To illustrate ongoing applications and cultural validation in different WHO health regions.

Learning Objectives:

- 1) To introduce the new ICF Core Sets for children and youth with CP.
- 2) To, through the use of scenarios, enhance learners' practical ability to apply the ICF Core Sets in everyday practice.
- 3) To describe ongoing work on cultural validation of the ICF Core Sets worldwide.

Speakers:

Dr. Veronica Schiariti is a Developmental Pediatrician working at the University of British Columbia, Canada. Dr. Schiariti led the development of the ICF Core Sets for children and youth with CP in collaboration with the ICF Research Branch of the WHO-FIC.

Dr. Anjan Bhattacharya, is a Senior Consultant Developmental Paediatrician, who established the first multidisciplinary CDC in Kolkata. Dr. Bhattacharya is leading the cultural validation in India.

Dr. Shahnaz Ibrahim is a pediatric neurologist working at the Aga Khan University Karachi, Pakistan. Dr. Ibrahim is leading the cultural validation in Pakistan.

Dr. Maria Krol is a mother of a disabled CP child and the President of The Step by Step Association for Help to Disabled Children in Zamosc. Dr Krol is leading the cultural validation in Poland.

Format:

Dr Schiariti: Introduction to the ICF Core Sets for children and youth with CP.

Drs. Bhattacharya and Ibrahim: Overview of cultural validation in India and Pakistan.

Dr.Maria Krol: Cultural validation in Poland.

Final remarks: Implications for services, teaching and administration.

Q&A



**Global Professional Education Programme (GPEP) - workshop**

Arnab Seal<sup>0</sup>, James Rice<sup>0</sup>, Peter Rosenbaum<sup>0</sup>, Sarah Love<sup>0</sup>, Jenny Carroll<sup>0</sup> and Diane Damiano<sup>0</sup>

This exciting session is the first open meeting of the Global Professional Education Programme initiative by the International Alliance of Academies of Child Disability (IAACD). The goal of the programme is to foster international collaborations, to have common evidence-based principles of practice, applicable in the local/cultural context and have a common platform of learning and sharing for all professionals working in this field. The team leading the initiative is undertaking a survey of training needs, existent expertise and resources. You will have received an invitation to complete the survey. The results of the survey and emerging themes will be presented at the session. It will offer an opportunity for all professional colleagues enthusiastic about teaching and training in child disability, involved in delivering and receiving training anywhere in the world, to share ideas, discuss needs, identify existent resources and help plan the next steps. Please join and be a part of this fantastic initiative. We need you!

## **Virtual Reality Based Therapy in Cerebral Palsy: Current Evidence and Future Directions**

Deepak Sharan<sup>1</sup>, Patrice L. (Tamar) Weiss<sup>2</sup> and Roslyn N Boyd<sup>3</sup>

<sup>1</sup>Orthopaedics, Rehabilitation And Ergonomics, RECOUP Neuromusculoskeletal Rehabilitation Centre, Bangalore, India

<sup>2</sup>Occupational Therapy, University Of Haifa, Haifa, Israel

<sup>3</sup>Queensland Cerebral Palsy And Rehabilitation Research Centre, University Of Queensland, Brisbane, Australia

Virtual reality based therapy (VRBT) is the use of interactive simulations to present users with opportunities to perform neurorehabilitation in virtual environments that appear, sound, and less frequently, feel similar to real-world objects and events. Interactive computer play refers to the use of a game where a child interacts and plays with virtual objects in a computer-generated environment. Because of their distinctive attributes that provide ecologically realistic and motivating opportunities for active learning, and for their possibility to quantify improvement, these technologies have been used in paediatric rehabilitation for the past 15 years. The ability of virtual reality to create opportunities for active, repetitive motor/sensory practice adds to their potential for neuroplasticity and learning in individuals with neurological disorders such as cerebral palsy (CP). The task of building VRBT systems that are both usable and useful is a challenging endeavour that requires an interdisciplinary mix of domain-specific knowledge. The objectives of this mini-symposium involving an Orthopaedic Surgeon, Rehabilitation Physician and Ergonomist, an Occupational Therapist and an Engineer is to provide an overview of how VRBT is used clinically in the rehabilitation of CP, its current limitations and to explore the likely future developments. All the speakers are published authors on the use of VRBT in CP.

Programme outline:

1. Introduction, scientific rationale, limitations and adverse effects of VRBT in CP (Marco Iosa, 16 min)
2. Indications and currently available types of off-the-shelf games or customised VRBT systems (Deepak Sharan, 16 min)
3. Current evidence regarding clinical efficacy of VRBT in CP and the key future directions (Tamar Weiss, 16 min)
4. Discussion, Q&A (12 min)

## **Spinal Deformity in Cerebral Palsy: A Discussion of Treatments and Review of Outcomes**

Wade Shrader<sup>1</sup>, Freeman Miller<sup>2</sup>, Joshua Hyman<sup>3</sup> and Athanos Tsirikos<sup>4</sup>

<sup>1</sup>Department Of Orthopedic Surgery, Children's Hospital Of Mississippi, Jackson, MS, USA

<sup>2</sup>Pediatric Orthopedic Surgery, A.I. Dupont Insitute, Wilmington, DE, USA

<sup>3</sup>Pediatric Orthopedic Surgery, Columbia University, New York, NY, USA

<sup>4</sup>Orthopedic Surgery, Scottish National Spine Deformity Centre, Edinburgh, Scotland

This course will present an overview of the management of spinal deformities in children with cerebral palsy (CP). Specifically, the speakers will discuss initial treatment strategies (bracing), surgical indications, preoperative assessment, intraoperative deformity correction, postoperative care, and a review of the treatment outcomes.

The impact of these deformities and spinal surgeries on the patient and their family will be discussed within the context of the International Classification of Functioning, Disability and Health (ICF). All types of spinal deformities that children with CP develop will be discussed, including the epidemiology and initial treatment strategies (bracing and seating modification). Surgical indications will be presented, and protocols for preoperative assessment will be demonstrated to reduce the risks of postoperative complications. In particular, the order of surgical priorities (hip reconstruction versus spine fusion) will be discussed about which should be done first. Surgical management will be discussed thoroughly, including intraoperative management, deformity correction and implant selection. Postoperative pathways will be provided, including post-surgical seating adjustments. A review of the health-related quality of life outcomes of spinal fusion from the literature will be presented. A critical analysis of perioperative complications will be discussed, including a discussion of ways to minimize the risk of complications in this at-risk, fragile patient population.

### **Course Format:**

Introduction, Overview of Course Objectives: M. Wade Shrader, M.D.

Initial Management/Bracing/Seating: Freeman Miller, M.D.

Preoperative Assessment/Medical Management: M. Wade Shrader, M.D.

Intraoperative Management, Deformity Correction and Implant Options: Athanos Tsirikos, M.D.

Review of the Literature and Outcomes: Joshua Hyman, M.D.

Case Presentations, Audience Participation, and Question & Answer session: All speakers

## **Cost effective prevention and management of Cerebral Palsy**

Pratibha Singhi<sup>1</sup>, Michael Johnston<sup>2</sup>, Michael Shevell<sup>3</sup> and Sunanda Kolli Reddy<sup>4</sup>

<sup>1</sup>Department Of Pediatrics, Advanced Pediatrics Centre, Postgraduate Institute Of Medical Education & Research, Chandigarh, India

<sup>2</sup>Pediatric Neurology, John Hopkins University, Kennedy Institute, Baltimore, USA

<sup>3</sup>Departments Of Pediatrics And Neurology/Neurosurgery , McGill University Health Centre (MUHC), Montreal, Canada

<sup>4</sup>Pediatrics , Centre For Applied Research And Education On Neurodevelopmental Impairments And Disability-Related Health Initiatives (CARENIDHI), New Delhi , India

Newer strategies for prevention and management of cerebral palsy are being discovered and used mainly in resource rich countries. However, almost 80% of children with disability live in resource poor countries. It is therefore important that these strategies be applied in countries where they are needed the most i.e. resource limited countries.

There have been recent developments in protecting the neonatal brain and modifying outcomes for infants at risk for later cerebral palsy. These include magnesium sulphate for preterm births and therapeutic hypothermia for term intrapartum asphyxia. If applied on a population-wide basis they are likely to significantly reduce subsequent disability. Cost-savings potentially exist that could be of an enormous magnitude in especially low resource settings. However, there is a lack of translation which may be due multiple factors. Various classes of barriers will be explored and potential solutions will be posited. Recently a convective cooling device has been developed that is effective but very inexpensive. There are also newer strategies such as nano particle dendrimer delivery techniques that deliver N-acetyl-cysteine across the blood brain barrier to reduce inflammation in a rabbit model of CP. Translation of these techniques in human beings would be very promising.

Only 2% of children in resource poor countries have access to rehabilitation facilities. Home based therapy wherein parents are partners in the care of their children, is being recognized as an important strategy in the management of children with special needs particularly in resource limited countries.

Early Intervention (EI) in the community and Institution based Rehabilitation may be viewed as complementary strategies in a developing world context. One of the many models of Community Based EI wherein the core components of an integrated service delivery approach to ECCD as well as and linkages to determinants of health in the community will be discussed.

## **Prevention of CP – where are we up to?**

Nadia Badawi<sup>1</sup>, Darcy Fehlings<sup>2</sup>, Iona Novak<sup>3</sup>, Sarah McIntyre<sup>3</sup>, Sue Reid<sup>4</sup> and Karen Walker<sup>1</sup>

<sup>1</sup>Grace Centre For Newborn Care, Cerebral Palsy Alliance/The Children's Hospital At Westmead, Sydney, Australia

<sup>2</sup>Division Of Developmental Paediatrics, University Of Toronto, Toronto, Canada

<sup>3</sup>Research Institute, Cerebral Palsy Alliance, Sydney, Australia

<sup>4</sup>Children's Research Institute, Murdoch Children's Research Institute, Melbourne, Australia

Increasing research efforts around the world have identified risk factors for CP in the perinatal, neonatal and infant period . The myriad of known etiological pathways that can interfere with brain development paints a complex picture. The ultimate goal of research is to prevent or ameliorate CP, with breakthroughs now starting to emerge.

Antenatal steroids and magnesium sulphate, as well as therapeutic hypothermia are now part of standard medical care. Whilst looking for possibilities for primary prevention, neuroprotective strategies for antenatal and intrapartum hypoxia such as erythropoietin, melatonin, creatine and xenon are currently being trialled. Stem cells trials are also currently under way using a variety of cell lines to reduce inflammation and induce neuro-regeneration.

The strong association between birth defects and CP is prompting a call for a shift in research priorities into the etiology of CP. Expanding the research focus to include congenital anomalies (such as congenital heart disease) has the potential to pave the way for the discovery of new preventive strategies.

CP registers are the gold standard for evaluating whether research breakthroughs and changes in practice are translating into real life improvements in motor outcomes .Studies from Australia and the Netherlands have shown a drop in the rate and severity of CP, particularly among preterm babies, which have been attributed to improvements in perinatal and neonatal care.

This panel will present evidence from the most up to date research and discuss with participants further possibilities to improve outcomes. Participants will be invited to join IMPACT for CP, the International Multidisciplinary Prevention and Cure Team for Cerebral Palsy.

## **Prevention of Cerebral Palsy and Childhood Disability - Is the Impossible Possible?**

David W. Walker<sup>1</sup>, Hayley Dickinson<sup>1</sup>, Jan Derks<sup>2</sup>, Jon J Hirst<sup>3</sup>, Suzie Miller<sup>1</sup>, Irina Burd<sup>4</sup>, Peta Grigsby<sup>5</sup>, Mary Tolcos<sup>1</sup> and Lawrence Sherman<sup>5</sup>

<sup>1</sup>The Ritchie Centre, Hudson Institute Of Medical Research, Melbourne, Australia

<sup>2</sup>Dept. Of Perinatal Medicine Wilhelmina Children'S Hospital, University Medical Center Utrecht, Utrecht, Netherlands

<sup>3</sup>School Of Biomedical Sciences And Pharmacy, University Of Newcastle, Newcastle, Australia

<sup>4</sup>Obstetrics & Gynecology, John Hopkins University, Baltimore, USA

<sup>5</sup>Oregon National Primate Research Center, Oregon Health Sciences University, Portland [OR], USA

In this mini-symposium we will discuss and evaluate the proposal that antenatal and very early post-birth treatments are available that can dramatically decrease, and even eliminate the brain damage that arises from fetal oxygen deprivation. While such treatments would be expected to be delivered only to 'at risk' patients (i.e., where fetal compromise is already suspected), we will present evidence that there are treatments that are not only protective against the effects of severe fetal hypoxia, but in themselves benign, and can therefore be recommended for use in most pregnancies. We will discuss treatments that are either inexpensive dietary interventions (e.g., creatine), or simple treatments that effectively decrease oxidative stress (e.g., allopurinol, melatonin) and the impact of infection on the feto-placental unit (e.g., maternal immunomodulation). We will present evidence that manipulation of neurosteroids, thyroid status, and hyaluronidases may each provide options for treatments that prevent devastating injury to white matter in the perinatal brain. Importantly, we will discuss the suitability of these approaches for use in environments other than tertiary level hospital care - for example, under-developed and developing countries - where the burden of intrapartum and postpartum brain damage and cerebral palsy is the greatest.

**Supporting lifelong health-related fitness and physical behaviour among individuals with Cerebral Palsy**

Wilma MA Van Der Slot, MD PhD<sup>1</sup>, Mark D Peterson, PhD<sup>2</sup>, Rita J.G. Van Den Berg-Emons, PhD<sup>3</sup> and Jan Willem Gorter, MD PhD<sup>4</sup>

<sup>1</sup>Rijndam Rehabilitation Institute And Erasmus MC, University Medical Center, Rotterdam, Netherlands

<sup>2</sup>Physical Medicine And Rehabilitation, University Of Michigan-Medicine, Ann Arbor, MI, United States

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<sup>4</sup>School Of Rehabilitation Science And Canchild Centre For Childhood Disability Research, McMaster University, Hamilton, Canada

Despite a paucity of evidence, health-related physical fitness and activity are thought to have a positive effect on health and quality of life in individuals with cerebral palsy (CP). This mini-symposium will integrate information based on research and ongoing clinical practice from the Stay-FIT Research Program in Canada, work pertaining to secondary health complications of chronic inactivity from the U.S.A., and the MoveFit Research Program in The Netherlands. Chronic disease burden in CP through the lifespan will be a central focus of this symposium. In addition, viable interventions that may lessen the health burden of ageing with CP will be presented. Health-related fitness impairments and intervention options will be discussed in the context for individuals with CP, but also with respect to other childhood onset disabilities.

This mini symposium will bring together research from three countries focusing on underlying mechanisms and promotion of health-related fitness and physical activity of individuals with CP during adolescence, and transition into and throughout adulthood.

It is relevant for everyone interested in health-related fitness and activity in individuals with CP including researchers, therapists, physicians, and kinesiologists.

## **Long term consequences of Cerebral Palsy**

Wilma MA Van Der Slot, MD PhD<sup>1</sup>, Marij E Roebroek, PhD<sup>2</sup>, Reidun B Jahnsen, PT PhD<sup>3</sup> and Johannes Verheijden<sup>4</sup>

<sup>1</sup>Rijndam Rehabilitation Institute And Erasmus MC, University Medical Center, Rotterdam, Netherlands

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<sup>3</sup>Oslo University Hospital And Oslo And Akershus University College, Oslo, Norway

<sup>4</sup>Association Of People With Physical Disabilities, BOSK, Utrecht, Netherlands

Cerebral palsy (CP) is a lifelong disability with many secondary conditions. As a consequence adults with CP often experience progressive activity and participation limitations. Also early ageing is suggested. These new challenges require self-management skills of persons with CP as well as adequate health care resources. In Norway and The Netherlands various scientific studies on adults with CP were performed. Common symptoms that were found in both the Dutch and Norwegian studies are chronic pain (up to 75%), fatigue (over 30%) and depressive symptoms (25%). Often reported difficulties in daily activities and participation were mobility, housing, recreation, employment and personal care. Furthermore, people with CP showed disadvantaged positions for living with a partner and having children, as compared to the general population. Participation restrictions may coincide with feelings of loneliness and affect well-being.

In this mini-symposium research data will be presented on ageing, health issues and participation from Norwegian, Dutch and other studies. Attention will be given to unravelling health issues in adults with CP and treatment options. We will present research data on expectations and experiences of adults and discuss the role changes while ageing. Finally, the user perspective will be presented by the Dutch Association of People with Physical Disabilities, including take home messages on training of self-determination early on in life.

This mini-symposium is relevant for adult health care workers, and for pediatric professionals to improve follow-up of children with CP and assist them throughout adulthood.



## **Physical activity in cerebral palsy across the continuum**

Olaf Verschuren<sup>1</sup>, Astrid Balemans<sup>1</sup>, Annet Dallmeijer<sup>2</sup>, Mark Peterson<sup>3</sup> and Edward Hurvitz<sup>3</sup>

<sup>1</sup>Brain Center Rudolf Magnus And Center Of Excellence For Rehabilitation Medicine, University Medical Center Utrecht And De Hoogstraat Rehabilitation, Utrecht, The Netherlands

<sup>2</sup>Rehabilitation Medicine And EMGO Institute For Health And Care Research, VU University Medical Center, Amsterdam, The Netherlands

<sup>3</sup>Department Of Physical Medicine And Rehabilitation, University Of Michigan, Ann Arbor, MI, USA

Levels of physical activity (PA) can be viewed on a continuum, with sedentary behavior (SB) on one end and the peak level of exercise training on the other end. The low levels of many people with CP are worrisome, as health outcome and survival may be directly related to PA. The focus of this symposium, that will integrate findings from research and clinical practice, is on PA across the activity continuum for improving health and fitness in CP. There will be specific emphasis on SB, peak level of exercise, relative intensity of walking, prevalence of preventable, secondary conditions, and implementation research.

The physiology of SB in persons with CP and the methodological nuances of measuring SB will be discussed. This will be followed by an overview of the knowledge on the peak level of exercise. Since most people with CP have an abnormal gait pattern, it is important to look at the relative measure of intensity of walking. Findings from the exercise lab in which insight in relative intensity of activities are obtained will be presented. Knowledge on how this information can attribute to a more tailored advice for people with CP will be shared. To summarize this part of the symposium CP-specific, evidence-based PA and exercise guidelines and recommendations will be presented.

Lastly, new research pertaining to the high prevalence of preventable, secondary conditions that occur among adults with CP, as well as the mediating role of functional preservation and PA to ameliorate those consequences will be presented. Research into benefits of PA in CP, and some implementation research that report solutions for the challenges associated with incorporating PA into the lives of persons with CP will be discussed. This symposium will be closed with a discussion of implementation research, the challenges that have been identified in making PA part of people's lives, especially with CP, and innovative ideas to surmount these challenges in the clinic and in the community.

## **Investigating brain structure and function in Cerebral Palsy – State of the art and emerging technologies**

Brigitte Vollmer<sup>1</sup>, Ingeborg Kraegeloh-Mann<sup>2</sup>, Roslyn Boyd<sup>3</sup>, Andrea Guzzetta<sup>4</sup>, Chris Clark<sup>5</sup>, Giovanni Cioni<sup>6</sup> and Diane Damiano<sup>7</sup>

<sup>1</sup>Clinical Neurosciences, University Of Southampton, Southampton, England

<sup>2</sup>Neuropaediatrics, University Children's Hospital, Tuebingen, Germany

<sup>3</sup>Queensland Cerebral Palsy And Rehabilitation Research Centre , The University Of Queensland, Centre For Children'S Health Research, Brisbane, Australia

<sup>4</sup>Infant Neurology Section, University Of Pisa - Stella Maris Scientific Institute, Pisa, Italy

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<sup>6</sup>Dept. Of Developmental Neuroscience , University Of Pisa-Stella Maris Scientific Institute , Pisa, Italy

<sup>7</sup>Functional &Applied Biomechanics Section, NIH Clinical Centre, Bethesda, USA

Neuroimaging and Neurophysiology provide essential information on etiology and pathogenesis as well as on associations between neural correlates and functional outcomes in Cerebral Palsy (CP). Both conventional structural and advanced MRI techniques are increasingly used in the investigation of different aspects of CP. Conventional structural MRI is used in both clinical and research context, whereas advanced techniques, such as Diffusion MR tractography, are primarily applied in research, but are fast approaching translation into clinical practice. Similarly, mobile functional neuroimaging and neurophysiology techniques such as Near Infrared Spectroscopy (NIRS) and electroencephalography (EEG) are now being used as stand-alone techniques or, increasingly, in combination with anatomical imaging. The purpose of this symposium is to provide an overview on current common approaches to use information from conventional structural MRI in a qualitative or semi-quantitative manner (pattern recognition, scoring systems), and also to provide an overview on established and emerging advanced structural and functional imaging techniques that can be applied to study the brain in CP. The emphasis will be on possibilities, complementary use, limitations, and pitfalls of such approaches when examining different aspects of CP.

Ingeborg Krageloh-Mann: MRI Classification system for children with cerebral palsy and relation to function

Roslyn Boyd/Andrea Guzzetta: Semi-quantitative and automated lesion scoring system for conventional structural MRI in CP and associations to function

Chris Clark: Diffusion MRI and tractography techniques for investigation of early acquired brain lesions and associations with motor function

Giovanni Cioni: Preliminary anatomical and functional MRI data from ultra-high field MRI in congenital brain lesions

Diane Damiano: Mobile technology for investigating brain function in CP - Near infrared spectroscopy and EEG

Chair: Brigitte Vollmer

**Brain structure and motor and cognitive development in infants, children, and young adults born preterm**

Brigitte Vollmer<sup>1</sup>, Kerstin Pannek<sup>2</sup>, Roslyn Boyd<sup>3</sup>, Ulrika Aden<sup>4</sup> and Ingeborg Kraegeloh-Mann<sup>5</sup>

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<sup>3</sup>Queensland Cerebral Palsy And Rehabilitation Research Centre , The University Of Queensland, Centre For Children'S Health Research , Brisbane, Australia

<sup>4</sup>Women's And Children's Health, Karolinska Institutet, Stockholm, Sweden

<sup>5</sup>Neuropaediatrics, University Children's Hospital, Tuebingen, Germany

Preterm children, in particular those born very and extremely preterm are at high risk for focal or diffuse brain injury and altered brain development from neonatal to adult age. This symposium will first provide an overview of recently developed advanced MRI acquisition, processing, and analysis techniques (e.g. multi-shell diffusion imaging, including tractography, Neurite Orientation Dispersion and Density Imaging) that are likely to be useful and increase sensitivity when investigating brain development after preterm birth in the preterm, neonatal and post-neonatal period. Second, we will discuss how early brain structure in very and extremely preterm infants assessed with conventional structural MRI (using semi-quantitative scoring scales) and advanced MRI (e.g. Diffusion MRI techniques, volumetry) is related to outcomes at infant, toddler and school age. Third, we will present cross-sectional data on brain structure and executive function in young adults born very preterm.

Kerstin Pannek: Advanced imaging techniques to study the neonatal brain

Roslyn Boyd: Early brain structure and relationships with neuromotor and neurobehavioural assessments at 30 and 40 weeks postmenstrual age

Ulrika Aden: Early brain structure and relationships with outcomes at age 30 months and 6.5 years in extremely preterm children

Brigitte Vollmer: Brain structure and associations with cognitive and executive functions in young adults born preterm

Chair: Ingeborg Kraegeloh-Mann



## **Instructional Courses**

## **When is a problem a problem? Evaluation of oropharyngeal dysphagia in preschool children with cerebral palsy**

Katherine A Benfer<sup>1</sup>, Kelly A Weir<sup>2</sup> and Roslyn N Boyd<sup>1</sup>

<sup>1</sup>Queensland Cerebral Palsy And Rehabilitation Research Centre, The University Of Queensland, Brisbane, Australia

<sup>2</sup>Speech Pathology Department, Lady Cilento Children's Hospital, Brisbane, Australia

### **Background**

Oropharyngeal dysphagia (OPD) is common in preschool children with cerebral palsy (CP), prevalent in about 60% of children, and affects oral and pharyngeal phases of swallowing, and saliva control. An understanding of the patterns of OPD across the full spectrum of CP (mild to severe) forms a critical foundation for planning feeding and nutritional management. Data based on the prevalence and patterns of OPD in a population-based longitudinal cohort of 181 children with CP assessed at 18, 36 and 60 months (with 438 data points) will be presented.

### **Learning objectives**

This workshop aims to facilitate participant discussion regarding the question “When is a problem a problem?” when considering evaluation of a child with OPD and CP. Specifically, this workshop focuses on the following learning objectives:

To identify the most effective measures for evaluating OPD in preschool children with CP (including clinical evaluation, cervical auscultation and videofluoroscopic swallow study (VFSS)). Results of systematic review and findings from application to a cohort of children with CP will be presented (including validation against a sample with typical development).

To understand the health impacts associated with various subtypes and severity of OPD.

To understand the potential longitudinal progression of OPD in children with CP at 18 months, during this important period of feeding development (18-60 months).

To review the OPD intervention literature, discussing the application of evaluation data in selecting treatment targets.

### **Audience targeted**

Clinicians involved in the management of dysphagia/ feeding difficulties (speech, occupational and physical therapists; dietitians; physicians), and those working in early intervention.

### **Format**

This interactive workshop centres around 3 longitudinal cases of children with CP and possible OPD (GMFCS I, III, V). It includes assessment results (clinical, and VFSS when available) from 18, 36 and 60 months.

**Motor learning-based approaches to intensive neurorehabilitation: dosage, ingredients and environment for efficacious treatment in children with cerebral palsy**

Yannick Bleyenheuft<sup>1</sup>, Kathleen M Friel<sup>2</sup>, Dido Green<sup>3</sup> and Andrew M Gordon<sup>4</sup>

<sup>1</sup>Institute Of Neuroscience, Université Catholique De Louvain, Brussels, Belgium

<sup>2</sup>Clinical Laboratory For Early Brain Injury Recovery, Burke-Cornell Medical Research Institute, White Plains, New York, USA

<sup>3</sup>Centre For Rehabilitation, Oxford Brookes University, Oxford, United Kingdom

<sup>4</sup>Biobehavioral Department, Teachers College, Columbia University, New York, USA

**Content:** Cerebral palsy (CP) is the most common pediatric motor disability. Many successful strategies of rehabilitation are based on use-induced plasticity, with key commonalities of being both intensive and active participation of the child. This course will focus on approaches providing high treatment dosages and variable ingredients to elicit neural plasticity to promote functional abilities of children with CP. The role of structured, skill practice will be discussed in relation to functional changes and neuroplasticity. The importance of treatment intensity, as well as the extent to which brain lesions and organization predict outcomes to unimanual vs bimanual training, will be considered in relation to subsequent changes in cortical hand maps and functional capacity. Alternative models for providing intensive treatment will be discussed. Finally, the addition of a lower extremity and postural component during bimanual intervention will be presented, as well as the potential application of these approaches to other forms of CP. These topics are of direct interest for translating research findings into clinical practice. **Learning objectives:** to provide useful information for translating research into clinical intervention programs for children with CP. **Audience targeted:** Physiotherapists, occupational therapists, scientists. **Format:** Talks (15 min) by the 4 instructors will target their specific knowledge, i.e. use-induced upper extremity therapy in children with unilateral CP, motor learning, treatment intensity, ingredients of training and neuroplasticity (AM Gordon); neural predictors of intensive training efficacy, and motor-cortical plasticity associated with training (KM Friel); theme-based training, motivational context (D Green); and, adding a lower extremity/postural component to bimanual training (Y Bleyenheuft). These outcomes will be considered with respect to intensity, duration and context of intervention in order to optimize long-term outcomes.

## **Getting started with your own virtual community of practice to implement best practice in childhood disability: an example in developmental coordination disorder (DCD)**

Chantal Camden<sup>1</sup>, Karen Hurtubise<sup>1</sup>, Lisa Rivard<sup>2</sup>, Jade Berbari<sup>3</sup> and Isabelle Demers<sup>4</sup>

<sup>1</sup>School Of Rehabilitation, Sherbrooke University, Sherbrooke, Canada

<sup>2</sup>Applied Health Sciences, McMaster University, Hamilton, Canada

<sup>3</sup>Pediatric, Sherbrooke University, Sherbrooke, Canada

<sup>4</sup>Children's Program, IRDPQ, Québec City, Canada

### **Background:**

Communities of practice (CoP) are described as formal or informal networks of people with a common interest who interact on an ongoing basis, sharing and co-creating knowledge over a sustained period of time. CoP are considered to be an effective KT strategy, having the potential of changing behaviour, improving the quality of patient care, and saving costs. The Internet provides interesting and novel learning, communication and resource sharing opportunities, bridging geographical gaps and facilitating the expansion and diversity of the networks and available resources. Despite the growing interest for CoP and the use of the Internet to decrease the knowledge-to- practice gap, little is known about to foster the use of virtual CoP (vCOP) in fostering the implementation of best practices in childhood disabilities.

A recent research initiative provided our group with unique skills, knowledge and experience in the use of a vCOP in promoting practice change in paediatric physiotherapists across a large geographically diverse area in Canada. Lessons learned could help others to resolve ongoing challenges in fostering evidence uptake related to childhood disabilities into clinical practice.

### **Learning objectives:**

1. Explore the reasons to initiate a vCOP for a specified childhood disability
2. Define the crucial characteristics for a CoP
3. Analyse the effectiveness of different features
4. Discuss the application of vCOPs in knowledge translation in childhood disabilities.

### **Audience targeted:**

Researchers, clinicians and administrators interested by knowledge transfer

Clinical and group leaders who can influence the implementation of best practices

Individuals interested in DCD

### **Format:**

Formal presentations (e.g., what are CoP, layout and features of our CoP, data showing how the participants used the CoP)

Group discussion – how can virtual CoP advance care for children with disabilities

Individual action plan and take home messages

## Measuring Functional Performance: The use of the Pediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT)

Wendy Jane Coster<sup>1</sup>, Marjolijn Ketelaar<sup>2</sup>, Lena Krumlinde-Sundholm<sup>3</sup>, Christina Schulze<sup>4</sup>, Michelle Stahlhut<sup>5</sup> and Ine Wigernæs<sup>6</sup>

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<sup>4</sup>Institute Of Occupational Therapy, Zurich University Of Applied Sciences, Winterthur, Switzerland

<sup>5</sup>Clinical Genetics Clinic, Rigshospitalet, Center For Rett Syndrom, Kennedy Center, Hvidovre, Denmark

<sup>6</sup>Department Of Research, Beitostølen Health Sports Center (BHSS), Beitostølen, Norway

### Background

The Pediatric Evaluation of Disability Inventory (PEDI) is a useful clinical and research assessment, but it has limitations in content and age range. A computer adaptive testing version, of the PEDI (PEDI-CAT) has recently been developed. The addition of new items extends the functional performance content assessing the domains of daily activities, mobility and social/cognitive functioning of children and youth through age 20 years. The new Responsibility domain is a useful addition providing information on the extent to which a person takes responsibility to manage daily life tasks. Each domain can be assessed separately. The use of a computer adaptive testing (CAT) platform offers an alternative to traditional, fixed-length paper and pencil instruments. Even though the number of test items has been extended, the test can be kept short by implementation of the CAT. A 'speedy' ( $\leq 15$ ) or a 'content balanced' ( $\leq 30$ ) item version can be chosen for each domain. Based on individual answers the program will choose the next questions of appropriate difficulty level, creating a measure of his/her ability. The results are presented as normative and scaled scores.

While the PEDI has been translated, adapted and validated for the use in many countries, the PEDI-CAT cross-cultural use has just started throughout Europe. This course will introduce the PEDI-CAT and describe the cultural validation process required.

### Learning outcomes

The participants will be able to:

Understand the content and construct of the PEDI-CAT

Understand how computer adaptive testing obtains precise scores

Understand how to interpret and use the different outcome scales

Discuss for which clients and settings the PEDI-CAT is useful

### Audience targeted

Health professionals who are aiming to evaluate activity and participation in life tasks in children and youth with various disabilities.

### Format

Interactive presentations and demonstration of the computer adaptive scoring system.



## **Walking economy and fitness in treatment of walking problems in youth with developmental disability**

Annet J Dallmeijer<sup>1</sup>, Astrid CJ Balemans<sup>1</sup>, Eline AM Bolster<sup>1</sup> and Annemieke I Buizer<sup>1</sup>

<sup>1</sup>Rehabilitation Medicine, VU University Medical Center, Amsterdam, Netherlands

**Summary:** Reduced walking distance and fatigue during daily life activities are common problems in youth with developmental disability, and reasons to consult rehabilitation professionals. These walking problems can both be associated with a low walking economy and a reduced fitness level, both often reported deficits in this population. Clinical exercise testing provides information about these exercise parameters that can be used to indicate and evaluate targeted treatment.

The course will provide understanding on the extent to which low walking economy and fitness relate to walking problems in youth with developmental disability, and will show to what extent walking problems can be reduced by treatment aimed at improving walking economy and/or fitness. Group results as well as case reports for different treatment approaches (fitness training, treatment of spasticity, orthotic treatment and orthopaedic surgery) will be presented and discussed with the audience.

**Learning objective:** To understand the value of walking economy and fitness testing for the treatment of walking problems in youth with developmental disability.

**Target audience:** Pediatric physiatrists, pediatric physical therapists, exercise and gait lab staff, orthopaedic surgeons.

The presenters have a multidisciplinary background in pediatric physiatry, pediatric physiotherapy and human movement sciences, and have many years of experience with research and clinical applications of exercise testing in children and adolescents with developmental disability and walking problems.

**Course format:** walking economy, fitness and walking problems (15 min), group treatment effects (15 min), case reports (20 min, interactive with audience), discussion (10 min)

## **Functional near-infrared spectroscopy (fNIRS) - a promising tool to investigate brain activity during motor tasks in individuals with cerebral palsy**

Ana Carolina De Campos<sup>1</sup>, Theresa Sukal-Moulton<sup>2</sup> and Diane L Damiano<sup>3</sup>

<sup>1</sup>Department Of Physical Therapy, Federal University Of São Carlos, São Carlos, Brazil

<sup>2</sup>Department Of Physical Therapy And Human Movement Sciences, Northwestern University, Chicago, USA

<sup>3</sup>Rehabilitation Medicine Department, National Institutes Of Health Clinical Center, Bethesda, USA

**Background/content:** Functional magnetic resonance imaging (fMRI) and diffusion tensor imaging (DTI) have lead to great advances in the understanding of brain reorganization in response to brain injury and as result of treatment in some groups of children with cerebral palsy (CP). However, the scanner is restricted in the types of movements that can be performed and many with CP are unable to remain sufficiently still in the scanner. Functional near-infrared spectroscopy is a maturing technology that uses near-infrared light to examine changes in blood flow and infer neuronal activity in the cortex. Because it can be used in more natural movement environments and is more robust to movement artifacts, fNIRS presents great potential for understanding both typical and atypical control of functional movements such as reaching and walking. Our laboratory at NIH has been using fNIRS for several years and have collected data during motor tasks on more than 50 individuals with and without CP.

This course will focus on the following topics:

Anatomy of the hemodynamic response, and the use of light to monitor blood flow

Literature review of the use of fNIRS to study movement in typically developing children and adults and in individuals with CP

Sharing experiences with fNIRS data acquisition and analysis in a young CP population

Illustrative examples of data obtained from fNIRS during motor tasks in CP

Learning objectives

After this course, participants will be able to:

Demonstrate a general understanding about the use of infrared light to infer brain activity

Critically discuss the challenges of using the technology with brains that have lesions, and potential benefits of the technique for this population

Summarize clinically relevant information in literature.

**Audience targeted:** Researchers and clinicians interested in motor control and measurement of cortical activity during movement in CP.

**Format:** Interactive presentation with audio-visual resources.

## **The Next Generation of Intensive Pediatric Rehabilitation Therapies: Efficacy to Effective Clinical Implementation**

Stephanie C Deluca<sup>1</sup>, Sharon L Ramey<sup>1</sup>, Patty Coker-Bolt<sup>2</sup> and Jill Heathcock<sup>3</sup>

<sup>1</sup>Virginia Tech Carilion Research Institute, Virginia Tech, Roanoke, Virginia

<sup>2</sup>Occupational Therapy, Medical University Of South Carolina, Charleston, United States

<sup>3</sup>Physical Therapy, Ohio State University, Columbus, Ohio

Pediatric CIMIT (P-CIMIT) is one of the most efficacious treatments for upper extremity function in children with cerebral palsy (Novak et. al, 2013) and has been implemented worldwide. Essential components of P-CIMIT were defined as: constraint of the less-impaired upper extremity; high-intensity therapy (many hours/day, many days/week, multiple weeks); shaping and repetitive practice; delivery in natural settings; and a bimanual transfer package (Ramey, DeLuca, & Coker-Bolt, 2013). This course will provide an in-depth summary on the theory, essential features, and findings of P-CIMIT interventions used in varied countries. Presenters will use videotapes to differing protocols and describe methods for assessing the fidelity of implementation and outcomes. Evidence-based therapies, such as P-CIMIT, face translational challenges – most importantly, ensuring that protocols are implemented with high-fidelity in order to obtain comparable benefits when applied to larger and more diverse (e.g. across ages & in varied settings) clinical populations. This course will include discussion about these topics as they potentially relate to neuroplasticity, combining intensive treatments, and “spillover effects” from treatments into other developmental domains (e.g. mobility, cognition, & social-emotional).

Objectives are to:

synthesize the history of P-CIMIT and the theories it is founded on, starting with the adult findings up until the most recent clinical trials;

present varied P-CIMIT protocols that produce significant benefits from around the world along with clinically practical guidelines for how to effectively adapt protocols;

describe the emerging field of Implementation Science and the increasing need to measure the Fidelity of Implementation; &

present information about the importance of documenting treatment efficacy as clinical dissemination continues.

Target Audience:

International Community of Clinicians & Scientists

## Let's Talk About Care of Cerebral Palsy in Developing Countries

Uri Givon<sup>1</sup>, Deirdre McDowell<sup>2</sup> and Feriha Hadazgic-Catibusic<sup>3</sup>

<sup>1</sup>Pediatric Orthopedics, Safra Hospital For Children, Sheba Medical Center, Tel Hashomer, Israel

<sup>2</sup>Pediatrics, Pediatric Specialty Clinic, The University Of Texas Health Science Center, Houston, TX, USA

<sup>3</sup>Pediatric Neurology, Pediatric Clinic, University Of Sarajevo, Sarajevo, Bosnia And Herzegovina

### Background / content:

The incidence and prevalence of cerebral palsy (CP) are 2-3/1000 live births in developed and developing countries, though the opportunities and quality of care available to children with CP differ significantly. Most technologies presented in scientific conferences fit developed countries, and many technologies are not adequate for developing countries due to cost or unavailability of resources. Therefore, when addressing an audience from developing countries the program should be aimed at answering the needs of the audience. Adjustments of technologies are necessary for developing countries, and presenters should be prepared to offer such adjustments to the audience. Opportunities for health personnel from developing countries to learn and obtain new skills should be offered by international organizations, and opportunities for volunteer work in disaster areas and developing countries should be offered to health workers from developed countries. The aim of this course is to present ways to prepare a conference in developing countries; show existing opportunities for training and volunteer work and initiate a discussion on development of new programs.

### Learning objectives:

The audience will learn about technology adjustment for developing countries

The audience will learn about ways to volunteer in developing countries and disaster areas

The audience will discuss new ways to improve teaching of CP care and technology adjustment for developing countries

### Audience targeted:

Physicians and therapists from developing and developed countries.

### Content:

Opening – Deirdre McDowell, PT, PCS – 5 min

Conferences and teaching in developing countries: What should you change? Uri Givon MD – 15 min

Volunteering in disaster areas and developing countries – Deirdre McDowell, PT, PCS, Feriha Catibusic MD – 15 min

Scholarship programs and opportunities – Uri Givon MD, Deirdre McDowell, PT, PCS - 10 min

Discussion: What should we do now? – 15 minutes

## **Classifications of Function in 21st Century: What are they good for?**

Mary Jo Cooley Hidecker<sup>1</sup>, Ann-Christin Eliasson<sup>2</sup>, Diane Sellers<sup>3</sup>, Robert J. Palisano<sup>4</sup> and Peter Rosenbaum<sup>5</sup>

<sup>1</sup>Communication Disorders, University Of Wyoming, Laramie, USA

<sup>2</sup>Women'S And Children'S Health, Karolinska Institute, Stockholm, Sweden

<sup>3</sup>Speech And Language Therapy, Chailey Heritage Clinical Services, North Chailey , United Kingdom

<sup>4</sup>Physical Therapy And Rehabilitation Sciences, Drexel University, Philadelphia, USA

<sup>5</sup>Canchild Centre For Childhood Disability Research, McMaster University, Hamilton , Canada

### **Background/Content:**

**Purpose:** This course will present classifications in childhood disabilities and how and when to use them.

With the availability of a family of classifications focused on function, practitioners and researchers should consider how one or more of the classifications may be useful for their programs, practice and research. The primary purpose of these systems is to discriminate meaningfully among functional variations in a health condition. Examples will include use of the Gross Motor Function Classification System (GMFCS), the Manual Abilities Classification System (MACS), the Communication Function Classification System (CFCS), and the Eating and Drinking Abilities Classification System (EDACS). Clinical cases will be presented that consider the classifications separately and together as a functional profile.

**Learning Objective 1:** To understand the purposes of classification systems.

**Learning Objective 2:** To classify using the GMFCS, MACS, CFCS, & EDACS.

**Learning Objective 3:** To use a functional profile of classifications to assist clinical decision-making and research objectives.

**Learning Objective 4:** To describe how classification systems should not be used.

**Target Audience:** All conference attendees

### **Format**

Rosenbaum (5 minutes): What are classification systems, what properties do they need to have, and why do we need them

Palisano (5 minutes): Overview and updates: the Gross Motor Function Classification System

Eliasson (5 minutes): Overview and updates: Manual Abilities Classification System

Hidecker (5 minutes): Overview and updates: Communication Function Classification System

Sellers (5 minutes): Overview and updates: Eating & Drinking Ability Classification System

Case Presentations (25 minutes) discuss how clinical management might be influenced by functional profile of GMFCS, MACS, CFCS, and EDACS.

Open Discussion: (10 minutes) discuss purposes & limitations of classification systems; questions & answers

## **GMFM in practice: Opportunities, challenges and future- what's app?**

Annika L Josenby<sup>1</sup>, Eva Nordmark<sup>2</sup>, Dianne J Russell<sup>3</sup> and Peter L Rosenbaum<sup>4</sup>

<sup>1</sup>Physiotherapy, Children's Hospital, Skåne University Hospital, Lund, Sweden

<sup>2</sup>Health Sciences, Health Sciences Centres, Faculty Of Medicine, Lund University, Lund, Sweden

<sup>3</sup>School Of Rehabilitation, McMaster University, Hamilton, Canada

<sup>4</sup>Paediatrics And Child, McMaster University, Hamilton, Canada

### **Background/ content**

The Gross Motor Function Measure was validated to measure change in gross motor function in children with cerebral palsy (CP) and has become the gold standard measure in clinical practice and research in CP. Since first introduced in 1989, the measure's psychometric properties have been improved, shorter forms and a challenge module has been developed. Further development of a user-friendly application (app) for entering data directly to the gross motor ability estimator (GMAE) analysis program for immediate results is on its way.

### **Learning objectives**

Learning objective 1: To discuss the opportunities and challenges integrating the GMFM in clinical work and evidence-based rehabilitation

Learning objective 2: To discuss how to use the GMFM assessment to collaborate with the child and family in individualized and goal-directed interventions

Learning objective 3: To exemplify the use of the GMFM in practice-based clinical research

Learning objective 4: To present the latest news on the development of a GMFM "app".

### **Audience targeted**

This session is designed to encourage interaction amongst service providers and clinicians who currently are using the GMFM, but also administrators, educators, parents and persons with CP who may learn more about the use of the measure.

### **Format**

### **Workshop**

## Measuring bimanual hand use across the ages in children with cerebral palsy

Lena Krupplinde-Sundholm<sup>1</sup>, Susan Greaves<sup>2</sup>, Annoek M. Louwers<sup>3</sup>, Ann-Kristin Elvrum<sup>4</sup> and Linda Ek<sup>1</sup>

<sup>1</sup>Department Of Women's And Children's Health, Karolinska Institutet, Stockholm, Sweden

<sup>2</sup>Occupational Therapy Department, The Royal Children'S Hospital, Melbourne, Australia

<sup>3</sup>Department Of Rehabilitation, Academic Medical Centre, Amsterdam, The Netherlands

<sup>4</sup>Children'S And Women'S Health, Norwegian University Of Science And Technology, Trondheim, Norway

### Background/content

In most everyday activities we need to use both hands together; however, to evaluate hand function in children with cerebral palsy (CP), most tests assess each hand separately using a specific set of actions. During the last decade, the Assisting Hand Assessment (AHA) has introduced another concept. This is to assess the spontaneous use of the hands in an engaging age appropriate activity, which naturally elicits the use of both hands. In this workshop systematic reviews of assessment tools evaluating bimanual hand use will be reported. The underlying concept of the different assessments, purpose, clinical relevance and evidence of psychometric properties will be scrutinized. Since very few tests evaluate bimanual performance, this workshop will focus on the updated versions of the AHA for children with unilateral CP (age 8 months -18 years): the Mini-AHA, the Kids-AHA and the Ad-AHA. Information and demonstration will be provided also for the Hand Assessment for Infants (HAI) (age 3-12 months) and for the Both Hands Assessment (BoHA) for children with bilateral CP (age 8 months to 12 years). Pros and cons of all instruments will be discussed.

### Learning objectives

After attending this workshop the participants will:

- Know what tests of bimanual performance are available for children with CP at different ages
- Understand what information is gained from the different tests
- Understand what psychometric properties are important for different test purposes

### Audience targeted

Clinicians (in particular pediatric occupational and physical therapists) managing children with cerebral palsy and interested in functional hand use.

### Format

A mix of presentations and discussions based on video examples of different tests.

Interactive participation will be encouraged.

## **Relationships and Sexuality: Important issues to address in helping individuals with child-onset conditions to improve quality of life**

Susan C Labhard<sup>1</sup> and Ronna S. Linroth<sup>2</sup>

<sup>1</sup>Transitions, Shriners Hospital For Children, Portland, Oregon, U.S.A.

<sup>2</sup>Management, Rlinroth Consulting, LLC, Chisago City, Minnesota, U.S.A.

### **Background/content**

Relationships and sexuality are an important part of the transition to adulthood for youth with child-onset conditions. However, dealing with the sexual outcomes of having a disability can offer unique challenges. It is up to the provider or trusted adult, to offer appropriate information on sexuality related to diagnosis. To improve knowledge of the importance of relationships and sexuality for youth with disabilities, evidence-based and diagnosis-based teaching solutions will be provided using a variety of media. Participants will learn how to confidently ‘challenge the boundaries’ throughout the lifespan. Over 90% of youth with special health needs reach their 21<sup>st</sup> birthday and desire to live and work as independently as possible as an adult, it is now time to address quality of life.

### **Learning Objectives**

1. To elevate understanding of the importance of friends, relationships and sexuality for individuals with child-onset conditions.
2. Learn how to apply evidence-based practice guidelines for teaching youth and adults with disabilities about the importance of social success in developing healthy relationships and sexuality.
3. Explore options to traditional sexual expression and obtain resources for future reference across the lifespan. Participants will learn that dealing with the sexual consequences of disabilities can offer unique challenges, but need not be an obstacle to sexual fulfillment.
4. To encourage the inclusion and attention to sexuality as a topic in health care.

### **Audience targeted**

Clinicians, therapists, care providers, educators of all disciplines and parents or caregivers.

### **Format**

PowerPoint presentation, instructional media and open discussion about implementation strategies, references and resources illustrate concepts. Participants will be encouraged to use a lifespan approach to discuss concerns and solutions about teaching individuals with child-onset conditions about expressing themselves sexually.



## **Spina bifida: Management towards an optimal upright standing and walking**

Eva Pontén<sup>1</sup>, Åsa Bartonek<sup>1</sup>, Marie Eriksson<sup>1</sup> and Elena Gutierrez Farewik<sup>2</sup>

<sup>1</sup>Dept Of Women's And Children's Health, Karolinska Institutet, Stockholm, Sweden

<sup>2</sup>Dept Of Biomechanics, Royal School Of Technology, Stockholm, Sweden

### **Spina bifida: Management towards an optimal upright standing and walking**

Spina bifida is a central neural system malformation associated not only with neurological deficits of motor and sensory function of the lower limbs, but also of impairments of a more central origin resulting in e.g. poor balance and sense of orientation. Ambulation is often possible if the child has knee extension power. In this symposia, the Stockholm Spina Bifida Team will describe their management of children with spina bifida, with emphasis on encouragement to sit, stand and possibly walk at the same time points as typically developed peers. As a luxated hip will result in reduced stability, attention is kept to keep the hips in joint. Treatment may include early abduction orthotics and bony surgery later.

For a plantigrade foot, Ponseti-like management may be used with serial casting and possibly Achilles tendon tenotomy. Stenders are aligned for perfect balance, and so are hip-knee-ankle-foot orthoses (HKAFO), knee-ankle-foot orthosis (KAFO) and ankle foot orthoses (AFO). These prerequisites will help the child to ambulate without using crutches, enabling them to use their hands for other things.

Åsa Bartonek PT PhD has more than 30 years of clinical experience of treating children with spina bifida, and has extensive research on spina bifida in regard to ambulation, postural orientation and quality of life.

Marie Eriksson, PhD student and orthotist, has 30 years of experience of advanced orthotic design and management for children with spina bifida.

Eva Pontén MD, PhD, orthopaedic surgeon, has worked together with Åsa Bartonek and Marie Eriksson for 15 years in the Stockholm MMC (spina bifida) team. They have recently written a chapter on Spina bifida for Chapman's Orthopaedics.

Elena Gutierrez Farewik, associate professor of Biomechanics at Royal School of Technology, Stockholm, has developed gait analysis with special emphasis on center of mass in spina bifida.

## Diffusion Tensor Imaging: Analysis Options in Pediatric Neuroimaging Research

Andrea Poretti<sup>1</sup>, Thierry A.G.M. Huisman<sup>1</sup> and Alec Hoon<sup>2</sup>

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<sup>2</sup>Phelps Center For Cerebral Palsy And Neurodevelopmental Medicine, Kennedy Krieger Institute, Baltimore, USA

**Background/Content:** Diffusion Tensor Imaging (DTI) is an advanced Magnetic Resonance Technique (MRI) that provides information about the three-dimensional degree of water diffusion in individual voxels of MRI images providing clues about the microstructure of the brain tissue and the course of white matter tracts. Fiber tractography (FT) combines this information between neighboring voxels allowing the graphical three-dimensional reconstruction of white matter pathways. Several analytic approaches are available for DTI data including qualitative analysis, regions of interest (ROI) based analysis, atlas-based analysis and voxel-based analysis. After an introduction about the principles of DTI and FT, we will discuss the different analytic approaches emphasizing the pros and cons of each of these methods based on clinical research projects. Finally, we will briefly discuss the structural connectome, which is a powerful new way of quantifying the brain's structural systems.

**Learning Objectives:** 1. The participant will identify the principles of DTI and FT; 2. The participant will recognize the significance of the DTI scalars including fractional anisotropy (FA), mean (MD), axial (AD) and radial (RD) diffusivity and their changes in different conditions; 3. The participant will describe different analytic approaches of DTI data and their advantages and disadvantages.

**Target Audience:** Researchers involved in the application of Diffusion Tensor Imaging and clinicians who want to learn more about this neuroimaging technique.

**Course Outline:** Introduction to DTI and FT (10 minutes), Qualitative evaluation (5 minutes), ROI-based analysis (10 minutes); Atlas-based analysis (10 minutes); Voxel based analysis (5 minutes); Connectome (10 minutes); Conclusions (5 minutes); Questions (5 minutes).

## **When spasticity and dystonia co-exist: re-thinking CP motor classification**

James Rice<sup>1</sup>, Darcy Fehlings<sup>2</sup> and Adrienne Harvey<sup>3</sup>

<sup>1</sup>Paediatric Rehabilitation, Women's And Children's Hospital, Adelaide, Australia

<sup>2</sup>Developmental Pediatrics, Holland Bloorview Kids Rehabilitation Hospital, Toronto, Canada

<sup>3</sup>Developmental Medicine, The Royal Children's Hospital, Melbourne, Australia

### **Background/Content**

Classification of motor sub-types in cerebral palsy is important as it promotes an accurate description of a child's neuromotor impairments, leading to appropriate treatment choices. It also facilitates clear communication between treating clinicians, and assists CP registries around the world in the use of common language for data collection. In general, current CP classifications usually results in the identification of a "dominant" motor pattern, such as spasticity, often at the expense of coexistent or secondary abnormal motor patterns and movements. This course will review the development and uptake of the Hypertonia Assessment Tool (HAT) and related measurement tools, in conjunction with findings from the authors' research on hypertonia patterns in a large CP population, to show that spasticity and dyskinesia frequently coexist ("mixed" tone). Dyskinesia in particular can be overlooked in a child's multidisciplinary management. The need to critically review and update current CP data collection methods and international CP classification systems will be discussed, including proposals for a way forward.

### **Learning objectives**

To understand the current range of tools used for classification of motor impairments in clinical and CP Register settings

To understand how spasticity and dyskinesia co-exist and how to differentiate between them

To understand how accurate identification and classification of movement disorders will affect outcomes of interventions

### **Target audience**

Physicians, physiotherapists and occupational therapists working with children with CP; CP Register staff.

### **Format**

Overview of CP classification systems used in registries with summary of key issues - 10 minutes

Overview of the HAT with case studies and videos - 15 minutes

Challenges of the current motor classification system illustrated with case studies and research findings - 15 minutes

Facilitated group discussion on potential "solutions" - 20 minutes

## **Transforming the Healthcare of Women with Disabilities**

David P Roye<sup>1</sup>, Eileen Fowler<sup>2</sup> and Laurie Glader<sup>3</sup>

<sup>1</sup>Weinberg Family Cerebral Palsy Center, Columbia University Medical Center, New York, United States

<sup>2</sup>Cerebral Palsy Center, UCLA Medical Center, Los Angeles, United States

<sup>3</sup>General Pediatrics, Boston Children's Hospital, Boston, United States

**Purpose:** This course will present best practices, data collected on health disparities encountered by women with disabilities when accessing obstetrical, gynecological and breast care and preliminary results from pilot interventions addressing these disparities. It will increase the knowledge of attendees on these topics and inform them of methods that can be used to enhance care for women with disabilities.

**Audience:** Healthcare providers involved with the care of adolescents and women with cerebral palsy and related disabilities.

**Summary:** This data is from a two year multi-site project designed to improve healthcare for women with disabilities. This course will present the results of base-line surveys distributed to women with disabilities and providers. Preliminary data from four pilot interventions will be presented. Disparities, best practices and interventions will be discussed on gynecological care, reproductive life planning, adolescent health and transition and mammography techniques as they relate to women with disabilities. The panel will include speakers who are medical and public health professionals affiliated with each project site focused on one of the domains of healthcare indicated. This course will also examine the implications for modifying clinical care for patients. This project is funded by the Cerebral Palsy Foundation (CPF).

**Format:** Introduction and Gynecological Care (15 minutes) Reproductive Life Planning (15 minutes) Adolescent Health & Transition (15 minutes) Best Practices/Barriers in Mammography (15 minutes)

**Learning Objectives:** 1. Identify the best practices and barriers to care that women with CP encounter when accessing gynecological care. 2. Describe the best practices of reproductive life planning and pregnancy as they pertain to women with CP. 3. Employ knowledge of best practices and adolescent health and transition with regard to females with CP. 4. List the best practices and barriers in mammography for women with CP.

## **Title: Hip Salvage Surgery in Cerebral Palsy: When is the Deformity too Great to Reconstruct?**

Benjamin J Shore<sup>1</sup> and Wade M Shrader<sup>2</sup>

<sup>1</sup>Department Of Orthopaedic Surgery, Boston Children's Hospital, Harvard Medical School, Boston, USA

<sup>2</sup>Department Of Orthopaedic Surgery, Children's Hospital Of Mississippi, Jackson, USA

### **Background/Content:**

Spastic hip displacement is the second most common musculoskeletal deformity in children with cerebral palsy (CP), after equinus. Population based studies have noted that hip displacement affects approximately one-third of children with CP and is directly related to gross motor function as measured by the Gross Motor Function Classification System (GMFCS).

Three principles guide the management of complex spastic hip subluxation. (1) The pathophysiology is different than developmental hip dysplasia and requires a different, comprehensive treatment protocol. (2) The natural history of spastic hip subluxation is marked by increasing dysfunction, with adverse effects on perineal hygiene, sitting intolerance, and pain in early adulthood. (3) Salvage options for the skeletally mature patient with a painful dislocated hip are limited.

The purpose of this instructional course will be to review a series of challenging cases of spastic hip subluxation where the treatment of reconstruction versus salvage will be discussed. In addition, we will review treatment protocols for complex reconstruction and salvage procedures at two institutions highlighting differences in practice pattern and health care delivery.

### **Learning Objectives:**

1. Recognize the pathophysiology associated with severe hip subluxation
2. Understand the adjunctive imaging tools necessary to help guide surgical decision making
3. Apply a treatment algorithm for complex reconstructions and salvage surgery in spastic hip subluxation from preoperative workup to postoperative management

### **Audience targeted:**

Orthopaedic Surgeons, Physical Therapists, Physiatrists

### **Format:**

1. Review of pathophysiology of neuromuscular hip displacement.
2. Presentation of current surgical salvage treatments and their outcomes in the literature.
3. Evidence based discussion through case based presentations with audience participation.

## **Do we do as we say? – meeting the communicative rights of children with disability during assessment, intervention and hospital care**

Gunilla M Thunberg<sup>1</sup>, Stefan Nilsson<sup>2</sup>, Ingrid Mattsson Müller<sup>1</sup>, Julia Eldblom<sup>3</sup> and Lisa Bengtsson<sup>4</sup>

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<sup>3</sup>Habilitation And Health, Region Of Västra Götaland, Gothenburg, Sweden

<sup>4</sup>Mun-H-Center - Swedish National Orofacial Centre, Gothenburg Institute Of Dentology, University Of Gothenburg, Gothenburg, Sweden

### **Background/content**

Many children with a communicative disability are frequent consumers of hospital and dental care. The United Nations Convention on the Rights of People with Disabilities (CRPD) and the Child Convention guarantee the right to be informed, to communicate and express opinions, using the preferred means of communication, including augmentative and alternative forms (United Nations, 2006). In spite of this, health care staff most often trust in the parents to act as interpreters, and have little or no knowledge about communicative disability and AAC. A working model, using the principle of universal design and augmentative and alternative communication (AAC) methods, was developed within the project KomHIT- communication support in paediatric and dental care.

### **Learning objectives**

The main purpose of this instructional course is to describe how assessment, intervention and hospital visits more generally can be managed to meet the communicative rights of children with disability and improve aspects of activity and participation.

### **Audience targeted**

The course will be of relevance to both researchers and practitioners from different disciplines who aim at improving information, communication and participation in their work with children with disability.

### **Format**

Video clips from different clinics within habilitation, pediatric dentistry and hospital will be shared alongside with examples of the pictorial supports of different types that has been used. The webb-resources that were developed are demonstrated and the participants will use these to develop materials in pairs using their tablets or smartphones.

## **Racerunning, from therapy to participation**

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<sup>2</sup>School Of Health Sciences, Center For Health Research, University Of Brighton, Eastbourne, United Kingdom

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### **Background/ content:**

The racerunner is a device for supported running that can be used by children and adolescents with several diagnoses, as for example cerebral palsy, neuromuscular diseases and syndromes, and with severe walking problems, but with some leg movement.

A racerunner is a three-wheeled frame in which children and adolescents who are wheelchair users in daily life can walk or even run. Most of these children have limited possibilities for exercise training and testing. The racerunner can be used in therapy, as sport and in daily life, to enhance an active lifestyle. In various European countries there are racerunner groups and competitions.

### **Learning objectives:**

After this instructional course, the participant will know:

### **User profiles:**

Who can use the racerunner (which children and adolescents)

Ways to use a racerunner (therapy, sports, daily living)

### **Technical information:**

How to assemble the Racerunning bike and its different parts

How to adjust a racerunner to an end user athlete

Current suppliers and routes of prescription and acquisition

### **Training and techniques:**

Instruction methods

How to measure progress

Some ongoing studies on physiology using RacerRunning as intervention

### **Implementation in Europe:**

Organizations involved

State of the art of racerunning in Denmark, Sweden, UK and the Netherlands

### **Audience targeted:**

Pediatric physical therapists, sports science, rehabilitation medicine specialists and other professionals involved or interested in physical fitness and pediatric rehabilitation.

### **Format:**

This instructional course consists of:

a PowerPoint presentation about the Racerunner (users profiles etc), including video's of RaceRunner training and competition (20 minutes)

presentation about implementation the different European countries (15 minutes).

RaceRunning in practice; there will be some RaceRunners present to try out; and practical advice will be given (25 minutes).

Co-authors: Kathleen Persson, Vicki Skure Eriksson, Connie Hansen



**Physical activity stimulation in children with physical disabilities: putting a family in motion**

Leontien Van Wely<sup>1</sup>, Eline AM Bolster<sup>1</sup>, Petra EM Van Schie<sup>1</sup>, Manon Bloemen<sup>2</sup>, Janke De Groot<sup>2</sup> and Annet J Dallmeijer<sup>3</sup>

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**Background:**

Regular participation in physical activities (PA) is important for children with physical disabilities. It contributes to the development of social and motor skills, and is essential for staying fit and healthy when growing up. Increasing PA can be either the goal itself (health) or a medium to reach goals at the level of mobility performance (climbing the stairs at home means practice of relevant skills). In daily practice changing the child's PA behavior has been shown to be difficult. Physiotherapists have indicated that they lack the skills to support PA behavioral change. The working method 'physical activity stimulation in pediatric physiotherapy practice' has been developed to facilitate pediatric physiotherapists in coaching children and their parents to increase PA. The method is characterized by a goal-directed, family-focused approach to support the child's and parents' self-management and commitment with regard to increasing PA. It consists of defining mutually agreed PA goals while focusing on opportunities for PA rather than on impossibilities, and addressing the transfer of skills to the daily situation. Child and parents are stimulated to bring forward solutions for improving PA behavior themselves.

**Learning objectives****Participants:**

- understand the value of integrating PA stimulation in pediatric physiotherapy practice
- can identify the opportunities for integrating PA stimulation in pediatric physiotherapy practice
- acknowledge the need for mutually agreement on PA goals.

**Audience targeted:**

Pediatric physiotherapists, and other professionals involved in pediatric rehabilitation

**Format:**

- Presentation about the rationale of the working method 'PA stimulation in pediatric physiotherapy practice' (20 min)
- Interactive discussion about opportunities for PA (goal or medium) based on a video case (20 min)
- Focused discussion about the need for, and ways to reach, mutually agreement on PA goals, based on a video case (20 min)



**Free papers - orals**

## **Motor Imagery Training in Children with Developmental Coordination Disorder (DCD)**

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<sup>2</sup>Department Of Health And Rehabilitation Sciences Faculty Of Health Sciences, University Of Cape Town, Cape Town, South Africa

**Background** - Previous studies (reviewed in Wilson et al. 2013; Adams et al., 2014) have shown that motor imagery and action planning are impaired in children with Developmental Coordination Disorder (DCD), most likely due to a deficit in the internal modeling of movements.

**Aim** - The aim of the present study was to examine whether a training focused on the mental imagery of motor skills, can help to improve the motor abilities of children with DCD.

**Method** - A pre-post design was used to examine the motor performance, motor imagery and motor planning abilities before and after a training of 9 weeks. Two groups were included in this study (1) one received motor imagery (MI) training focused on the forward modelling of purposive actions, (2) one received cognitive orientation to daily occupational performance (CO-OP) focused on identifying effective cognitive strategies that will increase motor competence. Motor imagery training was given via the use of instruction video of the motor skill that was trained. Both groups participated in 9 individual sessions of 45 minutes (once a week) with a paediatric physical therapist, added with homework sessions. Inclusion criteria were: (1) aged 7-12 years, (2) meeting the DSM-V criteria for DCD (mABC total percentile score  $\leq 16$  and motor problems that interferes with daily life (DCDQ, and request for help at a paediatric physical therapist)). Exclusion criteria were IQ  $< 70$  and other medical conditions.

**Results** - Preliminary results (MI training: n = 3, CO-OP training: n = 4) showed that in both groups the mABC total standard score increased with 1.5 – 2.0 standard scores after the intervention. Only the MI training group was faster and made less errors on a motor imagery task after the intervention. Both groups showed a small increase in planning for end-state comfort.

**Conclusion** - The first results of the training study show that MI training can be an effective method to train motor skills of children with DCD.

## **Mirror movements in unilateral spastic cerebral palsy (USCP): Effects of targeted bimanual therapy**

Caroline Adler<sup>1</sup>, Melanie Hessenauer<sup>1</sup>, Silke Kunze<sup>1</sup>, Johanna Lipp<sup>1</sup>, Andrea Hörning<sup>1</sup>, Carina Geigenberger<sup>1</sup>, Steffen Berweck<sup>1</sup> and Martin Staudt<sup>1</sup>

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### **Background**

Many children with USCP show involuntary movements of the other hand during voluntary unimanual movements, the so-called “mirror movements” (MM). Recently, we could demonstrate that these MM negatively influence many bimanual activities of daily living (Adler et al, Eur J Paed Neurol 2015).

### **Aim**

We therefore developed a specific therapeutic regimen addressing this specific problem, and present first results.

### **Methods**

Six girls (age range, 6 – 17 years) with USCP and MM underwent a 3-week period of intensive inpatient rehabilitation. Therapy by physio- and occupational therapists was strictly bimanual, with special regard to independent (simultaneous and asymmetric) movements of the two hands, both on a functional level and with regard to bimanual activities.

### **Results**

Improvements were seen in the goal attainment scaling (consisting exclusively of bimanual goal activities involving asymmetric hand movements; change score > 20 in 6/6 subjects), in the unimanual capacities of the paretic hand (Jebson Taylor Hand Function Test: improvement > 20% in 5/6 subjects), and in the bimanual performance (Assisting Hand Assessment: improvement  $\geq 5$  units in 3 / 6 subjects). Surprisingly, no change could be seen, however, in the standardized visual assessment of MM (Woods & Teuber scaling) nor in the degree of mirroring in an untrained artificial laboratory task including unimanual holding of an object with one hand while repetitively compressing a rubber ball with the other hand (similar to Kuhtz-Buschbeck, Dev Med Child Neurol 2000).

### **Conclusion**

Targeted therapy for children with USCP and MM improves unimanual capacity as well as bimanual performance, especially for the trained goal bimanual activities involving asymmetric hand movements. During these goal activities, the subjects improved by learning to control their MM voluntarily; when measured under artificial conditions, however, no general reduction of MM was observed.

## **Testing the feasibility of a national health registry program for children with Cerebral Palsy CPUP-Jordan**

Nihad A Almasri<sup>1</sup>

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This presentaion aims to describe the development and implementation of a national follow- up registry for children with cerebral palsy in Jordan (CPUP- Jordan), and to discuss the feasibility of implementing this register in Jordan. The registry aims to provide an epidemiological data about children and youth with CP, monitor and prevent development of secondary impairment; and improve communication among health professionals.

The participants were recruited during their therapy visits to clinics for children with CP in Amman. Children and youth were eligible to participate if they have CP medical diagnosis with CP.

A web-based, electronic medical record was developed, a trained and criterion tested research assistants completed demographic, birth history, physiotherapy, and occupational therapy evaluation forms. The forms were completed through parent's interview to applying a family-centered model and the ICF concepts. Therapists completed measures like spasticity assessments and range of motion and determined the GMFCS, MACS, CFCS levels. Participant children and youth were evaluated every six months.

During the first 18 months of the study 130 participant children completed at least 1 assessment, 59(45%) completed 2 assessments, and 3(2 %) completed 3 assessments and the recruitment is progressing. The average age of participants is 4.4 years (SD 3.8 years). Children varied across GMFCS levels and across the MACS levels. 32 % of the children had spastic diaplegia, 29 % spastic quadriplegia, 14% hemiplegia, 4 % dyskinesia, 3% ataxic, and 18 % were not categorized. Areas related to activity, participation, and environmental contextual factors were examined.

The creation of a National register for CP in Jordan has been feasible. The longitudinal data collection will allow to monitor changes in health conditions related to children with CP, and will act as a preventive measure for secondary complications which requires invasive measures.

## **Pain in children and adolescents with cerebral palsy -- a population based registry study**

Ann I. Alriksson-Schmidt<sup>1</sup> and Gunnar Hägglund<sup>1</sup>

<sup>1</sup>Department Of Clinical Sciences, Orthopaedics, Lund University, Lund, Sweden

**Background:** Pain in cerebral palsy (CP) is associated with reduced quality of life and less participation in society. In Sweden, CPUP, a national registry and follow-up program, systematically follows approximately 95 percent of children and youth with CP. Presence and location of pain are included in the CPUP assessment.

**Aim:** To assess (1) the occurrence of self or proxy-reported presence of pain, and (2) the location of pain in children and adolescents with CP based on the Gross Motor Function Classification System (GMFCS), age and gender.

**Method:** Cross-sectional study based on CPUP data from the last visit of all children born 2000-2012 reported in the registry 2013-2014.

**Results:** A total of 2777 children (1595 boys, 57.4%) were included. The median age was 7 years (SD = 3.56). Overall, 900 (32.4%) reported/proxy-reported pain, 1799 (64.8%) reported no pain, and 78 (2.8%) had missing data on this item. Pain was more frequent in girls (35.5%) than boys (30.1%) ( $p < 0.05$ ). Pain increased with age, from 17% in children aged 2-3 years to 50% in children aged 14 years (OR 1.11,  $p < 0.01$ ). Pain was most common in the lower extremities ( $n = 624$ ), stomach ( $n = 97$ ), back ( $n = 84$ ), head-neck ( $n = 82$ ) and arms ( $n = 81$ ). Pain in hip-thigh and/or stomach were most frequent in GMFCS V, knee pain in GMFCS III and pain in the lower leg in GMFCS I.

**Conclusion:** One third of the population of children and adolescents with CP in Sweden reported pain. Although still high, it is a lower prevalence than what is generally reported in the literature: many reports of pain in persons with CP are in the 50-75 percent ranges. Differences in methodology or the CPUP hip surveillance program are possible explanations for the lower prevalence rate.

## **Perceptions of the impact of the environment on their societal participation by young adults with cerebral palsy**

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**Background:** The effects of environmental factors on human functioning are complex and diverse. To improve participation and policy planning the assessment of environmental factors is essential.

**Aim:** To explore the perspective of adults with cerebral palsy (CP) about the influence of environmental factors on their societal participation.

**Method:** The work was carried out in Newcastle, UK and Porto, Portugal. Participants were people with CP aged 19-30 years (6 males, 6 females from UK; 5 males, 8 females from, Portugal). A qualitative approach based on a phenomenological framework involving semi-structured individual and group interviews was implemented. Interviews were audio recorded and transcribed. Transcripts were coded according to thematic categories.

**Results:** Factors discussed by participants could present as either barriers to or facilitators of participation. Factors identified as important were: attitudes towards and understanding of needs by family, service providers and public; availability of appropriate education and employment; availability of assistive technology in education; accessibility of the built environment including streets, buildings and transport ; adaptation and availability of leisure facilities; flexibility of personal assistance personnel and consistency and reliability of providers of support. Access to adequate health services, financial support programs and internet connection and social media also emerged as essential areas for participation.

**Conclusion:** This work provides information that can be used to generate items for instruments that assess environmental factors.

## **Validity of the Ugandan version of Paediatric Evaluation of Disability Inventory (PEDI-UG)**

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**Background:** Eighty per cent of persons with disabilities live in developing countries and yet established assessment tools to measure functional performance in these regions is limited. As part of the preparation of carrying out a rehabilitative intervention program for children with Cerebral palsy in Uganda, we translated and culturally adapted the Pediatric Evaluation of Disability Inventory (PEDI) to a Ugandan version (PEDI-UG). While the face and content validity of the PEDI-UG was achieved, there is need to further investigate its validity in the Ugandan population.

**Aim:** To investigate the validity of the PEDI-UG by testing the instrument's rating scale structure and internal structure.

**Methods:** This study was conducted in a number of representative rural and urban areas of five districts of Uganda. A total of 249 typically developing children (125 female) aged from 6 months to 7.5 years (mean age 3 years 3.5 months  $\pm$  SD 1.9) were included in the study. Validity was investigated by means of Rasch analysis using Winsteps<sup>®</sup> 3.81. The Rasch rating scale model was used for the Caregiver assistant part and the dichotomous model for the Functional skills part.

**Results:** The rating scale categories on the Caregiver assistant part were reversed and the rating scale was therefore changed from six-point to four-point rating scale. The PEDI domains showed good uni-dimensionality based on principal-component analysis of residuals. Most activities showed acceptable fit to the Rasch model. One item (D. Tub transfer) in the Mobility domain of the Caregiver assistance part was removed due to misfit and considered irrelevant for the targeted population.

**Conclusion:** The PEDI-UG with the four-point rating scale provides a valid measure of the functional performance of typically developing children from the age of 6 months to 7.5 years in the African context.



## **Does the presence of congenital anomalies affect the clinical presentation of cerebral palsy?**

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**BACKGROUND:** Congenital anomalies are important risk factors for cerebral palsy (CP). Previous studies have shown conflicting results regarding which types of congenital anomalies that are associated with CP and whether the severity of CP differs between children with and without congenital anomalies.

**AIM:** To study if CP subtypes, motor function and associated problems differ between children with CP born at or near term with and without congenital anomalies, and to investigate whether the same clinical manifestations differ between children with CNS- or with non-CNS anomalies and children without anomalies.

**METHOD:** Cross-sectional study using register data from the Cerebral Palsy Register of Norway and the Medical Birth Registry of Norway including all children with CP born in Norway between January 1<sup>st</sup> 1996 and December 31<sup>st</sup> 2008. Children born before 34 weeks, children with post-neonatally acquired CP, children whose diagnoses had not yet been confirmed by the five-year registration and children with missing information on congenital anomalies were excluded.

**RESULTS:** Among 583 children (mean age six years, four months; 337 (57.8 %) boys) with CP, 140 (24 %) had a congenital anomaly and of these eight of ten children (n=111) had a CNS-anomaly. Children with anomalies were more likely to have severe limitations in gross motor function, speech impairments, epilepsy, severe vision and hearing impairments and intellectual disability than children without anomalies (all p-values <0.005). These differences were mainly caused by children with CNS-anomalies. Children with congenital anomalies in other organs did not differ significantly from children with CP without anomalies.

**CONCLUSION:** Children with anomalies have the same distribution of CP-subtypes as children without anomalies, but are more likely to have severe limitations in gross motor function and associated problems. These differences were confined to children with CNS anomalies.

## **Prevalence and characteristics of children with Autism Spectrum Disorders among children with Cerebral Palsy**

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**Title :** Prevalence and characteristics of children with Autism Spectrum Disorders among children with Cerebral Palsy.

**Background :** Only few studies have specifically studied Autism Spectrum Disorders (ASD) among children with cerebral palsy (CP) whose proportion seems to be higher than in the general population.

**Aim :** The objectives were to evaluate the prevalence of co-occurring ASD among children and young people with CP and to describe the characteristics of children with CP who were diagnosed with ASD.

**Method :** Four population-based registries (in France -2 regions-, Iceland and Sweden) and one population-based surveillance program (UK) participating to the Surveillance of Cerebral Palsy in Europe Network (SCPE) provided data on characteristics of children with CP with a co-occurring ASD diagnosis. Data provided by the registries concerned children born between 1995 and 2006. Data from the UK were derived from a cross-sectional survey and concerned children aged 0-19 years old, registered in 2010. The child characteristics were compared according to the presence or absence of an ASD. Overall, 1773 children with CP were included in this study.

**Result :** Overall, 130 children with CP had an associated diagnosis of ASD, corresponding to 7.3 % of the studied population (95% CI [6.2 -8.6]). This proportion varied according to the registries from 3.9 to 16.7%. This variation was not related to differences in CP prevalence. Compared to children without ASD, children diagnosed with ASD were more frequently boys, had better walking ability, had more often co-occurring epilepsy and presented significantly more often an intellectual disability. Regarding neonatal data, the relationships with gestational age at birth and birth weight were not conclusive.

**Conclusion:** These results give additional arguments for promoting a multi-disciplinary approach in the management of children with cerebral palsy to adequately identify and address all facets of presentation.

**Identifying attention deficits in typical preschool children and neurodevelopmental disorders: a new iPad app of the Early Childhood Attention Battery (ECAB)**

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**Background.** Attention is a key area of cognitive competence, depending on multiple functional brain subsystems (for selective attention, sustained attention, attentional control/executive function). The ECAB is the first instrument designed to give an individual profile of abilities across these subsystems in preschool children and individuals of equivalent developmental age (Breckenridge et al, 2013).

**Aim.** To examine attention with the ECAB in Williams and Down Syndrome (WS/DS), and evaluate an iPad ECAB app for mental ages (MA) 3-6 years.

**Method.** (i) WS and DS children (N=32 each) were tested with ECAB and subtests from the WPPSI. MAs were between 3-6 yrs for each group - chronological age 5-15 yrs. (ii) Typically developing preschool children (N=31) were tested with the ECAB selective attention visual search task and two iPad versions of the test varying in items per screen.

**Results.** (i) both WS and DS groups showed significant impairments relative to MA in visual selective attention and attentional control, but not in sustained attention. WS performance on spatial attentional control reflected non-verbal better than verbal MA. DS children differed in the relation between spatial and nonspatial tests of attentional control. (ii) 3-6 yr old children adapted well to iPad use, with results on the iPad and original ECAB correlated  $r=0.68$ . Performance on the iPad was significantly better ( $p<0.02$ ) when the number of search items was low (3 screens x 60 items compared to 180 in the original), but equivalent for 2 screens x 90 items.

**Conclusion.** ECAB shows attention deficits beyond general cognitive impairment, and distinctive profiles of ability across subsystems, for different neurodevelopmental disorders. 3-6 yr old children respond well to touchscreen testing, which replicates results from original tests. The iPad app offers a portable, child-friendly test for identifying specific attention deficits in individuals with acquired or genetic developmental disorders.

**Hip status in children and adolescents enrolled in a Cerebral Palsy hip surveillance program: does distance from a tertiary centre matter?**

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**Background:** Hip surveillance is conducted routinely for children with Cerebral Palsy (CP) living in South Australia (SA), via a capital city-based tertiary paediatric hospital. Review of the effectiveness of the current statewide model of hip surveillance for patients from all geographical locations was completed.

**Aim:** To determine if children and adolescents living in regional and remote areas are at greater risk of hip displacement than those living in a major city.

**Method:** Retrospective audit of hip status and demographic data from established hip surveillance program (birth years 1990-2013, radiographs 1997-2015). Hip status based on migration percentage (MP) measured from most recent pelvic radiograph; MP<30% 'undisplaced', MP >30% 'displaced', and MP=100% 'dislocated'.

**Results:** Six hundred and thirty five patients with CP or like conditions were included in the audit; mean age 8.21 years at time of x-ray. Of the 635 patients, 423 (67%) reside in Adelaide, SA, with the remaining 212 (33%) living in regional and remote areas. Review of MP demonstrated 73% of patients from major cities had undisplaced hips, while 27% were displaced (including 6% dislocated). This was very similar to patients from regional and remote areas, with 76% = undisplaced and 24% = displaced (8% dislocated). Review by gross motor functional classification system (GMFCS) also demonstrated very similar patterns between those from major cities and other areas. Early review shows there may be a trend towards higher displacement and dislocation rates for children at GMFCS V living in remote and very remote areas, though there are very few patients in this group to analyse.

**Conclusion:** This audit is reassuring that the statewide hip surveillance program can provide effective surveillance for patients living many hundreds of kilometres from the tertiary centre. Ongoing work is needed to closely monitor those at greatest risk, including review of intervention accessibility for remote patients.

## **Measuring selective voluntary motor control of the lower extremity in children with upper motor neuron lesions – A COSMIN review**

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**Background:** A loss of selective voluntary motor control (SVMC) is a well-known clinical sign in children with upper motor neuron (UMN) lesions. Within the context of neuroplasticity, the potential for spontaneous recovery and training of impaired SVMC are widely discussed. However, it is unclear how SVMC can be measured best.

**Aim:** The aim of this review was to systematically evaluate the level of evidence of psychometric properties of SVMC measures in children with UMN lesions.

**Method:** MEDLINE, EMBASE, CINAHL, PsycINFO and SCOPUS databases were systematically searched up to June 2015. Studies evaluating psychometric properties of SVMC measures of the lower extremities in children and youth (6-21 years) with UMN lesion were included.

Methodological quality was scored in accordance to the Consensus-based Standards for the selection of health Measurement INstruments (COSMIN) checklist by two independent raters. The overall level of evidence was scored according to Cochrane criteria.

**Results:** Thirteen out of 2,448 studies including 6 different measures were finally included. Studies investigated validity and reliability, but not responsiveness. Methodological quality of six measures was assessed and COSMIN scores ranged from “poor” to “excellent”. Most studies investigated the “Selective Control Assessment of the Lower Extremity” (SCALE). The SCALE was scored highest on COSMIN items and evidence levels for their validity (content, criterion and construct) and reliability (inter- and intra-rater). Evidence level of two other SVMC assessments and five technical based measurements ranged from “unknown” to “moderate”.

**Conclusion:** Recovery of SVMC is widely discussed in neurorehabilitation, however, only few measures with adequate psychometrically properties are available. We recommend assessing SVMC of the lower extremity in children with spastic cerebral palsy with the SCALE, but more rigorous psychometric studies of SVMC measures are required.

## **Randomised controlled trial of a web-based multi-modal training program on gross motor capacity and performance for children with an acquired brain injury**

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<sup>1</sup>Queensland Cerebral Palsy And Rehabilitation Research Centre, School Of Medicine, The University Of Queensland, Brisbane, Australia

**Background:** Children with an acquired brain injury (ABI) may experience varying degrees of physical, cognitive and psycho-social impairments impacting participation in gross motor activities post-discharge. There is limited evidence to support the effectiveness of physiotherapy interventions to improve gross motor outcomes in children with an ABI.

**Aim:** To compare efficacy of a web-based multi-modal training program, “Move it to improve it” (Mitii<sup>TM</sup>), to usual care on gross motor capacity and performance for children with an ABI.

**Methods:** Sixty independently ambulant children minimum 12 months post ABI were recruited and randomly allocated to receive either 20 weeks of Mitii<sup>TM</sup> training (30 minutes/day, six days/week, total 60 hours) immediately, or waitlisted (usual care control group). Fifty-eight children proceeded to baseline assessments (32 males; mean age 11y11mo±2y6mo; GMFCS equivalent I=29, II=29). The Mitii<sup>TM</sup> program comprised of gross motor, upper limb and visual perception/cognitive activities. The primary outcome was 30 second repetition maximum (rep<sub>max</sub>) of three functional strength exercises (sit-to-stand, step-ups, half-kneel to stand). Secondary outcomes were the 6-Minute Walk Test, High-Level Mobility Assessment Tool, Timed Up and Go test and four-day accelerometer records.

**Results:** Groups were equivalent at baseline. The Mitii<sup>TM</sup> group demonstrated significantly greater improvements on combined rep<sub>max</sub> of functional strength exercises (mean difference 10.77 reps; 95% CI: 3.72-17.81; p=0.004) compared to the control group.

**Conclusion:** Mitii<sup>TM</sup> offers a home-based multi-modal training program that can improve functional strength with increased therapy dose for children with ABI and supplement rehabilitation.

## **An ultrasound platform to assess medial gastrocnemius muscle and Achilles tendon lengthening during slow passive stretch in typically developing children and children with cerebral palsy**

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### **Background**

Medial gastrocnemius muscle (MG) shortening contributes to decreased ankle mobility in children with spastic cerebral palsy (CPC). Shortened MG may also be compensated for with longer, more compliant Achilles tendon<sup>1</sup>. For appropriate treatment delineation, the contribution of muscle and tendon to ankle mobility are important to evaluate.

### **Aim**

To record MG and Achilles tendon resting lengths and their contributions to total muscle-tendon unit (MTU) lengthening during slow passive stretch in CPC and age-matched typically developing children (TDC).

### **Method**

Fifteen CPC (6/9 unilateral/bilateral involvement, 11+/-3yrs) and 13 TDC (9.9+/-3yrs) were included. Children lay prone with standardized knee angle. An US probe (Telemed, Lithuania) was fitted with reflective markers and tracked using 3D motion analysis (Optitrack, USA). Muscle and tendon lengths (femoral condyle to muscle tendon junction-MTJ; MTJ to calcaneus, respectively) were acquired at rest using the US probe as a spatial pointer and were normalized to tibia length. The US probe (+markers) was then fixated above the MTJ. US images, probe orientation, and ankle kinematics were simultaneously recorded during manually applied slow passive stretches across the full range of motion (ROM). Normalized lengths at rest and lengthening over the ROM were compared between groups using Mann-Whitney U tests (significance at  $p < 0.05$ ).

### **Results**

MG constituted a smaller portion of resting MTU in CPC than TDC ( $p = 0.01$ ). During stretch CPC achieved smaller ROM and less MG lengthening ( $p < 0.01$ ). The proportion of total MTU lengthening contributed by the MG was 51% in CPC and 64% in TDC ( $p < 0.01$ ).

### **Conclusion**

We confirmed previous findings of shorter MG in CPC.<sup>2</sup> Additionally, TDC MTU passive elongation occurs mostly from MG, while in CPC, muscle and tendon lengthen equally. This difference likely has implications for muscle function during gait and intervention effectiveness.

1. Gagliano et al. 2013

2. Fry et al. 2004

## **Psychometric properties of Movement Disorder-Childhood Rating Scale**

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**Background.** Movement Disorder-Childhood Rating Scales (MD-CRS) have been designed in two forms (0-3 and 4-18 years) to evaluate various movement disorders in children (Battini et al, 2008, 2009). The ability of MD-CRS to capture changes during treatment was tested for both scales with various longitudinal studies (Battini et al, 2014, 2015) and case report studies (Martinelli et al, 2012; Fons et al, 2012).

**Aim.** This study was aimed to evaluate psychometric properties of MD-CRS reliability when used by clinicians without a complete knowledge of this tool.

**Methods.** After brief training in scoring MD-CRS, three clinicians (a resident doctor, a child neurologist and a physical therapist) independently scored 20 patient videotapes, of children with movement disorders. In addition, the resident doctor scored 40 videos of 20 patients evaluated twice for test-retest. Reliability was assessed by Intraclass Correlation Coefficient (ICC), Standard Error of Measurement (SEM) and Minimal Detectable Difference (MDD) and was calculated separately for the two forms of the scale and for each score (Index I, Index II and Global Index).

**Results.** For both forms, inter-rater reliability of Global Index and Index I were good with an ICC ranged between 0.72 and 0.95 and a SEM ranged between 0.04 and 0.06. Instead, results of Index II were substantially moderate for both forms, with an ICC of 0.60 and 0.50, respectively and SEM values were 0.16. . Test-retest reliability values for all Indexes in both forms showed excellent values with ICCs ranging from 0.95 to 0.99. MDD values were between 0.04 and 0.12.

**Conclusion.** MD-CRS 0-3 and MD-CRS 4-18 remain reliable clinical measurement tools for evaluation of MD in developmental age when used by clinicians without a specific knowledge after specialized training.



## **Application of the Gross Motor Function Measure-66 (GMFM-66) in Dutch clinical practice: a survey study**

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**Background:** The Gross Motor Function Measure-66 (GMFM-66) is an observational clinical measure designed to evaluate gross motor function in children with Cerebral Palsy (CP). It is a shortened version of the GMFM-88. A free computer program, the Gross Motor Ability Estimator (GMAE), is required to calculate the interval level total score of the GMFM-66.

**Aim:** The aim of this study was to explore pediatric physiotherapists' experiences with the GMFM-66 and application of the measure in Dutch clinical practice.

**Method:** An explorative cross-sectional survey study was performed. Dutch pediatric physiotherapists were invited to complete an online survey. Data-analysis merely consisted of frequency tables, cross-tabulations and data-driven qualitative analysis.

**Result:** Fifty-six respondents were included in the analysis. In general, the therapists expressed a positive opinion on the GMFM-66, in particular regarding its user-friendly administration and benefits of the GMAE. The majority of questions revealed that therapists deviate from the guidelines provided by the manual to a greater or lesser extent though. The most worrisome finding was that 28.8% (15/52) of the therapists calculate the total score of the GMFM-66 using the score form of the GMFM-88 instead of the GMAE.

**Conclusion:** The consequences of the high number of therapists who stated that they calculate the total score of the GMFM-66 with the GMFM-88 score form are far-reaching; it has a misleading impact on the opinion of rehabilitation teams and parents on the development of the child, on decision-making in rehabilitation, and ultimately on the development of the child. Information currently available on psychometric properties, motor growth curves and percentiles cannot be generalized to clinical practice in the Netherlands, as they were generated in highly controlled testing conditions, which do not hold in clinical practice.

## **Longitudinal Study of Oropharyngeal Dysphagia in Preschool Children with Cerebral Palsy**

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**Background:** Oropharyngeal dysphagia is prevalent in approximately 60% of preschool children with cerebral palsy (CP), with the preschool years representing a time of feeding transition.

**Aim:** To determine changes in prevalence and severity of OPD in children with CP and relationship to health outcomes.

**Study Design:** Longitudinal study of a population-based cohort.

**Participants & Setting:** 109 children with confirmed CP diagnosis participated, assessed first at 18-36 months (Ax1 mean age 27.3 months c.a. (SD=5.1), 70 males, Gross Motor Function Classification System (GMFCS) I=50, II=10, III=21, IV=11, V=17) and again at 36-60 months (Ax2, average time between assessments was 15.3 months).

**Method:** OPD was classified on the Dysphagia Disorders Survey (DDS). Health outcomes included: (1) Nutritional status, measured using Z-scores for weight, height, and body mass index (BMI), (2) Parent stress during mealtimes, (3) Hospitalisations for pneumonia. Gross motor skills were classified on GMFCS and motor type/ distribution.

**Results:** Prevalence of OPD on the DDS reduced from 57% to 40% between assessments. 23% of children had an improvement to severity of OPD ( $>$ smallest detectable change), and 5% had poorer OPD. Gross motor function was strongly associated with OPD at both assessments, for OPD classification (Ax1 OR=2.2,  $p<0.001$ ; Ax2 OR=3.4,  $p<0.001$ ) and severity (Ax1  $\beta=3.8$ ,  $p<0.001$ ; Ax2  $\beta=3.9$   $p<0.001$ ). OPD at 18-24 months was related to health outcomes at 36 months: the DDS was related to low Z-scores for weight (adj  $\beta=1.2$ ,  $p=0.03$ ) and BMI (adj  $\beta=1.1$ ,  $p=0.048$ ).

**Conclusion:** 18 to 60 months appears to be a time of transition in OPD, with a quarter of children showing improvement in their OPD. OPD is predictive of important outcomes at 36 months, and so should be screened from a young age using standardized measures. These findings will contribute to developing more effective screening considering critical developmental transitions for children from different GMFCS levels.

**When I do I become someone - young adults with cerebral palsy experiences of occupational performance and participation in daily life.**

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**Background:** Studies have shown that persons with cerebral palsy (CP), even if they have good hand function and are able to move independently, have a lower level of independence and participation in daily life than persons without disabilities in the same age. In the interaction between the person, environment and activity the perception of participation occurs. No studies can be found showing how young adults with CP perceive their ability to perform activities and its relation to their participation in everyday life.

**Aim:** To investigate how young adults with CP perceive their ability of occupational performance and their participation in everyday life.

**Method:** A qualitative interview study, with a Phenomenographic approach, with 10 persons with CP (MACS I-III) in the age of 18-30 years, in the region of Västra Götaland, Sweden.

**Result:** Preliminary result show that young adults with CP perceive their occupational performance as very important in life, and that it is crucial to perform activities yourself and in the same way as others. The persons consider that occupational performance can affect self-esteem, self-image and self-confidence, and is viewed to help young adults to grow as person. Occupational performance is experienced to create feeling of affiliation or exclusion, depending on the possibility to be a part of an activity situation or how the people in the environment act. To perform activities describes as very demanding, especially cognitively, but with knowledge, compensation, adaptation, support and self-motivation it becomes possible. The persons describe that, even if it becomes possible, the occupational performance has a high price in form of motor impairment, pain, mental and physical fatigue, which can affect the possibility to continue performing activities.

**Conclusion:** Young adults with CP consider that despite the fact that life is so demanding, it is important to perform activities yourself, because "When I do I become someone".

## **Mental health in children with cerebral palsy**

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**Background:** Although questionnaire based studies had found mental health problems common in children with Cerebral Palsy (CP), we did not know the prevalence of psychiatric disorders when using stringent diagnostic criteria. Neither did we know the impact of co-existing medical conditions, nor the feasibility of using screening questionnaires to identify psychiatric disorders in children with CP.

**Aim:** To ascertain the prevalence of psychiatric disorders in children with CP, and the impact of with co-existing medical conditions. Further, to assess autism spectrum symptoms, and to compare mental health problems in children with CP to a population based sample using the Strengths and Difficulties Questionnaire (SDQ).

**Method:** The study included children with CP living in Western Norway, assessed at school starting age. Parents were interviewed using the child psychiatric diagnostic instrument, Kiddie-SADS, and diagnosed according to DSM-IV criteria. Mental health problems were assessed using the SDQ, and social functioning was assessed using the Autism Spectrum Screening Questionnaire (ASSQ). Medical information was gathered through medical records and a medical examination.

**Result:** Psychiatric disorders were found in one in two children with CP when using the Kiddie-SADS, and mental health problems were found in two in three children when using the SDQ, with peer problems being most common. One in five children scored above normal on the ASSQ. Co-occurrence of mental health problems was common

**Conclusion:** A high prevalence of psychiatric disorders in children with CP was found. Autism spectrum symptoms, possibly representing autism spectrum disorders, were highly prevalent. Co-existing medical conditions and co-occurring mental health problems were common, representing a challenge when diagnosing psychiatric disorders in children with CP. Mental health screening is recommended at school starting age in children with CP.

## **Hand-Arm Bimanual Intensive Therapy including the Lower Extremities (HABIT-ILE) for children with bilateral cerebral palsy (GMFCS II to IV)**

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**Background:** Intensive motor learning based treatments have been primarily directed toward the upper extremity (UE) (e.g., constraint-induced movement therapy, bimanual training) of children with unilateral cerebral palsy (CP). Children with bilateral CP present impairments in both the upper and lower extremities (LE). Recently we showed that an approach simultaneously engaging both the UE and LE, Hand-Arm Bimanual Intensive Therapy including the Lower Extremities (HABIT-ILE), improved function of both in children with unilateral CP. Whether children with bilateral CP would benefit is not known.

**Objective:** Examine the efficacy intensive treatment simultaneously targeting the UE and LE (HABIT-ILE) in children with bilateral CP.

**Methods:** A quasi-randomized trial design was used, whereby the 20 participants (11 males, age 6 to 15, GMFCS II to IV, MACS I to III) were assigned to a treatment (HABIT-ILE) and control group in the order in which they enrolled in the study. Children in the HABIT-ILE group were assessed prior and after 84h of intervention over 13 days, as well as at 3 month follow-up. Children in the control group were assessed at the same time points but did not receive HABIT-ILE. Children in both groups were assessed using the Gross Motor Function Measure (GMFM) and ABILHAND-Kids (UE and LE primary measures), and 7 secondary measures: Pediatric Balance Scale, 6 Minute-Walk Test, ABILOCO-Kids, Pediatric Evaluation of Disability Inventory, Box-and-Blocks (BBT), Jebsen-Taylor Test of Hand Function (JTTHF) and Canadian Occupational Performance Measure.

**Results:** A 2 (group) x3 (test session) ANOVA indicated significant improvements for all measures except the BBT and JTTHF on the more affected hand.

**Conclusion:** The findings suggest that HABIT-ILE is efficacious for improving both UE and LE function in children with bilateral CP.

## **Energy cost of walking in relation to age and body height in children with cerebral palsy compared to typically developing children**

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**Background:** Children with cerebral palsy (CP) often have pathological gait patterns, which are associated with an increased walking energy cost (EC). Accordingly, this may negatively impact the walking mobility and functioning in daily life. While the EC in children with CP is known to increase with an increase of gross motor function classification system (GMFCS) level (larger motor involvement), little is known about the development of EC over time in different GMFCS levels.

**Aim:** Assess the relation of EC with age and body height in children with CP with different GMFCS levels in comparison with typically developing children (TD).

**Methods:** EC was collected in 153 children (mean age 11y4mo, range 4y – 22y), including 102 children with CP (GMFCS level I, n=41; II, n=35; III, n=26) and 51 TD. EC was assessed by measuring the energy consumption during a 6-minute walk test at comfortable speed. Gross EC (J/kg/m) was calculated as the energy consumption divided by walking speed. Resting energy consumption was also assessed to calculate the net EC. Interaction effects were specified for age and body height (by group) to assess the differences between TD and GMFCS levels I, II and III in the relation between EC and age or body height ( $p < 0.05$ ).

**Results:** The interaction effects for age and body height by group were not significant, indicating similar relations between gross and net EC and age or body height among children with CP and TD. So, for both groups we observed a decline in gross ECw with increasing age (yrs) (regression coefficient:  $-0.215$  J/kg/m; SE 0.043;  $p < 0.001$ ) or body height (cm) ( $-0.055$  J/kg/m; SE 0.008;  $p < 0.001$ ). There was no significant relation with age and body height for net EC.

**Conclusion:** The relation between EC and age or body height is similar for TD and children with CP. As in TD, gross EC decreases when children with CP get older or taller while net EC remains stable over time.

## **Gaze-based assistive technology in daily activities by children with severe physical impairments**

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**Background:** Non-speaking children with severe physical impairments have limited opportunities for activities and social interactions. Gaze-based assistive technology (gaze-based AT) may be the only option to perform activities for children who only voluntarily can control their eye gaze. **Aim:** The aim was to establish the impact of a gaze-based AT intervention on activity repertoire, autonomous use, and goal attainment in children with severe physical impairments. **Method:** This study had a multiple baseline with single subject ABB design, with a before, after, and follow up approach. Ten children with severe physical impairments without speaking abilities (ages 1-15) were included in the study. Children, together with their parents and teacher, participated in a gaze-based AT intervention aiming at implementing the AT in daily activities. The gaze-based AT intervention consisted of having access to a gaze-based AT, and to services provided by a multiprofessional communication team during 9-10 months. Individual goals were formulated with Goal Attainment Scaling, activities were registered in computer use diaries at different time points. **Results:** All children started to use gaze-based AT in daily activities and had maintained use both at post intervention and at follow up (5-10 months after end of MPC team services). The gaze-based AT was mostly used up to one hour per user day. All children fulfilled individual goals covering topics such as communicating with others, interacting with others and performing school activities. Children expanded their activity repertoire by using gaze-based AT. **Discussion:** Using gaze-based AT may be an important contribution for children with severe physical impairments to perform childhood activities. A clinical implication is to provide families with follow-up services to continue to adapt the gaze-based AT to the children's changing needs due to their development and by that maintain autonomous gaze-based AT usage over time.

## **Relationship between brain structure and school readiness in pre-school aged children with cerebral palsy**

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**Background:** The domains of school readiness include: (1) physical wellbeing & motor development, (2) social & emotional development and (3) language development are important markers of development in children with CP but there is limited understanding of the relationship to brain lesion severity.

**Aim:** To examine the relationship between the type and severity of brain lesions on MRI and three of five domains of school readiness in pre-school aged children with cerebral palsy

**Method:** In a prospective longitudinal cohort 137 children with CP (57.7% male), mean age 58 months (SD 4.1), GMFCS I=51 (37.2%), II=27 (19.7%), III=20 (14.6%), IV=18 (13.1%), V=21 (15.3%) were assessed for school readiness, using the Paediatric Evaluation of Disability Inventory (PEDI) and the Communication and Symbolic Behavioural Scales Developmental Profile (CSBS-DP). MRI were classified using Krageloh-Mann classification and scored using a semi-quantitative scale for brain lesion severity. Linear regression was used to model the relationship between brain structure and school readiness.

**Results:** Brain lesion severity (global score sqMRI) was related to: self-care ( $\beta = -0.79$ ,  $p < 0.001$ ), mobility ( $\beta = -0.66$ ,  $p < 0.001$ ) and social function ( $\beta = -0.84$ ,  $p < 0.001$ ) and CSBS-DP: ( $\beta = -1.24$ ,  $p < 0.001$ ). The type of brain injury (KM) was only significantly related to social function domain of PEDI ( $p = 0.034$ ): children with periventricular white matter lesions had better social function than those with cortical or deep gray matter lesions ( $\beta = -11.7$ ,  $p = 0.012$ ).

**Conclusion:** Brain lesion severity is related to three of the five domains of school readiness domains: (1) physical wellbeing & motor development, (2) social & emotional development and (3) language development. More severe brain lesions are associated with lower levels of school readiness. Evaluation of brain lesion severity offers prognostic information in children with cerebral palsy which may enable prediction of outcomes such as school readiness.



## **Efficacy of intensive upper limb therapies on upper limb outcomes for children with unilateral cerebral palsy: Individual patient data meta-analysis of 3 trials**

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**Background:** Individual variability in response to constraint induced movement therapy (CIMT) and bimanual training (BIM) has been reported. Individual Patient Data Meta-analysis (IPD) allows investigation of subgroup responses to intervention.

**Aim:** To explore subgroup differences on treatment outcomes following hybrid or modified CIMT compared to BIM to improve upper limb function in children with unilateral cerebral palsy (UCP).

**Method:** IPD from three trials using single-blind randomized controlled designs comparing CIMT to BIM for children with UCP (5-16yrs, n=128, 74 male, 9.2yrs±SD2.7) were included. The Assisting Hand Assessment (AHA), Melbourne Assessment (MUUL), Jebsen Test of Hand Function (JEB) and Canadian Occupational Performance Measure (COPM) were compared immediately and 26wks post intervention. Analyses examined influence of age (<9yrs or ≥9), baseline AHA (≤62 or ≥63 AHAunits), dose (hrs) and duration of therapy (1, 2, 12wks) on outcomes. One step mixed modelling was used on pooled IPD data, accounting for study clusters.

**Results:** Characteristics of participants in CIMT (n=68) and BIM (n=60) were equivalent at baseline. Dose (30-60hrs) and therapy duration did not influence outcomes. Older children receiving CIMT compared to BIM had significantly greater gains on MUUL (post-intervention EMD 3.04, 95%CI 0.48, 5.61, p=0.02; 26wk EMD 3.52, 95%CI 0.85, 6.12, p=0.01). Children with poorer baseline AHA scores receiving CIMT compared to BIM had greater gains on MUUL (26wk EMD 3.25, 95%CI 0.43, 6.07, p=0.02). Children with higher baseline AHA scores had significantly greater gains on COPM performance and 26wk AHA outcomes following BIM compared to CIMT (EMD -1.01, 95%CI -1.12, 0.64, p=0.02; EMD -2.94, 95%CI -5.4, -0.49, p=0.02 respectively).

**Conclusion:** Older children with poorer baseline AHA scores had better outcomes following CIMT. Children with better baseline bimanual hand function had more favourable outcomes on AHA and COPM following BIM.

## **Effect of selective dorsal rhizotomy on daily care and comfort in non-walking children and adolescents with a bilateral spastic paresis**

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**Background:** In non-walking children and adolescents with a bilateral spastic paresis, severe spasticity can interfere with motor function and contribute to the development of musculoskeletal deformities. Daily care can be difficult and many patients suffer from pain. Although traditionally used for walking children to improve gait, Selective Dorsal Rhizotomy (SDR) is a surgical intervention that by reducing spasticity also has the potential to improve daily care and comfort.

**Aim:** To examine effects of SDR on daily care and comfort in non-walking children and adolescents with a bilateral spastic paresis.

**Methods:** Parents of all children and adolescents who were operated in our center (2009-2014), with at least one year follow-up, were asked to answer a questionnaire about changes since SDR (5 point Likert scale) and satisfaction with the effects (10 point scale). Presence of scoliosis, post-operative complications and physical examination details were derived from the medical records.

**Results:** Twenty-three of 24 children and adolescents participated. 19 Of 23 were male, GMFCS levels were IV (n=8) and V (n=15), mean age at SDR was 12y6m (range 2y8m -19y3m). Seven patients had a spondylodesis for scoliosis correction in the same session. Post-operative complications were rare. Most improvements were reported in dressing (n=14), washing (n=13), transfer (n=7) and sitting (n=6). Parents also noted improvements in comfort (n=9) sleeping (n=8) and pain (n=7). Mean score for satisfaction was 7.0. The most pronounced negative effect was the onset of dystonia in seven children after SDR.

**Conclusion:** SDR can have positive effects on daily care and comfort in non-walking children with a severe spastic paresis. An advantage in this vulnerable population is that SDR is a one-time intervention and can be combined with surgical scoliosis correction. However, not all children improve and satisfaction is moderate. Careful attention is necessary for risk factors for dystonia.

## **The Toddle Temporal-spatial Deviation Index: clinical assessment of pediatric gait**

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**Background:** Children born preterm with very-low birth-weight (VLBW) have increased risk of motor impairment including cerebral palsy. Early identification guides treatment to improve long-term function. Temporal-spatial gait parameters are easily-recorded and potentially revealing of gross motor function.

**Aim:** To develop a gait index for use in the pediatric clinic, quantifying gait deviation in 18-22 month-old children: the Toddle Temporal-spatial Deviation Index (Toddle TDI). We hypothesized that Toddle TDI values would be significantly lower in preterm children scoring <85 composite motor on the Bayley Scales of Infant Development-3<sup>rd</sup> Edition (BSID-III) compared to typically-developing (TD) children, and that preterm children's Toddle TDIs would correlate with BSID-III gross motor subscores.

**Method:** 81 children born preterm ( $\leq 32$  weeks) with VLBW ( $\leq 1500$  g) and 42 full-term TD children aged 18-22 months, adjusted for prematurity, walked on a pressure-sensitive mat. Preterm children were administered the BSID-III. Temporal-spatial gait parameters were selected using measures of sampling adequacy, informed by clinical relevance. Principle component analysis of TD children's gait parameters calculated raw deviation from typical, normalized to an average(standard deviation) Toddle TDI score of 100(10), and calculated for all participants.

**Result:** The Toddle TDI was significantly lower for preterm versus TD children (86 vs. 100,  $p = 0.003$ ), and lower in preterm children scoring <85 vs.  $\geq 85$  BSID-III motor composite (66 vs. 89,  $p = 0.004$ ). Toddle TDI correlated with BSID-III gross motor ( $r = 0.50$ ,  $p < 0.001$ ) and not fine motor ( $r = 0.19$ ,  $p = 0.09$ ). The Toddle TDI, which plateaus at average (BSID-III gross motor 8-12), correlates strongly with gross motor  $\leq 8$  ( $r = 0.60$ ,  $p < 0.001$ ).

**Conclusion:** The Toddle TDI is sensitive and specific to gross motor function in VLBW preterm children aged 18-22 months, and has potential as an easily-administered, revealing clinical gait metric.

## **Modified-Constraint Induced Movement Therapy for Infants with Hemiplegia: A Randomized Trial**

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**BACKGROUND:** In the past two decades a large body of evidence has shown that m-CIMT is an effective treatment for children and adults with hemiplegia. On the other hand, there is very little research regarding the effectiveness of m-CIMT, or other treatments, aimed at improving hand function in infants. This lack of research is surprising considering the fact that there is unanimity amongst researchers regarding the crucial importance of treatment during the very early years of human development.

**AIM:** The objective of this randomized controlled study was to test the efficacy of Modified-Constraint Induced Movement Therapy (m-CIMT) in treating infants diagnosed with hemiplegic cerebral palsy (CP) by comparing it with a non-constraining, bimanual treatment (BIM) of equal intensity.

**METHOD:** 33 infants with hemiplegia (corrected age  $11.1 \pm 2.2$  months) received either m-CIMT or BIM. Both interventions included a home program aimed to encourage the use of the affected hand during daily one-hour play sessions over a period of 8 weeks. Main outcome measures included the mini Assistive Hand Assessment for babies (mini-AHA) and the Functional Inventory (FI). In addition, at baseline parents filled out the Dimensions of Mastery Questionnaire (DMQ).

**RESULTS:** Both groups demonstrated a significantly large and equal improvement in hand function and gross motor function post treatment, together with high treatment compliance. However, in the m-CIMT group, improvement was associated with motivation, object-oriented persistence (OOP) - infants that had a low OOP score showed greater improvement compared to children with an initial high OOP score

**CONCLUSION:** BIM and m-CIMT are feasible and effective methods for treating infants diagnosed with hemiplegia and no differences were found between the two methods. Nevertheless, amongst infants treated with m-CIMT it is reasonable to expect that those with lower motivation (OPP) will have relatively greater gains.

## **Quantifying Real-World Activity and Upper-Limb Use in Children with Cerebral Palsy Using Accelerometers**

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**Background:** Constraint-induced movement therapy (CIMT) is a high-dosage rehabilitation approach used for children with hemiplegic cerebral palsy (CP). Questions remain regarding how much movement is required during CIMT programs to change the real-world affected upper-limb (UL) use of children with CP. Understanding optimal therapy dosage is important for maximizing outcomes and offering family-friendly, achievable interventions. Accelerometer data could further elucidate the relationship between high-intensity CIMT and changes in patterns of affected arm use. **Aim:** To quantify the real-world activity and affected UL use of children with CP who participated in CIMT 1) determine the feasibility of using accelerometers to quantify UL movements during CIMT 2) compare activity level of children with hemiplegic CP with typical peers 3) determine the relationship between change in activity/duration of affected UL movements (as measured by accelerometer) and change in performance on standardized assessments. **Method:** A pre-test post-test design was used with 12 children with CP (mean=4.9yrs) who completed a 30-hour camp-based CIMT program. Three developmental assessments were administered pre-post CIMT program. Accelerometers were successfully worn before, during, and directly after program to collect UL and activity data. **Results:** Participants demonstrated lower levels of moderate-to-vigorous activity compared to typical peers ( $p<0.05$ ). Significant improvements were seen on all three developmental assessments ( $p<0.05$ ), while no significant change was noted in affected UL activity/duration as measured by accelerometers. **Conclusion:** While improvements were seen in assessment scores measuring capacity of affected UL use, accelerometer data suggests that some children may not have incorporated new movements into daily habits. A CIMT program of greater than 30 hours may be required to change patterns of everyday affected UL use. Follow-up testing is planned 4-months post-CIMT.

## **The frequency and types of epilepsies in children with cerebral palsy and white matter injury**

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**Background:** Children with cerebral palsy (CP) are at higher risk of epilepsy. Few studies delineate the epileptic syndromes that occur in children with CP.

**Aim:** To describe the frequency, types and evolution of epilepsies in children with CP and white matter injury (WMI).

**Method:** MRI scans of children in the Victorian CP Register, Australia, born between 1999-2006 and recorded as having WMI were reviewed (n=309). Children were excluded if they had dual pathology, global WMI in keeping with a genetic condition, cortical injury (e.g. encephalomalacia) or a chromosomal disorder. Information on seizure phenomenology, clinical course and interictal EEG discharges were used to make an epileptic syndrome diagnosis, in accordance with the International League Against Epilepsy diagnostic scheme.

**Results:** 188 children (114 male, 74 female), mean age 12 years (range 9-15), born at 34 weeks gestation (range 23-42) were included. The most common CP subtypes were spastic diplegia 44% and hemiplegia 40%. 37 children (20%) developed epilepsy at a median age of 5 years (interquartile range 6.5). Five had infantile spasms (with hypsarrhythmia which resolved), 4 of whom then re-presented with focal seizures and centrotemporal spikes. 28 had focal seizures which in most cases were infrequent, nocturnal and stereotyped. Of these children, 16 had centrotemporal spikes, seven had occipital spikes and two had a combination of centrotemporal and occipital spikes. Three had normal (awake) EEGs, despite a history of nocturnal, stereotyped seizures. One child had idiopathic generalised epilepsy and another had a generalised tonic-clonic seizure, not otherwise specified. Seizures resolved in all children by 11 years.

**Conclusion:** The electroclinical features of epilepsy associated with CP and WMI are those of the age-limited, benign focal epilepsies of childhood with centrotemporal and occipital spikes. These findings have implications for prognosis, counseling and drug treatment.

## **Understanding the utility of long-term botulinum toxin administration in children with cerebral palsy**

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**Background:** In the last decade botulinum toxin has become a standard treatment for hypertonia in cerebral palsy (CP). International guidelines for toxin use exist and are evidence-based. Most evidence is on short-term outcome and relates to body structure rather than activity and participation. Concerns regarding progressive weakness and muscle volume loss following long-term use have been reported.

**Aim:** To review the utility of long-term botulinum toxin administration in children with CP.

**Method:** Eligible children who had repeated botulinum toxin injections over a five year period or longer were identified from our database. Retrospective chart review assessed Gross Motor Functional Classification System (GMFCS) level, Functional Mobility Scale (FMS), treatment goals, outcomes and child and family satisfaction.

**Results:** 45 children underwent repeated injections over 5-13 (mean 7) years. 18 children were GMFCS level I, 11 level II, 7 level III, 5 level IV and 4 level V. The most common treatment goals in GMFCS levels I-III were to improve gait and splint tolerance. In GMFCS levels IV and V the goals related to reduction in pain, improved seating tolerance, facilitating personal cares and improving upper limb position. 86% of children fully met treatment goals at first injection episode, compared to 67% at most recent episode. With repeated gastrocnemius injections the mean joint range loss was only 3°. Child and family satisfaction scores remained positive, at 5-8/10. FMS was stable over time inferring no progressive weakness or loss of activity.

**Conclusion:** Repeated botulinum toxin injections are indicated in children with CP following careful goal setting and evaluation of response. Our results demonstrate some evidence for repeated goal achievement and minimising contracture formation. Further studies using meaningful outcome measures of activity and participation are essential to investigate the long-term utility of botulinum toxin and its safety profile.

## **The trajectory of General Movements in infants following surgery in the neonatal period**

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**Background:** Neonates who have undergone major surgery have been shown to be at risk of neuro-developmental disability, including cerebral palsy (CP). The General Movements Assessment (GMA) is a validated and reliable method of identifying infants at risk of CP thus enabling early intervention at the time of optimal neuroplasticity. However, there are minimal published data on the use of the GMA among the infant surgical population.

**Aim:** This paper describes the trajectory of general movements in infants who have undergone major surgery in the neonatal period.

**Method:** This was a prospective cohort study of 213 infants (124 male) admitted to an Australian neonatal unit for cardiac surgery (n=106, 50%), non-cardiac surgery (n= 100, 47%), or both types of surgery (n=7), and followed-up in the Development Clinic. Infants were assessed using the GMA at term (mean 40 weeks, SD 2.3), and at 3 months of age (mean 12 weeks, SD 1.6). All videos were independently rated by three advanced trained assessors.

**Result:** The most common result in the writhing period was 'poor repertoire' (n=115, 54%), of which the majority (n=98) went on to demonstrate normal fidgety movements; 15 infants had absent fidgety and two had abnormal. For those with normal writhing (n=73, 34%), 71 remained 'normal' in the fidgety period, and 2 were rated as having absent fidgety movements. Cramped synchronised movements were seen in 10 infants, 6 of whom had normal fidgety movements at follow-up; 3 with absent, and 1 with abnormal fidgety. Overall, 21 infants (10%) had absent fidgety movements. There was no significant difference in the GMA results between the surgical groups.

**Conclusion:** This is the first report on the use of the GMA in a large cohort of infants who have undergone surgery in the neonatal period. Research is underway to determine rates of CP and developmental delay in this unique population.



**Investigation of developmental progress in sensorimotor cognition and functional vision from 1 to 2 years in infants with severe visual impairment (VI).**

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**Background:** Investigating sensorimotor understanding (SMU) and its relation to functional vision loss in infants with congenital VI has been limited by lack of standard developmental norms to chart progress. **Aim:** As part of the UK longitudinal study of VI infants (OPTIMUM project, Dale et al), this study undertook i) retrospective analysis of Reynell Zinkin Scales (Reynell 1978) – RZS scores on our clinic database (n=96) to provide standard norms for infants with ‘simple’ congenital disorders of the peripheral visual system (CDPVS) and ii) prospective investigation of the OPTIMUM cohort at 1 and 2 years to chart SMU and functional vision. **Method:** At Time 1, 71 infants (mean age 13 mths) with ‘simple’ CDPVS were assessed on the RZS SMU scale and functional vision Near Detection Scale- NDS (Sonksen et al 1983) and 53 infants were assessed again at Time 2 (mean age 26 mths). **Result:** Raw scores on the SMU were transformed to z-scores using the database norms. The distribution of SMU z-scores and NDS scores at Time 1 were Gaussian but by Time 2 the SMU were negatively skewed and the NDS were bimodal. Non-parametric analysis showed that SMU z-scores had strong cross-sectional correlations with NDS scores at Times 1 and 2, with lower scores at the most profoundly impaired level of vision (Spearman rho .66, .55,  $p < .001$  respectively). There were also strong longitudinal correlations between SMU z-scores and NDS scores from Times 1 to 2 (rho .61, .84,  $p < .001$ ). **Conclusion:** This is the first study to report on the developing specific levels of very low detection vision in a national cohort of infants with congenital VI and to show, using new standard SMU norms, that precise levels of low detection vision strongly determine the level and progress of SMU cognition across 1 to 2 years. These patterns will be discussed further including other potential factors from neural to psychosocial level that may be influencing SMU cognitive outcome at 1 and 2 years.

## **Association between body composition and bone health in pre-school aged children with cerebral palsy.**

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**Background:** Altered body composition and poor bone health is common in children with cerebral palsy (CP). Muscle development plays an integral part of bone mass accrual in the growing skeleton, with childhood being a critical time to achieve optimal peak bone mass.

**Aim:** To explore the associations between body composition, bone mineral content (BMC), and areal bone mineral density (aBMD) in children with CP.

**Method:** Dual-energy X-ray absorptiometry (DXA) was used to assess total body BMC, aBMD, fat free mass (FFM), bone free fat free mass (BFFFM, proxy for muscle mass) and fat mass (FM) in 18 children with CP (11M), age  $5.3 \pm 0.7$  years, with Gross Motor Classification: I=7, II=4, III=3, IV=2, V=2. Height and weight were measured to the nearest millimetre and 100grams, and converted to Z-scores. The indices FFM/height<sup>2</sup> (FFMI) and FM/height<sup>2</sup> (FMI) were calculated.

**Results:** BMC correlated positively with: LBM ( $r=0.83$ ,  $p<0.01$ ); height Z-score ( $r=0.80$ ,  $p<0.01$ ) and weight Z-score ( $r=0.57$ ,  $p<0.05$ ). FMI had significant positive correlations with weight ( $r=0.61$ ,  $p<0.01$ ) and BMI Z-scores ( $r=0.67$ ,  $p<0.01$ ), but not height Z-score ( $r=0.11$ , ns). Though not significant, aBMD Z-score correlated negatively with FMI ( $r=-0.34$ , ns) and positively with FFMI ( $r=0.26$ , ns).

**Conclusion:** These results shows increased BMC is strongly associated with increased BFFFM. Interestingly, lower aBMD Z-score tended to be associated with higher FMI. These data may suggest a greater influence on BMC may arise from muscle forces on bone rather than body weight, whereas increasing fat mass tends to have a negative effect on bone. Further investigation of body composition in young children with CP is warranted to ensure optimal bone mass accrual in childhood.

## **Reduced Mitochondrial Enzyme Activity in Skeletal Muscle in Children with Cerebral Palsy**

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**Background:** Compared to typically developing (TD) children, the energetic cost of movement is increased in children with cerebral palsy (CP). While these impairments have been primarily attributed to inefficient muscle activation patterns and cardiorespiratory factors, oxidative capacity (i.e., mitochondrial function) in skeletal muscle is an important contributor to energetics.

**Aim:** The purpose of this study was to evaluate the maximal activity of various mitochondrial enzymes in skeletal muscle of CP and TD children to potentially understand the mechanisms behind their increased energetics cost.

**Methods:** 13 subjects (CP, n=7, 12.6±5.6 years old; TD, n=6, 16.4± 1.3 years old) consented to participate in the study. Children with CP were undergoing hamstring lengthening while TD children were undergoing anterior cruciate ligament reconstruction.

Gracilis muscle biopsies were flash frozen in liquid nitrogen-cooled isopentane and stored at -80°C. Maximal activity of mitochondrial enzymes: Complex I (CI; NADH:ubiquinone oxidoreductase), Complex II (CII; succinate dehydrogenase), Complex III (CIII; ubiquinol cytochrome c oxidoreductase), Complex I+III (CI+III; NADH cytochrome c oxidoreductase) and citrate synthase (CS) were assessed using standardized protocols.

**Results:** Maximal activities of CIII (37 ± 8 vs. 73 ± 7 nmol/min/mg protein), CI+III (8 ± 2 vs. 32 ± 9 nmol/min/mg protein) and CII (8 ± 5 vs. 19 ± 7 nmol/min/mg protein) were reduced by 50, 75 and 60% (p<0.05), respectively, in CP vs. TD. There were no differences between groups in the maximal activities of CS or CI.

**Conclusions:** These results demonstrate that the maximal activity of complex II and complex III of the electron transport chain are impaired in children with CP. Taken together, these results may be relevant to the increased energy consumption seen during movement in children with CP and could potentially open up new avenues of therapeutic intervention.

**Measuring upper extremity muscle strength in children with Cerebral Palsy; can it be done reliable and how to interpret the results?**

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**Background:** Sixty percent of the children and adolescents with Cerebral Palsy (CP) experience problems with the skills of their upper extremities. Muscle strength of the upper extremity has been proven to be a predictive factor for the use of the arm and hand in daily activities. A recent published systematic review about measurement instruments for measuring upper extremity muscle strength in children with CP, conclude that results should be interpreted with caution, because research on clinimetric properties of these measurement instruments is limited and mostly done in studies of poor methodological quality.

**Aim:** to investigate the reliability of isometric upper extremity muscle strength in children with CP using a Hand Held Dynamometer (HHD), an E-Link and a new developed isometric functional upper extremity strength measurement test, in a study of good methodological quality.

**Method:** Cosmin criteria were leading for determining the methodological quality. A total of one hundred fifty-eight children (7-18y) with unilateral spastic CP (83 boys, 75 girls; mean age= 11,6y, SD= 3,15y) were included. Intraclass correlation coefficients (ICC) of test-retest reliability and interrater reliability, standard error of measurement (SEM), smallest detectable difference (SDD) and limits of agreement (LOA) were calculated for the total group, and for two subgroups (7-12y, 13-18y).

**Result:** Almost all ICC values for test-retest reliability and interrater reliability were above 0.80. The SEM, SDD and LOA were mostly acceptable but in some specific measurements, more than twenty-five percent difference in test results is needed to demonstrate change.

**Conclusion:** The Hand Held Dynamometer, E-link and a new developed functional upper extremity strength measurement test are reliable tests for measuring (functional) arm and hand muscle strength in children with CP. Some specific measurements are probably less suitable in clinical practice, due to reasonably high SEM, SDD and LOA.

## **Abnormal General Movements During The Fidgety Period And Abnormal Neurologic Examinations At 18-24 Months In A High Risk United States (US) Population**

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### **Background**

Assessment of General Movements (GMA) appears to be predictive of neuromotor function in preterm infants but it has not been studied in diverse groups of infants from the United States (US).

### **Aim**

To evaluate the association between the GMA during the fidgety period and neurologic examinations at 18-24 months corrected age (CA) in US infants with a variety of high risk biomedical and neurologic conditions.

### **Methods**

Infants were included if they were preterm (<30 wks gestation, n=44), had significant brain injury/abnormality (n=49), neonatal cardiac surgery (n=38) or prolonged hospitalization through 10 weeks post-term (n=17). Of the 121 infants studied, 23 had more than one risk factor.

Infants were videotaped in a quiet alert state and evaluated by 2 blinded, certified GMA observers. Fidgety Movements (FM) were classified as Normal if present (continual or intermittent) or Abnormal if absent, sporadic, or abnormal (exaggerated). A standard neurologic examination was performed at 18-24 months CA in the developmental follow up clinic and coded as normal, suspect or definite cerebral palsy (CP). The diagnosis of definite CP was confirmed by a pediatric physiatrist using the Surveillance of Cerebral Palsy in Europe.

### **Results**

FM classification was significantly correlated with the neurologic examination (p=0.0001). Eight infants had CP and 8 were suspect. For continual FM (n=14), no infants had CP or were suspect. For intermittent FM (n=78), 2 had CP and 5 were suspect. For sporadic FM (n=8), no infants had CP or were suspect. For absent FM (n=17), 6 had CP and 2 were suspect. For abnormal (exaggerated) FM (n=4), no infant had CP; one was suspect.

### **Conclusions**

The GMA correlated with abnormal neurologic examinations at 18-24 months CA but FM classifications were less predictive than previously reported. This suggests the development of general movements in this US group of medically complex infants differs from infants studied previously.

## **Facilitators and barriers for Thai children with cerebral palsy in caregivers' perspective: In-depth interview**

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**Background:** According to the ICF framework, environmental and personal factors could positively or negatively affect activity and participation of children with cerebral palsy (CP).

**Aim:** To explore facilitators and barriers in performing activity and participation for children with CP in caregivers' perspective.

**Method:** Qualitative in-depth interview was conducted in 27 primary caregivers of children with CP (GMFCS I-V) aged 4-12 years. Semi-structured questions related to environmental and personal factors were asked and audio recorded. Interviews were transcribed verbatim and analyzed for main themes based on the ICF categories.

**Result:** Twenty-seven primary caregivers of children with CP: GMFCS I-III (n=14) and GMFCS IV-V (n=13) were recruited. Facilitators reported by caregivers were in all chapters of the environmental factors, including proper assistive device, family and others' emotional support, government support and treatment. Barriers reported were unfit assistive devices, lack of social support, insufficient time of parents in caring children, social nonacceptance, financial problem, insufficient government support, inaccessibility (rough road and no road safety), poor transportation for children with disabilities and limited educational accessibility. Over half of all caregivers reported children's environmental barriers were in e1: Products and technology and e5: Services, systems and policies. Personal factors that impede children performing their activities reported by caregivers were shyness, laziness, poor cooperation and frustration of children. Whereas, the personal facilitators were their motivation, self-efficacy and good cooperation.

**Conclusion:** Barriers that caregivers concerned for their children covered primarily in e1 and e5 chapter includes design, construction and building transportation and economic services, system and policies. Motivation and co-operation of children were also reported to affect their activities and participation.

## **Grasp control in children with congenital hemiplegia in a discrete motor task of intersegmental coordination**

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**Background.** Precision grasping relies on predictive and reactive mechanisms, both affected in children with cerebral palsy. To avoid slips and early fatigue a good coordination between the grip force (GF) and load force (LF) is required. This coordination has been studied while sitting or walking, but never in a daily/functional activity such as descending a step while carrying an object, where the intersegmental upper/lower extremity coordination is needed.

**Aim.** During a stepdown task while carrying an object we compared the GF-LF synchronization in both hands of children with unilateral spastic cerebral palsy (UCP), with the synchronization in dominant and non-dominant hands of typically developing children (TD).

**Method.** Participants were 21 children with UCP and 21 age-matched TD. Standing on a step and holding in a precision grip a grip-lift manipulandum (GLM), the children were instructed to descend the step spontaneously and maintain subsequently a static ending position. The GLM provided LF and GF measures.

**Results.** Children with UCP had higher values of GFmax, LFmax and LFmax variability in both hands than TD children and higher values of LFmax on the paretic hand vs the non-paretic. Temporal analysis showed a longer anticipatory delay (LFmin->LFmax) in both hands of children with UCP. No relationship between LFmax and GF at LFmax in the paretic hand of children with UCP was observed while such correlation appeared in their non-paretic hand, and in both hands of TD children.

**Conclusions.** Children with UCP showed impairments for dynamic variables in both hands. The grip/lift coupling was altered in their paretic hand and preserved in the non-paretic hand. These findings highlight a global motor planning deficit in both upper extremities, and impairment in sensory motor integration solely focused in the paretic hand during this intersegmental task.

## **Association between respiratory symptoms indicative of asthma, orofacial dysfunction and gross motor function in children and young adults with cerebral palsy**

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**Background:** Respiratory problems of multi-factorial origin are frequent in cerebral palsy (CP) with eating and swallowing problems recognized as important risk factors. The possible association between eating and swallowing problems and asthma related symptoms is less explored.

**Aim:** To describe the prevalence of respiratory symptoms according to the International Study of Asthma and Allergy in Children (ISAAC) in children and young adults with CP and investigate the association with orofacial dysfunction and gross motor function.

**Method:** Altogether 129 of 132 eligible individuals (age 5–22 years, mean=14.1, SD=4.45) registered in Region Örebro County, Sweden, participated in a cross-sectional study. Respiratory symptoms, orofacial dysfunction and gross motor function were evaluated by the ISAAC protocol, Nordic Orofacial Test-Screening (NOT-S) interview, and Gross Motor Function Classification System (GMFCS), respectively. The participants represented all GMFCS levels (I–V 31%, 28%, 12%, 14%, 16%). The effect size values of association between ISAAC and NOT-S (Phi), and between ISAAC and GMFCS (Cramér's V) are interpreted as 0.10-0.29 small, 0.30-0.49 medium, and  $\geq 0.50$  large ( $p < 0.05$ ).

**Result:** Parent-reported wheezing in the chest at any time in the past was 21%. Present wheeze (in last 12 months) was reported in 8%. 'Wheeze ever' and 'present wheeze' were associated with decreased sensitivity in the mouth, not eating by mouth, difficulty to eat certain consistencies, eating main meals in  $\geq 30$  minutes, swallowing large bites without chewing, coughing during meals, and drooling (Phi=0.23-0.35). 'Wheeze ever' and 'present wheeze' were associated with GMFCS level (Cramér's V=0.44 and 0.52, respectively).

**Conclusion:** Wheeze is associated with orofacial dysfunction and with impaired gross motor function in young individuals with CP. Individuals with less gross motor function have higher prevalence of wheeze.



## **Relationship of school-based physical therapy to outcomes for children with disabilities in the United States**

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**Background:** Children receive physical therapy (PT) within schools to support their educational programs in many countries.

**Aim:** We examined relationships of school-based PT to change using Goal Attainment Scaling (GAS) and the School Function Assessment (SFA). We hypothesized that service amount, type, activities, and interventions would predict outcomes.

**Method:** Our United States study of school-based PT involved 109 physical therapists and 296 of their 5-12 year-old students with varied diagnoses and Gross Motor Function Classification System (GMFCS) levels. Physical therapists pre-tested students using GAS and SFA then reported weekly the PT amount, activities, interventions, service delivery types, and type of service on behalf of the student (consultation/collaboration/documentation) for 6 months and then post-tested. Group comparisons and regressions were used to examine services to outcomes relationships.

**Result:** Younger age (5-7 years) was related to better GAS and SFA outcomes as was higher functional level on the SFA. Students who improved most on GAS received more self-care activity, services on behalf of the student, functional strengthening, mobility for playground access, and cognitive-behavioral interventions. Significant predictors of SFA outcomes besides age and GMFCS level were more use of mobility assistance, motor learning, aerobic conditioning, ongoing assessment, balance, sensory processing, and mobility interventions, and higher student engagement in therapy.

**Conclusion:** Students exceeded their expected goal level for their primary goal and had positive changes on the SFA. Various positive outcomes were predicted by services on behalf of the student, active practice of mobility, use of motor learning interventions, and higher engagement during therapy. Therapists should consider these PT services for better school outcomes.

**Range of motion in upper extremities related to age and to Manual Ability Classification System. Results from the Cerebral Palsy follow-up program in Norway (CPOP).**

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**Background:**

All children with cerebral palsy (CP) in Norway are systematically followed up with both specialized and general health care. Since 2006 the children are included in the CP-follow-up program, which includes registration of hand function and is aiming for prevention of secondary impairments and functional limitations.

**Aim**

The aim of this study was to generate knowledge on the development of range of motion (ROM) in relation to age and to Manual Ability Classification System (MACS).

**Method**

A population based longitudinal study. The children are assessed according to a standardized protocol at their habilitation unit once or twice a year. Their upper extremity function is classified according to MACS and registrations of elbow extension, supination and wrist extension for children 1 - 10 years of age.

**Results**

Totally 961 children are included with 1 - 13 registrations. CP subtypes; spastic bilateral 43 %, spastic unilateral 46 %, dyskinetic 7 % and ataxic 4 %. MACS level: Level I 37 %, level II 28 %, level III 14 %, level IV 8 %, level V 13 %. The proportion of children with reduced elbow extension ( $< -10^\circ$ ) increases from 1 % by 4 years till 9 % by 10 years of age, the proportion with reduced supination ( $< 80^\circ$ ) increases from 3 % till 17 %, and the proportion with reduced wrist extension ( $< 60^\circ$ ) increases from 3 % till 12 %. Reduced elbow extension, supination and wrist extension are significantly related to lower MACS level and to higher age with MACS as the strongest predictor.

**Conclusion**

The analyses show that children with CP below 10 years of age experience reduced ROM in upper extremities, particularly supination. Reduced ROM in upper extremities is significantly related to lower MACS level and higher age, and a prevention program is needed.

## **Development and validation of the Both Hands Assessment for children with bilateral cerebral palsy**

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**Background:** To date, there are no outcome measures available that evaluate how children with bilateral cerebral palsy (BCP) use both hands together in bimanual activities. In order to describe ability, measure change over time and evaluate the efficacy of interventions reliable and valid tests, responsive to change are required.

**Aim:** To describe the development and validation of the Both Hands Assessment (BoHA) for children with BCP.

**Methods:** The BoHA test content was developed through modification of the Assisting Hand Assessment (AHA) test items and by generation of new items. Data from 171 children with BCP (18m-12y), MACS levels I-III, were entered into a Rasch measurement model analysis to evaluate internal scale validity and aspects of reliability. In addition associations between BoHA measures and MACS levels were investigated.

**Results:** The AHA test kit allowed observation of bimanual performance also for children with BCP. Unidimensionality and item fit was confirmed for two subscales; one for children with asymmetrical use of the hands (BoHA-A) and one for children with more symmetrical hand function (BoHA-S). Both subscales include 16 items, 11 which are scored for each hand separately and 5 bimanual items, all scored on a 4-point rating scale. The person separation ratios (4.12 and 4.64) and the person reliability (0.94 and 0.96) for the subscales indicate that the children's hand function can be separated into 5-6 ability levels. Strong correlation was found between BoHA measures and the MACS classifications (Spearman's rho: 0.74).

**Conclusion:** To our knowledge, the BoHA is the first observation based assessment of effective use of the hands in bimanual activities for children with BCP. Evidence of internal scale validity and aspects of reliability was found for two subscales (BoHA-A and BoHA-S). Both subscales have the potential to become useful and valuable in clinical work and research with children with BCP, MACS levels I-III.

## **Environmental Toxic Pollutant and Trace Elements in Egyptian Children with Autism**

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**Background:** The increase in the prevalence of autism in recent years has suggested the cause of environmental neurotoxic pollutant.

**Aim:** To investigate the impact of environmental toxic elements mercury (Hg), lead (Pb), and cadmium (Cd) and nutrient elements zinc (Zn), copper (Cu) and Selenium (Se) in children, in relation to severity and clinical manifestations.

**Method:** Forty autistic children diagnosed according to DSM IV criteria and 30 healthy children acted as control aged ranged between 3 - 12 years were enrolled in the study. All were subjected to full history taking and thorough clinical examination. Measurement of whole blood toxic elements (Hg, Pb, Cd) and serum nutrient elements (Zn, Cu, Se) was done by atomic absorption spectrophotometer. CARS, Vinland Social maturity Scale and EEG were done to the autistic group.

**Results:** Mean blood levels of Hg, Pb and Cd were significantly higher in autistic children compared to healthy children ( $p < 0.0001$ ). While both serum Zn and Cu were significantly lower in autistic children than healthy control ( $p < 0.0001$ ) but Cu/Zn ratio was significantly higher in autistic children versus healthy group. There was no significant difference between mean Se levels between autistic and healthy children. Children with severe autism had significantly higher Pb level than mild and moderate autistic children ( $p < 0.05$ ). Children with regressive autism had significantly lower Hg than children without ( $p < 0.05$ ). There were no significant correlation between Hg and the other elements in autistic children while it was significantly correlated with Pb, Cd, Se in healthy children.

**Conclusion:** These abnormalities might be a cause of the various clinical presentations in autistic children. It is recommended that preventive measures have to taken to reduce exposure to toxic elements and treatment of the cause of zinc deficiency of these patients.

**Keywords:** autism, toxic elements, trace elements,

**POWER to be children: measuring participation in everyday life for those benefiting from power mobility use**

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**Background:** All children benefit from participation in meaningful life situations such as playing with friends, learning at school, and engaging in community events. Yet, participation in daily life is often restricted for those with mobility limitations. Power mobility (PM) devices, typically power wheelchairs, improve mobility and promote child development. Understanding children's participation is important for improving interventions, however little is known about how children who benefit from PM participate in daily life.

**Aim:** The POWER (Paediatric Participation Outcomes in Wheelchair Evaluation in Rehabilitation) mobility study examined how children benefiting from PM participate in daily life from both children's and parents' perspectives.

**Method:** Thirty two parents and their children aged 5 to 17 years completed three participation measures: Participation and Environment Measure for Children and Youth (PEM-CY), Children's Assessment of Participation and Enjoyment (CAPE) and the individualized Wheelchair Outcome Measure for Young People (WhOM-YP).

The PEM-CY evaluated parents' perspective of participation in home, school and community; the CAPE evaluated children's perspective in out-of-school leisure pursuits; and the WhOM-YP explored participation in meaningful situations deemed important by children and parents.

**Result:** Children benefiting from PM participated in a variety of life situations. There were similarities and differences in how children and parents viewed children's participation in daily life using PM. Reliability and validity evidence supported the use of these three measures.

**Conclusion:** Similarities and differences exist between how these measures evaluate elements of participation. Understanding which elements of child participation to measure and from whose perspective will help guide the appropriate selection of measures and PM interventions, and provide a more fully-developed understanding of child participation in daily life.

## **Supports and barriers perceived by allied health practitioners prior to implementing routine clinical assessment of children with cerebral palsy: a qualitative study**

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**Background:** Routine clinical assessment for children with cerebral palsy (CP) is not universal, in spite of evidence of its benefits: that is, reduced incidence of hip dislocation and severe musculoskeletal contractures.

**Aim:** To examine the supports and barriers to routine standardised multidisciplinary assessment for children with CP aged 3-18 years, as perceived by occupational therapists, physiotherapists and speech pathologists.

**Method:** 227/356 (63.8%) eligible allied health professionals (AHPs) employed in five Australian organisations completed the Supports and Barriers Questionnaire. Participants reported supports, barriers and strategies to implementing routine assessment for children with CP related to: organisational structure, organisational resources, therapists at the organisation, content of the routine assessment, and children/families attending the organisation. Focus groups were convened at each organisation to explore topics in greater depth (n=8 groups). Thematic analysis was completed. Questionnaire data were coded by a single assessor and a random selection of codes verified by a second reviewer. Through a consensus process, like concepts were grouped into subthemes. Focus group data were reviewed for congruity with these subthemes by the research team and overarching themes identified. These data form part of the baseline analyses of an ongoing study of the effectiveness of a multi-strategy knowledge translation intervention on AHP research implementation behaviour.

**Results:** Five overarching themes were derived: ‘motivation to adopt routine surveillance’; ‘acquiring and utilising expertise’; ‘effective ongoing communication’; ‘availability and distribution of resources’; and ‘families want what is best for their child’.

**Conclusion:** Understanding clinician perceptions of supports, barriers and strategies help inform how to facilitate change. Implementing routine assessment is complex and requires tailoring to individual organisation’s needs.

## Maternal body mass index and risk of cerebral palsy

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**Background:** Cerebral palsy (CP) is the most common cause of physical disability in children, affecting about 2 per 1000 live-born. While a few prenatal risk factors have been identified, it's causes are mostly unknown.

**Aim:** To investigate the association between maternal pre-pregnancy body mass index (BMI) and risk of CP in offspring.

**Method:** The study population consisted of 185 985 children in the Mother and Babies in Norway and Denmark (MOBAND) study. MOBAND comprises data from two population-based, prospective birth cohorts: the Norwegian Mother and Child Cohort Study (MoBa) and the Danish National Birth Cohort (DNBC). Information on pre-pregnancy BMI was self-reported in early pregnancy while CP diagnoses were obtained from the respective national cerebral palsy registries. Associations were investigated using log-binominal regression models.

**Result:** The two cohorts included 387 cases of CP (2.1 per 1000 live born). For each unit increase in BMI, the risk of CP increased with approximately 4% (relative risk [RR] 1.04, 95% confidence interval 1.02-1.06). Compared with mothers in the lower normal weight group (BMI 18.5-22.9), mothers in the upper normal group (BMI 23.0-24.9) had a 40% excess risk of having a child with CP (RR 1.4, 1.04-1.8). Excess risk was 60% (RR 1.6, 1.2-2.0) for overweight (BMI 25.0-29.9) and for obese mothers (BMI $\geq$ 30) (RR 1.6, 1.1-2.2). Estimates changed little with adjustment for mother's occupational status, age and smoking habits.

**Conclusion:** Higher pre-pregnancy maternal BMI is associated with increased risk of CP in offspring. Increased inflammatory processes or other conditions associated with higher BMI may contribute to risk of CP.

## Upper and lower limb function in relation to neuroimaging results in cerebral palsy

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### Background

The direct relation between the effects of a specific brain lesion on functional outcome in cerebral palsy (CP) is still unclear.

### Aim

The aim of this study was to describe the relationship between the upper and lower limb function and neuroimaging results in CP.

### Method

Brain MRI results of 176 children born between 1999 and 2006 (97 boys, 79 girls), classified according to SCPE criteria, were compared to CP type, gross motor function classification (GMFCS) and the Bimanual Fine Motor Function (BFMF).

### Results

One hundred and sixty-three children (93%) were classified as having spasticity, 4 (2%) mixed pattern, 4(2%) dystonic and 2(1%) choreo-athetotic dyskinesia, 2(1%) ataxia and 1(1%) unclassified. Bilateral involvement was registered in 116(92%) children. Sixty-four (36%) were classified as level 1 of the BFMF, 49 (28%) level 2, 28(16%) level 3, 23(13%) level 4 and 12(7%) level 5. Distribution over the different GMFCS categories were 71(40%) level I, 40(23%) level II, 21(12%) level III, 23(13%) level IV and 20(11%) level V. Brain MRI revealed that 13(7%) of the children showed predominant maldevelopments, 101(57%) white and 33(19%) grey matter lesions.

Of all children demonstrating predominant white matter lesions, 81(80%) were BFMF level 1 or 2, compared to only 11(33%) of all grey matter lesions ( $\chi^2 < 0.001$ ). For the GMFCS, 71(70%) of the white matter lesions were at levels I or II, compared to 17(51%) of the grey matter lesions ( $\chi^2$  p=0.007). There was a significant association between the MRI results, the BFMF ( $\phi_c$  0.554, p<0.001) and the GMFCS ( $\phi_c$  0.227, p=0.007). Of all children demonstrating bilateral brain lesions (n=24, 46%), only 12 children showed clinical signs of bilateral involvement.

### Interpretation

Children with white matter injuries seem to be more functional in both upper and lower motor function compared to those with grey matter injuries. Bilateral brain lesions do not necessarily cause bilateral clinical involvement.



## **Relations between Grey and White matter lesions and language comprehension in children with severe CP; does it ‘matter’?**

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### **Background**

So far no study has reported the clinical consequences of brain abnormalities or lesions with regard to spoken language comprehension in children with severe CP who cannot speak.

### **Aim**

To identify relations between brain abnormalities and spoken language comprehension. Method: MRI characteristics of 80 non-speaking children with severe CP (GMFCS IV-V) were analysed for patterns of brain abnormalities and scored for specific MRI measures: white matter (WM) areas; size of lateral ventricles, WM abnormality/reduction, cysts, subarachnoid space, corpus callosum thinning and grey matter (GM) areas; cortical GM abnormalities, thalamus, putamen, globus pallidus and caudate nucleus and cerebellar abnormalities. Language comprehension was assessed with a new validated instrument (C-BiLLT).

### **Result**

Language comprehension was best in children with basal ganglia necrosis (BGN) pattern followed by malformations and miscellaneous patterns, and was poorest in periventricular leukomalacia (PVL). Overall, in our study population, we found no relation between central/cortical GM areas and spoken language comprehension. Linear regression modelling per pattern group (malformations excluded), with MRI measures as independent variables, revealed that corpus callosum thinning in BGN and parieto-occipital WM reduction in PVL were the most important explanatory factors for poor language comprehension. No MRI measures explained outcomes in language comprehension in the miscellaneous group.

**Conclusion:** In severe CP, concomitant damage to especially WM areas has consequences for development of spoken language comprehension. Language comprehension was most affected in children with WM lesions in the subcortical and then periventricular areas.

## **Supporting my mental health: what parents of children with a disability want paediatric health services to know**

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**Background:** Substantial inequalities exist in mental health care for parents of children with disabilities. Consistently higher rates of depressive symptoms are found in addition to elevated chronic stress, sleep deprivation and poor physical health. Poor mental health has the potential to reduce the much-needed quality of care by parents to children with disabilities. Supporting parental mental health within paediatric health services is essential for child and family wellbeing.

**Aim:** To explore mothers' views on discussing their mental health and wellbeing with paediatric health professionals and their preferences on the timing and type of support offered.

**Method:** A quantitative and qualitative approach. Semi-structured interviews with 25 mothers of children (aged 0-25 years) with a disability in addition to an online survey n = 294 to investigate their preferred means of support from paediatric health professionals. A parent engagement group was established to ensure maximum consumer involvement.

**Results:** A high proportion of mothers reported significant mental health needs. Qualitative data analysis highlighted the lack of service driven integrated approaches for supporting parents' mental health, in addition to the complexity of providing opportunity for mothers to talk openly about their mental health with health professionals. Mothers voiced the need for education about mental health and available supports at the time of diagnosis and referral pathways to access counselors. Survey data showed 85% thought it was essential for their child's health professional to make time to discuss their mental health and 78% thought it was vital to receive education about available mental health supports and have referrals into these supports.

**Conclusion:** This research highlights the gaps in the current service system for supporting parents' mental health. The results can inform preventative mental health initiatives within primary and secondary health services.

## **Functional skills acquisition following cognitive-based intervention in childhood movement disorders**

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**Background:** Deep brain stimulation (DBS) in primary dystonia has been proven effective. Results for secondary dystonia (ie. dyskinetic cerebral palsy (DCP)) remain controversial. In both groups, even with a significant improvement in dystonia reduction, their skills to perform every day activities post-DBS remain problematic.

**Aim:** To explore whether functional outcomes will improve in childhood hyperkinetic movement disorders (HMD) and DBS after they have received Cognitive Orientation to daily Occupational Performance (CO-OP) intervention.

**Methods:** Single case experimental design with n of 1 plus 8 systematic replications. Objective changes were measured using multiple assessments of the Performance Quality Rating Scale by an independent rater. As well, pre/post intervention changes were evaluated using the Assessment of Motor and Process. Client-centred scores were obtained using the Canadian Occupational Performance Measure.

**Results:** All participants showed improved performance in their 3 chosen functional goals independently of their diagnosis, motor severity, manual function or DBS duration indicating the strong potential of CO-OP to offer better outcomes for these participants. Improvement was also observed on 2 untrained goals, not worked in therapy, included to assess skill transfer; indicating that this cognitive intervention has the potential to enable children to find their own strategies to overcome motor problems outside of therapy.

**Results demonstrate the variability on functional performance for HMD and the need for more than 1 assessment at baseline and following any intervention.**

**Conclusions:** Outcomes indicate that CO-OP has the potential to improve children's functional performance. No other study using task-oriented approaches is yet available for children with HMD including DCP. The further investigation of adjunct therapy interventions to maximise the effects of DBS is warranted for children with significant motor performance issues.

## **An international survey of cerebral palsy registers and surveillance systems**

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**Background:** Population-based cerebral palsy (CP) registers and surveillance systems (surveillance programs) report on trends in population characteristics and prevalence. Nearly 40 surveillance programs exist worldwide. Collaborations between programs allow comparisons between birth year cohorts along with pooling of data and greater statistical power for subgroup analyses.

**Aim:** To describe the similarities and differences among CP surveillance programs, particularly across key topics of: governance and funding, aims and scope, definition, inclusion/exclusion criteria, ascertainment and data collection.

**Method:** Invitations to complete the online survey were distributed to representatives of 38 known CP surveillance programs and participants were asked to submit their program's data collection forms from which descriptive statistics were generated.

**Result:** Twenty-seven surveillance programs participated (response rate 71%); the earliest data available was from birth year 1954. Program aims included: resource for CP research (100%), surveillance (92%), aetiology/prevention (68%), service planning (48%) and information provision (20%). Published definitions of CP (n=5) guided decision making regarding case eligibility for most programs. Consent, case identification and data collection methods varied widely. While data items collected also varied, ten key items were collected by all programs and a further seven by at least 80% of programs. Sixty seven percent of surveillance programs reported prior collaborations, and all programs reported an interest in research collaboration in the future.

**Conclusion:** While programs varied in their methodologies, there were similarities in their aims, definitions and data collected. These results will help inform interpretation of publications and assist data harmonisation processes for future collaborative research. Given the heterogeneity of CP, such collaborations are essential to investigate more homogenous sub-groups.

## **Needs that of families have with a person with cerebral palsy aging**

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**Scientific background:** Nowadays, people with cerebral palsy live longer and their families have new problems and needs in this stage of life.

**Aim:** To analyze the main concerns and perceived needs for these families with people with cerebral palsy who are getting older to provide services and give a suitable answer.

**Methods:** One hundred thirty four families with CP people, mainly siblings (49.3%) and parents (35.8%) participated in an interview to establish their opinions and they proposed some relevant solutions from their own point of view.

**Results:** It has been established the following order of expressed needs by their families: needs related to health (care of their health 71.4%), with architectural barriers (64.5%), social services (home helpers 46.6%), and health attendance resources (physical therapy 35.4%), where and who with, their disabled relatives will live in the future (57.5%), and with economical resources (allowance 31.1%). Regarding to the solutions proposed we can point out, the increasing of their allowances (65.9%). These are most frequently proposed by families, followed by the removing environmental or architectural barriers (49.6%), the leisure and free time support services (45%) and daily personal cares (44.2%).

**Conclusions:** These families, who are also elderly people, require measures to facilitate and support care improvement of their family through intermediate complementary services and resources. They are interested in these resources to compensate for the lack of functionality, to avoid total dependence on another person and to facilitate social inclusion.

## **WHAT DOES THERAPY MEAN FOR CHILDREN WITH UNILATERAL CEREBRAL PALSY AND THEIR FAMILIES?**

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**Aims:** The extent to which children with unilateral cerebral palsy (UCP) engage in therapy has been linked to mastery motivation. Parental expectations have also been associated with achievements of children. This study explores whether expectations of children with UCP and their parents influence the child's experiences and progress in an intensive day-camp magic-themed bimanual intensive therapy.

**Methods:** A mixed-methods study using semi-structured interviews, questionnaires and standardised assessments. Thematic analysis using NVivo10 identified themes regarding experiences of having a hemiplegia and expectations for therapy. Expectations were contrasted with reported positivity (HOPE scale), competence and worry (Childrens Hand Experience Questionnaire) and motor skill outcomes (Jebsen Taylor Test of Hand Function).

**Results:** Data were available from 18 children with UCP and parents (12 males; mean age=8y9m, range=7yto12y). Thematic extraction identified four main themes relating to experiences of therapy, expectation for skill change, social relationships and self-identity. Some children reported on the isolating experiences of performing therapy exercises at school. The importance of meeting other 'kids like me' and being able to compete equally was raised by several children. Parents and children used more positive terms about themselves and friendships following the day camp. HOPE scores at pre-treatment correlated with positivity following treatment ( $r=0.53, p=0.01$ ) but were not associated with perceptions of competence or skills nor linked to progress in motor ability.

**Conclusion:** Complex relationships between positivity and perceptions of self-efficacy were evident. Interviews highlighted the social benefits of this group intervention programme. Detailed analysis of themes emerging across child and parent interviews will be reported in relation to expectations and experiences across outcomes considered important to children and parents.

## **Upper limb contracture development in children with CP; a population based study.**

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**Background:** Little is known about contracture development in the upper limbs in children with CP.

**Aim:** to describe the longitudinal development of passive range of movement (PROM) in the upper limbs in children with CP and to calculate the relative risk for decreased PROM related to age, functional level and CP-subtype.

**Methods:** Data from the CPUP-registry including annual assessments for an entire population of children with CP was used. Children with CP born 1990-2012, living in the Southern region of Sweden, were included. The registry use a traffic light code for categorizing data. Green means a normal value, yellow a slightly decreased PROM, a need for attention or treatment and a red value is a developed contracture.

Odds ratio was used to compare the decreased PROM in children with different CP subtypes and levels of MACS and GMFCS. Mixed models were used to analyze at what age changes in movement development takes place within subgroups.

**Results:** Data included 771 children 1-18 years old, in all, 5040 assessments. Dominating neurological symptom was spasticity in 63%. Fifty-seven percent were classified to MACS levels I-II and 43% to levels III-V. Yellow and red values were found at one or more time points for; shoulder flexion 32,6%, elbow extension 15,4%, supination 27,5%, wrist extension with fingers flexed 15,8% and with fingers extended 26,2%. The proportion of children developing restricted PROM increased with higher MACS levels. Decreased PROM was beginning at a mean age of 7 years for supination ( $P<0,028$ ) and at 4 years for wrist extension with extended fingers ( $P<0,039$ ). Children with dyskinetic presentation showed the highest risk to develop decreased PROM. Odds ratios with correction of the effect of age, functional level and CP-subtype will be presented.

**Conclusion:** A majority of children with CP do not develop contractures in the upper limbs, however for children at risk, preventing severe secondary movement restriction is essential.

## **Prediction of hip displacement in children with cerebral palsy using the CPUP hip score**

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**Background:** Hip displacement, defined in this study as migration percentage (MP) of more than 40%, is a common, debilitating complication of cerebral palsy (CP). Age, gross motor function according to Gross Motor Function Classification system (GMFCS) and Head-Shaft-Angle (HSA) are known risk factors for hip displacement.

**Aim:** 1. To analyze the risk of developing hip displacement within five years from the first pelvic radiograph calculated for GMFCS-level, age and initial MP and HSA in a total population of children with CP.

2. To construct a risk score for hip displacement with these variables.

**Method:** Inclusion criteria were children from the Swedish hip surveillance programme CPUP born between 1994 and 2009 with MP<40% at first radiographic examination. MP was measured prospectively once a year until hip displacement occurred or for five years without hip displacement. The risk score was constructed using multiple logistic regression analysis. The risk score was evaluated using the area under the receiver operating characteristics curve (AUC) and results were cross-validated to ensure prediction robustness.

**Result:** A total of 145 children in GMFCS level III-V were included with a mean age at initial pelvic radiograph of 3.5 years (0.6 to 9.7). Fifty-one children developed hip displacement within five years. All variables (GMFCS-level, age, MP, HSA) had a significant effect ( $p<0.05$ ) on the risk of hip displacement. The discriminatory accuracy of the constructed risk score ("CPUP hip score") was high (AUC=0.87), indicating a high ability to differentiate between high and low risk individuals for hip displacement. Cross-validation showed prediction results to be robust.

**Conclusion:** We have developed the CPUP hip score as a risk score to identify individuals with CP at high or low risk for hip displacement (MP>40%). The predictive ability to differentiate between high and low risk is high and the CPUP hip score may be a valuable tool in clinical decision making.



## **Of love and isolation: Narratives of siblings of children with cerebral palsy in Sri Lanka**

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**Aim:** Siblings of children with cerebral palsy are often in the periphery of discussions; their views not always taken into account. The aim of this study was to uncover the narratives of young siblings of children with cerebral palsy in Sri Lanka.

**Methods:** Semi-structured interviews and artwork were gathered from 10 children who have siblings diagnosed with cerebral palsy. The data was analyzed using the key principles of Framework Analysis (Ritchie & Spencer, 1994) to determine the key themes within the narratives.

**Results:** The key themes to emerge were complex and nuanced. These included themes of love and feeling of protectiveness; jealousy and uncertainty; guilt and hope.

**Conclusions:** The results highlight the need to take document the views of siblings who are often on the margins of the family and of family decisions and discussions. It also supports the need to offer safe spaces and opportunities for siblings of children with disabilities to express their feelings and to receive support where required.

## **Psychometric properties and reference values of the Trunk Control Measurement Scale in young children with cerebral palsy**

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### **Background**

The psychometric properties of the Trunk Control Measurement Scale (TCMS) were previously examined in children with spastic CP between 8-15 years. However, early evaluation and intervention of trunk problems require earlier use of the TCMS. Since development of trunk control is still in progress in younger children, the effect of maturation on trunk control needs to be examined in typically developing (TD) peers.

### **Aim**

To investigate the psychometric properties of the TCMS in younger children with spastic CP (5-8 yrs) and to define reference values per age in TD children.

### **Methods and results**

Twenty-five children with spastic CP were included (mean age 7.1y; GMFCS level I n=3, level II n=13, level III n=4, level IV-V n=5). Also, 105 TD children were assessed (mean age 6.11y). For inter-rater reliability, two testers scored all children with CP simultaneously. To determine test-retest reliability, children were reassessed within three to ten days. For construct validity, the Gross Motor Function Measure (GMFM) was also administered. Intraclass correlation coefficients (ICC) ranged from 0.84-1.00 for inter-rater and test-retest reliability. The majority of the (weighted) kappa values exceeded 0.60 (range 0.19-1.00). The standard error of measurement was 2% and 5.3% and the smallest detectable difference was 5.6% and 14.8% between raters and for test-retest respectively. Spearman rank correlation with the total GMFM was 0.84, with increasing correlation coefficients with dimensions A to D and to a lesser extent with dimension E. The TCMS discriminated between children with CP and TD children ( $p<.0001$ ). To set reference values, scores of TD children were grouped into four age groups. A trend of increasing total TCMS scores with increasing age was found.

### **Conclusion**

Good psychometric properties support the use of the TCMS in younger children with CP. Reference values are now available to interpret TCMS scores in relation to maturation of trunk control.

## **Inter-rater reliability of the Communication Function Classification System (CFCS) for Adults and Adolescents with Cerebral Palsy**

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**Background:** The Communication Function Classification System (CFCS) was developed to make a valid, reliable, and easy to use classification system that can distinguish between the communication performance of children. One limitation with the CFCS is that its original focus was on its use with children; however, adults and adolescent continue to be classified under the 'mild,' 'moderate,' and 'severe' ratings for their communication.

**Aim:** The purpose is to measure CFCS inter-rater reliability between professionals and between professionals collectively and individuals with cerebral palsy.

**Method:** Sixty-seven adults and twenty-seven adolescents with a diagnosis of CP have been recruited from Michigan, Ontario, and New Mexico clinics. Forty-nine participants were female. Adults who were legally competent or legal guardians of the adolescents and adults who were not legally competent signed an informed consent form. The participant or his/her caregiver and two clinical professionals interdependently assigned a CFCS level. The participant's demographics, GMFCS and MACS levels were obtained from previous medical records. Weighted kappas were used to compare inter-rater reliability between the professionals and between the professionals collectively and the participant.

**Result:** The CFCS inter-rater reliability was very good (weighted  $\kappa = .82$ ) between the professionals and was good (weighted  $\kappa = .63$ ) between the professionals and the person with cerebral palsy or a family member.

**Conclusion:** This study provides evidence for very good inter-rater reliability of the CFCS between the professionals in determining one of the five communication levels in adults and adolescents with cerebral palsy. Although professional tended to classify the communication level of adolescents and adults with CP as less functional than the individuals themselves or their proxy, the overall inter-rater reliability of the CFCS is considered good.

## **LEARN 2 MOVE 0-2 years: developmental outcome of an early intervention randomized controlled trial in infants at very high risk for cerebral palsy**

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**Background:** Little is known about effects of early intervention on developmental outcome of infants at very high risk (VHR) for cerebral palsy (CP).

**Aim:** To study effects of one year of early intervention with COPCA (Coping with and Caring for infants with special needs) in comparison to that of Traditional Infant Physiotherapy (TIP) in VHR infants.

**Method:** 43 VHR infants were included between 0 and 9 months corrected age (CA) and randomly assigned to either COPCA (n=23) or TIP (n=20). Inclusion was based on the presence of a significant brain lesion (n=37) or neurological dysfunction suspect for CP (n=6). Infants were examined at baseline, two times during and at the end of the intervention period, and at 21 months CA. Neuromotor and cognitive outcome were measured by the primary outcome measure Infant Motor Profile (IMP) and secondary outcome measures Touwen Infant Neurological Examination (TINE), Alberta Infant Motor Scale (AIMS), Gross Motor Function Measure (GMFM) and the Bayley Scales of Infant Development, Psychomotor Index (BSID-II-PDI) and Mental Index (BSID-II-MDI). Outcome was compared with non-parametric Mann Whitney U tests (MWU) and Hodges Lehmann Estimator (HLE) for median differences with 95% Confidence Intervals (95% CI).

**Result:** During the intervention period and at 21 months CA both groups did not differ in developmental outcome. For example, at 21 months CA medians of total IMP-scores were 79 (range 69-94) and 81 (range 69-89) for COPCA and TIP respectively (p=0.810, HLE -2.0 (95% CI -16.0-11.0)). Median BSID-II MDI raw scores were 104 (range 7-125) and 104 (range 20-125) for COPCA and TIP respectively (p=0.724, HLE -1.0 (95% CI -5.0-4.0)).

**Conclusion:** At RCT-level, no differences were present between COPCA and TIP in neuromotor and cognitive outcome. As contents of early intervention programs are heterogeneous and partially overlap, our secondary analyses will focus on associations between specific physiotherapeutic actions and outcome.

## **Psychosocial changes for children with hemiplegic cerebral palsy following participation in Amazing Magic Clubs**

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**Background:** Children with hemiplegic cerebral palsy (CP) can experience psychosocial and peer related challenges. Amazing Magic Club, run by the Arts Health Institute, offers intensive bimanual therapy within a motivating environment. Previous research has suggested anecdotally that Amazing Magic Club can potentially promote psychosocial gains.

**Aim:** To explore whether children attending Amazing Magic Clubs make gains in psychosocial function.

**Method:** Twenty-eight children (15 males; age range 7y 6mo–15y 2mo; M age 10y 6mo) with hemiplegic CP participated in Amazing Magic Clubs in Australia in 2015. At the Amazing Magic Club, children learn magic tricks and performance skills from professional magicians. Parents completed the Strengths and Difficulties Questionnaire (SDQ) and The Coping Inventory (TCI) at baseline, post-intervention, and three months follow-up. This research is still in progress. A subset (n=16) of baseline, post-intervention and three month follow-up data were analysed.

**Results:** Friedman's ANOVA found statistically significant differences between the three time points on the SDQ ( $p=0.031$ ), TCI Coping with Self ( $p=0.036$ ) and TCI Coping with the environment ( $p=0.023$ ). Post hoc analysis revealed significant improvements in Coping with Self and Coping with Environment from baseline (Mdn=3.60; Mdn=3.95 respectively) to post-intervention (Mdn=3.95;  $p=0.025$ ; Mdn=4.15;  $p=0.043$ ). No significant difference was found between baseline and either follow-up on the SDQ. Four of 6 children, however, who were identified as either medium or high risk of a disorder at baseline shifted to low risk post-intervention.

**Conclusion:** The Amazing Magic Club presents an opportunity to promote psychosocial function.

## What is the “true” prevalence of cerebral palsy (CP) in Norway?

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**Background:** The prevalence of CP in Norway has varied in published studies using different data sources. The Norwegian Social Insurance Scheme reported a prevalence of 1.8 per 1000 live births, the Cerebral Palsy Register of Norway (CPRN) 2.1 per 1000 live births and the Norwegian Patient Register (NPR) 3.0 per 1000 children residing in Norway. The CPRN is a consent-based national medical quality register that collects detailed clinical data from all habilitation centers. The NPR receives a standardized set of individual patient data from all hospital and outpatient clinics.

**Aim:** To determine the “true” prevalence of CP in Norway.

**Method:** National ID numbers were used to identify children with CP born 1996-2007 that were recorded in both registers. Children in both registers were considered to have CP. The hospital records of children not recorded in the CPRN were reviewed by two Child Neurologists for validation.

**Result:** The total number of live born children was 699,924. According to the NPR, 2110 children had CP resulting in a prevalence of 3.0 (95% CI: 2.9-3.1) per 1000 live births, whereas according to CPRN summative information, 1580 children had CP resulting in a prevalence of 2.3 (95% CI: 2.1-2.4) per 1000. Review of 780 hospital records revealed that 464 (59.5%) were correctly coded with CP, 302 (38.7%) did not have CP and 14 (1.8%) could not be classified. After validation, 1784 children were confirmed to have CP, with a corrected prevalence of 2.5 (95% CI: 2.4-2.7) per 1000 live births.

**Conclusion:** The best estimate of CP prevalence in Norway is 2.5 per 1000 live births. A more accurate prevalence can only be obtained by combining sources and scrutinizing individual cases. Our results suggest that hospital-based registers are liable to over-diagnosing, whereas consent-based registers relying on voluntarily reporting are liable to underreporting. Caution is needed when prevalence rates from different sources and populations are interpreted.

## **Efficacy of a knowledge translation approach in changing allied health professional knowledge of evidence-based assessment and interventions for children with cerebral palsy: the first 12 months**

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**Background:** Studies have demonstrated that children with cerebral palsy (CP) do not always receive evidence-based assessments or interventions, in spite of information available about best practice.

**Aim:** To improve allied health professional (AHP) knowledge of evidence-based assessments and interventions for children with CP via a multi-strategy knowledge translation intervention.

**Method:** A multi-centre pre-post knowledge translation intervention study recruited occupational therapists (OT), physiotherapists (PT) and speech pathologists (SP) employed in five Australian organisations that provide allied health services to children with CP. The intervention comprised 1) knowledge brokers in each organisation; 2) access to an electronic library of synthesised and critiqued evidence; 3) training and education in evidence-based practice and 4) an electronic clinical outcomes tool. Participants completed a 'knowledge quiz' at baseline, 6 and 12 months; 24 month data are pending. Quiz items related to goal-setting with children and families and selection of outcome measures and interventions. Items were scored using a reliable rubric (score range: 0-17). Data were summarised using means and 95% confidence intervals (CI) at each time point.

**Results:** 404 AHPs contributed data over the first year of this study (156 OT, 112 PT and 116 SP), however only 109 AHPs contributed data at all three time points. Mean knowledge scores at baseline, 6 months and 12 months were 10.21/17 (95% CI 9.8-10.6, n=259), 9.95/17 (95% CI 9.5-10.4, n=226) and 9.85/17 (95% CI 9.4-10.3, n=227) respectively. No change in AHP knowledge of evidence-based assessments and interventions for children with CP was demonstrated.

**Conclusion:** The mean score of 60% and lack of change in AHP knowledge during the first year of a two year intervention study warrants further investigation of organisation-specific data, coupled with qualitative data detailing AHP perceptions of supports and barriers to change.

## **Professionals' perceptions of pain communication of children with cerebral palsy in South African school settings**

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**BACKGROUND.** Most children with severe cerebral palsy experience daily pain which affects their school performance. School professionals need to assess pain in these children, who may also have communication difficulties, in order to pay attention to the pain and support the children's continued participation in school.

**AIM.** This study investigated South African school professionals' perceptions of how they observed pain in children with cerebral palsy, how they questioned them about it and how the children communicated their pain back to them.

**METHOD.** Thirty-eight school professionals participated in five focus groups. Their statements were categorised using qualitative content analysis.

**RESULTS.** From the results it became clear that professionals observed children's pain communication through their bodily expressions, behavioral changes, and verbal and non-verbal messages. Alternative communication strategies (such as augmentative and alternative communication) were seldom used.

**CONCLUSION.** This study highlighted the necessity of considering pain-related vocabulary in a multilingual South African context and advocated using alternative communication strategies, to enable children with cerebral palsy and complex communication needs to communicate their pain. It stresses the importance of offering the children means to self-report and express their pain experiences.



## **Childhood mobility function predicts education, employment and physical activity of young adults (18-21 years) with cerebral palsy**

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**Background:** High quality prospective, population-based register data can be paired with client interviews to explore predictors of long-term outcomes important to adults with cerebral palsy (CP).

**Aim:** Identify childhood factors predicting participation in major life roles by young adults with CP

**Method:** Participants were 100 young adults with CP aged 18-21 years (mean 19 years 5 months; 62 males; 57 ambulant, 11 marginally ambulant, 32 non-ambulant) recruited from the Queensland Cerebral Palsy Register (QCPR). QCPR records were audited for predictor variables of: childhood mobility level at 5 and 15 years (GMFCS-E&R I=29, II=22, III=24, IV=12, V=12) and associated impairments (e.g. IQ, vision). Young adults were interviewed for outcome variables: current mobility, participation diversity and frequency according to International Classification of Functioning Disability and Health (ICF) domains (e.g. education, employment, recreation, physical activity). Multiple regression was used to determine which childhood variables predicted each adult participation domain.

**Results:** High participation was reported for public (86%) or private recreation (86%), medical appointments (85%) and shopping (83%). Restricted participation was reported for employment (37%), education (51%) and physical activity (58%). Multiple regression showed that poor adult mobility restricted participation in education ( $p=0.007$ ), employment ( $p<0.001$ ) and physical activity ( $p=0.005$ ). Poor childhood mobility at age 15 predicted restricted participation in education ( $p=0.018$ ), employment ( $p<0.001$ ) and physical activity ( $p=0.003$ ); and at age five predicted restricted participation in employment ( $p<0.001$ ) and physical activity ( $p=0.031$ ).

**Conclusion:** Poor mobility of children with CP is a strong early risk factor for restricted adult participation in education, employment and physical activity. Childhood mobility classification should guide support planning required to optimise participation potential.

## **Nutritional status of children with Cerebral Palsy (CP) in rural Bangladesh: preliminary results from Bangladesh Cerebral Palsy Register (BCPR) pilot study**

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**Background:** Bangladesh is one of the top three countries with highest prevalence of malnutrition in South Asia; however, there is little is known about the nutritional status of children with cerebral palsy (CP) in Bangladesh.

**Aim:** We aimed to assess the prevalence of malnutrition among children with CP in rural Bangladesh and also exploring the risk factors for malnutrition.

**Methods:** This is a part of Bangladesh CP Register (BCPR) pilot study commenced since Jan 2015 in the Shahjadpur sub-district of Bangladesh. As part of BCPR registration, all children with CP in the study area were assessed and their detailed clinical and anthropometric information (i.e. height, weight, head circumference and mid upper arm circumference) were collected. We used WHO Anthro/AnthroPlus and CDC EpiInfo software to calculate Z-scores. The WHO growth standards were used to define the nutritional status (i.e. malnutrition-weight for age, stunting-height for age and wasting-weight for height).

**Results:** Since Jan 2015, 299 children with CP were assessed and anthropometric data were available from 291 children aged between 1 and 18.4 years (median 8.5 years), and 176 (60.7%) were male. Among all children with CP, 60.2% were malnourished and 65.2% were stunted. In those aged  $\leq 10$  years, 68.4% were malnourished and 71.7% had stunted growth. In the youngest cohort (aged  $\leq 5$  years); 71.7% were malnourished, 73.2% stunted and 46.2% were wasted. 75% of those young children had microcephaly (HC for age  $< -2$  SD). Home birth and maternal education were independent predictors for malnutrition in out cohort.

**Conclusion:** The prevalence of malnutrition among children with CP in rural Bangladesh is alarmingly high (over  $\sim 30\%$  than the national average). Urgent public health and nutritional interventions are warranted to improve nutritional status and overall quality of life of the children with CP in rural Bangladesh.

## **Malnutrition is common among children with cerebral palsy in Uganda particularly among the older children and those with history of neonatal complications**

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### **Background:**

Growth and nutrition disorders are seen in one-third of paediatric cerebral palsy (CP) patients in high income countries (HIC), however there is paucity of data regarding the growth and nutrition status of children with CP from low resource settings.

### **Aim:**

To determine the nutritional status and describe the factors associated with poor nutrition amongst children with CP attending a tertiary referral centre in Uganda.

### **Method:**

Using a three step cross-sectional design, 135 children age range (2-12 years) with CP were consecutively enrolled. Clinical and nutritional history were collected using a pre coded questionnaire. Basing on weight, height/length, age and sex, anthropometric indicators were constructed according to WHO growth standards. The recordings were converted into Z-scores using the 'WHO Anthro' and 'WHO AnthroPlus' software programs to calculate nutritional status, with Z-scores  $\leq -2.0$  indicating malnutrition. Multivariable logistic regression was used to identify factors associated with the poor nutrition.

### **Result:**

Over half the children were malnourished (53%), underweight being the most common category of malnutrition (42%), followed by stunting (38%), thinness (21%), and wasting (18%). The presence of cognitive impairment with an adjusted odds ratio (aOR) of 4.5, being 5 years or older (aOR = 3.4) and feeding difficulties in the perinatal period (aOR = 3.2) were independently associated with being malnourished.

### **Conclusion:**

Malnutrition was common in Ugandan children with cerebral palsy attending this specialized clinic at the tertiary referral centre. Emphasis should be placed on the close monitoring of children with CP for the timely detection of malnutrition especially those with diminished intellectual activity, those above the age of 5 years, and those with a history of complications in the neonatal period. The efforts to develop innovative, cost-effective ways of feeding them still remain a challenge.

## **Participation in home and community activities among preschool children with and without physical disabilities**

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**Background:** Participation in home and community life is vital for development of preschool children (2-6 years of age). Research is limited in describing participation in everyday activities of preschool children with and without physical disabilities as a function of age and disability status.

**Aim:** The study aimed to examine the effects of age (2 to <4 years and 4 to <6 years) and disability status (with and without physical disabilities) on intensity of participation.

**Method:** Participants were 101 children with physical disabilities and 88 children with typical development in Taiwan. Parents completed the Chinese version of the Assessment of Preschool Children's Participation (APCP-C). Intensity scores were calculated for Overall and for four activity areas: Play, Active Physical, Skill Development and Social activities. Two-way ANOVAs were used to examine the effect of age and disability status on intensity scores for overall participation and each activity area.

**Results:** The interaction effects were not significant. For age, compared to children less than 4 years, children older than 4 years had higher intensity scores in Skill Development activities ( $p=.004$ ) but not in Play, Active Physical, and Social activities ( $p>.01$ ) or Overall ( $p=.061$ ). For disability status, children without disabilities had higher Overall intensity scores than children with physical disabilities ( $p<.001$ ) and higher intensity scores in Play, Active Physical, and Skill Development activities (all  $p<.001$ ), but not in Social activities ( $p=.136$ ).

**Conclusion:** Children in the two age groups were similar in their intensity of participation, with the exception of skill development activities. Children with physical disabilities had lower intensity of participation than children without disabilities, with the exception of social activities. The findings provide a profile of children's pattern of participation in Taiwan.

## **THE EXPERIENCES OF ADULTS WITH ASD, THEIR EMPLOYERS AND CO-WORKERS IN THE WORKPLACE IN KWAZULU-NATAL**

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**Aim:** To explore the experiences of adults with Autism Spectrum Disorder (ASD), their employers and co-workers in the workplace in KwaZulu-Natal.

**Methodology:** A qualitative phenomenological case study design was used. Participants were identified using a non-probability convenience sampling technique. The study population consisted of 6 individuals with ASD, 3 employers and 2 co-workers. Individual semi-structured interviews of approximately 60 minutes were conducted. Thematic analysis was used to analyze the data obtained.

**Results:** Results revealed that participants with ASD experienced significant difficulty maintaining employment for longer than 3 months due to changes in routine, communication and social interaction, and becoming bored with job tasks. Disclosure of ASD and employers lack of awareness in specific cases resulted in poor confidence in the individual's abilities to complete tasks. Participants with ASD presented with verbal and nonverbal communication skills that limited their ability to express themselves appropriately, resulting in increased stress and decreased task completion. Difficulty understanding the rules of social interaction resulted in participants with ASD not seeing the purpose of socializing and finding it ungratifying, leading to poor working relationships, inappropriate behaviour, disputes and dismissals. Social support systems helped individuals with ASD to cope with functions related to employment.

**Conclusion:** The social and communication presentation of the individual with ASD significantly impacted on the completion of job tasks, job maintenance and maintaining social relationships. Fears related to disclosure played a key role in many of the negative experiences of the participants. Implications include the importance of early identification, exploring tertiary qualifications, and roles of other health professionals in the management of ASD in the workplace. The limitations of the study are also presented.

## **Relationship between gross motor function, physical activity, participation and quality of life in children with cerebral palsy at age 5 years**

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**Background:** Quality of life (QOL) of young children with cerebral palsy (CP) can be impacted by various factors.

**Aim:** To investigate the association between gross motor function and performance, habitual physical activity (HPA), time spent sedentary (TSS) and parent-reported QOL in children with CP aged 5 years.

**Methods:** Fifty-eight children with CP aged 5 years; GMFCS level I=33 (57%), II=8 (14%), III=6 (10%), IV=3 (5%) and V=8 (14%); MACS level I=34 (59%), II=13 (22%), III=1 (2%), IV=2 (3%), V=8 (14%) were recruited. Habitual physical activity (counts/minute) and time spent sedentary (TSS) were determined using the ActiGraph® triaxial accelerometer. Parents completed the Pediatric Evaluation of Disability Inventory (PEDI) mobility domain and the Cerebral Palsy Quality of Life Questionnaire for Children (CP-QOL-Child) parent-proxy version. Multiple linear regression analyses were used to examine the associations.

**Results:** The GMFCS and PEDI explained 15% of “social well-being and acceptance” variance (GMFCS:  $\beta=7.5$ , 95%CI=1.2, 13.8; PEDI:  $\beta=0.4$ , 95%CI=0.1, 0.6). The GMFCS, MACS and PEDI accounted for 52% of “feelings about functioning” (GMFCS:  $\beta=7.8$ , 95%CI=1.9, 13.8; MACS:  $\beta=-7.9$ , 95%CI=-11.7, -4.0; PEDI:  $\beta=0.3$ , 95%CI=0.04, 0.6) and 40% of “participation and physical health” variance (GMFCS:  $\beta=14.0$ , 95%CI=6.8, 21.3; MACS:  $\beta=-7.7$ , 95%CI=-12.3, -3.1; PEDI:  $\beta=0.4$ , 95%CI=0.1, 0.7). The PEDI explained 15% of “access to services” ( $\beta=0.5$ , 95%CI=0.1, 0.9) and 16% of “family health” variance ( $\beta=0.5$ , 95%CI=0.1, 1.0). The GMFCS and PEDI accounted for 32% of total CP-QOL variance (GMFCS:  $\beta=5.9$ , 95%CI=1.3, 10.5; PEDI:  $\beta=0.3$ , 95%CI=0.1, 0.5).

**Conclusion:** Gross and fine motor function (GMFCS and MACS) and motor performance (PEDI) are the strongest prediction of well-being of children with CP. Physical activity and participation, determined by HPA and TSS, may not predict QOL although they have benefits of physical and mental health in children with CP.

## **Design and Fabrication of "DataSpoon", a tangible user interface for assessment of self feeding skills of typically developing children and children with cerebral palsy**

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Young children with cerebral palsy (CP) often have significant difficulties mastering self-feeding. To date, little data exist concerning the biomechanics of grasping utensils or food and bringing it to the mouth for either typically developing children or those with CP.

The aim of this paper: To demonstrate a multi-disciplinary, iterative, rapid prototyping approach used to design and fabricate a tangible user interface for quantitative clinical assessment of self-feeding.

Method: The DataSpoon was designed via an iterative process by a multi-disciplinary team including experts in occupational therapy, industrial design, electronics engineering, human-computer interaction, software design and signals analysis. The challenge was to balance between three, sometimes conflicting, requirements related to user needs, technical constraints and safety.

Results: Reaching a compromise between the requirements was a significant challenge. An example of a conflict was fabricating an ecologically valid spoon (small, light and safe for eating) and identifying small batteries that provided sufficient power to operate the spoon for the duration of a 7 min meal. The initial prototype did not meet all of these requirements since its dimensions were too awkward and heavy for use by a young child. A series of prototype iterations guided by multi-disciplinary experts led to the current design (see figure) which consists of an IMUduino BTLE board (<http://www.femtoarduino.com/spex/imuduino-btle>), four button 1.5V batteries and a 9 degree of freedom motion sensor. It uses Bluetooth communication to transmit 3D motion of the spoon in real-time to an Android smartphone or tablet.

### **Conclusion:**

Using a participatory iterative design approach is a very dynamic process that presents many challenges related to user, technical and safety requirements. The ability to iteratively design and fabricate successive prototypes ensures that a reasonable balance can be achieved.

## **Why and how to assess 'family' in the context of practice and research**

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**Background:** The family environment (FE) is central in the development of children; it is one of the most proximal systems of influence and an essential aspect of their developmental context. FE is defined as the quality of interactions and relationships between individuals in the family and the ways in which those interactions and relationships are utilized and perceived by individuals within the family unit. Researchers and clinicians interested in examining the family environment of children with neurodisabilities (ND) seek measures to help them answer questions about the family context. Given the wealth of measures available to assess the family as well as the challenges experienced by these families, selecting the most appropriate measure for specific research or clinical issues is not an easy task.

**Aim:** To report on the various measures of FE used in research with families of children with ND.

**Method:** Using a comprehensive database of studies on families of children with ND, studies were selected that used a standardized measure of FE. The most frequently used measures were then analyzed in terms of the origins of their development, theoretical underpinnings, content, and validation with families of interest.

**Result:** 13 measures from 59 studies met our definition of FE. Five measures were most commonly used across a majority of studies (n=40). The measures varied considerably in terms of theoretical background, content, (sub)scales and populations for which the measures have been developed and validated. None of the measures have to date been validated for families of children with ND.

**Conclusion:** The review provides guidance to choose the most appropriate measure to assess FE and to answer selected questions. However, there are many unanswered questions in terms of how these instruments respond to the realities of families of children with ND. Suggestions on how to improve the use of measures of FE for families of children with ND will be discussed.



## **Participation in physical leisure in children with motor impairments: a child-friendly interview study with 6-8-year-olds**

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**Introduction:** Children with motor impairments experience low levels of participation in physical leisure and play. The current literature about leisure participation is based on data from parents and older children. We investigated participation in physical play from the perspective of younger children.

**Methods:** A convenience sample of children (6-8 years) with motor impairments was recruited through six National Health Service organisations. Child-friendly interview methods were employed: children were invited to construct narratives about participation in physical play and leisure by drawing on large paper sheets which consisted of a visual-grid of representations of participation contexts. The researcher encouraged articulation of narratives through prompts. The narratives were recorded verbatim and transcribed. The transcripts and drawings were analysed for emerging themes.

**Results:** Seventeen children participated in data collection, including two children with communication limitations. All but one child chose to draw. Four consistent themes emerged from the analysis. “Places and activities”: the children’s descriptions of important participation contexts and activities. “Rules, norms and the way it’s done”: perceptions that children’s participation and activities are largely regulated by people other than the child. “Play, imagination and fantasy”: the children’s agenda and how they inject this in everyday activities. “Scary and too hard”: situations outside the children’s comfort zone.

**Conclusions:** Even relatively young children are aware of the influence of the social context on the leisure participation of disabled children. Injecting playfulness in ordinary activities is an important way for young children to bring about leisure in their day-to-day lives.

## ACUTE WHOLE BODY VIBRATION IMPROVES MOTOR CONTROL IN SUBJECTS WITH SPASTIC CEREBRAL PALSY

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**Background:** Neuropathological disease patterns of exaggerated reflex activity reduce voluntary motor control and hence functional mobility in subjects with spastic cerebral palsy (SCP). Lately, whole body vibration (WBV) has been promoted for its beneficial influence on functional performance in subjects with neurological disorders. Despite the evidence that WBV reduces Ia-afferent transmission in healthy subjects, neuromuscular effects for neuro-rehabilitation are still deficiently researched.

**Aim:** This study aimed to investigate acute neuromuscular adaptations after WBV in subjects suffering from SCP.

**Method:** 29 subjects with SCP were exposed to a 1min-bout of WBV (16-25Hz, 1-3mm). Before and after WBV, stretch reflexes in the m. soleus (SR) and neuromuscular coordination during active range of motion (AROM) were measured in the affected leg. Coordination-ratios were determined by comparing selected agonists vs. antagonists for concentric contraction (m. soleus, SOL; tibialis anterior, TA; biceps femoris, BF; vastus medialis, VM). SR were provoked by passive dorsiflexion on an ankle ergometer. Muscle activity was recorded by electromyography; ankle and knee joint excursions were assessed by electro-goniometry.

**Result:** After WBV, (1) a reduction of SR ( $-12 \pm 16\%$ ,  $P < 0.05$ ) was observed opposed to (2) increased coordination-ratios in lower limb muscles during AROM (SOL/TA  $+54 \pm 145\%$ , TA/SOL  $+117 \pm 272\%$ , BF/VM  $+67 \pm 232\%$ , VM/BF  $+63 \pm 226\%$ ,  $P < 0.05$ ). Functional changes of AROM were shown in the knee joint only (Ankle  $-1 \pm 42\%$ ,  $P = 0.46$ , Knee  $+15 \pm 20\%$ ,  $P < 0.05$ ).

**Conclusion:** Following WBV, a decline of reflex-activation came along with improved intermuscular coordination and mobility of the lower limb during the respective task. The opposing neuromuscular effects for antagonistic muscle groups point towards enhanced voluntary motor control in subjects with SCP. Thus, WBV may be applied for improving movement training immediately after WBV and treating neuropathological exaggerated SR.

## **EMPOWERING CARERS AND CHILDREN WITH CEREBRAL PALSY FROM IMPOVERISHED AFRICAN SETTINGS – HOW DO WE MEASURE OUTCOMES?**

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**Background:** In resource-constrained cross-cultural settings measuring outcomes of therapy intervention for children with Cerebral Palsy (CP) is challenging. Most outcome measures are designed for well-resourced settings with high literacy levels whilst outcomes of interest in these settings may differ as caregiver priorities and concerns are not necessarily the same.

**Aim:** To determine what tools most effectively capture changes following a short course of therapy.

**Method:** Accompanied by their caregivers, children from rural Southern African areas received two weeks of residential intensive therapy at an urban centre. Immediately before and after the block, an occupational therapist administered the GMFM and established GAS goals whilst a cultural broker administered a structured parent interview assessment and the Care and Comfort Hypertonicity Questionnaire in the caregiver's own language. Following the block, the cultural broker assisted caregivers to complete a narrative feedback questionnaire whilst therapists recorded changes they had observed.

Measuring tools were evaluated according to ease of administration; ease of translation; cultural relevance; understandability; and consistency.

**Results:** Fifty-nine children and their caregivers participated in the study. Almost 90% (n=53) were GMFCS Level 4 or 5. Tools relying on a Likert Scale or high degree of literacy proved unsuccessful whilst the GMFM was time consuming in this population and insensitive to measuring observed changes. Dependence on a cultural broker for translation and administration tools increased time taken. Qualitative feedback from parents; comparing therapist and caregiver perceptions of change and pre- and post-status photographs proved most useful.

**Conclusion:** Qualitative tools where changes are described rather than measured worked best in this setting. Quantitative tools need to be visual whilst narrative feedback facilitated by a cultural broker provides insightful information.

**The Hand Assessment for Infants (HAI); a new test for measuring asymmetries and use of hands in infants 3-10 months of age.**

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**Background:** Asymmetric hand-use is commonly the first clinical signs of unilateral cerebral palsy (CP) in infants, however, there is no assessment available which can detect and measure hand function in infants 3-10 months old.

**Aim:** To describe the development of the Hand Assessment for Infants (HAI), the concept and construct and to report psychometric properties.

**Methods:** Test items were developed from literature review, expert groups and from systematic observations of goal-directed hand/arm actions of infants. Internal scale validity was evaluated by Rasch measurement model analysis of 157 assessments of a clinical convenience sample of infants with a brain damage and clinical signs of CP in Italy and in Sweden. Infant's age range was 3-10 months. Normative data was collected from 492 typically developing infants.

**Results:** The test items describe both unilateral and bilateral actions. After stepwise exclusion of items showing misfit to the Rasch model assertions, 17 items scored on a 3-point rating scale was found to form a unidimensional construct. The HAI outcome is presented both for each hand separately, showing magnitude of asymmetry, as well as by a measure of bimanual hand use. Rasch analysis confirmed excellent internal construct validity; rating scale categories showed monotonically increasing step calibrations. Principal component analysis for the bimanual measure demonstrated unidimensionality by variance explained by measure 76.4% with variance explained by first contrast 4.8%. Item fit was demonstrated for  $\geq 95\%$  of items for all three subscales. Internal consistency ratios (reliability coefficients  $\geq 0.80$ ) was demonstrated for all three subscales. Tentative age norms were constructed.

**Conclusion:** The HAI showed to be a promising tool for measuring hand function in infants with signs of unilateral CP, making it possible to detect and measure asymmetries, follow development over time and evaluate effects of early intervention on hand function.

## **A shearwave elastography muscles comparison between children with cerebral palsy and control children.**

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**Background:** New techniques are developed to allow quantitative measurement of soft tissue stiffness using ultrasound as the Shear Wave Elastography (SWE) by calculating the shear modulus. The benefits of this technique are to obtain quantitative measures of the muscle elasticity, well described on adults, applications on children are still lacking.

**Aim:** The aim of this study was to compare on children the shear modulus of healthy and spastic muscles from Cerebral Palsy (CP) at rest and under passive stretching, after the reproducibility of SWE on healthy children has been assessed.

**Method:** The reproducibility is evaluated: at rest, on 7 children without any musculoskeletal pathology by 3 different operators, on biceps brachii long head and medial gastrocnemius.

The comparison study was made, on the same 2 muscles, at rest and under passive stretching, on 45 children divided in 3 groups: (1) control group : 29 healthy children, (2) spastic group: spastic muscles of 16 children from CP, (3) non-spastic group: non-spastic muscles of 14 children from CP. The same operator assessed 4 measurements by muscle and position.

**Results:** The reproducibility study, on the 7 children without any musculoskeletal pathology, finds that the intra-operator reliability and inter-operator reliability are respectively: 0.6kPa (11.2%) and 0.8kPa (14.9%) for the biceps, 0.4kPa (11.5%) and 0.5kPa (13.8%) for the gastrocnemius.

At rest, the comparison between the 3 groups shows no significant difference for both muscles. Under passive stretching, the non-spastic CP biceps were significantly stiffer than the control ones ( $p=0.033$ ). Spastic gastrocnemius had a higher shear modulus than in the control muscles ( $p=0.0003$ ) or the non-spastic muscles ( $p=0.017$ ).

**Conclusion:** The SWE is a simple and reliable tool and allow quantifiable measures to precise muscle spasticity on children. The measurements on the biceps have to be improved. The results on the stretched gastrocnemius are consistent.

## **Validating the ICF Core Set for Cerebral Palsy by Using National Disability Sample in Taiwan**

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**Background:** The newly developed ICF Core Sets for children and youth with Cerebral Palsy (CP) serve as a 'framework' for guiding the functional assessment, evaluation, and follow-up of children and youth with CP worldwide..

**Aim:** To validate the activities and participation (d) codes of the Brief ICF Core Sets for children with CP aged 6-14 and  $\geq 14$ -18 years by a national sample of children with disabilities in Taiwan.

**Method:** A total of 546 primary caregivers of students with CP aged 6-17.9 years were interviewed in a cross-sectional nationwide survey using the Functioning Scale of the Disability Evaluation System - Child version (FUNDES-Child). Items of the d-part of the FUNDES-Child were mapped to the Brief ICF Core Sets for CP. The restriction percentage of the linked codes of frequency and independence dimensions were calculated. Random Forests regression was applied to select the important codes.

**Result:** Items of the FUNDES-Child were linked to 9 d-codes of both Brief Core Sets for children aged 6-14 and  $\geq 14$ -18 years. The majority of the codes covered areas of self-care, mobility, education and family relationships. Restriction % of the 9 d-codes ranged from 56% to 93%. The important codes of the Brief CP Set, that predict School frequency score, were different in the two age-groups. Some important codes identified in this study were not in the Brief ICF Core Sets, e.g. d740 (Formal relationships, such as teachers) in the 6-14, and d640 (Doing housework) in the  $\geq 14$ -18 year group.

**Conclusions:** Most d categories of the Brief ICF Core Sets could be confirmed. Some additional categories not covered by the present version of the Brief ICF Core Sets emerged from the national disability sample and should be considered for inclusion in the revised Taiwanese version.

## **EFFECT OF ANKLE-FOOT ORTHOSES ON GAIT IN CHILDREN WITH CEREBRAL PALSY : A META-ANALYSIS**

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**Background:** Different ankle-foot orthoses (AFO) are often prescribed in children with cerebral palsy (CP) although their efficiency on gait remains unclear.

**Aim:** (1) To determine the effect of AFOs on gait in children with CP and (2) to evaluate the effect of each types of AFO.

**Method:** A search was conducted using relevant keywords on the Pubmed, CINAHL+, Web of Science, Cochrane Library databases. Studies in english evaluating the effect of AFO on gait in children with CP with a control condition were selected. Quality of each study was assessed. 10 gait parameters were extracted in each study. Effect size and 95% confidence interval were calculated for each parameter.

**Results:** 17 studies (490 subjects) were included. Comparing AFOs to control condition, stride length increased (15 studies)  $d=1,261$  [IC95 0,868 ; 1,653], velocity increased (16 studies)  $d=0.368$  [IC95 0.085 ; 0.652], cadence decreased (15 studies)  $d=-0.73$ , [IC95 -0.99 ; -0.46]. Ankle dorsiflexion increased at initial contact (10 studies)  $d=2.024$ , [IC95 1.613 2.436] and in swing phase (4 studies)  $d=1.90$ , [IC95 1.13 ; 2.67]. Ankle power generation in stance phase decreased (4 studies)  $d=-0,676$ , [IC95 -1,033 ; -0,318]. Motor function improved (3 studies)  $d=0,436$  [IC95 0,252 ; 0,620]. The duration of tibialis anterior activation and energy data did not changed significantly. Six types of orthosis were found: Dynamic AFO, Hinged AFO, Solid AFO, Supra Malleolar Orthosis, Posterior Leaf Spring and Tone Reducing AFO. Hinged AFO was the orthosis that improved the greater number of gait parameters and was the only one to improve velocity with an effect size  $>0.8$  (large effect).

**Conclusion:** This study shows medium to large effect of AFO on various gait parameters which supports its recommendation for use in clinical practice. The different orthoses do not have similar effects. New data are needed to refine the choice of the orthosis according to the child gait pattern.

## **Randomized controlled clinical trial of the effect of gait training on muscle function and gait kinematics in adults with Cerebral Palsy**

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**Background:** Strength training interventions, which lead to large increase in muscle strength and size, have in several studies failed to demonstrate functional relevant improvements in neurological patients.

**Aim:** Here we report data from a randomized clinical trial (RCT) of the effect of treadmill training on muscle function and structure and its relation to improvements in gait kinematics in adults with CP.

**Methods:** 32 adults with CP (GMFCS 1, n=10; 2, n=7; 3, n=15) aged 38.1 years  $\pm$  12 (SD) years were randomly allocated to either a training group (n=16) where uphill gait training on a treadmill was performed daily for 30 min for six weeks in addition to their usual activities or a control group (n=16) that performed their usual activities. Evaluation of maximal voluntary contraction (MVC), rate of force development (RFD) and torque respons to supramaximal electrical stimulation (Mmax) in the ankle joint plantar- and dorsi flexors, ultrasound determined cross section of tibialis anterior (TA) and medial gastrocnemius (MG), gait kinematics recorded by 3D video analysis was made twice on all participants before and after the six week of training or control period.

**Results:** Participants with pathologically reduced muscle function in plantar and dorsi flexors showed a significant increase in MVC, RFD, Mmax following training compared to the control group. No change in muscle cross section was found. Kinematic improvements were found in gait speed, active range of motion and toe lift and amplitude of toe lift towards the end of swing phase during gait. No correlation between kinematic improvements and muscle function parameters were found.

**Conclusion:** These data show that daily intensive gait training influence muscle function of ankle joint muscles in adults with CP. However, these changes are not likely to be responsible for the observed functional gait improvements, and we propose that the improvements are due to improved coordination of muscle activity.



## **Development of the Assisting Hand Assessment for adolescents (Ad-AHA) and validation of the AHA for the whole age range 18 months to 18 years**

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### **Background**

For adolescents with unilateral Cerebral Palsy (UCP) there is no instrument designed to assess quality of use of the affected hand in bimanual activities. Since the Assisting Hand Assessment (AHA) has proven its merits in both clinical practice and research in children with UCP, the logical next step was to expand the AHA for use in adolescents, 13 to 18 year olds.

### **Aim**

To develop an adolescent version of the AHA (Ad-AHA) for teenagers with UCP by (i) developing a new test activity allowing observation of bimanual performance suiting adolescents and (ii) to investigate whether the Kids-AHA scoring criteria could be used also for adolescents by evaluating the internal scale validity of the AHA for the whole age range 18 months to 18 years.

### **Method**

The content of the new board game “Go with the Floe” was evaluated for its ability to provoke bimanual actions in adolescents with (n=20) and without (n=10) CP. The AHA scores from 126 adolescents (age range 12-18 years) and 157 children (age range 18 months-12 years) with UCP were analysed for internal scale validity using the Rasch measurement model. Differential Test Functioning (DTF) was performed to evaluate the use of the same AHA-scale for both age groups.

### **Results**

The new board game elicited bimanual hand use in 100% of the typically developing adolescents and in 96.8% and 57.9% of adolescents with UCP and moderate and low ability respectively. Goodness-of-fit was demonstrated for 95% items of the unidimensional scale. The AHA items could separate nine groups of person-ability-levels within the sample and DTF showed that the scale functioned well for the whole age group.

### **Conclusion**

The Ad-AHA board game has proven suitable to elicit bimanual performance in adolescents with UCP allowing observation and scoring of the AHA items. The same AHA scoring criteria can be used for both children and adolescents with UCP, age range 18 months – 18 years.

## **“Neural mechanisms supporting observational motor learning in children with Developmental Coordination Disorder - An EEG study”**

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### **Aim**

Children with Developmental Coordination Disorder (DCD) experience problems in the learning and performance of motor actions. Learning a new movement by action observation is very important in for example class room settings and entails the transposition of the observed action to the existing internal motor representations of the observer. The automatic activation of motor representations during action observation, as well as the functional coupling between perception and action were suggested to be important neural processes supporting observational action learning. In the present study we study these mechanisms in children with and without DCD.

### **Method**

Motor neural network activation is measured by electroencephalography (EEG), specifically event-related desynchronization (ERD) of mu rhythms and fronto-parietal coherence. We included 15 children with DCD and 15 matched controls in two task conditions: observational learning (imitate an action following observation of that same action) and detection (report a deviant movement after observation). Children with DCD are expected to imitate the action with a lower level of accuracy, show less mu-suppression and decreased fronto-parietal coherence during observational learning compared to controls.

### **Results**

Preliminary results (based on 12 children; 6 DCD, 6 matched controls) confirmed that children with DCD show a lower level of accuracy than controls in the imitation condition. Moreover, the expected decreased degree of mu suppression in children with DCD was confirmed. Results of the complete data set in children with and without DCD will be presented at the EACD conference.

### **Discussion**

Findings will be discussed in the context of the internal modeling deficit hypothesis for children with DCD.

## **Is the acetabulum an etiological factor in the Internal Hip Rotation Gait Profile in Children with Cerebral Palsy?**

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### **Background**

Internal hip rotation(IHR) during gait in children with Cerebral Palsy(CP) is often thought to be related to excessive femoral anteversion(FA) and to decreased muscle lengths. However, studies based on generic models and physical examination have not shown involvement of these parameters<sup>1,2</sup>.

### **Aim**

To assess the causes of IHR, in CP children based on 3D subject-specific musculoskeletal parameters and explore the possible effect of acetabular parameters in this gait profile.

### **Method**

30 spastic CP children(23 diplegic, 7 hemiplegic, mean age 11.8 years  $\pm$  4), had undergone 3D gait analysis. The following kinematic parameters were used to evaluate IHR: hip rotation at initial contact(P1), peak(P2) and mean(P3) hip rotation during stance. Patients underwent EOS<sup>®</sup> biplanar X-rays in order to calculate in 3D: FA, sacro-acetabular angle(SA), pelvic incidence(PI), sacral slope and pelvic tilt. Acetabular rotations around the 3 axes of the pelvis were calculated. Axial MRI acquisitions were performed in order to calculate belly muscle lengths in each lower limb(LL). CP children were age-matched to 21 typically developing(TD) children. Correlations between muscle lengths, 3D skeletal parameters and hip kinematics were investigated.

### **Result**

20 LL, in CP group, presented excessive IHR compared to the control group and thus constituted the IHR group. These lower limbs' FA and SA angle were significantly increased compared to TD children( $p < .001$  and  $p = .02$  respectively). FA showed no significant correlation with hip kinematics. PI was significantly increased in the IHR group compared to TD children( $p = .005$ ) and was significantly correlated to P1( $R = -0.5$ ). 3D acetabular tilt and Abd were correlated to P2( $R = -0.6$  and  $R = -0.5$  respectively) in the IHR group. Adductor magnus and longus were correlated to hip kinematics( $R = -0.8$ ).

### **Conclusion**

These results showed that while 3D FA doesn't contribute to IHR during gait, 3D acetabular parameters do.

<sup>1</sup> Aktas S et al. 2000, <sup>2</sup> Lovejoy SA. et al. 2007.

## **Effects of gait training using a Robot Suit of Hybrid Assistive Limbs on spastic diplegia in Cerebral Palsy**

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**Background?** Although rehabilitation in gait using a robot suit has been somewhat reported to be effective for patients with stroke or spinal cord injury, there have been few papers for children with cerebral palsy (CP). **Purpose?** To assess the effects of gait and standing exercises using robot suit Hybrid Assistive Limb (HAL) on children with cerebral palsy. **Method?** We studied five children with CP (9-16 years). They all had spastic diplegia of GMFCS levels II to III and needed ankle-foot orthosis. The wearing HAL training consisted of hip and knee extension exercises for 30-40 minutes, and gait exercises of two 50 m trials with a walker. The center of gravity in body during standing posture was recorded for five minutes on a monitor of HAL. The data from two trials of 10-meter walk test after the training were compared those before the training. Walking speed change was statistically analyzed by Wilcoxon rank sum test and the change of their standing figures were evaluated by a physical therapist. Written informed consent was obtained from all three participants with CP and their parents. This study conformed to the tenets of the Declaration of Helsinki. **Result?** The mean pace in gait of  $60.0 \pm 16.6$  m/min was improved to  $66.5 \pm 15.0$  m/min after the training ( $p < 0.05$ ). The mean stride of 0.52m was lengthened to 0.56m after the training ( $p < 0.05$ ). They all were noticeably improved in their walking forms at all the stages, especially in extension movement of hip and knee, and these effectiveness were continued after undressing a HAL for a short period. **Conclusion?** The HAL training of just one time quickly improved the gait disturbance in CP for a short period, suggesting the HAL modulate the motor control in children with CP. In particular, the visual feedback for the center of gravity in body on a HAL monitor seemed to be useful for correcting a walking form by oneself. Further study is requested for confirming this effectiveness of a HAL on spastic gait in childhood CP.

## **Spina Bifida in Iceland: Epidemiology, Health and Well-being among adults**

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**Background:** Spina bifida (SB) is a congenital deformity with complications that require comprehensive multidisciplinary care. Physical limitations and complications associated with SB might set individuals with SB at increased risk for developing lifestyle-related conditions.

**Aim:** To perform an epidemiological investigation of the SB population in Iceland and to assess health and well-being of the adult SB population.

**Methods:** The incidence of SB between 1972 and 2011 was examined retrospectively. Mobility and cognitive functioning of children with SB at 5 years of age was described. In addition, 25 adults with SB answered the survey “Health and well-being of Icelanders in 2012” and the results were compared with results from a group of Icelandic participants (n=2159). They also an accelerometer for 7 days to measure physical activity (PA). Waist circumference was measured to evaluate risk of metabolic complications.

**Results:** The incidence of SB has declined significantly in Iceland during the last 40 years. Most 5 year old children with SB could walk. The results concerning health and well-being of adults with SB showed that most of them considered their health as being good or very good and similar or better than last year. They drank less alcohol than comparison group but tended to eat unhealthily. They did not carry out moderately intense PA for 30 minutes a day. Most of them had an increased waist circumference.

**Conclusions:** Induced abortion is the main reason for decline in incidence. Physiotherapists (PTs) can play an important role in improving and prolonging gait function of children with SB. Adults with SB are at increased risk of developing life-style related conditions because of poor diet, lack of PA and prolonged sitting. PTs should inform and educate clients with SB and their families about the importance of a healthy diet and promote PA which takes into account individual possibilities, preferences and limitations.

## **Illness and social background affect education in young adults with cerebral palsy**

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### **Background**

Adults with cerebral palsy are disadvantaged regarding educational level. Education and social skills are important determinants of achieving adult social roles such as employment. Narrow age band studies following persons with cerebral palsy (CP) into adulthood, investigating why adults with CP have lower levels of education are needed.

### **Aim**

To identify health and social predictors of education in persons with CP.

### **Method**

Register based study with linkage of the Danish Cerebral Palsy Registry with public health and social registries in Denmark. Persons without CP are representatively sampled from the Danish Civil Registration System matched on birth year and gender. Achievement of education at age 30 was analysed with logistic regression in 467 persons with CP and 2177 children without CP born 1970 to 1983.

### **Results**

Very few persons with CP and an estimated IQ<85 in childhood achieved an education. Adults with CP and an estimated IQ>85 in childhood had a significantly lower chance of education compared with adults in the general population: adults walking without aid OR=0.29 (0.23-0.37), adults walking with aid OR=0.25 (0.16-0.39) and adults not walking 0.03 (0.00-0.21). The multivariate analysis of adults with CP showed that also health and social factors were significantly associated with decreased chance of education. For example persons hospitalised more than two weeks had an OR=0.51 (0.27-0.94) for education, persons with psychiatric contact an OR=0.55 (0.32-0.93), persons having parents without education OR=0.47 (0.27-0.83), persons living with a single parent at the age of 15 years OR=0.53 (0.32-0.86) and persons living with parents at the age of 25 years OR=0.51 (0.30-0.86).

### **Conclusion**

Parental social background as well as somatic and psychiatric illness during childhood affected chance of education in adults with CP. Being able to walk, but not whether it is aided or not, increased chance of education.

## **Improving motor outcomes in infants at high risk of cerebral palsy: GAME randomised controlled trial**

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**Background:** Cerebral palsy (CP) is caused by a lesion in the developing infant brain. Recent neuroscience literature suggests that intensive, task-specific intervention ought to commence early, during the period of rapid neural development.

**Aim:** The aim of this study was to determine whether a motor-learning environmental enrichment intervention known as GAME (Goals-Activities-Motor Enrichment), improves the motor outcomes of infants with or at high risk of CP after 16 weeks of intervention and at a corrected age of 12 months.

**Method:** A single-blind pragmatic randomized controlled trial was conducted. Thirty infants (corrected age 17.90 [SD 5.31] weeks) at high risk of CP were randomized to GAME (n=15) or standard care (n=15). The primary outcome was motor skills as measured on the Peabody Developmental Motor Scales-2 (PDMS-2). Secondary outcomes included the Canadian Occupational Performance Measure (COPM), Bayley Scales of Infant and Toddler Development (BSID-III) and Gross Motor Function Measure-66 (GMFM-66). Data was analyzed using multiple regression with severity of brain injury a covariate.

**Results:** All 30 infants received the assigned intervention for 16 weeks and at 12 months, n=26 completed assessments. Significant between group differences in raw scores on the PDMS-2 in favour of GAME ( $p < .03$ ) were found after 16 weeks of intervention. At 12 months, significant between group differences favoured GAME participants on the PDMS-2 total motor quotient ( $p < .05$ ), the BSID-3 composite cognitive ( $p < .03$ ) and motor scales ( $p < .03$ ), the GMFM-66 ( $p < .05$ ) and satisfaction scores on the COPM ( $p < .02$ ). Mean dose of therapist delivered intervention was 21.91 (SD 4.25) hours for GAME participants and 14.82 (SD 12.89) hours for standard care.

**Conclusion:** GAME intervention appears to result in improved motor and cognitive outcomes when compared with standard care. Further research is needed to evaluate whether these gains have any impact on severity of CP in the long term.

## **Range of motion related to age and gross motor function – results from The Cerebral palsy follow-up program (CPOP) compared with a group of youth who had not been registered in CPOP**

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### **Background**

Since 2006 all children with CP in Norway are included in The CP-follow-up program (CPOP).

### **Aim**

One aim of CPOP is to contribute to the prevention of severe contractures in persons with CP. The aim of this study was to evaluate the development of range of motion (ROM) related to age and GMFCS level and to compare the results with ROM in a group of adolescents born before the establishment of CPOP.

### **Methods**

The study design is a population based prospective, longitudinal cohort study. The children born from 2002 are assessed in 21 habilitation units once or twice a year according to a standardised protocol including; CP subtype, GMFCS level and ROM. The adolescents born 1992/1993 (n=76) were assessed when they were 16/17 years old. The registrations are saved in a database at Oslo University Hospital, and analysed with appropriate statistical methods.

### **Results**

From 2006-2014 1088 children are included in CPOP. CP subtype in the CPOP children and the adolescents are as follows: bilateral CP 44%/50%, unilateral CP 45%/35%, dyskinetic CP 7%/12% and ataxic CP 3%/3%, not classified 1%/0%, respectively. GMFCS levels are: Level I 51%/36%, Level II 16%/25%, Level III 8%/8%, Level IV 9%/12%, Level V 14%/20%, not classified 2%/0%, respectively. Reduced hip abduction and increased popliteal angle were significantly related to GMFCS III-V and to higher age. Reduced ankle dorsiflexion was significantly related to GMFCS level I-III and higher age. Hip abduction and ankle dorsiflexion were significantly more reduced in the adolescents compared to the children in CPOP.

### **Conclusion**

Analyses of CPOP data show that children with CP up to 12 years of age experience less reduced ROM in hips and ankles compared to the adolescents not included in CPOP. A prevention program is needed from early childhood, adapted to the specific risk factors in the different GMFCS levels at different ages.



## **The emerging new Neurodevelopmental syndromes- Are we ready for it?**

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**Background:** Array-CGH (array comparative genomic hybridisation) is a novel genetic test with the ability to detect previously unknown micro deletions and duplications in children with developmental delay, intellectual disability and autism. This means that rare diagnoses are becoming more common than some well-known syndromes. Impact of finding these is significant as current community paediatric services are not set up to cater for this new yield.

**Aim:** To review and understand the impact of these new diagnoses on existing services.

**Methods:** Retrospective observational study across a large city in the United Kingdom was performed reviewing the clinical outcomes of children who had Karyotype (cohort1) and Array-CGH (cohort 2) as genetic test for developmental delay/intellectual disability and Autism.

**Results:** Array-CGH group (n=95) had a diagnostic yield of 14.74% compared to zero in Karyotype group (n=52). 13 out of 14 of these abnormalities were new recurrent micro duplication or duplications. There were two children with 17q12 duplication. The service usage needs for children with abnormal results mainly involved geneticist review (91.66%), targeted screening for other organ involvement as a part of syndrome (33%). None of them had been discharged (compared to Karyotype group 50% and Array-CGH normal results group 41.81% discharges).

**Conclusions:** The increasing yield consists of new emerging conditions and is out pacing long-standing conditions like Fragile X syndrome. This highlights the importance of paediatrician's need to have a collaborative working pattern with clinical geneticist. There is an emerging pool of children with similar variation necessitating the importance of developing clear pathways for more common syndromes. There is significant shift from investigating child for cause towards predictive screening, implying a positive move towards preventive than therapeutic medicine.

## **Professionals' perceptions of pain management of children with cerebral palsy in South African school settings**

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**Background:** Pain is common in children with cerebral palsy (CP) and research has shown that pain in childhood negatively influences individuals' participation in later years. This emphasises that educators and clinicians working with children need to know how to manage the children's pain to ensure participation in classroom activities. The goal of pain management is to facilitate children's participation.

**Aim:** This study investigated how educators and clinicians in South African school settings respond to children's need for pain management in an attempt to enable the children to be active participants in school activities, despite their pain.

**Method:** The study followed a qualitative design according to Hsieh and Shannon, and in total 38 educators or clinicians participated in five different focus groups. The educators and clinicians worked in government schools in the Gauteng province (Johannesburg and Pretoria).

**Results:** Two strategies of management emerged, i.e., accommodation and treatment. There was a risk of neglecting older children when available resources were provided to the youngest in first hand. Access to services was a challenge, and highlighted in the focus groups. Treatment related to hip dislocation was frequently mentioned in the focus groups.

**Conclusion:** This study stresses that it is important to train educators and clinicians in pain management and to implement structured models for pain management to ensure that best practices are adhered to for children with CP who suffer from chronic pain. Difficulties in pain management were also observed, mostly because the level of hip dislocations.

## **Speech problems affect more than one in two children with cerebral palsy: Swedish population-based study**

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### **ABSTRACT**

**Aim:** To describe speech ability in a population-based study of children with cerebral palsy (CP), in relation to CP subtype, motor function, cognitive level and neuroimaging findings.

**Methods:** A retrospective chart review of 129 children (66 girls, 63 boys) with CP, born in 1999–2002, was carried out. Speech ability and background information, such as type of CP, motor function, cognitive level and neuroimaging data, were collected and analysed.

**Results:** Speech impairment was found in 21% of the children and was present in all types of CP. Forty-one per cent of the children with speech impairment also had mental retardation, and 42% were able to walk independently. A further 32% of the children were nonverbal, and maldevelopment and basal ganglia lesions were most common in this group. The remaining 47% had no speech impairment, and this group was most likely to display white matter lesions of immaturity.

**Conclusion:** More than half of the children in this CP cohort had a speech impairment (21%) or were nonverbal (32%). Speech ability was related to the type of CP, gross motor function, the presence of mental retardation and the localization of brain maldevelopment and lesions. Neuroimaging results differed between the three speech ability groups

**Prospective cohort study of relationship between growth and diet, physical activity and time spent sedentary in preschool aged children with cerebral palsy**

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Children with cerebral palsy (CP), particularly those with severe motor impairment, grow differently than children with typical development. The effect of energy intake, habitual physical activity (HPA) and sedentary time (ST) on growth is not known.

To investigate the longitudinal relationship between height Z-score (HZ), growth velocity Z-score (GvZ), energy intake, HPA and ST across all Gross Motor Function Classification System groups (GMFCS I-V) in young children with CP.

Children with CP (n=175; 109 boys; recruitment age: 2.8±0.9 years; GMFCS I:n=83; II: n=21, III: n=28; IV n=19; V: n=25) were assessed on 440 occasions between ages 1.5 and 5 years. Height or length was measured or estimated using knee-height. Age-and sex-based standards were used to calculate HZ and GvZ. Feeding method and gestational age at birth (GA) was collected from parents. Three-day ActiGraph® and food diary data was used to measure HPA/ST and energy intake respectively. A speech therapist scored a Dysphagia Disorder Survey (DDS) assessment. Analysis was by mixed-effects linear regression.

For children classified as GMFCS I, HZ (mean difference (MD)=-0.22, 95%CI= -0.77 to 0.03) and GvZ (MD=0.18 95%CI= -0.25 to 0.62) did not differ from growth standards developed for children with typical development, while groups II-V were significantly shorter (MD= -1.04 to -0.34; 95%CI= -1.45 to -0.11), and groups III-V grow significantly slower (MD=-1.15 to -0.73; 95%CI= -1.6 to -0.72), than group I. Height Z-score and GA were positively associated in all groups (MD=0.25; 95%CI= 0.11 to 0.39). Energy intake, HPA, ST and DDS-score or feeding method did not contribute to either model once GMFCS level was controlled for.

GMFCS level and GA should be taken into consideration when assessing the growth of a child with CP. Research into interventions aimed at increasing active movement in GMFCS III-V groups and their efficacy in improving growth and health outcomes is warranted.

## **G(anspoel).CVI.Tod(dler)s, a novel diagnostic tool in the assessment of Cerebral Visual Impairment in the young child**

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### **Background**

Cerebral Visual Impairment (CVI) has a large negative impact on global development. Early detection and intervention leads to an improved quality of life.

In children under 3 years or with a multiple handicap, diagnosis of CVI is difficult due to language or motor disabilities. Moreover, normative data for visual field size are lacking.

### **Aim**

We set out to construct a standardized battery for the assessment of visual perceptual skills in the age group under 3, independent of language and motor abilities.

### **Participants and methods**

The battery was first developed based on expert knowledge and extensive piloting, resulting in a compilation of subtests, assessing object recognition in isolation and in context, motion pursuit and visual field. In a second phase, Flemish children of 18, 24 and 30 months with typical development and a normal refraction, performed the GCVITods. Lastly, congruent and discriminative validity of the battery was investigated.

### **Results**

Sixty-four children were examined at 18 months, 67 at 24m and 77 at 30m. Sum scores of the visual recognition tasks and of the motion pursuit task, the highest scores for every quadrant of the visual field and the questionnaire of daily visual functioning were plotted in frequency distributions per age. Split-half reliability, Cronbach alpha and correlations between the different subtests of the visual recognition tasks showed good reliability for the tests at 24 and 30m. In the 18 month old children, less reliable results were seen.

Validity of the GCVITods is being evaluated in 60 children from three groups: suspicion of CVI, low acuity and hard of hearing children. Data collection is still on-going. In the meantime, interesting results have already been seen in children with CP and in specific ophthalmological disorders such as achromatopsia.

## **A qualitative study highlighting the association between self-efficacy and outcomes in teenagers with developmental coordination disorder**

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**Background:** Developmental coordination disorder (DCD) is one of the most common disorders of childhood (Wann 2007). Difficulties often persist into adulthood (Kirby et al 2011) yet little is known about the impact of DCD in adolescence.

**Aim:** To examine the lived experience of DCD from teenagers' perspective

**Method:** This qualitative study applied the principles of interpretative phenomenological analysis (Smith et al 2009). Study design, delivery and analysis were guided by a Reference Group of older teenagers/young adults with DCD. Sixteen accounts from teenagers aged 13-15 years were subjected to a systematic process of ideographic, inductive and interpretative analysis. A conceptual framework illustrating factors affecting the lived experience of teenagers with DCD was developed. Ethical approval was given by Coventry University.

**Findings:** Self-efficacy (Bandura 1986) emerged as a strong influence on the lived experience and outcomes for adolescents with DCD. Strong self-efficacy beliefs were expressed regarding activities of daily living (ADL), academic skills and social participation. Factors influencing self-efficacy were motor ability; process skills; activity context and interactions. Self-efficacy also influenced teenagers' sense of agency; ambition; emotional resilience and identity. These concepts are included in the conceptual framework as 'personal outcomes'.

**Conclusion:** Findings suggest self-efficacy is an important but little recognised factor affecting teenagers' performance of ADL at home, school and in social settings. The need for a tool to measure self-efficacy for ADL to be used in intervention planning and outcome measurement is highlighted. The study also broadens understanding of outcomes for teenagers with DCD to include sense of identity, agency, resilience and ambition as well as motor performance. Focusing on these outcomes will enable services to develop interventions that positively affect the lives of adolescents with DCD.

## **Transition of young people with long term conditions: the difference between intended provision and actual experience.**

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### **Background**

Policy documents and some evidence suggest there are components of transition services for young people which improve outcomes.

### **Aim**

To compare young people's experiences of nine components of transition services with what service providers stated they offered.

### **Method**

A questionnaire was completed by researchers, at home visits, with 302 young people aged 14-17 years with cerebral palsy (85), diabetes mellitus (126) or autism with associated mental health problem(s) (91) who were in transition and close to the point of transfer of their healthcare. A similar questionnaire was completed by the 34 providers of services for those young people.

### **Result**

For 'Meeting the adult team before transfer', 'Having a written transition plan' and 'Providing life skills training', only 16%, 12%, and 10% of young people experienced the component when the service stated it was provided. For those at the point of transfer of their healthcare, the agreement was slightly better (35%, 19%, 12%). For 'Having a transition coordinator' there was evidence for this in medical records of 33% of those where the service stated it was provided.

There was good agreement for 'Involving parents appropriately' and 'Promoting health self-efficacy' (77%, 75%) when the service stated it was provided.

There was moderate agreement for 'Having a key worker', 'Team approach', 'Age-banded clinic' (51%, 55%, 61%) when the service stated it was provided.

'Having a key worker' and 'Promoting health self-efficacy' were often experienced (32%, 57%), even when the service stated it was not provided.

### **Conclusion**

Observational studies or trials which examine the influence of components of transition services on outcomes should ensure that the young person's experience of the components is captured, and not rely on the service specification.

In our longitudinal study, we will capture again these components to see if they are experienced more frequently as more young people reach the point of transfer or have transferred.

## **Prediction of speech intelligibility of children with cerebral palsy (CP) from characteristics at 2 years of age**

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**Background:** Approximately half of children with CP have difficulties communicating. The ability to predict speech outcome from early childhood characteristics would enable tailored early intervention to promote communication development and inform decisions about the introduction of augmentative and alternative communication (AAC) systems.

**Aim:** To investigate the strength with which early medical history, CP characteristics and speech and language function at two years of age predicts speech intelligibility and AAC use by children with CP at five years of age.

**Method:** 137 (86 M) children born 2005-2010 in Norway (n=61) and northern England (n=76) had a confirmed diagnosis of CP at five years. Medical histories were taken from case notes at 2.0-2.06 years for all children. Speech and language performance, including the four level Viking Speech Scale rating speech intelligibility, was assessed at 2.0-2.06 and 5 years of age.

**Result:** Preliminary analysis suggests that when all variables are entered into an ordinal logistic regression model there are no associations between sex, birth weight, gestational age at birth, neonatal seizures, epilepsy, type and distribution of motor disorder or language comprehension at 2 years and Viking score at 5 years. Children with eating difficulties at 2 years were 9 times less likely to have intelligible speech at 5 years ( $p=0.03$ ) than those without eating difficulties. Children who spoke in sentences at 2 years of age were 12.5 times more likely to have intelligible speech at 5 years than those who produced vocalizations or single words ( $p=0.03$ ). Thirty-one (27%) children used AAC at 5 years. AAC was more frequently used by children with higher Viking scores ( $p<0.001$ ) but only half of children in Viking level IV used AAC.

**Conclusion:** Spoken language at 2 years of age is highly predictive of intelligible speech at 5 years. Prediction of AAC use requires further investigation including data on motor function, vision and cognition.



## **Effects of ventilation following intrauterine inflammation on the cerebral cortex of preterm lambs.**

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**Introduction:** Ventilation of preterm lambs causes cerebral white matter inflammation and injury, which is exacerbated by intrauterine inflammation<sup>1</sup>. However, the effects on the cerebral cortex are not known. Our aim was to examine the effects of a protective or injurious ventilation strategy on the cerebral cortex with and without prior exposure to intrauterine inflammation.

**Method:** Newborn lambs (0.85 gestation) were ventilated using either an injurious ventilation (n=6) strategy for 15 min followed by a protective ventilation strategy for 75 min or a protective ventilation (n=5) strategy for 90 min. An additional two groups were exposed to intra-amniotic lipopolysaccharide (LPS; 10mg; to induce intrauterine inflammation) 7 days prior to delivery and injurious (n=5) or protective (n=6) ventilation. At autopsy, sections of the cerebrum were immunohistochemically stained to identify microglia (Iba-1), astrocytes (GFAP), neurons (NeuN), apoptotic cells (all stages of cell death, caspase-8 and end stage, TUNEL) and vascular protein extravasation (sheep serum) within the cerebral cortex. Results were compared using 2-way ANOVA.

**Results:** There were no significant differences between groups in the overall density of microglia or astrocytes. LPS exposure reduced the overall density of neurons ( $P_{LPS}=0.02$ ), caspase-8 positive apoptotic cells ( $P_{LPS}=0.01$ ) and TUNEL positive apoptotic cells ( $P_{LPS}=0.03$ ) compared to controls with ventilation strategy having little effect. LPS exposure increased the number of sheep serum positive leaky vessels ( $P_{LPS}=0.01$ ) compared to controls. Ventilation strategy had no effect.

**Conclusion:** Intrauterine inflammation prior to ventilation reduced neuronal cell density, reduced apoptotic cell density and increased vascular protein extravasation. A protective ventilation strategy did not reduce brain injury in LPS exposed lambs.

<sup>1</sup>Barton SK et al. PLoS One. 2014 Nov 7;9(11):e112402.

## **Participation in lessons of physical education: a national survey between 8- to 15- year old children with CP in Denmark**

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### **Background.**

Children with cerebral palsy (CP) tend to be less physical active than their peers. Participation in physical education lessons (PE) is crucial for the level of physical activity. Knowledge about the reasons for non- participation in PE lessons is sparse.

### **Aim.**

To describe participation in PE lessons regarding child's age, gender, Gross Motor Function Classification System (GMFCS) level, cognitive function, school setting, frequency of physiotherapy, family characteristics, and the reasons for non-participation in PE lessons.

### **Method.**

A cross-sectional national study. Parents of 446 children answered the questionnaire about participation in PE and reasons for non-participation. Descriptive and logistic regression analyses were performed, followed by the qualitative analysis of the answers.

### **Result.**

Participation in PE was strongly associated to Gross Motor Function Classification System level (from 97% in GMFCS I to 39% in GMFCS V), but not to the school type, when stratified for GMFCS level. Lower participation in older children was only significant in GMFCS level III (odds ratio 0.63 (CI 0.40 - 0.97)). The most frequent reasons were a preference of physiotherapy instead of PE lessons and a lack of resources in school. Other reasons like child's fatigue were also reported. Examples of successful participation were reported by some parents.

### **Conclusion.**

As expected, a low participation in PE lessons was observed in children with low gross motor function. Parents reported multiple reasons for non-participation. The results indicate a lack of awareness about low participation of children with disabilities in PE lessons. Positive examples should be actively provided by health professionals to the schools in order to increase the participation of children with CP in PE lessons.

## **Four direction square test as tool for measuring standing balance in children with cerebral palsy: a validation study**

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### **BACKGROUND**

A quick tool to assess balance in children with cerebral palsy (CP) is an under studied area in the literature. Hence the four direction square test(FDST) was developed by our team through years of clinical practise and research in CP.

### **AIM**

The aim of this study was to validate the four direction square test (FDST) as a tool for measuring standing balance in children with cerebral palsy.

### **METHODS**

Thirty-five children with CP (12 boys and 23 girls; mean age of  $8.45 \pm 2.56$  years) were tested with the FDST. Three physiotherapists with varied experience served as independent raters to establish the inter-rater reliability for the FDST. FDST was performed in standing inside a square (1 feet x 1 feet) with or without support asking the individual to step forwards, side-wards and backwards on the right leg and then similarly on the left leg. After each step, the testing leg had to be brought back inside the box. Two scores are available: 1. Timed scores: calculated by time taken to complete the full test in both the legs; 2. Scaled scores: (5) unable to stand (4) able to stand and complete test with adult support, (3) able to complete test with assistive device, (2) able to complete test independently with one leg, (1) able to complete independently with both the legs. Paediatric balance scale (PBS) and Timed up and go (TUG) test were also measured to establish the concurrent validity.

### **RESULTS**

Intra-class correlation coefficients (ICC) with 95% confidence interval and the Spearman rank correlation coefficient were computed for the obtained scores. The FDST showed good inter-rater reliability, ICC >0.99; 95% CI and showed good concurrent validity with correlations among other balance measures such as PBS and TUG.

### **CONCLUSION**

The four direction square tests (FDST) is a valid and reliable tool that can be used as a quick mode of balance testing among children with cerebral palsy.

## Predictors of parent-reported quality of life of adolescents with cerebral palsy

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### Background

Parent-reports of their child's quality of life (QoL) are needed to examine QoL of children with cerebral palsy (CP) across all severities. This study determines whether QoL changes between childhood and adolescence, and what predicts adolescent QoL.

### Methods

SPARCLE is a European cohort study of children with CP. Among 818 8-12-year-olds entering in 2004/5, 594 (73%) were revisited aged 13-17 years. For 551 children the same parent reported QoL on both occasions, using KIDSCREEN-52. The influences of child factors (impairment, pain and psychological problems (Strengths and Difficulties Questionnaire)), and family factors and parenting stress (Parenting Stress Index)) on adolescent QoL were assessed on nine KIDSCREEN domains using linear regression models reinforced by multiple imputation and bootstrapping.

### Results

Between childhood and adolescence, QoL was stable in three domains Physical wellbeing, Autonomy and Social acceptance and slightly reduced in the other six. Higher childhood QoL predicted higher adolescent QoL in all domains; contemporaneous pain predicted lower adolescent QoL in seven domains. More psychological problems in childhood and their worsening by adolescence were associated with lower QoL in five domains. Higher parenting stress in childhood and its increase by adolescence predicted lower adolescent QoL in all domains except Physical wellbeing, School life and Social acceptance. Impairment, socio-demographic characteristics and recent stressful family life events did not predict adolescent QoL, except that severe intellectual impairment had a small positive effect. The regression models explained around 40% of the variance in adolescent QoL.

### Conclusion

Impairment severity and socio-demographics are difficult to influence but had little impact little on adolescent QoL. However, pain, psychological problems and parenting stress predicted lower QoL. These are modifiable and addressing them may improve adolescent QoL.

## **A Systematic Review and Meta-Analysis of the Efficacy of Therapy and Behaviour Change Interventions to Increase Physical Activity Participation in Children with Cerebral Palsy**

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**Background:** Children with cerebral palsy (CP) are less physically active than their typically developing peers. There is a paucity of evidence for interventions to increase participation in physical activity (PA) in this population. **Aim:** To determine the efficacy and active ingredients of interventions aimed at increasing participation in PA in children with CP. **Method:** Five databases were systematically searched. Included studies had: (1) a control group and/or period; (2) a population of children 5 to 18 years with CP; (3) an aim or objective related to increased participation in PA and isolated outcomes for PA participation. Methodological quality was assessed against a modified Downs and Black Scale and quantitative analysis was performed using RevMan 5 with Standardised Mean Difference (SMD) and Random Effects. Intervention components were evaluated against the ICF and Theoretical Domains Frameworks to identify 'active ingredients'. **Result:** 2254 articles were identified and 7 (6 studies) were included investigating physical training (n=3), combined physical training and behaviour change therapy (n=1), an online behaviour change intervention (n=1), and context therapy (n=1). Study quality varied from moderate-high. There was a modest effect of therapy and/or behaviour change intervention compared to usual care to increase participation in PA (n=2, p=.54, SMD 0.40, 95% CI: -0.40,1.19), and a weak effect to increase number of steps (n=3, p=.55, SMD 0.22, 95% CI: -0.36,0.79). Most intervention components targeted Body Structures & Functions or Activity domains and acted to modify PA behaviour through the practice of skills. Contextual barriers were less frequently considered. **Conclusion:** Therapy and behaviour change interventions have the potential to increase PA participation in children with CP, although there is a need to depart from impairment-focused approaches. Inconsistent use and reporting of outcomes are significant barriers to advancement in this field.

## Changing trends in cerebral palsy in Victoria, Australia, 1983 - 2009

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**Background.** Cerebral palsy (CP) registries are well placed to monitor trends in the prevalence and profile of CP that not only afford insight into changing clinical and health service delivery needs, but are valuable markers for the impact of innovations in perinatal practice and the effectiveness of neuroprotective treatments.

**Aim.** To use an Australian CP birth cohort to examine gestation-specific temporal trends in the rates of CP, both overall and in subgroups stratified on gender, motor function, and medical complexity.

**Method.** Data were extracted from the Victorian CP register for birth years 1983-2009. Annual CP rates per 1000 neonatal survivors were plotted for groups dichotomised on gross motor function, motor laterality, intellectual impairment, epilepsy, and gender, for the entire CP cohort and by grouped birth gestation. Regression modelling was used to fit prediction curves for visual inspection of temporal trends, and likelihood ratio tests were used to test for differences in trends between groups.

**Result.** From the mid-1990s, overall CP rates in Victoria declined. There was strong statistical evidence for a difference in rate trajectories between subgroups stratified on gross motor function ( $p=0.004$ ), motor laterality ( $p<0.001$ ), epilepsy ( $p<0.001$ ), and intellectual impairment ( $p<0.001$ ). Visual inspection of the modelled curves for each birth gestation group saw relatively greater declines in CP rates for the more severely affected and/or complex subgroups at birth gestations from 28 weeks. More dramatic declines in rates of CP for males compared to females were observed in neonatal survivors of birth between 28 and 36 weeks but there was no overall gender difference in rate trajectories.

**Conclusion.** Declines in rates of CP of all levels of severity and complexity from the mid-1990s provides 'real-world' support for the effectiveness of neuroprotective strategies and innovations in perinatal management, some of which may be gender specific.

## **From childhood to adulthood: what care management for individuals with cerebral palsy?**

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### **BACKGROUND**

There is a lack of data available about the evolution of care management according to age in children and adults with cerebral palsy, especially during transition from childhood to adulthood.

### **AIM**

The aim of this study was to describe and compare the medical and paramedical cares of cerebral palsied patients according to age.

### **METHOD**

970 self-administered questionnaires interviewing about medical and rehabilitative treatments, at the moment the participants were interviewed, were sent through a Breton (French) network of professionals involved in the management of children and adults with cerebral palsy. The frequencies of the different treatments were analyzed using six age groups and in "walking" and "not walking" patients. A multivariate logistic regression test evaluated whether there was an increase or decrease of cares with age.

### **RESULTS**

53% (282 adults / 230 children) of the patients responded. Results showed, regardless to the functional level, that drug consumption (psychotropic and painkillers especially) was more prevalent with age. Conversely the rehabilitative care (orthoses, follow up by a physiatrist or rehabilitation therapists) were less prevalent with age. Other treatments were not influenced by age such as botulinum toxin injections which were as frequent at 5 yo than at 40 yo. There was also a significant decrease of the frequencies of orthoses, follow up by a physiatrist and occupational therapist at the age of the transition from childhood to adulthood (12-17 yo).

### **DISCUSSION**

Despite cares that naturally change according to the specific needs of each age group, the large reduction of specific rehabilitative therapies, especially when patients reach adulthood, reinforces the idea of a break in access to care during the transition to adult services. The knowledge brought by this study would help in building recommendations for transition consultation and in setting up longitudinal studies.

## **Effects of twin-births on IQ, handedness and brain volumes in 8-years-old preterm born twins and matched singletons: a pilot study**

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### **Background**

Children born preterm have a high prevalence of long-term cognitive and behavioral disturbances. Still, studies of how preterm-twin-births may effect brain maturation and thus, contribute to long-term effects on brain-behavioral development and functions are rare.

### **Aim**

To investigate whether brain volumes differ between twin (TPB) and singleton preterm born (SPB) and full-term born children (FTB) and associate to long-term cognitive and behavioral outcomes as well as to gestational age (GA), birth weight (BW) and head circumference (BHC) at birth.

### **Method**

A sample of 22 twin born preterm (Mean GA=32.1, BW=1781), 23 matched singletons preterm (Mean GA=31.8, BW=1751), and 22 full-term singletons were included. All children were investigated by means of their cognition functions (WISC-IV), handedness performance index and brain volumes (3Tesla MRI) at early school ages (M=7.8 years) in 40 children (9 TPB, 10 SPB, 21 FTB).

### **Result**

The FTB-children performed better than both TPB and SPB on cognitive performance, and showed higher IQ. Brain volumes, especially Gray matter were stronger associated with IQ in the twins. Furthermore it was found that the SPB singletons had smaller Total Brain volume and less Grey Matter than FTB. The twins showed a higher prevalence of non-right handedness associated to GA, than both SPB and FTB. Independently of birth status, GA, BW and BHC were found to correlate positively with IQ, Total Brain volume, and Gray- and White matter volumes.

### **Conclusion**

Discordant handedness in TPB children and associations to lower GA indicate effect of twin-births on early functional laterality. The overall associations found between low GA/BW and smaller BHC at birth in preterm born and associations with lower IQ and smaller brain volumes at 8-y indicate that a very preterm birth are a higher predictor for long-term effects on brain development and cognitive performance than twin-birth per se. Note; small sample size speaks for further, expanded studies.



## **Poor description of upper limb therapies in cerebral palsy: what were they really testing?**

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**Background:** Incomplete description of interventions in randomized trials impacts the uptake of therapies with proven efficacy into practice.

**Aims:** To evaluate the completeness of reporting of research and control/comparator interventions in trials of upper limb therapies for children with unilateral cerebral palsy.

**Method:** Sixty randomized trials were included encompassing 60 research and 69 control interventions. Using the 12-item Template for Intervention Description and Replication (TIDieR) checklist, two reviewers independently rated intervention and control descriptions by assessing the primary trial report and published protocols.

**Results:** Procedures were adequately reported for 57% of research and 28% of control interventions. Materials used in the research interventions (e.g. home programs, splints) were mentioned in 94% of trials, yet only 23% provided sufficient details to access/replicate all the materials. Training materials for intervention providers were used in 37% of trials, 10 studies (17%) had procedure manuals, yet only 3 reported details to access materials. Sufficient detail about location of where intervention was provided was included for 80% of research and 33% of control interventions. More than one clinician provided the research intervention in 60% of trials, yet intervention fidelity was assessed in only 40% of trials.

**Conclusion:** Few research interventions were described with sufficient detail to enable replication of the intervention, with crucial details missing in many. Materials required for intervention delivery was the most poorly reported. Even poorer reporting occurred for control interventions. Lack of comprehensive reporting of interventions contributes to worldwide waste in research funding and potentially limits uptake of research findings in clinical practice. The TIDieR checklist and guide is a potential solution and makes it easier to structure accounts of interventions.

## **Children with severe motor impairment: assessment of functional visual skills underpinning communication and interaction**

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### **BACKGROUND**

Children with severely restricted movement and vocalisation are often encouraged to make choices or communicate through use of controlled gaze. Functional visual skills in this group refer predominantly to the active use of gaze and gaze shifts to inspect and select targets and to signal choice, establish shared attention and to transmit shared meanings to a communication partner. Previous work by our group has demonstrated that gaze behaviour may not be systematically described or observed by therapists working with such children.

### **AIM**

To describe the development and use of a new, simple assessment of functional gaze control for use with non-speaking children with severe cerebral palsy

### **METHOD**

Teachers referred children with cerebral palsy, GMFCS IV/V, receptive language level of at least 12 months, and without severe visual impairment. 65 children were referred; 41 children meeting inclusion criteria were assessed. Parents were invited to complete a functional visual skills questionnaire. The child's capacity to establish fixation on a single target, to shift fixation between two targets in competition and non-competition situations, and to follow a moving target, was observed.

### **RESULTS**

Performance varied with some demonstrating marked difficulties with fixation and/or tracking. Some children were inappropriately referred, with vision too poor to engage in testing. The ability to establish, sustain and shift fixation could be easily established using simple assessment materials. The strength of agreement for inter-rater and test-retest reliability was good and excellent across observations of gaze control ( $k=0.4 - 0.97$ ; Cohen 1968).

### **CONCLUSION**

Functional gaze control can be assessed by non-vision specialists. Structured history taking of functional visual skills with parents sometimes yields descriptions that match direct observations, but for others a discrepancy between reported and observed skills is noted, which requires further investigation.

## **What do pediatric pain tools really measure?: content analysis using the International Classification of Functioning, Disability and Health**

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**Background:** Pain is an important factor that affects functioning and quality of life of children and youth with Cerebral Palsy (CP). Prevalence of pain in pediatric studies in CP, ranges from 14% to 73%. However, pain in CP is under recognized, and nowadays there is no consensus on how to assess pain in this population.

**Aims:** To identify measures used to address pain in children and youth with CP, and to characterize the content of each measure using the International Classification of Functioning, Disability and Health (ICF) and the ICF Core Sets for children and youth with CP.

**Methods:** Systematic review. Inclusion criteria: studies on children and/or youth with CP and interventional or observational studies published in English (1998-2013). All generic measures addressing pain and all pain-specific measures were retrieved. Construct of the measures were linked to the ICF by two trained professionals. Subsequently, the content of each multiple-item measure (i.e. questionnaires) was analyzed using the ICF.

**Results:** Overall, 80 multiple-item measures were identified of which only 18% contained a pain-related domain. Primarily, measures covered the ICF components of body functions (60%). Few measures covered the components of activities and participation (20%) and environmental factors (2%). Sensation of pain, pain intensity and pain location were the most frequent areas represented by the measures.

**Conclusions:** This study describes, for the first time, the content of all pain-related measures used in studies with children and youth with CP using a common framework, namely the ICF. This information provides a clear representation of the content of each measure. Our findings show that the majority of the pediatric pain-related measures address pain intensity and pain location as opposed to functional impact of pain in everyday activities. Thus, a combination of measures is warranted in order to address the multidimensional impact of experiencing chronic pain.

## **The natural history of Duchenne Muscular Dystrophy with corticosteroids using the Motor Function Measure**

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**Objective:** Monitoring evolution of motor function in patients with Duchenne Muscular Dystrophy (DMD) treated by corticosteroids (CS) in comparison with untreated patients and to study the responsiveness of Motor Function Measure (MFM) as outcome measure in this population, and provide estimations of the number of patients with DMD needed for clinical trials to prove the effectiveness of a given drug. **Design:** observational, retrospective, multicenter cohort study. **Participants:** A total of 74 patients with DMD, aged 5.9 to 11.8 years, with at least 6 months of follow up and 2 MFM were enrolled for a 24 months period, 29 in the CS treated group ( $8 \pm 1.5y$ ) and 45 in the untreated group ( $7.91 \pm 1.50y$ ). **Main Outcome Measures:** the relationship between MFM scores and age was studied in two separated group. The evolution of these scores was compared between groups, on a 24 months period by calculating slopes of change. Standardized response mean was used to study responsiveness of the MFM. **Results:** At 6, 12 and 24 months, significant differences in the mean score change were found, for all MFM scores, between CS treated patients and untreated patients. For D1 subscore specifically, at 6 months, the increase is significant in the treated group ( $12.6 \pm 15.5 \%/y$ ; SRM 0.8) while a decrease is observed in the untreated group ( $-17.8 \pm 17.7 \%/y$ ; SRM 1). At 24 months, D1 subscore stabilized for treated patients ( $-4.8 \pm 7.6\%/y$ ; SRM 0.6) but declined significantly for untreated boys ( $-18.8 \pm 7.1 \%/y$ ; SRM 2.6). 23 patients lost the ability to walk during the study: 7 in the CS treated group (25% at 24 months, mean age:  $10.62 \pm 1.18y$ ) and 16 in the untreated group (64.71% at 24 months, mean age:  $9.20 \pm 1.78y$ ). **Conclusions:** Patients with DMD treated by CS present a different course of the disease described in this paper using the MFM. Based on these results, an estimation of the number of patients needed for clinical trial could be done.

## **The Relation Between Postural Control, Quality of Upper Extremity Motor Skills and Gross Motor Function in Early-aged Spastic Quadriplegic Cerebral Palsy**

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**Background:** Motor functions are affected by several reasons as tone changes, joint limitations, deficiencies of trunk control in children with CP. In literatur, the number of research related postural control and upper limb function about quadriplegic children with CP especially in the early years (18 months-5 years) is limited.

**Aim:** The purpose of this study; investigate the relationship between postural control, gross motor functions, quality of upper limb skills in early age period (18 months-5 years) of children with spastic quadriplegic.

**Method:** 41 children with spastic CP [mean age:44.04±11.3, girls:21(51.2%), boys:20(48.8%)] included this study. According to gross motor functional level (GMFCS) 21 was in Level III and 20 was in Level IV. Gross motor function were assessed with Gross Motor Function Measurement (GMFM), postural control with Early Clinical Assessment of Balance (ECAB) and upper limb motor function with Quality of Upper Extremity Skills Test (QUEST). Spearman rank correlation was used to evaluate GMFM, ECAB and QUEST scores.

**Result:** The median of GMFM lying subparameter was 100(80.39-100), sitting was 73.33 (31.66-100), kneeling and crawling was 26.19(0-92.85), standing was 5.12(0-56.41), walking-stairs was 5.55(0-31.94) and total, 44.62(23.19-72.09). Median score of ECAB for Part 1 was 28(14-36), part 2 was 0(0-11); total 32(14-45)] and median of QUEST for dissociated movements was 71.87(25-100), grasps was 61.66(11.11-92.59), weight bearing was 69.44( 16.66-100), protective extension was 61.11(11.11-100), total was 66.11(11.80-94.90). There were significant high correlation between QUEST, GMFM ( $r=0.732, p<0.001$ ) and ECAB ( $r=0.688, p<0.001$ ).

**Conclusion:** This study showed that there were significant correlation between quality of upper limb abilities and postural control in early period of children with spastic quadriplegic CP. When postural control is improved, quality of upper limb abilities are increased in children with spastic CP.

## **Effect of CareToy Early intervention on visual development in preterm infants**

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**Background.** CareToy System (CT) is a new technological tool, inspired by baby gyms, that allows to provide a tele-monitored, intensive, individualized, highly flexible, home-based and family-centred EI in preterm infants (Clinical Trial.gov NCT01990183) based on the concepts of enriched environment. A RCT study was recently carried out to provide evidences that CT intervention, compared to standard care (SC), is useful to promote neurodevelopment (e.g. motor, perceptual development) in low-risk preterm infants (Sgandurra et al, 2014) evaluate the effects of CT intervention on neurodevelopmental outcomes (e.g. motor, perceptual and cognitive) in low-risk preterm infants.

**Aim.** The present study aims to evaluate the effects of CareToy intervention on visual development in preterms involved in the RCT study.

**Method.** 44 preterm infants were enrolled and randomized in two groups (CT and SC). 22 infants randomized in the CT group performed 4 weeks of CT training, while 22 infants allocated in SC group performed SC. Teller Acuity Cards, chosen as one of secondary outcome measures, were carried out at baseline (T0) and at the end of CT training or SC period (T1, primary endpoint) by scorers blind to the infant's allocation.

**Result.** A significant ( $p<.05$ ) improvement of visual acuity in the CT group versus SC was found. Moreover positive correlation between changes in Teller and CT training in hours was found (T0-T1:  $p=.009$ ).

**Conclusion.** These data show that the EI delivered at home thanks to new technologies (tele-rehabilitation) could represent a valid approach to provide an enriched environment with positive effects on visual development. Further studies on preterm infants at high risk are needed. This work was supported by CareToy EU project - GA: 287932; 7FP, ICT-2011-7.

## **Neuropathic pain following a single event multilevel lever arm restoration antispasticity surgery for children with cerebral palsy**

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### **BACKGROUND**

Neuropathic pain which usually follows a tissue injury is a complication following Single Event Multilevel Surgery for children with cerebral palsy (CP).

### **AIM**

The aim of this study was to estimate the prevalence and describe the clinical features, risk factors and outcome of treatment of neuropathic pain among children with CP following Single Event Multilevel Lever Arm Restoration Anti Spasticity Surgery (SEMLARASS).

### **METHODS**

A prospective study was done among 500 children with CP who underwent SEMLARASS by a single Orthopaedic Surgeon from the year 2010 to 2015. Children with complaints of pain, burning sensation, numbness, inability to bear weight and dysesthesia were assessed for neuropathic pain and were treated by a standardized rehabilitation protocol including sensory desensitization, myofascial release, aquatic therapy, proprioceptive neuromuscular facilitation, EMG Biofeedback and TENS for 1 to 2 hours per day for 6 per week for 2 weeks. The outcome measure used was the VAS scale.

### **RESULTS**

A total of 81 children (mean age of 13.66 years) were diagnosed to have neuropathic pain (16.2% of the total). The regions involved were plantar aspect of foot (n=37, 45.67%), lateral aspect of thigh (n=25, 30.86%), and lateral aspect of tibia (n=19, 23.45%). Of these 3 children received a diagnosis of Type 1 Complex Regional Pain Syndrome according to the Budapest criteria. The risk factors for neuropathic pain included older age (> 8 years), severe cerebral palsy (GMFCS levels 4 and 5), longer duration of plaster immobilization (> 6 weeks), previous chemodenervation using Phenol injections and neurosurgical procedures. 72 persons recovered completely following the rehabilitation. There was a significant difference between the baseline and outcome scores of VAS ( $P < 0.01$ ) for neuropathic pain.

### **CONCLUSION**

Neuropathic pain is a common complication following SEMLARASS, and the protocol based rehabilitation was found to be effective for its treatment.

## CP2: Community Partners for Children's Participation

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**Background:** Children with Cerebral Palsy (CP) participate less in community life and leisure activities than their peers. Socio-political factors in given geographic areas may be linked to participation levels.

**Aim:** To identify socio-demographic and policy-related indicators of participation of children with CP in the community, and to explore trajectories of participation and community access that can contribute to shape policy-community interventions.

**Method:** This study used mixed methods and a Participatory Action Research (PAR) approach. 100 persons (5-21) registered in the Quebec CP registry were recruited using stratified randomized sampling based on material and social deprivation index quintiles and GMFCS levels. Parents responded to questionnaires on their socio-demographics, existing policies and programmes, and their perceived usefulness. Participation levels and environmental barriers were measured using the Participation and Environment Measure for Children and Youth (PEM-CY). Contextual factors associated with participation levels were modelled to identify environmental indicators that can be modified to promote participation for children with CP.

**Results:** Policies and programs implemented may facilitate community participation for children, but continued enforcement and provision of these programs is necessary. Environmental factors such as accessible play areas, disability awareness, and adapted transportation are important indicators of participation. Social and material deprivation are mediators in participation levels. Barriers encountered at various levels discourage families and deprive children from participation that is crucial for development and well-being.

**Conclusion:** Interventions promoting children with CP's participation should target macro level changes and consider environmental factors such as policies and social deprivation. Population level changes can cost-effectively promote equal access to participation for children with CP.



## **Proximal Femoral Osteotomy in Children with Cerebral Palsy: The Effect of Age, Gross Motor Function Classification System Level and Surgeon Experience on Surgical Success**

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**Background:** Spastic hip displacement is the second most common musculoskeletal deformity in children with cerebral palsy (CP).

**Aim:** The purpose of this study was to evaluate mid-term results of proximal femoral varus derotation osteotomy (VDRO) in children with cerebral palsy and determine what effect age, Gross Motor Function Classification System (GMFCS) level, surgeon volume and preoperative radiographic measures of hip displacement have on survivorship.

**Methods:** We analyzed a cohort of children with CP undergoing VDRO for hip displacement between 1994 and 2007. Patient, surgical and clinical variables were recorded. Results were analyzed via univariate and multivariate analysis for association with the need for revision hip surgery. Kaplan-Meier survivorship curves were generated determining time from index surgery to "failure," defined as the need for subsequent surgical procedures on the hip/pelvis, stratified according to revision of bone versus soft tissue.

**Results:** A total of 566 VDROs were performed on 320 children (mean age 8 years (std 3.3years). Mean follow up was 8.3 years (3-18). Of the initial 320 patients, 117 patients (37%) were considered failures. Multivariate Cox regression analysis confirmed that age at surgery ( $p<0.001$ ); GMFCS ( $p=0.01$ ) and annual surgical hip volume ( $p=0.02$ ) were significant independent predictors of any type of surgical revision, furthermore soft tissue surgery at VDRO was protective against revision ( $p=0.02$ ). Five-year survivorship analysis revealed a 92% success rate for GMFCS I/II children compared to a 76% success rate for GMFCS V children ( $p<0.01$ ).

**Conclusion:** This study demonstrates a 37% revision rate after VDRO in children with CP. Older age, lower GMFCS and increased surgeon volume are strong predictors of surgical success; illustrating the challenge of hip surgery in children with cerebral palsy as younger children, with greater disease, experience the highest revision rates after VDRO.

## **Interrater Reliability of Pelvic Obliquity Measurement Methods in Patients with Neuromuscular Scoliosis**

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### **Background:**

Neuromuscular scoliosis (NS) is a common complication of disease processes which cause abnormal development of the myoneural pathways. It is characterized by rapid progression, often causing pelvic obliquity.

Complications of pelvic obliquity can be quite serious including low back pain, discomfort with sitting, pressure ulcers, and necrosis of the ischial tuberosity requiring fixation to avoid life threatening comorbidities and diminished quality of life.

### **Aim:**

This study is the evaluation of reliability of 5 methods commonly used to determine pelvic obliquity in the frontal plane.

### **Method:**

Radiographic images of 55 patients with NS involving the pelvic girdle were identified and evaluated by a team of 5 raters. The team was made up of 4 Pediatric Orthopedic Surgeons and 1 Orthopedic Surgery resident.

Statistical analysis was completed using intraclass correlation coefficient.

### **Result:**

The data results of the 5 methods of measuring pelvic obliquity by intraclass correlation coefficient produced reliability values of 0.846 for Maloney method, 0.753 for O'Brien method, 0.782 for Osebold method, 0.594 for Allen and Ferguson method, and 0.638 for Lindseth method.

### **Conclusion:**

We conclude that when multiple evaluators are establishing pelvic obliquity on an anteroposterior radiograph, the Maloney method should be used. Other methods evaluated in this study were found not as reliable.

## **Trends in prevalence and characteristics of Cerebral Palsy among Icelandic children born 1991 to 2010**

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**Background:** In Iceland, all preschool children with cerebral palsy (CP) are comprehensively evaluated by a multidisciplinary team at one central developmental centre.

**Aim:** To study the prevalence and characteristics of CP among children born during two time periods; 1991 through 2000 (period one) and 2001 through 2010 (period two).

**Method:** Population-based study using systematically collected data on motor functioning and associated impairments of children with congenital CP. Children who died before two years of age were excluded. Mild disability was defined as motor skills at GMFCS levels I-II or IQ/DQ  $\geq 50$  and severe disability as motor skills at GMFCS levels III-V or IQ/DQ  $< 50$ . Mean age at assessment was 5.3 years in both periods.

**Result:** In all, 186 children with CP were identified (107 born in period one and 79 born in period two). Prevalence of CP decreased from 2.45 in period one to 1.77 in period two per 1000 live births (LB) ( $p=0.03$ ). The decline among children born at 28 to 36 weeks gestation (22.7 to 12.3 per 1000 LB) was statistically significant ( $p=0.008$ ) while among extremely preterm (97.0 to 78.3 per 1000 LB) and full term births (1.2 to 0.95 per 1000 LB) it did not reach statistical significance. CP subtypes changed ( $p=0.055$ ) over time whereby the proportion of children with bilateral spastic CP decreased from 59% to 51%, the proportion with unilateral spastic CP decreased from 28% to 23% while the proportion with dyskinetic CP increased from 7.5% to 20%. Half (52%) of the children born in period two had severe disability compared with 41% in period one ( $p=0.145$ ).

**Conclusion:** While the prevalence of CP in Iceland was stable from the 1950s to 1990s, we have observed for the first time a clear decline during the last twenty years. However, the severity of the condition as judged by limitations in movement and intellectual abilities did not decrease. The latter finding may be consistent with changes in proportions of children with various CP subtypes.

## **Developmental trajectories of self-care capabilities among children and adolescents (1-16 years) with cerebral palsy**

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**BACKGROUND** Scarce information exists about the development of basic self-care capabilities (e.g. eating, washing, dressing) among youth with cerebral palsy (CP). Therefore, we need developmental trajectories for children and adolescents with various severity levels of CP, based on a large longitudinal dataset. **AIM** To describe developmental trajectories of self-care capabilities among children and adolescents (1-16 yrs) with CP, by severity levels. **METHOD** This study concerned an analysis of data from a prospective longitudinal research in The Netherlands (PERRIN). The dataset included 321 individuals with CP, aged 1-13 yrs at study onset, who were measured annually over a period of 2-4 yrs. Severity levels according to the Gross Motor Function Classification System (GMFCS) were 50% Level I, 15% Level II, 12% Level III, 11% Level IV, and 12% Level V. Self-care capabilities were assessed with the Functional Skills Scale of the Pediatric Evaluation of Disability Inventory (PEDI-FSS). The developmental trajectories for self-care capabilities over age were analysed using multilevel modelling. **RESULTS** Based on a total of 995 PEDI observations, developmental trajectories were created for each of the five GMFCS levels. All trajectories were characterized by increase in PEDI-FSS self-care scores over age, which was best described using a quadratic model. Significant interactions between GMFCS level and age were found, indicating less favourable trajectories for individuals in GMFCS level IV and V. Individuals in GMFCS level I, II and IV reached a ceiling at age 12 yrs, while individuals in GMFCS level III and V did not show a ceiling between 1 and 16 yrs. **CONCLUSIONS** This study provided developmental trajectories of self-care capabilities for individuals (1-16 yrs) with different severity levels of CP. The trajectories add to the existing knowledge and can be used in clinical practice as a reference for individuals with CP, their families and health care providers.

## **The effectiveness of a running group program in children with a neurological condition**

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**Background:** Children with a neurological condition often suffer from physical symptoms that impede acquisition of high level mobility skills and therefore limit participation in home, school and community life. Emerging evidence supports running intervention in children and adults with a neurological condition.

**Aim:** To evaluate the effectiveness of a running group program on high level mobility, endurance and agility in children with a neurological condition.

**Method:** 20 children; mean age 11 years 7 months, SD 2 years 0 months; n=10 females, n=10 males; n=10 with mild cerebral palsy (CP) and n=10 non-CP neurological condition were randomised to Running or Control Group. During the six week intervention phase, the Running Group participated in a twice weekly running group program while the Control Group underwent usual care. Running Group is individually tailored, child-friendly and based on achieving the biomechanical demands of running. Outcome measures included High level mobility assessment tool (HiMAT), Shuttle run test and 10x5m agility test. Assessments were completed before, directly following and eight weeks following the intervention phase by a blinded assessor. Raw data were analysed using independent and paired t-tests.

**Results:** There was no significant difference between the groups at baseline or following the intervention phase. The Running Group mean change for high level mobility (HiMAT) was an improvement of 6.1 (SD 5.2) and running speed was an increase of 0.37m/sec (SD 0.44) compared to the Control Group mean HiMAT change of -0.8 (SD 2.2) and -0.19 m/sec (SD 0.44) speed. Although these changes did not reach statistical significance, 7/10 of Running Group participants made significant improvements in high level mobility while none in the Control Group did.

**Conclusion:** Children with a wide range of neurological conditions can participate in this relatively short, group based running program and make improvements in high level mobility skills.

## Assessment of cognition in children with severe CP

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**Background:** Children with CP are at risk of cognitive impairments. Degree of motor and cognitive impairments correlate, but not all children with severe motor impairments have cognitive impairments. This is often not well documented, as it is considered challenging to accurately assess cognition in children with poor control over limb movements.

**Aim:** To a) describe a method of neuropsychological assessment with eye gaze pointing on standardized tests of cognition that allows for assessment of children with severe speech and motor impairments, and b) present results from such assessment for a geographical sample that includes children with severe speech and movement impairments.

**Method:** Seventy-three children with CP of various degrees of severity were assessed with cognitive tests. Mean age was 9;10 years (range 5;1–17;7), and 39 were girls. Test items were presented on computers with technology to monitor eye gaze. Motor functioning was classified according to the GMFCS.

**Results:** Eighteen of the 73 children had GMFCS levels IV and V. GMFCS level explained 17.7% ( $p=.000$ ) of the variance in overall cognitive functioning. Nine of the 18 (50%) had an intellectual disability. The mean IQ was significantly lower in the group with GMFCS levels IV-V ( $F(2,70)=10.349$ ,  $p=.000$ ) than in the group with GMFCS levels I-III, mainly due to a subgroup of seven children who had severe cognitive challenges. The rest of the group scored similar to children with less severe motor impairments on tests of working memory ( $F(2,57)=1.334$ ,  $p=.272$ ), memory ( $F(2,44)=0.364$ ,  $p=.697$ ) and executive functioning ( $F(2,49)=0.632$ ,  $p=.536$ ).

**Conclusion:** A comprehensive neuropsychological assessment is possible even if children have severe motor impairment, if their overall level of cognitive functioning permits such assessment. It is important to perform adapted neuropsychological assessment as this may reveal cognitive strengths in children with severe motor impairments.

## **Intrathecal baclofen: Impact at all levels of the ICF for children with severe dyskinetic cerebral palsy**

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**Background:** Intrathecal baclofen is an established and effective intervention for children with both spastic and dyskinetic presentations of cerebral palsy. Many studies report the effectiveness of ITB therapy at the Body Function and Structure level of the ICF with fewer studies reporting the effects at the Activity and Participation ICF levels.

**Aim:** This retrospective study investigates the effectiveness of ITB therapy at all levels of the ICF.

**Method:** Convenience sample (N=10) from a prospective, longitudinal, clinical audit. Mean age at implant 14y (SD1.5); 60% males; 100% bilateral involvement CP, predominant motor type dystonia; GMFCS levels (V=4, IV=6); MACS (V=3, IV=5, III=2) and CFCS (V=1, IV=3, III=4, II=1, I=1). Outcome measures included: Canadian Occupational Performance Measure (COPM); Goal Attainment Scaling, Caregiver Priority and Child Health Index of Life with Disabilities (CPCHILD), Care and Comfort Hypertonicity Questionnaire, Barry Albright Dystonia Scale (BAD) and Modified Ashworth Scale. Clinical outcomes were collected at baseline, 6, 12 months and yearly following pump implant.

**Results:** At 12 months following implant all participants demonstrated statistically significant positive change in all quality of life outcomes across all domains (CPCHILD  $p<0001$ ). Mean change in COPM Performance scores was 2.4 (SD1.8)( $t=4.28$ ,  $p<.002$ ) and COPM Satisfaction scores 3.5(1.9)( $t=5.97$ ,  $p<.0001$ ). BAD scores dropped from a mean of 23.2 (SD4.2) to 21 (5.2)( $p<.05$ ).

**Conclusion:** In the more severely effected cohort of children with dyskinetic CP undergoing ITB therapy, individualised goal attainment, improved quality of life and decreased caregiver burden are important outcomes in addition to the body function and structure reductions in spasticity and dystonia. Data from this small convenience sample illustrates the functional consequences of ITB therapy for children and their families.

## **Early mobilisation by locomotion therapy following minimally invasive multi-level surgery for children and young adults with cerebral palsy**

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**Aim:** This study compares the outcomes of locomotion therapy following minimally invasive single-event multi-level surgery with conventional mobilisation following conventional single-event multi-level surgery.

**Method:** A retrospective study of two groups was undertaken. 32 children and young adults with bilateral spastic cerebral palsy GMFCS II-IV with a mean age of twelve years and three months (5.4 to 21.2) had multi-level minimally invasive surgery following early verticalisation, full weight bearing, and locomotion therapy from day 3 (1 to 5) postoperatively. They were provided by ankle foot orthoses at the same day and underwent a rehabilitation program by 3,5 (2 to 5) weeks postoperatively. This group was compared with 30 children and young adults with a mean age of twelve years and six months (6.9 to 20.8) who had conventional single-event multi-level surgery, conventional osteotomies, following short leg casts and a conventional step by step rehabilitation program including standing and walking exercises by 6,8 (4 to 11) weeks postoperatively. Goal attainment scale, isometric muscle strength and gross motor function were assessed before and 12 months after interventions. Postoperative pain has been measured by visual analog scale.

**Results:** The early mobilization group had significantly less pain, significantly improved muscle strength as well as gross motor function, and significantly improved GAS outcome. Minimally invasive surgery provided reduced operation time and blood loss with a significantly improved time to mobilisation. There were no complications intraoperatively or during rehabilitation in either group.

**Conclusion:** We consider that early mobilisation by functional orthoses and locomotion therapy following minimally invasive single-event multi-level surgery can be achieved effectively and safely with significant advantages over conventional surgical and rehabilitation techniques in children and young adults with bilateral cerebral palsy.



## **THE 10,000 FOLD EFFECT OF RETROGRADE NEUROTRANSMISSION-A NEW CONCEPT FOR CEREBRAL PALSY REVIVAL: USE OF NITRIC OXIDE DONARS (INTRATHECAL SODIUM NITROPRUSSIDE AND ORAL TADALAFIL)**

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NITRIC-OXIDE-DONORS (NODs) (Intrathecal Sodium Nitroprusside (IT SNP) and oral tadalafil) studied here. proposes three mechanisms for cerebral palsy cases, for swift physiological recovery.

### **a) RETROGRADE NEUROTRANSMISSION:**

1) Normal excitatory impulse: at the synaptic level, glutamate activates NMDA receptors, with nitric oxide synthetase (NOS) on the postsynaptic membrane, for further propagation by the calcium-calmodulin complex. Nitric oxide (NO, produced by NOS) travels backward across the chemical synapse and binds the NO receptor at presynaptic neuron, regulating anterograde neurotransmission (ANT) via retrograde neurotransmission (RNT). Heme is the ligand-binding site of the NO receptor. Heme exhibits > 10,000-fold higher affinity for NO than for oxygen (the 10,000-fold effect).

2) Pathological: normal synaptic activity, including both ANT and RNT, is absent. NO donors release NO from NOS at the postsynaptic region generates an impulse, same as under normal conditions.

### **b) VASOSPASM:**

Perforators show vasospastic activity reversed by NOD.

### **c) LONG-TERM-POTENTIATION (LTP):**

At many synapses for memory/learning.

**MATERIAL AND METHOD:** Case-control prospective study. 60 random CP (30 control without NOD or with 5% dextrose superfusion, and 30 patients comprised the NOD group in which ITSNP and oral tadalafil 1.5 mg per kg/bo/wt per alternate days for 3 months was given). Mean age 3.75 yrs. Monitored by Gross Motor Function Measure-66 (GMFM-66) with videography.

**RESULT:** the mean increase in GMFM-66 at Post 7 days (37.29%) and 3 months (37.15%) in the NOD group, than control-group increase of 0% at 7 days or 3 months.

**CONCLUSION:** NOD (ITSNP boosts up the recovery and oral tadalafil maintains the recovery) acts swiftly in the treatment of CP.

**KEYWORDS:** CEREBRAL PALSY; INTRATHECAL SODIUM NITROPRUSSIDE; ORAL TADALAFIL; PERFORATORS; VASODILATIONS; RETROGRADE TRANSMISSION; THE 10,000-FOLD EFFECT; LONG TERM POTANTiation.

## **Risks for neurodevelopmental disorders or perinatal death in siblings of children with cerebral palsy**

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### **Background**

The causes of cerebral palsy and other neurodevelopmental disorders are poorly understood.

### **Aim**

To explore whether cerebral palsy and other disorders share underlying causes by examining risks of developmental problems in siblings of children with cerebral palsy.

### **Method**

The Medical Birth Registry of Norway comprises more than 2.5 million births from 1967 to 2010. We identified 1.5 million pairs of full siblings (singletons) and 32,000 sets of twins. We used national registries to identify stillbirths and early deaths, and to find diagnoses of cerebral palsy, epilepsy, intellectual disability, autism spectrum disorders, attention deficit hyperactivity disorder, blindness, deafness, schizophrenia, and bipolar disorder. Associations between cerebral palsy in one sibling and neurodevelopmental disorders in other siblings were estimated using logistic regression models.

### **Result**

There were 6109 children with cerebral palsy (2.4/1000). As expected, these children had substantial comorbidity (e.g. 29% had epilepsy). Siblings of cerebral palsy children had increased risk of neurodevelopmental problems, including epilepsy (odds ratio (OR) 1.9; 95% confidence interval 1.5-2.3), intellectual disability (2.3; 1.8-3.0), autism spectrum disorders (1.6; 1.2-2.3), attention deficit hyperactivity disorder (1.3; 1.1-1.6), blindness (2.2; 0.97-5.0), and schizophrenia (2.0; 1.2-3.2). There was no increase in risk of bipolar disorder (1.0; 0.6-1.6). Families with cerebral palsy children also had increased risk of stillbirth (1.9; 1.5-2.3) and neonatal death (1.7; 1.3-2.2). All associations were stronger within sets of twins.

### **Conclusion**

Parents with a cerebral palsy child are at increased risk for a variety of other neurodevelopmental morbidities, or early death, in their other children, indicating the presence of shared underlying causes.

## **Two wheel bike riding ability in children with ambulatory cerebral palsy: a case control study**

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**Background:** Bike riding may be a way to increase participation in physical activity in children with cerebral palsy (CP). Limited information exists on the ability of children with CP to ride a two wheel bike.

**Aim:** Primary aims were to determine the proportion of children aged 6-15 with CP (Gross Motor Function Classification System (GMFCS) levels I and II) able to ride a bike, probability of skill acquisition at each age and age at skill acquisition, compared to typically developing (TD) children. Secondary aims were to examine variables associated with ability to ride, and barriers and facilitators encountered when learning to ride, in both groups.

**Method:** Parents of 114 eligible children with CP recruited through a CP register and parents of 87 TD children completed an online survey. Questions related to child and family characteristics, riding ability, age at skill acquisition and facilitators and barriers. Groups were compared using chi-square analysis for proportions, the Kaplan Meier method for probability of skill acquisition, and a Wilcoxon test for age at skill acquisition.

**Result:** A lower proportion of children with CP (GMFCS I-II) were reported as able to ride independently (36.8%) compared to their TD peers (87.4%;  $p<0.001$ ). Children with CP had a lower probability of skill acquisition at each age ( $p<0.001$ ) and those who had learnt to ride, learnt at a later age (CP median=6.4, TD median=5.0;  $p<0.001$ ). GMFCS level, use of a balance bike, parent rated importance of riding and current age were associated with ability to ride in the CP group. Facilitators and barriers included intrinsic personality and extrinsic motivating factors, as well as physical and environmental factors.

**Conclusion:** Results suggest children with CP (GMFCS I-II) can learn to ride a bike, however most do not and skill acquisition is delayed. Knowledge of associated variables, and facilitators and barriers, will assist in developing future bike riding programs in this population.

## **Mini-MACS; development of the Manual Ability Classification System for children with CP below 4 years of age**

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**BACKGROUND:** Functional classifications have shown to be of major importance for the description of the heterogeneous group of children with cerebral palsy (CP). The Manual Ability Classification System (MACS) has successfully been used for children with CP between 4-18 years of age, however there has been a request for using MACS also with younger children.

**AIM:** To describe the development of the Mini-MACS, and to investigate validity and reliability of parents' and therapists' classifications of manual ability of children  $\leq 4$  years.

**METHOD:** Development of Mini-MACS was based on the intention to keep the main concept and structure of the MACS, and on interviews with parents to find relevant descriptors of hand use. Necessary adjustments regarding manual ability to handle objects in children below 4 years of age were performed in a pilot project and by consensus discussions within an expert group. The adjustments resulted in a field trial version of the Mini-MACS, which was evaluated in 64 children, 11-51 months old. The children were classified by one parent and two occupational therapists. Agreements between parents' and therapists' ratings were evaluated using Intraclass Correlation Coefficient (ICC) (2:1), and percentage of absolute agreement.

**RESULT:** For Mini-MACS, only minor adjustments were made to the core sentences of each level while further clarifications were done in the distinctions between levels. The ICC between parents and therapists was 0.90 (95% CI 0.84-0.94) and between two therapists 0.97 (95% CI 0.85-0.98). Both parents and therapists expressed that they found the descriptions in the Mini-MACS useful and easy to understand.

**CONCLUSION:** These initial results indicate that the Mini-MACS can be applicable to classify manual ability for children below 4 years of age. Both parents and therapists can classify the children although the interrater reliability was highest between therapists.

**The Norwegian Physiotherapy Study in Preterm Infants, a randomized controlled study of early intervention: outcome at week 37 postmenstrual age**

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**Background:** Many preterm infants are referred to physiotherapy because of risk for impaired motor development. However, evidence for the effect of physiotherapy conducted before term-equivalent age is sparse.

**Aim:** To investigate effect of physiotherapy conducted before term-equivalent age.

**Method:** A multicentre, pragmatic randomised controlled study with 153 infants, gestational age (GA)  $\leq 32$  weeks, randomised to an intervention (n=74) or a control group (n=79). The intervention aimed at increasing postural control, head control and midline orientation. After being trained by a physiotherapist, the parents performed the intervention 10 minutes twice a day for three weeks from 34 – 36 weeks postmenstrual age (PMA). The control group received care as usual. All infants were assessed by the Test of Infant Motor Performance Screening Items (TIMPSI) at baseline and by the Test of Infant Motor Performance at week 37 PMA. Linear mixed models were used to assess changes between groups. The TIMPSI z-score and GA was used as fixed effect variables, twins and hospital as random effect variables. Effect size post intervention was measured by Cohens d.

**Result:** Mean TIMPSI score at baseline was 27.3 (SD 10.7) in the intervention group and 26.0 (SD 8.7) in the control group. Post intervention mean TIMP score was 53.7 (SD 8.5) in the intervention group and 50.0 (SD 9.7) in the control group. There was significant between group difference from baseline to week 37 PMA ( $p=0.005$ ), effect size 0.40.

**Conclusion:** This study addressing effect of physiotherapy before term-equivalent age is the first study with parents performing the intervention. Parent driven intervention supervised by physiotherapists improved motor function more than conventional care. All infants will be followed by motor assessments until two years corrected age in order to evaluate long-term effects.

## **St Andrew's Children's Clinic: 43 yrs of caring for children with disabilities through bi-national cooperation**

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**Background:** It is well recognized that the care of children with disabilities, even in the best of circumstances, poses a challenge that requires coordination of multiple and, in many instances, costly resources. This challenge is exacerbated in countries, which lack manpower, infrastructure or economic support for their medical delivery systems.

**Aim:** Present a 43-year experience of continuous privately funded bi-national cooperation along the US-Mexico Border.

**Methods:** St Andrew's is a local privately funded secular charitable organization that has provided specialized medical care at a monthly clinic for children living in Mexico that cannot afford or find appropriate medical assistance. The clinic started in 1973, when seven children with cerebral palsy and their mothers gathered in Nogales, Mexico with one orthopedic surgeon from the US.

**Results:** Since its inception the clinic has evolved from an orthopedic clinic to currently include over a dozen disciplines and sees 225-250 visits per clinic while providing a learning environment for future professionals. The program has recently expanded to include a cleft lip/cleft palate program. The clinic operates solely on private funding and donated services and has been able to overcome logistical, economic and political (9-11-2001) uncertainties to continue its' mission.

The success of the clinic lies in the combined efforts of patients, families, donors, local volunteers, medical professionals in both academic and private practice, and governmental approval from both sides of the US -México border.

**Conclusion:** The St Andrews Children's Clinic stands as a notable example of innovative bi-national cooperation.

## **Is working memory associated with explicit learning in children with low motor abilities?**

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**Background:** Children with low motor abilities (e.g., Developmental Coordination Disorder) experience difficulties with learning and executing coordinated movements, leading to problems performing daily activities. Compromised working memory (WM) functioning is a frequent comorbidity in these children. It has been suggested that explicit motor learning might be less effective for these children, as it places a high demand on WM capacity.

**Aim:** The study aimed to investigate if WM capacity affects the effectiveness of explicit motor learning for improving motor skills in children with low motor abilities. Additionally, we assessed to what degree an explicit learning context indeed leads to an explicit learning process in these children.

**Method:** In total, 69 children attending mainstream primary education performed the M-ABC. Based on the scores, 20 children with low motor abilities were identified. These children practiced an aiming task following an explicit motor learning paradigm. Pre-, post- and WM-tests were performed. A verbal protocol and conscious monitoring questions were administered to assess the degree to which learning processes were explicit.

**Results:** Children improved their aiming skill. Regression analyses indicated trends that this improvement was related to spatial WM capacity and conscious monitoring, but these results disappeared when controlling for initial skill levels. Contrary to our expectations, the explicit context did not lead to explicit processes.

**Conclusion:** The children with low motor abilities improved their skills after a short bout of practice. Yet, there were no indications that these improvements were related to the explicit learning context. That is, the expected relation between skill learning and WM capacity was not found, and the children also failed to develop the (expected) declarative skill-related knowledge. These findings will be discussed in light of implicit and explicit motor learning theories

## **A Delphi approach to arrive at European consensus on the concepts and measurement of spasticity**

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### **Background**

To support clinical decision making, physical examination is used to assess spasticity via passive muscle stretch at different velocities. However, what exactly is being assessed is expressed in different ways. A clear diagnostic conceptual framework of the responses to passive muscle stretch is lacking, which hampers communication between clinicians. It is a prerequisite for development of precise assessment using instrumented measures.

### **Aim**

To arrive at unambiguous terminology about the concepts of and phenomena around response to passive muscle stretch and to design the assessment of the conceptual elements.

### **Method**

During 2 consensus meetings, 30 clinicians and researchers from 10 European countries filled online questionnaires based on a Delphi approach (anonymous, 2 rounds, 20 statements, using the Likert-scale), followed by plenary discussion after rounds. Consensus was reached when agreement  $\geq 75\%$ .

### **Results**

The term hyper-resistance should be used to describe the phenomenon of impaired neuromuscular function during passive stretch, instead of 'spasticity' or 'hypertonia'. It is essential to distinguish non-neural (tissue-related) from neural (central nervous system related) contributions to hyper-resistance. Tissue properties consist of elasticity, viscosity and muscle shortage. The neural contributions are velocity-dependent stretch hyperreflexia and non-velocity dependent involuntary background activation. The term spasticity should only be used next to the term stretch hyperreflexia. When joint angle, moment and electromyography are measured, the 3 components of hyper-resistance can be quantitatively assessed.

### **Conclusion**

A conceptual framework of the pathophysiological responses to passive muscle stretch is defined. Components are related to objective parameters from instrumented assessment. After experimental validation, these parameters can be used to develop treatment algorithms that are based on the aetiology of the clinical phenomena.



## **Evaluation of implementing a working method for stimulating physical activity in pediatric physiotherapy**

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**Background:** Regular participation in physical activities (PA) contributes to the development of social and motor skills, and is essential for staying fit and healthy when growing up. Changing the child's PA behavior is difficult. Pediatric physiotherapists (PTs) have indicated they lack the skills to support PA behavioral change. A working method has been developed to facilitate PTs to stimulate PA in pediatric physiotherapy. The method focuses on counseling to support the child's and parents' autonomy with regard to increasing PA, and on transferring of skills to the daily situation.

**Aim:** To determine the effect, barriers and facilitators of implementing the working method 'physical activity stimulation (PAS) in pediatric PT practice'.

**Method:** 13 pediatric PTs followed a 4-month PAS course. Simultaneously they implemented PAS during treatment of a child with a physical disability. Video recordings of treatment sessions at baseline and at six months were analyzed to determine changes in interview style and time talking of child/parents and PT. To determine barriers and facilitators for implementation PTs were interviewed after the PAS course.

**Result:** 10 PTs completed the study. Preliminary analyses showed an improved interview style, increased time of child/parents talking, and decreased time of PT talking. Facilitators were the offered structure (n=10), provided support to stimulate PA (n=10) and autonomy of child/parents (n=9), improved self-confidence of PTs in stimulating PA (n=8), and improved interaction with child/parents. Barriers were the extra expenses, and that the method did not always suit expectancies of child/parents.

**Conclusion:** Preliminary results indicate that the PAS course leads to an improved interview style and foresees in a need among pediatric PTs. Challenges are ahead in improving the expectancies of families with regard to pediatric physiotherapy sessions and to improve the skills of PTs with regard to supporting PA behavioral change.

## **Effectiveness of functional power training on walking ability in young children with cerebral palsy**

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**Background** Strength training programs are commonly used in clinical practice in children with cerebral palsy (CP). Despite increase in strength there is inconclusive evidence of its effectiveness in improving walking ability. Recent studies suggested that strength training with high movement velocity is more effective than traditional resistance training for increasing functional abilities like walking.

**Aim** The aim of this study is to evaluate the effectiveness of resistance training at high velocities in functional exercises (functional power training) on walking ability in young children with CP.

**Method** 15 children with spastic CP (9 bilateral, GMFCS level I (7) and II (8), 7.2 years (4–9 y) participated. A 14-weeks usual care period was compared with a 14 weeks functional power training (in groups, 3x/wk) in a double baseline design. Each training 3 to 4 loaded functional power exercises were performed (at 50-70% of maximum unloaded speed), with a focus on improving push-off.. Outcome measures were the muscle power sprint test (MPST), 1-min walk test (1MWT), 10-m shuttle run test (SRT), gross motor function (GMFM-66), strength of plantar flexor, hip abductor and knee extensor muscles (hand held dynamometer) and parent-reported mobility performance (Mobility Questionnaire (MobQues-28)).

**Results** Improvements during the training period were significantly larger than during the usual care period for all outcome measures ( $P < 0.05$ ), except for knee extensor strength ( $p = 0.07$ ). Large improvements were found during the training period for walking ability (MPST [mean $\pm$ SD]: 22 $\pm$ 23W (76% increase), 1MWT: 12 $\pm$ 17m (17%), SRT: 2.8 $\pm$ 1.7 (42%), gross motor function: 6.1 $\pm$ 3.4%, mobility performance 8 $\pm$ 6% and muscle strength (35-48%), while outcomes remained stable in the usual care period.

**Conclusion** These preliminary results suggest that functional power training is an effective training to improve walking ability in young children with cerebral palsy.

## **Comparing risks of cerebral palsy in births to Australian Indigenous and non-Indigenous mothers**

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### **Background**

In Australia, health outcomes tend to be less favourable among persons claiming Indigenous heritage than in the non-Indigenous. Western Australia's (WA) long-standing Cerebral Palsy (CP) Register has reported consistently higher proportions of CP in the Indigenous population. The three jurisdictions in Australia with the largest Indigenous populations are WA, Northern Territory (NT) and Queensland (Qld). As CP registers in NT and Qld are now considered to have a sufficient level of ascertainment, data from the three registers have been combined to compare the occurrence of CP in their Indigenous and non-Indigenous populations.

### **Aim**

To compare proportions of live births subsequently described as having CP, the distributions of associated impairments and causes of postneonatal (PNN) CP between Indigenous and non-Indigenous populations in Australia.

### **Method**

Data from statutory birth records and CP registers for 1996-2005 birth cohorts in WA, NT and Qld were stratified by Indigenous status and whether the CP was acquired pre/perinatally or postneonatally. Relative risks associated with Indigenous status were estimated and the distributions of causes of PNN CP compared.

### **Results**

Indigenous births had a relative risk of 4.9 (95% confidence interval 3.0, 7.9) for PNN CP but only of 1.42 (95% CI 1.2, 1.7) for pre/perinatal CP. Almost half of PNN CP in Indigenous infants resulted from infection, whereas for non-Indigenous infants the most frequent cause was cerebrovascular accident. The impairments of Indigenous CP and of PNN CP tended to be more numerous and more severe.

### **Conclusion**

Indigenous children are at significantly greater risk of CP, particularly PNN CP. The predominant cause of PNN CP in non-Indigenous children has shifted to cerebrovascular accident over time; however, infections followed by head injury are still the most frequent causes in Indigenous infants.

## **Sleep disturbance in children with and without Developmental Coordination Disorder (DCD)**

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**Background:** Impaired sleep is associated with negative effects on quality of life and daytime functioning. Higher rates of sleep disturbance are reported in children with various developmental disorders. However, little is known about sleep in children with DCD, a condition characterized by everyday movement difficulties. Previously we found higher rates of parent-reported sleep disturbance in children with DCD compared to controls.

**Aim:** To examine sleep in DCD using objective measures and to examine links with daytime fatigue and sleepiness.

**Method:** Two groups (primary and secondary school-aged) of 15 children with DCD, plus matched controls, participated. Parent reported child sleep was assessed using the Child Sleep Habits Questionnaire and actigraphy gave an objective measure of sleep-wake patterns over one week (weekdays/ weekend). Aspects of self-rated child functioning were assessed with questionnaires (Pre-sleep Arousal Scale, Pediatric Daytime Sleepiness Scale, PedsQL Multidimensional Fatigue Scale).

**Results:** The DCD group had greater parent-reported sleep disturbance. There were no differences between the weekday actigraphic sleep variables of DCD and control groups. However at weekends there were differences between the DCD and controls groups, suggesting reduced quantity of sleep for the primary aged DCD group and impaired quality of sleep for the secondary aged DCD group. Daytime fatigue, aspects of pre-sleep arousal and daytime sleepiness were reported as greater in the DCD groups and were particularly related to objective sleep parameters in the DCD groups.

**Conclusion:** Children with DCD had more problematic sleep than typically developing children and there seem to be links between the sleep disturbances and aspects of daytime functioning. The nature and underlying cause of sleep disturbance in this group requires further research. Meanwhile, awareness of sleep problems in DCD is important to ensure early identification and implementation of support.

**Enabling physical activity participation for children with disabilities: Goal attainment, performance, and satisfaction following intervention**

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**Background:** The Local Environment Model (LEM) is a goal-directed intervention operating at Beitostolen Healthsports Centre (BHC), with focus on empowering families and communities to facilitate physical activity participation for children with disabilities. **Aim:** To determine the transferability of children's physical activity goal attainment, performance and satisfaction into local communities following the 18 day intensive LEM intervention, and to identify related barriers. **Method:** A pre-test post-test quasi-experimental design was applied to evaluate changes over time. Recruitment occurred over a one year period during standard clinical service provision at BHC. The Canadian Occupational Performance Measure (COPM) was administered to children and parents pre (T1) and post-intervention (T2), and at 12 weeks follow-up (T3). Goal Attainment Scaling (GAS) was applied to assess goal attainment at follow-up. Wilcoxon signed rank tests determined changes in COPM and GAS scores over time. Qualitative inquiry described barriers to goal attainment at follow-up. **Results:** 92 children with a range of disabilities (aged 6-17; 49 males) showed clinically and statistically significant improvements in parent ratings of COPM performance ( $Md_{T1}=5.0$ ,  $Md_{T2}=7.0$ ,  $Z=-7.24$ ,  $p<0.01$ ), and satisfaction ( $Md_{T1}=5.3$ ,  $Md_{T2}=8.0$ ,  $Z=-7.32$ ,  $p<0.01$ ) of physical activity goals post-intervention. At follow-up, there was no clinically significant difference in COPM performance ( $Md_{T3}=6.8$ ) or satisfaction ( $Md_{T3}=7.7$ ) ratings compared to post-intervention, and 32% of children attained their COPM-derived GAS goal (GAS T-score  $\geq 50$ ). Environmental factors were the most frequently identified barriers to goal attainment (i.e. access to services and assistive equipment). **Conclusion:** These results provide evidence for goal-directed, intensive interventions to enable physical activity participation in children with disabilities. Environmental factors are a primary barrier to goal attainment in community settings.

## **Hip health at skeletal maturity: A population-based study of outcomes for young adults with cerebral palsy**

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**Background:** In non-ambulant children, neglected hip displacement can proceed to dislocation, poor hip health and pain.

**Aim:** To investigate associations between GMFCS, hip morphology and pain in young adults with CP at skeletal maturity.

**Method:** Of a birth cohort of 367 children born in 1990-1992, 103 developed hip displacement (MP >30). Ninety-eight of these young adults attended a transition clinic where radiographs of the hips were obtained. Severity and frequency of pain were recorded using Likert scales. Motor function was classified by the GMFCS and hip morphology using the Melbourne Cerebral Palsy Hip Classification Scale (MCPHCS E&R). A Pearson correlation coefficient was used to describe the relationship between pain severity and frequency. Kruskal-Wallis tests of differences examined relationships between pain severity, GMFCS and MCPHCS. Non-parametric tests compared pain severity between those who had hip surveillance and those who did not.

**Results:** There was a strong association between hip morphology, GMFCS and pain. The median (IQR) pain score for MCPHCS 1-4 was 2 (1.0-3.0) compared to 7 (6.0-8.0) for MCPHCS 5-6 ( $p<0.001$ ). This association was also true for GMFCS: those at GMFCS I-III reported a median pain score of 2 (1.0-3.0), compared to 3 (2.0-5.0) for those at GMFCS IV-V ( $p<0.001$ ). Hip surveillance was associated with improved hip morphology and less pain. Adolescents with worse hip morphology (MCPHCS 6-7) had fewer hip radiographs compared to those with hips graded 1-5 ( $p<0.001$ ). The 14% of patients not under hip surveillance had a median pain score of 7 (5.0-8.0) compared to 2 (1.0-3.5) in the 86% patients under surveillance ( $p<0.001$ ).

**Conclusion:** Increasing GMFCS level, combined with limited or no hip surveillance, is associated with poor hip morphology and high pain levels. Conversely, adolescents at all GMFCS levels with access to hip surveillance and appropriately timed surgery had satisfactory hip morphology and less pain at skeletal maturity.

## **Motor and Cognitive Mechanisms in Developmental Coordination Disorder: A review of experimental evidence as part of the ICG for DCD (2015)**

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### **Background**

The most recent meta-analysis of experimental research on DCD was conducted as part of current European Guidelines on DCD and covered work published between 1997 and June 2011 (Wilson et al., 2013). Since this time, there has been an almost exponential growth in published research, prompting a re-appraisal of the field.

### **Aim**

The aim of this review was to evaluate systematically the body of research on mechanisms of DCD published since 2011.

### **Method**

A Cochrane-style systematic review was conducted on experimental studies of DCD (published after June 2011), covering (i) behavioural and (ii) neurobiological studies of basic mechanisms.

A total of 95 studies were included in the review, 84 behavioural and 11 neurobiological (involving neuroimaging and neurophysiological work).

Key findings are discussed in relation to implications for current theory and intervention.

### **Results**

Research showed a constellation of motor control, learning, and cognitive deficits in DCD, with evidence of persistence into early adulthood. In the motor domain, critical areas of difficulty were in predictive control, multi-joint synergies supporting balance, rates of motor learning, multisensory integration, oculomotor control, and graphomotor control. Cognitive deficits were evident across behavioural, questionnaire and observational measures, including aspects of task planning and daily organisation. Atypical neural connectivity was observed across distributed perceptual-motor and attentional networks. However, the review highlights a number of conceptual and methodological limitations. Surprisingly, much of the research is still atheoretical. As well, many participant samples remain poorly defined and relatively small in size.

### **Conclusion**

DCD may be more than just a motor disorder. However, a more theory-driven approach to research and tighter methodologies is needed to crystallize theory. Specific pointers for research scientists and practitioners are discussed.

## **Society and Environment: Health-enhancing participation for children with Cerebral Palsy**

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**Background:** Children with Cerebral Palsy (CP) can have limited mobility reducing participation in society. Considerable innovation and engagement is required from experienced professionals to increase participation. Increasing mobility in society enhances participation, aiding children and young people to achieve optimal potential.

**Aim:** Access to buildings and outdoors has improved for individuals with limited mobility, but risk concerns still limit children to wheelchairs. Adapted cycling offers opportunities within the community where children can increase mobility and participate in physical activity, experiencing periods of “uprightness” with correct support. This study explored effects of participation in outdoor cycling, for children with CP, in a non-clinical public setting.

**Method:** This mixed methods study received ethical approval from Cardiff University. The study explored children and families’ experiences of adapted cycling and effects on muscle strength. Bilateral lower limb strength was measured using a Hand-held dynamometer, before and after 6 cycling sessions, increasing distance and time as able. Children and families kept diaries and were interviewed adapting mosaic methods. A control group did not participate in cycling and underwent identical methods.

**Results:** 17 children participated in cycling sessions, 18 in the control group. Qualitative data was analysed using a thematic template. Emergent themes included: learning a new skill, impact on family, cycling set-up and fun participation. Strength changes demonstrated children who cycled increased muscle strength up to 28% while control group strength decreased.

**Conclusion:** Children enjoyed cycling with an improved sense of well-being. Cycling provided physical health-enhancing opportunities for increasing strength. Society, including policy makers, must work to ensure specialist community-based expertise is available to make participation in society more accessible for children with CP.



## **Skeletal muscle gene expression in children with cerebral palsy favors collagen production and net muscle loss**

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**Background:** Children with cerebral palsy (CP) have thin and weak muscles. Compared to typically developed children (TD) muscle function is decreased and muscle composition is altered. Despite a static cerebral lesion, muscle pathophysiology progresses and muscle function deteriorates with advancing age. No underlying mechanism has been identified and no effective countermeasures developed.

**Aim:** Characterize the biceps muscle with respect to gene expression, pro-fibrotic processes and muscle size homeostasis, collagen content and satellite cell number in CP as compared to TD children.

**Method:** Open muscle biopsies were taken during surgery in children and adolescents with CP, who due to elbow flexion contractures were planned for biceps tendon lengthening's (n=18, mean age 15,6 years, range 9-18 years). Control muscle was harvested from age-matched healthy donors (TD) post-mortem following accidental deaths (n = 10, mean age 15 years, range 7-21 years). Collagen content was assessed histologically using Picro Sirius red staining. Satellite cells were quantified using immunofluorescence-based labeling of CD56 positive nuclei within the muscle laminin border. mRNA levels of selected transcripts were quantified using qRT-PCR.

**Result:** Biceps muscle collagen content was increased in CP as compared to TD subjects ( $6.6 \pm 2\%$  vs  $5 \pm 1.2\%$ ,  $p < 0.05$ ). Satellite cell content in CP muscle was decreased -40% as compared to control ( $p < 0.05$ ). qRT-PCR data showed increased expression of pro-inflammatory cytokines (IL1B, IL6, TNF) and elevated levels of pro-fibrotic/atrophic regulators (CTGF, TGFB1, TGFB2, MSTN, FBXO32). Ribosome biogenesis, as indicated by 45S pre-rRNA abundance, was suppressed (-37%,  $p < 0.05$ ) and ribosome content reduced (28S rRNA, -57%,  $p < 0.05$ ).

**Conclusion:** Muscle gene expression analysis indicates a pro-fibrotic and pro-inflammatory state in CP, likely driving collagen production and negatively affecting growth capacity and size homeostasis.

## **Parents' experiences of conducting a goal-directed intervention based on children's self-identified goals, a qualitative study**

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**Background:** Research shows that children with disabilities have the ability to articulate goals, their goals often differ from those of their parents and with goal-directed intervention their goals are achievable to the same extent as parent-identified goals. However knowledge about how the child's personal goals influence goal-directed intervention, and how parents perceive an intervention based on children's self-identified goals, is still lacking.

**Aim:** To explore and describe parents' perceptions and experiences of conducting a goal-directed intervention focused on children's self-identified goals.

**Method:** Individual semi-structured interviews were performed with nine parents (8 mothers, 1 father). The parents had participated actively in conducting goal-directed intervention addressing their child's self-identified goals. The interviews were analysed using qualitative content analysis.

**Result:** From a parent perspective, working on children's self-identified goals was a positive experience. The findings revealed three categories: "Goals challenged the parents", describes the parents' experiences of the complexity of goal setting. "The intervention demanded an intensive and flexible parental engagement", here the parents expressed the importance of active parental engagement, which for some parents could be challenging. "The child's personal goals gave more than anticipated", describes the parents' experiences of how the child's personal goals positively influenced the child's self-esteem, increased the child's motivation for practice and helped their children develop more than they as a parent had anticipated.

**Conclusion:** Even though in the parents' experience, goal-directed intervention comprehensively relies on their engagement, their own child's personal goals gave them and their child more than they could have expected. This indicates the importance of letting children participate in goal setting to prioritize their own goals for intervention.

## **Dynamic control during gait under single and dual-task situations in Williams syndrome**

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### **Background**

Children with Williams Syndrome (WS), a rare genetic disease with a prevalence of 1 in 7.500 individuals have difficulties in visual-motor integration and motor function (1), especially under dual-task conditions (2). Coping with dual-task situations is important for managing complex everyday life competencies. Impaired dynamic postural control proved to be an intrinsic risk factor for falls (3), with gait variability and walking speed under dual task conditions being predictors for falls (4).

### **Aim**

Aim of the study is to assess the fall risk of children with WS under single and dual task conditions in order to identify an intervention for falls prevention.

### **Method**

Gait parameters of people with WS (N=27) were measured under single- (ST) and dual- (DT) task conditions using the Optogait analysis system. The subjects were divided in 3 age groups (group I 7-13; group II 14-17; group III 18-30). Data for stride length and walking speed was normalized for height.

### **Result**

Results show a significant decrease ( $p=,019$ ) in stride length in age group I (group II:  $p<01$ ; group III:  $p=,36$ ) comparing ST and DT. Walking speed also decreases significantly ( $p<0.01$ ) from ST to DT in age group I, respectively in group II and III. The coefficient of variation, a fall predictor, increases from 9,56% (ST) to 12,47% (DT) in age group I ( $p=,17$ ), from 7,45% (ST) to 9,35% (DT) in group I ( $p=,22$ ) and from 7,44% (ST) to 10,03% (DT) in group III ( $p=,047$ ).

### **Conclusion**

Children with WS decrease their walking speed during DT situations, while at the same time the probability for falls increases. Thus result in an enhanced falls risk especially in complex situations. An intervention aiming at improving motor competencies could prevent falls.

1 Hocking, D.R., Thomas, D., Menant, J.C., Porter, M.A., Smith, S., Lord, S.R. & Cornish, K.M. (2013). The interplay between executive control and motor functioning in Williams syndrome. Dev Sci, 16(3), 428-42.

## **Children as partners in developing good rehabilitation practices – LOOK-project**

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### **Background**

The importance of child's participation is recognized as fundamental to successful rehabilitation process. However, rehabilitation services for children lack practices that enhance children's participation and agency. We need new child-friendly methods to collect data with children when developing and planning rehabilitation.

### **Aim**

The aim of this study was to describe a new method of data collection with children that focuses on catching the child's views of meaningful participation in everyday life and in rehabilitation.

### **Method**

The data was gathered in two phases: 1) Child took one or more photographs by themselves or with a help from her parents about activity/ participation that she considered important or what she wanted to learn in her daily life. A description of the photographs was written down by the child or parents. 2) Individual interviews were held with the children based on photographs and descriptions. Six children (5-10 years) who have received rehabilitation services over six months participated in this study. The local ethics committee approved the study.

### **Results**

The photographs helped the children to describe different aspects in the activities and participation that they found important. The photographs described mostly participating in leisure activities with family members or peers. Many of the children wanted to also draw, play or show their doing concretely. Flexibility, the use of different communication methods and creating a trusting relationship with the child were the key factors in catching the children's own views of participation.

### **Conclusion**

To strengthen child's participation and agency in activities and in life situations that are meaningful for the child, we must consider child-friendly ways to gather information and individual strategies to facilitate child's agency. Photograph-based interview showed potential to act as a tool when planning and developing rehabilitation services with children as partners together with adults.

## **Developmental Disregard in children with unilateral Cerebral Palsy is accompanied by a lack of movement related mu-suppression**

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**Background:** Some children with unilateral Cerebral Palsy (uCP) disregard the preserved capacity of the affected hand (AH), a phenomenon known as developmental disregard (DD). While it is known that voluntary hand movement in DD is accompanied by enhanced cognitive effort, the accompanying neural mechanisms are still largely unknown. One line of reasoning suggests that DD is related to an underdeveloped sensorimotor integration.

**Aim:** To study whether DD may be related to a deficient development of the sensorimotor system, the pattern of cortical activation during motor activity was observed through analysis of the movement related EEG mu rhythm. This mu rhythm is tightly associated with the sensorimotor system and is typically suppressed during movement.

**Method:** Twenty-four children with uCP participated, 11 with DD. Participants performed an unimanual repetitive squeezing task. EEG mean mu rhythm (8-10Hz) was recorded over the sensorimotor cortex during rest and movement of each hand. A repeated measures GLM analyses was conducted with hand (AH vs. less AH) and state (resting vs. movement) as within- and group (noDD vs. DD) as between-subject variable. Whenever interaction effects were found, Paired Samples T-Tests were performed.

**Results:** The repeated measures GLM revealed a trend for a state\*group interaction ( $F(22)=3.402$ ,  $p=.079$ ). Posthoc tests revealed no difference between states within the DD group for either hand, whereas significant differences between resting and movement state for both hands were observed in children with uCP without DD (AH: $t(12)=-2.035$ ,  $p<.05$ ; less-AH: $t(12)=-2.299$ ,  $p<.05$ ).

**Conclusion:** No movement related mu desynchronization was observed in children with DD. This lack of cortical desynchronization might suggest an inability of the somatosensory and motor cortex to successfully interact, possibly contributing to DD. These results suggest a need for interventions to target sensorimotor integration of both hands when treating children with DD.

## **VISUAL IMPAIRMENT AFFECTS FUNCTIONAL BALANCE IN CHILDREN WITH CEREBRAL PALSY**

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**Aim:** The aim of this study was to investigate the effects of visual functions on balance and functional movement skills in children with Cerebral Palsy (CP).

**Method:** 10 Hemiplegic, 10 diplegic total 20 spastic type children (11 boys, 9 girls) with CP, age between 5-17 (mean  $9,50 \pm 4,40$  years), Level I-II according to Gross Motor Function Classification System and 20 typical developing (TD) children (10 girls, 10 boys) age between 5-17 (mean  $9,65 \pm 3,03$  years) were included to this study. None of the children were have any visual loss. Computerized Dynamic Posturography, Sensory Organization Test (SOT) was used to evaluate the visual, vestibular and somatosensory functions and composite balance. The timed up and go test (TUG), timed up and down stairs (TUDS) and pediatric balance scale (PBT) were used as functional movement skills tests. Statistical analysis was performed with SPSS 15.0 package program.

**Results:** When children with CP and TD compared, visual function score and composite balance score of SOT, TUG, TUDS and PBT scores were significantly lower in children with CP ( $p < 0,01$ ), but there were not any differences at vestibular and somatosensory functions. Additionally, visual preference was similar between groups. There were a negative relationship between SOT visual function score and balance score of SOT, TUG, TUDS and PBT scores ( $p < 0,01$ ), but there were not any similar significant relationship with somatosensory and vestibular scores of SOT ( $p > 0,05$ ). When hemiplegic and diplegic children compared, hemiplegic children were significantly have visual function scores ( $p < 0,05$ ), but vestibular, somatosensory and composite balance scores of SOT were similar ( $p > 0,05$ ).

**Conclusion:** Visual function has critical importance in children with CP in terms of balance and functional movement skills and may include therapy programs. In future, studies with larger sample and including with different levels of CP should plan.



**Free papers – posters**

**Arranged according to day of presentation:**

**Thursday, Friday, and Saturday**

## **Gestalt perception and computer-based video analysis of General Movements is associated with motor development at one year age in Very Low Birth Weight infants in India**

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**Background:** Feasible, low-cost assessment tools for prediction of outcomes in preterm infant are needed for parental counseling and planning of health care services worldwide. Gestalt perception of general movements (GMs) is a valuable method for predicting motor outcomes, but its use is limited to personnel with special training.

**Aim:** To investigate associations between GMs during the fidgety movements' (FMs) period at 3 months post term age (PTA) and motor development at one year PTA by use of gestalt perception and computer-based video analysis.

**Method:** 243 Very Low Birth Weight (VLBW) infants (135 boys, median gestational age 31 weeks (range 26-39), median birth weight 1300 grams (range 760-1500)) were video recorded at median 11 weeks PTA (range 9-16). FMs were classified according to gestalt perception as abnormal if absent, sporadic or exaggerated and as normal if present. One of two observers was unaware of the clinical status of the infants. A sub-set of 215 infants had their videos analyzed by software calculating the variability of the spatial center of motion in the infant (Centroid of motion standard deviation;  $C_{SD}$ ). The Peabody Developmental Motor Scales (PDMS-2) was used to assess motor development at one year PTA.

**Result:** 31 (13%) of 243 infants were classified with abnormal FMs. Among 10 (4%) children with a Total Motor Quotient (TMQ) scores  $< 80$  (2SD) on the PDMS-2, 6 and 4 infants had normal and abnormal FMs, respectively, compared to 206 and 27 infants with normal and abnormal FMs, respectively, with higher TMQ scores ( $p=0.030$ ). The median computer-based  $C_{SD}$  scoring was 6.43 in children with TMQ scores  $< 90$  (1SD) compared to median 5.41 for those with higher TMQ scores ( $p=0.002$ ).

**Conclusion:** Normal FMs assessed by gestalt perception as well as low variability of the spatial center of motion assessed by computer-based video analysis, indicated a normal one year motor development in VLBW infants in India.



## **Assistive Technology – A Systemic change for Individual Success**

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While it is well-established that assistive technology can support students' engagement in classrooms, develop independence in learning and student achievement can be improved through the appropriate use of technology, it is important to note that the multitude of rapidly evolving assistive technology devices can leave interventionists feeling unprepared for supporting their use in classrooms.

In this paper/presentation, the author aims to demonstrate how assistive technology has been integrated into the service provision and training of children with special needs in a school setting. The emphasis is on how integration of assistive technology was planned, structured and implemented, within an existing model of service delivery as well as within the available resources – material and human, with a multi-national work-force with varied professional backgrounds.

The paper/presentation aims to trace the 6 - year journey of Al Noor Training Centre for Children with Special Needs, Dubai, in the field of AT from 2008-2014, by detailing the whole school AT plan, highlighting key milestones and attainments as well as by elaborating the multi-dimensional process by which AT has been integrated into the teaching/learning component of service delivery for students with disabilities.

The presentation/paper focusses on the specific strategies that the Centre adopted to ensure the full integration of assistive technology into the methods and materials used by interventionists on a day-to-day basis.

By emphasizing on how integration of AT has been conceptualized, planned, structured, implemented and woven into an existing service delivery model, within the scope of available human and material resources through intensive capacity-building, professional training, and putting in place the necessary support structures to enhance the interventionists' ability to effectively use AT tools, the presentation / paper hopes to benchmark its service delivery practices within the region.

## Screening for dysphagia and malnutrition in adults with multiple neurological disabilities

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**Background:** Although 85-90% of all adults with cerebral palsy are estimated to suffer from dysphagia at some point in life the prevalence of dysphagia among adults with multiple neurological disabilities (MND) is still uncertain (Reilly et al, 1996). Dysphagia may lead to malnutrition, dehydration, pneumonia or choking. (Macdonald et al, 1989; Rogers et al, 1994; Kennedy et al, 1997; Fine Tone et al 1998).

**Aim:** To identify the presence of dysphagia among adults with MND within Habilitation & Health, Stockholm and their possible need for interventions by health care.

**Method:** Within this development project 3 speech and language therapists (SPL) and a dietician developed a tool of 5 questions for the screening of dysphagia among adults with MND. Eligible were all adults with MND scheduled for their annual follow-up at one Habilitation Centre in Stockholm during 2014. Those who tested positive during the screening were assessed by a SPL to verify the results and to initiate interventions by health care when needed.

**Result:** 44 adults with MND were approached and 39 gave their consent and answered the questions in person or by proxy (25 men, 14 women, average age 39 years). 32 (82%) were identified as being in need of further investigation due to possible dysphagia and/or nutrition-related difficulties. Weight changes were found in 14 of 39 persons, ie 36%.

A SPL verified dysphagia and the need of recommendations and further investigations for all 32 . 11 patients, (34%), were considered to have extensive dysphagia- and/or nutrition problems and needed further investigations by physicians and dieticians.

**Conclusion:** The result indicates that the screening tool may be useful to identify dysphagia among individuals with adults with MND. Further, there seems to be an extensive need to repeat systematic screening for dysphagia in adults with MND and to offer individual interventions addressing eating and nutrition problems by SPL, dieticians and physicians.

## **Supervision supports individual and communal professional development**

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### **Background**

Research is based on doctoral dissertation how supervision supports inclusive teacherhood and its development (Alila 2014). Supervision is a multidimensional concept which is understood in numerous ways. The theoretical background is diverse.

### **Aim**

The study focused on opportunities presented by supervision concepts and manifold methods to support inclusive teacherhood and its development. Main research question was: How do supervisors with a teaching background perceive the quality of support supervision provides to inclusive teacherhood? The following questions were: According to supervisors with a teaching background, how does supervision support inclusive teacherhood and its development? What are the special features of supervision that support inclusive teacherhood, according to the supervisors with a teaching background?

### **Method**

The data were obtained using the focus-group interview method focused on supervisors with a teaching background. The interviews were conducted in five places in Finland. The analysis involved a combination of phenomenography, particularly the application called the variation theory, and the classic analysis of the focus-group research method.

### **Results**

Supervision supports inclusive teacherhood both at the individual and at the communal level. Individual support consists of: empowering and promoting new teacherhood, clarifying teachers' professional growth and roles, helping teachers to evaluate their work and supporting teachers in challenges at work. Communal support was manifested as strengthening collaboration, promoting a change in the work culture of a school and developing a communal work approach.

### **Conclusion**

Study showed that supervision can be target-oriented support. Supervision has to be aware of other similar methods and not be tied to one theoretical framework. Supervision can enable professional, communal, and personal development. Supervision can function as a learning environment for inclusive teacherhood.

## Early markers of associated impairments in children with cerebral palsy (CP)

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**Background:** Most CP registers record data at only one point in time. The Cerebral Palsy Register of Norway (CPRN) is a national medical quality register that records data at 3 points in time: when CP is first diagnosed, at preschool age (5 years) when the diagnosis has been confirmed, and during adolescence (15-17 years). This allows the CPRN to evaluate the course of various impairments over time and to identify areas of concern early.

**Aim:** To study to what extent associated impairments recorded at the time of diagnosis are present at five years of age.

**Method:** Among 1,201 children with CP born 2002-2010 and registered in the CPRN, information both at the time of diagnosis (mean age 1.6 years) and at 5 years was available for 323 (27%) children. The distribution of CP subtypes, gross motor function and gender among the 323 children was representative for the entire CP population.

**Result:** At diagnosis, 53 (18%) children had experienced more than two unprovoked seizures after the newborn period, and of those 47 (88%) had epilepsy at 5 years. 40 (13%) children took anti-epileptic medication at time of diagnosis, and of those 34 (87%) continued to take anti-epileptic medication at 5 years, and 22 (55%) had no speech at 5 years. 68 (22%) children had eating difficulties at the time of diagnosis, and 60 (88%) of these continued to have eating problems at 5 years, whereby 36 (56%) were in need of gastrostomy tube feeding. Furthermore, 44 (66%) of those with early eating difficulties at diagnosis had no speech at 5 years.

**Conclusion:** These results show that a majority of children who already present signs of epilepsy and eating difficulties at an early age continue to be affected by various severe associated impairments at 5 years. This can be used to raise awareness of these areas of concern to initiate targeted and individualized interventions as early as possible.

## **Gender differences in transient and calculated visual event related potential latency in infants with risk factors for neurodisability**

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**Background:** Findings from one study identify prolonged pattern reversal visual event related potential (PR-VERP) latency in typically developing infant (TDI) males. Calculated steady state PR-VERP latency is a novel measure obtained by plotting phase against temporal frequency (TF), reaching adult levels around 12 months in TDI, reflecting developing cortical connectivity. In infants with risk factors for neurodisability (RFND) tested to age 2 years, calculated latency fails to reach adult levels.

**Aim:** To establish if PR-VERP latencies show gender differences in an infant RFND cohort.

**Methods:** Infants with RFND were participants in a randomised control trial of neurotrophic nutritional supplementation. Eligibility criteria included:  $\leq 31$  weeks, weight  $< 9$ th percentile;  $\leq 31$  weeks with  $\geq$  Grade II intraventricular haemorrhage (IVH) or preterm white matter injury (PWMI); 31- 40 weeks with  $\geq$  Grade II IVH or PWMI,  $\geq$  Sarnat Grade II hypoxic ischaemic encephalopathy or defined brain MRI abnormalities. Infants' PR-VERP was tested at 2/4/6 and 8 reversals/sec (r/s), at spatial frequency 0.24 cycles per degree, on 4 visits between 0-24 months. Gender differences were compared using mixed linear regression accounting for multiple measures.

**Results:** PR-VERP transient latency at 4r/s was significantly longer between 20-40 weeks corrected gestational age in males than in females with RFND (interaction gender x age,  $z = -3.39$ ,  $p < 0.01$ ,  $n = 43$ ; 23 males, 20 females). Trends in the same direction (longer male latency) were seen at 2 r/s ( $n = 37$ ; 21 males, 16 females) and in calculated latency ( $n = 51$ ; 28 males, 23 females). A TDI cohort tested with the same protocol showed no gender effects ( $n = 125$ ).

**Conclusion:** Transient and calculated VERP latency are prolonged in males with RFND compared to females. The comparison with TDI results suggests differential vulnerability to RFND. Gender differences should be considered when using VERP latency to assess early brain development in at-risk infants.

## **Case notes review of perinatal stroke in term and preterm infants in the UK Northern region over a 10 year period**

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**Background:** Perinatal stroke (PS) is the commonest cause of unilateral cerebral palsy. Research into effective early management and guideline development are needed. **Aim:** to document the range of current practice in diagnosis and management of PS within the Northern region, highlighting areas for improvement. **Method:** Patients with PS born 01.01.2000-31.12.2009 were identified from 4 hospitals with neonatal intensive care units, using ICD-10 codes and verifying via imaging findings. Data on presentation, management and outcome were extracted to a standard proforma. **Result:** 101 cases (60 male) met eligibility criteria. Of 58 term infants, 46 had presumed perinatal stroke (PPNS), 11 had acute symptomatic stroke, and one was an incidental finding. Of 43 premature infants, 16 had PPNS, 11 had acute symptomatic stroke, and 16 were incidental findings. The commonest presentations were seizures (symptomatic stroke) and decreased arm and hand use unilaterally (PPNS). Infants with PPNS had signs at median age 7m. Median delay between first reported signs and radiological diagnosis was 8.4m. 86 patients developed hemiparesis, 10 had asymmetrical quadriparesis, 2 had normal motor outcomes and in 3 cases motor outcome was unclear. 25 patients developed epilepsy, only 5 of whom had had neonatal seizures. A number of learning points were identified. In one patient, neonatal seizures were attributed to drug withdrawal and not investigated. In another, there was delay in recognition of neonatal seizures. In two cases, cranial ultrasound examinations were normal but MRI (performed after later presentation with motor signs) showed abnormalities. Documentation was problematic: copies of letters from therapists were not consistently found, and language outcomes were often unclear. **Conclusion:** Areas for improvement include recognition, prompt referral and investigation of neonatal seizures and early lateralising motor signs, early definitive imaging and improved documentation.

## Having fun and staying active!

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**Background:** Children with disabilities are at risk of limited participation in physical activities compared with peers without disabilities. The consequences of inactivity are more extensive for persons with disabilities compared with peers. Enjoyment in participation is an aspect characterized as a key indicator of successful participation. Staying active during adolescence has not only immediately impact in children's mental and physical health, but can also stimulate to a more active lifestyle in adulthood

**Aims:** The objective of this study was to describe the change in participation profile over 15 months after a three week intensive rehabilitation stay using physical activity as the main approach. The results are discussed in the light of the critical decline in physical activity during adolescence described among children in general and in children with disabilities particularly.

**Methods:** The Children's Assessment of Participation and Enjoyment (CAPE) was used in a longitudinal prospective study, with three waves of measurement over 15 month. Participants who completed all three measurements were 80 children with disabilities, 6-17 years old (Mean 11.1; SD 2.4).

**Results:** Overall participation diversity and intensity in leisure activities showed a significant decrease during 15 months. The largest decline appeared between 10-13 years. However, in activities of physical character there was a stabile level of participation both in the total group , in the different age groups and in both genders. Boys preferred physical activities, while girls preferred skill-based activities. There was a higher level of enjoyment in the preferred activities in both genders.

**Conclusion:** The participants showed a stabile level of participation in activities of physical character over a 15 month period after rehabilitation intervention with focus on physical activity. There was a high level of enjoyment in the activities with a stabile participation level.

## **Children with Cerebral Palsy and Low BMI-for-Age on GMFCS Stratified Growth Charts may be at Increased Risk of Surgical Site Infection Following Spinal Instrumentation Procedures**

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**Background:** There is currently weak evidence that pre-op malnutrition increases surgical site infection (SSI) risk in pediatric patients after scoliosis surgery. Though not considered an indicator of nutritional status, BMI has been indirectly introduced as a marker of malnutrition. Obesity is a known risk factor for SSI in adults undergoing spinal deformity surgery, but there is no evidence that low BMI is a risk factor for SSI in patients with CP.

**Aim:** To compare nutritional indicators in patients with CP who developed SSI to those who did not after spinal deformity surgery.

**Methods:** This is a case-control study of patients with CP aged <26yr who developed SSI and who didn't. Nutritional indicators included age, height, weight, BMI (standard & CP-specific growth charts), pre-op Hct, GMFCS level, and mode of feeding. SSI is defined as a deep wound infection within 1yr post-op.

**Results:** 57 patients with 69 procedures were included in the study. 6 patients (11%) developed SSI. 70% were GMFCS V, but remaining 30% was balanced across other GMFCS levels. 60% of patients fed orally, 40% tube fed. Patients with BMI < 10<sup>th</sup> percentile on CP-specific growth charts (BMI < 10CP) had 5x greater risk of developing SSI than those above it (RR = 4.8, 95% CI: 1.0–20.0, p = 0.049). Patients with BMI < 5<sup>th</sup> percentile on CP-specific growth charts (BMI < 5CP) had 7x greater risk than those above it (RR = 6.7, 95% CI: 1.3–33.9, p = 0.035). All other nutritional indicators were not associated with SSI risk.

**Conclusion:** Patients with CP and BMI < 10CP or BMI < 5CP are at greater risk for SSI within 1yr of spine surgery compared to those above these percentiles. This information will allow orthopedic surgeons to risk stratify patients prior to spinal surgery, and also guide pre- and post-op management.



## **Calf muscle growth in ambulant children with unilateral and bilateral cerebral palsy age 2-9 years**

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**Background:** The calf muscle of preschool children with CP grow at a slower rate than children with typical development (CTD) peers however muscle growth in children with unilateral (UCP) and bilateral (BCP) may grow at different rates.

**Aim:** The cross-sectional study examined whether ambulatory children with UCP and BCP and CTD, age 2-9 years, have different medial gastrocnemius (MG) muscle growth rates. It was hypothesised that children with UCP would have a greater MG muscle growth rate than the BCP group and that the UCP and BCP groups would have a reduced MG muscle growth rate compared to their CTD peers.

**Method:** 50 children with UCP (mean age 66 (SD 18) months, 29 males, GMFCS I=32, II=18), 50 children with BCP (age 64 (19) months, 31 males, GMFCS I=21, II=29) and 78 CTD (age 64 (16) months, 40 males) participated in the study. The MG muscle volume was measured at rest using a validated freehand 3D ultrasound method. Linear regression examined the relationship between age and MG muscle volume for each group and a univariate general linear model was used to compare the slopes of the regression lines (ml/month, MG muscle growth rate),  $p < 0.05$ .

**Result:** Medial gastrocnemius muscle volume was significantly related to age in all groups. In children with UCP there was a 0.17ml increase in MG muscle volume per month which was significantly less than the MG muscle growth of 0.48ml/month in BCP ( $p=0.02$ ) and CTD 0.73ml/month ( $p<0.01$ ). MG muscle growth was less in the BCP than the CTD group ( $p=0.04$ ).

**Conclusion:** The growth rate of the MG muscle in children aged 2-9 years with UCP is lower compared to BCP and both CP groups are lower than CTD. The growth rate differences in the children with UCP compared to BCP raises questions about the underlying mechanisms that lead to reduced growth in each CP group and potential differences in muscle recovery response in UCP and BCP following treatment.

## **Navigating through apertures: perceptual and action judgements in children with Developmental Coordination Disorder (DCD)**

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**Background:** The decision to rotate the shoulders when passing through a narrow gap or aperture is important in everyday life. This involves making perceptual judgements about the size of the gap in relation to the body as well as executing an appropriate movement. It has previously been found that children with DCD have difficulties in making perceptual judgements in near space. Judgements in far space have not been examined and call upon different neural systems.

**Aim:** The aim of the current study was to examine the perceptual abilities and motor behaviour of children with DCD and their peers while looking at or walking through apertures.

**Methods:** 29 children with DCD, aged 8-17 years, and 29 typically developing (TD) age and gender matched children took part. Participants completed two tasks: a perceptual task, where they looked at a series of apertures and judged whether or not they would need to turn their shoulders to pass through and an action task where they actually walked through the same apertures. In both tasks the critical ratio (ratio between shoulder width and aperture size at which participants no longer needed to rotate the shoulders) was recorded.

**Results:** In the perceptual task the children with DCD showed a significantly smaller critical ratio compared to the TD children (1.41 compared to 1.55). In the action task the children with DCD showed a significantly larger critical ratio compared to the TD children (1.73 compared to 1.65).

**Conclusion:** Children with DCD demonstrate perceptual judgements which are out of line with their action judgements; judging that they need less space to pass than they actually need. This may in part explain the slowness of movement which characterises DCD.

## **The spastic velocity threshold predicts Botulinum toxin-A treatment outcome in the medial hamstrings of children with cerebral palsy**

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### **Introduction**

Data collected using an innovative instrumented spasticity assessment (ISA) in the medial hamstrings (MEH) of children with cerebral palsy (CPC) has revealed a large variability among subjects in the velocity threshold (VT) at which hyperreflexia (spasticity) occurs. Intramuscularly injected Botulinum toxin-A (BTX) temporarily decreases spasticity in the MEH, although a large variability in response is reported.

### **Aim**

To investigate whether the spastic VT pre-treatment can predict the effect of BTX in the MEH of CPC.

### **Method**

14 CPC (10±2yrs; 8/6 bilateral/unilateral involvement; GMFCS I-III) were measured pre- and post-BTX with ISA and gait analysis. During ISA, kinematics and electromyography (EMG) were recorded during slow and fast passive MEH stretches. Average normalized root mean square EMG was calculated pre-BTX during slow stretch (pre rms-EMG<sub>slow</sub>) and post-BTX as the change between slow and fast stretch (rms-EMG<sub>post</sub>). Muscles with high pre rms-EMG<sub>slow</sub> values were categorized as low-VT, and those with low pre rms-EMG<sub>slow</sub> values, as high-VT. Using Man-Whitney U tests, rms-EMG<sub>post</sub> and post-BTX improvement in knee extension during terminal swing (Knee<sub>post</sub>) were compared between low-VT and high-VT muscles. The relationships of pre rms-EMG<sub>slow</sub> with rms-EMG<sub>post</sub> and with Knee<sub>post</sub> were investigated using Spearman rank correlation (significance set at p<0.05).

### **Results**

Rms-EMG<sub>post</sub> was lower (p=0.01) in those muscles categorised pre-BTX as high-VT. There were significant negative correlations for pre rms-EMG<sub>slow</sub> with rms-EMG<sub>post</sub> (r=-0.63, p<0.05) and with Knee<sub>post</sub> (r=-0.48, p<0.05) indicating that muscles with low-VT are less likely to respond to BTX, as assessed both passively and by gait analysis.

### **Conclusions**

Assessment of the spastic threshold in the MEH in children with CP can be used to choose the most effective management option for the individual patient. The etiology behind the different spastic thresholds requires further investigation.

## **The Effect of Antenatal Betamethasone and Intrauterine Inflammation Exposures on White Matter Inflammation and Injury in Fetal and Ventilated Preterm Lambs**

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**Background:** Chorioamnionitis and antenatal betamethasone (BM) administration are common antecedents to preterm birth but their effect in combination on the developing brain is unknown. Given the established link between chorioamnionitis and cerebral palsy, and the prevalence of preterm infants receiving BM, we aimed to compare the effects of chorioamnionitis and maternal BM in combination with mechanical ventilation, on the preterm brain.

**Methods:** At 0.85 gestation pregnant ewes were randomly assigned to receive intra-amniotic (IA) saline + intra-muscular (IM) saline (n= 9), IA saline + IM BM (n=13), or IA LPS + IM BM (n=13). Lambs were delivered and unventilated controls (UVC<sub>Sal</sub>, n=4; UC<sub>BM</sub>, n=6; UVC<sub>LPS+BM</sub>, n=6) were humanely killed without intervention; ventilated lambs (Vent<sub>Sal</sub>, n=5; Vent<sub>BM</sub>, n=7; Vent<sub>LPS+BM</sub>, n=7) were ventilated with a tidal volume (V<sub>T</sub>) targeting 12 mL/kg for 15 min then conventionally ventilated for another 75 min. The cerebral white matter (WM) underwent molecular and histological assessment of inflammation and injury.

**Results:** In the UVCs, BM increased the density of astrocytes and the number of blood vessels with protein extravasation above UVC<sub>Sal</sub> (p<0.05 for all); LPS+BM increased pro-inflammatory cytokines, density of microglial aggregations, percentage of amoeboid microglia and protein vascular extravasation above UVC<sub>Sal</sub> (p<0.05 for all) but not above UVC<sub>BM</sub>. Ventilation, with BM and LPS+BM, decreased pro-inflammatory cytokines, tight junction protein gene expression and protein vascular extravasation compared to their UVC counterparts (p<0.05 for all).

**Conclusion:** Antenatal BM, with and without LPS, increased inflammation in the UVCs compared to control. Despite this, BM administration prevented ventilation-induced brain injury by stabilizing haemodynamics and mitigating the inflammation response; this was irrespective of LPS.

## UK-based survey of current practice in management of perinatal stroke

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**Background:** Perinatal stroke is the leading cause of hemiplegic cerebral palsy (HCP). The optimal early therapy management approach remains unknown, especially as not all perinatal strokes lead to motor deficits. Our clinical impression was of striking variability in management.

**Aim:** To survey UK Paediatric Physiotherapist (PT) and Occupational Therapist (OT) management of perinatal stroke.

**Method:** Web-based cross-sectional survey, sent to members of the Association of Paediatric Chartered Physiotherapists and Occupational Therapists Specialist Section-Children Young People and Families, July-August 2015. Questions included age at referral, waiting times, assessments, frequency of review and therapy approaches. Analysis was descriptive.

**Result:** Of 196 respondents, 116 PTs and 29 OTs saw infants with perinatal stroke. Age at referral varied from 0m to over 18m. Whilst infants referred with motor dysfunction were generally considered to be a high priority, 14.3% of OTs and 6.8% of PTs indicated a wait time of 8 weeks or longer. 14.4% of physios and 14.3% of OTs indicated that infants referred without motor signs would wait 8 or more weeks for first assessment. The modal frequency of follow-up by PTs for infants with and without motor signs was 2 and 4 weeks respectively. 41.9% of PT and 40.0% of OT respondents used no specific named neurological assessments; the Alberta Infant Motor Scale (AIMS), Bayley Scales of Infant Development III (BSID) and General Movements Assessments were most often used. The most frequently used interventions were neurodevelopmental therapy, positioning aids and passive movements.

**Conclusion:** Variability was seen in therapy services provision following perinatal stroke. More frequent input for infants with motor signs, and more use of standardised assessments, are needed. Comparisons with practice in other European countries is planned. Evidence-based early interventions and guidelines for perinatal stroke are urgently required.

## **Gross Motor Interventions Reported in 2006, 2008 and 2010 Surveillance Records for Children with Cerebral Palsy: Findings from the U.S. Autism and Developmental Disabilities Monitoring (ADDM) Network**

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**Background:** Interventions aid in minimizing the consequences of cerebral palsy (CP) among children, but little is known about the frequency of their use.

**Aim:** To describe gross motor interventions prescribed for children with CP identified through public health surveillance and to compare by child characteristics.

**Method:** Using health record review, the ADDM Network conducted surveillance on the prevalence and characteristics of CP among 8-year-old children living in four areas of the United States in 2006, 2008, and 2010. Trained clinicians reviewed records to identify children with CP (N = 1302), assigned Gross Motor Function Classification System (GMFCS) levels and, after age 4, recorded interventions prescribed to address gross motor impairments including: (1) orthotics, (2) mobility devices, and (3) medical interventions, specifically orthopedic or neurological surgeries and pharmaceuticals for spasticity or dystonia.

**Result:** Among children with CP, 40% had no mention of interventions in their records while 14% had one reported intervention and 46% had two or more. Among children for whom gross motor function could be classified, 64% of those with no reported interventions were functioning at GMFCS Level I. Among children with at least one reported intervention in a specified category, the mean number of orthotics documented in records was 1.26 [Standard Deviation (SD)=.51; range: 1-4], for assisted mobility devices mean=2.4 [SD = 1.59, range: 1-9], and for medical interventions mean=1.7 [SD=.96, range: 1-5]. The overall mean number of interventions was 3.4 [SD=2.2, range: 1-14]. Use varied by type and location of motor function and cognitive level. For example, children with bilateral CP used more interventions than children with unilateral CP ( $\chi^2=79.1$ ,  $p<.001$ ).

**Conclusion:** Consistent, clear documentation on type and frequency of interventions can further our understanding of the resources used by children with differing CP characteristics.

## **Missed Willis Ekblom Disease (WED) in Children and Adolescents with Fetal Alcohol Spectrum Disorders (FASDs) leads to Overmedication and Polypharmacy**

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**Background:** Due to their challenging/disruptive sleep and wake behaviours, children and youth with FASDs are at high risk for multiple medication prescriptions. The familial neurological condition, WED, which can mimic ADHD and cause insomnia, non-restorative sleep and subsequent sequelae, has never been investigated in-depth in children and youth with an FASD.

**Aim:** To describe how undiagnosed chronic sleep problems can pave the pathway for polypharmacy in adolescents with FASDs, including the prescription of multiple, off-label, and concurrent pharmaceutical medications.

**Method:** We analysed the challenging/disruptive sleep and wake behaviours and medication history of 17 adolescent patients with a pharmacotherapy timeline, capturing (1) the medications and order of prescriptions, and (2) the age at the time of first prescription.

**Result:** All patients presented with chronic insomnia and fulfilled the diagnostic criteria for WED and/or familial WED. 11/17 had additional clinical signs of sleep disordered breathing, and 14/17 showed excessive daytime behaviours (sleepiness and/or hyperactive-like behaviours to fight fatigue/sleepiness). The medication analysis revealed two patterns in prescription strategies: (a) targeting sleep problems with melatonin, second-generation antipsychotics, and/or combination of both (10/17); and (b) targeting hyperactive-like daytime behaviours with a psychostimulant (7/10). In addition, many medications were prescribed in combination and at alarmingly young ages.

**Conclusion:** Based on our findings we suggest assessment of sleep before any assessment of challenging/disruptive daytime behaviours and prescription of psychotropic medications. This observation raises the question to what degree children with neurodevelopmental conditions are subject to overmedication due to the missed underlying condition of WED which presents with challenging/disruptive behaviours.

## **Observable Movement Patterns and Sensorimotor Sensations of Paediatric Patients/Parents with Familial Willis Ekbom Disease (WED) during the Suggested Clinical Immobilization Test (SCIT)**

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**Background:** Diagnosis of WED is difficult in children with neurodevelopmental conditions (NDCs) due to their varying verbal abilities and/or lack of reference point. We investigated an office-based clinical test, the SCIT, which uses structured behavioural observations, to help overcome current diagnostic challenges.

**Aim:** To gain a better understanding of described sensorimotor sensations and observable movement patterns of patients and family members with a history of WED.

**Method:** Patients: 31 patients with chronic early-onset insomnia and NDCs were seen with their mothers who presented with a history of WED. WED was diagnosed by sleep/family history and observable movement patterns during the SCIT (clients get up, shake out, sit bare-foot on an a chair, and try to remain still). Observable movement patterns accompany descriptions of sensorimotor sensations.

**Result:** SCIT of mothers: 26/31 (84%) could participate actively: 100% described an urge to move and 53% had sensorimotor symptoms in their legs/toes/feet, the remaining 47% could not specify; 69% had observable movement patterns, the remaining 31% suppressed observable movement patterns by increasing tension. SCIT of children: 17/31 (55%) could participate actively: 82% described an urge to move and 47% had sensorimotor sensations in their legs/toes/feet, the remaining could not specify; 76% had observable movement patterns. Out of this group, only 10/17 (59%) described sensorimotor sensations accompanied by the urge to move and had observable movement patterns; the remaining could either describe sensorimotor sensations (4/17) or had observable movement patterns (3/17).

**Conclusion:** The SCIT captures observable movement patterns as a new structured diagnostic criterion. This test initiated collaborative discussions about sensorimotor sensations that result in an urge to move, and observable/non-observable movement patterns for being able to sit still, but need electrophysiological validation.



## Parenting stories and service needs in families raising a child with ASD

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**Background:** The risk for parental stress and depression in conjunction with autism spectrum disorders (ASD) in the child is increasingly recognized. Recent results emphasized that parents of children living with ASD show different patterns regarding their readiness to contribute actively to the care of their children: some of the parents develop highly devoted 'therapeutic' knowledge and/or skills, others rather wish to rely on the care system.

**Aim:** The study aimed to describe the primary caregiver parents' narrative strategies several years after the diagnosis of a child with ASD. Further, the parental narrative accounts were related to specific service needs.

**Method:** The research was based on semi-structured retrospective interviews with twenty primary caregiver parents of children living with ASD – nineteen mothers and a father – about the period of their lives from the birth of the child to the present. The interviews were recorded in the framework of a national project about the life quality of families caring for an autistic member in Hungary. Main steps of the analysis were: 1. By cross-case analysis, thematic categorization and meaning condensation were carried out on parental care. 2. Case-by-case analysis to structure interview texts according to narratives.

**Result:** Parental narratives could be classified into two main groups: NON-TRANSFORMATIONAL PARENTING and TRANSFORMATIONAL PARENTING. Non-transformational parenting implied either a prolonged complex crisis in the primary caregiver mother or on the opposite, resilient coping in the family. Transformational parenting involved considerable long-term, gradual learning processes was either an active coping type and in the specific circumstances implied the experience of personal growth.

**Conclusion:** Service needs should be carefully assessed in accordance with learning style of the parents, which highlights the need for significant flexibility in parental supporting services.

## **A decision scheme for monitoring and intervention in hip disorders in bilateral spastic cerebral palsy**

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**Background:** Hip displacement occurs frequently in patients with cerebral palsy (CP). Monitoring and surveillance has proven to be successful in Australia and Scandinavian Countries. A variety of interventions is used to treat hip displacement in CP, once diagnosed. There is no consensus on the exact timing and nature of the surgical interventions related to age, GMFCS level, and radiological assessment.

**Aim:** The algorithm aims to assist clinical decision making to reduce the number of dislocated and painful hips in children and adults with CP in the Netherlands.

**Method:** We developed a decision scheme for the monitoring of hip displacement in children with bilateral spastic CP and its consequences for intervention, based on the current Australian and Swedish surveillance scheme, and the available literature.

**Result:** A decision scheme for the monitoring of hip displacement in bilateral spastic CP and its consequences for intervention. The main criterion for decision is the GMFCS classification. Between the ages of 2 and 7 the GMFCS levels II and III are combined, just as IV and V. After the age of 8 the levels II and V are treated individually, and III and IV are combined. CPHCS and MP are used as a tool to decide about intervention. The scheme was accorded by Dutch Pediatric physiatrists as the Dutch Consensus for monitoring and intervention of hip displacement in bilateral spastic CP.

**Conclusion:** With this scheme we provide an instrument for the surveillance and intervention on hip displacement in patients with bilateral spastic cerebral palsy, to be used in daily practice. It is the first scheme that combines a surveillance algorithm with intervention measures. Intervention includes soft tissue and bony surgery.

## Optimization of MRI-based scoring scales of brain injury severity in children with unilateral cerebral palsy

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**Aim:** A semi-quantitative MRI scoring system (Fiori Scale) for measuring brain injury severity is valid and reliable. This study aimed to use statistical techniques to optimize the clinical utility of the Fiori template-based scoring method by weighting individual anatomical scores of injury, while maintaining its simplicity by retaining only a subset of scored anatomical regions.

**Participants and setting:** 52 children with periventricular white matter (PWM) injury (29 male, mean age 11y2mo [SD 3y4mo], Manual Ability Classification System I=31, II=21 and 24 with cortical and deep gray matter (CDGM) injuries (12 male, mean age of 12y3mo [SD 2y3mo], MACs I=7, II=17 were included.

**Materials/Methods:** All children with UCP were evaluated in terms of upper limb motor function using the Assisting Hand Assessment (AHA) and brain lesion severity visible on MRI were recorded using a semi-quantitative approach. A subset of the template-derived cerebral regions was selected using a data-driven region selection algorithm. Linear regression was performed using this subset, with interaction effects excluded.

**Results:** Linear regression improved the correlation between the MRI-based assessment and the Assisting Hand Assessment for both periventricular white matter (R squared increased to 0.45 from 0,  $P<0.0001$ ) and cortical and deep gray matter (0.84 from 0.44,  $P<0.0001$ ) cohorts. In both cohorts, the data-driven approach retained fewer than 8 of the 40 template-derived anatomical regions.

**Conclusion:** The strong and significant correlation between Assisting Hand Assessment scores and image-based assessments using a small subset of anatomical regions highlights the potential for computer-based methods to enhance the quantification of injury, while maintaining the clinical expediency of image-based scoring approaches. Optimisation of the Fiori semi-quantitative MRI scoring provides potential for prediction of brain structure and functional outcomes in children with UCP.

## **Inter-rater reproducibility of the Hammersmith Neonatal Neurological Examination in very preterm infants at 30 and 40 weeks postmenstrual age**

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**Background:** The Hammersmith Neonatal Neurological Examination (HNNE) is a discriminative, evaluative and predictive tool that assesses infant neuromotor status in six domains.

**Aim:** The aim of this study was to determine the inter-rater reproducibility of the HNNE when used in the assessment of very preterm infants at 30 weeks and 40 weeks (30<sub>WKS</sub>; 40<sub>WKS</sub>) postmenstrual age (PMA).

**Method:** Thirty infants were assessed at 30<sub>WKS</sub> PMA: 20 male, mean gestational age 27 weeks 5 days (SD 2 weeks 1 day), mean birthweight 1082g (356 g). Five infants were assessed at 40<sub>WKS</sub> PMA: 3 male, mean gestational age 28 weeks 0 days (2 weeks 0 days), mean birthweight 801g (205 g). At each assessment, the HNNE was delivered by one rater and scored independently by two raters. Agreement between raters was assessed using Bland & Altman's limits of agreement (LOA). Reliability between raters was assessed using intra-class correlation coefficient (ICC).

**Results:** There was strong agreement between raters at 30<sub>WKS</sub> PMA, with 95% of total HNNE optimality scores differing by less than 2 points and 19/30 scores differing by 1 point or less. Total HNNE optimality score had 'excellent' reliability at both 30<sub>WKS</sub> PMA (ICC 0.95, n=30) and 40<sub>WKS</sub> PMA (ICC 0.99, n=5). Of the six domains, agreement and reliability were highest for 'Tone Patterns' and lowest for 'Movements'.

**Conclusion:** The HNNE is a highly reproducible tool for assessing very preterm infants. It is an appropriate neurological screening assessment for this population because it is quick, cheap, valid and reproducible.

## Relationship between white matter integrity and neurological function in preterm infants at 30 weeks postmenstrual age

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**Objective:** To examine the relationship between very early brain structure (structural MRI), white matter integrity (diffusion MRI) and neurological function at 30 weeks post menstrual age (PMA) in infants born very preterm.

**Design:** Prospective cohort study.

**Method:** At 30 weeks PMA 57 infants born <31 weeks: 24 male, mean gestational age (GA) at birth 28.3wks (SD=1.6), mean birthweight (BW) 1099g (SD=269g), mean age at MRI 32.1wks (SD=1.4), mean HNNE scores 15.5 (SD=4.3). Infants underwent 3T MRI using an MRI compatible incubator without sedation at 30-32 weeks PMA. The structural MRI was segmented in gray matter (GM), white matter (WM) and CSF, and labelled using the Albert Atlas in infants classified as normal, poor repertoire and cramped synchronized on General Movement's assessment. A population specific Fractional anisotropy (FA) atlas was created using John Hopkins Unit neonatal Atlas. The Hammersmith Neonatal Neurological Examination (HNNE, scores 0-34) was related to regional volumetric or diffusion scores (Frontal, Parietal, Temporal, Occipital, Thalamus, Ventricle) using multivariate regression with 5% (R).

**Results:** HNNE scores, brain size and age at MRI were associated with volumetric measures. GM fraction ( $R^2=0.3$ ;  $F=7.0$ ;  $p<0.05$ ), occipital ( $R^2=0.33$ ;  $F=7.4$ ;  $p<0.02$ ), and temporal ( $R^2_{adj} 0.09$ ;  $F=5.0$   $p<0.04$ ; GM superior posterior part). HNNE scores were associated with FA, in particular, Corpus Callosum ( $R^2=0.1$ ;  $F=2.7$ ;  $p<0.05$ ) and fornix ( $R^2=0.09$ ;  $F=2.7$ ;  $p<0.05$ ). Adjustment for gestation age and age at MRI were important.

**Conclusion:** Very early brain development in infants born preterm has a modest relationship on a bed-side neurological assessment and structural or diffusion MRI at 30 weeks PMA. Infants can be scanned safely early and advanced imaging with corresponding clinical tools has an important role to play in earlier detection of motor delay and infants at risk of a later diagnosis of Cerebral Palsy.

## **Very early brain structure and neurological function detects brain injury in preterm infants at 30 and 40 weeks postmenstrual age**

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**Objective:** Relationship between neurological function and structural MRI at 30 and 40 weeks postmenstrual age in very preterm infants.

**Design:** Prospective cohort study

**Method:** At 30 weeks postmenstrual age (PMA) 94 infants born at <31 weeks gestation were assessed, 58 males, mean gestational age at birth 28 weeks 1 day (1 week 6 days), birth weight 1092g (321g) and PMA at MRI 32 weeks 1 day (1 week 3 days). Of these, 83 were reassessed at mean PMA 40 weeks 6 days (1 week 3 days). Infants underwent 3T MRI and Hammersmith Neonatal Neurological Examination (HNNE) at 30-32 weeks and 40-42 weeks PMA. An structural MRI scoring system (Kidokoro et al) generated white matter, grey matter and global injury scores. Univariable and multivariate logistic regression were conducted ( $p < 0.05$ ).

**Results:** At 30 weeks PMA, significant associations were found between HNNE scores and grey matter scores [median (IQR)= 2(1-3)], regression mean difference (MD) = -0.16, 95% CI = -0.25 to 0.07,  $p < 0.01$ ; and global scores [4(3-7)], MD = -0.28, 95% CI = -0.47 to -0.1,  $p < 0.01$ . At 40 weeks, HNNE scores were significantly associated with white matter [2(1-4)], MD = -0.14, 95% CI = -0.28 to -0.01,  $p = 0.04$ ; grey matter [0(0-2)], MD = -0.11, 95% CI = -0.18 to -0.04,  $p < 0.01$ ; and global scores [3(1-5)], MD = -0.25, 95% CI = -0.42 to -0.08,  $p = 0.01$ .

**Conclusion:** MRI brain structure is significantly related neurological function in preterm born infants at 30 weeks postmenstrual age and is reconfirmed at 40 weeks. Early MRI is feasible at 30 wks PMA and early brain structure and neurological function have an important role in the very early detection of brain injury in infants at risk of CP.

## Relationship between MRI brain lesion severity and hip displacement outcomes in children with cerebral palsy

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**Background:** Hip displacement is the second most common deformity in CP. Previous studies have examined both hip displacement and brain structure in CP separately, but to our knowledge none have examined the relationship directly.

**Aim:** To explore the relationship between brain lesion severity on MRI and hip displacement outcomes in children with CP.

**Methods:** This cross-sectional study examined a prospective population-based longitudinal cohort of children with CP. 124 children (70 males) born from 2004 to 2009 were included. Gross Motor Function Classification System (GMFCS) levels were I=53, II=18, III=16, IV=17 and V=20, and motor type distributions were unilateral spastic=36, bilateral spastic=65, dystonia=7, ataxia=4, hypotonia=5 and athetosis=6. Hip radiographs with migration percentage (MP), acetabular index (AI) and Hilgenreiner Epiphyseal Angle (HEA) measures, and brain MRIs with qualitative and semi-quantitative scoring were performed before age 5.

**Results:** A higher global score on the semi-quantitative MRI scale (Fiori) was associated with a higher MP (mean difference, MD 0.5, 95%CI 0.3-0.7,  $p<0.001$ ) and AI (MD 0.2, 95%CI 0.1-0.3,  $p<0.001$ ) but not a lower HEA. Qualitative KM classification of brain lesions had no association with hip displacement. Higher levels of GMFCS were associated with higher MPs and AIs ( $p<0.001$ ). A significant association was found between motor type and the MP and AI ( $p<0.001$ ). Multivariable regression modelling examining brain MRI global score, GMFCS, motor type and GA in relation to hip displacement outcomes found that GMFCS was the only significant contributor.

**Conclusions:** The semi-quantitative brain MRI scale is useful in determining children with CP at risk of hip displacement. GMFCS had the strongest importance in predicting hip displacement severity. The semi-quantitative MRI scale could be used clinically to complement the GMFCS in screening for those children with CP at risk of hip displacement.

## **Access to employment: the achievement of life projects**

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A pressing concern with the integration of people with disabilities leads to rethinking and reinventing strategies in order to better fit the existing services. The Oporto Cerebral Palsy Association has a Qualification and Employment Resources Center that aims to challenge people with disability to redefine and achieve their life goals, aiming that each one has the opportunity to try their skills in different contexts.

The aim is to describe an intervention developed at this center, which goal is to support people in making vocational decisions, providing information necessary for defining career paths; evaluating their functioning and determine the means and support necessary to the definition and development of their personal employment plan.

Participants were 26 persons with disabilities, 58% female, and 42% female, with a mean age of 30 years old.

Intervention lasts for 4 months and is divided into 4 phases: Interview and evaluation of adult life skills (self-advocacy, recreation, independent living, health and wellbeing); Group sessions (Vocational and Professional Guidance, Education for Citizenship, Information on rights and duties at work, Support measures to employability, Mobility within the Community); Vocational training (opportunity to perform tasks / roles in the workplace); Evaluation of habits, attitudes and performance skills at work, using the Becker Work Adjustment Profile.

The initial assessment shows that the main difficulties are the management of adult life skills, particularly in the social and civic domain and in mobility in the community.

According to the Becker Work Adjustment Profile, the employability profile is adequate, with a percentile of minimum value of 60 and maximum of 98, being the most frequent the percentile 70.

This new methodology seems to foster people's confrontation with their expectations, needs and abilities in order to promote their self-determination and the achievement of their life project.



## **MRI Patterns associated with function and comorbidities in 494 children from a SCPE affiliated National Registry**

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**Background and Aims.** Magnetic resonance imaging (MRI) is an important tool in the characterization of cerebral palsy (CP). The function and morbidity of children with CP are described according to their MRI.

**Methods –** Cross-sectional study based on active surveillance data of 5-years-old children born in Portugal in 2001-2006, reported to the National Surveillance of Cerebral Palsy in Portugal. SCPE definitions, functional classifications (GMFCS, BMFM, MACS, IQ, vision, hearing, communication) and MRI classification of pediatric MRI based on the predominant pattern (Krägeloh-Mann et al.) were used. Chi-squared test and relative risks were calculated.

**Results –** In 1107 children, MRI was performed in 613 and a report was available for classification in 494 (17 deceased before 5yoa were excluded). The sample included 58% born at term, 81.7% with spastic CP (66.4% bilateral), 7.4% had post-neonatal CP. The predominant MRI pattern was: Congenital anomaly (A) 14.2% (70), White matter lesion (B) 37.7% (186), Grey matter lesion (C) 32.2% (145), non-classified 10.1% (50) and Normal 7.9% (39). Highly significant differences on functional severity assessments and prevalence of morbidities were found. Overall, the best outcomes were found in children with pattern B MRI. Comparing levels IV-V with levels I-II, patterns B vs. C had a RR = 0.62 [95%CI 0.473-0.822] for GMFCS and 0.42 [95%CI 0.311-0.571] for BMFM, a RR of IQ<50 0.61 [95%CI 0.464-0.803] and for epilepsy, a RR = 0.69 [95%CI 0.531-0.906]. Among the patterns most predominant in children born at term, a RR = 1.29 [95%CI 1.037-1.602] for epilepsy if pattern A vs. C.

**Conclusions -** Major morbidity and function in children with CP are strongly associated with the predominant patterns found in MRI. Early MRI may be a useful aid for prediction of later outcomes.

## **The Poor Outcome of Soft Tissue Orthopedic Surgery in Adults with Cerebral Palsy**

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Title: The Poor Outcome of Soft Tissue Orthopedic Surgery in Adults with Cerebral Palsy

### **Background**

There is little known about the outcomes of soft tissue orthopedic surgery in adults over the age of 21. We started an adult cerebral palsy clinic in 1995 and have seen over 3500 unique patients. It is critical to know what surgeries will be successful in treating adults with fixed joint and muscle contractures

### **Aim**

To evaluate the short and long term results of soft tissue orthopedic surgery on a large cohort of adult patients with cerebral palsy

### **Method**

A review of the surgeries performed during this period of 1995-2013 was performed using CPT surgery codes and a billing database. Those patients who had surgery had complete chart reviews and when possible longer term histories and physical examinations.

### **Result**

375 patients underwent soft tissue surgery only, 223 patients had soft tissue and bony surgery combined and 187 had only bony surgery. The soft tissue surgery included upper extremity tendon lengthenings and tendon transfers. The lower extremity soft tissue surgery included adductor lengthening, hamstring lengthening, rectus femoris transfer, gastroc soleus recession and tendoachilles lengthening, and/or tibialis posterior lengthenings or transfers.

The only surgeries which had long term success were gastrocssoleus recession and tendoachilles lengthenings for those who had severe equinus contractures. In 78 percent of the other surgeries, there was a rapid return to their initial position despite bracing. The long term outcomes demonstrated no change in these contractures. 87 percent of those who had bony surgery either in isolation or in conjunction with soft tissue surgery had acceptable surgical outcomes.

### **Conclusion**

Soft tissue surgery alone should not be performed in adults with cerebral palsy unless there is a limited goal of improving equinus contractures and even this must be accompanied by therapy and long term bracing.

## Factors associated with daily activity in preschool children with cerebral palsy

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### Background:

Identifying the factors associated with activity in daily living (ADL) in children with cerebral palsy (CP) can allow clinicians early anticipating the ADL outcome.

**Aim** This study aims to identify the factors associated with ADL outcome in preschool children with CP.

### Methods:

Seventy eight children with CP (1–6 years) were enrolled in this cross-sectional study. Eight factors were identified and assessed at baseline: age; sex; gross motor function classification system (GMFCS) level; manual ability classification system (MACS) level; pediatric balance scale (PBS), Spinal alignment and range of motion measure (SAROMM), modified Ashworth scale (MAS), and cognition abilities measured by Comprehensive Developmental Inventory for Infants and Toddlers (CDIIT-Cog). ADL outcome was assessed by pediatric functional independence measure (WeeFIM), which consists of self-care, mobility, and cognition domains.

**Results:** Regression analyses showed PBS and age predicted all domains and total WeeFIM (adjusted  $r^2=0.67-0.75$ ,  $p<0.01$ ). The CDIIT-Cog was the predictors for all domains and total WeeFIM except mobility domains. The GMFCS levels predicted mobility domains.

**Conclusion:** The best predictors for WeeFIM are PBS and cognition abilities in children with CP. Findings suggest that good balance control and cognition abilities in children with CP may benefit most from therapy on ADL.

**kinematics during gait in hemiplegic cerebral palsy and typically developing children: ages 4-18**

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**Background:**

Children with hemiplegic cerebral palsy (hCP) exhibit a typical posture of elbow flexion during gait. However, the change in elbow kinematics and symmetry during gait across age span in both hCP and typically developing (TD) children is not well described.

**Aim:**

To quantify the change in elbow kinematics and symmetry across age span in hCP children compared to TD children.

**Methods:**

UE kinematic data was extracted and analyzed from a database for gait studies performed between 2009-2015. 35 hCP and 51 TD between the ages of 4-18 (mean age: TD=11.2±0.6, hCP=9.8±0.5) met inclusionary criteria. The groups were further subdivided by three age categories: 4-7, 8-11, 12+ years old. Elbow angles were extracted and maximum joint angle position, overall range of motion during gait and asymmetry indices were calculated. A one-way ANOVA was performed on each group with post hoc Tukey HSD pairwise comparisons.

**Results:**

Elbow flexion increased with age in TD ( $p<0.05$ ) and decreased with age in hCP on the affected side ( $p<0.05$ ). There was no change on the unaffected side. TD children demonstrated significantly less elbow flexion (mean =  $51.9^{\circ}\pm 2.1^{\circ}$ ) compared to the affected side in hCP (mean =  $82.1^{\circ}\pm 3.8^{\circ}$ ) across all age categories ( $p<0.05$ ). There was no change in elbow asymmetry index (0=perfect symmetry) across age in either controls or hCP children; however, there were differences between hCP and TD groups in younger age groups (TD=28, CP=62,  $p<0.05$ ) that resolved by adolescence (TD=32, CP=40).

**Conclusions:**

hCP children typically demonstrate more elbow flexion on the affected side compared with TD children. In TD children the elbow flexion angle progressively increases with age, whereas in hCP elbow flexion angle decreases with age. Thus, elbow symmetry during gait improves with age in hCP, approximating symmetry of TD children by adolescence. These findings have serious implications for the timing of intervention to improve elbow spasticity.

## **Food group energy intake of pre-school aged children with cerebral palsy in relation to gross motor function and oropharyngeal dysphagia**

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**Background/Aim:** To examine energy intake from food groups in relation to feeding difficulties and gross motor function in children with cerebral palsy (CP).

**Method:** Prospective cohort study. Hundred-eighteen children with CP (81 male), mean age  $2.7 \pm 0.8$  yrs. GMFCS levels: I=48, II=17, III=18, IV=12, V=23. 66 children had no, 24 mild, and 28 moderate/severe oropharyngeal dysphagia (OPD) determined by parent-reported questionnaire. Sixteen were partial/totally tube-fed. Food groups were categorised according to Australian Guidelines. Energy (KJ) and food group intake were determined by parent-completed 3-day food-record analysed by Foodworks<sup>TM</sup>. Data analysis utilised ANOVA and Welch's tests. Data are mean difference (KJ) (95% confidence interval).

**Results:** The greatest contribution to energy intake (excluding tube-feeds) for children GMFCS V and those with moderate/severe OPD was from dairy and 'extras' (non-core foods) in children GMFCS I-IV. Children GMFCS V compared to GMFCS I had lower energy intakes from all food groups (dairy:-817(-1333 to-237), meat:-228(-406 to-49), fruits:-342(-474 to-211); 'extras':-1243(-1647 to-840), cereals:-590(-821 to-358)) except vegetables. For children with no/mild OPD 'extras' contributed the greatest energy intake. Children with moderate/severe OPD had lower energy intakes from all food groups except vegetables than those with no OPD (meat:-180(-327 to-34); dairy:-617(-1060 to-175); cereals:-500(-760 to-239); fruits:-281(-381 to 182); 'extras':-1148(-1553 to-742)).

**Conclusion:** Dairy provided greatest energy for children GMFCS V and severe OPD; these children had low intakes from all food groups. All levels had low intakes of vegetables. The greatest energy intake from 'extras' for children GMFCS I-IV may reflect intentional use of these foods to increase energy intakes of children with CP. These results highlight that recommendations for food group intakes may not be relevant in the CP population due to altered energy requirements.

## Association between nutritional status, energy intake and health and participation in pre-school aged children with cerebral palsy.

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**Background:** Nutritional status is variable in children with cerebral palsy (CP).

**Aim:** To explore the relationship between nutritional status, energy intake and health and participation in children with cerebral CP.

**Methods:** Prospective cohort study of 135 children (42% male) with CP mean age  $4.1 \pm 1.2$  yrs, GMFCS: I=63; II=15; III=24; IV=10; V=23. Anthropometric measures were collected: height/length and weight, converted to Z-scores. Fat mass (FM) and fat free mass (FFM) were determined via deuterium dilution technique or bioelectrical impedance analysis (with published hydration constants). The indices FFM/height<sup>2</sup> (FFMI) and FM/height<sup>2</sup> (FMI) were calculated. Energy intake was calculated by parent-completed 3-day food-record analysed by Foodworks<sup>TM</sup>. Health and participation data for a 4-week period were collected via parent-reported questionnaire. Statistical analysis utilised logistic and multiple regression.

**Results:** There was no significant relationship between the children being ill and height Z-score, weight Z-score, BMI Z-score, body fat (BF%), FMI, FFMI or energy intake. This sixty-eight children (67% male) reported illness: Mean height/length and weight were  $-0.42 \pm 1.2$  and  $-0.28 \pm 1.4$  and FFMI and BF% were  $12.6 \pm 1.4$  and  $21.4 \pm 6.1$  respectively. Mean energy intake was  $4.8 \pm 1.6$  MJ/day. Children who had more days in bed had greater weight Z-scores ( $\beta = 0.37$ ,  $p < 0.05$ ), though was not related to FFMI, BF% or energy intake. There were no significant relationships between child/family unable to perform usual program/activities or days in bed and FFMI, BF%, weight Z-scores or energy intake.

**Conclusion:** Nutritional status and energy intake were not related to acute illness. Ill children who were heavier spent more days in bed. No other relationships between nutritional status and energy intake existed with health and participation of children and families. Further research investigating the relationship between nutritional status, energy intake and chronic illness is warranted.

## **Reduced muscle stem cell number impairs serial sarcomere addition and causes muscular contractures**

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**Background:** Children with cerebral palsy (CP) develop muscle contractures that show a reduced number of muscle stem cells, i.e. satellite cells (SC), required for postnatal growth and a decreased number of sarcomeres, the basic contractile proteins.

**Aims:** Use a transgenic SC knockdown mouse model to test the hypothesis that reduced SC number could lead to impaired sarcomere addition and to create a murine contracture model.

**Methods:** Transgenic mice (Pax7-DTA) were treated with Tamoxifen to reduce SC number, casted in dorsiflexion for 2 weeks to promote stretch-induced serial sarcomere addition in the soleus. The mice were sacrificed and soleus muscles were harvested to determine muscle architecture. To create a contracture model Pax7-DTA mice were casted in plantarflexion, i.e. soleus lost sarcomeres, treated with either Tamoxifen or Vehicle (control). Subsequently, casts were removed and animals were allowed to recover their ankle range and sarcomere number.

**Results:** Mice had 65-75% reduction in SC vs. control, similar to children with CP, but were able to add sarcomeres under stretch ( $p < 0.05$ ). However histologically the quality of muscle was poor with increased areas of fibrosis, decreased muscle area fraction and decreased fiber size. The contracture model revealed that the Tamoxifen group developed a contracture (maximal dorsiflexion angle  $-16^\circ$  vs.  $31^\circ$ ,  $p < 0.05$ ) and, correspondingly, sarcomere number did not recover ( $-13\%$  vs.  $-3\%$ ,  $p < 0.05$ ). Importantly, a strong association ( $p < 0.05$ ,  $r^2 = 0.99$ ) was observed between the degree of contracture and serial sarcomere number.

**Conclusions:** Reduced SC number in children with CP could be responsible for impaired sarcomerogenesis and contractures. A reduced cohort of SC is sufficient for stretch-induced sarcomere addition, but a full cohort is necessary for optimal adaptation. With reduced SC number recovery from a shortened position by sarcomere addition is significantly impaired and associated with contracture development.

## **Changing Geographical Boundaries of Queensland CP Population in First 15 Years of Life**

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**Background:** There is evidence the long held belief that families of children with disabilities move less remotely towards services may not be correct. The CP population of Australia, birth years 1996 – 2005, did not reduce average remoteness by five years of age, because 11% moved more remotely and 9% moved less remotely.

**Aim:** To determine if the profile in change of residential remoteness in the Queensland cerebral palsy population changes after 5 years and to investigate if the motivation for change in residence is different between families who move less remotely and more remotely.

**Method:** Postcode data at birth, 5, 10 and 15 years along with reason for change of address were collected by phone interview for 138 registrants (63%) born during birth years 1993 – 95 from the CP register. Each postcode was assigned an approximate remoteness value, and individual change in remoteness values at 5, 10 and 15 years were averaged for the whole population and compared using t-test to show change in population remoteness. Individual change in residential remoteness values were grouped into those who moved less remotely, those who moved more remotely and those who did not change remoteness. The frequency distributions of reasons for residential change were compared between groups.

**Results:** Consistent with previously analysed populations under 5 years, changes in average remoteness were very small and did not increase after 5 years ( $p=0.54$ ). The frequency distribution of factors between moves less and more remotely changed. Forty-three percent of moves to less remoteness were for employment and 31% of more remote moves were due to housing tenure concerns. Access to health and Education combined motivated less than 20% of moves in both directions.

**Conclusion:** Services in Australia must plan for continuing regional and remote service provision while other countries should not assume their populations will move closer to services until evidence is provided.



## **Cumulative prevalence, clinical features and MRI findings in children with cerebral palsy in Zadar County from 2003-2010**

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**BACKGROUND:**The prevalence of children with cerebral palsy is 2-3/1000 of live-born infants in Europe, according to Surveillance of Cerebral Palsy in Europe (SCPE) CP data base.

**AIM:**To determine the cumulative prevalence and MRI of children with cerebral palsy and associated neurodevelopmental impairments in Zadar County during period 2003-2010.

**METHOD:**This study involved children with cerebral palsy living in the Zadar County, born from 1<sup>st</sup> of January 2003 to 31<sup>st</sup> of December 2010. Functional classification of CP, associated neurodevelopmental impairments and MRI was done according to SCPE.

**RESULTS:**The study comprised 38 children with CP with age between 5 and 11, included in "C28 RCP-HR" Register of cerebral palsy of SCPE. Given the number of patients with CP (38) to the total number of live births in Zadar County during the eight years (13579), that makes the cumulative prevalence of 2.79/1000. 33 children were diagnosed with spastic (87%), 4 of them (10%) had dyskinetic and only one child ataxic (3%) CP. 21 children (64%) had bilateral spastic CP and 12 children (36%) had unilateral spastic CP. 50% of the total number of children with CP were prematures. MRI in most cases showed damage to the brain's white matter (53%).

Subsequently, the most frequent was the predominant damage to grey matter in 34%. Only 5% of children had brain maldevelopment, 3% miscellaneous, whereas in 5% children with CP MRI was normal. Visual disturbance was present in 53% of patients, hearing disturbance in only 2,6%, speech disorder in 55%. 36,8% of children with CP had epilepsy, while some degree of the intellectual deficit was present in 66% of patients.

**CONCLUSION:**Cumulative prevalence of children with cerebral palsy in Zadar County corresponds to the rate of CP prevalence in Europe. Associated neurodevelopmental disorders are present in similar rate whereas brain malformations are represented in lower rate as well as normal MRI findings.

## **Short- and midterm evolution of self-care and functional mobility after single event multilevel surgery in children and adolescents with spastic diplegic cerebral palsy**

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### **Abstract**

**Background:** Most studies after single event multilevel surgery (SEMLS) investigated the effect on gait. However there is a lack of studies focusing on the impact of SEMLS on activity level like self-care and functional mobility.

**Aim:** The aim of this study is to assess the short- and midterm evolution of self-care and functional mobility after multilevel surgery in children and adolescents with spastic diplegic cerebral palsy and to identify which factors impact on these outcomes.

**Methods:** Thirty-four participants were evaluated before surgery, at nine weeks and six months. Twenty-six participants out of 34 completed follow-up at one year. Self-care was assessed with the Pediatric Evaluation of Disability Inventory-NL (PEDI-NL). The Mobility Questionnaire47 (MobQues47) and Functional Mobility Scale (FMS) measured functional mobility. Evolution in time and interactions between CP, personal and environmental characteristics were assessed with linear mixed models.

**Results:** All outcomes revealed a significant decrease nine weeks post SEMLS (p-values between <0.0001 and 0.04) followed by a significant increase at six months (p-values between p<0.0001 and 0.01). At six months the baseline scores were obtained for the PEDI-NL but there was a significant lower score compared to baseline for FMS 5, 50 and 500 meters and the MobQues47 (p-value between <0.0001 and 0.004). Between six months and one year, a further significant increase was revealed for the MobQues47 (p<0.0001). MACS, initial muscle strength and the baseline score influenced significantly time trends for self-care and functional mobility. Age and number of surgical interventions also had a significant influence on time evolution of self-care.

**Conclusion:** Children and adolescents needed more time to recover for functional mobility than for self-care. Participants with a higher functional level before surgery will lose more than participants with lower initial functional ability.

## **Postural control in children with cerebral palsy: a Delphi driven status report on current practice definitions, frameworks, assessments and interventions**

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**Background:** Although postural control dysfunction is a defining feature of Cerebral Palsy (CP), and a common treatment focus, our recent systematic review identified limited published consensus on definitions, theoretical frameworks, assessment items or interventions for this clinical problem.

**Aim:** Investigate current practice perspectives regarding postural control definitions, frameworks, assessments and interventions for children with CP and synthesize these in a consensus status report to guide future psychometric and outcomes research.

**Method:** A 3-round Delphi survey was distributed to: international postural control authors in CP; Australasian CP and Developmental Medicine academy members; and rehabilitation providers. Round-I sought item nominations in all categories. Systematic review items were then added. In Round-II/III participants ranked each item on a 7-point Likert scale. Threshold for consensus was  $\geq 85\%$  agreement.

**Results:** 43 researchers and clinicians from 7 countries with a mean of 20 years (sd 11 years) experience responded. Of 306 items nominated, 173 reached consensus. Definition reached easy consensus (19 of 21 items), with items collated as 'Control of the body's position in space for postural orientation and postural stability'. Framework knowledge and consensus were low. Two general frameworks, the 'ICF' and 'motor learning', were accepted (2 of 12 items), but no postural control specific frameworks. Assessment generated most items, but low consensus (42 of 88 items). Interventions were prevalent, including many new approaches. Of 52 of 87 items accepted, 'Goal directed task training' showed strongest consensus. No intervention reached consensus for dose.

**Conclusion:** Postural control frameworks, assessments and interventions lack consensus for CP. Psychometric research is needed to develop a comprehensive test battery. Outcomes research is needed to improve intervention selection and dosage. Knowledge translation must follow this work.

## Development of Executive Functions in Preschool Children with Sickle Cell Anaemia

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### Background

Sickle cell anaemia (SCA) is a blood disorder caused by inheriting two S-type genes for haemoglobin. Children with SCA are at a high risk of stroke, but even without stroke, they can develop difficulties in executive functioning (EF). EF is the ability to execute cognitive control in high-level processes such as planning or problem solving. SCA research with pre-school children has previously relied on parent-report, making it difficult to ascertain the extent of possible EF deficits. Early detection could lead to the development of targeted interventions and improve school readiness.

### Aim

Develop a neuropsychological profile of EF in preschool children with SCA.

### Method

Twenty-two children with SCA aged 3-5 years, with no history of stroke, were compared with a matched comparison group. EF tasks included behavioural, parent-report, and event-related potential (ERP) measures. The battery was comprised of novel tasks and established measures including the Behaviour Rating of Executive Function (BRIEF)-Preschool, NIH toolbox tasks, and the EF Scale for Early Childhood. The Wechsler Intelligence Scales were used to match for intellectual ability.

### Results

Children with SCA obtained poorer scores on specific EF tasks, particularly switching, with significant differences observed for underlying executive-related neural correlates on the ERP task. However, no significant differences were observed on the parent-report measure.

### Conclusion

Differences in neural correlates and specific aspects of EF did not translate to parent report. Specific deficits in EF, detected with behavioural measures, may not yet have translated into problems with EF in everyday life. Previous studies using the BRIEF in older children with SCA found poorer EF, which suggests that direct assessment, instead of reliance on parent report, could be important in the detection of early deficits. This study helps guide future early neuropsychological assessment and intervention.

## Daily living pain in children with Autism Spectrum Disorder: the NCCPC-ASD

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**BACKGROUND:** Assessment is a very complex and challenging issue in people with autism spectrum disorder (ASD) because of social and cognitive deficits, behavioral particularities and because there is no pain assessment tool specifically designed for this population in daily living context. The purpose of the present study is to improve knowledge of daily living pain expression and assessment in children with ASD.

The objectives are 1) to describe daily living pain expression with the Non Communicative Children Pain Checklist-revised (NCCPC-r) rated by the parents and 2) to examine psychometric properties of this scale for children with TSA, testing the internal structure validity.

**METHOD:** Thirty-five children with TSA were recruited (median age: 58 months; developmental age: 32 months). The French version of the NCCPC-r (Grille d'Evaluation Douleur - Déficience Intellectuelle; Zabalia et al., 2011) was used and rated by parents.

**RESULT:** Qualitative analysis has shown that children with ASD displayed behavioral pain reactions in daily living context. Some reactions are normative and related to the pain (e.g., cry, seeking comfort); some others are unusual and seem to be specific to this population (e.g. change in eyes, flinching). Analysis of the psychometric properties highlighted a 4-factors solution which explained 54.4% of the total variance. Cronbach's and Pearson's coefficients showed good properties in terms of factorial validity ( $r > .40$ ), internal consistency ( $\alpha > .70$ ) and discriminant validity ( $r > .40$ ). The NCCPC-r adapted for children with ASD contains 24 items divided into 4 subscales. This tool is named NCCPC-ASD.

**DISCUSSION:** This study contributes to specify daily living pain expression in children with ASD. The NCCPC-ASD seems to be fitted to assess daily living pain in this population. This scale could help careers and family to better identify pain in children with ASD.

## Analysis of the medical causes of death in cerebral palsy

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**Aim:** To investigate causes of death and age at death in cerebral palsy subjects compared with the general population.

**Method:** Analysis of data supplied by the Centre of Epidemiology on the Medical Causes of Death within the National Institute of Health and Medical Research in France was conducted. 3,031 death certificates indicating a diagnosis of cerebral palsy (ICD-10 code G80) were reported between 2000 and 2008.

**Results:** Median age at death was between 45-54 years and principal cause of death (24%) comprised the category 'Symptoms, signs, and abnormal results of clinical and laboratory tests, not classified elsewhere'. Of these, 66% were related to the circulatory and respiratory systems. 'Diseases of the respiratory system' were the second most common cause of death (19% compared with 6% in the French general population). The third most common cause of death was 'Diseases of the circulatory system' (15% compared with 29% in the French general population). While deaths caused by tumour pathologies in the general population are the most common cause of deaths, these represented only 7% of deaths in subjects with cerebral palsy.

**Interpretation:** These results concur with other published data, i.e. subjects with cerebral palsy die younger than the French general population, and the principal causes of death are respiratory and circulatory problems. This study emphasises the importance of access to epidemiological data about the French cerebral palsy population.

## **Treatment of Spasticity in Hereditary Spastic Paraparesis.**

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### **Introduction:**

Hereditary Spastic Paraparesis (HSP) is group of inherited disorders characterized by lower extremity weakness and spasticity due to genetic mutations. Gait disturbance start at any age and gradually progresses. Some patients may also show dementia, visual impairment, mental retardation, epilepsy, ichthyosis of the skin.

We describe our experience with their spasticity treatment.

### **Patients and Methods:**

Retrospective study of medical records based on diagnosis of Hereditary Spastic Paraparesis/Paraplegia. Fifty patients aged 6-26 were identified, 25 female. Thirty seven patients had first or second degree family members having the same diagnosis. Consanguinity of parents was reported in twenty cases. Genetic confirmation of diagnosis was recorded in 25 files. Majority of the patients (38) were of Arab descent.

Function was assessed by GMFCS. Half of the patients were functioning at GMFCS level II.

### **Results:**

During follow up, 32 patients had either Botulinum injection or surgery or both.

9 patients were treated with Botulinum injections, followed by three month period of intensive rehabilitation with no subsequent surgery. Seven patients underwent Botulinum injections as first line of treatment, and later on necessitated surgical intervention (tendon recession/lengthening with or without osteotomy). Sixteen children had surgical intervention with no prior Botulinum injection.

Eighteen patients had no intervention as per our records.

### **Discussion:**

HSP is a progressive genetic condition. Mostly treated similar to CP patients using Botulinum injections, intensive physical therapy, orthotics and surgery. However, the need for intervention is not universal. Almost a third of the patients did not have an invasive intervention. Interestingly, the "Botulinum-injection only" subgroup is our younger patients, potentially indicating a more conservative approach that was adopted during recent years.

## **Aquatic rehabilitation of patients with external fixators – feasibility and primary results**

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### **Introduction:**

Patients treated with external fixators may develop limitations in ROM and contractures of joints, and in great need of physiotherapy treatments. Hydrotherapy as part of the treatment plan allows work with gradual progress to increase weight bearing, builds confidence for gait training, decreases pain, enhance circulation and reduce swelling/edema, enables to bring joint further into its range of movement, support strengthening, train balance reactions and postural muscles, and allow aerobic exercises to improve cardiovascular fitness. This therapy is not prescribed on a regular basis.

There may be clinical and technical limitations to this treatment modality, i.e. infections. We established a protocol to allow this treatment to be possible for this patient population

### **Patients & methods:**

During the years 2010-2015 eleven patients with external fixators were referred to a combined therapy protocol of physiotherapy and hydrotherapy. 4 male, 7 female. Age ranged 7.5-26.5 average 17. 7 had unilateral fixator, 4 had bilateral. 7 patients had fixators at the level of the femur, 4 at the level of the tibia.

### **Results:**

2 patients were unable to participate in the hydrotherapy treatments due to recurrent infections/secretions from the fixator pins. All other patients completed the therapy protocol almost without cancelations of treatments. There were no infections during the therapy periods. ROM improved in all patients and all are ambulatory.

### **Conclusions:**

Hydrotherapy as part of the physiotherapy treatment is feasible and allows the patients other modes of treatment. The various additive advantages of the hydrotherapy still need to be explored.



## The effects of ganaxolone on hypoxic ischaemic term lambs

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**Background:** Seizures in neonates are common after hypoxia at birth, and are associated with long-term cognitive and developmental impairment. Current anti-seizure therapies (e.g. phenobarbitone) have been shown to cause brain injury and do not always prevent seizures. We propose that ganaxolone, a GABA<sub>A</sub> agonist, will be more effective at treating seizures, and will reduce markers of brain injury following birth asphyxia. **Aim:** We investigated the effects of ganaxolone or phenobarbitone on electrographic seizures and indices of brain injury following hypoxia ischemia at birth. **Method:** Hypoxia ischemia was induced via umbilical cord occlusion (UCO) during caesarean delivery in near-term lambs. UCO lambs with seizures were treated with either phenobarbitone (20mg/kg i.v. over 30 min) or ganaxolone (5mg/kg i.v. over 30 min); or ganaxolone from 6 h following UCO (5mg/kg/bolus followed by 5mg/kg/day for 2 days). At 48 h, lambs were euthanased for brain collection and analysis. **Results:** At the time of birth, asphyxiated lambs had a pH <7.0 (6.92±0.02) and a base excess >12mmol/L (-14.2±1.1), indicating severe birth asphyxia. Ganaxolone reduced the number of seizures after UCO (7 Vs 2). Unlike phenobarbitone, suppression of the EEG and impaired sleep cycling did not persist with ganaxolone treatment in which normal sleep cycling returned within 6 hours post-treatment. Brain histology showed phenobarbitone-treated lambs had an increase in the number of inflammatory cells and cell death when compared to control lambs. Histology data for ganoxolone is pending. **Conclusion:** Ganoxolone was more effective at suppressing seizures after UCO than phenobarbitone, and facilitated a quicker return to normal sleep state cycling. Our data confirm that phenobarbitone is potentially neurotoxic to the developing brain and further work is required to fully assess the longer-term neurological effects of phenobarbitone and other routinely used anti-seizure treatments as well as ganoxolone.

## Hypermobility in children: pathology or normal variation?

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### Background

Generalized Joint Hypermobility (GJH) is defined as having more-than-normal range of movement in multiple joints. Children with GJH are at greater risk of developing painful arthralgias (especially knee pain) and are more likely to have motor coordination difficulties. Current opinion is that hypermobility in combination with poor motor control, causes repetitive injuries and ultimately leads to joint pain. However, most studies concerning the relationship between pain and GJH were conducted retrospectively in selected populations where joint motions were estimated and motor performance was not directly tested.

### Aim:

To determine the relationship between GJH, pain and motor coordination in children. Our specific objectives were to determine: 1) whether children with GJH experience more pain, 2) whether pain occurs more frequently in children with GJH after activity, and 3) whether children with GJH perform poorer on tests of motor proficiency than children with normal mobility (NM).

### Method:

452 typically developing (TD) South African children (6-10 years) were tested for range of motion (Beighton Scale), and motor performance measures (MABC-2).

### Results:

Children with GJH had higher MABC scores ( $p=0.05$ ) compared to children with NM. The correlation between total Beighton score and MABC total score was  $r=0.13$ ,  $p=0.07$ . 15.1% of children tested reported having pain, with two children reporting moderate to high levels of pain and the majority (42.1%) mild joint pain. Knee pain was the frequently cited area of pain and 8% had pain in two or more joints. Children with GJH experience equal (less) joint complaints and equal (less) pain after exercise.

### Conclusion:

In healthy TD children, hypermobility does not co-occur with and increased risk of a coordination disorder. Hypermobility per se does not co-occur with more pain. The challenge remains to interpret symptoms correctly as being related to the hypermobility and to predict why some individuals are symptomatic.

**Intensive training of hand function for adults with spastic unilateral cerebral palsy. A pilot study using Constraint Induced Movement Therapy (CIMT).**

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**Aim:** The aim of this study was to explore the feasibility and benefit of intensive training with CIMT related to improvement of hand function in adults with spastic unilateral CP. Further, the aim was to evaluate if the results provided a basis for a larger study?

**Method:** The pilot study is based on a prospective experimental design with two randomized groups. The intervention group (n=7) trained intensively for 10 days with CIMT, while the control group (n=5) received no intervention. Outcome measures were Jebsen-Taylor Hand Function Test, Biometrics E-Link and the Canadian Occupational Performance Measure (COPM). The participants were tested at project start, after two weeks, and after three months. The intervention group was interviewed post-intervention.

**Results:** The intervention group showed a significant improvement in fine motor efficiency post-intervention, still significant after three months, while the control group showed no significant changes. The intervention group showed no significant changes in grip strength. None of the groups displayed any significant changes in subjective activity performance appraisal or satisfaction with performance. Two participants in the intervention group showed a clinically relevant increase in satisfaction with activity performance after three months.

**Conclusion:** CIMT is a viable training method for adults with spastic unilateral CP, and the promising results provide a basis for a larger study. The participants reported that intensive training in a group setting provided increased motivation and effort. A larger study should include individual goal directed and maintenance training to strengthen the transfer of new skills to everyday life. Assisting Hand Assessment (AHA, bimanual performance) and Goal Attainment Scaling (GAS) should be included as outcome measures.

## Quality of life of adults with cerebral palsy living in britanny

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**Introduction:** Just a few studies have been published about health related quality of life of adults with cerebral palsy and no at our knowledge in the French population. The objective of this study is to obtain an image of health related quality of life of BreizhPC network users.

**Methods:** A questionnaire was sent to all network users. This questionnaire concerned the people living: work, leisure, clinical complaints, as well as a self SF36 quality of life questionnaire. The SF-36 quality of life give information in different fields: physical activity, emotional life, vitality, general health. The questionnaires were analyzed according to the disability, the influence of social status, level of disability and major clinical disorders. The statistical analysis used the student test.

**Results:** 800 questionnaires were sent out, 173 users responded, 81 women and 92 men, with a mean age of 42. That represent 22 % of the contacted population. The data from 115 people have been exploited. The average age of the population is 42 years. The level of motor disability, travel difficulties, sleep disorders, pain, urinary and transit disorders negatively influence the quality of life. On the other side, sex, employment, epilepsy, communication and swallowing disorders, active sexuality had no influence.

**Discussion Conclusion:** Our results are closed to the literature with some variations, they emphasize the decrease in quality of life in adults with cerebral palsy. Some factors appear more important and require definitely more attention to improve the quality of life experienced by patients: travel difficulties, pain, urinary and transit disorders and sleep disorders.

## **Suggested Clinical Immobilization Test with a Smartphone-Based Electromyography System for Screening Willis Ekbom Disease**

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**Background:** Willis Ekbom disease (WED) might often be missed/misdiagnosed due to diagnostic criteria, which are based on the patients' ability to vocalize the experienced sensorimotor discomfort. The Suggested Clinical Immobilization Test (SCIT) is a clinical test to support diagnosis of WED that relies on physician observations of behaviours and movement patterns.

**Aim:** We developed a smartphone/tablet-based electromyography system that can be used as a clinical tool to provide objective physiological information during the SCIT.

**Method:** The prototype was created by a student team from the UBC department of Electrical and Computer Engineering as part of a Capstone Design Project. This project was pitched at the June 2015 UBC event, the Apps4Kids Hackathon, where video integration was added by volunteer students.

**Result:** The current prototype is based on Android and the Bitalino development board. The device is small (4x2x1.5cm), child-friendly (elastic enclosure band, low-voltage), and rechargeable. It connects to an Android app using Bluetooth, which provides live display and recording of the EMG signal. Preliminary volunteer testing (n=17) shows comparability to physician observations and commercially available portable PSG devices.

**Conclusion:** This EMG system will be a vital tool for clinical assessment of challenging sleep/wake behaviours. The system is currently under refinement by software engineers recruited at the Hackathon. Once finalized, the software will be freely accessible. Future steps will include integrating database storage for analysis with our customized Annotator© software.

## Characteristics of head position and spontaneous movements of limbs in preterm-born infants who later developed ASD

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### [Background]

Previous studies have reported that spontaneous movements between 2 and 4 months post-term age can be associated with minor neurological disorders and cognitive and/or behavioral problems at school age (Hadders-Algra et al. 2004, 2009, Butcher et al. 2009). Furthermore, early prediction of autism spectrum disorder (ASD) has been examined by observing quality of spontaneous movements (Einspieler et al. 2014) or postural asymmetries (Eposite et al. 2009) in early infancy.

### [Aim]

The aim of this study was to investigate the relationship between the characteristics of spontaneous movements of neck and limbs in preterm-born infants aged 2 to 5 months and diagnosis of autism spectrum disorder (ASD) at 6 years of age.

### [Method]

Participants were 42 typically developed (TD) infants (14 males and 28 females, birthweight 492–1468g) and 15 infants who were diagnosed as ASD at 6 years old (8 males and 7 females, birthweight 546–1414g). We analyzed video recordings of the spontaneous movements in the supine position of participants at 49 to 61 weeks postmenstrual age (PMA). The head position in each video frame was classified into 3 ones (midline/right/left). Two-dimensional trajectories of all limbs were captured. Group differences in the movement indices calculated from head position and limb movements were analyzed.

### [Result]

Midline position percentage of head in the TD group was higher than that in the ASD group ( $p < 0.05$ ). Average velocity of upper limbs movements was higher in the TD group than ASD group ( $p < 0.05$ ). There were no significant differences about average velocity of lower limb movements, number of movement units and correlation between limb velocities.

### [Conclusion]

Our results demonstrated that fewer holding of the head in the midline position and poor activity of spontaneous movements of limbs (especially upper limbs) in early infancy can be associated with later development of ASD.

## **An international survey to establish a cerebral palsy and congenital anomalies collaboration**

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**Background:** The reported proportion of children with cerebral palsy (CP) with a cerebral and/or non-cerebral congenital anomaly (CA) ranges from 12-40%, compared with approximately 3% of all births. Data linkage between CP and CA registers, and pooling of high quality data from a large population, is required to describe the co-occurrences of CP and CAs, along with their aetiologies. However, data pooling can be complicated by significant variations between registers, including geographical coverage, inclusion criteria, classifications, scope and timing of data collection.

**Aim:** To determine the most comprehensive dataset available from CP and CA registers in Europe and Australia for a collaborative study.

**Method:** Representatives from all known CP and CA registers in Europe and Australia were invited to participate in an online survey. Information was summarised using descriptive statistics and compared by type of register and geographical region.

**Result:** Of the 47 CP and CA registers contacted, 37 responded: 26 European and 11 Australian (79% response rate). Registers differed in their sources of data, coding, maximum number of anomalies recorded, consent requirements, inclusion/exclusion criteria and availability of data. While 100% CP registers (n=20) recorded diagnosed congenital anomalies for CP cases, only four obtained data from linkages with CA registers. 91% of registers reported an interest in participating in the planned collaborative study, with a further 6% unable to participate due to insufficient data.

**Conclusion:** A collaborative project, pooling linked CP and CA register data from at least six geographical regions of Europe and Australia (covering >180 000 live births/year) appears possible. Differences between registers can be addressed in methodology and selection of data for the linkage. This will be the largest study of its kind; at least tripling the largest population studied to date, essential given the heterogeneity of CAs found in CP.

## **Lessons from evaluation of processes of care for chronically ill or disabled children**

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**Background:** The Measure of Processes of Care (MPOC-20) was developed as a self-administered questionnaire for parents to report on behaviours of health-care providers. The MPOC-SP version was developed for care providers to report on their own behaviour.

**Aim:** The aim of the study was to investigate processes of care for chronically ill / disabled children in several health care and rehabilitation institutions in Slovenia and find weaknesses to be potentially improved.

**Methods:** Parents of children who were admitted as inpatients or outpatients of several hospitals and health centres were invited to participate and fill in MPOC-20. Health-care providers from the same institutions were invited to fill in MPOC-SP.

**Results:** Parents of 235 children participated in the study (80% mothers). They reported high general rates of expected behaviours of health-care providers: the mean subscale item scores were 5.83 (SD 1.10) for Coordinated and Comprehensive Care, 5.62 (SD 1.12) for Respectful and Supportive Care, 5.45 (SD 1.23) for Enabling and Partnership, 5.33 (SD 1.61) for Providing Specific Information (PSI) and 4.59 (SD 1.65) for Providing General Information (PGI).

67 health-care providers (91% were women) reported intermediate general rate of different expected behaviours. MPOC-SP mean subscale scores were 5.2 (SD 0.9) for Showing interpersonal sensitivity, 4.3 (SD 1.3) for PGI, 4.8 (SD 1.5) for PSI and 5.7 (SD 0.7) for Treating people respectfully. The ranking order of the mean subscales scores for MPOC-20 and MPOC-SP was the same as in other studies. Specific item analysis exposed some weaknesses in processes of care that could be improved by better organisation of working process.

**Conclusion:** Parents reported higher general rates of expected behaviours of health-care providers as they did for themselves. Both reported lower rates of providing general and child specific information. These results and specific item analysis will help us to improve processes of care.



## Lesion overlap analysis in pediatric stroke: Preliminary results

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### Introduction

Lesion location is only a broad prognostic sign for clinical symptoms and functional outcome. Diffusion-weighted imaging (DWI) has higher accuracy, sensitivity and specificity for ischemic lesions than conventional MRI.

### Aim

Create DWI lesion overlap maps according to symptoms at stroke onset and functional outcome.

### Material and Methods

This retrospective study of prospectively registered patients included children aged 4-16 years with ischemic stroke confirmed with MRI. MRICroN was used to manually outline the lesions on the DWI sequence. An age average template created by means of Template-O-Matic toolbox was used for analysis. Lesions were flipped into the left hemisphere for representation. Symptoms at presentation and follow up were collected prospectively in the Swiss Neuropaediatric Stroke Registry and functional outcome (Pediatric Stroke Outcome Measure [PSOM] at 6 months) was retrospectively analyzed in this dataset.

### Results

Overall 62 patients were included (mean age  $9.4 \pm 4$  years). Forty patients (63%) had a left sided stroke and 6 bilateral (9.6%). Forty-six (74%) had an anterior stroke. Basal ganglia was the most frequently affected brain area (32% overlaps, n=15). Patients with hemiparesis at stroke onset presented lesion overlaps involving predominantly putamen, globus pallidus and posterior limb of capsula interna, whereas patients with seizures at stroke onset presented a pattern involving cortical areas. Patients with poor outcome (PSOM) at 6 months after stroke showed more noticeable overlaps, predominantly in capsula interna and globus pallidus.

### Conclusion

Basal Ganglia was predominantly affected in patients with hemiparesis and the globus pallidus was also frequently involved in patients with poor outcome at 6 months. DWI lesion overlapping maps can be helpful in the analysis of location related symptoms and functional outcome at 6 month in pediatric stroke, this will improve prognostic possibilities for these children.

## **Knee jerk responses in infants at high risk for cerebral palsy: an observational EMG study**

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**Background:** Following our clinical observation of tonic responses (TRs) in response to the knee jerk in infants at very high risk for cerebral palsy (VHR infants), we systematically studied TRs, clonus and reflex irradiation.

**Aim:** To compare responses in VHR infants and typically developing (TD) infants and to evaluate possible associations with general movement (GM) quality.

**Method:** 24 VHR (11 girls; median gestational age 30.5 weeks, range 25.9-41.1; median birth weight 1470 grams, range 720-3800) and 26 TD (12 girls; median gestational age 40.2 weeks, range 36.7-41.7; median birth weight 3710 grams, range 2680-4650) infants were assessed around 3 months corrected age. Surface electromyograms of leg, trunk, neck and arm muscles were recorded while eliciting the knee jerk. GMs and the knee jerk examination were video-recorded.

**Results:** The median number of appropriate trials was 17 (range 6-37). More VHR than TD infants showed TRs (VHR 22 out of 23, TD 7 out of 26, Chi-square;  $p=0.005$ ) and clonus (18 out of 23 infants and 4 out of 26, respectively; Chi-square;  $p=0.0005$ ) in the ipsilateral quadriceps. VHR infants more often than TD infants demonstrated phasic responses in the contralateral quadriceps (VHR 63% of the trials vs TD 34%, Mann-Whitney U;  $p=0.002$ ) and hamstring (VHR 63% vs TD 40%, Mann-Whitney U;  $p=0.003$ ). Widespread reflex irradiation occurred in VHR and TD infants. Definitely abnormal (DA) GMs and stiff movements were associated with TRs (DA GMs 34% vs non-DA GMs 0%, Mann-Whitney U;  $p=0.0005$ , and stiff 25% vs non-stiff 0%, Mann-Whitney U;  $p=0.007$ ) and clonus (DA GMs 19% of the trials vs non-DA 0%, Mann-Whitney U;  $p=0.003$ , and stiff movements 23% vs non-stiff 0%, Mann-Whitney U;  $p=0.0005$ ) in the ipsilateral quadriceps.

**Conclusion:** Similar to clonus, TRs may be regarded as a marker of a loss of supraspinal control. Reflex irradiation primarily is a neurodevelopmental phenomenon of early ontogeny.

## **Specific characteristics of abnormal general movements are associated with functional outcome at school age**

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**Background:** assessing the quality of general movements (GMs) is a non-invasive tool to identify at early age infants at risk for developmental disorders.

**Aim:** to investigate whether specific characteristics of definitely abnormal GMs are associated with developmental outcome at school age.

**Method:** Parents of 40 children (median age 8.3 years, 20 girls) participated in this follow-up study. In infancy (median corrected age 10 weeks), the children (median gestational age 30.3 weeks; birth weight 1243 grams) had shown definitely abnormal GMs. Information on specific GM characteristics such as the presence of fidgety movements, degree of complexity and variation, and stiff movements, was available (see Hamer et al, Dev Med Child Neurol 2011). Outcome at school age was assessed using a standardized parental interview (Vineland Adaptive Behaviour Scale) and questionnaires (Developmental Coordination Disorder Questionnaire and Child Behaviour Checklist). Non-parametric test were used for statistical analyses.

**Results:** six children had cerebral palsy (CP), ten children attended a school for special education, and eight children had behavioural problems. Both absence of fidgety movements and presence of stiff movements were associated with CP (fidgety absent: 56% CP, present: 0% CP,  $p=0.001$ ; stiff movements present: 35% CP, absent: 0% CP,  $p=0.003$ ). Stiff movements were also related to need of special education (stiff movements present: 47%, absent: 9% special education,  $p=0.009$ ). A lack of movement complexity and variation was associated with behavioural problems (variation absent: 55%, some variation present: 9% behavioural problems,  $p=0.007$ ).

**Conclusion:** evaluation of fidgety movements and movement stiffness may increase predictive power of definitely abnormal GMs for motor outcome - in particular CP. This study endorses the notion that the quality of GMs reflects the integrity of the infant's brain, assisting prediction of long-term outcome.

## **Typical oral medication prescribing patterns of rehabilitation and developmental paediatric specialists for the management of dystonic cerebral palsy**

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**Background:** A range of medications are used by physicians to manage dystonia in children with cerebral palsy (CP), however side effects are common and there is limited evidence regarding their effectiveness.

**Aim:** To examine current clinical practice of medication prescription by physicians for managing dystonia in children with CP.

**Method:** A custom designed online 13 item survey capturing usual prescribing patterns was sent to 11 eligible doctors with varying clinical experience. These doctors also prospectively completed a small survey over a 10 month period each time they prescribed a new medication for reducing dystonia in a child with CP.

**Results:** Most doctors used more than one medication with 6/11 using 4 or more. Oral Baclofen was the first choice by nearly all (10/11). Data on 50 children showed that medication was prescribed mainly for children aged 3-10 years (n=30/50), classified within GMFCS levels IV/V (n=34/50) and with a mixed movement disorder (n=32/50). Gabapentin and Baclofen were most frequently prescribed (n=19/50 and 17/50 respectively). Benzhexol hydrochloride was prescribed in 5/50 children. Other medications used less frequently were Diazepam, Tetrabenazine, Levodopa and Clonazepam. Gabapentin was mainly prescribed to improve pain and comfort whereas Baclofen was prescribed when multiple indications were identified. Dosage regimes varied considerably. Measurement of medication effectiveness was primarily by parent report and impairment based clinical examination in paediatrician outpatient clinics. Objective measurement tools were only used in the context of a multidisciplinary rehabilitation team.

**Conclusion:** Medication prescription varied in this small but representative sample of doctors managing dystonia. Some of this variation is likely related to a lack of evidence-based guidance for best care. The effectiveness of medications commonly used in dystonic CP needs to be synthesised as a first step towards guideline development.

## **A team for habilitation in a medical setting**

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<sup>1</sup>Habilitation Of Adults, The Rehabilitation Clinic Of Danderyds Hospital, Stockholm, Sweden

**Background:** Children with lifelong disabilities grow up to adults with remaining disability. Focus within health care has mostly been on children.

The team started in 1989 to ensure access to specialist care regarding the disability and its consequences for adults (>18) with lifelong movement disorders since birth and with or without mental retardation. Since 2009 the team also welcomes adults born with mental retardation without movement disorder.

Over the years more than 1500 patients have been in contact with the habilitation team

A vast majority of patients have cerebral palsy.

**Aim:** An exposition over 27 years of habilitation work with adult patients in a medical setting.

**Method:** To view the following aspects: patient groups, the team, interventions/patient satisfaction, development, cooperation, education, transition, future areas of development

**Results:** The patients have shown to have a longterm need of a team for consultations, education and support beyond ordinary health care. Patientsatisfaction are positive. Smoother processes for the transition of child to adults are needed, as well of the process of getting a gastro feeding tube. Teamwork has shown to be successful.

**Conclusion:** A specialist team, within the medical /hospital setting, with great knowledge and experience of the physical, mental, cognitive and social consequences of lifelong disability can be of much help to patients and their families both directly and indirectly through consultation, education and support to the medical community as a whole

## **What are the benefits of a local hip surveillance programme in a PMLD population**

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### **Background**

Soo et al (2006) demonstrated that 90% of children with cerebral palsy (CP), GMFCS V (n=58), presented with hip displacement (migration >30%). Recently, hip surveillance programmes have been more widely adopted e.g. Australia, Sweden, Scotland to identify children at risk of hip dislocation who need regular surveillance and to ensure timely referrals to orthopaedic services (Wynter et al, 2008). Under a local hip surveillance programme all children and young people (CYP) at a specialist school have a pelvic x-ray every 6 or 12 months and are seen by an orthopaedic consultant. On site physiotherapy provides and monitors 24 hour postural management.

### **Aim**

To review the current hip surveillance programme.

### **Method**

Collection of current hip x-ray's for CYP who:

- attend the school (multiple diagnoses)
- attend the school aged 5-18 and present with CP

X-ray analysis by the same therapist to establish hip migration percentage

Collation of data and compilation of a traffic light system to easily identify level of hip migration and risk of further displacement

Comparison of data with published data

### **Result**

Data from 48 CYP was collected. 5 presented with a classification comparable to GMFCS I-IV and all hips were <30% migrated. 43 were classified as GMFCS V: 60% of hips showed migration < 30%, 14% had migration of 31-74% and 22% had migration of 75-100%. For those aged 5-18 with a diagnosis of CP (n=15) all were classified as GMFCS V, 50% of hips showed migration < 30%, 10% had migration of 31-74% and 40% had migration of 75-100%. In comparison to the 90% found by Soo et al (2006) 66% of CYP aged 5-18 with CP had at least one migrated hip.

### **Conclusion**

Our data compares favourably to migration rates in the literature. Having regular reviews provides information which influences our treatment plans and identifies those who require orthopaedic intervention. The aim now is to reduce these figures further through more effective monitoring and management.

## **Informative diffusion tensor tractography in an ataxic boy with traumatic brain injury**

So Youn Jun<sup>1</sup>, Bo Young Hong<sup>1</sup>, Youngkook Kim<sup>1</sup>, Joon-Sung Kim<sup>1</sup> and Seong Hoon Lim<sup>1</sup>

<sup>1</sup>Rehabilitation Medicine, St. Vincent's Hospital, College Of Medicine, The Catholic University Of Korea, Suwon, South Korea

### **Background**

Ataxia is defined as poor coordination of muscle activity resulting in inappropriate and dysfunctional movement related to cerebellar lesion.

### **Aim**

Patient's cranial nerve dysfunctions, ataxic movement and tremor in all extremities were not explainable with conventional MRI. And we tried to figure out these signs by diffusion tensor imaging (DTI).

### **Method and result (Case report)**

A 5 year-old-boy who developed normally, had a traumatic brain injury after a pedestrian traffic accident. On the initial brain CT, intracranial hemorrhage at the left pontine, midbrain, cerebellum, temporal and frontal lobes was detected. He came to our hospital for rehabilitation 9 months after the accident.

At admission, he had dysarthria, impaired lateral gaze was in the right eye and right facial muscle weakness. Motor power was weaker in the right extremities. and muscle tone was increased in both ankle plantarflexors.

The patient could crawl, but assistance was needed for sit up and for maintaining a standing position due to poor balance and ataxia. Grasping was possible only with left hand.

MRI showed encephalomalacic change in left inferior temporal lobe, pontine tegmentum, and cerebellar hemisphere and atrophy of left cerebellar hemisphere. Also, injury of left superior peduncle and splenium of corpus callosum was detected. Corticospinal tracts, cortico-ponto-cerebellar tracts, dentato-thalamo-cortical pathways and corpus callosum were reconstructed by DTI. Efferent fibers from right dentato-thalamo-cortical pathway and cortico-ponto-cerebellar tract showed more degeneration compared with left side. Though injuries of left superior peduncle and cerebellar hemisphere were noted only in conventional MRI, left side was less affected on DTI.

### **Conclusion**

DTI provided injuries in the tracts that could not expected in conventional MRI. Reconstruction of tracts might be more informative for white matter injuries in the patients with traumatic brain injury.

## **Informative diffusion tensor imaging in an ataxic boy with traumatic brain injury**

Bo Young Hong<sup>1</sup>, So Youn Jun<sup>1</sup>, Youngkook Kim<sup>1</sup>, Joon-Sung Kim<sup>1</sup> and Seong Hoon Lim<sup>1</sup>

<sup>1</sup>Rehabilitation Medicine, St. Vincent's Hospital, College Of Medicine, The Catholic University Of Korea, Suwon, South Korea

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**Conclusion :** DTI provided injuries in the tracts that could not expected in conventional MRI. Reconstruction of tracts might be more informative for white matter injuries in the patients with traumatic brain injury.



## **A proposed disability complexity scale to describe the multi-faceted needs of disabled children and young people**

Karen A Horridge<sup>1</sup>, Carl J Harvey<sup>1</sup>, Kenneth McGarry<sup>2</sup>, Jane Williams<sup>3</sup>, Gabriel Whitlingum<sup>4</sup>, Mary Busk<sup>5</sup>, Suzanne Fox<sup>6</sup> and Fawzia Rahman<sup>7</sup>

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### **Background**

There are validated measures of functioning for disabled children<sup>1</sup> but no recognised scale of complexity. Many disabled children have multi-faceted needs. All need to be addressed to achieve best participation and quality of life.

### **Aim**

To develop a scale of complexity that is easy to apply in a range of clinic settings, relevant to individual clinical care and service planning.

### **Method**

Data were analysed from a retrospective review of 8392 structured electronic clinic letters from 1999 children accessing the paediatric disability clinics in Sunderland, north-east England, June 2007-May 2012. The numbers of health conditions (C), technology dependencies (T), family-reported issues (F) and need for round the clock care (R) were calculated and compared for those with different conditions.

### **Results**

The 699 children with intellectual disabilities (ID) compared to the 1299 without ID had significantly more:

Needs overall (mean 5.81, range 1-23 with ID; mean 2.22, range 0-19 without ID)

Health conditions (mean 5.41, range 0-18 with ID; mean 2.40, range 0-12 without ID)

Technology dependencies (mean 0.16, range 0-4 with ID; mean 0.03, range 0-2 without ID)

Family reported issues (mean 0.53, range 0-5 with ID; mean 0.19; range 0-5 without ID) and were

Need for round the clock care (mean 0.18, range 0-1 with ID; mean 0.02, range 0-1 without ID) p-value <0.0001 in all cases.

Children with ID plus cerebral palsies and epilepsies had more than double the number of needs overall than those without. The group who died had the highest burden of needs overall (mean 15, p-value <0.05).

### **Conclusion**

A disability complexity scale has been proposed and field-tested. It is a practical way to quantify complexity in a way that identifies the resources required to care for individuals as well as to commission and design services for populations of disabled children and young people.

### **References**

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## **Prospective Pilots of Routine Data Capture by Paediatricians in Clinic settings and validation of Disability Complexity Scale**

Karen A Horridge<sup>1</sup>, Williams Jane<sup>2</sup>, Gabriel Whitlingum<sup>3</sup>, Kenneth McGarry<sup>4</sup>, Jill Kisler<sup>5</sup>, Toni Wolff<sup>2</sup>, Katherine Martin<sup>2</sup> and Ian Male<sup>6</sup>

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### **Background**

There is lamentably little accurate population data about disabled children internationally. Information is however needed to articulate, quantify and address multi-faceted needs for individuals and populations equitably.

### **Aims**

Pilot data collection by paediatricians at the point of care across England using a defined terminology set.

Demonstrate feasibility of data collection and utility of data outputs.

Confirm that counting the number of needs per child is valid for quantifying complexity.

### **Methods**

Paediatricians in 16 hospital and community settings collected and anonymised data. Participants completed a survey regarding the process. Data analysed using R version 3.1.2.

### **Results**

8117 needs captured from 1224 consultations were recorded. 16 clinicians responded positively about the process and utility of data collection.

The sum of conditions varied significantly between children with:

Cerebral palsies at Gross Motor Function Classification System levels I-III (mean 9, range 2-27) compared to IV (mean 14, range 2-32) & V (mean 19, range 5-41), p-value <0.01;

Epilepsies needing paediatric epilepsy expertise (mean 9, range 1-27) compared to those needing paediatric neurology (mean 16, range 2-46) or children's epilepsy surgical service (mean 19, range 4-39), p-value <0.01;

Mild/moderate intellectual disabilities (ID) (mean 8, range 1-32) compared to severe ID (mean 11, range 1-31) or profound ID (mean 17, range 1-41), p-value <0.01.

### **Conclusion**

Prospective data collection at the point of clinical care did not disrupt clinics even for those with the most complex needs, taking least time if done electronically. Presenting this as the number of health conditions (C), technology-dependencies (T), family-reported issues (F) and need for round the clock care (R), conveys information about the complexity of individual children in a way that could inform clinical care and more appropriate design and charging for quality services.

## **SATISFACTION, PERCEIVED EFFECTIVENESS AND TOLERANCE OF CARES IN INDIVIDUALS WITH CEREBRAL PALSY**

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### **Background**

A better understanding of the perception of the rehabilitative and medical cares by persons with CP and their families may help in providing better adherence to these cares.

### **Aim**

The main objective of this study was to assess overall satisfaction, self-perception of effectiveness and tolerance of the rehabilitative and medical cares in individuals with CP.

### **Methods**

This was a cross-sectional questionnaire-based study. 950 questionnaires were sent to french children and adults with CP. Perceived effectiveness and tolerance were evaluated for each types of care using a Likert scale from 1 to 7 and overall satisfaction by a visual analog scale. Comparison of means and uni-and-multi variate analyzes for correlation analysis were carried out.

### **Results**

512 (53.9%) questionnaires were analyzed. 228 (44.9%) were children and 275 (53.7%) were GMFCS I, II or III. The overall satisfaction was 6.83/10 (SD 2.21). Orthoptic, orthosis and physical therapy were reported to be the most effective cares (5.33/5.29/5.28) while botulinum toxins, intrathecal baclofen, and speech therapy the least effective (4.41/4.51/5.01). Intrathecal baclofen, orthosis and botulinum toxin were the less well tolerated therapies. Antiepileptic drugs were reported to be the most effective and best tolerated drug contrary to analgesics. Overall satisfaction was inversely correlated to the GMFCS in the multivariate analysis ( $p=0.013$ ). The tolerance and effectiveness of the orthosis and mobility aids were positively correlated to the GMFCS ( $p = 0.017$ ,  $p = 0.008$ ).

### **Conclusion**

This study shows a good overall satisfaction on medical and paramedical care but highlights a large discrepancy between user self-perception and evidence base medicine. More communication about the therapies between professionals and individuals with cerebral palsy is needed.

## Life experiences of disease, family, and social interactions for the cerebral palsy patient

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I want to describe the relationships of cerebral palsy, how he can do with the disease, the families, and the social relationships in a different observation way. I think, as a patient with CP, I have to know I am not same as others after born. Also, it has to bear pains during the rehabilitations, worry about the acceptance of family members, and interactions with friends. Such as, when a CP were born, it is going to face challenges for future. Meanwhile, parents and siblings must carry huge negative voice among relatives.

So I focus on the disease, family and interpersonal interaction as the theme. In order to fully descript "daily life" of a CP and the Family, and rediscover the value of the life of a CP and experiences, as well as the linking of "family" and "social".

Research Method: Personal life history study

### Case Research Analyses

I was an inborn error of Cerebral Palsy. During the delivering, both mother and I suffered danger of life, mother got metrorrhagia and I was only 32 weeks old. My brother saw the occasion and was scared. Mother and father did not know I am a CP till I was 6 months old. Then, mon began to bring me to do many rehabilitations in different hospitals. Papa worked hard for money, because I was too young to have social insurance.

In the school, I began to suffer friendship problem. Lot of schoolmates do not like to be friend with me. Till the high school, these problems were solved. Since then, I started my sun-light smiles and got a lot of friends.

I got 6 times operations since childhood, and found my physical agility is getting down. So, I always arrange the rehabilitations during summer and winter vacations. It is important for my health.

I have attended some associations and had good interactions with the members. And I chose Catholicism as belief, though my parents are Buddhists.

### Conclusion:

Family supports are important for CP. And they needs time to learn how to have social relationships.

## **Cerebral Palsy in Young Adults: Cross-Sectional Survey on Health and Social Outcomes Using a Population-Based Approach**

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**Background:** Cerebral Palsy (CP) has an incidence of 0.25% in Sweden. The vast majority reaches adulthood, but little is known on the health and social situation after childhood.

**Aim:** To explore health and social situation in young adults living in Sweden using a population-based approach.

**Method:** All young adults born 1992-1995 previously diagnosed with CP at Stockholm clinics were invited to participate (n=206). Assessments included the questionnaires on Health-related Quality of Life (SF-36), fatigue (FSS), pain (BPI) and on social and educational factors as well as clinical examination. Data collection will be finished in 2016.

**Result:** Preliminary results show an inclusion rate at >30% of the population with a mean age of 21 years 2 months (SD +/- 6 months) with 52% females. Subtypes of CP and GMFCS levels are representative. Social outcomes reveal 14% living independently, 19% regularly employed and 21% with ongoing tertiary education, often combined with employment. Forty-eight percent have experience of intimate relationships. Health outcomes demonstrate: a mean BMI at 21.7 (SD +/- 3.6), contractures (any severity) present in 97% of the individuals, 36% have epilepsy, 19% are using anti-depressive medication, 43% have sleep problems, 33% experience severe fatigue and about 30% of the young adults report pain.

Regarding health-care utilization, 48% have not had any contact with habilitation services within the past twelve months.

**Conclusion:** This population-based sample of young adults, representative with respect to subtype and severity of CP, shows that only a few have independent living, employment and/or higher education. Mental health issues, sleep problems, fatigue and pain stand out as needing special attention.

## **Self-Rating of Daily Time Management in children: Validity of the Time-S**

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### **Background**

Impaired ability to manage time has been shown in several diagnoses common in childhood. Ability to manage time is important for functioning in everyday life and has an impact on both academic and career achievement. Impaired ability involves activity and participation level as well as body function and structure level. It is important that influences on daily life is evaluated from a child's own perspective.

### **Aim**

1/ to describe the validity of Time-S – a self-rating questionnaire on daily time management - when used in children aged 10-17 years with a diagnosis of ADHD, Autism, CP or mild ID.

2/ to investigate the relation between time-processing ability (KaTid) as rated by external observer and managing time in daily life as rated by the child.

### **Method**

A convenience sample of children (n=83) with disabilities aged 10-17 years participated in the study. Construct validity of the Time-S was assessed by using item response theory, IRT.

Correlation between Time-S and KaTid was assessed.

### **Result**

The 21 items of the Time-S questionnaire fit into a unitary construct measuring self-perceived daily time management of a child. The person reliability of the Time-S was good (.82) and the scale could separate the participants into three groups. The mean Raw score for the KaTid for the full sample was 43.4 (range 18- 60). No significant correlation occurred between Time-S and KaTid measures.

**Conclusion** The results indicate an acceptable level of validity for the questionnaire Time-S. The correlational analysis of Time-S and the KaTid indicate that these two instruments give different information. Thus, Time-S is a valuable complement in the assessment of children with impaired ability to manage time. The questionnaire is potentially useful in both intervention planning and evaluation.

## **Cerebral Palsy in rural South Africa and Lesotho: Clinical subtypes and gross motor function**

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**BACKGROUND:** Limited but emerging data from sub-Saharan Africa suggests that the clinical spectrum of Cerebral Palsy (CP) may be different to that found in high-income countries.

**AIM:** To describe and analyse the clinical sub-type and gross motor function in children with CP in rural South Africa and Lesotho.

**METHOD:** A retrospective clinical record review of children seen over the past nine years by a non-profit organization working with children with CP in rural community based settings. Data regarding age, sex, clinical subtypes (based on the Surveillance of Cerebral Palsy in Europe classification system), and Gross Motor Function Classification (GMFCS) level were extracted and grouped according to geographical regions - Eastern Cape, Limpopo, KwaZulu-Natal (KZN) and Lesotho.

**RESULTS:** Of the 972 records reviewed, 570 were excluded, either due to incomplete data or an unconfirmed diagnosis of CP. Of the 402 participants included in the analysis, 65.4 % were male and ages ranged from 6 months to 25 years. Dyskinetic CP was the commonest clinical subtype (n= 169, 42%), followed by bilateral spastic CP (n= 134, 33%), unilateral spastic CP (n=46 , 11%) and ataxia ( n=19, 4.7% ) Almost three quarters (74%, n=297) of children were either GMFCS Level 4 or 5 whilst 12% were Level 3; 7.7% Level 2 and 3.7% Level 1. Clinical subtypes also varied across regions – half the children in Limpopo (50%; n=80) were dyskinetic compared with 31% in Lesotho.

**CONCLUSION:** This study confirms that the clinical spectrum of CP in sub-Saharan Africa is different from that reported in high income countries. There is a greater proportion of children with dyskinesia and children are more severely disabled. The high proportion of dyskinetic children warrants further investigation.

## Participation of adults with cerebral palsy aged 40-50 years: impact of mobility, intelligence and communication function

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**Background:** Population data on predictors of functional participation of middle-aged adults with cerebral palsy (CP) is scarce.

**Objective:** Determine if CP register data can predict participation of middle-aged adults with CP.

**Method:** Participants were 57 adults with CP aged 40-50 years (mean 44 years 4 months); 35 males; 10 ambulant, 13 marginally ambulant, 34 non-ambulant) from the Queensland CP Register (QCPR). QCPR data was audited for demographics; mobility at 5 and 15 years (GMFCS); and associated impairments (IQ, epilepsy, sensory impairment). Adults (or proxies) were interviewed for participation frequency and diversity in ICF major life domains (e.g. employment, education, recreation); and facilitators/barriers to participation. Multiple regression examined relationships between QCPR data and participation outcomes. Content analysis was used to classify contextual responses according to ICF environmental factors.

**Results:** High participation was seen for medical visits (96.3%) and shopping (87.5%). Moderate participation was seen for public (69.9%) and private recreation (68.6%). Low education participation was as expected for the cohort's age (10.5%). Participation restrictions were reported for employment (36.3%) and physical activity (59.2%). Employment restriction was predicted by poor current mobility ( $R^2=0.189$ ,  $p=0.021$ ), and intellectual ( $R^2=0.076$ ,  $p=0.037$ ) and speech impairment ( $R^2=0.210$ ,  $p=0.008$ ). Poor current mobility approached significance for physical activity restriction ( $R^2=0.161$ ,  $p=0.060$ ). Childhood mobility did not predict participation. Most frequent barriers were environment and most frequent facilitators were people.

**Conclusion:** Employment and physical activity restrictions are common in middle-aged adults with CP. Restrictions are not just predicted by mobility level, but a combination mobility, intellectual and communication function. Participation is restricted by physical environments and mediated by personal supports.



## Health-related quality of life of adults with cerebral palsy

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### Background

Most patients with cerebral palsy (CP) reach adulthoods, and the life expectancy of the patients do not show much difference with that of general population. A number of studies have shown that the health-related quality of life (HRQoL) of children with CP is associated with multiple factor such as impairment, pain, and psychological difficulties. However, it has not been fully understood what factors could affect the HRQoL of adults with CP.

### Aim

The objectives of this study are to estimate the HRQoL of adults with CP and to explore the major influencing factors on the HRQoL of adults with CP.

### Method

Adults (aged 20 years or older) with CP completed a structured questionnaire containing questions covering 3 domains; (1) demographic data, (2) physical and psychological function, and (3) CP-specific domains. The HRQoL was evaluated with the European Quality of Life 5 Dimensions Questionnaire (EQ-5D) - 3L. EQ-5D index was calculated using the time trade-off (TTO) method. The HRQoL lowering risk estimates were adjusted for the effect of all other factors using multiple regression models. Statistical significance was accepted at  $P < 0.05$ .

### Result

154 subjects (93 males) were included in the study (mean age of  $40.2 \pm 9.15$  which was ranged 20 - 68). The most common type of CP was spastic type (40.9%). Paresis was involved at 4 extremities in 61.0% of subjects. Among subjects, 58.4% could not walk (GMFCS IV or V) and 47.5% could not handle objects without help (MACS III, IV, or V). The mean value of EQ-5D index was  $0.50 \pm 0.33$  (range: -0.17 – 0.95). The HRQoL of adults with CP was affected by physical function, manual dexterity, depression, age and gender.

### Conclusion

The HRQoL of adults with CP was significantly lower than that of the general population and patients with other diseases. Physical function, manual dexterity, depression, age and gender were the major influencing factors for the HRQoL of adults with CP.

## **Influence of Spinal Manipulation on Muscle Spasticity in Cerebral Palsy Patients**

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**Background.** Muscle spasticity is one of the treatment targets in children with Cerebral Palsy. According to preliminary studies, spasticity reduction could be achieved by special chiropractic technique - spinal manipulation. Spinal manipulation is a component of the Intensive Neurophysiological Rehabilitation System (INRS), that combines different treatment modalities: physical therapy, reflexotherapy, special massage, mechanotherapy, computer games (daily duration 3 - 4 hours).

**Aim.** The aim of the study was to evaluate influence of one spinal manipulation and two-week treatment course according to INRS on wrist muscle spasticity in patients with Cerebral Palsy.

**Method.** Group of 29 children with spastic forms of Cerebral Palsy, without fixed contractures of the wrist, aged 7-18 years, were included into the study. Children were evaluated before the treatment, after one spinal correction and in the end of two weeks intensive treatment course. Spasticity of wrist muscles was assessed using Neuroflexor device (Aggero MedTech AB) that measures resistance while applying passive movements to the wrist at two different velocities. Neuroflexor was proved to reliably measure the muscle tone and distinguish between its components: neural component (NC), attributed to spasticity from non neural components of elasticity and viscosity, attributed to muscle and tendon mechanical properties.

**Results.** Significant decrease of NC (spasticity) was noted already after the first spinal manipulation (mean difference 1.65,  $p < 0.01$ ). After the treatment course level of spasticity has further decreased with mean difference 2.09 ( $p < 0.01$ ). In cases of higher spasticity significant decrease of NC was achieved only after the two weeks treatment course.

**Conflict of interest.** Authors are working in the institution that is providing evaluated treatment.

**Conclusion.** Spinal manipulation may have influence on the muscle spasticity; further studies are required.

## Neuroimaging patterns and clinical correlates of children with cerebral palsy in Uganda.

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### Background:

Neuroimaging in cerebral palsy (CP) performs an important role in providing information about aetiology, potential mechanisms and timing of the brain damage. Presently literature on brain imaging studies in children with CP in low and middle income countries is sparse.

### Aim:

To establish the neuroimaging patterns of children with CP attending a tertiary referral centre in Uganda, determine how they differed from studies reported from high income countries (HIC) and their relationship with pre and post-natal factors.

### Method:

Using a cross-sectional study design, pre and post contrast computed tomography (CT) scans of 78 CP children aged 2–12 years were conducted using a Philips MX 16-slice CT scanner. Two radiologists, blinded to the patient's clinical status, independently reviewed the scans. The CT scan findings were categorised according to CP clinical subtype, level of fine and gross motor function, and the relation to pre-and postnatal factors. Pearson  $\chi^2$  analysis was used to determine association between pre-and postnatal factors.

### Result:

Abnormal CT scans were detected in 69%, with very few having primary white matter injuries (4%). Primary grey matter injury (PGMI) (44%) and normal scans (31%) were most frequent. Grey matter injuries were accompanied with severe gross and fine motor impairment in over half (59%) of the children. Children with a history of hospital admission following birth were three times more likely to have PGMI (Odds ratio [OR] 2.8; 95% CI 1.1- 7.1), suggesting a perinatal period with medical complications.

### Conclusion:

Neuroimaging patterns in this group of CP children markedly differs from imaging studies reported from HIC suggesting a perinatal aetiology in full term infants and reduced survival in preterm infants. Support in the prevention and emergency treatment of medical complications around birth may prevent brain injuries and development of CP, and play a role in reducing its incidence in Uganda.

## **Relationship between habitual physical activity, time spent sedentary, motor capacity and performance in children with cerebral palsy aged 4-5 years**

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**Background:** Habitual physical activity has many health benefits in children with CP.

**Aim:** To examine the association between motor capacity and performance on habitual physical activity and time spent sedentary (TSS) in children with cerebral palsy (CP) aged 4-5 years.

**Methods:** Sixty-seven children with CP were 43 male, mean age 4 years 9 months (SD=5 months); GMFCS level I=37 (44%), II=9 (11%), III=7 (8%), IV=3 (4%), V=11 (13%). Three days activity data were recorded by the ActiGraph® triaxial accelerometer for all waking activity except water-based activity. Wear time was checked against activity diaries recorded by parents. Activity counts (counts per minute) and time spent sedentary as a percentage of wear time (%TSS) were computed. Gross motor function measure (GMFM-66) was performed by research physiotherapist. The Pediatric Evaluation of Disability Inventory (PEDI) mobility domain was completed by parents. Multiple linear regression analyses were used to determine relationships.

**Results:** Motor capacity (GMFM-66) explained 69% of activity counts ( $\beta=17.2$ , 95%CI=9.2, 25.2,  $p<0.001$ ) and 74% of %TSS variance ( $\beta=-0.4$ , 95%CI= -0.7 to -0.2,  $p<0.001$ ). The GMFM-66 dimension E (walking, running and jumping) accounted for 35% of activity counts ( $\beta=17.5$ , 95%CI=6.9, 28.0,  $p=0.002$ ) and 41% of %TSS variance ( $\beta=-0.4$ , 95%CI=-0.6, -0.1,  $p=0.01$ ).

**Conclusion:** Gross motor capacity has a strong positive association with physical activity intensity and strong negative association with %TSS in children with CP aged 4-5 years. Additionally, only dimension E of the GMFM-66 are associated with activity counts and TSS. Improving gross motor function especially walking, running and jumping may increase HPA and reduce TSS level. High HPA and low TSS levels can improve both physical and mental health in children with CP. Furthermore, HPA and TSS can be quantitative indicators for the evaluation of interventions to measure community performance in preschool age children with CP.

## **Bangladesh Cerebral Palsy Register (BCPR): a pilot study towards developing a national cerebral palsy (CP) register and surveillance of children with CP**

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**Background:** The causes and pathogenesis of cerebral palsy (CP) are poorly understood, particularly in low- and middle-income countries (LMIC) like Bangladesh.

**Aim:** We aimed to develop, implement, and evaluate a CP population register in Bangladesh (i.e. Bangladesh Cerebral Palsy Register - BCPR) to facilitate studies on prevalence, severity, aetiology, associated impairments and risk factors for CP.

**Methods:** We are using community based Key Informants Method to identify children with CP in a rural sub-district (i.e. Shahjadpur) of Bangladesh. Standard BCPR record form are used to capture information about maternal health, birth history and the nature of disability in all children with CP aged <18 years.

**Results:** Since Jan 2015, 299 children with CP has been registered of which 184 were male (61.5%). Majority (n=216, 72.2%) had spastic CP; 61 (20.4%) with spastic quadriplegia. GMFCS classification showed 110 (36.8%) with GMFCS IV-V. Almost all had associated impairments; intellectual 141 (47.1%), epilepsy 88 (29.4%), visual 44 (14.7%), hearing 43 (14.4%) and speech impairment 193 (64.5%).

The majority (75.6%) of these children were delivered at home (89.4% by TBA) and 19.7% were born pre-term (11% extreme pre-term). Diagnosis of CP was delayed (mean age at CP diagnosis 4.9 years). 22.1% of all children with CP experienced neonatal seizure most likely due to severe neonatal encephalopathy (NE). The timing of CP were unknown for over half of the children (n=159, 53.2%); however, among those children, 61 had signs of intra-partum related neonatal respiratory depression (IPR NRD, i.e. birth asphyxia). Over a third (34.4%) had confirmed pre and peri-natal cause of CP; mainly IPR NRD (27%) and infections (8.0%).

**Conclusion:** Our preliminary analysis shows that the diagnosis of CP is delayed in rural communities of Bangladesh and the major causes of CP might be prevented by interventions such as institutional delivery, improved peri-natal and post-natal care.

## **Risk Factors of Cerebral Palsy in Preterm and Low Birth Weight Infants in Korea**

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### **Background**

Cerebral palsy (CP) is a childhood neurodevelopmental disorder that comes with considerable medical expense, as well as other social costs. There are several risk factors of CP associated with preterm and low birth weight.

### **Aim**

In this study, we analyze the risk factors related with CP occurrence in preterm infants and low birth weight infants.

### **Methods and Materials**

Based on medical claims data submitted to the National Health Insurance Service from 2003 to 2012, patients with history of diagnosis classification codes such as prematurity (gestational age less than 37 weeks), low birth weight (LBW) infants (birth weight less than 2500 gram), and CP were investigated by year. In addition, certain diseases accompanying in the neonatal period which were known as risk factors related CP were defined and collected. The history of medication and procedures, operations were collected also.

### **Results**

Among the risk factors known to related with CP in prematurity and LBW infants, periventricular leukomalacia (PVL) showed to be the most significant influence (Odd Ratio (OR) prematurity:14.9, LBW:14.4), followed by bronchopulmonary dysplasia (BPD) (OR prematurity:6.2, LBW:5.1) and infantile respiratory distress syndrome (RDS) (OR prematurity:3.2, LBW:3.1).

Among the procedures and surgeries done in premature and LBW infants, hydrocephalus operation (OR prematurity:29.3, LBW:27.2), patent ductus arteriosus (PDA) operation (OR prematurity:7.1, LBW:5.4), and ventilator care (OR prematurity:5.5, LBW:6.1) showed to contribute of increase the CP incidence. With administration of drugs such as indomethacin (or ibuprofen) (OR prematurity:9.8, LBW:8.0); postnatal steroids (OR prematurity:7.3, LBW :6.6); and caffeine (or aminophyllin) (OR prematurity:5.7, LBW:5.5), there was significant higher incidence of CP.

### **Conclusion**

PVL and hydrocephalus operation were found as the most significant risk factors of CP in infants with preterm and low birth weight in Korea.

## Incidence of Cerebral Palsy in Preterm and Low Birth Weight Infants in Korea.

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### Background

Cerebral palsy (CP) is a childhood neurodevelopmental disorder that comes with considerable medical expense, as well as other social costs. In Korea, whether increased high-risk birth rate affects the incidence of CP is still uncertain.

### Aim

In this study, we analyze changes of the incidence rate of CP in preterm infants and low birth weight infants over time in the last 10 years.

### Methods and Materials

Based on medical claims data submitted to the National Health Insurance Service from 2003 to 2012, patients with history of diagnosis classification codes such as prematurity (gestational age less than 37 weeks), low birth weight (LBW) (birth weight less than 2,500 gram), and CP were investigated by year.

### Results

Preterm birth was increased from 2,619 in 2003 to 10,825 in 2012; and in the case of low birth weight, the numbers increased from 1,909 in 2003 to 10,143 in 2012.

In prematurity, 166 babies (6.3%) out of 2,619 born in 2003 and 394 babies (3.7%) out of 10,519 born in 2010 were diagnosed with CP, showing a statistically significant decrement over time ( $p < 0.001$ ). The incidence of CP in the group of gestational age less than 27 weeks of the total prematurity didn't showed meaningful change, but the group of gestational age 28-36 weeks showed significant decrease.

For LBW infants, 141 babies (7.4%) out of 1,909 born in 2003 and 367 babies (4.3%) out of 8,580 born in 2010 had diagnosed with CP, showing a statistically significant difference ( $p < 0.0001$ ). In the group weighing less than 1,000 grams the incidence of CP didn't showed meaningful change, but the group weighing 1,000-2,499 grams showed significant decrease.

When comparison was made between the genders, the incidence of CP in males was significantly higher than that in females, particularly in LBW infants ( $p < 0.001$ ).

### Conclusion

The incidence of CP in infants with prematurity or LBW was on the decline during the last 10 years in spite of rapid increase of high-risk birth rate in Korea.

## Speech and Linguistic Features of Children with Articulation Disorders

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### Background

The articulation disorders are disability characterized by phonological errors of consonants or vowels and can be diagnosed according to the standardized criterion for age of acquisition.

### Aim

The aim of this study is to analyze the speech and the linguistic features between children with functional articulation disorder (FAD) and children who had been diagnosed with developmental language disorder overlapped with articulation disorder (DLD+AD).

### Methods and Materials

Among the children who had visited department of Physical Medicine and Rehabilitation in 2014 with complaint of inaccurate pronunciation, the interview, physical and neurological exam, full speech and language evaluation were done. Abnormal articulation was assessed based on PCC (Percentage of Consonants Correct) in APAC (Assessment of Phonology for Children).

### Results

In children with complaint of inaccurate pronunciation, children with FAD were 29 and DLD+AD were 14. The male preponderance was relatively not distinctive in FAD compared with DLD+AD.

PCC showed improvement according to age in FAD whereas there was no significant change by aging in DLD+AD ( $p < 0.05$ ).

In terms of various consonants, abnormal numbers of articulatory error of plosive, nasal, palatal affricate, liquid and fricative sounds were analyzed. In FAD the number of error in plosive and nasal sounds decreased by aging. But DLD+AD didn't follow usual consonant development order.

Receptive and expressive language quotient were 84.6 and 82.4 in FAD and 59.8 and 53.9 in DLD+AD, and significant differences between two groups were evident ( $p < 0.05$ ). There was no significant correlation between expressive language quotient and PCC ( $p > 0.05$ ).

### Conclusion

The consonant development pattern of children with FAD and DLD+AD showed some differences in two groups. The linguistic assessment of children with inaccurate pronunciation as well as the articulation test could be helpful for making diagnosis and adequate treatment plan.



## Maternal thyroid disorder in pregnancy and risk of cerebral palsy in offspring

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### Background

Thyroid hormone plays a substantial role in the neurodevelopment of the fetus, and previous studies have found impaired neurodevelopment in children born to mothers with thyroid disorder. However, the evidence on a potential association between maternal thyroid diseases and risk of cerebral palsy (CP) is limited.

### Aim

To investigate the association between maternal thyroid disorder including treatment with thyroid medication and risk of CP in the child.

### Method

We are conducting two cohort studies: The first is a register based study of 1,011,905 children born in Denmark 1979-2003 with information on diagnosis and redeemed prescriptions for thyroid medication. The second study makes use of the MOthers and BABies in Norway and Denmark (MOBAND) collaboration cohort with maternal reports of thyroid disorders in pregnancy on 192,918 children born 1996-2009. In both studies CP cases are identified by record linkage with national CP registers.

### Result

The analyses of the register based study are in preparation, and will include 24,815 children exposed to maternal thyroid and approximately 2,000 children with CP. The register based study will be the largest of its kind. In the MOBAND study, we included 3,042 children of mothers with thyroid disorder and 404 children with CP. The adjusted odds ratio for bilateral spastic CP was 1.90 (95% CI:0.83-4.33) among children exposed to maternal thyroid disorder in pregnancy compared with unexposed. The estimate for untreated thyroid disorder indicated a more pronounced risk, but was also statistically insignificant and attached with great uncertainty. Importantly, MOBAND data allowed us to adjust for lifestyle factors in pregnancy, which had no influence on the results.

### Conclusion

These two studies will provide us with a greater understanding of the extent to which maternal thyroid disorder contributes to the multifactorial etiology of CP, and whether treatment against thyroid disorder in pregnancy is beneficial.

## Motor Functions and Daily Activities in Various Domains in Preschool Children with CP of Different Motor Severities

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### Background

Cerebral palsy (CP) not only affects movement and posture, but also was accompanied cognition or speech problems. These problems further cause limitation in activities of daily living (ADL) in children with CP.

### Aim

This study aims to investigate the motor functions and the ADL in children with CP of different motor severities.

### Method

Eighty three parents of preschool children with CP (age range 14.6~81.4 months; mean age: 30.69±20.09 months; male: female = 55: 28) were enrolled and classified into three groups based on the Gross Motor Function Classification System (GMFCS): mild (GMFCS levels I-II, n= 36), moderate (GMFCS levels III- IV, n= 29) and severe group (GMFCS level V, n=18). The motor function was assessed by Gross Motor Function Measure 66 version (GMFM 66). The ADL was assessed by Pediatric Functional Independence Measure (WeeFIM) which consisting of three main domains covering the self care, mobility, cognition. The differences in the motor function and ADL among 3 groups were calculated by analysis of variance.

### Result

The GMFM 66 score, total WeeFIM score, and WeeFIM subscores in all domains achieved significant differences among 3 groups ( $p < 0.01$ ). Mild and moderate groups had greater scores in the GMFM 66, total WeeFIM, and all WeeFIM domains than severe group ( $p < 0.01$ ). The mild group also had greater GMFM 66 and total WeeFIM scores than moderate group ( $p < 0.01$ ). Furthermore, the mild group had greater scores in all WeeFIM domains except cognition domains than moderate group ( $p < 0.01$ ).

### Conclusion

The GMFCS levels were not only associated with self-care and mobility domains of ADL, but also related to cognition domains in children with CP. These findings may allow clinicians early predict the ADL in all domains for these children based on a simple GMFCS levels.

## **The gait pattern of children with spastic diplegia due to HIV encephalopathy – A two year follow-up study**

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**BACKGROUND:** Worldwide about 3,3 million children are infected with human immunodeficiency virus (HIV), which can result in HIV encephalopathy (HIVE). Recent study shows that 63% of children with HIVE attending an HIV clinic in Cape Town, South Africa, were diagnosed with spastic diplegia<sup>1</sup>. Their gait abnormalities show some similarities with spastic diplegia in Cerebral Palsy (CP). However, it is not certain if HIVE is non-progressive as defined in CP. Therefore it is not clear if similar orthopedic interventions for secondary abnormalities should be performed.

**AIM:** To determine changes in gait pattern of children with HIVE and spastic diplegia in 2 years time.

**METHOD:** This is a prospective 2 year follow-up<sup>2</sup> study. Fourteen children with HIVE and spastic diplegia participated in the baseline study<sup>2</sup> of which 12 children (age: 7,9±0,9 years; GMFCS: 5 level I, 7 level II; gender: 7 boys) were followed-up after 2,3±0,2 years. Three-dimensional gait analysis (3DGA) was performed using a Vicon system synchronized with frontal and sagittal digital video cameras. Based on the gait patterns (video and 3DGA) the cohort was divided into 2 groups. Group I showed only limited abnormalities, while children in Group II walked with a more pathological gait pattern. Similar methods were used to determine changes over time.

**RESULT:** No significant changes were determined 2 years after the baseline study. Children in Group I (n=7) showed only limited abnormalities, while Group II (n=5) had a more pathological gait pattern including stiff knee and equinus ankle characteristics.

**CONCLUSIONS:** The gait pattern of children with HIVE and spastic diplegia didn't progress in 2 years time. However, the follow-up time and sample size is limited to state definite conclusions. Further research is in progress, what should result in evidence-based guidance for optimizing management of children with HIVE and spastic diplegia.

<sup>1</sup>Donald et al, AIDS Res and Ther, 2015; <sup>2</sup>Langerak et al, DMCN, 2014

## **Correlation of Asymmetric Hip migration and Pelvic Obliquity in Non-ambulatory Cerebral Palsy**

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**Background:** Prevention of hip dislocation and scoliosis is the major concern in treatment of cerebral palsy patients because high incidence of pain in these population. Patterns of pelvic obliquity cannot predict the severity and pattern of scoliosis because 3 dimensional multifactorial factors contribute the development of deformity in previous study.

**Aim:** The purpose of the study is to investigate the effect of the asymmetric superior migration of hip on the pelvic obliquity and scoliosis progression.

**Method:** Retrospective chart review was done. 54 Cerebral palsy patients, 5 to 19 years( $11.0 \pm 2.8$ ), GMFCS 4-5 with whole spine scannogram were enrolled. Asymmetric hip index(AHI) was measured at the tilting angle of superior margin of both humeral head in coronal plane. Pelvic obliquity index (POI) was measured at tilting angle of superior margin of both iliac crests. Cobb's angle of major scoliosis curve was acquired. Hip migration index was graded with very mild( $<30$ ), moderate( $30 \leq x < 66$ ), severe( $\geq 66$ )

**Result:** AHI was significantly correlated with POI ( $p < 0.05$ ) but neither of the two parameters were correlated with Cobb's angle or hip migration index.

**Conclusion:** The more asymmetric superior migration of humeral head, the more pelvic obliquity developed in non-ambulatory cerebral palsy patient. But we cannot define the relation between the pelvic obliquity and scoliosis. Limitation of this study was that all the radiography was taken in supine position.

## **Developmental Plasticity After Injury to Neonatal Motor Cortex: An Animal Study**

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**Background:** The severity of motor impairments in children with cerebral palsy is determined by initial injury and subsequent developmental plasticity. However, the plastic reorganization in response to early brain injury could either be adaptive to achieve functional recovery or ineffective in preventing injury-induced disability. It remains unclear what factors contribute to these two opposite outcomes.

**Aim:** To test our hypothesis that adaptive plasticity is associated with defined lesions in motor cortex, whereas maladaptive remodeling may occur when motor cortex is unevenly injured.

**Method:** A modified cryocoagulation was employed to introduce lesions at the targeted location and depth on one side of the motor cortex in neonatal rodents. The resulting motor disability and the development of corticospinal tracts (CSTs) were analyzed.

**Result:** Neonatal mice with uneven lesions on one side of the motor cortex exhibit discernible hemiparalysis in daily activity in adulthood. Immunostaining for protein kinase C, a CST marker, showed uneven loss of damaged CST as well as abnormal distribution of the intact CST in the dorsal funiculus of the spinal cord. In contrast, mice with discrete lesions did not exhibit obvious abnormality in CST development and motor skills.

**Conclusion:** The size of the brain lesions did not predict the severity of the motor impairments in mice. However, uneven/diffuse lesions in motor cortex may result in ineffective repairing, rendering the emergence of CST maldevelopment and motor disability.

## **Motivation for Change of Residence over 15 years in Queensland Cerebral Palsy Population Born 1993-1995**

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### **Background**

There is evidence the commonly held belief that families of children with disabilities move less remotely towards services may not be correct. The CP population of Australia, birth years 1996 – 2005, did not reduce remoteness by five years of age overall, however 40% did move residence and 20% changed residential remoteness.

### **Aim**

To propose a method and investigate the motivation for change in residential remoteness for families with children who have CP in Queensland.

### **Method**

Whether a family moved residence between birth and 5 years, 5-10 years and 10-15 years along with the reason for change of residence when made, were collected by structured phone interview for 138, 63% of the known CP population, born in Queensland during 1993 – 95. This qualitative data was subjected to inductive thematic analysis, identifying 42 basic codes which were refined by constant comparison method to 8 higher-level categories describing the predominant reasons for change. Data were presented by frequency distribution for each of the 3 periods.

### **Results**

Moves decreased with age; 51% moved at least once during 0-5 years while 30% during 10-15 years. The most frequent reasons for residential change were housing tenure and employment related. Access to health or education services were consistently the least frequent factors that were identified by analysis.

### **Conclusion**

The proposed method is suitable for determining the motivations for residential mobility of families with a child who has CP. While some families did change residence to access education and health services, competing factors cause families to move much more often.

## **“Development of motor planning in children with cerebral palsy – a longitudinal approach”**

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### **Aim**

Motor planning is important for daily life motor functioning. Deficits in motor planning can result in slow, inefficient and sequential behaviors and have been suggested to contribute to compromised performance of activities of the daily living in children with cerebral palsy (CP). Motor planning abilities were repeatedly shown to be deficient in children and adults with CP. However, these conclusions are based on cross sectional data focusing on differences between age groups. Longitudinal data on motor planning are not yet available. The question thus remains whether the reported motor planning deficits in children with CP reflect a developmental delay or deficit. The present study aimed at answering this question by studying the development of motor planning in children with CP using a longitudinal design .

### **Method**

The longitudinal study, consisting of three measurement occasions separated by one year, was conducted in a sample of 22 children with CP and 22 age- and sex-matched controls. Children performed a bar placing task, in which some conditions (‘critical angles’) required subjects to sacrifice initial posture comfort in order to end with a comfortable posture. End posture was our variable of interest and effects of group and measurement occasion were analyzed.

### **Results**

Results show that children with CP show less motor planning, specifically with ‘critical angles’. Importantly, the motor planning did not improve across the three measurement occasions, in contrast to controls that did improve.

### **Discussion**

The present longitudinal results suggest that the absence of cross sectional age differences reported in earlier studies did not reflect a developmental delay, but a deficit in development. The present study underlines the importance of incorporating motor planning in rehabilitative strategies.

## **Study of the prevalence and assistance of the obstetric brachial plexus palsy in Catalonia**

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**Background:** Obstetrical brachial plexus palsy (OBPP) is an injury of the nerves by increased traction on the plexus and may vary from slight stretching to complete rupture and can cause serious functional disability of the upper extremity.

**Aim:** The purpose of this study was to determine the incidence of this condition in Catalonia, identify potential risk factors for OBPP for a preventive work in the hospitals with the highest incidence.

**Method:** Data from the 2006 to 2011 Kids outpatient database data sets were utilized for this study. Early Intervention services of Catalonia reported data base of risk factors for this condition. Multivariate logistic regression analysis was utilized to assess the association of neonatal brachial plexus palsy with its risk factors, sociodemographic characteristics, type of palsy, gender, race, hospital-based characteristics, hospital location, region, age starting early intervention; and the effect of time.

**Results:** Collecting a total of 76 cases for the study was obtained from 50% of early Intervention services. We found high incidence born with OBPP 2006, 2008 and 2011. 80% of these children had upper-type palsy and 9% had total-type palsy. 69% received surgical intervention before 6 month of age, 58% did not received. 83% underwent surgery in public hospitals. We found five hospitals where they were born the majority of the cases.

**Conclusion:** This study has permitted a preventive work in the hospitals with the highest incidence of OBPP by increasing the coordination with all services involved in the attention of these children. A protocol to solve shoulder dystocia and improve care during pregnancy and child birth in cases of higher risk has developed.



## **How satisfied are you with your relationships? Quality of life in adults with cerebral palsy**

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### **Background**

Cerebral palsy (CP), as condition that affects significantly motor and functional abilities, may limit activity and participation and, thus, the quality of life (QL) of children and adults. QL refers to one's individual perception of wellbeing across various domains of life. Although there are some studies on QL of children and adolescents with CP, there is little evidence concerning adults.

### **Aim**

Our main aim was to assess the QL of adults (and young adults) with CP when compared to motor able peers (namely the relationship between QL dimensions and motor impairment, gender, or occupation). Results may be useful for evaluating interventions designed to improve lives of adults with CP.

### **Materials/Methods**

Forty adults with CP (20 male; 16-45 yrs) participated in the study. WHOQOL-Bref (World Health Organization Quality of Life) was used to measure the QL. GMFSC (Gross Motor Function Classification System) was used to evaluate participants' functionality. The relationship between the variables was calculated through a Spearman correlation test.

### **Results**

Participants showed significantly lower scores in the psychological and social relationships domain of QL. Moreover a negative significant correlation was found between motor difficulty and scores in these domains.

### **Conclusions**

These results may help planning strategies for intervention with adults with CP. Previous studies show that children don't differ in QL from their peers. Although, it seems that with the age QL decreases, namely regarding psychological and personal relationships, especially in those who are more severely impaired. We still have a long path to walk concerning social inclusion. Intervention with people with CP cannot stop when they move into adulthood. There's an important job to do in the development of social competences, coping strategies, relationships, as well as a determinant work near community where each one of us has to right to social activity and participation.

## Are Spino-Pelvic Parameters correlated to Gait Kinematics in Children with Cerebral Palsy?

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### Background

The balance of children with Cerebral Palsy (CP) during gait is altered due to muscle tone abnormalities and skeletal deformities<sup>1,2</sup>. Sagittal spinal balance and pelvis morphology of children with CP and its correlation to gait abnormalities has yet to be described.

### Aim

To compare spino-pelvic parameters of ambulant children with CP to those of typically developing (TD) children and study their correlation with lower limb kinematics during gait.

### Methods

28 ambulatory spastic CP children (17 hemiplegic, 21 diplegic, GMFCS levels I: 16, II: 12, mean age =11±3 years) had undergone an EOS<sup>®</sup> biplanar X-rays with 3D reconstruction. Spino-pelvic parameters were calculated: thoracic kyphosis(TK) T1/T12 and T4/T12, lumbar lordosis(LL) L1/L5 and L1/S1, pelvic incidence(PI), sacral slope(SS), pelvic tilt(PT), sacro-acetabular angle (SA). Acetabular rotations around the 3 axes of the pelvis were calculated for the first time. All CP children had undergone 3D Gait Analysis. CP population was age-matched to 12 TD children. Spino-pelvic parameters were compared between CP and TD groups and correlations with kinematics were investigated.

### Results

PI was significantly increased in children with CP compared to TD children ( $48^{\circ}\pm 10$  and  $43^{\circ}\pm 8$  respectively,  $p=.004$ ). This was also true for SS and SA angles ( $41^{\circ}\pm 9$  in CP vs.  $34^{\circ}\pm 10$  in TD,  $p=.014$  and  $64\pm 12$  in CP vs.  $58\pm 9$  in TD,  $p=.02$  respectively). Significant correlations were found between spino-pelvic and kinematics in CP but not in the TD group: pelvis sagittal kinematics to LL ( $r=-.66$ ) and SS( $r=-.71$ ), acetabular anteversion( $r=-.69$ ), hip horizontal kinematics to LL( $r=-.3$ ) and SS ( $r=.56$ ).

### Conclusion

Pelvic deformities in CP children were shown to affect pelvis and hip kinematics. Even though TK, LL and acetabular parameters did not significantly differ between CP and TD groups, they were shown to be correlated to lower limb kinematics only in the CP group.

<sup>1</sup> Theologis,et al. 2013. <sup>2</sup>Suh,et al. 2013.

**Umbilical cord blood cells reduce neuroinflammation: a potential treatment for cerebral palsy**

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**Background:** Recently, human clinical trials have reported safety data and shown some efficacy following treatment of established CP using umbilical cord blood (UCB) cells. UCB is made up of many different cell types, including endothelial progenitor cells (EPCs), T regulatory cells (Tregs) and monocyte derived suppressor cells (MDSCs), where each may contribute towards reducing neuroinflammation and/or repair of brain injury. In this study we examined whether UCB, or UCB-derived individual cell types, could reduce peripheral and neuroinflammation and promote brain repair when given early after hypoxic-ischemic brain injury.

**Methods:** Human UCB mononuclear cells were isolated and EPCs, Tregs and MDSCs separated. Hypoxic-ischemic (HI) brain injury was induced in PND7 Sprague-Dawley rat pups, by single left carotid artery ligation followed by 8% oxygen exposure for 3 hours. Cells were administered 24 hours post HI injury. MRI brain scans were performed using a 9.4T MRI at 24h and 7 days post HI. On day 7 brains and spleens were collected. Spleens were assessed for immune cell phenotype. Brains were analysed for cell death (Caspase-3), inflammation (IBA-1), immune cell phenotype (Th1, Th17, Th2) and neuronal injury (NeuN).

**Results:** Peripheral inflammation was increased following HI injury. This was reversed with the administration of Tregs and EPCs. In the brain, Th17 cells were increased and microglia activated following HI injury and Treg administration reduced this. Our results also demonstrate that UCB, EPCs and Tregs reduced cell death, inflammation and neuronal loss following neonatal brain injury.

**Conclusions:** The neuroprotective and anti-inflammatory role of human UCB, and its constituent cells, can be effectively studied in hypoxic-ischemic newborn rats. As this study progresses it will inform the mechanisms via which UCB-derived cells mediate neuroprotection. This work has the potential to develop tailored UCB therapies for perinatal brain injury.

## **Courage and community in rehabilitation for young adults with disabilities. The case of adapted physical activity**

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### **Background**

The last decades of rehabilitation services research have emphasized the relations involved in rehabilitation processes, through concepts such as coordination, participation and user-control. In those relations, social recognition is important in at least three ways: Political recognition underpins service provisions, health care systems and rehabilitation-relevant policies. Interpersonal recognition shapes how rehabilitation services are provided in practice, and how users interact in the rehabilitation context.

### **Aim**

The aim of the present study was, during three-week stays at Beitostølen Healthsports Center for young adults, to generate knowledge on: how the dynamic of recognition and misrecognition unfolds in the relations within the user group, and how similar dynamics unfolds between the users and the professionals.

### **Method**

The study searches to grasp actual interaction by employing fieldwork methods. In order to remain sensitive to issues of identity and social recognition, the theoretical framework relies primarily upon the work of A. Honneth.

### **Results**

The young adults enter the rehabilitation stay hoping to be recognized as alike other young adults and safe from misrecognition or stigma. Preliminary results show: That recognition experiences are very productive in the rehabilitation processes. And recognition of one activity or user can be intertwined with misrecognition of another user or activity. We also found that interpersonal processes of recognition and misrecognition seem to correspond to intrapersonal processes of courage and discouragement.

### **Conclusion**

Rehabilitation contexts are vulnerable settings, where users face physical, mental and social boundaries. We have found that the social dynamics of recognition and misrecognition are important to the rehabilitation process. These processes are often based on knowledge of individual effects and structured by individual goal-setting, so this is also an important reminder for practitioners.

## DEFORMITIES OF THE LOCOMOTOR SYSTEM IN CHILDREN WITH CEREBRAL PALSY

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**Background:** Deformities of the musculoskeletal system in children with cerebral palsy (CP) are a common problem. **Aim:** The aim of this study was to determine the frequency of deformities of the musculoskeletal system (spinal column, hips and feet) in children with cerebral palsy aged 5-12 years. **Method:** The study was retrospective and included 70 patients diagnosed with CP, aged 5-12 years. Medical documentation is reviewed in order to collect data. The degree of functionality of the patients was determined according to GMFCS scale. **Results:** The most common deformities in children with CP (74.29% of the patients) were deformities of the feet (talocalgus vs. equinovarus- 42.86% vs. 31.43%), followed by deformities of the spinal column with 27.14% of the patients ( kyphosis vs. scoliosis - 15.71% vs. 11.43%) and paralytic dislocation of the hip in 10% of cases (dislocations subluxations- 7.14% vs. 2.86%). Percentage of each of the deformity was higher among children who were born prematurely. Deformities of the foot were most common in children with hemiplegia, deformities of the spine existed in patients with quadriplegia, while the paralytic dislocation of the hip was present in children with diplegia, quadriplegia and hemiplegia. In relation to the functional status of patients the largest number of spinal deformity and paralytic dislocation of the hip was in patients who were in the IV and V group, according to the GMFCS scale. Deformities of the foot were more represented in patients who were in the II, III and IV groups. The largest percentage occupied hip surgery (14.29%). The average age of children who had surgery was 10.2 years.

**Conclusion:** Continuous habilitation treatment with active participation of parents, the use of botulinum toxin type A and regular evaluation of the patient, are essential to the prevention of the occurrence and in the prevention of the deterioration of deformities.

## **Type of CP and motor outcome in relationship to gestational age, neonatal risk factors and brain injury**

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Aim of this study was to analyze relationship between GA, type of brain lesion and neonatal risk factors with type of CP and neurodevelopmental outcome.

Method: Data on CP type and subtype, GMFCS, BFMF level, classification of MRI, neonatal risk factors (APGAR, birth weight, ventilation in NICU) and accompanying impairments (visual and hearing impairment and epilepsy) collected in Croatian register of cerebral palsy on 171 children with cerebral palsy, born from 2004-2006 were analyzed according to proposal of SCPE.

Children were classified in three groups: 30,5% born as early preterm (GA 24-31 weeks), 31,1% as late preterm (GA 32-37 weeks) and 38,4% born at term (GA  $\geq$  38-41 weeks).

Result: 92,4% of children were classified as spastic, 6,4% dyskinetic type, and 1,1% as ataxia. MRI classification showed 58,9% of children had predominant white matter injury (WMI), 11,6% predominant grey matter injury (GMI), 9,82% had maldevelopments, 11,6% miscellaneous changes on MRI and 8% normal MRI. Children with spastic CP had significantly better motor outcome than dyskinetic and lower GA (34,3 vs. 37,8 weeks). Children with GMI had significantly higher GA than children with WMI (38,2 vs. 34,1). Children classified as bilateral type had worse outcome on GMFCS, were born significantly earlier (33,1 vs. 36,5 weeks), and were ventilated in NICU significantly often than unilateral subtype. Early preterm children had significantly worse GMFCS, were more often ventilated in NICU, and had visual impairment more often than children born at term. There were no differences in BMFM and hearing impairments between GA groups. Children that were ventilated in NICU had significantly worse gross and fine motor outcome than non-ventilated children.

Conclusion: There is a relationship between gestational age, early and late 3rd trimester patterns of brain injury, and neonatal factors with significant impact on type of CP and neurodevelopmental outcome in observed group.

## **High-density EEG recordings during sleep in children and adolescents with acquired brain injury: a novel approach to investigate neuronal reorganization**

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### **Background**

Acquired brain injuries (ABI) such as traumatic brain injury (TBI) or stroke can result in various neurological deficits (e.g., motor deficits, language impairments or cognitive deficits). While a considerable amount of studies have investigated functional recovery, underlying neuronal reorganization processes remain poorly understood. Increasing evidence indicates that plastic processes in the brain are linked to changes in electroencephalographic slow wave activity during deep sleep (SWA, EEG spectral power 1-4.5 Hz).

### **Aim**

In the present study we investigated SWA in children and adolescents with ABI and compared them to a healthy control population.

### **Methods**

We used high-density EEG (128 electrodes) to record sleep in 22 young patients with ABI (age range: 4-14 years). The healthy control population was selected from earlier studies (n=52). Neurological deficits were assessed using the Pediatric version of the NIH Stroke Scale (PedNIHSS) and the Neurological Outcome Scale for Traumatic Brain Injury (NOS-TBI).

### **Results**

Compared to healthy children and adolescents 20 out of 22 patients with ABI showed clear differences in SWA. In patients with bilateral stroke (PedNIHSS score 25-34) SWA was globally reduced across the entire scalp. Patients with unilateral stroke (PedNIHSS score 1-4) showed a reduction in SWA over lesion areas and an increase over perilesional and contralateral brain areas. In patients with severe TBI (NOS-TBI score 17-32) we found a reduction in SWA over the midline and an increase over lateral brain areas. We found no consistent pattern in patients with mild to moderate TBI (NOS-TBI score 0-2).

### **Conclusions**

Our results suggest that SWA is a sensitive marker for plastic processes after ABI. Reduced SWA may indicate impaired neuronal function whereas, increased SWA might reflect neuronal reorganization. Further research in this direction is worthwhile as this marker could provide new prognostic information.

## **Cerebral Palsy Research Registry: Updated Application for Patient-Reported Longitudinal Outcomes on Health, Functioning, and Participation**

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**Background:** A national cerebral palsy (CP) registry has not been attainable in the United States . We chose to seek the input of those closest to the data – individuals with cerebral palsy and their caregivers to advance understanding of health, functioning and participation across diverse ages.

**Aim:** We developed an online-accessible portal through which individuals with CP and their families could provide information for the purposes of describing their current health status, functioning , participation and community supports. We allow individuals to describe their current status as well as inform them after their assent of current research studies. We have put in place the ethical and legal framework to allow for collaborations between multiple sites for recruitment and research.

**Method:** A web-based application has been created to longitudinally collect data about health status, functional activities, participation and biomedical, socioeconomic and family risk factors for individuals with CP. The web application can also be utilized to directly notify participants about potential studies, as well as capture their responses. In addition, we have maintained the option for individuals to register via paper forms in order to allow for those who do not have internet access to become involved. A multi-pronged recruitment strategy has been employed to make those with CP aware of the CPRR existence and efforts.

**Result:** More than 1,000 individuals with CP(age range 3-86Y), or their guardians, have consented to register from 41 states. They represent all levels of the GMFCS in both pediatric and adult participants.

**Conclusion:** We have demonstrated the feasibility of an online partnership between individuals with cerebral palsy, their families, and descriptions of physical and behavioral health, functioning and participation . Our data provide the basis of informing life course outcomes as well as recruitment to clinical and translational research studies.



## Disparities in family adversity among children with disabilities: A population-based US study

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**Background:** Adverse childhood experiences (ACES) are stressful or traumatic experiences before the age of 18 and include abuse, neglect and household dysfunction. The purpose of this study was to identify the prevalence of ACES among families of children with and without children with DD using a population-based sample.

**Methods:** Data from the US 2011-12 National Survey of Child Health (NSCH) were analyzed to estimate prevalence of ACES among families of children with and without DD, age 2-17 years (N=74,438; DD= 12,714). Children with DD included autism, intellectual disability, cerebral palsy, Tourette's syndrome, hearing, vision or speech impairments, epilepsy, traumatic brain injury, learning disorders, ADHD and developmental delays. The modified Adverse Childhood Experiences Scale was used and included: severe poverty; parental divorce, death or incarceration; child witnessed domestic or neighborhood violence; child residing with anyone with mental illness or drug/alcohol abuse. Responses were aggregated to calculate composite family ACES scores (0-8) and categorized as low, moderate, or high risk based on 0, 1-3,  $\geq 4$  reported ACES. Bivariate and multinomial logistic regression were utilized to investigate the relationship between ACES and child DD status.

**Results:** DD status among children was significantly and independently associated with higher probability of reporting 1-3 family ACES (vs no ACES) (aRRR 1.56; 95% CI 1.36-1.80;  $p < .01$ ) and 4+ family ACES (vs. 0 ACES) (aRRR= 2.46; 95% CI 1.85-3.28;  $p < .01$ ). DD status also differentiated high risk vs moderate risk families (aRRR=1.57; 95% CI 1.19-2.09;  $p < .01$ ).

**Conclusion:** Children with DD experience a greater number of family and neighborhood adversities, potentially compromising their long term physical, behavioral and social health outcomes. Research on reduction of ACES among vulnerable families of youth with DD could contribute to the reduction of population health disparities.

## Hospital cared injury in Finnish Children with Cerebral Palsy—a Population-Based Cohort Study

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### Background

Cerebral palsy (CP) associates with a wide range of comorbidities, which predispose to injuries. Literature is limited concerning injuries related to combination of risk factors including socioeconomic disadvantages in children with CP.

### Aim

To investigate the risk of injury and to estimate the effects of comorbidities and socioeconomic variables in children with CP.

### Methods

We have established a population-based cohort of 341 033 Finnish children born in 2001–2006. In this national register-based study children were followed from birth until first injury or 31 December 2012. A total of 667 children were diagnosed with CP. Children were classified by individual (sex, age, gestational age and weight, multiple births, comorbidities, type of injury) and maternal characteristics (smoking during pregnancy, parity, occupational and education level, marital status, age, social assistance recipient) and estimated the risk of injury.

### Results

Among children with CP, the incidence of injury was 3233 per 100 000 person-years, while among children without CP, the corresponding figure was 2276. Children with CP had a significantly higher risk of injury, compared to children without CP, Hazard Ratio (HR) 1.42 (1.22–1.65) and after adjusting for individual and maternal variables HR 1.39 (1.18–1.63). Premature birth had no significant risk effect on injury risk in children with CP. Socioeconomic disadvantages, male-sex ADHD, epilepsy, intellectual disability, visual and hearing impairment increased the risk of injury in all children. Highest incidence rate ratio (IRR) of injury was among zero-to-1 year children with CP compared to controls IRR 2.09 (1.38–3.17), after adjusting 1.85 (1.15–2.98). Across all injury types, traumatic brain injuries (48, 7.8 %) were the most prevalent reasons for hospital-cared injury in children with CP.

### Conclusion

In addition to CP, ADHD, epilepsy, intellectual disability, visual and hearing impairment increased the risk of injury in all children.

## **Physicians' attitudes faced with life threatening events in children with profound neurological disabilities**

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### **Background**

Children with profound neurological disabilities are at risk of life threatening events, especially related to respiratory morbidity. Taking decisions in these acute situations faces physicians with complex medical, ethical and judicial issues.

### **Aim**

To assess the attitudes of Swiss physicians when faced with life threatening events in children with profound neurological disabilities.

### **Method**

An online survey was sent to paediatric neurologists, physiatrists and intensive care specialists in tertiary centres (with child ICU facilities) in Switzerland. The questionnaire included personal characteristics, and explored participants' attitudes in life threatening situations in 2 scenarios: a. a child in minimal consciousness state (MCS); b. an infant with SMA type I. Responses were graded on a 4-point Likert scale from total agreement to total disagreement.

### **Result**

52/95 physicians took part (55% participation). In both scenarios there was a consensus between physicians for the following attitudes: 1) favouring non-invasive ventilation, 2) favouring comfort care, 3) avoiding tracheotomy and long term invasive ventilation.

In the MCS scenario 61% of participants opposed complete cardiopulmonary resuscitation (CPR), 39% supported it. In the SMA I scenario 51% opposed complete cardiopulmonary resuscitation (CPR), 49% supported it. In the SMA I scenario if parents requested tracheotomy with long term ventilation based on religious grounds, 50% participants agreed with the attitude.

Physicians with > 20-year experience were significantly more opposed to complete CPR and favoured non-invasive attitudes. Physicians from French-speaking Switzerland were significantly more prone to withholding/withdrawing life support than their German-speaking peers.

### **Conclusion**

Physicians' attitudes differ significantly, influenced by personal and cultural factors. This highlights the importance of codified multidisciplinary processes to approach these complex situations.

## **CEREBRAL PALSY MANAGEMENT AT CENTRE FOR THE REHABILITATION OF PARALYSED IN BANGLADESH**

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Cerebral Palsy is a non progressive lesion of the brain occurring before or after birth. It is an incurable condition but improvement in function is possible if appropriate treatment is given. For treatment of cerebral palsy not only medication but rehabilitation is required to make the child independent. Bangladesh is one of the high density populated country in the world with limited rehabilitation facilities.

The objective of this presentation- to share with different foreign delegates about the affluent multidisciplinary rehabilitation service for cerebral palsy at CRP as well as Bangladesh.

Rehabilitation service in Bangladesh is developing day by day. Since 1998 paediatric unit of CRP has been providing their rehabilitation service by multidisciplinary team which are included Pediatricians, Physiotherapist, Occupational Therapist, Nurse, and Counselor, Orthotics, Seating specialist and Special educator for improving the ability of the children with CP. Evidence-based quality service providing is the main goal of this team. CRP is only one institute which provide in patients rehabilitation service for fifteen days for CP children. The two weeks inpatient program with 51 children is designed to integrate children with cerebral palsy into family and community life. To achieve this, children participate in physical, Psychosocial therapy and play therapy while mothers are trained- how to take care for the child and create awareness of disability issues and rights. In about 4000 CP Children got the 15 days residential rehabilitation service from this unit. From those children many of them are able to live independently in the society. CRP is providing this rehabilitation services at its Head Office Savar and also Dhaka city office premises.

Along with other developing countries, it is crucial need to develop skilled rehabilitation professionals by which spread this important service to the country wide.

## **A prospective cohort study of body composition and modifiable lifestyle factors in preschool aged children with CP**

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The impact of modifiable lifestyle factors on body composition in children with cerebral palsy (CP) has not been examined.

To assess longitudinal relationships between body composition and energy intake, habitual physical activity (HPA) and sedentary time (ST) in preschool aged children with CP across Gross Motor Function Classification System groups (GMFCS I-V).

Children with CP (n=161; 98 boys; recruitment age: 3.2±1.1 years; GMFCS I-II: n=99; III: n=22; IV-V: n=40) were seen for 365 assessments between 1.5 and 5 years. Body weight (kg), height (cm) and feeding method (oral or tube) were collected. Fat free mass (FFM; kg) and fat mass (FM; kg) was measured via deuterium dilution technique or bioelectrical impedance analysis. Energy intake (MJ), HPA (counts per minute: CPM) and ST (% of day) was measured via three-day weighed food diary and ActiGraph® wear. Analysis was by mixed-effects linear regression.

Group IV-V has a lower FFM and higher FM than group I (mean difference (MD)=-0.4 kg; 95%CI=-0.8 to -0.1 and MD=1.8 kg; 95%CI=1.0 to 2.6 respectively). Group III had higher FM than group I (MD=0.8 kg; 95%CI=0.1 to 1.4). Relative to height, FFM decreases each year (MD=-0.4kg/yr; 95%CI=-0.6 to -0.1) while relative FM does not change. Height has a positive association with FFM and FM (MD=0.16 kg/cm; 95%CI=0.12 to 0.20 and MD=0.07 kg/cm; 95%CI=0.02 to 0.11 respectively) and is a positive predictor of FFM gain each year (MD=0.03 kg/cm/yr; 95%CI=0.02 to 0.04). Energy intake and FFM are positively associated (MD=0.12 kg/MJ; 95%CI=0.01 to 0.24).

Differences in body composition in children with CP are evident at a very young age. The discrepancy in FFM increases with age, as height gain is an independent positive predictor of FFM gain and children with more severe motor impairment tend to grow slower. The positive relationship between energy intake and FFM warrants further investigation.

## **enAble Games: Designing active video games to promote fitness and physical activity in youth with cerebral palsy**

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**Background:** Youth with cerebral palsy (CP) are less physically active and more deconditioned compared to peers with typical development. Active video games (AVGs) promote physical activity (PA). Customized games provide flexible parameters to promote PA and fitness while addressing physical therapy goals.

**Aim:** Design and test KOLLECT, a customized AVG for youth with CP that focuses on increasing aerobic fitness and PA

**Method:** Twelve youth (mean age: 15.7 yrs, SD: 3.7 yrs), males (75%) at GMFCS I (16%), II (42%), and III (42%) participated in two KOLLECT AVG sessions. Each session consisted of 3 games (20 min/game) with warm-up, conditioning, and cool-down phases. Each game was played in a different condition (sit, stand, steps). Youth wore heart rate (HR) monitors and hip accelerometers to measure PA intensity and frequency during game play. To estimate the influence of game, condition, and session on HR, repeated measures ANOVAs (3 (Conditions) X 3 (Games) X 2 (Sessions)) were conducted with Tukey post hoc comparisons. Percent maximum HR (% MHR) was calculated from HR responses for each phase of exercise to determine if youth reached target HR zones (THRZ) for game exercise phases. Accelerometer counts and PA intensity were calculated for game phases and conditions.

**Results:** Significant interactions between: condition and youth ( $F = 11.67$ ,  $p < 0001$ ); condition and game ( $F = 5.16$ ,  $p < .001$ ); and game and session ( $F = 3.91$ ,  $p < .025$ ). Significant main effects between games ( $F = 5.06$ ,  $p < .007$ ) and AVG sessions ( $F = 21.99$ ,  $p < .00001$ ).

Preliminary results on post hoc comparisons suggest specific game conditions and duration to promote fitness and PA. Preliminary results on %MHR and activity counts suggest that most youth achieved THRZ during games and most reached moderate to vigorous PA levels during conditioning phase.

**Conclusion:** Findings support the effectiveness of KOLLECT in promoting aerobic fitness and PA in youth with CP during game play.

## **Frontal EEG asymmetry as a measure of emotional and behavioural vulnerability in infants with congenital visual impairment**

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**Background:** Children with visual impairment (VI) are at increased risk of emotional and behavioural vulnerabilities, yet a possible neural substrate of these vulnerabilities is not known. EEG frontal asymmetry response to emotional vocalisations has been established as an early biomarker of concern in other clinical populations. **Aim:** As part of the first longitudinal study of VI infants (OPTIMUM Project, Dale et al), this study assessed i) EEG frontal asymmetry in response to emotional vocalizations at 1 year of age and (ii) established any association between frontal asymmetry at 1 year and behavioural difficulties at 2 years. **Method:** At Time 1, 27 infants (mean age  $13 \pm 2.5$  months) with 'simple' disorders of the congenital visual system underwent EEG recording (128-channel sensor net) whilst being presented with happy, sad and neutral vocalizations. Frontal EEG asymmetry ratios were calculated from power spectral density in the alpha frequency band (6-10Hz). At Time 2, parent-rated Achenbach Child Behavior Checklist (Achenbach 2001) data on 22 infants was obtained (mean age  $26.2 \pm 2.5$  mths). **Result:** A significant effect of emotion condition on EEG frontal asymmetry was revealed, with infants showing the expected response of greater left frontal asymmetry to happy sounds (Coan et al., 2001). However the expected greater right frontal asymmetry response to sad affect was not found. A significant positive correlation between EEG frontal asymmetry (Time 1) and behaviour difficulties (Time 2) was observed. **Conclusion:** Our findings suggest i) atypical emotion processing of negative affect at neural level, in line with previous behavioural reports of emotion recognition dysfunction in children with VI (Dyck et al., 2008) and (ii) the role of frontal asymmetry as a potential early biomarker of behavioural difficulties in young children with VI. The wider OPTIMUM project will incorporate these findings to look at potential factors influencing longer-term behavioural outcome.

## HEMISPHERE DOMINANCE AND LATERALITY AS POSSIBLE INDICATORS OF STUTTERING IN CHILDREN

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## HEMISPHERE DOMINANCE AND LATERALITY AS POSSIBLE INDICATORS OF STUTTERING IN CHILDREN

**Introduction** Stuttering is a multifactor disorder and its aetiology is a big unknown for the experts from various fields. Hemisphere dominance as the highest level in the process of cortical functions' integration is of special significance for the entire development. Cortical activity organizers are definitely set at that age and thenceforth act from one hemisphere which becomes dominant for that function. Laterality is determined by hemisphere dominance, but it occurs as a special phenomenon and it is of great significance for personality. The aim of this research was to examine the influence and the relationship between hemisphere asymmetry and stuttering in children. **Methods.** Sixty children aged 5 to 7 participated in this research.

Individual testing was used as a test method. Laterality assessment test was used as an instrument, which consists of 6 sub-tests as follows: the assessment of hand-use laterality, the assessment of gestural hand-use laterality, the assessment of praxis speech zone laterality, the assessment of foot laterality, the assessment of auditory laterality and the assessment of visual laterality. **Results.** Gestural hand-use laterality in the PWS examinees is considerably worse in comparison to the PWNS examinees ( $p=0.002$ ). Laterality of praxis speech zone in 33.3% is on the left side, in 36.7% is on the right side, and it is not differentiated in 30% of the PWS examinees, which makes them considerably worse ( $p=0.000$ ) in comparison with the PWNS. Auditory laterality is considerably worse in the PWS examinees ( $p=0.003$ ).

Male examinees had worse scores in comparison with female examinees. **Conclusion.** There are certain changes in establishing a dominant hemisphere and differentiation of laterality in children who stutter.

**Key words:** stuttering, dominant hemisphere, laterality.



## **Characterization of Physical and Occupational Therapy Services for Children with Cerebral Palsy**

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**Background:** The amount and focus of physical (PT) and occupational therapy (OT) for children with cerebral palsy (CP) are complex issues. Motor function, age, and family needs are considerations for decision making. **Aim:** Characterize the amount and focus of PT and OT and parent perceptions of services. **Method:** Participants were 692 children with CP, 1.5 to 12 years, and their parents in the USA and Canada. Children were grouped by age (<59 months; ≥60 months), Gross Motor Function (GMFCS) and Manual Ability (MACS) levels (I, II/III, IV/V). Parents completed a services questionnaire on the amount and focus of therapy, family centered practices, and the extent services met needs the past 12 months. **Results:** Children in GMFCS and MACS levels IV/V received the most PT (M=55.2, SD=51.8) and OT (43.1, SD=43.8) sessions, respectively, while children in level I received the fewest PT (M=22.8, SD=30.5) and OT (M=12.4, SD=19.1) sessions. Therapy for children in GMFCS level I focused more on activities compared to children in levels II/III. Therapy for children in levels II/III focused more on assistive technology and environmental modifications. Therapy for children in levels IV/V focused more on primary impairments and structured play, recreation, and leisure. Parents rated that therapists engaged in family-centered practices a moderate to great extent, interacted effectively with the child a great to very great extent, and assisted the family in finding community resources and provided therapy in community settings a small to moderate extent. Parents rated needs related to their children's motor abilities, self-care, participation, and overall health were met a moderate to great extent. **Conclusions:** Decisions on the amount and focus of therapy for children with CP are partly based on gross motor function and manual ability. Therapists are encouraged to reflect on considerations regarding the amount and focus of services and engage families in collaborative decision-making.

## **Cognition in spina bifida and it's consequences in everyday life - a life-span perspective - A systematic review**

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**Introduction** The number of children born with spina bifida in Sweden today is 10-15 per year compared with 80-100 about thirty years ago. About half of the individuals with spina bifida in Sweden are 20 years old or more. It is important to maintain and spread knowledge about this disability to secure professional care, understanding and help for this decreasing group. Therefore the association of the managers of Habilitation centers in Sweden gave the assignment to the authors to produce an evidence-based report on actual knowledge about cognition in spina bifida.

**Aim** To describe actual knowledge on cognitive characteristics in children, youths and adults with spina bifida and its consequences for development, learning, process skills and practical everyday functioning in a life time perspective.

**Method** Systematic data-base search and quality assessment of articles on cognition produced from 2000 and forward. 67 were chosen relevant according to the McMaster Rating of Evidence.

**Results:** About 70% have an intellectual function above an IQ of 70. Difficulties in visual perception, attention and memory function and problems with planning and initiation were described as common despite IQ-level, as well as pragmatic language problems. The difficulties still remain into adulthood. Difficulties with planning and initiation were the most hindering factors for autonomy in adult years. Cognitive dysfunction was found to be hindering in all domains of everyday-life when using the International Classification of Functioning and Health (ICF)

Knowledge of cognitive functions is necessary to provide optimal care and treatment of children, youths and adults with spina bifida. Throughout life they need support to overcome especially executive dysfunctions, in preschool, school, at home and at work. Many need continuous support of an assistant or mentor. This is crucial to ensure quality of life and equal participation in society.

## **NORMALIZED THERAPY VERSUS INTENSIVE PETÖ THERAPY: A COMPARATIVE STUDY.**

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**INTRODUCTION:** The Petö method, also known as “Conductive education”, is a system that integrates educational and pedagogical methods and strategies to rehabilitation, both on a physical and cognitive level. The main aim of this study was to compare the effects of intensive Petö therapy versus weekly Petö therapy on the gross motor function scale (GMFS) of children with cerebral palsy (CP).

**MATERIAL AND METHODS:** A quasi-experimental study was performed on a sample of 30 children with CP. Of these, 15 (experimental group) received intensive Petö therapy (5 days a week, 7 hours a day), and the other 15 children (control group) received Petö therapy twice a week, until an equal number of sessions was completed by both groups. The inclusion criteria of the study included: children diagnosed with CP aged between 2 and 16 years, and with grade III and IV on the GMFM (Gross Motor Function Measure).

**RESULTS:** In the intensive therapy group (experimental) improvement was evident in less time than in control group, but the benefits remain longer in the control group than in the experimental. These changes were not significant for all the scores, and were dependent on the ages and motor items analyzed (lying-turning/ sitting / standing / walking).

**CONCLUSION:** Our findings indicate that the Petö method is a valid option for the treatment of physical disabilities in children with CP, whether in the form of intensive or conventionally dosed sessions.

## **The association between spastic Cerebral Palsy, intellectual impairment, and gestational age: results from the Northern Ireland Cerebral Palsy Register**

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### **Background**

Studies suggest a complex relationship between Cerebral Palsy sub-types, severity of impairment, and risk factors such as gestational age. To investigate these relationships, we conducted analyses on over 1,100 children included in the Northern Ireland Cerebral Palsy Register (NICPR) whose clinical CP subtype was Bilateral Spastic or Spastic Hemiplegia, and for whom information was available on the relevant variables.

### **Methods**

We tested for the association between Bilateral and Hemiplegia subtypes, severe intellectual impairment, and gestational age (term; moderately preterm; very or extremely preterm) while controlling for sex, socio-economic deprivation, year of birth, and birth weight (using a standardized birth-weight score based on deviance from the birth weight average within each gestational age band). Severity of intellectual impairment was dichotomised (severe intellectual delay vs. moderate or no delay).

### **Results**

Logistic regressions indicated a good fit of the model, and the predictors included explained approximately 19% of variability in the outcome. The results indicated a strong association between the Bilateral subtype and severe intellectual impairment: compared to children with the Hemiplegia subtype, those with Bilateral Spastic CP displayed a 10-fold increase in the odds of severe intellectual impairment. The results revealed a significant interaction between CP subtype and gestational age: for the Bilateral CP subtype, being born at term was associated with increased probability of severe intellectual impairment.

### **Discussion**

Results are consistent with other studies (Hemming et al., 2008) in indicating that the likelihood of cognitive impairments of Bilateral Spastic CP children increases with increasing gestational age at delivery. The results will be discussed in light of hypotheses that suggest the brain might be able to reorganise and compensate the effects of lesions and injuries when it is still less developed.

## SHORT TERM RESULTS OF SPINAL DEFORMITY OPERATIVE TREATMENT IN ADOLESCENTS WITH CEREBRAL PALSY (CP) AND ASSOCIATION WITH HIP DEFORMITIES AT SKELETAL MATURITY

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### Background

Cerebral palsy scoliosis and hip dislocation are more common and severe in children GMFCS levels IV and V. In countries where preventive surgery for hip instability is not generally practiced, the two pathologies often coexist in CP adolescents.

### Aim:

To document the short term results of scoliosis surgery in CP adolescents and detect possible association with pelvic obliquity and hip deformities.

### Method

We retrospectively reviewed the files of CP patients operated on for scoliosis in our hospital, who had hip radiographs available at skeletal maturity and after spinal fusion.

### Result

We identified 24 patients treated operatively at an average age of 15.5 years for spinal curves  $\geq 50^\circ$ . Fifteen patients were GMFCS IV and 6 GMFCS V. Average fu was 41 months and mean age at latest examination was 18 years. In total, 17/24 patients had long C curves, all patients had posterior spinal instrumentation and 7/24 were fused to the sacrum. The mean preoperative scoliosis was  $80^\circ$  with correction postoperatively to a mean of  $36^\circ$  maintained at  $39^\circ$  at final fu. Complications occurred in 10/24 patients (41%), most commonly early postoperative wound infection. Pelvic obliquity was present in 18/24 patients preoperatively (in all, the higher pelvic side was opposite the lower spinal curve convexity). Pelvic obliquity was reduced by 37% on average after spinal instrumentation. Fourteen patients had previous hip surgery at an average age of 10 years and 10/24 patients had hips with  $MP \geq 40\%$  at final fu, but in general, no deterioration of hip instability was recorded after spinal fusion.

### Discussion

Less extensive spinal surgery for larger, stiffer curves which may be associated with fixed supra- or infrapelvic obliquity can yield less satisfactory trunk and pelvic alignment. Reactive rather than prophylactic surgery for hip instability can be implicated for residual hip instability and deformity at skeletal maturity.

## **Congenital anomalies and syndromes in a cross-sectional study of 240 children with Cerebral Palsy (CP), according to the SCPE guidelines, in Greece.**

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### **Objective**

To document the relative frequency and types of related congenital anomalies and syndromes in children and youth with CP.

### **Methods**

Data were retrieved from the Greek CP registry, for all children, youth and young adults currently registered (birth years ranging from 1981–2013). The malformations were classified as cerebral malformations or non-cerebral malformations, diagnosed syndromes and documented chromosomal anomalies.

### **Results**

Overall 35 out of 240 CP patients registered (14.5%) were also diagnosed to have a related congenital or chromosomal anomaly or syndrome. The majority (10/240) were diagnosed with a congenital brain malformation. The most frequent types of cerebral malformation were schizencephaly and micropolygyria. Other congenital brain anomalies included congenital hydrocephalus, septo-optic dysplasia, lissencephaly, hemi-megalencephaly and reduction anomalies of cerebrum. Non-cerebral malformations were present in total in 18/240 patients (in 2 patients in association with cerebral malformations). The most frequent types of non-cerebral malformations involved the urinary system (most frequently ante-natally diagnosed hydronephrosis), cardiac and circulatory system (VSD, patent ductus arteriosus, transposition of great vessels), upper limb reduction defects, anomalies of the genital organs (cryptorchidism) and congenital malformations of the eye (congenital cataract) . Six children (6/240 = 2.5%) were diagnosed with a syndrome (including Angelman, nail-patella, Di George and Adams-Oliver syndromes) and in another 6/240 children (2.5%) a chromosomal anomaly was documented.

### **Conclusion**

The percentage of congenital anomalies coexisting with CP which was documented in our sample (14.5%) is much higher than the prevalence of all congenital anomalies per 10,000 live births reported by EUROCAT (approximately 2%) for a large European population but is in accordance with the relevant data already published by the SCPE Collaborative Group.

## Structural and functional correlates of aberrant fidgety movements

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**Background:** Aberrant fidgety movements (FM) at 12 weeks post-term age (PTA) have been associated with later abnormal neurodevelopmental outcome. However the structural correlates of FM are not well understood.

**Aim:** To identify specific brain regions that differentiated preterm infants who had normal neurodevelopmental outcome at 2 years of age and normal FM at 12 weeks PTA from those infants who did not have normal outcomes and FM.

**Method:** 43 infants with birthweight <1500g and <31wks gestation received MRI at term-age, general movement assessment at 12 wks PTA and Bayley-3 testing at 24 months PTA. Infants with aberrant FM (absent, sporadic or exaggerated FM) and abnormal Bayley outcome (“doubly abnormal”) were compared to infants with normal outcome and FM (“doubly normal”) using tract-based spatial statistics. Cognitive, language, and motor Bayley subscales were analyzed separately.

**Results:** With respect to cognitive outcomes, “doubly abnormal” infants exhibited significantly lower fractional anisotropy (FA) in the corpus callosum and the inferior longitudinal fasciculus. For language outcomes, “doubly abnormal” infants exhibited significantly lower FA in the corpus callosum, the inferior longitudinal fasciculus, and the fronto-occipital/inferior/superior longitudinal fasciculi. In contrast, for motor outcomes, “doubly abnormal” infants exhibited significantly lower FA in the anterior and posterior limbs of internal capsule and cerebral peduncles, as well as in the optic radiation and the fronto-occipital/inferior/posterior longitudinal fasciculi. Notably, these infants did not demonstrate significant voxels in the corpus callosum.

**Conclusion:** Specific brain regions functionally related to cognitive, motor and language outcomes were identified as having lower fractional anisotropy in infants with abnormal movements. These imaging findings indicate that aberrant FM have specific anatomic substrates.

## Medical and rehabilitative management and care profiles in adults with cerebral palsy in Brittany

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### Background

There is a lack of knowledge on the actual care consumptions in the population of adults with cerebral palsy (CP). Because of the heterogeneity of the population, the concept of profile of care as defined as a group of person with the same care needs is needed.

### Aim

The aims of this study were to report the frequencies of the medical and rehabilitative care in a cohort of french adults with CP and to evaluate whether the GMFCS was a determinant of care frequencies. The last aim was to establish care management profiles in adults with CP according to the GMFCS.

### Method

A questionnaire based cross sectional study was conducted. Between February 2010 and June 2011, 520 questionnaires interviewing on the current medical and paramedical management were sent to a french network for adults with CP. The questionnaire was filled by the patient itself and by an helper when needed.

### Results

Among the 282 responders (54.2%), 7.80% were level I on the GMFCS, 14.18% II, 17.73% III, 29.08% IV and 31.21% V. Adults with CP had an important amount of medical and rehabilitative cares. 79.78% of the adults with CP were followed by a general practitioner, 53.90% by a physiatrist. 71% had orally administered drugs. The most frequent were antiepileptics (28.7%) and antispastics (23.4%). 89.01% were supported by at least one paramedical therapist, 87.2% had a physiotherapy management. 78.01% reported at least one mobility aid, 69.50% had at least one orthotic device. The frequencies of numerous treatments increased with the GMFCS levels. Some specificities according to the GMFCS level were noticed, for instance, GMFCS III patients had more orthopaedic insoles than other classes. Profiles based on the GMFCS could be established.

### Conclusion

These data provide a reflect of adults with CP “health issues”. Specific needs like motor and autonomy managements are pointed. GMFCS profiles can be used as reference in daily clinical practice to facilitate patient targeted support.



## **Improvements in active elbow and wrist extension is maintained 10 years after upper limb surgery in cerebral palsy and stroke.**

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**Background:** Children with cerebral palsy (CP) may eventually develop a pronation and flexion deformity of the wrist and a flexion deformity of the elbow, further impairing the function of the already paretic limb. Many teenagers also complain about appearance of the arm. We have previously shown that tendon transfer surgery and tendon lengthening improve the usefulness of the arm (AHA) when assessed 6-months after surgery. Whether these improvements are maintained many years after surgery is unknown.

**Aim:** Investigate whether short-term improvements in ROM, bimanual hand function (AHA) and self-rated perception of the arm/hand following upper limb surgery are maintained up to ten years.

**Method:** Fifteen individuals with unilateral or bilateral spastic paresis (n=12) were followed up 9 years (104±14, range 71-126 months) after surgery of the upper extremity. Mean age at initial surgery was 11±3 years. Outcome measures were ROM, hand function (AHA, Zancolli and House classifications).

**Result:** Elbow extension deficit (average 17.2°±12) was present in 12 out of 15 children pre-OP. Biceps lengthening (n=9) reduced the deficit (pre 23.7°±12, post 13.3°±9 & follow-up 15.9°±10, p<0.05) and was maintained 9 years after surgery. In the children who did not have biceps surgery, a significant deterioration in active ROM was observed (pre 7.5°±10, post 5°±10 & follow-up 16.3°±10, p<0.05). Wrist extension, was improved >50° when evaluated 6-months post-surgery and this was maintained at long-term follow-up (pre -7.1°±51, post 44.3°±21 & follow-up 38.6°±38, p<0.5). Short-term improvements in the usefulness of the operated hand (AHA) deteriorated slightly long-term to the pre-OP level.

**Conclusion:** Short-term improvements in active elbow and wrist extension are maintained 9 years after upper limb surgery in spastic paresis. However, the Assisting Hand Assessment (AHA) was unchanged, indicating that cerebral control of complex movements is the limiting factor for use.

## **Causes of internal foot progression angle in children with spastic diplegia**

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Title: Causes of internal foot progression angle in children with spastic diplegia

Background:

Internal foot progression (IFP) angle is commonly observed in children with cerebral palsy (CP). In patients with spastic diplegia, this pattern has often thought to be related to excessive femoral anteversion. However, normal foot progression alignment is not always reestablished after femoral derotation osteotomy. Furthermore, recent studies have shown no significant correlation between femoral anteversion and hip kinematics in patients with CP. These studies have indicated that multiple parameters can contribute to foot progression deviations in patients with CP.

Aim:

To analyze the contribution of kinematic and morphological parameters to IFP during gait in children with spastic diplegia.

Method:

One hundred eighty-eight children with spastic diplegia and full gait analysis were reviewed. No previous surgery was recorded. Mean age was 12 years. Kinematic (foot progression angle, ankle, hip and pelvic rotations in stance phase) and clinical parameters (femoral anteversion, patellar and knee alignment) were evaluated. The association between these parameters and IFP was assessed statistically.

Result:

Foot progression angle was abnormal in 90% of patients and internal in 60% of limbs. Internally oriented patella was an indicator of femoral anteversion in 75% of cases. Otherwise, it was related to internal pelvic rotation. Femoral anteversion showed no significant correlation with hip kinematics. Internal foot progression angle was correlated to pelvic rotation ( $R = 0.4$ ) and to ankle rotation ( $R = 0.5$ ).

Discussion:

These results showed that IFP is related to transverse plan ankle and pelvic kinematics. Femoral anteversion did not correlate to internal hip rotation during gait, which is in concordance with previous studies. Further research will be oriented to analyze IFP causes, in function of different types of gait and anatomical patterns of CP.

## **Inequalities in access to treatment with Botulinum toxin A (BoNT-A) of children with CP in Norway**

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**Background:** Intramuscular injections of Botulinum neurotoxin serotype A (BoNT-A) has been used to reduce spasticity in children with cerebral palsy (CP) during the last two decades. The intention is to improve gross and fine motor function, reduce pain and facilitate care. Despite extensive use, there is a lack of evidence based guidelines, and thus, great variations in dosage, dosage intervals and supportive treatment. BoNT-A treatment is provided by 21 paediatric habilitation centers within 19 counties in Norway. The 19 counties are organized into four health regions. An important principle of social healthcare in Norway is that all inhabitants have similar access to health services.

**Aim:** To study if the proportion of children with CP treated with BoNT-A differ between counties and health regions in Norway.

**Method:** All 1207 children with CP born during 1999-2008 recorded in the Cerebral Palsy Register of Norway were eligible. Children with ataxic or unclassified CP, and children with missing data on CP subtype and BoNT-A treatment were excluded, resulting in a study population of 880 children.

**Result:** In all, 541 (61.5 %) children were treated with BoNT-A, and of these the highest proportion was found among children with GMFCS levels III and IV, and MACS level III. The proportion of children treated with BoNT-A varied considerably between the counties, from 33% in the county with the lowest proportion to 88% in the county with the highest ( $p < 0.001$ ). Significant differences were also found between the four health regions, varying between 50% and 72% ( $p = 0.005$ ). On average, the proportion of children treated with BoNT-A was lower in counties with lower population density, and thus, fewer children with CP ( $N < 60$ ) compared with counties with higher density.

**Conclusion:** The access to treatment with BoNT-A varies significantly between counties and health regions in Norway. This difference reflects the lack of evidence, and consequently of national guidelines.

## New insights into white matter injury in term born children with cerebral palsy

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**Background.** Neuroimaging classifications in term-born children with cerebral palsy (CP) include a predominantly white matter injury (WMI) pattern that is typical of preterm birth. WMI in term-born children has received scant attention and little is known about causal pathways and timing of insult.

**Aim.** To compare neuroimaging and clinical variables between term and preterm children with CP and WMI in a 1999-2008 Australian birth cohort and to explore perinatal symptomatology in the term group.

**Method.** Using data from the Victorian CP Register, frequency distributions of clinical and neuroimaging variables were compared between term (n=130) and preterm (n=138) children. Term-born children were categorised on neonatal symptomatology, and routinely collected perinatal variables provided evidence for the presence or absence of peripartum compromise, overall and in groups stratified on laterality/symmetry.

**Result.** The term group was more likely to have unilateral WMI (21% vs 4%) and hemiplegic CP (67% vs 33%). More than 50% of term singleton neonates had indicators of peripartum compromise and half were symptomatic, requiring more than routine postnatal care. The presence of neonatal symptoms was associated with a higher frequency of symmetrical WMI (52% vs 24%) and quadriplegic CP (25% vs 6%), whereas routine postnatal care was associated with a higher frequency of unilateral WMI (38% vs 12%). Discrepancy between signs of peripartum compromise and admission to a nursery was most pronounced in the group with unilateral WMI.

**Conclusion.** Variation in imaging and clinical profiles between preterm and term-born children with WMI suggests a higher likelihood of haemorrhage as the sole pathogenic mechanism in the term group. Neonates whose later imaging showed unilateral WMI were more likely to have had signs of peripartum compromise but no nursery admission or neonatal imaging. This group may represent a missed opportunity for early intervention.

## **Exploring possible neural mechanisms of children with probable developmental coordination disorder: A look at cortical structure and function**

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**Background:** Despite the relatively good understanding of the motor impairments impacting children with Developmental Coordination Disorder (DCD), there is limited understanding surrounding the causal mechanisms at a structural or functional level.

**Aim:** This study examined the structure-function relationship to reveal cortical areas that may contribute to the movement difficulties seen in children with probable DCD (pDCD). Specifically, we explored hypothesized deficits in mirror neuron system (MNS) function, a neural system that responds to both observed and performed actions.

**Method:** 10 boys with pDCD (mean = 10.46years  $\pm$  1.64, range = 8.25–13.33years) and 10 typically developing controls (mean = 10.28years  $\pm$  1.18, range = 8.33–12.25years) participated. High resolution structural, functional and resting state MRI scans were performed. During functional scans, participants observed, imagined, executed and imitated a finger sequencing task.

**Results:** Voxel based morphometry identified no substantial relative grey or white matter brain volume differences in children with pDCD. Group comparisons of neural activation for each functional task condition over rest revealed minimal between-group activation differences in MNS (inferior frontal gyrus, ventral premotor cortex, inferior parietal lobule and superior temporal sulcus) or other cortical regions. Positive correlations with imitation and motor imagery behavioural tasks performed outside the scanner revealed significant activation clusters in the caudate body, caudate tail, posterior insula and medial frontal gyrus.

**Conclusion:** Although the MNS dysfunction hypothesis was not supported, correlations seen between behavioural tasks and activation implicate motor planning and attentional processes as mechanisms associated with DCD at a neural level. Connectivity analyses are currently being performed and will also be presented.

## TRANSITION OR TRANSFER IN THE HEALTH CARE OF CHILDREN WITH SPECIAL NEEDS?: A SURVEY ON THE PERCEPTION OF HOW IT IS DONE IN SPAIN

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**BACKGROUND:** Planning the transition to adulthood of children with disabilities has become particularly important in recent years due to improved survival rates of these patients. The transition in health care is the process by which a young patient with a chronic disease develops the skills and the resources available for health care during the transition from adolescence to adulthood. This process begins in early adolescence, but does not end until the young adult is fully integrated in an adult unit. Moreover, the transfer is a static process, occurs only once and is to pass medical information from one specialist to another. The purpose of a planned transition is to maximize the functioning and well-being of young people with or without special health requirements.

**AIM:** The aim of this study is to evaluate how is carried out the transition in the health care of children with special needs and if it is performed at the appropriate stage.

**METHOD:** It has conducted a survey of 23 questions sent by email to medical specialists in physical medicine and rehabilitation partners of the Spanish Society of Children's Rehabilitation.

**RESULTS:** 100% of respondents answered that follows patients over the 14 years (48% to 16-18 and 52% beyond 18 years). Regarding the desirable age for monitoring none answered until 14, and 65% believe it should be done until the end of growth is the age that is. There is great variability in responses regarding how the transition is performed and differ also in how they believe that should be done.

**CONCLUSION:** the following over 14 years means commitment to the patient and family, but has negative consequences for the organization of the unit. Most considers that makes clinical reports correctly but instead believes that the transition is not performed properly. Is it because we only transfer patients? In view of the great variability, developing protocols for monitoring of these diseases as they reach adolescence seems to be necessary.

## Healthcare Gaps Perceived by Women with Cerebral Palsy

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**Background:** Women with disabilities are more likely to experience lower quality of health care. 80% of US doctors graduate medical school without treating a woman with significant disabilities. For women with Cerebral Palsy, their concerns tend to be attributed to their disability rather than the underlying pathology. Currently, there is little information on the adequacy of healthcare delivered to women with CP.

**Aim:** To identify the self-reported unmet medical needs of women with CP.

**Method:** A single center study was performed at an academic institution's CP center. Survey items were developed through consensus-based expertise and review of the literature. Surveys determined administrative and clinical barriers to care, and the three medical fields least able to meet the patient's needs. Surveys were completed as part of the standard of care and were retrospectively collected for analysis.

**Result:** 25 respondents with a mean age of  $26.63 \pm 9.37$  (13-53) years completed surveys. 52% (13) were self-reporters; 44% (11) indicated assistance or proxy response. 28% (7) ranked obstetrics and/or gynecology (OB/GYN) as the #1 medical field least able to meet their needs; 16% (4) ranked primary care as #2; 12% (3) ranked mental health, dentistry, and rehabilitation/physiatry as #3. Knowledge and understanding of CP was ranked as the major administrative barrier to care compared to transportation and insurance. Specialty physical examination was ranked as the major clinical barrier to care compared to imaging and medication prescriptions.

**Conclusion:** Patients reported OB/GYN as the medical field least able to meet their needs, with major administrative and clinical barriers related to knowledge/ understanding of CP and specialty physical examination, respectively. There is an apparent need to create clinical educational interventions for healthcare staff involved in the obstetrical and gynecologic care of women with CP to further promote positive change in health outcomes.

## **The Intellectual and Developmental Disabilities Classification Matrix: A Reliability Study**

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**Background** – Patient Reported Outcomes Measurement Information System (PROMIS) has been validated for reporting outcomes in the pediatric setting to better understand the quality of life of patients, but it has not been validated in the intellectual and developmentally disabled (IDD) population.

**Aim** – The purpose of this study was to test the reliability of a classification matrix used by allied medical professionals with various levels of experience and training that stratifies IDD patients based on their ability to utilize PROMIS.

**Methods** – Prospective validation study of 26 patients age 8-21 years with cerebral palsy between July and September 2015, performed at two large children's hospitals. We tested a classification matrix developed onsite using expert consensus data designed to identify those possessing the overall capability to self-report their perception of health status. An unweighted kappa analysis was conducted to determine interrater reliability between team members of differing clinical experience (Level I = physician; Level II = resident or NP/RN/PA; Level III = medical student or medical/administrative assistant).

**Results** – Overall interobserver agreement was 92.3% for all members of the team. Kappa values and percent agreement between clinicians Levels I vs. II, Levels I vs. III, and Levels II vs. III were 0.948/96.2%, 0.898/92.3%, and 0.950/92.3%, respectively, all in the near perfect agreement range ( $\kappa > 0.80$ ).

**Conclusion** – Many patients with IDD currently rely on proxy report when answering PROMIS questions, however discrepancies in level of agreement between caregivers' and their children's responses have been shown.[1] The proposed matrix is a reliable measure for enhancing patient report in the IDD population, concurrently reducing inaccurate proxy reported outcomes.

[1] Varni, James W., et al. "Item-level informant discrepancies between children and their parents on the PROMIS® pediatric scales." *Quality of Life Research*(2015): 1-17.



## **Aggravation of Hip Subluxation after Using Seating Device in Children with Disability**

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**Background :** The sitting devices are used worldwide for disabled children. These devices could help managing these children and the satisfaction rates are high. As flexed hip and increased spasticity could be risk factors of hip subluxation, sitting device might aggravate hip subluxation. The purpose of this study was to identify whether seating device could aggravate hip subluxation.

**Method:** This study was retrospective study. 41 children with disability (36 cerebral palsy, 4 genetic disease, 1 fibrodysplasia ossificans progressiva) without history of hip surgery were included (Table 1). Participants were evaluated with hip joint and pelvis X-ray before and after using seating device (Squiggle, Mygo I, II, Ottobock<sup>®</sup>)..

We measured the duration of seating device use. The Reimer's migration index (MI), lateral center edge angle (CEA), and femur neck shaft angle (NSA) were used to evaluate the hip subluxation. The progression of each scale was divided by the duration of seating device use (progression degree per year). The initial MI, CEA, and NSA before using seating device were compared with follow up X-ray using paired t-test.

**Result:** The initial average age and duration of seating device use were  $5.48 \pm 2.70$  years and  $504.88 \pm 309.38$  days (Table 1). There were significant differences between before and after using a seating device in MI and CEA. (Table 2) The mean progression rates of MI were 15.87% (Rt.), 13.93% (Lt.). The mean progression rates of CEA were 58.41% (Rt.) and 18.77% (Lt.). The mean progression rates of NSA were 1.15% (Rt.) and 0.15% (Lt.) (Table 3).

**Conclusion:** As the use of a sitting device could aggravate hip subluxation, therefore, we should pay attention to hip subluxation while using a seating device.

## Development of Play in Children with Severe and Profound Visual Impairment over the First Two Years of Life

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**Background:** Delays in the hierarchical progress of play are seen in children with visual impairment (VI); functional vision level may affect play as children with profound VI (PVI, light perception at best) show less complex play than those with severe VI (SVI, basic 'form' vision) (Hughes et al., 1998). However there is little research on play in children with VI before the age of two years. **Aim:** To longitudinally examine the development of play in children with VI from age one to two. **Method:** As part of the national OPTIMUM project (Dale et al., 2015), 42 children with 'simple' congenital disorders of the peripheral visual system (11 PVI, 31 SVI) participated in videotaped 5-minute independent free-play sessions with standard toys, aged 9-16 months (Time 1) and 21-28 months (Time 2). Videos were coded using an adapted Belsky & Most (1981) coding scheme. Mann Whitney-U tests were run for between group analyses and Kruskal-Wallis tests were run for within group analyses. **Result:** There was marked individual variation in play. At Time 1, the SVI group showed more functional play than the PVI group,  $p=.028$ . At Time 2, the SVI group showed less stereotypical play,  $p=.009$ , and more functional play than the PVI group,  $p=.030$ . The highest behaviour in the PVI group was relational play while the SVI group showed higher enactive naming and pretend-other play. The PVI group showed no change in play from Time 1 to Time 2 and no progression in the hierarchy. The SVI group showed progress in the play hierarchy and a decrease in stereotypical play over time,  $p<.001$ . **Conclusion:** On average, children with SVI showed more complex play than those with PVI at one and two years, and showed increased play complexity over time which was not seen in the PVI group. In the context of previous studies, these findings suggest vulnerability in the development of early play for children with VI and especially for children with no functional vision, and indicate a target for early intervention.

## **Correlation of gross motor functional measurements with mobility status post single event multilevel surgery among children with cerebral palsy**

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### **BACKGROUND**

Recent studies on the rehabilitation of children with cerebral palsy (CP) have focussed on increasing functionality in their daily activities.

### **AIM**

The aim of the study was to evaluate the relationship between gross motor function classification system (GMFCS) with functional mobility scale (FMS) post single event multilevel surgery among children with CP. The type of surgery was Single Event Multilevel Lever Arm Restoration and Anti Spasticity Surgery (SEMLARASS) comprising myofascial surgeries and osteotomies.

### **METHOD**

A retrospective analysis was done among 540 children with CP (230 males, 310 females) who underwent SEMLS by a single orthopaedic surgeon. Among them, 260 (48.14%) were diplegic, 195 (36.11%) were quadriplegic, and 85 (15.74%) were hemiplegic. The age range was between 3 to 32 years. The children were classified according to the GMFCS based on their age based motor function. The mobility status was measured by the functional mobility scale (FMS). Other demographic data of the child were also collected. The data was collected one day before the surgery and after 6 to 8 months of postoperative rehabilitation.

### **RESULT**

A negative correlation was found between the GMFCS and FMS ( $p < 0.01$ ). As the severity of GMFCS was less, greater was the functional mobility status of the children and vice versa. It was also evident that the GMFCS was not static and it could be altered through SEMLARASS followed by an intensive rehabilitation protocol. The use of both the GMFCS and FMS in clinical practice would provide an easy, practical and simple way for assessing the progress in children with CP.

### **CONCLUSION**

This study proves that a relationship exists between GMFCS and FMS among post SEMLARASS children with CP. The adaptation of both of these scales and using these scales together give the opportunity for a detailed analysis of the functional level of children with CP and reflect the differences between different clinical variations of CP.

## **Concern, self impact, support and socio economic strain among caregivers of children with cerebral palsy post single event multilevel surgery: a longitudinal survey**

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### **BACKGROUND**

Provision of care for children with disabilities is a daunting task due to physical and emotional demands of care giving, changes in the social life of caregiver, economic consequences of care giving etc. and these effects are even more pronounced on caregivers in developing countries where basic facilities for the disabled are limited and respite care is virtually unavailable.

### **AIM**

Aim of the study was to evaluate the concern, self impact, support and socio economic strain perceived by the caregivers of children with cerebral palsy (CP) before and after a type of single event multilevel surgery called Single Event Multilevel Lever Arm Restoration Anti Spasticity Surgery (SEMLARASS) and protocol based rehabilitation.

### **METHOD**

A longitudinal survey was done on 38 caregivers of children with CP post SEMLARASS of age between 5 to 18 years. The study was conducted using caregivers difficulty scale (CDS) questionnaire. CDS was administered one day before the surgery, 1 month, 3 months and 6 months after the surgery. Demographics of the caregiver and child and clinical data were also collected.

### **RESULT**

Concern for the child had an average score of 19, impact of self had an average score of 9, support for care giving had an average score of 3.6 and social and economic strain had an average score of 6.86 among the caregivers of the children with CP 6 months post SEMLARASS. Total CDS average score was 60.89 before surgery, 60.82 one month after surgery, 50.38 three months after surgery and 34.03 six months after surgery.

### **CONCLUSION**

Caregiver burden although was on higher range in the preliminary month post SEMLARASS, it decreased in the subsequent month showing a positive effect of SEMLARASS on care giving burden. The data on caregiver burden obtained in this study can be utilized in rehabilitation to decide on the type of support services needed by the caregivers and to evaluate the effectiveness of supportive interventions.

## Physical Activity Levels in Ambulatory Children with Cerebral Palsy Compared to Typically Developing Children

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**BACKGROUND** Physical activity (PA) is crucial to maintaining function as children with Cerebral Palsy (CP) grow<sup>1</sup>. It is recommended that children with disabilities should be as active as typically developing (TD) children<sup>2</sup>. PA trends for ambulatory children with CP are not as clear as for non-ambulatory children due to conflicting research results<sup>3</sup>. Some studies report children with CP are less active than TD children<sup>4</sup> while others report no differences<sup>5</sup>. Inconsistent findings around the effects of Gross Motor Function Classification Scale (GMFCS) level and age on PA levels in CP have also been highlighted, with some research demonstrating GMFCS level<sup>6</sup> and age<sup>7</sup> can impact on PA levels and others demonstrating no impact<sup>8</sup>.

**AIM** To compare PA levels of ambulatory children with cerebral palsy (CP) to TD children using objective and subjective outcome measures and to investigate the effects of GMFCS level and age on PA levels in ambulatory children with CP.

**METHOD** 7 children with CP classified at GMFCS level I-III and 8 TD children participated. PA was objectively assessed over a 7 day period using an activPAL<sup>TM</sup> accelerometer. Subjective evaluation of PA was completed using the Previous Day Physical Activity Recall Questionnaire and the Physical Activity Questionnaire for Children. Between group differences were assessed using independent sample t-tests and one-way ANOVA with significance set at  $p < 0.05$ .

**RESULTS** Ambulatory children with CP spent significantly more time sitting/lying (1.56 hr,  $p = 0.048$ ), less time walking (0.6 hr,  $p = 0.041$ ) and took less steps (3,781.9,  $p = 0.02$ ) than TD children. Children with CP GMFCS level III took significantly less steps than level I ( $p = 0.018$ ) and II ( $p = 0.012$ ). A strong negative correlation was found between GMFCS level and walking ( $r = -0.817$ ,  $p = 0.025$ ) and between GMFCS level and step count ( $r = -0.769$ ,  $p = 0.043$ ).

**CONCLUSION** Ambulatory children with CP are less active than TD children and PA levels decrease as GMFCS levels increases.

## **Inter and Intra-Observer Reliability of the Robin and Graham Classification System for Hip Disease in Cerebral Palsy**

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**Background:** The ability to accurately and reliably classify the degree of hip abnormality in cerebral palsy (CP) patients has the potential to improve outcomes, serve as a research tool, and provide hip surveillance.

The most commonly used measurement is the migration percentage (MP), which fails to include additional morphological features of the hip. The Robin and Graham classification system is based off of four gross morphologic features in addition to the MP.

**Aim:** Reliability of the Robin and Graham Classification System has been demonstrated by the authors of the original study. Our aim in this study is to test the inter and intra-reliability of this classification system in a different geographic region, independent of the creators.

**Method:** 65 hip radiographs were obtained from patients with a diagnosis of CP.

The blinded, randomized radiographs were presented to 5 orthopedic surgeons and 1 resident. Each reviewer classified the 65 radiographs bilaterally using the Robin and Graham classification system. After one month, reviewers were asked to rate the same radiographs again.

**Result:** The overall intraclass correlation coefficient (ICC) for the inter observer analysis was 0.853 and 0.839, indicating an excellent level of rater agreement among surgeons.

The intraclass correlation coefficient for intra-observer reliability ranged from 0.838 to 0.933 indicating excellent intra-observer reliability.

Of the 130 hips classified in the first round, four radiographs in the first round were rated with a difference of greater than 2 classifications between surgeons. There were five in the second round.

**Conclusion:** The Robin and Graham classification system was developed as an ordinal classification system using both quantitative and qualitative input. Our data indicates that the most variance in rater's classification occurs between classification I and III. Overall, our data suggests excellent intra and inter-observer reliability in this patient population.

## **Cytomegalovirus (CMV) viraemia in the newborn period is common in children with all forms of cerebral palsy (CP)**

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**Background:** Congenital cytomegalovirus infection (cCMV) occurs in 0.5-2.5% of newborn infants. It can damage the developing brain resulting in disabilities including cerebral palsy (CP). We have recently reported that 1.5% of children with CP notified to the Australian Cerebral Palsy Register (ACPR) list cCMV as the attributable cause, more so in children with severe disability, including spastic quadriplegia. **Aim:** Here we sought to : i) determine the true incidence of CP due to cCMV in Australia, and ii) verify the association with spastic quadriplegia and cCMV using retrospective testing of newborn screening cards (NBSC) for CMV DNA. **Method:** Children with CP reported to two state CP registers (NSW, ACT) and/or a tertiary paediatric state-wide rehabilitation service were recruited with consent. CMV DNA was extracted from NBSC using rigorous attention to prevent contamination and analysed for CMV DNA by nested PCR using primers against gB. Positive samples were validated using quantitative PCR for CMV UL83. **Result:** 323(80.5%) of 401 consented individuals had an available NBSC. Of those, 31(9.6%) tested positive for CMV DNA, compared to published reported frequency of approximately 0.6% in NSW. Individuals with spastic quadriplegia were represented in similar proportions across both CMV DNA positive and negative groups (23.1% vs 23.7%). There were no significant differences between the clinical profile of individuals within the positive and negative groups. **Conclusion:** CMV viremia at birth (indicating cCMV) occurs more frequently amongst children with CP, than in the general community. Detection of cCMV viremia occurred equally across all CP subtypes including individuals with relatively mild associated impairments. This suggests that cCMV may be under diagnosed in individuals with less severe CP in the absence of newborn screening for cCMV. Further research is required to understand the role of CMV as a potentially preventable risk factor in CP.

**Increasing motor impairment in extremely preterm or extremely low birthweight children assessed at 8 years: a population-based study of 3 cohorts born between 1991 and 2005**

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**Background:** Survival rates have improved since the 1990s for infants born extremely preterm (EP: gestational age <28 weeks) and/or extremely low birth weight (ELBW: birthweight <1000 g). However, long-term motor outcomes for these children are unclear.

**Aim:** The aims of this study were to (i) compare rates of motor impairment at 8 years in three cohorts of EP and/or ELBW children born in Victoria, Australia in 1991-92, 1997 or 2005, and (ii) explore predictors of motor impairment at 8 years.

**Methods:** Survivors from the 3 eras were assessed for cerebral palsy (CP) and motor function (using the Movement Assessment Battery for Children - MABC) at age 8 years. Motor impairment was defined as CP or a score <5<sup>th</sup> centile on the MABC. Perinatal predictors of motor impairment were assessed by multivariable logistic regression.

**Results:** Follow-up rates were 92% (n=275/298), 92% (n=185/201) and 87% (n=191/219) for 1991-92, 1997 and 2005, respectively. There was a significant increase in motor impairment in EP/ELBW children over the three eras from 24% in 1991-92, 28% in 1997 to 37% in 2005 ( $\chi^2=12.4$ ;  $p<0.001$ ). This was due to an increase in non-CP motor impairment (13% 1991-92; 17% 1997; 26% 2005;  $\chi^2=13.6$ ;  $p<0.001$ ) and not CP (11% 1991-92; 11% 1997; 12% in 2005). Increased motor impairment was related to being born in 2005 compared with 1991-92 (odds ratio [OR] 2.8;  $p<0.001$ ), poorer fetal growth (OR 1.5 per SD decrease in weight;  $p=0.001$ ), patent ductus arteriosus (OR 1.6;  $p=0.033$ ), postnatal corticosteroids (OR 2.4;  $p=0.001$ ), grade 3 or 4 intraventricular haemorrhage (OR 3.9;  $p=0.002$ ), cystic periventricular leukomalacia (OR 2.3;  $p<0.001$ ) and neonatal surgery (OR 2.3,  $p<0.001$ ).

**Conclusion:** Motor impairments in children born EP and/or ELBW at 8 years are increasing over time, mostly contributed to by non-CP motor impairment.



## Brain volumes and developmental trajectories after preterm birth

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**Background:** Cognitive outcome after preterm birth is heterogeneous. We have previously shown in a cohort of very preterm children that cognitive ability at 5½ years was highly predictive of ability at age 18. However, a substantial proportion of preterms improved their relative performance (in comparison to term born peers); this was not conclusively explained by perinatal or environmental factors (Stalnacke, 2014).

**Aim:** To investigate whether relative improvement in cognitive abilities in the preterm participants could be explained by variations in regional brain volumes measured in adolescence.

**Methods:** As part of a prospective longitudinal study, 118 preterm individuals (birth weight < 1500 g) participated in neuropsychological assessments at age 5½ and 18. Fifty-seven (32 female) underwent MRI (including 3D T1-weighted images) at mean age 15.2 years. Total and regional brain volumes (corrected for intracranial volume) were calculated using Freesurfer version 5.3.0 (<http://surfer.nmr.mgh.harvard.edu/>). Student's t-test was used to compare volumes between those who improved (n=20) and those who did not (n=36).

**Results:** Improvement in cognitive abilities was significantly associated with larger cortical (p=0.005) and subcortical (p=0.041) grey matter volumes, cortical white matter (p=0.027) volumes, larger volumes of the right thalamus (p=0.022), hippocampus (p=0.032), amygdala (p=0.019); insula (right p=0.04; left p=0.05) and accumbens (right p=0.004; left p=0.027) bilaterally, and left cingulate (p=0.023). There were no significant correlations between improvement and cerebellar white or grey matter volumes, or corpus callosum volume.

**Conclusions:** Whilst in individuals born preterm improvement in cognitive abilities from pre-school age to late adolescence could not be predicted from perinatal factors, there was a correlation with brain volumes measured in adolescence. Individuals who improved had larger volumes compared to those who showed no catch-up.

## **Long-term outcome of hip instability following non-surgical and surgical interventions in children with cerebral palsy**

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**Aim:** This study compares the long-term outcome of hip instability following single-event multi-level surgery with a botulinum toxine treatment program.

**Method:** A retrospective study of two groups was undertaken. The first group included 68 adults with bilateral spastic cerebral palsy GMFCS III-V who had infant hip instability of MI 32% treated by multi-level soft tissue surgery at a mean age of three years and two months (2.0 to 5.8). The second group included 72 adults with bilateral spastic cerebral palsy GMFCS III-V who had infant hip instability of MI 28% treated by a botulinum toxine (BoNT) program starting at a mean age of two years and ten months (2.2 to 3.8). Both groups underwent examination in early adulthood, the first/surgery group at a mean age of 21.3 years, the second/BoNT group at a mean age of 16.8 years. ROM, hip CE angle, acetabular index, pain by visual analog scale, isometric muscle strength and gross motor function were assessed.

**Results:** The first/surgery group had significantly better ROM, and hip CE angle, and acetabular index. They underwent additional soft tissue surgery in 7% and additional hip reconstructive surgery by osteotomies in 18%. 6% of hips were dislocated at follow-up. The second/BoNT group had significantly reduced ROM, and hip CE angle, and acetabular index. They underwent additional soft tissue surgery in 36% and additional hip reconstructive surgery by osteotomies in 28%. 17% of hips were dislocated at follow-up. There was one re-dislocation, and no complications intraoperatively or during rehabilitation in either group. There were two cases of osteonecrosis of femur and acetabulum in each group.

**Conclusion:** We consider that physiologic hip function in young adults may be achieved effectively and safely more often by early surgical soft tissue interventions with significant advantages over a BoNT program in children and young adults with bilateral cerebral palsy and infant hip instability MI >28%.

## Computer based video analysis identifies Fidgety Movements in high-risk infants

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### Background:

The most accurate method to predict cerebral palsy (CP) in high-risk infants is the General Movement Assessment (GMA) based on Gestalt perception. The absence of Fidgety Movements (FMs) is highly predictive of CP using this method. A computer based video analysis of general movements has been developed and validated to provide an automated measure of movement features typical for infants with present FMs.

### Aim:

To investigate the association between FMs identified by Gestalt perception and a computer based video analysis.

### Method:

270 video recordings from 162 infants (99 boys, median gestational age 30 weeks (range 24-42), median birth weight 1150 grams (range 385-4980)) at risk of neurodevelopmental adverse outcome were prospectively included at 4 neonatal intensive care units. Recordings were assessed using Prechtl's method for GMA and computer based video analysis. Normal FMs were defined as present (intermittent or continual) and abnormal if absent, sporadic or exaggerated. The computer based video analysis variable "Centroid of motion standard deviation" ( $C_{SD}$ ) representing the variability of the spatial center of motion in a video was used based on previous findings of an association with later CP.

### Results:

123 (46%) recordings were of preterm infants (birth weight <1 kg and/or gestational age <28 weeks). Using the Gestalt perception, 69 (26%) recordings were classified with abnormal FMs and 201 (74%) with normal FMs. The  $C_{SD}$  was significantly higher in the recordings with abnormal (0.38, SD 0.073) than normal (0.32, SD 0.067) FMs ( $p < 0.001$ ).

### Conclusion:

In this large study of high-risk infants a computer based variable representing the variability of the spatial center of motion in a video was significantly lower in infants with normal vs. abnormal FMs. This suggests that a more stable and evenly distributed movement pattern is characteristic of FMs. The predictive value of  $C_{SD}$  for long term outcome remains to be seen.

## Cortical activity during unilateral leg movements in diplegia cerebral palsy

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**Background:** There has been limited investigation of cortical activity during upright movements in diplegic cerebral palsy (DCP). Previous stimulation studies have shown motor hot-spots for the lower extremity to move laterally in DCP, but it is unknown if these connections are used during volitional movement.

**Aim:** The aim was to identify the location of cortical activation during a unilateral multi-joint movement in DCP.

**Method:** 13 individuals with DCP (mean age 16.7 years) and 13 typically developing controls (mean age 18.1 years) completed a unilateral cycling task with their non-dominant lower extremity. An 8x15 cm flexible plastic frame was used to hold 8 infrared light sources and 16 detectors against the participants' scalp over the sensorimotor cortex. The cycling task was performed in a block design with visual and auditory instruction to standardize performance. Data were processed to remove artifacts from motion, low signal intensity, and physiological interference such as scalp blood flow. Resulting signals were back projected to generate an activation map. Location of the peak in oxygenated hemoglobin (HbO) and total hemoglobin (HbT) was located and normalized to interauricular distance, and a students t-test was used to compare averages.

**Result:** Activation peaks were significantly (HbO  $p=0.05$ ; HbT  $p=0.001$ ) more lateral in CP. The typically developing cohort peak activation occurs within a narrow distance from Cz (5% of the inter-articular length), while CP ranged up to 20% of the inter-articular length from Cz. Activation distance from midline was not related to GMFCS level, Abiloco measure, or Pedi-CAT daily activity or mobility scores.

**Conclusion:** Non-invasive neuroimaging offers insight to the functional brain reorganization of very early brain injury. Damage to the descending motor pathways to the lower extremities requires control of the lower extremities to be taken on by different neural areas, with more lateral areas of the motor cortex.

## Stability of Pain in Children and Youth with Cerebral Palsy

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**Background:** Prevalence of pain for children/youth with cerebral palsy (CP) is high, ranging from 20-65%. Pain can limit activities and negatively impacts quality of life. Longitudinal studies of adults with CP show pain to be stable over time. To date, no longitudinal studies of pain in children/youth with CP have been conducted. Here we evaluate the presence and stability of pain in an out-patient population of children/youth with CP over two time-points at least 6 months apart.

**Aim:** To examine the stability of pain in children/youth with CP over time.

**Methods:** Children/youth with CP and caregivers were consecutively recruited from rehabilitation clinics at two time-points at least 6 months apart. Pain was assessed by caregivers (on a dichotomized Health Utilities Index 3 (HUI3-pain subset) scale with scores > 3 representing 'pain') and by physicians identifying presence/absence of pain and cause if applicable. Pain ratings were compared between visits using McNemar Chi Square tests.

**Results:** 148 children/youth of 207 approached (71% response), (8 years 8 months, range 3-16 years) from all GMFCS levels (I:21%, II:11%, III:24%, IV:22%, V:22%) were included. Caregiver and physician pain ratings were stable between visits ( $\chi^2=14.36$ ,  $df=1$ ,  $p=0.55$ , and  $\chi^2=10.90$ ,  $df=1$ ,  $p=0.05$  respectively). 109 (74%) participants had stable caregiver HUI3 pain ratings, with 20 (14%) participants experiencing pain at both visits and 89 (60%) participants with no pain at either visit. 39 (26%) participants had changes in pain ratings, with 17 (11%) having pain initially that resolved at visit two and 22 (15%) developing pain at visit two.

**Conclusion:** The majority of participants (74%) had no change in pain status between visits. With one in seven children/youth with CP (14%) having pain at both visits and almost one in six (15%) developing new pain at visit 2, ongoing assessment and improvements in preventative approaches and treatment of pain for children/youth with CP are needed.

## Balancing for differences in gross motor function between youth with CP at GMFCS levels II and III while Exergaming

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**Background:** Multi-player exercise videogames (exergames) help youth with cerebral palsy (CP) exercise and socialize. In Liberi Exergames, players pedal a recumbent bike to move their avatar and get game rewards when at or above 40% of their heart rate reserve ( $\geq$ THR), a target linked to fitness gains. But, gross motor function of people with CP varies and affect how exergames are played. Game balancing algorithms, which scale gameplay to functional ability, need assessment. Here, we evaluate how well Liberi Exergames' algorithms adjust for differences between youth at Gross Motor Functioning Classification System (GMFCS) levels II & III.

**Aim:** Do 3 algorithms differ in playtime  $\geq$ THR between youth at GMFCS levels II & III?

**Method:** 3 algorithms were randomly tested twice in 6, 30 minute sessions with participants/researchers blinded to order:

“one-speed-for-all” (avatars go the same speed regardless of pedaling cadence)

“effort-based” (avatar speed scaled to player specific ‘pedaling cadence at THR’)

“direct-speed” (avatar speed directly relates to pedaling cadence).

A mixed ANOVA evaluated differences between algorithms/GMFCS.

**Result:** Ten youth (5 female;  $12.4 \pm 1.8$  years) at GMFCS level II ( $n=4$ ) and III ( $n=6$ ) participated. Across algorithms,  $53 \pm 32\%$  of 176 minutes was  $\geq$ THR. Players at GMFCS level II had  $16 \pm 30\%$  more time  $\geq$ THR than those at level III. GMFCS level affected time  $\geq$ THR differently based on the algorithm ( $F_{2,16} = 4.83$ ,  $p=0.02$ ). “Effort-based” had players at GMFCS level II spend more time  $\geq$ THR than level III, compared to the other 2 algorithms.

**Conclusion:** Liberi Exergames help players of different abilities play together, but GMFCS level affects playtime  $\geq$ THR even with game balancing algorithms. While “effort-based” showed the least balancing here, with adjustments (i.e. a GMFCS based progressive reward system linked to 'pedaling cadence at THR'), it may be best at balancing time  $\geq$ THR between typically developing players and those at GMFCS level III.

## **Treatment Of Hip Subluxation Of Cerebral Palsy With Matsuo's Muscle Release Procedure**

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### **Scientific background**

The concept of Matsuo's procedure is the release of both of antagonistic polyarticular muscles while preserving monoarticular muscles as possible in patients with cerebral palsy.

### **Aim**

We have performed Matsuo's procedure for treatment of CP. The purpose of this study was to evaluate the short-term results of treatment for subluxation of the hip in children with CP.

**Purpose:** The concept of Matsuo's procedure is the release of both of antagonistic polyarticular muscles while preserving monoarticular muscles as possible. Matsuo's procedure for the hip consists of lengthening or section of the psoas, rectus femoris, adductor longus, adductor magnus, gracilis and hamstring muscles. We have performed Matsuo's procedure for treatment of cerebral palsy (CP) since 2003. The purpose of this study was to evaluate the effect of the section of HM for the treatment of dislocation of the hip in patients with GMFCS level 4 and 5.

**Methods:** We had surveyed children with CP, who were performed Matsuo's procedure for their hips in Saga Children's Hospital by one surgeon and observed more than two years since 2008. The candidates were classified with the Gross Motor Function Classification System (GMFCS). Twenty-six hips in 13 patients (10 boys and 3 girls) were included. We examined retrospectively the radiographic images by Migration Percentage (MP%) to evaluate subluxation of the hip.

**Results:** The average age at surgery was 5.7 (2-13) years of age. Observation period after surgery was 3.8 (2.3-5.0) years on average. MP improved from 45.6% to 35.7% on average ( $p < 0.005$ ).

**Conclusions:** We proposed that Matsuo's procedure was useful for the treatment of subluxation of the hip in CP.

## **New biomarker for autism spectrum disorders in children based on the nonlinear analysis of complexity, coherence and synchronization in EEG waves to facilitate early diagnosis and intervention**

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**Background** Diagnosis of autism spectrum disorders (ASD) depends on clinical recognition of significant problems with an individual's communication, social interaction and flexible thought processes. There is no definitive diagnostic test. Identifying a biomarker to enable early diagnosis may increase the impact of interventions and reduce the period of diagnostic uncertainty. Previous research has suggested differences in structure and connectivity of brains of ASD individuals that potentially could be detected by sophisticated analysis of EEG waves. **Aims** 1.To establish if ASD children have a distinct pattern of brain dynamics that can be detected and quantified by the application of nonlinear methods to EEG signals 2.To test the feasibility and acceptability of obtaining EEGs from young ASD children of sufficient quality to enable detailed analysis. **Method** A standard 23-electrode EEG was performed on ASD and typically developing comparison children aged between 3 and 5 years. Inclusion criteria: clear diagnosis of ASD or no developmental concerns. Exclusion criteria: epilepsy, structural brain or chromosome abnormalities and medications known to affect brain function. The EEGs were subjected to a range of nonlinear analyses including complexity analysis, frequency spectra and EEG wave interactions. **Results** Thirty-three children consented to be involved\*. EEGs were obtained on 16 ASD and 13 comparison children. One child refused the EEG and one child did not attend in each group. A segment suitable for detailed analysis was obtained from all children who had the EEG. Differences were noted between ASD and comparison groups and between males and females. **Conclusion** It was feasible though challenging to obtain the EEG recordings. Analysis has revealed potentially diagnostic findings and these will be discussed. Further refinement of the method would allow a shorter recording time with less electrodes improving acceptability.\*Data on 40 children expected by end of 2015



## **Trends in severe neurodevelopmental disabilities in relation to mortinatality and infant mortality rates**

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**Background:** A reduction in spontaneous stillbirths, infant mortality and child morbidity rates is a major challenge in public health. Therefore, in 1991 the French register for severe neurodevelopmental disabilities and perinatal observatory was created in Grenoble, in order to survey child morbidity, stillbirth and terminations of pregnancy (TOP).

**Aim:** To describe trends in severe neurodevelopmental disabilities in parallel with trends in mortinatality and infant mortality rates.

**Method:** Data on children of the 1980-2004 generations with severe neurodevelopmental disabilities living in their 8<sup>th</sup> year of life in the French alpine County Isere and on stillbirth and TOP for the 1988 - 2012 birth cohorts of the same County were extracted from databases at the register. Data on infant mortality for the 1988 - 2012 birth cohorts were obtained from the French national institute for statistics and economy studies.

**Result:** Between 1990 and 2004, the period in which data on all events were simultaneously available, prevalence rates of severe neurodevelopmental disabilities increased ( $p < 0.001$ ), which was entirely due to increased prevalence of autism spectrum disorders. TOP rates increased significantly ( $p < 0.001$ ) in this time span, which could be assigned to an increase in terminations for both chromosomal and birth defects. Fetal intrauterine and per partum deaths decreased in the period under study ( $p = 0.002$ ), which was mainly due to a decrease in fetal causes, while causes related to the placenta and the amniotic fluid increased.

**Conclusion:** Improved surveillance of high risk pregnancies and care of the premature newborn seem to reduce stillbirth and infant mortality rates, but not the prevalence of severe neurodevelopmental disabilities. However, other (risk) factors may have emerged explaining rising figures of ASD.

## What constitutes a trend? Cerebral palsy prevalence in the United States

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**Background:** Declines in infant mortality resulting from improvements in obstetric and neonatal care over the past several decades were accompanied by concerns about concomitant increases in the frequency of cerebral palsy (CP). Population-based data on trends in CP prevalence are necessary to monitor the potential impact of these advances, yet methodologic factors warrant consideration when interpreting prevalence trends.

**Aim:** To evaluate the role of factors such as sample size and time period choice when examining overall and birthweight trends in CP prevalence.

**Methods:** Data include children with CP ascertained at 8 years of age by two population-based surveillance systems using the same multiple source, records based methodology over time: 1) Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), 1985-2002 births (n=1326) and 2) Autism and Developmental Disabilities Monitoring (ADDM) Network, 1998-2002 births (n=1201). Overall period prevalence and birthweight trends are evaluated.

**Results:** CP period prevalence among 8-year-olds in MADDSP born 1985-2002 was relatively stable; 3.5 to 3.4, respectively (p-value for trend=0.33), with a high of 4.1 and low of 3.1, compared to a decrease within ADDM among children born 1998-2002; 3.5 to 2.9, respectively (p<0.04). Among children born very low birth weight (VLBW, <1500 grams), MADDSP CP prevalence was stable from 1985-2002 compared to a decline in the relative risk between CP and VLBW in ADDM (1998-2002). Similar decreases were observed for MADDSP when data were restricted to the ADDM five year period albeit with less power.

**Conclusion:** The significance of CP prevalence trends is influenced by the time periods and sample size examined. Comparisons of trends in CP prevalence across geographic areas and birth characteristics may provide a means of monitoring the net effects of improvements in survival of infants at high risk of CP and advances in their care on CP prevalence in the population.

**Trends in birth prevalence of cerebral palsy; a United States population-based study, 1985-2002**

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**Background:** While a meta-analysis reported a pooled CP prevalence of 2.1 per 1,000 live-births that remained constant in recent years, a multi-site European CP prevalence study observed an overall decrease from 1980-2003 driven by declines among children born moderately and very low birthweight. Comparable population-based data in the United States on cerebral palsy (CP) birth prevalence trends are limited.

**Aim:** To examine trends in the birth prevalence of congenital spastic CP by birthweight and race/ethnicity in a heterogeneous US metropolitan area.

**Methods:** Children with CP were identified by a population-based surveillance system for developmental disabilities (DDs). This study included children born in Atlanta, Georgia from 1985-2002, resided there at age 8 years and did not have a post-neonatal etiology (n=766). Birthweight, gestational age, and race/ethnicity sub-analyses were restricted to children with spastic CP (n=640). Trends were examined by CP subtype, sex, race/ethnicity, co-occurring DDs, and birthweight.

**Results:** Birth prevalence of spastic CP per 1,000 one-year survivors was stable from 1985-2002 [1.9 in 1985 to 1.8 in 2002; (0.3% annual average prevalence (95% CI: -1.1, 1.8)]. While no significant trends were observed by sex, subtype, birthweight overall, CP prevalence with co-occurring moderate to severe intellectual disability significantly decreased (-2.6%, 95%CI: -4.3, -0.8). Racial disparities persisted over time between non-Hispanic black (NHB) and non-Hispanic white (NHW) children (Prevalence ratio: 1.8 95% CI: 1.5, 2.1). Different patterns emerged for NHW and NHB children by birthweight.

**Conclusions:** Given improvements in neonatal survival, evidence of stability of CP prevalence is encouraging. Yet, lack of overall decreases supports continued monitoring of trends and increased research and prevention efforts. Racial/ethnic disparities, in particular, warrant further study.

## **Motor and mental outcome of symptomatic neonatal arterial ischemic stroke: Prognostic value of early neuroimaging findings**

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### **Background**

Neonatal ischemic stroke is known to be associated with cerebral palsy (CP), epilepsy and cognitive impairment. Involvement of the corticospinal tract is known to be predictive for poor motor outcome.

### **Aim**

The aim of the study is to test the prognostic value of neuroimaging data at stroke onset regarding CP symptoms and mental development after 2 years.

### **Method**

We included 58 children with a mean age of  $2.2 \pm 2.1$  days at stroke manifestation. MRI was performed within the first 15 days of life. Infarct localizations were compared with CP and mental development at 2 years.

### **Result**

Of all children, 37.9% had CP and 24.1% showed delayed mental development. The infarct was bilateral in 24.1%. All infarctions involved the middle cerebral artery (MCA) territory, 37.9% had also an involvement of the posterior cerebral artery (PCA). Children with MCA/PCA involvement had a higher risk for CP and for impaired mental development. The highest odds ratio regarding CP at 2 year was found for the involvement of the thalamus and the basal ganglia (OR=17.0, 95% CI 3.26-88.77). Children with thalamus involvement are 8.1 times as likely to have impaired mental development as children without thalamus involvement (95% CI 1.99-33.05).

### **Conclusion**

Early MRI in children with neonatal ischemic stroke has a prognostic value for motor and mental development. Interestingly, involvement of the thalamus and the basal ganglia was more predictive for CP than the internal capsule. Moreover, involvement of thalamus seems to play a crucial role in predicting mental development 2 years post stroke.

## Evaluation of hip surveillance practices at a Canadian Pediatric Rehabilitation Hospital

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**Background:** Risk of hip displacement for children with cerebral palsy (CP) is directly related to Gross Motor Function Classification System (GMFCS) level; almost 90% of children in GMFCS V have hip displacement compared to 15% of children in GMFCS level II (Soo et al., 2006). Early treatment of hip displacement is considered best practice for prevention of progression of hip subluxation, which can result in dislocation, pain, and decreased functional abilities. **Aim:** to describe current practices for hip surveillance and surgery for children with CP at the Glenrose Rehabilitation Hospital. **Method:** A randomly selected sample of children with CP (n=98) aged 2-18 years represented GMFCS and age strata. Charts were reviewed for documentation of variables used to guide radiograph frequency for hip surveillance using the 2008 Australian Standards of Care (MP, Winters, Gage and Hicks (WGH) Classification of Hemiplegic gait, reports of hip pain and hip range of motion (ROM)). In addition, dates of radiographs and type of surgeries were extracted from the medical records. **Result:** MP was reported on 49 of 366 (11.8%) radiographs, WGH Classification was recorded for 3 of 10 (33%) children with hemiplegia, hip pain (presence or absence) was noted for 124 of 1114 (11.4%) clinic visits, and hip abduction and hip extension ROM was documented for 653 (35.5%) and 396 (58.6%) clinic visits, respectively. Mean annual number of radiographs increased with GMFCS level (range 0.17, GMFCS level I to 0.99, GMFCS V). Twenty six children (26.5%) had soft tissue surgery, 11 (11.2%) had femoral osteotomies and 4 (4.1%) had pelvic osteotomies. No children had femoral head resections. **Conclusion:** Although documentation was inconsistent, surgical rates were comparable to countries with established monitoring systems. Implementation of a standardized documentation process is warranted to increase efficiency as aspects of routine monitoring can be delegated to non-physician clinicians.

## HURDLES OF A NATIONAL SURVEILLANCE OF CEREBRAL PALSY. OVERVIEW OF THE FIRST EIGHT SURVEYED YEARS IN PORTUGAL (BIRTH-COHORTS 2001-2008)

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**Background.** Active epidemiological surveillance of cerebral palsy (CP) provides evidence for trends in prevalence, severity and inclusion and to support adequate care. **Aim.** An overview of difficulties and drawbacks of the first 8 years of the Portuguese Surveillance of Cerebral Palsy at 5 years of age (PVNPC5A) is presented. **Methods.** PVNPC5A is a national registry; it actively registers 5-years-old children with CP, using multiple sources and active recapture strategies (allowing indefinite register of missed cases). It shares definitions, classifications and tools with SCPE. Children born in 2001-2008, both 5-years-old survivors and deceased at an earlier age were included. Official demographic data are used as denominators. Prevalence rates of CP at age 5 are given for birth-cohorts (BC). **Results.** 1172 cases were registered (52 deceased). BC prevalence was 1.99‰ in 2006, 1.45-1.68‰ in 2007-10 and  $\leq 0.7\%$  onwards. Cases born in Portugal are 94%. Sources are healthcare (81%), education (17%) and deaths register (1.7%); notifiers are physicians (94%) (physiatrists 65%, paediatric neurologists 18%, paediatricians 17%), therapists, nurses, teachers, social workers; multiple notifiers (25.7%) or sources (16.6%) coexisted. The clinical questionnaire is absent in 73 cases (6%). Missing values for CP classification are 7%, birth variables 13-24%, GMFCS/BFMR 14-16%, cognition 20%, hearing impairment 23%, MRI classification 54%. No temporal trend was seen for predominant spastic CP cases; cases reported with GMFCS grades IV-V are 36-43% in 2001-4 BC and 45-53% in 2005-8 BC. Cases born at term are 54-60% in 2001-6 BC; in 2007-8 BC 54-59% are born preterm. **Conclusions.** A sustained, active surveillance of CP requires multiple sources and recapture strategies for adequate coverage, validity and representativeness on a population and region basis. Private and state support is primal. Special care should be taken when analyzing data with inadequate coverage or notification biases.

## **Guided growth in children with a spastic paresis for knee flexion deformity: Clinical aspects and effects on gait**

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**Background:** Knee flexion deformity occurs frequently in children with a spastic paresis and it is often accompanied by negative consequences for their gait and walking ability. Surgical guided growth by anterior hemi-epiphysiodesis of the distal femur using eight-plates possibly provides an effective and safe treatment option.

**Aim:** To evaluate the outcome of anterior hemi-epiphysiodesis of the distal femur using eight-plates, on knee flexion deformity and gait in children with a spastic paresis.

**Methods:** We retrospectively reviewed the effect of anterior hemi-epiphysiodesis because of a knee-flexion deformity (KFD) in the children with a spastic paresis treated at our center between 2011- 2014, with the goal to maintain or improve standing and/or walking function. Outcome measures were degree of passive knee extension and knee kinematics during gait.

**Results:** 19 Children (33 knees), age 10-17, GMFCS I-IV, were included in the study. Since the knees of children who underwent bilateral surgery were not independent of each other and barely differed from one another in the degree of KFD, all analyses in bilaterally operated patients were conducted with the averages of both knees. The passive knee extension improved in 12 children, remained equal in 3 children and decreased in 4 children. There was an average improvement in KFD of 12.09 degrees,  $P=0.003$ , after 1-1.5 years and 9.34 degrees,  $P=0.016$ , after a follow-up of >2 years. Furthermore, an improvement in knee kinematics during the stance phase was seen, with a significant improvement of 8.79 degrees,  $P=0.048$ , in knee extension at terminal stance. There were complications in 4 children (1 infection 1, hydrops, 1 anterior knee pain and 1 neuropathic pain).

**Conclusion:** Guided growth treatment by anterior hemi-epiphysiodesis of the distal femur with eight-plates is an effective and relatively safe method for improving knee flexion deformity and knee kinematics during gait in growing children with a spastic paresis.

## **Scooter for Children is More Than Fun; An Appealing Approach to Improve Function and Promote Fitness**

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**Background:** Pediatric rehabilitation focuses on fun, fitness, function, and friends while acknowledging the resources of the family. Functional goals for children with cerebral palsy often involve improving ambulation. Scooter is a fun activity that has the potential to address impairments, improve function, and promote participation.

**Aim:** The aim of this presentation is to share the first observations through motion analysis of scooter in children with cerebral palsy and those with typical development.

**Method:** In a case series of five children with cerebral palsy and four children with typical development, kinematic analyses and electromyography were used to examine scooter. Scooter was also reviewed as a function within the framework of the International Classification of Functioning, Disability, and Health.

**Result:** Many of the movement characteristics identified in the activity of scooter reflected desirable gait attributes that are often addressed in gait training for children with motor problems. These included muscle activity and range associated with pelvic stability, shock absorption through eccentric quadriceps activity, propulsion/push-off, balance, stance/swing limb coordination, and endurance. These data demonstrate that scooter has the potential to provide children with cerebral palsy who have limitations in walking with a relatively easy to learn skill that can allow them to participate with their peers, boosting confidence and self-esteem, while addressing impairments associated with functional ambulation. In addition, scooter has been identified as having fitness benefits similar to bicycling.

**Conclusion:** Scooter is a fun activity that has the potential to improve function, promote fitness, is not expensive for families, and can be done with friends. We plan to further investigate this activity in a systematic manner in children with and without disabilities.



## **The application of ARFI sonoelastography in CP children with hip subluxation : A preliminary study**

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### **Background**

Hip subluxation or developmental hip dysplasia is the common musculoskeletal problem of the children with cerebral palsy and this condition is associated with spasticities of hip adductor muscles.

### **Aims**

To investigate the hip adductor muscle stiffness through elastography using acoustic radiation force impulse (ARFI) imaging and to inquire the relationship between hip migration and the severity of muscle stiffness in children with spastic cerebral palsy (CP).

### **Methods**

10 CP patients aged from 3 to 7 years old participated in the present study. Inclusion criteria were (a) diagnosis of spastic CP (b) scissoring posture and exclusion criteria were (a) previous surgery on the lower limbs (b) nonspastic type of CP.

ARFI imaging was obtained by one physiatrist using a ultrasonography system with 9L4 linear transducer (Virtual Touch Imaging., ACUSON S2000 Ultrasound Unit, Siemens, Mountain View CA). Shear-wave propagation velocity (meter per second) was measured by scanning the longitudinal plane of Adductor magnus. Three trials were performed and the mean was used. We measured hip migration percentage through hip AP radiograph. Simple regression analysis was used to relationship between variables.

### **Result**

The data 20 legs of 10 children were collected. The relationships between shear wave velocity and GMFCS level, degree of spasticity, hip migration percentage did not show the statistical significance ( $P>0.05$ ). However there was a tendency as shear wave velocity was faster, hip migration index was higher,

### **Conclusion**

Although ARFI elastography showed the limitation for quantification of muscle spasticity, it may be helpful to understand the physiology of spastic muscles in children with hip subluxation.

## **The three years change of the hip dislocation in the children with severe cerebral palsy after selective hip joint muscle release surgery**

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### **1. Background**

A selective hip joint muscle release surgery (hip surgery) is enforced as first choice for the hip dislocation for children with cerebral palsy in Japan. Medium-term reports comparing to the control group about the progress of hip dislocation are little found.

### **2. Aim**

Therefore, in this study, we investigated the medium-term change of the hip dislocation in the children with severe cerebral palsy after hip surgery.

### **3. Method**

As the intervention group, 13 patients (13 hip, Gross Motor Function Classification System; GMFCS level ?; 3, V; 10, average age in month; 61.5m) whom a follow-up was possible for three years after surgery were collected at Orthopedic Hospital in Japan. As the control group, 13 patients (13 hip, GMFCS level ?; 3, V; 10, 66.2m) who had not been had the hip surgery were collected at Children's Medical Center. We evaluated Migration Percentage (MP), Sharp angle, Acetabular ridge angle, Shenton line (SL), Tear drop distance (TDD) by the X-ray image at the preoperation and one year, three years after surgery. We analyzed the data by a repeated-measures two-way layout analysis of variance, and multiple comparisons using the Bonferroni method. The procedures performed in this study were approved by the ethical review board of Tokyo University of Technology (approval no. E14HS-008) and Kanagawa Children's Medical Center (91-07).

### **4. Result**

MP, SL and TDD had been confirmed interaction between groups. MP significantly decreased in one year and three years after surgery compared with preoperation in the intervention group. SL and TDD significantly worsen in one year and three years in the control group.

### **5. Conclusion**

By differences of the postoperative progress of MP, SL and TDD, it became clear that differed the progress of lateral and upper dislocation for children with severe CP for three years after surgery.

## **Do children with neurological disabilities use disproportionately more inpatient resources than children without neurological disabilities?**

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**Background:** Studies in the US have shown that children with neurological disabilities (ND) have higher health care expenditures. In the UK, studies have focused on emergency care rather than on the inpatient admissions.

**Aim:** To test the hypothesis that children with ND use a disproportionately greater amount of inpatient resources at St George's Hospital, looking specifically at 3 factors: the number of hospital admissions, length of inpatient stay, and reasons for admissions.

**Method:** A retrospective cross-sectional study was conducted, collecting the number of inpatient admissions, length of inpatient episodes and reasons for admissions of 942 inpatients between the 1<sup>st</sup> January 2015 to the 31<sup>st</sup> March 2015.

**Results:** 148 children with ND were identified using ICD-10 codes including cerebral palsy, intellectual impairment, seizures and sensory impairments. The number of disabled children in the UK is estimated to be between 3.0-5.4%, but they accounted for 15.7% of the inpatient population, 18.1% of hospital admissions, and 28.6% of the total inpatient days in our study.

On average, children with ND had 0.202 (95% CI: 0.097-0.307) more hospital admissions ( $p < 0.001$ ), and 1.76 (95% CI: 1.43-2.01) more total inpatient days ( $p < 0.001$ ). A factorial ANOVA showed a significant main effect of neurological disability on the average total length of inpatient stay ( $p < 0.001$ ). There was also a significant main effect of admission reason on the average total length of inpatient stay ( $p < 0.001$ ).

**Conclusion:** Children with neurological disabilities use a disproportionate amount of inpatient healthcare resources, with more frequent admissions and longer total inpatient stays. Future areas of research may include whether this disproportion is nationwide, and what measures could be implemented to reduce this disparity. It is important to ensure that hospitals are educated and prepared for this population group.

## Developing of Family Functioning Scale in Rehabilitation

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### Background

Recently there has been an increasing interest in family-based approaches in rehabilitation of children with special needs. It is important to focus on families as a interdisciplinary team members

### Aim

The aim of this study is to develop a reliable and valid instrument, which measures family functioning in rehabilitation programs.

### Method

Semi-structured interviews were conducted with 100 individuals working in pediatric rehabilitation field in order to identify characteristics to be measured. Being presented to 14 expert's opinions provided content validity of the items that was developed after analysis of qualitative data. The scale obtained from expert opinion evaluations was administered to 440 parents of children with special needs. Item analysis was performed for internal consistency of the scale. Exploratory Factor Analysis Techniques were applied to explore the construct validity of the scale.

### Results

The factor loadings of items on the scale ranged from .492 to .773. Factor analysis revealed that the scale contains 48 items within four factors, representing 49.94 % of the total variance. These factors were identified as awareness, attitude and behavior, community participation and engagement in rehabilitation. Internal consistency reliability of the scale was found .943 by using Cronbach alpha coefficient. Data, obtained from second administration to 200 people from the sample after a two-week interval, were analyzed in order to evaluate test-retest reliability. Pearson correlation coefficient between two administrations was found to be .772. This value indicates that the scale has an acceptable level of test-retest reliability.

### Conclusion

it can be said that the Family Functioning Scale in Rehabilitation meets the required criteria and has quite adequate psychometric properties to measure roles of families of children with special needs in rehabilitation programs.

## Action Planning and Position Sense in Children with Developmental Coordination Disorder

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**Background** – Children with DCD show motor performance that is substantially below expected levels, given the child's chronologic age and previous opportunities for skill learning (American Psychiatric Association, 2013). According to the internal modeling deficit (IMD) hypothesis, children with DCD have a reduced ability to use predictive motor control (Wilson et al., 2013). During action planning tasks predictive motor planning is needed to anticipate the end state of a movement. In this study we examined whether accurate position sense is related to predicting the comfort at the end of a movement in children with DCD.

**Aim** - The present study examined action planning and position sense in children with Developmental Coordination Disorder (DCD).

**Method** - Thirty children aged 6-10 years were included in the DCD group and 90 age-matched children in the control group. Children in the DCD group had a mABC-2 total score < 5<sup>th</sup> percentile, children in the control group had a total score > 16<sup>th</sup> percentile. Participants performed two well-researched action planning tasks, the sword task and the bar grasping task, and an active elbow matching task to examine position sense.

**Results** – Results from the sword-task showed that children with DCD planned less for end-state comfort. On the bar grasping task, however, no significant differences in planning for end-state comfort between the DCD and control group were found. There was no significant difference in the position sense error between the two groups.

**Conclusion** – The present study shows that children with DCD plan less for end-state comfort, but that this result is task-dependent and becomes apparent when more precision is needed at the end of the task. In that respect, the sword-task appeared to be a more sensitive task to assess action planning abilities than the bar grasping task. The action planning deficit in children with DCD cannot be explained by an impaired position sense during active movements.

## **EFFECT OF OCCUPATIONAL THERAPY ON FINE MOTOR SKILLS AND THE DEGREE OF MOTIVATION IN CHILDREN WITH CANCER**

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**Background:** In literature, it is thought that one of the side effects of cancer is on fine motor skills besides motivation. Chemotherapy can also delay gross and fine motor development.

**Aim:** This study aimed to investigate the effect of occupational therapy on fine motor function and motivation in children with cancer.

**Methods:** Fourteen children (8 boys, 6 girls) with mean age of  $10.3 \pm 3.5$  years who were staying at hospital for chemotherapy participated to the study. They were all referred to occupational therapy and volunteered to participate to the study. Fine motor function was evaluated with The Bruininks-Oseretsky Test of Motor Proficiency (BOTMP) and Perdue Pegboard Test. Degree of motivation was evaluated Pediatric Volitional Questionnaire (PVQ). Intervention plan aiming to improve fine hand skills was formed by selecting activities that match needs and interests of children. This plan was applied 6 sessions during their hospital stay, and each session lasted 1 hour. The results were compared before and after treatment.

**Results:** Fine motor function subtest of BOTMP, Purdue pegboard test and PVQ scores were all increased after short period of treatment, the increase was statistically significant for all parameters ( $p < 0.01$ ).

**Conclusion:** This study showed the rapid and positive effect of occupational therapy on fine motor function, upper extremity speed and dexterity and motivation. As motivation is very important in treatment of cancer and fine motor skills are very much needed in school activities; our results presented the need of occupational therapy intervention focusing on these parameters.

## **Contents of physical therapy in infants at high risk for neurodevelopmental disorders in Switzerland and the Netherlands**

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**Background:** Little evidence is available that currently applied methods in paediatric physical therapy (PPT) are effective in improving high risk infant's motor development. In part this lack of evidence may be attributed to the heterogeneity in PPT application. However, limited information is available on the actual contents of PPT. **Aim:** To quantify the contents of PPT in infants in Switzerland (CH) and the Netherlands (NL) and to assess differences between countries. **Method:** In a cross-sectional study, treatment sessions of 30 Swiss infants (mean age 24 weeks corrected age (CA), range 17-32) and 21 Dutch infants (mean age 21 weeks CA, 14 - 27) were video recorded. The contents of therapy sessions were analysed with the Groningen Observation Protocol and the software program Observer XT. This allowed for quantification of the relative duration of therapeutic actions (percentage of the total treatment time). Non-parametric statistics were used for group comparison (Mann Whitney U test and Hodge's Lehmann difference between medians (HL)). **Results:** Contents of PPT varied largely in both countries, but also differed between countries. In CH primarily neuromotor actions like challenged to self-produced motor behaviour (CSPMB) overflowing into hands-on techniques (median CH 25.1%, NL 8.5%, HL: +16.6%, 95%CI 11.1-24.7) were applied. In the Netherlands CSPMB where the infant was allowed to continue activity (NL 26.7%, CH 6.4%, HL: +16.8%, 95%CI 23.1-11.3) was used. While instructing caregivers, Swiss physical therapists (PTs) mostly gave strict instructions (HL +23.5%, 95%CI 13.1-52.6), Dutch PT's more instruction about multiple ways to perform actions (HL +9.4%, 95%CI 0.0-18.3). **Conclusion:** In both countries application of PPT is very heterogeneous. Swiss PTs utilise more hands-on techniques and instruct caregivers in a stricter way than Dutch PTs. Knowledge of the contents of PPT is a first step on the way to identify PT actions associated with improved motor development.

## **Functional domains for children and youth with CP in Portugal: comparative study based on the ICF Core Sets for CP**

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**Title:** Functional domains for children and youth with CP in Portugal: comparative study based on the ICF Core Sets for CP

**Background:** the ICF Core Sets for children and youth (CY) developed by Schiariti et al., (2014) provide a novel and standardized approach to describing the functional profile of CY with Cerebral Palsy (CP) worldwide.

**Aim:** To compare the functional areas included in the ICF Core Sets for CY with CP with a Portuguese health professional's consensus on functional domains developed in 2008.

**Methods:** qualitative methodology using focus group for comparison of the documents.

**Results:** The Portuguese health professional's consensus dated 2008 identified a total of 130 ICF categories as follows: body structures 7 categories, body functions 45 categories; activities and participation 51 categories; contextual factors 27 categories. The Comprehensive ICF Core Set for CY aged 0 to 18 years with CP consists of 135 ICF categories including: body structures 7 categories, body functions 34 categories, activities and participation 58 categories, and environmental factors 36 categories. Main differences were seen in the component environmental factors.

**Discussion/Conclusion:** the ICF categories selected by the Portuguese health professional's team were similar to the selected by the International experts for the Comprehensive ICF Core Set. Our results validate the content of the Comprehensive ICF Core Set for CY with CP in Portugal. Further studies are warranted to validate the content of the ICF Core Sets based on the clients' perspectives on functioning in Portugal.



## **Applying the ICF Core Sets for children and youth with CP in Community-Based Rehabilitation programs in Malawi**

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**Title:** Applying the ICF Core Sets for children and youth with CP in Community-Based Rehabilitation programs in Malawi

**Background:** The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) provides a common language, classification system and framework across disciplines to describe, monitor and evaluate health status, functioning and disability globally. To our knowledge, the ICF and/or ICF-based tools are not routinely implemented in Malawi.

**Aim:** To inspect the feasibility and validity of the use of the ICF Core Sets for CP in a Malawian pediatric population with CP.

**Methods:** Participants consist of children between 0-18 years recruited from the CBR program of an NGO operating in Malawi. Recruitment is currently ongoing, we expect to recruit 40 children and youth with CP. One health care professional, familiar with the use of the ICF-CY, carries out all the assessments. Information is gathered during clinical interviews and examination.

Additional information provided by the children and/or caregivers is also collected and linked to the ICF-CY. The content validity of the ICF Core Sets will be evaluated using the frequency and percentage of subjects who have a strength/problem in each category.

**Results:** Preliminary data shows that the ICF Core Sets facilitate a holistic functional approach, guiding the assessment process, and promoting collaborative work. As recruitment is underway, content validity will be performed when complete data is available.

**Conclusion:** This is the first research project on the feasibility and validity of the ICF Core Sets for children and youth with CP within this particular “cultural environment” – Malawi. Our results can be useful to guide the rehabilitation management process, therefore improving clinical practice. Finally, it can be used to inform health care policies on the management, rehabilitation and integration of this specific population within a community with low resources.

## **Applying the ICF Core Sets for children and youth with CP in Portugal: a case series**

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**Background:** The application of the ICF Core Sets for children and youth (CY) with Cerebral Palsy (CP) standardize the functional assessments of CP worldwide (Schiariti et al., 2014). In Portugal, the ICF classification is primarily used as a communication tool between health services and Education services. However, the ICF Core Sets are not used in daily clinical practice in Portugal.

**Aim:** To address the feasibility of applying the ICF Core Sets in Portugal.

**Methods:** Case series design. Six children from the Portuguese Association for CP (APPC - Leiria) center, age range 0-18 years, covering all GMFCS levels were identified. All five ICF Core Sets were used a framework. An interdisciplinary team filled the checklists. Professionals use interviews, clinical examination, clinical tools (i.e. seizures inventory, Griffith), self and proxy-reported questionnaires (i.e. Vinland, inclusion and participation), and/or technical investigations to collect information related to each ICF category.

**Results:** Using the ICF Core Sets for CY with CP as a framework, promoted a common language for effective teamwork, facilitated a systematic description of the functional profile of each CY with CP and helped identify, in a systematic way, which measures aligned with the content of the ICF Core Sets.

**Conclusion:**

This is the first clinical experience applying the ICF Core Sets for CY with CP in Portugal. From our experience, the application of the ICF Core Sets is feasible in Portugal. Further larger studies are warranted to promote the systematic application of the ICF Core Sets in research, clinical, administration and education in Portugal.

## **How children and adults with severe cerebral palsy can achieve efficient driving of an electric wheel chair.**

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How children and adults with severe cerebral palsy can achieve efficient driving of an electric wheel chair.

L. Antonietti<sup>1</sup>, C. Holenweg-Gross<sup>1</sup>

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**Background:** children and adults with severe cerebral palsy are most often transported by wheelchair. When they are able to drive an electric wheelchair, it requires enormous effort, which often diminishes motivation. Even worse, the effort to drive leads to pathological compensatory movements and asymmetric postures which increase the risk of long-term orthopedic deformities.

**Aim:** to develop an independent way of driving avoiding the use of abnormal patterns of movements.

**Method:** we developed a seat that can be built by any therapeutic/technician team to fit to most all electric wheelchairs. Its principle is to allow the person to drive without the risk of pushing backwards. The seat keeps hip joints in alignment with appropriate weight bearing from the feet. It offers a larger surface of support and better head and trunk alignment. Each person needs individual and progressive adaptations to achieve an efficient posture control for their own specific driving ability.

**Results:** three school age children and one young adult with severe cerebral palsy (Gross Motor Function Classification System level V, Bimanual Fine Motor Function level IV or V and severe mental retardation) were included. All of them were unable to drive a conventional electric wheelchair because of compensatory movements. After six months of training, they were all able to drive independently on an electric wheelchair equipped with our special adapted seat in a familiar environment. Head and trunk alignment was attained for all, even when driving.

**Conclusion:** children and adults with severe cerebral palsy can achieve efficient driving with the help of an electric wheelchair which controls specific body parts in order to sustain proper postural stability against gravity.

## **Trunk Control Training in Children With Spastic Diplegic Cerebral Palsy**

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**Purpose:**The aim of this study was to investigate the effects of trunk control and specific trunk training that is performed particularly on a child, on motor function, which plays an important role in the daily activities of children with Cerebral Palsy (CP) and often observed as a deficiency in children with CP.

**Method:**Fourty children with spastic diplegic CP, ages between 3 to 10 years and with Gross Motor Function Classification System (GMFCS) level I, II, III were included in this study. Children were divided into two groups using randomisation and in training group, trunk training, decided based on individual assessment which is suitable for neurodevelopmental treatment principles, for trunk control in addition to classical physiotherapy programs was performed for 45 minutes, for two days a week, for 6 weeks. In control group, existing physiotherapy program, 45 minutes for two days a week, continued. Any addition was not made into the existing program of the control group. Modified Ashworth Scale (MAS), Pediatric Berg Balance Scale (PBBS), Trunk Control Measurement Scale (TCMS), 1 Minute Walk Test, Timed Up and Go Test (TUG) were applied to both groups before and after 6 weeks. Trunk muscle strength of children was evaluated.

**Results:**After therapy, differences were found in results of MAS and PBBS, and trunk extensor strength between the training group and the control group in favor of the training group ( $p<0.05$ ). TCMS, PBBS, 1 minute walking test, TUG showed significant improvement compared to the average of the pre-treatment of the entire body muscle strength ( $p<0.05$ ). After treatment, training group's averages of TCMS, PBBS, 1 Minute Walk Test, TUG and all trunk muscle strength were higher compared to the ones before treatment ( $p<0.05$ ).

**Conclusion:** This study shows adding exercises which aim trunk to conventional physiotherapy and exercise programs of children with CP, affects motor function positively

**Keywords:** Spastic Diplegic Cerebral Palsy, Trunk Control

## Retrospective study on cognitive development of children with cerebral palsy

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### Background

Cerebral palsy (CP) is a very heterogeneous diagnosis, especially when cognitive development is considered. Very little is known about the longitudinal cognitive outcome of children with CP. However, in clinical follow-up, there is evidence that indicated decline in cognitive performance over time.

### Aim

Aim of this study was to investigate longitudinal cognitive development of children with CP from kindergarten to the end of secondary school. We were also interested in studying whether cognitive development trends of children with CP are different in children attending governmental special schools and children in communal schools.

### Method

Data from psychological assessments were retrospectively collected from 220 children with CP. Minimum of two evaluation points were required. Children's cognitive level was categorized in to one of the following categories: 1) age equivalent performance, 2) age equivalent performance with specific learning disability, 3) well below age equivalent performance, 4) extremely below age equivalent performance. Longitudinal development trends were analyzed and the differences in trends were investigated according to the school type.

### Result

Preliminary results indicate a decline in cognitive level with time. Cognitive development of children with CP was slower than expected. Therefore, these children were later classified into a lower cognitive class because of slow development (not absolute decline in development). The differences in trends according to school type will be analyzed.

### Conclusion

Based on these preliminary results, we suggest that cognitive development of children with CP should be monitored until the end of secondary school. We suggest that psychological evaluation should be routinely administered to children with CP at regular intervals. These results also indicate the need for large scale prospective study on the cognitive development of children and adolescence with CP.

**The Italian Network for Cerebral Palsy (Ita-Net-CP): working for training, improving assistance and research activities, disseminating evidence-based assessment and treatment protocols.**

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**Background:** Cerebral Palsy (CP) is the most frequent cause of disability in childhood. The majority of interventions show limited evidence of efficacy, or are even unnecessary or harmful. Nevertheless, a proportion of such ineffective protocols of rehabilitation and models of intervention and assistance are still provided in many Care and Rehabilitation Services in our country. Additionally, research activities and systematic and homogeneous collection of data, particularly on long-term outcome and natural history of the disorder, are limited because of several barriers to research implementation.

**Aims:** 1) to promote the systematic collection of data on the longitudinal evolution of Italian patients with CP in the different aspects of functioning; 2) to stimulate research activities and improve knowledge and clinical assistance in the field of CP throughout the Italian territory; 3) to facilitate cooperation and training activities between highly-specialized and primary centers.

**Method:** The network includes both highly specialized referral centers and first-level rehabilitation services located in different areas covering all the national territory. Specific meetings and working groups have been planned with the purpose to identify and detail evidence-based protocols of assessment and rehabilitation; training activities dedicated to less specialized centers, aimed at disseminating evidence-based protocols of assessment and rehabilitation, have been planned.

**Result:** 22 partners agreed to participate. A detailed protocol and database including evaluation of different aspects of “functioning” and daily life has been developed on a consensus basis. Training activities on evidence-based assessment and rehabilitation protocols have been planned.

**Conclusion:** these data will be helpful to describe the natural history of CP in Italy and to bridge the gap between the advances of neurosciences in the field of rehabilitation and the clinical management of such patients.

## **Validity of Accelerometry to Measure Physical Activity in Children and Adolescents with an Acquired Brain Injury**

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**Aim:** To determine the criterion validity using oxygen consumption compared with accelerometry activity counts to measure physical activity intensity in ambulant children with an acquired brain injury (ABI).

**Methods:** 27 children (15 males, age  $13.5 \pm 2.4$  years, independently ambulant) at least 12 months post ABI were recruited. Oxygen consumption (MetaMax 3B portable indirect calorimeter), activity counts (ActiGraph GTX3+ accelerometer) and heart rate (Polar RS400) were recorded in 15 second epochs while participants completed: quiet sitting (metabolic equivalent (MET), 1.2 METS, slow walking (0.33m/s, 2.9 METs), moderate walking (0.67m/s, 3.6 METs), fast walking (1.37m/s, 4.6 METs) and stepping on/off a block (4.6 METs). One-way repeated measures ANOVA were used to evaluate differences in oxygen consumption and activity counts in activity tasks. Receiver operating characteristic (ROC) curves were used to determine sedentary, moderate and vigorous activity cut-points. Cut-points were cross-validated by participant and activity using a leave-one-subject-out (LOSO) method.

**Results:** Oxygen consumption was significantly different between all activity tasks ( $p < 0.001$ ). Activity counts were significantly different between sitting and each walking task ( $p < 0.001$ ) but not between fast walking and stepping ( $p > 0.05$ ). Discrimination of cut-points were excellent, with area under the ROC curve  $\geq 0.98$ . Cut-points demonstrated an 82.87% overall accuracy with LOSO validation.

**Conclusion:** Accelerometers have strong criterion validity to differentiate between activity intensities in children with an ABI. Activity classification results were high for sedentary and vigorous activity intensities. The determined cut-points were slightly lower than previously published cut-points in other child neurological populations. Future paediatric ABI studies can use population specific cut-points to evaluate differences in physical activity performance in clinical trials.

## **Axivity activity monitor as evaluation tool of gait in children with cerebral palsy – a validation study**

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### **Background:**

Quantitative assessment of gait and ease of walking in children with cerebral palsy (CP) is most commonly performed in a lab environment using conventional methods such as 3D-analysis and oxygen-consumption tests. However these tests are demanding both for the children and the hospitals. A more cost-efficient and less demanding method is activity monitors, such as AX3 Axivity accelerometer. These sensors are able to measure out of lab and over long periods of time, and open a range of possibilities for gait assessment in everyday living. However the validity of the sensors for assessment of gait quality in children with CP still needs to be evaluated.

### **Aim:**

To assess if differences in gait economy and temporal gait characteristics can be detected from the AX3 Axivity sensor in children with CP and typically developing (TP) children.

### **Method:**

15 children with CP (age: 4-17 years) and 15 TD children (age: 6-13 years) will participate in a clinical gait analysis and a 5 min walk test (5MWT). The signal from accelerometers placed at the thigh and the trunk will be compared to 3D motion capture recordings from the gait analysis and gas exchange recordings from the 5MWT.

### **Results:**

The data will be collected from October 2015 to January 2016.

Temporal parameters of gait, such as step frequency, heel strike, toe-off and stance-, swing-, single-limb support-, and double-limb support-time will be calculated from the gait analysis and related to the pattern of the acceleration signal. Oxygen consumption will be estimated from the 5MWT and related to a regression model based on the mean and variation of the acceleration signal in addition to sex, weight and height.



## **Consensus Classifications of the Gross Motor, Manual Ability, and Communication Function Classification Systems between Therapists and Parents of Children with Cerebral Palsy**

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**Background:** The Gross Motor Function Classification System (GMFCS), initially designed for service providers, was later validated for parent completion. Both the Manual Ability Classification System (MACS) and the Communication Function Classification System (CFCS) were developed for service providers to use collaboratively with parents. **Aim:** To develop a consensus approach for all three classifications. **Method:** Participants were parents of 671 children with CP (56% male; 2-12 years) and 90 trained and reliable physical or occupational therapists. Parents completed the classifications before a therapist visit. During the visit, parents and therapists discussed the classifications and the therapist documented: i) immediate agreement with the parent, ii) consensus with the parent after discussion, or iii) disagreement with the parent. Percentage agreement of consensus ratings, either immediately or after discussion, was calculated. **Results:** Consensus was reached 96.9, 95.5 and 92.9% of the time for the GMFCS, MACS and CFCS, respectively. To reconcile disagreements, we first relied on parents' classifications (they know their children best, see them in multiple settings, and are most able to describe usual performance) unless the therapist provided compelling comments. Reasons to accept the therapists' ratings included: description of capability was lower than parent-reported performance, the incorrect age band was used for the GMFCS, information was provided that the parent was not ready to discuss relatively lower function, parents' desire to classify each hand separately or not recognizing alternative ways of using the hands for the MACS, or for the CFCS, some parents appeared to over-estimate children's communication performance with unfamiliar partners. **Conclusions:** Parents and therapists were able to come to consensus on GMFCS, MACS and CFCS classifications frequently. In most cases, consensus agreement was readily obtained.

## Spatial navigation during locomotion in children with motor disorders

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### Background

During locomotion, the control of spatial orientation through dynamic updating between the body and the environment is required. Beside information from sensory system receptors, also motor signals contribute to spatial representations during navigation. Difficulties during navigational tasks may lead to problems in everyday life.

### Aim

The aim of the study was to explore spatial navigation during locomotion in children with motor disorders.

### Method

Nineteen children with cerebral palsy (CP), 13 walking (WA) and six using wheelchair (WC) (mean age  $11.8 \pm 2.9$ ), 19 with myelomeningocele (MMC), 10 WA and nine WC (mean age  $12.4 \pm 2.9$ ), all recruited from Karolinska University Hospital, and 82 typical developing (TD) children, all WA (mean age  $10.9 \pm 2.5$ ) participated in examination of topographical working memory (Walking Corst test, WalCT) and visuo-spatial memory (Corsi block-tapping Test, CBT). Cognitive non-verbal test (Raven's Coloured Progressive Matrices, CPM) was performed in CP and MMC to assess cognitive development. WalCT and CBT were performed, in randomized order, and analyzed according to the longest list of items that the children could repeat. To control for variations between WA and WC, WC was compared with hand pointing (WP). Parametric statistics was performed using SPSS version 22.

### Result

CP had lower WalCT and lower CBT scores than TD ( $3.63$  vs  $4.57$ ,  $p=0.005$  and  $4.16$  vs  $5.10$ ,  $p<0.001$  respectively). MMC had higher CBT score than CP ( $5.05$  vs  $4.16$ ,  $p=0.003$ ). No differences were found in neither CP nor MMC between WC and WP and in CPM.

### Conclusion

At similar cognitive development in children with CP and MMC, no significant differences in WalCT and CBT were found between MMC and TD. In children with CP, the results showed deficiencies in spatial orientation both with respect to extrapersonal and peripersonal spaces, indicating difficulties both with topographical working memory as well as with visuo-spatial working memory.

## **Real-time Detection of 7 Phases of Gait in Children with CP Using Minimized Sensor Setup**

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### **Background**

Functional electrical stimulation (FES) has been effectively used as an intervention to correct gait deviations associated with pathologic gait. Real-time gait phase detection (GPD) is one control method for FES walking systems; it is challenging and requires optimization of the inputs to minimize processing and to reduce detection delays.

### **Aim**

To evaluate a real-time GPD system, with minimized sensor input, capable of detecting all 7 phases of gait in children with cerebral palsy (CP).

### **Method**

A gyroscope was attached to each shank of a 15 year old with CP (Male) while he walked on a treadmill at self-selected speed. Medio-lateral shank angular velocity was streamed to a PC and a rule-based algorithm was used to identify characteristics associated with each phase. All 7 phases of gait (Loading Response, Mid-stance, Terminal Stance, Pre Swing, Initial Swing, Mid Swing and Terminal Swing) were detected in real-time. GPD from sensor data was compared to motion capture data to assess the onset detection delay for each phase. Delay was defined as the time difference between onset of each phase detected by motion capture data and the output of the real-time GPD system.

### **Result**

All 7 phases of gait were detected using only 2 input signals and a rule-based algorithm. Delays of the GPD system were less than 55ms for all phases except Mid-Swing, having delays of 74ms and 144ms for the left and right side, respectively. Out of 228 phases detected, the GPD system only missed 4 phases. Mid-Swing detection delays require further investigation.

### **Conclusion**

The present system, consisting of 2 sensors and minimized processing, is precise, cosmetic, economical, and serve as feedback control option for portable applications that deliver FES.

## "At the brink of leaving work"

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“At the brink of leaving work”

What can be done to make individuals with CP able to stay in their jobs at a higher age? A 1-year project concerning individuals with CP and employment.

### Background

Research shows that many individuals with CP are involuntarily unemployed. (SSBs Workforce Survey, 2014)

### Objective

The objective is to reveal the challenges people with CP encounter as employees, and show how the right measures taken can make people with CP keep their employment longer.

### Method

A group of 5 individuals with CP aged between 30 and 50 shared their experiences as employees and assisted the project management in creating a QuestBack survey, asking all members of the Norwegian Association of Cerebral Palsy aged between 30 and 50 about their present work-situation .

### Preliminary Results

Number of respondents: 134 (46%). Employed in regular jobs: 79. In permanently adapted jobs: 23 and 51 were unemployed (earlier employed). Never had a job: 14. Of those in regular jobs, 15 worked 100% and 29 worked part time. 21 of the latter had a higher percentage of employment earlier.

Reasons for reducing the hours or quit job were tiredness, fatigue, little capacity at their spare time, little energy to combine work and family, less time for exercise, late effects of CP, sensitivity, reduced skills and mobility.

The respondents answered that these (in their opinion) factors were the most important for making individuals with CP able to keep their jobs at a higher age: Flexible workplace, reduced hours, workassistant, improved healthsituation, better coordination between NAV and the employer, employers who appreciate competence, education, help to find suitable employment, home office-solution, appropriate facilitation (better expertise in NAV), better understanding of CP and the changes that triggers tiredness and fatigue.

### Conclusion

Adult individuals with CP aged 30 to 50 need flexibility and adaptations in order to stay in their jobs at a higher age.

## Family-Centred Care for Children with Cerebral Palsy in Latvia

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### Background

Family-centred care (FCC) is an extensively used model in paediatrics, and it is seen as the best way to provide services to children with a disability and their families. However, the medical or standard health care model in which the main focus is on the child's illness and its treatment and families are generally expected to comply with treatment recommendations, is still present.

### Aim

To examine the perceptions of the families with pre-school children with cerebral palsy (CP) of the extent to which family-centred services were being implemented by service providers in Latvia.

### Methods

A translated version of the Measure of Processes of Care 20 (MPOC-20) questionnaire was used to evaluate the experience of parents with FCS. Families with children aged 2-7 with a primary diagnosis of CP who received services from two rehabilitation centres and one hospital in Latvia and who were willing to participate received the questionnaire.

### Results

A cohort of 234 families completed the questionnaire, rating FCS quite poorly. The highest ratings were in the domains "respectful and supportive care" (M=4.84, SD = 1.18), "enabling and partnership" (M=4.65, SD=1.29), and "co-ordination and comprehensive care" (M=4.62, SD=1.17). The lowest scores related to domains related to the provision of information – "providing specific information about the child" (M=3.62, SD=1.21) and "providing general information" (M=3.32, SD=1.20).

### Conclusions

Service providers in Latvia must be aware of the perceptions of families about FCS, thus moving toward the provision of services that are more family-centred.

## **Manual function outcome measures in children with developmental coordination disorders: a systematic review**

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**Background:** Children with Developmental Coordination Disorders (DCD) face problems of fine motor skills that may contribute to poorer participation at school and weaker performance of daily activities.

To advance our understanding of manual function deficits and to plan targeted interventions, knowledge of the available measurement tools already used in this clinical population is indispensable.

**Aim:** This study systematically reviewed the clinical and psychometric properties of manual function outcome measures for children with developmental coordination disorder (DCD).

**Method:** Three electronic databases (Pubmed, CINAHL, Web of Science) were searched to identify studies published from 1980 until 2014, using outcome measures assessing manual function at the ICFs body function and/or activity level, in children with DCD aged 3-18 years old. Handwriting measures were excluded.

Can Child Outcome Measures Rating Form was used to report the validity, reliability, responsiveness and clinical utility.

Measures investigating manual function used in other pediatric populations were described if potentially feasible for use in DCD.

**Results:** According to the ICFs body function level, two outcomes were identified measuring manual strength in children with DCD.

Nine outcome measures at the ICFs activity level used in DCD met the inclusion criteria of which six were questionnaires and five structured evaluations.

The MABC-2 is the most widely used test in DCD and has the strongest psychometric properties with high internal consistency ( $\alpha = 0.90$ ) and excellent test-retest reliability ( $ICC = 0.97$ ). However, it covers very limited aspects of manual function.

**Interpretation:** This review shows that current instruments do not provide a comprehensive assessment of manual function for children with DCD. Measures addressing speed and accuracy during tasks of manual dexterity, or fine motor skills during activities of bimanual coordination are lacking.

## **Visual motor integration and hand function at school age in extremely preterm children and relation to neonatal brain volumes.**

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### **Background:**

Extremely preterm children risk later visual motor integration and hand function problems. How this relates to neonatal brain volumes is not known.

### **Aim:**

To assess VMI problems and hand function in extremely preterm children, and to relate this to neonatal brain volumes.

### **Method:**

Population based cohort study.

All children born < 27 weeks, birth years 2004- 2007 in Stockholm, Sweden. Term born controls. MRI of the brain was done at term age. Global and regional grey and white matter volumes were assessed by voxel based morphometry.

At 6.5 years Beerys VMI test for testing visual motor integration and Movement ABC (M-ABC) 2 manual dexterity for testing hand function was used.

Statistics: Students t-test, Mann Whitney U test, Fisher's exact test and Pearson's test were used.

### **Result:**

Of 117 preterms, 107 did MRI. 83 (77.6%) were assessed at 6.5 years After excluding major cerebral lesions, 64 preterm and 93 term born children were left.

VMI standard scores and M-ABC scores were lower in preterms than in controls; VMI mean 90.57, SD 13.18 vs 102.96, SD10.80,  $p<0.001$ ; M-ABC median (range) 24,5 (7,0-38,0) vs 30.0 (16.0-40.0),  $p<0.001$ . The differences remained when children with visual acuity below 0.8 were excluded. VMI and M-ABC scores did not differ significantly between boys and girls.

33 preterms had high qualitative MRI data available for analyses of brain volumes.

Brain volumes did not correlate to VMI scores. M-ABC scores correlated to brainstem volume ( $p=0.031$ ) and had a non-significant trend to cerebellum volume ( $p=0.051$ ) on a global level. It also correlated to grey matter volume in the right parahippocampal gyrus ( $r=0.80$   $p<0.001$  uncorrected) and the white matter in the left occipital cortex ( $r=0.82$   $p<0.001$  uncorrected) on the regional level.

### **Conclusion:**

Preterms had lower VMI and M-ABC scores than term controls. M-ABC scores correlated to brain stem volume and brain volumes involved in memory encoding and recognition of environmental scenes.

## **The energy cost of walking and aerobic capacity in children with physical disabilities having walking complaints**

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**Background** Children and adolescents with physical disabilities often report walking complaints, like fatigue and a reduced walking distance, which may be caused by an increased walking energy cost (EC) and/or a decreased aerobic capacity (AC). Clinical exercise tests can help to understand the underlying mechanisms of these complaints.

**AIM** The aim of this study was to determine the prevalence of increased EC and/or a decreased AC in children and adolescents having walking complaint referred for exercise testing in our center.

**METHOD** Seventy-one children and adolescents with walking complaints participated in this study (mean age 12y9mo, range 5y–22y), including 51 children with cerebral palsy (CP), with GMFCS levels I (n=15), II (n=25), and III/IV (n=11), and 20 children with spina bifida or other non-progressive disabilities. The gross EC ( $J \cdot kg^{-1} \cdot m^{-1}$ ) was assessed during 6 min of walking at comfortable speed. The AC was measured during a maximal aerobic exercise test on a cycle ergometer and defined as the highest VO<sub>2</sub> over 30 s (VO<sub>2</sub>peak). Increased EC and a decreased VO<sub>2</sub>peak were determined by cut-off values based on age and gender. These values were developed based on literature (VO<sub>2</sub>peak < 25th percentile) and reference values from our own laboratory database (EC > 2SD's).

**RESULT** An increased EC and/or a decreased VO<sub>2</sub>peak were found in 42% and 62% of the participants with GMFCS level I, 85% and 82% of GMFCS level II, 100% and 100% of GMFCS levels III and IV, and in 50% and 45% for the group with other diagnosis, respectively. Of all participants, 54% had both an increased EC and a decreased VO<sub>2</sub>peak, while 20% had solely an increased EC, and 14% a decreased VO<sub>2</sub>peak. Merely 12% had an EC and VO<sub>2</sub>peak comparable with that of typically developing children and adolescents.

**CONCLUSION** The majority of children and adolescents with physical disabilities who experience walking complaints, have an increased EC and/or a reduced AC, which, in part, depends on the type of diagnosis.



## CARE-RELATED PAIN AND DISCOMFORT IN CHILDREN WITH MOTOR DISABILITIES IN REHABILITATION CENTRES

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**BACKGROUND:** Children with motor disability require multidisciplinary care and are followed in paediatric rehabilitation centres. Despite the care and consideration of the professionals, the combination of motor and cognitive disabilities, the presence of chronic pain and the frequent care-interventions means that these children have a high risk of experiencing daily pain and discomfort. The main purpose of this study was to identify daily care-related pain and discomfort in children with motor disabilities in rehabilitation centres, and the characteristics of children at risk of induced-pain.

**METHOD:** Patients were recruited from two paediatric rehabilitation centres (France). The level of pain or discomfort experienced during each daily care activity was evaluated for 5 days and 1 night using the Face Leg Activity Cry Consolability – revised scale (FLACC-r; Malviya et al., 2006) and a visual analogue scale rated by the carer (VAScarer) and the patient (VASpatient).

**RESULTS:** Thirty-two children aged from 1-15 years (med. = 7 years) were included in the study. 1302 care activities were evaluated. 3.6% were rated as painful and 11% as uncomfortable. The most frequently painful activities were mouth care, transfers, standing and dressing. The most frequently uncomfortable activities were passive limb mobilisation and dressing. Children with neurological disorders were more at risk of induced pain.

**CONCLUSION:** Children with motor disabilities experienced pain during daily care activities in rehabilitation centres. These results highlight the importance of considering pain in children who require assistance with activities of daily living several times a day. A large scale study is necessary to confirm these preliminary results and to specify the risk factors for care-related pain. These researches will increase knowledges of pain-induced in children with motor disability and improve the wellbeing of patients admitted in rehabilitation centres.

## **Relationship between brain structure and the early manual ability in preschool aged children with cerebral palsy**

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**Background:** There is emerging evidence for early detection and assessment of manual abilities in children with Cerebral palsy (CP).

**Aim:** To examine the relationship between early brain structure and manual ability in preschool aged children with cerebral palsy (CP).

**Method:** Prospective population-based cohort of 256 children with CP were followed six- to twelve-monthly for manual ability using the Manual Ability Classification System (MACS) from 18-60 months old. Structural magnetic resonance imaging (MRI) was performed for 123 children (MACS I=52, II=37, III=10, IV=7, V=17) at median 19mo (range 0-107mo) and were classified for aetiopathology (Krageloh Mann scale) and a semi-quantitative scale of brain lesion severity (Fiori). Motor type, limb distribution and gross motor function (GMFCS) were recorded at first visit. Multinomial logistic regression was used to assess associations between brain structure and 48mo MACS. Stability of the MACS was assessed with intraclass correlation coefficient (ICC), percentage agreement and kappa.

**Results:** Global MRI scores were positively associated with MACS levels, accounting for the most variance (Nagelkerke  $R^2=0.225$ ,  $p<0.001$ ). Poor manual ability (MACS V) was most associated with scores of posterior limb of the internal capsule (OR=6.18,  $p<0.001$ ), corpus callosum (OR=2.17,  $p<0.001$ ), basal ganglia/thalamus (OR=1.63,  $p<0.001$ ) and brain lesion asymmetry (OR=0.002,  $p=0.001$ ). The MACS had excellent stability between early ( $\leq 30$ mo) and late (48-60mo) classification (ICC=0.90, 95% CI 0.87-0.92), with almost perfect agreement for MACS V classifications (Fleiss' kappa=0.83, 95% CI 0.75-0.91) compared to MACS I-IV (kappa range 0.53-0.68,  $p<0.001$ ).

**Conclusion:** Early MRI brain lesion severity scores are modestly associated with poorer manual ability. Our findings also confirm the excellent stability of manual ability (MACS) from two years old with preliminary implications for clinical prognostication.

## **Commonly used muscle fatigue calculations used in other patient groups are not applicable in children with Cerebral Palsy**

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**Background:** Problems in arm and hand function (AHF) in children with Cerebral Palsy (CP) cause limitations in daily activities. The main determinants for AHF are distal muscle strength and the ability to produce (sub)maximal isometric force over a prolonged period of time (30-60sec). During this time, the muscles fatigue, thereby limiting the ability to keep producing muscle strength. Today, no research on isometric muscle fatigue (IMF) in children with CP is done and studies on IMF in the upper extremities are limited to other patient groups. Generally, IMF is calculated, based on ratios between initial strength and final strength or the Area Under the Curve (AUC). The best method of calculating muscle fatigue parameters is unknown. Current research proposes a new IMF calculation based on three existing calculations and specific pathology and physiology of muscles of children with CP.

**Purpose:** To evaluate whether three existing methods for quantitatively measuring IMF during grip and pinch contractions in MS patients are usable in children with CP or if a newly developed method is more adequate.

**Method:** 121 Children with CP between 6 and 18 years of age were measured with an isometric grip and pinch dynamometer. IMF was determined based on 30 seconds maximal voluntary contraction curve, from which time to peak, AUC and the Hypothetical Area Under the Curve were calculated. The applicability of these four IMF calculations was assessed with four criteria: a) the mathematical calculations, b) if time to peak is reached within five, and c) ten seconds and d) the number of curves in which calculations did not start at peak force. Overall, IMF calculations that led to the exclusion of less than 10% of the children were considered adequate.

**Results and conclusion:** Based on the criteria it was concluded that in children with CP, the three existing IMF calculations were not applicable. Only the new IMF calculation was adequate to use.

## **Minor neurological dysfunction is associated with developmental outcomes and neonatal brain abnormalities in extremely preterm children**

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**Background:** The prevalence of Cerebral Palsy (CP) in preterm children is decreasing. However, there is evidence that a substantial proportion of preterm children develop minor neurological dysfunction (MND) and that this can be associated with motor, cognitive and/or behavioural difficulties.

**Aims:** To study the prevalence of MND at age 6.5 years in extremely preterm children and investigate associations between MND and 1) brain injury (neonatal cranial ultrasound (CUS) or Magnetic Resonance Imaging (MRI)) 2) behaviour and visuo-motor integration skills at age 6.5 y.

**Methods:** Prospective population-based cohort including 75 children born < 27 weeks' gestation. They were assessed at 6.5 years with the modified Touwen examination (Fily, 2003), Visual Motor Integration Test (VMI), and Strengths and Difficulties Questionnaire (SDQ). At term equivalent age CUS and MRI were performed. MND was classified as MND-1 (simple) or MND-2 (complex).. Student's t-test, ANOVA, Kruskal-Wallis test or Chi-square test were used for statistical analysis.

**Results:** 48 % of the children had normal neurology, 42.7 % MND-1, 9.3 % MND-2. Periventricular haemorrhagic infarction ( $p=0.046$ ) on CUS, delayed myelination ( $p=0.002$ ), severity of white matter injury ( $p=0.02$ ) and high grade intraventricular haemorrhage on MRI ( $p=0.04$ ) were related to MND. Both children with MND-1 and MND-2 had higher scores for conduct problems on the SDQ (parent version) compared to children with normal neurology ( $p=0.02$ ). SDQ teacher rating indicated a higher risk for hyperactivity in children with MND-1. Children with both MND-1( $p=0.003$ ) and MND-2 ( $p=0.03$ ) had significantly lower mean VMI scores than children with normal neurology.

**Conclusions:** In our cohort of extremely preterm children, both MND-1 and MND-2 co-occur with impairment of behaviour and visuo-motor integration. Brain injury on neonatal imaging, in particular, periventricular white matter abnormalities, were associated with MND at school age.

## FEATURES OF SPASTIC CEREBRAL PALSY IN FULL-TERM BABIES

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**Background.** Cerebral Palsy (CP) is main cause of child disability. CP incidence varies from 1 to 6 per 1000 children (Semyonova, 2007; Rosenbloom et al., 2012).

**Aim.** To define causes and functional disturbances in babies with spastic CP.

**Methods.** At Children Hospital we examined 54 full-term babies under 7 years old with confirmed spastic CP. Children underwent routine somatoneurological examination, standard neurovisualization (cranial ultrasound, CT, MRI). Severity of gross motor abilities was evaluated by means of Gross Motor Function Classification System (GMFCS) (Palisano et al., 2007).

**Results.** Examined children were classified as follows: 23 babies had intrauterine hypoxia, 15 – birth asphyxia, 4 – combined ante- and intranatal hypoxia; 31 child had hemiplegic CP, 17 – spastic diplegia, 6 – mixed CP. Neurovisualization showed intraventricular haemorrhages (IVH) in 10 cases, cerebral infarctions – in 11, ventriculomegalia – in 17, cysts – in 9 cases. Two babies had brain malformations (schizencephaly and polymicrogyria).

Hemiplegic CP developed more frequently in babies with cysts than in children with IVH, infarctions and ventriculomegalia ( $\chi^2 = 4.09-8.81$ ;  $p = 0.003-0.043$ ). Children with ventriculomegalia had spastic diplegia more frequently than babies with cysts ( $\chi^2 = 7.29$ ;  $p = 0.007$ ). Mixed CP was diagnosed more frequently in case of IVH than of ventriculodilatation ( $\chi^2 = 4.23$ ;  $p = 0.04$ ). Severe stages of CP (GMFCS<sub>3-5</sub>) developed more frequently in children with mixed CP than in ones with diplegic and hemiplegic CP ( $\chi^2 = 9.24-25.2$ ;  $p = 0.0001-0.0024$ ), in children with IVH and infarctions than with cysts ( $\chi^2 = 4.56-6.11$ ;  $p = 0.0135-0.032$ ).

**Conclusion.** CP is caused by different cerebral damages developed in perinatal period. Our study showed prevalence of hemiplegic CP in babies with cysts, diplegia – in cases of ventriculomegalia, mixed CP – in IVH cases. Children with IVH, infarctions and mixed CP had severe motor disability.

## **Using a virtual community of practice to foster the implementation of best practice in childhood disability: an example in developmental coordination disorder**

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### **Background**

Evidence-based online information can increase self-perceived knowledge and skills about a disorder but has limited effectiveness in changing clinical behaviours. To change behaviours, KT strategies should be longitudinal and allow for interactions between knowledge users and researchers. Virtual communities of practices (vCoP) could be a promising KT strategy, but little is known about their effectiveness in childhood disability. A vCoP facilitated by 4 knowledge brokers was experimented during 6 months with 64 physiotherapists (PTs) working with children with DCD.

### **Aim**

Identify PTs behavioural changes goals

Explore factors impacting changes in behaviours

Examine the impact of PT behavioural changes

### **Method**

This study uses a pre/post design combining mix methods. PTs behavioural goals were self-assessed using a questionnaire prior to engaging in the vCoP. Questionnaires (pre-post) and interviews explored changes in behaviours, and impact of these changes. Analyses explored whether the amount of use of the vCoP influence changes in behaviours.

### **Result**

PTs wished to increase their ability to build capacity to manage DCD and to improve their evaluation (respectively 30 and 27%). Other goals include using cognitive interventions. Factors related to the vCoP, such as the resources shared, helped PTs modify their practice. The amount of time spent on the vCoP was not correlated with changes in behaviours. Behavioural changes lead to positive outcomes, including better support for families.

### **Conclusion**

This virtual CoP seems to be effective in changing clinical behaviours. However, further research is needed to better understand factors influencing the use and the outcomes of vCoPs.

## THE RELATION BETWEEN FUNCTIONAL INDEPENDENCE AND GROSS- FINE MOTOR FUNCTION, COMMUNICATION AND EATING-DRINKING FUNCTIONS IN CHILDREN WITH CEREBRAL PALSY

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### Background:

Cerebral palsy (CP) is a group of permanent movement disorders. There may be problems with sensation, vision, hearing, swallowing and speaking so these problems may effect independence in daily life activities.

### Aim:

The purpose of this study was to investigate the relation between functional independence and gross-fine motor function, communication and eating-drinking functions in children with CP.

### Method:

Forty three children with spastic CP [mean age:  $7.20 \pm 3.87$ , girl: 13 (30.2%), boy : 30 (69.8%)] included in this study. Body structure and functions that are indicated in ICF-CY such as gross motor functions were assessed with Gross Motor Function Classification System (GMFCS), fine motor functions with Manual Ability Classification System (MACS), eating and drinking levels (Eating and Drinking Ability Classification System) EDACS with ICF. We measure functional independence with Pediatric Functional Independence Measure (WeeFIM) according to activity component of ICF-CY. Spearman rank correlation was used to evaluate these assessments.

### Result:

Mean age was  $7.20 \pm 3.87$ . There was significantly relation between GMFCS and WeeFIM ( $r_{\text{motor}} = -0.84$ ;  $r_{\text{cognitive}} = -0.79$ ;  $r_{\text{total}} = -0.84$ ;  $p < 0.001$ ), MACS and WeeFIM ( $r_{\text{motor}} = -0.80$ ;  $r_{\text{cognitive}} = -0.68$ ;  $r_{\text{total}} = -0.68$ ;  $p < 0.001$ ), EDACS and WeeFIM ( $r_{\text{motor}} = -0.75$ ;  $r_{\text{cognitive}} = -0.77$ ;  $r_{\text{total}} = -0.77$ ;  $p < 0.001$ ). CFCS and WeeFIM ( $r_{\text{motor}} = -0.85$ ;  $r_{\text{cognitive}} = -0.92$ ;  $r_{\text{total}} = -0.88$ ;  $p < 0.001$ ).

### Conclusion:

The level of activity independence is related with gross-fine motor and communication functions. Therefore we suggest that children with CP are evaluated by therapists with these classifications and tests according to framework of ICF.

## Cognition and Language Functions in Pre-school Children with Cerebral Palsy

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### Background

The cerebral palsy (CP) not only results in motor impairment, but also cognition and language problems. However, few studies investigated the relationships between motor severities and cognition and language functions.

### Aim

This study aimed to investigate the cognition and language outcomes in preschool children with CP of various motor deficits.

### Method

Eighty eight children with CP (6 to 72 months) were collected in this study. All participation was classified into 3 groups based on gross motor function classification systems (GMFCS) levels: group A (GMFCS levels I-II), group B (GMFCS levels III-IV) and group C (level V). Developmental functions for cognition and language (receptive, expressive and total language) were measured with Comprehensive Developmental Inventory for Infants and Toddlers (CDIIT). The developmental quotients (DQs) were calculated as developmental age divided by chronological age. A one-way ANOVA was used to compare the outcomes among three groups.  $p < 0.05$  was considered to be statistically significant.

### Result

The DQs in cognition, receptive, expressive and global language domains differed among three groups ( $p < 0.05$ ). The group C (GMFCS level V) had lower DQs in these functional outcomes than other 2 groups ( $p < 0.01$ ). Compared with group A, group B had poor DQs in cognition, receptive, expressive and global language ( $p < 0.05$ ).

### Conclusion

The motor severity was associated with the cognition and language development in preschool children with CP. These findings may allow clinicians early identifying the development outcomes and setting up the goals in children with CP based on the GMFCS levels. In future, we should focus on longitudinal follow-up and effect of early intervention in pre-school children with CP.



## **Kinematic analysis of gait while walking over an obstacle in ambulatory children with cerebral palsy**

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**Background:** The goal of physical therapy for children with cerebral palsy (CP) is to enable them to walk in natural environments, which often have an obstacle in the path of ambulation. Therefore, it is important to understand how these children adapt their gait in response to the presence of obstacles in their pathway.

**Aim:** This study aims to analyze gait kinematics while walking over an obstacle in ambulatory children with CP.

**Methods:** Twenty seven children with CP (8.3–20.0 years) were collected and classified into level I (n = 14) or level II (n = 13) according to Gross Motor Function Classification System (GMFCS) levels. Vicon system was used to measure the gait kinematics of two walking tasks (free walking and walking over an obstacle). Kinematic parameters of gait included temporal-stride parameters and joint angles.

**Results:** In free walking, children with GMFCS level I have larger stride length and walking speed than those with level II ( $p < 0.05$ ). Children with GMFCS level II have greater pelvic tilt and knee flexion at heel strike ( $p < 0.05$ ). In walking over an obstacle, children with GMFCS level I have greater cadence and walking speed than those with level II ( $p < 0.05$ ). Furthermore, children with level II have greater stride time and double-support time than those with level I ( $p < 0.05$ ).

**Conclusion:** Children with GMFCS level I had better gait performance under the free-walking and walking an obstacle than those with level II. Findings may allow clinicians understand the underlying motor control strategies of walking in different conditions in children with CP.

## Reaching kinematics and upper limb dysfunction in children with cerebral palsy

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### Background:

Therapies for upper limb dysfunction in children with cerebral palsy (CP) may target underlying motor control impairments. Kinematic analysis can disclose the motor control strategies underlying the motor performance.

### Aim:

This study aims to investigate the relationships between the reaching kinematics and upper limb function in children with CP.

### Methods:

Thirty five children with CP (3–12 years) were collected. All children underwent assessment for reaching kinematics and upper limb function. The reaching kinematics were reaction time (RT), normalized movement time (nMT), normalized movement unit (nMU), and peak velocity (PV). Upper limb function was assessed by Box block test (BBT) and Bruinicks-Oseretsky Test of Motor Proficiency, Second Edition (BOT-2), including fine manual control (FMC) and manual coordination (MC) domains.

**Results:** Regression analyses showed RT and nMT were negatively related to FMC and MC of BOT-2 (adjusted  $r^2=0.35-0.47$ ,  $p<0.01$ ). The nMT was negatively associated with BBT (adjusted  $r^2=0.27$ ,  $p<0.01$ ).

**Conclusion:** The movement preplanning and execution are associated with fine motor control and manual dexterity. Findings may allow clinicians understand the underlying motor control strategies of upper limb dysfunctions in children with CP.

## **Correlation between unimanual capacities and bimanual performances in unilateral cerebral palsy: the role of lesion timing**

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**Background** The type and the timing of the lesion are considered the main factors that determine the clinical characteristics of unilateral cerebral palsy (UCP). According to the literature (Cioni et al,1999; Krageloh-Mann,2009) there are three main forms related to the timing: early malformative (Type 1), prenatal (Type 2) and connatal (Type 3). Holmefur et al.(2013) have investigated the relation between the neuroradiological findings and the development of hand function in UCP.

**Aim** The present study aims to evaluate the role of the timing of brain lesion on predicting the unimanual capacities and bimanual performances in children with UCP.

**Method** A sample of 45 children (mean age  $7.38 \pm 1.97$ ) with congenital UCP (33 right, 12 left) and focal brain lesion, detected by MRI (8 Type 1, 17 Type 2, 20 Type 3), were recruited at school age. They were assessed with Assisting Hand Assessment and MUUL. A rho Spearman correlation analysis was performed among the bimanual performances (AHA), the unimanual capacities (MUUL) and the timing of lesion. Moreover, the Wilcoxon non parametric test was used to compare the unimanual AHA and MUUL values among the three different types of timing of lesions.

**Result** A significant positive correlation among the values of AHA and of MUUL was found ( $r = .942$ ,  $p < .00001$ ) and a negative correlation between AHA and type of lesion ( $r = -.324$ ,  $p < .05$ ) and MUUL and type of lesion ( $r = -.375$ ,  $p < .05$ ). The scores of AHA and MUUL of Type 1 were higher, at limit of significance, than those of Type 3 while were similar than those of Type 2. The scores of AHA and MUUL of Type 2 were significantly higher than those of Type 3.

**Conclusion** These data show that the timing of lesion in UCP could be considered as a predictor of the unimanual capacities and bimanual performances. The connatal lesions have the worse prognosis in the manual abilities even if there is a high variability. This work was supported by Italian Ministry of Health-RF2012 GR-2011-0235005.

## Eye-pointing classification in non-speaking children with severe cerebral palsy

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### BACKGROUND

Eye-pointing is a term used to describe looking behaviours used by children with cerebral palsy to serve the same functions as finger pointing in non-disabled children. Careful observation of looking behaviours in the child's response to assessment materials is an effective way of determining a profile of co-morbidity in this population. However, there is often no agreement between clinicians concerning which looking behaviours constitute genuine eye-pointing in response to assessment stimuli and which do not.

### AIM

This paper will present the first iteration of an eye-pointing classification system. It has been designed to help clinicians and families describe and categorise looking behaviours in young, non-speaking children with cerebral palsy who are unable to fist or finger point.

### METHOD

The scale has been developed via: 1. a literature review; 2. an initial drafting and development stage informed by clinical experience within the research group; 3. amendment via focus group discussion, and 4. enhancement through international survey. The scale is currently undergoing reliability testing.

### RESULTS

A broad consensus on the design and content of a classification scale was achieved. Mirroring the structure of other successful classification systems (e.g. GMFCS), a 5-point rating scale has been established based on careful observation of the child's looking behaviours (rather than interpreted functions of those actions). These describe the child's ability to fix gaze, display object recognition, disengage fixation and transfer gaze. Early indications suggest that the scale can achieve good levels of reliability.

### CONCLUSION

The requisite skills for effective eye-pointing may not be available to many children with severe cerebral palsy. Careful description of these skills is both desirable and possible.

## **Can parents become generic therapist and administer high frequency therapies to their child with cerebral palsy?**

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**Background:** Severely affected cerebral palsy (CP) patients (GMFCS 4 and 5) have, perhaps due to a lack of ambulation, very poor structural integrity and poor musculoskeletal performance. These groups often struggle to benefit from standard rehabilitation platforms and higher frequency therapies may be required.

**Aim:** The feasibility of a high frequency home-based therapy that utilizes parents as the primary caregiver was explored in a non-randomized prospective cohort treatment study.

**Methods:** A non-randomized prospective cohort treatment study of GMFCS types 4 and 5 over five years old. At baseline and every 6 months, parents of CP patients were taught a simple home-based manual therapy. Therapy was encouraged for at least 30 minutes 5 times a week. CPCHILD questionnaires were collected at baseline and bi-annually for 3 years by the physical therapists. GMFCS classification was also performed via function testing. Measures of intra-abdominal pressure (force of 1 compressive inch) and seated spinal stability (minimal support for 10 seconds of independent sitting) were also taken initially and bi-annually for 24 months.

**Results:** Baseline CPCHILD scores agreed with published mean values. To date, GMFCS 4 patient CPCHILD scores improved from baseline at 51.55 to 61.85, 57.54 and 56.02 ( $p<0.05$ ) and GMFCS 5 improved from baseline at 48.16 to 49.28, 51.10 and 55.54 ( $p<0.05$ ) after 12, 24, and 36 months of home therapy respectively. Qualitatively GMFCS classification mean values of type 5 changed to type 4 after 24 months while types 4 remained the same. Measures of intra-abdominal pressure improved from 3.23 to 4.46 lbs/inch of compression and, correspondingly, seated spinal stability improved from 2.3 to 3.1 after 36 months ( $p<0.05$ ).

**Conclusions/:** Results suggest a high frequency home based therapy for CP patients to be a feasible platform for the improved health and wellbeing of severely affected cerebral palsy patients GMFCS types 4 and 5.

Conclusion: Ankle KPS decreases following intense exercise. Youth who show more stable patterns for their dominant side, are those who are younger, and who spent more time in vigorous PA and less time being sedentary.

## **The Effect of Balance on Activities of Daily Living in Children with Intellectual Disability**

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**Background:** Intellectual disability (ID) is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior. In the literature, it was observed that there are insufficient number of studies evaluating the factors may affect the activities of daily living (ADL) in children with ID.

**Aim:** This study was done to evaluate the balance in children with ID and to assess its effect on ADL.

**Method:** 20 children who diagnosed as ID (IQ scores ranging 35-69) with non physical disability and 20 children with normal mental developing were included in the study. Ages ranged from 8-15 years. Balance was evaluated with single leg balance test (SLBT) in both sides. ADL were assessed with Pediatric Functional Independence Measure (WeeFIM). Data analyses were performed using SPSS 20, version. Independent t test was used to compare the parameters and correlation analysis was used to measure the relationship between the SLBT and WeeFIM.

**Result:** Compared the balance, SLBT times were found lower in children with ID but only difference in left SLBT time with eyes open was found statistically significant between groups ( $p=0.030$ ). Self-care ( $p=0.001$ ) and mobility ( $p=0.023$ ) scores of motor area and communication ( $p=0.000$ ) and social cognition ( $p=0.000$ ) scores of cognitive area of WeeFIM were found statistically significantly different between two groups. Between general motor score in WeeFIM and SLBT with eyes open were found statistically significant and positive correlation (right side  $p=0.036$ ; left side  $p=0.042$ ).

**Conclusion:** To improve rehabilitation program, there is a need more studies to evaluate the balance of children with ID. The development of balance can facilitate child's daily activities. In this regard, balance training programs could be in rehabilitation program of children with ID and increasing independence in ADL have been as a purpose with these programs.

**Evolution of functional capacity, assessed with the Egen Klassifikation scale in the Spanish population with spinal muscular atrophy or Duchenne Muscular Dystrophy. A three year longitudinal study.**

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**Background:** Spinal Muscular Atrophy (SMA) and Duchenne Muscular Dystrophy (DMD) are two Neuromuscular Diseases which evolve with a progressive loss of muscle strength and, therefore, the loss of functional capacity. The valuation measurement scales are used to understand better and to quantify this involution as well as making treatment to anticipate problems and improve the quality of life of people suffering from these diseases. **Aim:** To study the changes in the functional capacity of a group of patients with Spinal Muscular Atrophy and Duchenne Muscular Dystrophy, over a period of 3 years. **Method:** 19 individuals of the Spanish population affected with Spinal Muscular Atrophy and Duchenne Muscular Dystrophy, which were assessed with the Egen Klassifikation Scale (EK) twice, with a time interval of three years. **Results:** The results show a decrease in the functional capacity of these persons during this time period, with a significant difference in the total amount of the scale ( $p = 0.003$ ). All scale items showed lower valuations after three years, reaching statistical significance during the assessment, containing the ability to move his hands and coughing. **Conclusions:** The functional capacity of patients with SMA and DMD decreases significantly within three years



## **General movements and the quality of concurrent motor repertoire at 3 months of age in healthy term infants in USA and Norway**

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**Background:** Recent studies have shown that abnormal concurrent motor repertoire can be seen in healthy term infants.

**Aim:** To examine quality of general movements and quality of the concurrent motor repertoire in healthy term infants at 3 months of age in Norway and USA.

**Method:** Assessment of Motor Repertoire 3 - 5 Months, which is part of Prechtl's General Movement Assessment, is used to describe quality of the motor repertoire by observation of video recordings. One of two observers was unaware of the clinical status of the infants. FMs were classified as normal if present and abnormal if absent, sporadic or exaggerated. The quality of the concurrent motor repertoire was classified as abnormal if the movements were monotonous, stiff or jerky.

**Result:** Eighty-seven infants from a region in Central Norway (42 boys, birth-weight mean 3670(SD 429)) grams, gestational age 40(SD1) weeks) were video-taped at mean 13.2 weeks post-term age. Twenty-four infants from Illinois, USA (18 boys, birth-weight 3452(SD494) grams, gestational age 40(SD1) weeks) were video-taped at mean 13.1(SD1.5) post-term age. All infants were born after uneventful deliveries and had no medical complications in the neonatal period.

Abnormal FMs were seen in two infants (2%; both sporadic) in the Norwegian group and one infant (4%; exaggerated) in the American group. Among infants with normal FMs abnormal quality of the concurrent motor repertoire was seen in 15 (18%) of 85 Norwegian infants and 7 (30%) of 23 American infants (not significant).

**Conclusion:** Among healthy, term infants with normal FMs, abnormal quality of the concurrent motor repertoire was common, and twice as common among American as among Norwegian infants although this difference was not statistically significant. Follow-up studies must clarify the clinical significance of this phenomenon among low-risk infants. The influence of ethnicity, environmental and cultural factors on infant motor performance warrants further studies.

## **Reliability and validity of the Task-oriented Arm Capacity instrument during bimanual activities in children with unilateral Cerebral Palsy**

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**Background** A new measurement, the task-oriented arm hand capacity (TAAC) instrument, was developed to measure task-oriented strength in children with Cerebral Palsy (CP). Rehabilitation therapy principles are shifting towards task-oriented training, indicating the importance to measure task-oriented strength while executing daily activities. In this study the strength needed to lift a crate was measured. The TAAC instrument contains a sensor, which measures the force while the crate is lifted and pulled straight up, and contains a task-oriented component because the task is comparable to daily activities.

**Aim** This study will focus on the methodological quality of the crate task of the TAAC instrument compared to handgrip strength, measured with Biometrics H500 dynamometer, of the affected hand (AH) and non-affected hand (NAH).

**Method** The data of 45 children diagnosed with unilateral CP, aged between five and 17 years was used. First, the test-retest reliability of the TAAC instrument was determined. Second, the validity of the TAAC instrument compared to handgrip strength of the AH and NAH was determined. Furthermore, the influence of the Manual Ability Classification System (MACS) on the measurement methods was determined.

**Results** The results showed a good test-retest reliability of the TAAC instrument (ICC = 0.837; CI = 0.702 – 0.911), and the MACS levels did not influence the test-retest reliability. The TAAC instrument had a low significant correlation with the handgrip strength of the AH ( $r = 0.316$ ) and with the handgrip strength of the NAH ( $r = 0.306$ ). The handgrip strength of the NAH in MACS level II also significantly correlated with the TAAC instrument ( $r = 0.691$ ).

**Conclusion** These results suggest that the TAAC instrument is a good measurement method, and a good addition to the existing methods. The results also suggest that not only strength is needed to pull up a crate, but also other aspects such as muscle coordination and endurance.

**Feasibility of a portable, virtual-reality based neuro-pediatric upper limb training system**

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**Background** Home-based, virtual-reality enhanced therapy of hand and arm function has the advantage of saving travel time of patients and it can increase the amount and intensity of training. Furthermore, treatment costs might be reduced, as therapists are not always present. **Objective** To investigate the feasibility and clinical utility of the portable YouGrabber® (YouRehab AG, Zurich, Switzerland). **Methods** Fifteen families of children (7 girls, mean age: 11.3y) with neuromotor disorders and affected upper limbs participated. They received instructions and took the system home to train for 2 weeks. After returning it, they answered questions about usability, motivation, and general opinion of the system (Visual Analogue Scale; 0 indicating worst score, 100 indicating best score). Furthermore, total pure play time and number of sessions were quantified. To prove the clinical utility of the system, number and sort of support requests were logged. **Results** The usability of the system was rated high (mean 66.5-93.1), except for the occurrence of technical errors (mean 60.1). Parents had to motivate their children to start (mean 66.5) and continue (mean 68.5) with the training. But in general, parents estimated the therapeutic benefit as high (mean 73.1) and the whole system as very good (mean 87.4). Children played on average 7 times during the 2 weeks; total pure play time was 185±45min. Especially at the beginning of the trial, systems were very error-prone. Fortunately, most problems could be solved before giving the systems to the patients home (we contacted the company 24 times to solve problems before we provided the system to the families). Nevertheless, 10 of 15 families contacted us at least once because of technical problems. **Conclusions** The portable YouGrabber® is a promising and highly accepted home-based training tool. However, currently, the system is still error-prone and the requested support exceeds the support that can be provided by clinical therapists.

## **Characteristics of sentence comprehension in non-speaking children with severe cerebral palsy; delayed or deviant?**

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**Background:** Children with severe cerebral palsy (CP) (i.e. ‘non-speaking children with severely limited mobility’) are restricted in many domains that are important to the acquisition of language.

**Aim:** To investigate comprehension of spoken language on sentence type level in non-speaking children with severe CP.

**Method:** This study investigated 68 children with severe CP (mean age 6;11 years) with a specifically developed computer-based instrument for low motor language testing (C-BiLLT) for comprehension of different sentence types: phrases, simple active, and compound sentences. The C-BiLLT provides norm data of typically developing (TD) children (1;6 to 6;6 years). Binomial logistic regression analyses were used to compare the percentage correct of each sentence type in children with severe CP with that in TD children and to compare percentage correct within the CP subtypes.

**Result:** Sentence comprehension in children with severe CP followed the developmental trajectory of TD children but at a much slower rate; nevertheless, they were still developing up to at least age 12 years. Delays in sentence type comprehension increased with sentence complexity and showed a large variability between individual children and between subtypes of CP.

Comprehension of simple and syntactically more complex sentences were significantly better in children with dyskinetic CP than in children with spastic CP. Of the children with dyskinetic CP, 10-13% showed comprehension of simple and compound sentences within the percentage correct of TD children, as opposed to none of the children with spastic CP.

**Conclusion:** In non-speaking children with severe CP sentence comprehension is delayed rather than deviant. Results indicate the importance of following comprehension skills across all age groups, even beyond age 12 years. The subtype of CP should be considered when establishing educational programs for sentence comprehension, and augmentative & alternative communication support.

## **Repeatability and uncertainty assessment of the Lebanese version of Test of Aided-communication Symbol Performance (TASP) in typically developing children**

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### **Background**

Augmentative and alternative communication (AAC) assessment for children with cerebral palsy (CP) remains difficult due to the lack of validated tools. The test of aided-communication symbol performance (TASP)<sup>TM</sup> is one of the evaluation tools used among Lebanese speech and language therapists<sup>1,2</sup>, but its validity has not been studied yet.

### **Aim**

To evaluate the uncertainty and repeatability of the Lebanese version of the TASP<sup>TM</sup> among Lebanese typically developing (TD) children.

### **Methods**

The TASP<sup>TM</sup> is composed of four subtests (ST) including several items each, assessing the capacity of the child 1) to memorize symbols, size and numbers (ST1), 2) to encode grammatical skills (ST2) 3) to categorize symbols (ST3) and 4) to sequence symbols to form sentences (ST4). The English version was translated into Lebanese spoken Arabic. The test was administrated to 20 TD children with a mean age of 7years  $\pm$  2(min-max: 4- 11years). All children were filmed during the assessment. The recorded data were analyzed by 4 different trained and experimented speech therapists separately. A percentage score was calculated by each operator for 68 items generated by the TASP<sup>TM</sup>. The mean values between the operators were compared using Friedman's test. The uncertainties between operators (2SD of differences) were evaluated for each ST<sup>3</sup>.

### **Results**

The uncertainties on the items of each ST were ranged as the following: ST1: 0 to 29%, ST2: 0% to 19%, ST3: 0% to 23%, ST4: 0% to 59%. The inter-operator repeatability showed that there were no significant differences for all the ST items except one item in ST1 relative to the memory for location ( $p > 0.05$ ) due to the subjectivity of the operator in the quotation of this item.

### **Conclusion**

TASP<sup>TM</sup> Lebanese version is a reliable tool that can be used with Lebanese TD children. Work is in progress in order to apply the TASP<sup>TM</sup> in children with CP.

<sup>1</sup> McDougall S.et al.2012,<sup>2</sup> Bruno J.et al.2007 <sup>3</sup>Bland J.M. et al.2006

## **Motor- Perceptual and Cognitive Procedural Skill Learning Patterns of Children with Cerebral Palsy and Children with Traumatic Brain Injury- A Comparative Study**

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**Background:** Procedural skill learning (SL) is the ability to learn incidentally, as a result of repeated exposure and practice. Through procedural SL children acquire skills critical for school performance and activities of daily living (ADL). Relatively little is known regarding SL potential among various clinical pediatric populations.

**Aim:** To examine differences in SL patterns and potential between children with congenital brain injury (Cerebral Palsy- CP), acquired brain injury (Traumatic Brain Injury- TBI) and typically developing (TD) controls.

**Methods and Subjects:** 14 children with spastic CP, 14 children with TBI and 14 healthy controls, aged 9-18 years. The three groups matched with regard to age and gender. All children performed two different SL tasks: (1) a motor- perceptual task: The Serial Reaction Time (SRT) task in which learning is examined via a repeated sequence of finger movements, and (2) a cognitive learning task: The Probabilistic Classification Learning (PCL) task in which cue-outcome associations are gradually learned over many trials.

**Results:** A different pattern of results was revealed for each SL task. All three groups demonstrated significant improvement on the explicit component of the SRT task. However, only the TBI and TD groups demonstrated a learning pattern indicative of implicit learning of the task. In the PCL task, improvement in performance was observed for all children, with TD children improving in a relatively faster rate.

**Conclusion:** This preliminary comparative study demonstrated that the use of implicit SL tasks yielded a different pattern of results for the two clinical groups. The present comparisons have important implications. Characterizing the unique learning patterns and potential for each pediatric population can help rehabilitation and educational professionals to plan efficient and effective, interventions allowing the children with CP and TBI to maximize their potential in school performance and ADLs.

## **Core-set of Cerebral Palsy applied in a group of students in a Special Education School in Spain**

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**Background:** Planning rehabilitation is the basis for service delivery in the care of children and adolescents with cerebral palsy. Planning rehabilitation is often conducted by a multidisciplinary team together with the child and his/her parents. Goal setting and the importance of children's participation in the immediate environment during development and all the transition phases are considered as the core of any rehabilitation practice.

**Aim:** The aim was evaluate the procedure when multidisciplinary team members plan rehabilitation for children and adolescents with cerebral palsy with the Cerebral Palsy Core Set based in a International Classification of Functioning, Disability and Health-Child and Youth (ICF-CY) background.

**Methods:** The therapeutic team has used the Cerebral Palsy Core Set of the group lead by Veronica Schiarti like a framework to assess and planning the therapeutic program in a special education school. It was Influenced by the theories of Family-centered service, goal-setting and ICF-CY. One multidisciplinary group of a speech therapy, one social worker, one teacher and two physical therapist used the ICF Core Set for Cerebral Palsy to prove its efficiency.

**Results:** 15 students of one Special Education School were assessed with the Cerebral Palsy Core Set to get information to planning and develop their therapeutic program. Goal-setting was experienced as difficult or challenging. Goals were mostly set by the different professionals solely and brought as information to the team meeting. Parents involvement in the planning process was systematic. Transition to day-care was clear. It would be better use a more friendly informatics tool to apply the ICF-CY.

**Conclusions:** The rehabilitation planning procedure could benefit from a clear structure. The ICF Core Set for Cerebral Palsy can serve as a structure for identify treatment objectives. The ICF language is a good way to exchange points of view between families and professionals.

## Use of ICF-CY principles in habilitation practice

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**Background** Children with Cerebral Palsy (CP) present impairments, activity limitations and participation restrictions. The goal of habilitation is to achieve and maintain optimal functioning in interaction with environment.

Use of ICF principles help to perform a holistic assessment of CP children and to plan the most appropriate interventions.

Aim of this study is to explore and analyze functioning of CP children and to evolve problems and needs in relation to functioning limitations.

**Method** 74 children with CP born in Riga, birth years 2000-2004 were assessed using ICF-CY Model (WHO, 2007).

CP decision tree (SCPE) was used to identify CP form.

ICF Core Set based on clinical tools for CP was withdrawn.

Clinical activity focused assessment tools consistent with ICF were:

Gross Motor Function Classification System (Palisano et al., 1997)

Manual Ability Classification System (Eliasson et al., 2006)

Viking Scale (Pennington et al., 2010)

Communication Function Classification System (Hidecker et al., 2011)

Gross motor function measure (Russell et al., 2013)

PEDI parts II and III- (Haley et al., 1992)

Assessment results were implemented into ICF Categorical profile (scale 0-4) and ICF Intervention Table (WHO).

**Results** 47% boys, 53 % girls, mean age 11,5 years (SD-1.5) participated. 82% were children with spastic, 15%- dyskinetic, 3%- atactic CP. 82% children had associated vision and/or hearing pathologies, epilepsy. In 53% of cases children had several associated pathologies. 38% had severe CP (GMFCS level IV,V).

## Conclusion

ICF Categorical Profile reflects patient's functioning status, helps to document meaningful habilitation goals and intervention targets.

The ICF Intervention Table provides an overview of assignment of interventions to intervention targets and to the relevant health professionals and family members.

Use of ICF principles and documentation contributes to family centered habilitation by increasing communication in goal-setting.



## **Goal-orientated group intervention for children with Developmental Coordination Disorder (DCD) transitioning to secondary school**

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**Background:** Transition to secondary school is a significant event in a child's life. An unsuccessful transition has long-term consequences on an individual's academic attainment and psychological well-being (West, Sweeting and Young, 2010). Children with developmental coordination disorder (DCD) are often a vulnerable group at school experiencing bullying and other difficulties (Evangelou et al., 2008; Stephenson and Chesson, 2008). It is not yet understood the type of support that might help this population at this key life stage.

**Aim:** To examine whether a group based intervention programme delivered in a concentrated timescale to children with DCD, transitioning to secondary school, improved their satisfaction in achieving specific goals.

**Method:** Single group pre and post test design using secondary data analysis. The setting was a london outpatient paediatric occupational therapy clinic. 10 children with DCD or other co-ordination difficulties (aged 10-11 years) transitioning to secondary school, recruited from clinical records, received over 8.3 hours of occupational therapy on 10 school occupations over one week from a team of experienced paediatric occupational therapists combining motor learning and cognitive strategies.

**Results:** Satisfaction scores on the adapted version of the Canadian Occupational Performance Measure (COPM) significantly improved following intervention (Mdn scores gain post intervention +16.1,  $p < .01$ ). Parents' satisfaction with their child's goal performance were significantly higher than their individual child's ratings (gain in COPM (adapted) satisfaction Mdn scores 21.0 vs. 15.4,  $p < .05$ ).

**Conclusions:** A goal-oriented group intervention focused on transition to secondary school shows potential as an effective intervention method. Further research using adequately powered studies and rigorous methodology is required to provide higher-level support to the intervention's effectiveness.

## **The reliability of the segmental assessment of trunk control (SATCO) in children with cerebral palsy**

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**Background:** Impaired postural control and ability to maintain a sitting position are often seen in children with cerebral palsy (CP). Defining postural trunk control is important in the planning of treatment and to describe changes in response to a given intervention. Previous methods which objectively describe trunk control consider the trunk as a single segment. The SATCo test has been developed for clinical purposes and seeks to estimate the degree of sitting trunk control. Although used in clinical examinations of children with CP, the reliability has not yet been investigated in this population. It is relevant to know whether the reliability differs between mild and severe CP.

**Aim:** The aim of this study was to assess the intrarater interday and interrater interday reliability of the test Segmental Assessment of Trunk Control (SATCo) for children with mild compared to severe cerebral palsy.

**Method:** Children with mild (GMFCS 1, 5-13years, n = 11) and severe CP (GMFCS 5, 3-16years, n = 7) were included. Static, active and reactive control were assessed and scored dichotomously by presence or absence of control at seven different levels in the trunk. Two physiotherapists carried out tests and retests. Wilcoxon Signed-Rank Test, ICC (2.1) and a descriptive measure for absolute reliability were used in the statistical analyses.

**Result:** No systematic differences were found in scores between tests and retests for either group of children and all ICC values were excellent (ICC above 0.9). For children in GMFCS 1 complete agreement varied between 57% (active scores) and 86% (static scores). For children in GMFCS 5 complete agreements were seen in 83% of all static scores and in 100% of all active and reactive scores between raters or between days.

**Conclusion:** Relative reliability is excellent in both groups, but absolute reliability is better in children with severe CP. A few minor modifications could improve the absolute reliability when testing the children with mild CP.

## Reliability of Bimanual Fine Motor Function (BFMF) – an easy-to-use version

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### Background

The Bimanual Fine Motor Function (BFMF) classifies hand function in children with cerebral palsy (CP) at the activity level according to the International Classification of Functioning, Disability and Health, measuring the child's capacity to use each hand separately. BFMF has been found to have good construct and content validity.

### Aim

To investigate intra- and inter-rater reliability of an easy-to-use version of BFMF, for children with CP at Manual Ability Classification System (MACS) levels I-V.

### Method

To facilitate the understanding and applicability of BFMF, a flow chart with explanatory figures and text was added to the original classification.

Children with all CP types were recruited.

Inter-rater reliability testing: One video recording of each child was independently classified by four experienced raters using the BFMF.

Intra-rater reliability testing: After two weeks, the same video recordings were classified by the raters.

Percentage of agreement and weighted Kappa values with 95% confidence intervals (CI) were calculated.

### Results

Of the 79 children, (3-17 years old, 45 boys), 19 had unilateral and 43 bilateral spastic CP, 14 dyskinetic and three children had ataxic CP. In pairwise comparison of the four raters' classification of manual capacity according to the BFMF five levels, the absolute percentage of agreement was 63% to 75%. The weighted Kappa values varied between 0.71 (CI: 0.62-0.81) and 0.82 (CI: 0.75-0.89). The absolute percentage of agreement between assessments by the same rater was 75% to 91%. The weighted Kappa values varied between 0.80 (CI: 0.72 – 0.88) and 0.94 (CI: 0.89-0.98).

**Conclusion:** The easy-to-use version of BFMF has high intra- and inter-rater reliability as a classification of manual capacity, and may be a useful tool for research as well as for clinical use as a supplement to the MACS classification of performance.

## **Concurrent and divergent validity of the Bayley Scales of Infant and Toddler Development, Third edition**

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**Background:** The Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-III) is a comprehensive tool to assess the cognitive, language, motor, social-emotional and adaptive behavioral development. Another frequently used tool to assess gross motor development during the first 18 months is the Alberta Infant Motor Scale (AIMS).

**Aim:** The first aim was to evaluate the concurrent validity of the Bayley-III Gross Motor Scale (GMS) in relation to the AIMS. Secondly, the divergent validity of the other Bayley-III subscales in relation to the AIMS was investigated, as well as the relation between the different Bayley-III subscales. The third aim was to compare the Flemish results to the American norm referenced values.

**Method:** A sample of 122 typically developing Flemish children between birth and 18 months (mean age=8mo27d, SD=5mo3d), born full term was assessed with both scales. Pearson correlation coefficients ( $r$ ) were used to assess validity. To evaluate differences between scores of the Flemish and American children the Mann-Whitney U-test was used.

**Result:** The concurrent validity of the Bayley-III GMS and the AIMS was very high ( $r = 0.98$ ) and coefficients above 0.89 were found for the comparison between the Bayley-III and the AIMS scores in prone, supine, sitting and standing. Additionally, high correlations between the other Bayley-III subscales and the AIMS were found ( $r \geq 0.84$ ), which confirmed a lack of divergent validity. The Bayley-III also showed high correlations between subscales ( $r \geq 0.83$ ). Finally, Flemish children scored significantly lower on the language and gross motor subscales compared to American children.

**Conclusion:** This study provides support for the concurrent validity of the Bayley-III GMS. However, the Bayley-III scales did not differentiate between the different developmental domains in children younger than 18 months. This study also demonstrates the importance of region-specific norms to allow adequate interpretation of results.

## Assisted participation in adolescent's everyday life

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### Background

According to Swedish disability policy, all people, regardless of their functional abilities, should have the same opportunities to participate in society and take part of human rights (LSS, 1994). The World Health Organization (WHO) defines participation as "a person's involvement in a life situation". Personal assistance has resulted in improved quality of life (National Board of Health, 2015). Access to personal assistance presents both opportunities and obstacles to participation, (Barron, 1997, Skär & Tamm, 2001, Hultman et. al, 2015). We need to find out more about in what situations children and adolescents want to participate and clarify the options available for them to be involved in.

### Aim

To explore how access to personal assistance affect adolescents possibilities to participate in different contexts.

### Method

35 individual interviews with 16 Swedish adolescents between 16-21 years. The adolescents had different types of physical disabilities, such as; CP, muscular diseases and acquired brain injury. Interviews were analyzed according to grounded theory methodology.

### Results

The adolescents' experience of participation varied depending on the context, the adolescents' age and the variety of available activities. Participation often required a high degree of organization and was dependent on access to personal assistance. When parents were personal assistants participation could be hindered by role conflicts related to the child/ parent relation. Emotional barriers to participation was ascribed to other peoples' discriminating attitudes and adolescents own acceptance of the disability. It was easier to come to terms with barriers related to "doing" than barriers related to "being".

### Conclusion

Participation is a complex issue and both objective and subjective experiences must be taken into account in order to understand how participation is perceived.

## **Adaptation, Reliability and the Validity Testing of a Turkish Version of the Short Child Occupational Profile (SCOPE)**

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**Background:** Increasing participation level is one of the most important aim of pediatric rehabilitation.

**Aim:** The aim of this study was to translate the Short Child Occupational Profile (SCOPE) to Turkish and evaluate the validity and the reliability of the Turkish version in children.

**Method:** SCOPE was translated into Turkish by using appropriate translation steps. Data, including demographic variables and scores on the SCOPE were recorded from 301 children with different diagnosis and 63 normal developing peers. For reliability analysis, internal consistency and test-retest method were used. The Cronbach's alpha coefficient and item-total statistics were calculated. For validity analysis, T test, Wilcoxon test, one-way ANOVA test, Chi square test and factor analysis were used.

**Result:** Children ranged in age from 25 months to 254 months and 50.4% were female and 49.6%. For internal consistency, Cronbach's alpha coefficients of all factors ranged between 0.944 and 0.948 and were calculated as 0.947 for the overall. In test-retest reliability, the correlation coefficient ranged between 0.566 and 0.975 for each question and were calculated as  $r=0.921$  for the SCOPE score ( $p<0.001$ ). For validity; SCOPE scores of the children with diagnosis were statistically different from the normal developing peers ( $p<0,001$ ). According to factor analysis six factors explains 79.28% of the variance.

**Conclusion:** Results supports an acceptable reliability and validity of Turkish version of the SCOPE for use in reseach and clinical purposes. Turkish version of SCOPE offers occupational therapists a valid and reliable measure of volition, habituation, communication/interaction skills, motor skills and environmental influences on occupational participation of the children.

## **The role of knowledge brokers in a virtual learning context: a descriptive case study in paediatric physiotherapy**

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**Background:** Knowledge transfer (KT) to improve interventions for children with childhood disabilities and facilitate evidence uptake into clinical practice remains a challenge. The use of knowledge brokers (KB) is reported as an effective KT strategy. The success relies on KB's ability to adapt to stakeholders' changing needs, whether clinical, organisational or discipline specific. KB's have been studied in clinical settings, but not in emerging virtual environments fostering KT. Therefore, it is essential to understand the KB role in these contexts.

**Aim:** The objective of this study is to describe the role of, and the strategies used by four KB's involved in a virtual community of practice (vCOP) for paediatric physiotherapists aimed at improving their practice with children with Development Coordination Disorder.

**Methods:** This study used a descriptive case study design. The postings published by the KB's on the vCOP were analysed for repetitive patterns. The PARIHS (Promoting Implementation in Health Services) model and andragogical theories guided the theming and interpretation of the posting excerpts.

**Results:** Ninety-five posts were analysed. Three roles emerged: 1) Context Architect, promoting a respectful learning environment, 2) Knowledge Sharing Promoter, building capacity, 3) Evidence and Clinical Application Facilitator, linking research and practice change. The strategies used reflected invitational, constructivism and connectivism teaching theories. The roles and the primary strategies utilised changed over time. A decrease in the Environment Architect role while an increase in Clinical Application Facilitator role were observed.

**Conclusion:** This study describes the roles, their evolution and the strategies used by KB's in a virtual learning context. These results provide an initial description of a role that could hold promise in facilitating knowledge implementation and ultimately leading to improved care for children with childhood disabilities.

## Ontogenesis of Visuospatial Attention in Typically Developing Children

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**Background:** Visuospatial neglect is a common and well documented condition following brain lesion. Over the past decades, several tests have been developed for diagnostic use in adult subjects and subsequently applied for research purposes. Though children with brain lesions are likely to develop visuospatial attention deficits, the ontogenesis of diagnostic tests for visuospatial neglect developed for adult subjects has never been studied and normative data for children are not available till now. Visuospatial attention has attracted increasing interest in different pediatric pathologies such as attention-deficit-hyperactivity disorder and cerebral palsy. Therefore, normative values are needed in typically developing children.

**Aim:** The aim of the present study was to investigate the ontogenesis of visuospatial attention in typically developing children and to create normative values for children in six tests used to diagnose visuospatial neglect: star cancellation, Ogden figure, reading test, line bisection, proprioceptive pointing and visuo-proprioceptive pointing.

**Method:** A hundred and thirty-four typically developing children between 4 and 19 years old from 4 different schools of the Fédération Wallonie Bruxelles participated in this study.

**Results:** The results showed that the performance on star cancellation, Ogden figure and reading test improved until the age of 10 whereas performance on the proprioceptive pointing, visuo-proprioceptive pointing and line bisection did not appear to evolve with age.

**Conclusion:** These data suggest that different neural networks with different maturation velocities could be required to perform different types of visuospatial tasks. In future research, the described normative values could be used to study visuospatial deficits in children with pathological conditions.



## **Impairments of Visuospatial Attention in Children with Unilateral Cerebral Palsy**

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**Background:** Cerebral palsy occurs in 2 to 3.6 out of 1000 children. Various motor impairments may be observed, depending on the timing, extent and location of the lesions and the subsequent reorganization of the descending motor pathways. While the disorders are characterized as mainly motor, some associated symptoms may be present, including somatosensory symptoms. The role of sensory abilities is mainly to provide feedback in order to optimize motor learning and control. In children with CP, sensory feedback is largely abnormal, and thus vision plays a crucial role for compensation during motor control and learning new motor behaviours, i.e., new functional motor abilities. However, visual feedback may be difficult to interpret and/or to integrate due to problems of visual attention to the paretic hemibody. Visuospatial attention is seldomly studied in children with unilateral cerebral palsy (UCP). A better understanding of visuospatial attention deficits in children with UCP may lead to the adaptation of rehabilitation tools according to these deficits.

**Aim:** The aim of the present study was to assess the prevalence of visuospatial attention deficits in children with UCP.

**Method:** Eighty-five children with UCP were assessed with six tests; a star cancellation test, an Ogden figure copy, a reading test, a line bisection test, a proprioceptive test and a visuo-proprioceptive test.

**Results:** 75% of children with UCP presented a deficit in at least one test compared to typically developing (TD) children.

**Conclusion:** In our sample, the majority of children with UCP (75%) presented with a deficit of visuospatial attention compared to TD controls. The present results shed new light on the interpretation of motor impairments in children with UCP. Future studies should include an ophthalmological examination to exclude underlying anatomical impairments of vision.

## **Mirror movements during repetitive squeezing: a quantitative approach in children with unilateral cerebral palsy**

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### **Background**

Mirror movements (MM) are a physiological feature in young children and gradually disappear during the first decade of life. However, children with unilateral cerebral palsy (UCP) often present with more pronounced MM.

### **Aim**

To date, studies have mostly used a simple ordinal rating scale to assess MM (Woods & Teuber 1978). We propose a quantitative assessment based on a unimanual repetitive squeezing task with whole-hand grip force measurements.

### **Method**

We assessed 10 children with UCP (age 7-12 years, MACS level I to III). During the squeezing task, forces were simultaneously recorded from both hands using custom handles. Children were instructed to launch a spaceman over a meteorite by repetitively squeezing one of the handles during 3 x 30 sec at a frequency of 0.67Hz (total of 60 squeezes, minimum force 15% of the maximum voluntary contraction (MVC)). A child was considered to display MM if peak forces in the non-active hand greater than 15% MVC were identified on more than 10% of squeezes performed with the active hand.

### **Result**

Eight children showed MM in the paretic hand during squeezing with the non-paretic hand. Frequency of mirrored squeezes ranged from 45 to 100% of the number of squeezes of the active non-paretic hand (27-60 vs. 56-60); the magnitude of mirrored peak forces (scaled to MVC) was highly variable and ranged from 44 to 195% of the peak forces produced by the active non-paretic hand. A cross-correlation between force profiles of both hands indicated a highly similar pattern of force production ( $r_{\text{cross}} = 0.81$ ), with MM occurring at a mean delay of 30 msec. Performing the squeezing task with the paretic hand only elicited MM in the non-paretic hand in 3 children in 27 to 79% of the squeezes performed with the active paretic hand.

### **Conclusion**

We present a clinically feasible measurement to quantify MM in children with UCP on a continuous scale, allowing for a more sensitive and precise assessment compared to ordinal ratings.

## Five Pairs of Twins with Autistic Spectrum Disorder

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### BACKGROUND

Genetics plays an important role in the aetiology of autistic spectrum disorder (ASD). The risk of ASD in siblings of children with ASD is up to 200 times the general population rate.

### AIM

The aim of the study was to analyse clinical features in twins with ASD from our outpatient office.

### PATIENTS AND METHOD

Medical files of five pairs of twins with diagnosed ASD were analysed. We searched for their family history, gestational age, complications during pregnancy, developmental milestones, results of diagnostic tests and therapy

### RESULTS

All participants were boys, aged from 6 years 5 months to 8 years 9 months (mean age 7 years 5 months).

There was a male sibling with ASD and global developmental delay in one family and another one with some problems in social contact. The other siblings (2 girls and 2 boys) were healthy.

All except one pair were premature (from 30- 35 weeks of gestational age). There was hyperbilirubinemia in three pairs.

Psychomotor development was delayed in all the participants.

EEG changes were found in one pair of siblings and antiepileptic drug (lamotrigine) was introduced. EEG was normal in three pairs of siblings.

Among comorbidities there was Down syndrome diagnosed in one pair of twins, attention-deficit/hyperactivity disorder (ADHD) in three participants and thyroid disorder in one participant.

Magnetic resonance head imaging was performed in two participants and was normal.

All children had severe learning disability.

### CONCLUSION

The concordance rate of ASD as well as pervasive developmental disorders is higher in some families. Further studies including more participants with additional investigations are planned for future.

## Gross motor function in children after perinatal ischemic stroke.

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**Background.** Perinatal stroke (PS) may cause lifelong motor and functional impairments. There is little information about how these children function in their daily lives. There are plenty of studies on hemiparetic hand function, but less is known about the gross motor functioning.

**Aim.** To assess the gross motor functioning of children with perinatal stroke and its influence on everyday movement.

**Methods.** Patients were from Estonian Pediatric Stroke Database. The diagnosis of perinatal ischemic stroke was confirmed by neuroradiological studies. The study included 26 term born children with perinatal stroke - 8 with neonatal stroke (NS), 18 with presumed perinatal stroke (PPS). All children had unilateral sensorimotor deficit i.e. hemiparesis (right-sided in 18 cases): mild in 6, moderate in 15 and severe in 5 cases. Gross motor ability and everyday functional ability were assessed with Gross Motor Function Classification System (GMFCS) and Gross Motor Function Measure (GMFM-66). Median age was 10.5 years, range: 2.0 to 17.4 yrs.

**Results.** GMFCS was in level I in all children. The mean GMFM score was 90.61 (SD±11.36). Children with NS had lower mean GMFM scores (87.67) compared to children with PPS (93.36). Most problematic exercises were standing and jumping on paretic leg or high on both feet (mean scores 2.4, 2.0 and 2.6 respectively). Standing and jumping on paretic foot was worse in children with left than with right hemiparesis (2.0 vs 2.6, P<0.01 and 1.6 vs 2.1, P=0.26). The degree of sensorimotor deficit did not differ between left- versus right hemiparesis groups (P=0.85). Children with NS had lower scores in jumping high on both feet than children with PPS (2.5 vs 2.2, P=0.01).

**Conclusions.** Children after PS scored near GMFM-66 age-equivalent normative mean scores. As the paretic foot function is limited, difficulties occur in exercises where speed and good coordination are needed.

This study was supported by the Estonian Research Council grant PUT (148).

## **Associations between manual dexterity scores from the M-ABC 2 and kinematic properties of goal-directed upper-limb movements and in school-aged children born preterm**

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### **Background**

Children born preterm (PT; (<38 gestational weeks, GW) are frequently reported to have deviations in motor proficiency. Most studies use standardized test batteries to determine motor function in these children. Few studies have however examined the relations between test battery outcomes and outcomes from more detailed movement analysis.

### **Aim**

To investigate associations between outcomes on the manual dexterity subtests from the Movement-ABC 2 with detailed 3D kinematic registrations during performance of a sensorimotor task with demands on fine motor skills and precision in school-aged children born PT and a comparison group born at full-term (FT).

### **Methods**

As part of an ongoing quasi-longitudinal study, 7-8 year old children born PT (< 36 GW; n = 17) and an aged matched typically developing comparison group (n = 19) performed the M-ABC 2 and a fine motor task where 3D kinematic registration technique was applied. M-ABC 2 scaled scores from the manual dexterity index (MDI) were correlated with kinematic parameters sensitive to planning and on-line control (movement units, distance and speed). Differences between the PT and FT group were also analyzed.

### **Results**

Preliminary analyses show no group differences on the outcomes from the 3D kinematic analyses but differences were evident on two (peg-board and follow-track) of the subtests constituting the MDI and the MDI where children born PT have lower scores than FT. For both groups but, within-group correlations show some associations between extracted kinematic properties and dexterity outcomes (follow track within PT; peg-board within FT).

### **Conclusions**

As the groups differed on the MDI outcomes it is surprising that none were found on the kinematic properties examined. Further, relatively few associations were found between the kinematic and M-ABC 2 outcomes. Investigation of the influence cognitive and executive functions have on these performances may offer explanations for this inconsistency.

## **Change in gross motor function in preschool children with cerebral palsy (CP) participating in a Norwegian intensified habilitation program.**

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### **Background**

Program Intensified Habilitation (PIH) is a one year multidisciplinary and family-centered program for preschool children with cerebral palsy (CP). Focus on gross motor function is central in the program.

### **Aim**

To evaluate whether the participating children have a change in gross motor function after finishing PIH. To examine any differences in motor outcome according to Gross Motor Function Classification System (GMFCS) levels and ambulatory versus non ambulatory children.

### **Method**

Thirty-four children aged 2-5 years with CP of all GMFCS levels participated in this prospective non-randomized study. Gross Motor Function Measure 66 (GMFM-66) was employed and calculation of GMFCS percentile was performed at the start and at the end of the program. We used Gross Motor Ability Estimator (GMAE) and descriptive statistics to present the results.

### **Results**

Sixteen children (47%) showed significant change in GMFM-66 score. A positive change in GMFCS percentile was reported for 22 children (65%), of which 16 showed an increase of more than 10. Nine children had decreased in GMFCS percentiles of which seven showed a decrease of more than 10. Three children had no change in GMFCS percentile. A large variability in change score and percentile change is shown in children at level I(11) and V(8). The 18 ambulatory children presented a larger change in mean GMFM-66 score and GMFCS percentile than the 16 children in the non-ambulatory group.

### **Conclusion**

This study implies that the PIH program has a positive impact on gross motor function for most of the participating children although the group as a whole shows great variation.

## **A tool for a multiprofessional team to unite the goals of habilitation and education**

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**Background:** Our research (Häyrynen 2014) has showed that the function of the school aged children with a physical disability can be viewed through participation, learning and environmental factors. It is well known that the days of children with physical disabilities include not only school and hobbies but also habilitation and different treatments. There is often lack of time because the active functioning and e.g. the postural care needs take time. The child, his/her parents and the multi-professional team should have the common understanding about the functioning and things which effect on it. Also they should have common goals of habilitation, assistance and learning. This is the way to create a well-functioning school day which also makes the participation possible. In Valteri school we have developed a model which links the functioning (CY-ICF) to the key competencies of lifelong learning.

**Method:** The concepts of functioning in the key competencies of lifelong learning were contextualized with content analysis and linked in CY-ICF.

**Result:** As a tool for a multiprofessional team there is a table which shows ICF categories linked in the key competencies of lifelong learning; that makes the child's functioning visible.

**Conclusion:** It is possible to set common goals for learning, habilitation and assistance in the framework of functioning.

## **Cross-Cultural Adaptation and Translation of the Paediatric Evaluation Disability Inventory (PEDI) in Uganda.**

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### **Background:**

The Paediatric Evaluation of Disability Inventory (PEDI) clinical assessment tool was developed and standardized to measure functional performance for typically developing American children. Currently there has been no published study of the use of the PEDI in sub Saharan Africa.

### **Aim:**

To develop a more culturally relevant PEDI and describe the process of its adaptation and translation in Uganda.

### **Method:**

The translation and transcultural adaptation of the PEDI was performed in nine steps in accordance with international guidelines, using a series of technical advisory group (TAG) meetings. The adapted PEDI was pilot tested on 75 caregivers of children aged 6 months to 7.5 years. A series of in depth interviews were held with 10 caregivers to provide feedback on the questions. Ambiguous terms were clarified, culturally inappropriate items modified and new items generated.

### **Result:**

Three field versions of an adapted PEDI were developed and pilot-tested before the face and content validity of the final PEDI was established. Revisions made included: deletion of irrelevant items; insertion of new items; modification in the wording of some items; provision of alternative questions and the use of local examples. Overall, 7 new questions were inserted, 10 alternative questions created and 19 questions deleted implying that 178 of the original 197 items (90%) were retained in the final 185 items PEDI-UG.

### **Conclusion:**

On the whole the PEDI is appropriate in the African context with a number of adaptable items, however some are culturally inappropriate. The PEDI-UG thus offers a linguistically valid instrument for the measure of functional performance of typically developing children with the potential to evaluate the outcome of rehabilitative procedures in patients with developmental disabilities in the African context. We have proposed a few adjustments to improve its clarity and will conduct psychometric analysis for its further evaluation.



## **Supported standing programs in pre-school children with Cerebral Palsy: Could we do it any better?**

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### **Background**

Supported standing programs (SSP) have been widely used in children with Cerebral Palsy (CP) over several decades, yet there is limited evidence to show how they should be implemented optimally.

### **Aim**

To explore the current use of SSP for pre-school children with CP by British paediatric physiotherapists in order to identify implications for research and practice.

### **Method**

An electronic questionnaire was developed, piloted and distributed in June 2015. Data was transferred to SPSS and analysed using descriptive and inferential statistics.

### **Results**

298 questionnaires were returned of which 276 were suitable for analysis. Over 70% of respondents worked in the community and had >10 years of experience. The majority relied on clinical experience in implementing SSP, rather than guidelines or research, citing lack of quality evidence and unawareness of guidelines as main reasons.

Choice of standing frame (stander) and age at commencing SSP was primarily influenced by clinical experience in >96% of respondents. Half commenced SSP according to chronological age (9-10months) and half according to developmental milestones, despite the latter potentially increasing risk of hip dysplasia in children with severe CP.

Over 94% agreed SSP would improve social interaction. However, most preferred static-standers than mobile-standers. Most (83%) agreed SSP facilitates hip development, yet straddle-weight-bearing was the least preferred option (2.9%), despite it is shown to improve hip stability.

### **Conclusions**

Discrepancies were found between the therapists' perceptions and their clinical practice. This may be due to therapists' reliance on experience in decision-making, rather than evidence. Therapists recognized the need for further guidelines. "Experience-based practice" may not facilitate the safest, most efficient and beneficial outcomes and provide satisfactory justifications for the funders. Could we do this any better?

## Effects of respiratory distress syndrom in preterm infants at the corrected 12 months of age

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**Background:** Respiratory distress syndrome (RDS) is the most important morbidity associated with prematurity and despite to the developments in the field of neonatal care, it is still the leading cause of mortality. The developmental insufficiency of pulmonary surfactant synthesis and structural immaturity causes RDS.

**Aim:** The aim of this study was to investigate the effects of RDS on the development of preterm infants at the corrected 12 months of age.

**Method:** Twenty-two preterm infants whose gestational age was <37 weeks and birth weight under 2500 g in the neonatal intensive care unit were included in the study. There were 10 infants with RDS and 12 without RDS. At the corrected 12 months of age, motor development was assessed by Gross Motor Function Measurement (GMFM) and Bayley III Scale was used to assess motor, cognitive and language development. Student's t test were used to comparison the results of GMFM and Bayley III. Differences with a p value <0.05 were considered to be statistically significant.

**Results:** The results of GMFM and Bayley III were compared between preterm infants with and without RDS, no significant differences were found on GMFM (total p=0,706) and Bayley III scores (cognitive p=0.645, language p=0.993, motor p=0.597).

**Conclusion:** There were limited number of studies in literature that investigates the effects of RDS in long term. In our study the test results were compared to examine the effects of RDS on motor, language and cognitive development, statistically significant differences were not found on the results of GMFM and Bayley III. Consequently, RDS has been shown to not affect in cases negatively in the present study.

## THE RELATIONSHIP BETWEEN DEMOGRAPHIC CHARACTERISTICS OF PRETERM INFANTS AND A DETAILED ASSESSMENT OF FIDGETY MOVEMENTS

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**Background:** The general movement assessment (GMA) method is used to predict cerebral palsy in infants with high risk of developing neurological dysfunctions. Fidgety movements period is highly predictive for cerebral palsy in the Prechtl classification system for GMA. A detailed assessment of Fidgety Movements (FMs) estimated value was chosen because the predicted value of movements is expected to be high.

**Aim:** We aim to learn the relationship between FMs and demographic characteristics of preterm infants, which are corrected age; duration of intensive care unit; and mothers' ages.

**Method:** Demographic datas of 31 infants without neurological, genetic or metabolic problems and their mothers were recorded. Corrected age of infants have been calculated, postterm 12-15 week video recordings were taken for evaluation FMs and detailed FMs scoring were made. We investigated the relationship between demographic characteristics and FMs results.

**Result:** Nine (29%) extremely, 22 (71%) moderate of 31 preterm infants were included. While the average of gestational age  $32.66 \pm 3.20$  weeks, the birth weight  $1836.69 \pm 700.24$  grams, the duration of stay in intensive care unit  $24.44 \pm 22.46$  days and average age of mothers  $30.10 \pm 6.92$  years were recorded; FMs average score was  $26.16 \pm 1.83$ . There was no statistically significant difference between FMs score and gestational age, duration of in intensive care unit of the infant and the mother age ( $p > 0.05$ ).

**Conclusion:** There was no association with detailed assessment of FMs results and gestational age, duration of stay in intensive care unit and mothers' age. We believe that what results in more work to be classified according to their gestational age of preterm infants will be achieved.

## Unifying multiprofessional evaluation in clinical practice: CP as an example

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**Background:** In order to be able to evaluate real-time effectiveness of various interventions in childhood-onset disabilities or to conduct clinical studies a common core set of valid and reliable outcome measures is needed/required. However, a diversity of used/applied outcome measures is often a reality in clinical practice. Both a wide variety of outcome measures and content of intervention have been identified between the various multiprofessional neurodevelopmental teams in Finland.

**Aim:** To identify valid and reliable outcome measures for children with CP that are sensitive for change and clinically feasible.

**Method:** The project was conducted in a multiprofessional co-operation. A step-wise process included identification of the possible outcome measures, testing their clinical feasibility, implementation into clinical practice and dissemination with continuous evaluation to new hospitals and national Learning and Consulting Centres. At each step both barriers and facilitators were identified and they were carefully scrutinized before proceeding to the next step.

**Results:** After 6 years of comprehensive and determined work, a national recommendation on how to measure the functioning of children with CP was finished in 2014. It will be published in the national TOIMIA network which provides recommendations and valid measurement tools via an open access database. TOIMIA network was created in Finland in 2007 based on a broad collaboration of partners in research and clinical institutions in order to harmonize the measurement and terminology.

**Conclusions:** Unifying national clinical practice in the use of multiprofessional outcome measures is possible but requires a collaborative network and long-span effort. Training and commitment of the whole team working with children with CP is necessary. Everyone has to consider their practice and be ready to exercise new tools based on the International Classification of Functioning, Disability and Health (ICF).

**Muscle fatigue during isometric grip tasks in adolescents with unilateral cerebral palsy**

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**BACKGROUND** Distal muscle strength is known to be a major determinant of both unimanual capacity and bimanual performance in children with unilateral cerebral palsy (CP). The impact of muscle fatigue is far less known, although it can be hypothesized that it plays a crucial role in everyday tasks.

**AIM** The aim was to compare muscle fatigue during a sustained maximal grip contraction between adolescents with unilateral CP and typically developing (TD) adolescents.

**METHOD** Twenty-three adolescents with CP (11 males, 12 females; mean age 14y (SD 1.4y), 11-17y; Manual Ability Classification System, MACS levels 1-3) and 23 sex and age matched TD adolescents were included. Muscle fatigue was measured during a 30 second maximal isometric contraction in both hands in two grip positions: hand grip and pinch grip with a digital Jamar dynamometer. Muscle fatigue was analysed with the static fatigue index (SFI), based on the time-strength curve where the actual area under the curve is compared with the hypothetical area under the curve if maximal strength was constant. Anthropometric variables included weight, length and hand length.

**RESULT** For both hand and pinch grip, the SFI was significantly higher in the CP group compared to the TD group in both hands ( $p < 0.0001$ ). Within the CP group, the SFI of the affected hand was significantly higher compared to the non-affected hand for the pinch grip ( $p = 0.02$ ). No significant differences were found in SFI between the MACS levels. Only in the TD group, significant correlations were found between SFI and age, weight and hand length ( $r = -0.44$  to  $r = -0.61$ ).

**CONCLUSION** Adolescents with unilateral CP showed more muscle fatigue compared to TD adolescents during a 30 seconds isometric hand grip and pinch grip contraction. These results offer interesting insights in the phenomenon of muscle fatigue in CP.

## **Longitudinal resting-state changes after sub-acute arterial ischemic stroke in a seven-year-old boy**

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**Background/aim:** Data on reorganizational patterns in resting-state brain networks of children after an arterial ischemic (AIS) stroke is rare when compared to adults. We therefore examined changes in resting-state activity of a seven-year-old boy with a small right-sided, periventricular lesion one, four and seven months post-stroke and related them to neuropsychological and neurological performance.

**Methods/design:** Because of acute hemiparetic and speech symptoms, resting-state activity of the ipsilesional precentral gyrus (rPCG) and pars triangularis (rPT) were investigated. MR images were acquired using a 3T scanner. High-resolution T1-weighted MR structural images and functional imaging were performed. Conn toolbox 15 was used to descriptively compare resting-state-activity. One and seven months post-stroke, a neurological and a neuropsychological examination were performed.

**Results:** One month post-stroke, activation is bilateral in the rPCG and unilateral in the rPT. Four months post-stroke, right-sided pronounced activation occurs in the rPCG, the rPT is bilaterally activated. Seven months post-stroke, the activation becomes more widespread. The rPCG reveals a pronounced right-sided and the rPT a bilateral activation. Clinically, the boy showed normal neuropsychological and neurological performance at one and seven months post-stroke.

**Conclusions:** The results suggest that in the child's brain, dynamic reorganization processes in resting-state-activity occur, supporting clinical recovering before resting-state connectivity returns to normal. Resting-state activity becomes more widespread over time. The child's brain might use contralateral support during reorganization in order to improve clinical function on the lesion side. The present results are based on one single case only, but may serve as an important indicator for function-preserving changes in the pediatric brain connectivity after stroke.

## **Cognitive impairment in children with cerebral palsy and relation to neonatal factors and motor outcome**

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**Background:** Cognitive impairment is frequent in cerebral palsy (CP) and it can be related to motor outcome and both to degree of perinatal lesion.

The aim of study was to analyze frequency of cognitive impairment in Croatian SCPE Register and explore relationship between cognitive and motor outcome and neonatal factors.

**Method:** Data of 165 children with CP, collected in Croatian register from 2004-2006 were analyzed. For the purpose of this study, subjects were classified in 3 intellectual level groups (group 1 IQ level <50, group 2 with IQ 50-69 and group 3, IQ ≥ 70). GMFCS, BFMF, neonatal (gestational age, birthweight, Apgar, ventilation) and clinical variables (CP type, MRI, epilepsy) were analyzed.

**Results:** There were 33% of children in lowest intellectual group 1 (IQ <50), 21% in impairment group 2 (IQ 50-69) and 46% in group 3 (IQ ≥ 70). We found significant difference between all 3 groups in GMFCS and BFMF – better cognitive groups having better gross and fine motor results.

Frequency of ventilation differed significantly - highest frequency of ventilation in lowest IQ group 1 and lowest in group 3. Epilepsia was significantly highest in lowest IQ group 1. In spastic bilateral subtype, there were significantly more severely cognitively impaired children than among spastic unilateral (who had higher cognitive levels). Apgar score was significantly lower in group 1 than group 3. There were no difference in sex, gestational age, birthweight and frequency of white and gray matter injury.

**Conclusion:** Cognitive impairment is related to fine and gross motor outcome. We previously proposed that damage to central cortico-cortical pathways in periventricular white matter can explain concomitant motor, cognitive and sensory deficits in CP. Frequency of ventilation, epilepsy and CP subtype differed across different cognitive level groups. In practice and future research, cognitive functions in CP should be more precisely assessed.

## Comparison of videofluoroscopic findings and clinical symptoms of pediatric dysphagia

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### Background

Children shows various types of feeding problem. The clinical manifestation and results can be somewhat different from adults.

### Aim

To document VFSS findings of children with swallowing problem and to find the association with clinical symptoms in children with feeding and swallowing difficulty

### Method

Medical records of 41 pediatric patients (25 males, 16 females) who had taken videofluoroscopic swallowing study (VFSS) at Chungnam national university hospital from January 2013 to May 2015 were reviewed retrospectively. Chi-square test and univariate analysis methods were used to find the relevance between the videofluoroscopic findings and clinical symptoms.

### Results

The main causes for VFSS were aspiration symptom (34.1%), swallowing difficulty (17.1%), oromotor dysfunction(17.1%), poor oral intake (14.6%), decreased oxygen saturation during feeding (12.2%). The most prevalent underlying medical condition was brain disease (n=19, 46.3%) and 13 subjects (31.7%) had various genetic diseases and 4 subjects (9.8%) had anatomical structural abnormalities. At VFSS, 27 children (65.9%) showed abnormal findings at least one of swallowing phases but there were no abnormal findings in 14 children (34.1%). Patients having brain diseases showed 15(71.4%) impaired pharyngeal phases, 5(23.8%) impaired oral phases and 1(4.8%) abnormal esophageal phase.

As we underwent chi-square analyses to identify factors associated with swallowing problem, gestational age, body weight, cause of referral to VFSS, diet status were not significantly associated with penetration or aspiration.

### Conclusions

Children with feeding problem may have various impairments of swallowing process and there may be some differences between clinical symptoms and VFSS findings. Therefore, prior to treatment for dysphagia, it is desirable to evaluate appropriately through VFSS and to establish treatment plan.



## Prediction of cognitive outcome at two years of age by using DTI in preterm infants

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**Background:** Magnetic resonance imaging (MRI) and ultrasound at term equivalent age (TEA) have been used as predictors for neurological outcome of the preterm infants. Diffusion tensor imaging (DTI), a quantitative MRI technique focusing on the white matter tracts in the brain, has been suggested to be a future biomarker for motor outcome and cognitive development including visual performance.

**Aim:** To study the correlation between DTI at TEA and the cognitive outcome at 2 years of corrected age in a cohort of very low birth weight infants (VLBW).

**Method:** This study includes the very low birth weight infants born in Turku University Hospital in 2004-2006 and is a part of a larger follow-up study (the Development and Functioning in Very Low Birth Weight Infants from Infancy to School Age, PIPARI study). The infants with birth weight (BW) <1,501 g, as well as all infants with a gestational age <32 weeks regardless of the BW were included.

Imaging was performed on a 1.5-T MRI system. FA and MD values were measured using manually drawn regions-of-interest (ROI). At two years of corrected age cognitive development was assessed using the Mental Development Index (MDI) of Bayley Scales of Infant Development (BSID-II).

**Results:** A total of 61 preterm infants were included. The FA-values of optic radiation (OR) (right side 0.35 [SD 0.05], left 0.36 [SD 0.06]) were significantly related to the variation of the MDI even after controlling with the degree of the brain pathology, birth weight, gestational age and the parental level of education: right  $p=0.021$  ( $b=7.3$ ,  $SE=3.1$ ) and left  $p=0.034$  ( $b=6.0$ ,  $SE=2.8$ ).

**Conclusion:** This study shows that the ROI acquired FA values of the optic radiations are associated with the cognitive outcome at 2 years of corrected age in a cohort of VLBW infants. The result is likely to reflect the association between the myelination of not only in the optic radiation but also in more general associative networks.

## Basic course in sequential oral sensory approach to feeding (SOS)

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The SOS approach to feeding course is held in both Denmark and Sweden in 2016:  
Middelfart 20.-23/09  
Uppsala 26.-29/09

The SOS Approach uses a multidisciplinary team approach which assesses the “whole child”: organ systems, muscles, development, sensory, oral-motor, learning/behavior, cognition, nutrition and environment.

The program is an effective way to address problematic feeding behaviors in a variety of settings and populations.

Parents and caregivers of children who will not eat are faced with a difficult and often puzzling challenge. Because the interplay between weight gain and a child's experience of food can be complicated, there is rarely an easy solution when a feeding problem arises.

The SOS Approach focuses on increasing a child's comfort level by exploring and learning about the different properties of food.

It allows a child to interact with food in a playful, non-stressful way, beginning with the ability to tolerate the food in the room and in front of him/her; then moving on to touching, kissing, and eventually tasting and eating foods.

Lecturers:

Kay Toomey, PhD, Pediatric psychologist, director at SOS Feeding Solutions at STAR Center.  
Erin Ross, PhD, Speech-Language Pathologist and Infant Feeding Specialist.

Learning Objectives for the workshop:

1. Identify oral, sensory, motor, cognitive and emotional developmental milestones key to feeding
2. Recognize and describe the major reasons why children won't eat, as based on learning theory principles
3. Identify physical, behavioral, motor, oral-motor, and sensory factors as a part of a Feeding Assessment
4. Apply behavioral and social learning principles, and systematic desensitization, to feeding problems
5. Create and implement a S.O.S feeding program for toddlers and young children, in group and individual treatment formats
6. Identify adaptations to the SOS approach for special populations

## **Sensory-motor function in children with bilateral spastic cerebral palsy in relation to standing ability with or without support**

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**Background:** Standing arms free may be difficult for children with bilateral spastic cerebral palsy (BSCP). Besides compensating for contractures, muscle weakness and spasticity, standing without support requires a continuous interaction between the sensory systems to control body position in space.

**Aim:** To explore gross motor function in children with BSCP with respect to standing ability.

**Method:** Thirty-six children with BSCP, GMFCS level I-IV (mean age  $11.5 \pm 3.0$  years); 17 required support for standing (SwS), and 19 stood without support (SwoS), participated in the study. Gross motor function measure (GMFM-88) was assessed and time to complete the Timed Up and Go test (TUG) was recorded. Independent t-test was used to compare groups.

**Result:** Children SwS compared to SwoS had lower GMFM total mean score (65.1 vs 87.8,  $p < 0.001$ ) and lower dimension mean score for E: walking, running and jumping (20.9 vs 72.3,  $p < 0.001$ ), and D: standing (36.7 vs 82.2,  $p < 0.001$ ), but not for C: crawling and kneeling (79.8 vs 90.1,  $p = 0.181$ ), B: sitting (92.5 vs 97.6,  $p = 0.065$ ) or A: lying and rolling (96.4 vs 96.9,  $p = 0.690$ ). Additionally, while performing the TUG the children SwS required longer mean time (30.3s vs 12.2s,  $p < 0.001$ ).

**Conclusion:** With the GMFM, items performed in a lying, crawling and sitting position (dimensions A-C) were similarly scored among the children despite their various standing abilities. In the dimensions requiring an upright position on the feet (D, E), GMFM scores in children in SwS were lower. Difficulties performing motor tasks in positions requiring weight bearing may be due to the motor disorder, but also due to challenging of the somatosensory system. Perceptual disturbances with difficulties interpreting gravity as a reference frame may reflect the inability to maintain standing arms free in the children in SwS. Most children in SwS required a walker when performing the TUG, which also indicates difficulties with spatial body perception.

## NEEDS OF ENVIRONMENTAL ADJUSTMENTS FOR STUDENTS WITH COGNITIVE DISABILITIES IN UPPER SECONDARY SCHOOL

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**Background:** Students with disabilities are overrepresented among young people who do not graduate upper secondary education and they are thus also at high risk of being excluded from the labor market. The present study is the first part in a Swedish intervention project focusing on individualized information and communication technology as a feature in the school environment to support the students to complete their studies. In this study the student-environment fit, i.e. the fit between demands in the environment and the abilities of the student, at baseline before intervention are described.

**Aim:** The aim was to investigate the need of environmental adjustments for students with cognitive disabilities in upper secondary school.

**Method:** The participants were 514 students with mainly cognitive, with no diagnosis (53%), dyslexia/speech impairment (20%) and neuropsychiatric diagnosis (23%) and Others (5%). The data collection was performed with the School Setting Interview (SSI). SSI focuses on identifying school activities where adjustments need to be done to accommodate students' environments to enable the students reaching their educational goals. Non-parametric statistics were used to describe and compare the need for environmental adjustment concerning gender, and students' diagnosis.

**Result:** All most all students had needs of environmental adjustments in order to participate actively and frequently need adjustments related to remembering (87%), writing (86%), do homework (74%), take exams (71%) and reading (70%). Statistically significant differences in need of adjustments were found between boys and girls and also between students with no diagnosis, dyslexia/speech impairment and those with neuropsychiatric diagnosis.

**Conclusion:** A large gap in the student-environment fit was found, despite the fact that students with disabilities have the rights to get the support and adjustments they need to be active and participate in mainstream upper secondary school.

## **Inter-rater and test-retest reliability of the adolescent version of the Assisting Hand Assessment (Ad-AHA) and alternate-form reliability of different test activities of the AHA in adolescents with unilateral Cerebral Palsy**

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### **Background**

While evidence of good construct validity of the Adolescent version of the Assisting Hand Assessment (Ad-AHA) recently has been provided for adolescents age 13-18 years with unilateral cerebral palsy (UCP) additional measurement properties of the Ad-AHA for evaluative purposes are needed.

### **Aim**

The aim of this study was firstly to investigate the inter-rater and test-retest reliability of the Ad-AHA outcomes when scored from the new test activity. Secondly, to evaluate the alternate form reliability of different test activities.

### **Method**

Agreement was calculated using the intraclass correlation coefficient, two-way random model and single measure (ICC 2,1). The inter-rater reliability was evaluated for 40 and test-retest reliability for 30 adolescents. The alternate forms reliability for the two different activity situations, i.e. the School-Kids and the Ad-AHA games used for children around the transition age (12-13 years), as well as consistency of scores obtained from two choices of test sessions for adolescents, i.e. the Present or the Ad-AHA board game, was analysed for 29 children and 30 adolescents respectively.

### **Results**

The ICC (2,1) for interrater reliability was excellent, 0.97 (95% CI 0.95-0.99). There was also an excellent test-retest agreement of 0.99 (95% CI 0.96-0.99), for individual items (range 0.75 to 1.0). For children in the transition age performing both the School-Kids and the Ad-AHA board games, the alternate forms reliability was excellent (range 0.82 to 1.0) and good to excellent between the two different activity situations of the Ad-AHA (range 0.71 to 1.0).

### **Conclusion**

Excellent inter-rater and test-retest reliability were demonstrated indicating that the Ad-AHA results are consistent between raters and time points with a high precision of the measures. The good alternate form reliability showed that the different test activities are directly comparable and can be used interchangeably with adolescents with UCP.

## Assessment of Selective Motor Control by Using Electromyography

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**Background:**Reduced selective motor control (SMC) is one of many impairments that leads to functional motor deficits in patients with cerebral palsy (CP). It is unclear to what extent the clinical evaluation detect the simultaneous activation of muscles during isolated, ballistic movement of a single joint at self-paced velocity, such as during the SMC clinical tests. The aims of this study are: (1) To determine whether the level of activation of selected muscles, and (2) To determine the incidence of muscle coactivation differs between SMC grade levels.

**Participants:**Forty-two participants were enrolled into this study: 23 patients with CP (F=13, M=10; Age =  $15 \pm 5.59$  years; Bilateral involvement; GMFCS level I-III) and 19 able-bodied participants (F=14, M=5; Age =  $22 \pm 1.59$  years). All participants were examined in the motion analysis laboratory of the university hospital.

**Materials/Methods:**Subjects were instructed to flex each knee 3 times with self-paced velocity. Examined limbs were classified into three SMC types: 0 = CP limbs have no ability to isolate movement; 2 = CP limbs with complete isolation of movement; C = Control limbs. The surface electromyography was used to measure muscle activation levels of hamstring, rectus femoris, hip adductor, gastrocnemius and tibialis anterior on both sides. The incidence of muscle coactivation was determined based on the occurrence of active or non-active muscle status.

**Results:**Comparing the mean activation levels of the majority of muscles, we found: CP limbs (Type 0+2) > Control limbs ( $p < 0.001$ ); Type 0 > Type 2 ( $p < 0.05$ ); and Type 2 > Type C ( $p < 0.01$ ). Also, the incidence of muscle coactivation was affected ( $p = 0.008$ ) by CP, and was influenced by SMC types as well ( $p < 0.001$ ).

**Conclusions:** SMC is worse in Type 0 limbs than in Type 2. Moreover, Type 2 in CP patents are not equivalent to that of Type C in able-bodied subjects. SMC is affected by CP.

## **The relevance of nerve mobility on function and activity in children with Cerebral Palsy**

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**Background:** In children with cerebral palsy (CP), stiffness can influence range of motion and motor performance. Stiffness can be caused by muscular, capsular or neural structures. While mechanical characteristics of sciatic nerves can be tested with the straight leg raise test (SLR), additional structural differentiation will help identify neural involvement in stiffness.

**Aim:** This study sought to determine whether neural structures had a relevant impact on motor performance in children with CP. We hypothesized that a positive SLR would relate better than a smaller SLR hip range of motion (ROM) to lower leg muscle strength, reduced motor capacity and less motor performance in children with CP.

**Method:** Thirty children with CP (6-18 years) participated in a cross-sectional study. Data from SLR, leg muscle strength, gross motor function measurement (GMFM-66) and number of activity counts during daily life, recorded with an actiwatch, were included in Receiver operating characteristics and correlation analyses.

**Results:** A positive SLR could distinguish with acceptable sensitivity and specificity between children with low versus high leg muscle strength, GMFM-66 scores, and activity counts. For example, a positive SLR of the right leg differentiated with a sensitivity of 87% and a specificity of 90% between children with a better versus poorer motor score (cut-off value: 70%). The SLR hip ROM correlated moderately with leg muscle strength (right  $r_s = 0.41$ ;  $p=0.038$ ; left  $r_s=0.49$ ;  $p=0.009$ ), but correlations with GMFM-66 (right  $r=0.25$ ; left  $r=0.27$ ) and activity counts (right  $r=0.25$ ; left  $r=0.27$ ) were smaller and not significant.

**Conclusion:** This study suggests that neural impact of SLR is higher on functional and activity outcome than the measured SLR hip ROM. Further studies should investigate whether improving neural mobility can lead to an amelioration of function in children with CP.

## **Comparative results of the health-related quality of life of children with hemiparesis and their parents.**

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### **Background**

A primary objective in the management children affected with hemiparesis along with other chronic diseases is the improvement of quality of life (QOL). As a subjective concept it is crucial to gather information directly from patients.

### **Aim**

The purpose of this preliminary study was to examine the level of agreement between parents and child QOL's report and their agreement with the European reference population data.

### **Method:**

We conducted a prospective study with a group of patients suffering hemiparesis due to cerebral palsy or stroke in childhood.

Eighteen children, 13 females and 5 males, aged from 8 to 16 years old, completed a clinical examination and were classified according to their GMFCS and MACS.

Children and their parents separately also completed parallel forms of the Kidscreen-27 self-report and parent proxy-report Spanish version. Concordance between the children's and the parents' scores were analysed using Paired t-test.

### **Result**

The Kidscreen results of parents and children were similar in the domains of physical activity, psychological well-being and autonomy. However, there was disagreement in the domains regarding "peers and social support" and "school environment", being the lowest scores in the survey conducted by parents, reaching statistical significance in both cases.

When we compare the results of the domain of "peers and social support" to the European reference data, we find that the average results in that domain is within the 44th percentile for the children answers and 50<sup>th</sup> for the parents answers. However, the average score on "school environment" is within the 75th percentile for the children answers and 64<sup>th</sup> for the proxy answers.

### **Conclusion**

Although patients with hemiparesis with GMFCS type I and II, as were all of our patients, have a mild- moderate disability, quality of life is affected in those aspects related to peers relation and the school environment.



### 3D muscular parameters in children with cerebral palsy with no medical history

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#### Background

Spasticity in children with cerebral palsy (CP) affects muscle function and geometry[1]. However, little is known about these alterations, especially that history of Botox injection, casting or surgery, have never been controlled.

#### Aim

Our aim was to compare 3D muscular lengths and volumes between typically developing (TD) children and ambulant spastic children with CP according to GMFCS levels. The CP group presented no medical history at the lower limbs (LL), other than botox injection at the gastrocnemii at least one year prior to the enrollment.

#### Materials

Seventeen spastic CP children with a mean age of 12 years  $\pm$  4 (diplegia N=14, hemiplegia N=3, GMFCS levels I: N= 9, II: N= 8) had undergone an MRI exam for the lower limbs. 3D subject-specific muscle reconstructions were performed for the hamstrings, hip adductors (brevis, magnus and longus), vastii, rectus femoris, gracilis, sartorius, gastrocnemii, soleus and anterior tibialis in order to calculate belly muscle lengths (normalized to LL length) and volumes (normalized to weight)[2,3]. Seventeen TD children aged matched to the CP group were also enrolled. The mean values of the calculated parameters were compared using Anova test.

#### Results

Belly muscle volumes were significantly reduced for all the muscles in children with GMFCS level II compared to TD children ( $p < 0.05$ ). Belly muscle lengths were also reduced in CP with GMFCS level II except for the adductor magnus, semi-tendinosus, femoral biceps brevis and longus. Only the Gastrocnemii length showed a significant difference in children with GMFCS level I compared to TD children ( $p < 0.05$ ).

#### Conclusion

For the first time belly muscle lengths and volumes of LL were calculated in spastic children with CP with no medical history, based on subject-specific 3D reconstruction. LL belly muscle volumes and lengths are significantly reduced in children with GMFCS level II.

[1]Barrett RS.et al. 2010, [2] Jolivet E et al. 2008, [3] Hausselle J. et al.2014

**The Kids Rehab eMR Project - Improving non-clinical support systems for clinicians working in an ambulatory rehabilitation setting.**

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**Background:** As part of a strategy to bring together hybrid and satellite records into one electronically accessible patient record (eMR), Kids Rehab has developed an electronic workflow to standardise referral management, document clinical assessments, intervention and outcomes and streamline communication about rehabilitation goals. This multidisciplinary team project designed an electronic solution to integrate team processes into the patient eMR and support coordination of patient care through broader accessibility of patient information.

**Aim:** To improve clinical efficiency by reducing duplication of clinical documentation across multiple systems, improve accessibility of management plans in the patient record and capture mandatory activity reporting.

**Method:** Over a 12 month period from 2013, the project team designed their work flow into electronic forms by combining an existing patient database, and electronic and paper records. These were trialled in a mock electronic environment and training in system functionalities was provided to clinicians as part of the implementation phase.

**Results:** The build consists of forms, automated family letters, and mandatory clinical activity, captured as a real-time by-product of documentation. Prior to the project, one generic form existed for electronic clinical documentation. Six months prior to the project 2089 ad-hoc entries of patient information were made on this form. Six months post implementation 3549 entries on the newly designed forms were made, a 70% increase in clinical documentation. Recording of clinical activity has increased by 30%.

**Conclusion:** Documentation is an administrative component of clinical work that draws together information into a multidisciplinary patient care plan and is a critical element of decision making for safe patient care. Engaging clinicians as the end users in all aspects of this project has facilitated a smooth implementation and built capacity in the new workflow system.

## Hospital admissions in children and young people with cerebral palsy: a data linkage study

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### Background

The ability of disease registries to inform health service management and evaluation through linkage with other datasets is being increasingly recognised. Geographically-defined cerebral palsy (CP) registers are well placed to investigate medical service use in the CP population by linking with other datasets.

### Aim

To investigate the frequency and characteristics of hospital admissions in children and young people with cerebral palsy (CP) in the Australian state of Victoria, and make population comparisons.

### Method

This was a retrospective data linkage study. The Victorian CP Register and the Victorian Admitted Episodes Dataset were linked using a stepwise deterministic approach. The CP cohort comprised registered individuals who had a date of birth between 1st July, 1995 and 30th June, 2009. General population data for the same age group were also obtained.

### Result

The CP cohort comprised 1,748 individuals. The proportions classified at GMFCS levels I, II, III, IV and V were 37%, 27%, 10%, 12%, and 14% respectively. Of the 1,748 members of the CP cohort, 80% (n=1404) had at least one same-day or multi-day admission to a Victorian hospital between July 2007 and June 2015. Children and young people with CP had a total of 11,317 admissions during this period, which represented 0.9% of all admissions in this age group.

### Conclusion

The availability of population-based data on medical service use in the CP population is important given that CP is the most common cause of physical disability in children, and the need for medical care in this group remains high throughout childhood and adolescence, and into adulthood. By linking a CP register to a state-wide hospital admissions database, we could estimate the proportion of admissions to Victorian hospitals that were attributable to CP, while investigating factors associated with the frequency and type of admissions in the CP cohort using data on severity and complexity taken from the CP register.

## **Discriminative ability of SOMP-I for infants at risk for Cerebral Palsy**

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**Background:** Early identification of infants at risk for Cerebral Palsy (CP) is important to enable timely intervention. The purpose of Structured Observation of Motor Performance in Infants (SOMP-I) is to identify infants that are in need of intervention at the time of the assessment, among those infants at-risk for a later diagnose such as CP. SOMP-I measures both level of motor development and quality of motor performance during the first year of life.

**Aim:** To analyze discriminative ability of SOMP-I for infants at risk for CP.

**Method:** Between 1986-1989, infants (n=226) who needed neonatal intensive care (NIC) were enrolled in a longitudinal study and were assessed with SOMP-I. At three years of age, 18 of these infants had CP. A comparison of the total scores of both level and quality was made between these infants and the other infants who needed NIC at 2 months (CP=18; NIC=201), 4 months (CP=18; NIC=198), 6 months (CP=18; NIC=197) and at 10 months (CP=13; NIC=195) corrected age.

**Result:** For all ages, the total score for both level of motor development and quality of motor performance for the children later diagnosed with CP was significantly poorer. Within the CP group, there was a wide range in the total score for both level and quality.

**Conclusion:** SOMP-I demonstrate discriminative ability for CP, both for level of motor development and quality of motor performance. The wide range of the total scores in infants later diagnosed with CP might also be an indicator of discriminative ability for different degrees of CP in these children.

**Conflict of interest:** Kristina Persson is the developer of SOMP-I. SOMP-I is owned by Barnens rörelsebyrå ekonomisk förening (economic association) Uppsala, Sweden. Kine Johansen and Kristina Persson are partners of Barnens rörelsebyrå. The other authors have no conflicts of interest to disclose.

## **Are we addressing upper limb function? An audit to identify goal setting priorities in children with cerebral palsy**

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### **Introduction:**

Children with cerebral palsy (CP) often have difficulties with their upper limb skills which impact on their level of functional performance. It is therefore important to highlight and address hand function in order to optimise a child's participation. Although hand function may be recognised, there may be more emphasis placed on the importance of other areas, such as mobility, which may be a primary focus for intervention. In order to evaluate the effectiveness of intervention for individual's receiving therapy, goals are set which also reflect the concerns raised by families. Goal Attainment Scaling (GAS) can be used to evaluate outcomes, particularly where specific outcome measures may not be sensitive enough to pick up small individual changes.

### **Aim:**

To identify the ratio of upper limb goals set for children with CP receiving therapy intervention at a specialist centre.

### **Method:**

An audit of children's data was carried out between 2007 and 2014. Gas scores were collated which were directly related to improving upper limb function. Outcomes were collated and compared in relation to a child's classification.

### **Results:**

A total of 2428 GAS goals were set for children between 2007 and 2014. 513 (21.13%) were identified as directly addressing upper limb function. 256 children were classified as having spastic bilateral CP, 154 with spastic unilateral CP, 39 with Ataxia and 62 with athetosis (35 Chorea, 27 Dystonic).

### **Conclusion:**

Numerous goals were set in relation to hand function however the data demonstrates a lower than expected percentage score. This is the first stage of analysis with further identification required to compare data with other specific functional areas and to also highlight if goals are reflective of parental concerns or whether further training and support is required for therapists when identifying and setting goals in relation to upper limb function.

## EBM versus ICF

Lars Mullback<sup>1</sup>

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There seems to be 2 contradicted trends within the habilitations activities and research.

Represented by

1. WHO Classification (ICF),
2. Evidence-Based Medicine (EBM).

Aim

EBM has quickly gained a dominant position and are on the way to change the perception of cerebral palsy and which interventions are appropriate. Any changes are never just about facts, but include always philosophical, political and moral aspects.

Method

Review of the article: A systematic review of interventions for children with cerebral palsy: the state of the evidence by IONA NOVAK, University of Notre Dame, Sydney, Australia, 2013.

result

The 15 interventions presented as EBM-approved to be used, can be categorized as follows:

- 7 are directly medical
- 3 are using various types of restraints to reduce the child's ability to move
- 1 concerns arranging the environment
- 4 concerns physical training for the child to spontaneously develop their ability to move

Common to these EBM recommended actions are that they all focus on detail problems from only one ICF aspect. No intervention is proven good, based on more than one ICF aspect.

Actions that are not considered proven, according to EBM, is for example, communication training and conductive education. Physiotherapy according to Bobath considered even inappropriate.

Common to these interventions; the child's general development are considered more important than the development of detail abilities.

Conclusion

The article indicates; certain types of interventions are better suited than others, for evaluation according to EBM.

It appears in the systematic review that EBM systematically verifies from only one ICF aspect, not from many.

If so, the increasing use of EBM counteracts WHO's intention with ICF, which says that disabilities should be treated and evaluated from many aspects, such as Body and function, Activity, Participation, Environment (Personal factors)

## **The frequency and nature of use of the speechBITE website: A tool for evidence based intervention.**

Elizabeth Murray<sup>1</sup>, Leanne Togher<sup>1</sup>, Patricia McCabe<sup>1</sup>, Emma Power<sup>1</sup>, Natalie Munro<sup>1</sup>, Melissa Brunner<sup>1</sup>, Katherine Smith<sup>1</sup> and Emma Pagnamenta<sup>2</sup>

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**Background:** speechBITE is a free international database of speech-language pathology (SLP) intervention studies. It covers the entire scope of SLP practice. This includes all aspects of paediatric disability in regards to age, client groups and diagnoses (e.g. cerebral palsy, down syndrome and autism spectrum disorders) and interventions used (e.g. augmentative and alternative communication, language therapy and computer based intervention). speechBITE also provides methodological ratings of group comparison studies using the reliable PEDro-P scale (Murray et al, 2010). The website aims to help practitioners find and appraise the evidence within the EBP process. To date, the impact of the website has not been tested.

**Aims:** (1) What is the frequency of use of speechBITE by SLPs internationally? (2) How do speech pathologists use the website? (3) How useful is speechBITE to SLPs' work and to the SLP profession?

**Method:** An online survey comprising 10 questions and an open comments section to address the aims. Survey was circulated by SLP professional associations in Australia, United States, Canada, Europe and the UK to their members, and also via Twitter and Facebook.

**Result:** 725 SLPs responded. The majority of respondents were Australian but European SLPs from Sweden, Norway, Germany and the Netherlands also participated. The majority who used speechBITE were clinicians looking for evidence to support clinical practice. 87% rated speechBITE as very useful or useful for the profession. 20% had not heard of speechBITE. Respondents indicated a need for further EBP training and access to full text articles.

**Conclusion:** speechBITE was rated by SLPs a useful tool for evidence based practice. Increasingly more SLPs are using the website. Further examination of the use of methodological ratings and the online training package is needed.

## **Variation of unknown significance detected by array comparative genomic hybridisation (Array-CGH) and their clinical impact.**

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**Background:** Introduction of Array-CGH has not only increased the diagnostic yield but also the chances of finding a variation of unknown significance (VOUS). Literature related to its clinical implication is limited.

**Aim:** To study the detection rate and clinical impact of a VOUS detected while testing a child with developmental delay or intellectual disability and Autism.

**Methods:** A Retrospective observational study was performed looking at the VOUS detected in above mentioned group of children who had aCGH testing across a large city in the United Kingdom.

**Results:** Data was obtained from 95 out of 98 children. There were twenty-five children with a total of 27 VOUS noted (28.42%). This was higher than the abnormality yield (14.74%). Data from five children who had abnormal genetic variation along with VOUS as excluded. One variation that was reported to be VOUS was later noted to be a causative abnormality in light with new evidence.

Genetic reports were based on clinical information on request form, which was not always as elaborate as the clinic letter. The way results were explained varied considerably. It ranged from- 'entirely normal' to 'no clinically significant abnormality noted' to 'some abnormality seen but not related to the child's problem'.

**Conclusions:** There are a significant number of children with VOUS detected since introduction of aCGH. They have a potential to become recognised with specific clinical phenotypes overtime with emerging research and case studies. It is imperative to inform this at the time of consenting and to provide adequate and relevant clinical details to ensure geneticist can match the clinical details to the variation seen. Consistent and methodical process explaining VOUS and their management, when present, is crucial to optimise patient care.



## Measuring upper limb function in children with hemiplegia with 3D inertial sensors

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### Background

Upper limb assessments in children with hemiplegia rely on clinical measurements, which despite standardization are prone to observer bias and error. Recently 3D movement analysis using optokinetic setups has been used to measure upper limb movement and function, but generalization is hindered by setup/analysis time as well as cost. Portable inertial sensors may provide a simple, cost-effective alternative.

### Aim

To explore and implement the use of 3D inertial sensor devices in the measurement of upper limb function in children with hemiplegia.

### Method

A subset of 30 participants in a mirror therapy RCT were instrumented during baseline (T0), post-treatment (T1) and follow-up (T2) assessments (incl. Melbourne assessment 2) with wireless inertial devices, positioned on the paretic and non-paretic arms as well as on the trunk to monitor motion during reaching tasks.

### Result

We collected 71 successful and interpretable measurement sessions.

Contrary to the clinical measurements the inertial sensor measurements were insensitive to change during the clinical trial, with no significant differences on post hoc analyses between T0, T1 and T2.

Inertial sensor measurements successfully distinguished paretic and non-paretic limbs with significant differences ( $P < 0.01$ ) in movement duration, power, range of angular velocity, elevation and smoothness measured by jerk index and spectral arc length.

Inertial sensor measurements showed correlations with functional clinical tests: movement duration and smoothness (Higuchi fractal dimension) showed moderate to strong negative correlations with measures of amplitude, accuracy and fluency of the Melbourne assessment.

### Conclusion

Inertial sensor measurements reliably identify paresis and correlate with clinical measurements, however their sensitivity to change is limited. They may therefore have a limited interest as a monitoring tool during clinical trials aimed at improving upper limb function.

## **Functional outcome of preterm children at school age: association between cognitive assessments and teacher evaluations**

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### **Background**

Preterm children are at risk for a wide range of cognitive impairments. When composing an overall picture of functional outcome of preterm children at school age teacher evaluation on school performance is recommended to be combined to findings in cognitive assessments.

### **Aim**

To study the functional outcome of Very Low Birth Weight (VLBW,  $\leq 1500\text{g}$ ) infants at school age by combining data from cognitive assessments and school performance evaluated by teachers.

### **Method**

The group of 134 VLBW children born between 2001 and 2004 in the Turku University Hospital was assessed with Wechsler Intelligence Scale for Children –IV (WISC-IV) at the age of 11 years. Their responsible teachers were asked to fill in a questionnaire including specific questions about child's school performance, learning difficulties and need for special education or other type of support. The same information was collected from the Full Term (FT) age matched control group.

### **Result**

The cognitive profile of VLBW children and the school performance of VLBW and FT children will be presented, and the associations between cognitive profile and school performance will be analyzed. Our preliminary results suggest that VLBW children perform better at school than their cognitive profile would suggest.

### **Conclusion**

Our results highlight the importance of long-term follow-up of VLBW children and the importance of teacher evaluations in composing an overall picture of functional outcome of preterm children at school-age.

## **Hand Function Test in Down Syndrome: comparison of three validated evaluation protocols**

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The manual dexterity has been studied in the literature from the use of standardized for people with normal development or with peculiar characteristics. However, few studies discuss the use of these tools for people with intellectual deficit. Down syndrome is characterized by being one of the most common intellectual disabilities. Therefore, further studies are required directed to this population. The present study aimed to evaluate motor skills in young people with Down syndrome through the use of three different tests and compare the results of each application in this population. This sample consisted of 10 children and young people with SD, between 9 and 13 years, of both sexes attending a specialized institution. The Test Box and Block (TBB), the Minnesota Dexterity Test and the Test Manual Function Jebsen and Taylor were used.

Correlation was found between almost all the tasks proposed to the participants in the tests. However, there was greater difficulty in the application of Minnesota, in which performance was hampered by scattering during its realization. We conclude that the choice of test might influence the results and should therefore be concern in search of the best instruments to test the abilities of people with intellectual deficits.

**Keywords:** Motor Skills; Evaluation; Down Syndrome

## **Movement acceleration in practice of virtual games: a study with Down's syndrome children and adolescents**

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**Aim:** To evaluate the acceleration of the movement of adolescents with Down Syndrome and adolescents with typical development, during the pawn in the game of bowling video game Nintendo® Wii™. **Method:** The study was performed with 20 adolescents of both sexes, aged between 7 and 14 years, divided into two groups: 10 adolescents to GSD (Group Down Syndrome) and 10 adolescent students to GC (Control Group). For the data collection the subjects did the throws necessary to complete the game with the hand of preference and the accelerometer attached to the wrist, after the control of the researcher. The data were collected by means of the software "Coleta 2 Final" and subsequently analyzed, considering only the first 3 pitches. **Results:** it was observed that the maximum acceleration mean was higher for the GC when compared with the GSD in all attempts, however, with the average number of attempts equivalent. **Discussion:** The bowling presented the GSD as a proposal for easy understanding and simple rules. The group studied showed good performance, requiring few attempts to wrap up. You can check that, due to the clinical features present in DS individuals of GSD had lower mean values of acceleration during the pitch, but the performance was shown to be effective for this group in learning motion control during the game. **Conclusion:** In light of the data presented it can be concluded that the games pawn in the virtual environment can encourage the throttle control of movement. However, it is the need for further studies in the area.

**Keywords:** Down Syndrome; Accelerometry; Video games.

**Use of classification tools by allied health professionals for children with cerebral palsy: a survey of practice.**

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**Title:** Use of classification tools by allied health professionals for children with cerebral palsy: a survey of practice.

**Background:** Routine use of the suite of validated classification tools is integral to best practice in cerebral palsy management. A recent systematic review suggests classification tools were not widely used by allied health practitioners (AHPs).

**Aim:** To determine the extent to which three classification tools; Gross Motor Function Measure (GMFCS), Manual Abilities Classification System (MACS) and Communication Functional Classification System (CFCS), were used and perceived to be used by AHPs, in two Australian community rehabilitation services.

**Method:** A cross-sectional case file audit and separate survey of AHPs were conducted. Case files of 37 children with cerebral palsy (11 female:26 male), aged 4-17 years, were audited for tool entries for a pre-defined 6 month (age < 6 years) or 12 month (age ≥ 6 years) period. AHPs completed a self-report questionnaire to determine perceived levels of tool use. Fifty-five of 73 eligible AHPs participated: 18 occupational therapists (OTs), 19 physiotherapists (PTs) and 18 speech pathologists (SPs) with a median of 10 years' experience in disability.

**Result:** GMFCS was documented in 30/37 files (81%); MACS in 8/37 files (22%) and CFCS in 2/37 files (5%). No tools were recorded in 6/37 files (16%). All three tools were documented in 2/37 files (5%). Eighty-nine percent of SPs, 67% of OTs and 5% of PTs reported they rarely used and documented a child's functional classification. Conversely, 53% of PTs, 11% of OTs, 0% of SLPs reported they nearly always documented at least one classification tool.

**Conclusion:** Evidence of classification tool use was variable. GMFCS was most highly documented. Low levels of documented MACS and CFCS use was matched by a high proportion of OTs and SLPs reporting they rarely used classification tools. Self-reported and actual practice did not appear to match best practice.

**WANTED: Partners for translation and validation of the C-BiLLT for standardized language assessment appropriate for non-speaking children with severe cerebral palsy**

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**Background:** Our group developed the Computer-Based Instrument for Low Motor Language Testing (C-BiLLT), a new innovative measure of language comprehension specifically for Dutch speaking children with severe CP (GMFCS IV and V). Assessment of spoken language comprehension is paramount for early, well targeting intervention with the ultimate goal to prevent or at least minimize communication problems. World-first data produced by our team changed the face of practice by showing that despite severe speech impairments, children (particularly those with dyskinetic CP) can demonstrate no or little impairment in spoken language comprehension. The C-BiLLT revolutionizes how we assess children with CP, overcoming the limitations of currently available assessments. It provides a powerful means for understanding the communication profiles of children with CP who cannot be assessed conventionally because of severe speech and motor impairments.

**Aim:** We want to take our groundbreaking work and expand its reach internationally by translating the C-BiLLT into different languages. First initiatives to translate the C-BiLLT into Australian-English are recently taken.

**Significance:** Translation (and validation) of the C-BiLLT into different languages will enable accurate diagnosis of spoken language comprehension worldwide, transforming management of children with severe CP. It will support the implementation of treatments that specifically target children's level of comprehension, resulting in improved child outcomes and service delivery.

**Question:** Are you in ?

**Reference:**

Geytenbeek JJ, Vermeulen RJ, Becher JG, Oostrom KJ. Comprehension of spoken language in non-speaking children with severe cerebral palsy: an explorative study on associations with motor type and disabilities. *Dev Med Child Neurol.* 2015 ;57:294-300.

**Children with spastic CP in mainstream education are as accurate in mathematical skills as their peers, but need more time to do so.**

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**Background** Children with Cerebral Palsy (CP) generally seem to have mathematical difficulties, but it is not clear which specific aspects of mathematical performance these children, particularly in mainstream education, have difficulties with. Such information is crucial to design tailored interventions.

**Aim** This study aimed to investigate specific mathematical skills in children with spastic CP type in mainstream education and whether they were dependent on intelligence, reading skills or fine motor abilities.

**Method** We recruited 14 CP children with spastic CP (8 with a hemiplegia, 5 with a diplegia and 1 with a triplegia) in first and second grades of primary school. Controls were 14 matched typically developing peers from the same class. Individually administered measures were block design, vocabulary, one minute reading, motor speed, arithmetic facts (ARFT), addition, subtraction, counting, and a symbolic and non-symbolic comparison task.

**Results.** Children with CP were as accurate as their TD peers in all mathematical skills. However, they had a significant lower number of correct answers on the ARFT ( $p = 0.01$ ). Also, they showed a significantly larger reaction time in the addition, subtraction and non-symbolic comparison task and in counting ( $p < .05$ ). This increased reaction time could only partly be explained by non-verbal and verbal intelligence, reading skills and motor speed.

**Conclusion**

CP children in first and second grade are accurate but slower in specific mathematical skills compared to their TD peers. Future research should investigate the underlying mechanisms for this finding and perform longitudinal follow up.

## CVIT 3-6, A SCREENING TEST FOR CEREBRAL VISUAL IMPAIRMENT IN YOUNG CHILDREN

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**Background:** Current instruments for diagnosis of Cerebral Visual Impairment (CVI) often measure only one aspect of visual functioning, results are confounded by comorbid cognitive or motor impairments, and tests are often too complex for young children.

**Aim:** To develop a new instrument for 3 to 6 year olds covering several mid- and high-level visual functions in four domains (object recognition, degraded object recognition, motion perception and global-local processing).

**Method:** Six pilot studies (100 children) resulted in a user-friendly, computer-based test consisting of 14 subtests, the Cerebral Visual Impairment Test (CVIT 3-6). Normative data from 250 typically developing (TD) children between 3 and 6 showed a positive correlation between age and the total score ( $p = .62$ ,  $p < .001$ ), no sex differences, and no correlation with postmenstrual age or birth weight. Based on our norm sample, age-specific percentile scores can be calculated with a score below the 10<sup>th</sup> percentile as indicative for impairment in the tested domain.

**Results:** Currently, validity and reliability of CVIT 3-6 are being evaluated in 80 children from four groups: CVI, intellectual disabilities, low acuity and TD children. Data collection is still on-going. Results so far indicated a good test-retest reliability. CVIT 3-6 performance was independent of autism traits. A weak convergent validity was found between the new test and the BEERY-VMI but a high correlation with the L94. The CVIT 3-6 further showed a good discriminant validity compared to TD children and those with an intellectual disability.

**Conclusion:** Further investigation of the CVI group and the control groups is needed before we can conclude which outcome measure (subtest scores, domain scores, overall scores) provides the best sensitivity.



## **Autism spectrum disorder in ex-preterms is preceded by altered neonatal brain volumes in multimodal association areas and altered patterns of brain asymmetry**

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**Background:** in children autism spectrum disorder (ASD) disrupts the systems organization of the brain.

**Aim:** to study whether brain volumes and patterns of asymmetry in the primary sensory (PS), unimodal association (UA), and higher-order association (HOA) cortices at term-age (TEA), differ between extremely preterm (EPT) children with positive and negative screening for ASD at 6.5 years.

**Methods:** we included 33 EPT infants < 27 weeks of gestational age (ASD-positive=11, with scores above cut off on the Social Responsiveness Scale and ASD-negative=22). We used atlas-based segmentation. Volumes were calculated by summing the voxels in each region. Regions were grouped by processing type (PS, UA, and HOA cortices). The volumetric asymmetry was calculated for anatomical regions at each of these levels by using the symmetry index  $S_i = 100 * \frac{2(\text{Volume right} - \text{Volume left})}{\text{Volume right} + \text{Volume left}}$ . Group comparisons were performed (multivariate analysis) adjusted for total grey matter volume and full-scale IQ.

**Results:** Compared with the ASD-negative group the ASD-positive group had significantly smaller volumes in the left-HOA cortex ( $p=0.01$ ), specifically involving the cingulate cortex ( $p=0.009$ ), the insula ( $p=0.003$ ), and the superior orbito-frontal cortex ( $p=0.03$ ). A non-significant trend was found in the left-UA ( $p=0.06$ ) involving the fusiform gyrus ( $p=0.03$ ). The  $S_i$  was significantly different between groups in the rolandic operculum ( $p=0.02$  left-asymmetry), and the supplementary motor area ( $p=0.04$  right-asymmetry). We found a non-significant trend in the superior orbito-frontal cortex ( $p=0.07$  left-asymmetry).

**Conclusions:** volumetric abnormalities in the HOA cortex and different patterns of asymmetry were identified in the neonatal period in EPT infants that later developed ASD symptoms. This may reflect alterations in multi-sensory integration and abnormal brain growth trajectories reported in older ASD subjects.

## **Low-grade intraventricular hemorrhage in extremely preterm infants: relation to brain volumes and cognition**

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### **Title**

Low-grade intraventricular hemorrhage in extremely preterm infants: relation to brain volumes and cognition

### **Background**

Low-grade intraventricular hemorrhages (IVH) are common among extremely preterm (EPT) infants. Its impact on the cognitive outcome is not clearly understood.

### **Aim**

To determine the effects of IVH-1-2 on cognitive outcome at 6.5 years in children born EPT, and to relate the cognitive scores with brain volumes at term-equivalent age (TEA).

### **Methods**

EPT children (< 27 weeks of gestational age) born in Stockholm, with cranial ultrasound and MRI of the brain at TEA were included (n=112). Brain morphometric studies were performed in infants with high-quality MRI. Cognitive assessment (WISC-IV) was done at 6.5 years. We performed comparisons between groups (t-test and MANCOVA), correlations between brain volumes, and cognitive scores on a global level (Pearson's correlations), and on a regional level (Voxel-based morphometry).

### **Results**

88/112 (79%) children underwent cognitive assessment. We found IVH 1-2 in 41(36.6%), IVH 3-4 in 11 (9.8%), and IVH 3-4 in 60 (53.6%). The IVH 1-2 group had lower gestational age (p=0.02) and higher frequency of patent ductus arteriosus ligation (p=0.006) compared with the non-IVH group. Analyses were adjusted for these variables. At 6.5 years the two groups did not differ in the cognitive outcome that were assessed. Compared with the non-IVH group (N=23) the IVH 1-2 (N=14) group tended to have smaller global brain volumes, and a positive regional correlation between perceptual IQ and grey matter volume in the lateral left occipital cortex (r=0.80, p<0.005 uncorrected). Different from the non-IVH group the IVH I-II group had no significant correlation between cognitive scores and global brain volumes.

### **Conclusions**

Low-grade IVH was related to a different pattern of brain growth compared to infants with non-IVH. However, the cognitive domains assessed at 6.5 years were not affected.

## **Mapping pediatric rehabilitation Across Canada –Challenges in providing services to children with childhood disability**

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**Background:** Service mapping is a means of compiling information about service interventions. Its results serve the dual purpose of presenting a condensed overview of services and providing a basis for evaluation and comparison. Knowledge of existing services and its evidence base are essential for effective public health planning. Unfortunately, a dearth of literature exists internationally related to pediatric services maps for children with childhood disabilities.

**Aims:** This study aims to identify services information, the existence of system gaps and the challenges of providing pediatric rehabilitation services.

**Methods:** A parallel two-phased mixed methods descriptive study design was used. Survey questions were developed, informed by healthcare sector evaluation standards. The survey was distributed to members of a national child and youth rehabilitation network. Descriptive statistics analyzed these data. Semi-structure interviews were conducted with key informants and analyzed using thematic analysis.

**Results:** An 84% survey response rate was achieved and 21 structured interviews were conducted. Survey analysis suggests that 1) Population density did not correspond with facility clustering, 2) Facilities specific government funding varied greatly based on the type of facility and geographical region, 3) An increased reliance on philanthropic funding to fulfill programming financial requirement was demonstrated. Key themes emerging from the qualitative data included 1) Family voiced services needs no longer match government funded core services, and 2) Complex ministerial policies and powerful patient advocacy groups are contributing to national service gaps.

**Conclusion:** This study, the first to map pediatric rehabilitation in Canada, not only describes the services provided nationally, but highlights the challenges of pediatric rehabilitation service provision for children with childhood disabilities in a complexly funded and administered health system.

## Falls risk in children with Williams Syndrome under single- and dual-task conditions

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### Background

Children with Williams Syndrome (WS), a rare genetic disease with a prevalence of 1 in 7.500 individuals (Stromme, Bjornstad & Ramstad, 2002), have difficulties in visual-motor integration and motor function (Hocking et al, 2008), especially under dual-task conditions (Wuebbenhorst, 2015). Coping with dual-task situations is important for managing complex everyday life competencies. Children in general have a high prevalence of falls resulting in injuries (Kahl et al., 2007). Impaired static and dynamic postural control proved to be an intrinsic risk factor for falls (Kambas et al., 2004), with gait variability and walking speed under dual task conditions being predictors for falls (Beauchet et al., 2008; Kressig et al., 2008).

### Aim

Aim of the study is to assess the falls risk of children with WS under single and dual task conditions to identify a need for falls prevention.

### Method

Gait parameters of people with WS (N=27) were measured under single- (ST) and dual- (DT) task conditions using the Optogait analysis system. The group was divided into 3 age groups (group 1 < 13 years; group 2= 14-17 years; group 3 = 18-30 years). Data for stride length and walking speed was normalized for height.

### Result

Results show a significant decrease ( $p=,0195$ ) in stride length in age group 1 (group 2:  $p=,0035$ ; group 3:  $p=,36$ ) comparing ST and DT. Walking speed also decreases significantly ( $p<,0001$ ) from ST to DT in age group 1, respectively in group 2 ( $p<,0001$ ) and in group 3 ( $p<,0001$ ). The stride length coefficient increases from 9,56 (ST) to 12,47 (DT) in age group 1 ( $p=,17$ ), from 7,45 (ST) to 9,35 (DT) in group 2 ( $p=,22$ ) and from 7,44 (ST) to 10,03 (DT) in group 3 ( $p=,047$ ).

### Conclusion

Children with WS slow down in walking speed during DT exercises and show high values in stride length coefficient under ST and DT conditions. Thus they have a high falls risk especially in complex situations. A therapy aiming at improving motor competencies could prevent falls.

**Unilateral cerebral palsy is not always the mildest type of cerebral palsy in daily life activities.**

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**Background:** it is frequently assumed that children with unilateral cerebral palsy (UCP) have better functional abilities in daily life than children with bilateral CP.

**Aim:** to investigate the functional abilities differences between CP topographical distributions (i.e. UCP, diplegia, quadriplegia) and to study whether children with UCP have better functional abilities than children with bilateral CP.

**Method:** this is a retrospective study investigating 30 items removed from the validation study of the ACTIVLIM-CP, a new questionnaire measuring activity level (upper, lower extremity and combination of both), because their difficulty varied significantly depending on topographical distribution. For each item, 16 experts were asked to classify the type of the daily activity as: locomotor, bimanual, intersegmental upper/lower extremities (UE/LE). Within each activity type, activity difficulty variations observed across topographical distributions were analysed to highlight topographical-specific functioning patterns.

**Result:** children with UCP were significantly less able to perform bimanual activities compared to children with bilateral CP but were significantly more able to perform locomotor activities. For intersegmental UE/LE activities with a predominant implication of LE (locomotion and/or trunk in movement) we observed the same pattern as in locomotor activities. For intersegmental UE/LE activities with a predominant implication of UE (bimanual and antigravity posture) we observed mainly the same pattern as in bimanual activities.

**Conclusion:** bimanual and intersegmental activities with a predominant implication of UE were perceived as more difficult to be achieved for children with UCP. These findings are of clinical interest in breaking the general assumption about the mild aspect of UCP and in planning more relevant and precise functional objectives in rehabilitation.

## Neurodevelopmental outcomes of children with central gray matter lesion

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**Background:** Central gray matter lesion (CGML) is common abnormal brain magnetic resonance imaging (MRI) findings in the children with cerebral palsy (CP). In general the children with CGML have more severe motor and cognitive impairments than the children with other abnormal brain MRI findings in CP. Recently the outcomes can vary according to the severity of CGML.

**Aim:** To investigate the neurodevelopmental outcomes in children with CP with CGML on brain MRI.

**Method:** Sixty-nine children with central gray matter lesion (CGML) on brain MRI and who had regularly checkup until the age of 3 years or over were recruited. CGML were grouped into HIE and kernicterus (K) patterns by a neuroradiologist. The severity of HIE were grouped into 4 grades from I to IV. The outcome was assessed with gross motor function classification system (GMFCS), manual ability classification system (MACS), communication function classification system (CFCS). And the cognitive function and the presence of other associated problems were investigated.

**Result:** The distributions of GMFCS, MACS, and CFCS levels were significantly different between brain lesion types. The overall outcomes of the children with grade I were favorable while the children with grade IV were most unfavorable outcomes in gross motor, upper arm function, communication and cognition. The severity of these neurodevelopmental impairments (NDIs) were strongly related with the severity of HIE. The children with K pattern showed wide ranges of NDIs in these areas. The children with grade III or IV were at very high risk of intellectual disability (ID) or epilepsy. Forty percent of the children with K pattern had hearing impairment (HI).

**Conclusion:** The severity of NDIs in gross motor, upper arm function, communication and cognition were strongly related with the severity of HIE and the risk of ID or epilepsy. The children with K pattern had unfavorable outcomes in most of the children and also at risk of HI.

## PHYSICAL THERAPY TREATMENT IN OBSTETRIC BRACHIAL PALSY

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**Background:** Obstetrical brachial plexus lesions can affect different nerve roots. In general, these lesions have a very good prognosis, however controversy still exists regarding the optimal treatment strategies for these types of patients.

**Aim:** To increase our knowledge regarding the treatment of obstetric brachial plexus palsy, by analyzing and comparing the different conservative procedures used throughout history.

**Methods:** We performed a literature search in CINAHL, IME-Biomedicina, Lilacs, Pedro, PubMed, Science Direct, Scopus, Web of Science and TESEO databases.

**Results:** Twenty-two studies met the predefined inclusion/exclusion criteria. These studies contained information regarding 588 patients and 159 carers. Different protocols and techniques were described such as passive and active movement therapy, static and dynamic splints, massage therapy techniques, muscle stretches, weight-bearing exercises, home exercises, heat applications, electrostimulation, kinesiотaping, constraint induced movement therapy (CIMT) and Vojta therapy.

**Conclusions:** A multidisciplinary approach for this pathology is necessary in order to achieve optimal functional results. In recent years, the application of procedures such as CIMT or kinesiотaping constitutes a valid complement to the classical treatment protocol for this lesion. Further experimental studies are required in order to improve the reliability of these results.

## **Immersive virtual reality platform for walking rehabilitation in children with neurological disorders**

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### **Background**

Improving walking ability is one of the main goals of a rehabilitation procedure. New technologies based on Virtual Reality (VR) has been recently flanked standard therapies. The use of VR system in pediatric patients is promising thanks to the high plasticity of neuronal circuits in children, but a scientific evidence of its benefits still lacks.

### **Aim**

The aim of this study is to preliminary evaluate the efficacy of a short rehabilitative treatment on a gait real-time analysis interactive lab (GRAIL) in a small group of children affected by neurological disorders.

### **Methods**

The GRAIL is an integrated platform made up of an instrumented dual-belt treadmill, a two degrees of freedom motion frame and integrated force plates. It is equipped with 10 optoelectronic cameras for kinematic data acquisition, a motion-capture system and 3 video cameras, integrated with synchronized VR environments projected on a 180° cylindrical surface. The self-paced functionality of the treadmill is designed to simulate a more realistic walking.

10 patients aging 9-18 years were recruited for an intensive rehab program (one session a day for 4 weeks). Treatment included exercises to improve walking and balance ability in engaging VR environments.

### **Results**

The biggest improvements between T0 and T1 were at the ankle level: data report significant improvements of the maximum dorsi-flexion in stance. A trend in improving of knee flexion/extension was observed.

### **Conclusions**

The study aimed to be a preliminary explorative evaluation of GRAIL efficacy on children rehabilitation, which at our knowledge lacks in the literature.



## **Clinical transition for adolescents with developmental disabilities in Hong Kong- a pilot study**

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### **Background**

More children with developmental disabilities (DD) have reached their adulthood and transit from the paediatric to adult health services after 18 years of age. Information about clinical transition is limited and fragmented in Hong Kong. There is only one local study in this area on adolescents with chronic medical diseases but none on adolescents with DD.

### **Aim**

This pilot study was designed to understand the needs and concerns of adolescents with DD and their care-givers when transiting from the paediatric to adult health services in Hong Kong.

### **Methods**

A convenience sample of 22 parents and 13 adolescents recruited from two special schools was separately interviewed using a semi-structured questionnaire.

### **Results**

Most of the study parents and adolescents were unwilling to transit from the paediatric to adult medical services. The main themes of the underlying reasons were reluctance to changes and discontentment towards the adult medical service. The participants also urged for a structured clinical transition service to support them during this challenging time.

### **Conclusion**

This study was the first study in Hong Kong to understand the needs and concerns of adolescents with DD and their families during clinical transition. Although Hong Kong is considered to be a developed city, clinical transition is at a very infancy stage, unlike other developed countries such as USA, UK or Australia. There is an urge for a structured clinical transition service in Hong Kong. Further studies are required to analyse the needs and concerns of this population group and the service providers in both sectors in depth for establishing a local clinical transition service.

## **Early Social Communication Skills of Children with Cerebral Palsy: measuring the range**

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### **Early Social Communication Skills of Children with Cerebral Palsy: measuring the range**

#### **BACKGROUND**

The assessment of communication skills development for children with cerebral palsy helps define their “next-step” targets. However, as many of these children rely on use of gaze to convey their responses in assessments, it can be difficult for the clinician to establish a full profile of all communication domains. The assessment of social communication/interaction skills in this group is particularly difficult, as many of the standard assessments involve the manipulation of toys/objects. This presentation shows the use of two new measures developed as part of a study of such skills, for use with children with limited physical abilities.

#### **AIM**

The study aims to describe the range of ability in using “looking”/ gaze responses to show early social communication skills by a group (35) primary school aged children with severe cerebral palsy (GMFCS IV-V). We used two target procedures (Very Early Processing Skills and Spontaneous Joint Attention-Rabbits) to investigate such skills as response to give and respond to requests for joint attention, response to facial expression, understanding of symbolic representation and response to emotion.

#### **METHOD**

This group of children were tested on background and target measures at their schools. We will present data from these two target measures, developed and/or adapted to study the use of communicative eye gaze for early social communication skills in children with cerebral palsy.

#### **RESULT**

There is a range of abilities shown in the group, with this range not obviously related to language cognition, non-communicative gaze fixation abilities or chronological age. The two target measures showed good correlation.

#### **CONCLUSION**

Findings and implications will be discussed in relation to the developing understanding of social communication skills in children with cerebral palsy, and to clinical practice.

## **Use of activity monitors as an outcome assessment tool in children with cerebral palsy - a systematic review**

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### **BACKGROUND**

Effective assessment of physical outcomes in children with cerebral palsy (CWCP) is important to monitor their progress, evaluate interventions and guide healthcare policy. There is also a lack of systematic reviews, regarding the usage of activity monitors (AM) among CWCP.

### **AIM**

The aim of this systematic review was to evaluate the published literature studies on use of commercially available AM in the assessments of physical activity in CWCP.

### **METHOD**

This systematic review was conducted among the studies extracted from multiple online literature database including MEDLINE, Cochrane Library, CINAHL, PEDro and Google Scholar. Appropriate key words and Boolean terms were used and limits were set for publication dates from 1995 to 2015. Three reviewers conducted the systematic review based on the PRISMA criteria. The major inclusion criteria were as follows: 1. Studies should have used a commercially available activity monitor with a previously established validity and reliability, 2. Participants recruited for the studies must be CWCP and 3. At least one of the outcomes studied was a physical activity parameter. The studies were reviewed and summarized for research design, methodological quality, type of AM, parameters measured, results and conclusions.

### **RESULTS**

A total of 90 articles met the inclusion criteria and were selected for the review. The commonly used activity monitors were: vita move, Active pal, Actigraph GT3X, Step watch and sense wear. Some of the common physical activity measurement parameters, which the studies used to gather from the activity monitors were number of steps taken, calories burnt, sleep quality, heart rate, body temperature and type of exercise activity.

### **CONCLUSION**

Activity monitors, although considered to be a valid and reliable tool for assessing the level of physical activity in CWCP, large scale controlled trials are critically needed to support its specificity of usage among various group of CWCP.

## Task-oriented arm strength training in children with cerebral palsy

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**Background:** Based on the latest research and clinical insights, we recently developed a promising and innovative approach to increase manual performance of daily activities in children with spastic Cerebral Palsy (CP), namely Task-Oriented Arm Strength Training (TOAST-CP).

**Aim:** To compare the effectiveness of TOAST-CP with manual skill learning in improving the performance of manual daily activities in children with spastic CP. Primary aim of the training is to improve the level of performance of both hands in manual daily activities and primary outcome will be measured at the level of activity.

**Methods:** This multicenter randomized controlled trial will investigate the effectiveness of TOAST-CP in children with spastic CP, involving 60 participants aged 7-18 years. Participants will be recruited from nine rehabilitation centers.

**Intervention:** The participants of the intervention group will perform a TOAST-CP program, based on individual goals and guided by an algorithm. The control group will receive usual care related to manual skill learning program, without strength training. TOAST-CP consists of an individual-based 30 minute session, three times a week over a 16 week period. **Outcome:** Outcome will be measured at baseline at eight, 16 (end of training), three and six months after training.

As a primary outcome the Assisting Hand Assessment (AHA) will be used. At the activity and participation level (ICF-CY), the most important goals for the child and his/her parents will be scored by Goal Attainment Scaling (GAS). Task-oriented strength, muscle related strength and isometric grip task will be measured.

**Discussion:** This is the first randomized controlled trial comparing TOAST-CP with usual care related to manual skill learning. Using high-quality methodology, this trial will add evidence to the gap in knowledge about the effect of strength training in children with CP.

## **The impact of hip displacement on four domains of the CPCHILD questionnaire. A population-based study of 67 children with severe cerebral palsy.**

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### **Background**

CP surveillance programmes recommend consultation by an orthopaedic surgeon when hip displacement exceeds 33%. The Caregiver Priorities & Child Health Index of Life with Disabilities (CPCHILD) questionnaire was developed to measure care-giver reported effectiveness of interventions such as hip surgery.

### **Aim**

To explore the impact of hip displacement on selected CPCHILD domains.

### **Method**

Inclusion criteria: Enrolment in the Norwegian CP follow-up programme, birth year 2002-2006, bilateral CP, and GMFCS level III-V. Participants were 27 females and 40 males, with mean age 9.1 years (SD 1.4) and GMFCS level III 12, IV 17 and V 38. Comparison participants/non-responders revealed no significant differences. 39 children had undergone hip surgery. Outcome measures were scores on the CPCHILD domains Personal Care (Care), Positioning, Transferring and Mobility (Positioning), Comfort & Emotions (Comfort) and Overall Quality of Life (QOL). Lower score indicates more problems. Hip migration percentage (MP) was measured on radiographs. Hips were classified as normal ( $MP < 33$ ) or displaced ( $MP \geq 33$ ) with reference to the worst hip.

### **Results**

Hip displacement was present in 30 children (45%). Mean CPCHILD scores were: Care 40 (SD 16), Positioning 39 (SD 18), Comfort 73 (SD 18), and QOL 67 (SD 25). GMFCS level V was associated with lower scores on all domains. Hip displacement was associated with lower score on the Comfort domain only (mean score 77 in children with normal hips and 67 in those with displaced hips;  $p = 0.019$ ). In univariate regression analyses of each CPCHILD domain score vs. increasing MP by 1%, the Comfort domain score obtained the only significant association ( $B = -8.1$ ;  $p = 0.005$ ).

### **Conclusion**

CPCHILD Comfort domain score (which mainly reflects the amount of pain) seems more sensitive to changes in MP than scores on the Personal care, Positioning and QOL domains. This may have implications for the selection of outcome measures after hip surgery.

## **Identification of children with developmental coordination disorder with EACD diagnostic recommendations**

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**Background:** Developmental Coordination Disorder (DCD) significantly interferes with motor capacity and performance in daily activities. The disorder necessitates early and accurate identification in order to provide adequate support to the child. In Switzerland, the need of occupational therapy for children with developmental motor concerns is determined with a list of symptoms elaborated out of the CIM-F.82 criteria.

The EACD DCD-recommendations and Clinical Practice Guidelines for Germany and Switzerland advocate a multidisciplinary procedure of identification of the condition with the evaluation of the diagnosis criteria with culturally adapted, reliable and valid instruments. The evaluation of the child's motor capacity (criterion A) is better estimated with a norm-referenced motor test such as the MABC-2 and the performance in daily activities (criterion B) with a self-report questionnaire such as the DCDQ'07.

**Aim:** The aim of this study is to examine (1) the correspondence and complementarity between both the European-French version of the DCDQ'07, the QTAC-FE (Ray-Kaeser et al., 2015) and MABC-2, and F82 list of symptoms (2) how these two instruments help the health professionals filling in the F82 list.

**Method:** The participants (n=max) will be pairs of parent and child ranging in age from 5 to 15 years, clinically referred for motor difficulties and their occupational therapist (OT). Parents will fill in the QTAC-FE and the children will be tested with the MABC-2. The OT will be interviewed on the process of filling-in the F82 list. (1) Descriptive and (2) qualitative methods will be used.

**Result:** the data collection is in progress.

**Conclusion:** The results will be useful for implementing the EACD recommendations for the identification of DCD and need of support of the children in Switzerland.

## **Requirements to train a physiological walking pattern in the Lokomat with a dual task in children with neurological diagnoses**

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### **Background**

Robot-assisted gait training (RAGT) in combination with virtual reality (VR) enhances repetition, feedback and motivation especially in children. Still, one problem of RAGT is the limited transferability to over-ground walking, which requires more cognitive and motor skills. Dual task (DT) training has already shown to improve gait related outcomes in other populations. Nevertheless, no study evaluated RAGT with DT in children with neurological diseases so far.

### **Aim**

We aimed to determine what functional or cognitive characteristics patients require to perform a demanding DT RAGT physiologically, and whether leg muscle activation amplitudes change during DT training.

### **Method**

We combined RAGT with a newly developed VR, where reaching movements are included to increase task-difficulty and may stimulate the automation of walking in children with neurological diagnoses. EMG sensors were attached to muscles of the more affected leg and dominant arm. The children were instructed to walk in the Lokomat in four conditions, namely with and without reaching movements during normal RAGT or when playing the VR. Physiological performance was rated by the therapist. ROC analyses were done to differentiate between those who performed the task physiologically or not.

### **Result**

Included were 7 children (2 females, age 8.8-16.2 years, GMFCS I-IV, MACS I-IV, recruitment is still ongoing). Children with scores exceeding 3.5 (FAC), 24.5 (WeeFIM mobility), 4.5 (SCALE of more affected leg) or 26.5 (%TONI4 cognitive-score) or with a GMFCS level below 3.5 performed the task physiologically. Mean EMG amplitudes of all muscles seemed to decrease during DT compared to RAGT without DT. This decrease in EMG due to the DT appeared stronger while game playing compared to normal RAGT.

### **Conclusion**

DT affects the walking pattern and muscle activity depending on childrens' functional and cognitive characteristics. Therefore, DT training during RAGT might be beneficial for some children.

## **Immediate and delayed improvements in bimanual coordination after bimanual intensive intervention in children with cerebral palsy**

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**Background:** Children with unilateral cerebral palsy (UCP) have impairments in bimanual coordination that makes difficult their activities of daily living. The two-arm coordination test (TACT) is a discriminative method to measure bimanual coordination in children with UCP. Nevertheless, no study has reported its responsiveness to change. **Aim:** The aim of this study was to evaluate the responsiveness of the TACT after a HABIT-ILE intervention. **Methods:** 24 children with UCP (age range=6-12 years) attended 90 hours of HABIT-ILE during 2 weeks. Measurements with the TACT were performed before (pre-intervention), immediately after (post-intervention) and at follow-up. Number of errors and time used to complete the task were scored and combined in a performance index (PI). Responsiveness analyses were conducted by using global, group and individual approaches. **Results:** The global approach showed a significant PI improvement between pre-intervention and post-intervention that continued with small size effects in the post-intervention/follow-up period. PI improvement was associated to improvement of unimanual dexterity tests during the therapy and of bimanual performance in the follow-up. The group approach discriminated a group of children who improved their PI in the intervention period and still showed improvement in the follow-up, and a group of children who improved only in the follow-up. **Conclusions:** The TACT exhibited good responsiveness in detecting changes – even slight - in bimanual coordination of children with UCP, showing evidence of different timing in motor learning. This test can be reliably used to evaluate short and long-term changes due to therapy in this population.



## Clinical Implications of Bimanual Interference in Children with Unilateral Cerebral Palsy

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**Background:** Children with unilateral Cerebral Palsy (uCP) show more sequential movement with little temporal cooperation between hands during bimanual tasks. In addition, interference from extraneous movements (e.g. mirrored or associated movements) may further impact on bimanual function.

**Aim:** Investigate the impact of bimanual interference in children with uCP on clinical measures of manual function.

**Methods:** Children diagnosed with uCP (n=37; aged 10.9 +/- 2.6 years, MACS I-III, 20 male) participated in this study. They performed a bimanual task requiring opening a box with one hand and pressing a button inside with the other. We identified two movement strategies when box opening was performed with the affected hand (AH): Group I showed sequential movements with late start of less affected hand (LAH) and little or no overlap (n=26) and Group II showed interference with early start of the LAH and redundant movement (n=11).

Jebsen-Taylor Test of Hand Function (JT) assessed unimanual function. Functionality of the AH during bimanual tasks in daily life was assessed using the Children's Hand-Use Experience Questionnaire (CHEQ). A CHEQ ratio (CR) score was calculated from number of tasks that were performed with two hands divided by total number of tasks that were performed independently. Scores closer to 1 indicate better scores.

**Results:** JTAH was worse for group II (W=72.5, p=.32, location difference (diff)=-58 CI[-195,51]). The interference group also showed worse JT LAH scores as opposed to the group with sequential execution (W=74, p=.35, diff=-5.9 sec CI[-15.8,5.5]). For CR, significantly better performance was found for group I as opposed to group II (W=214, p=.016, diff=0.09 CI[0.01,0.28]).

**Conclusion:** The presence of strong movement interference (as in mirror movements) seems to have different clinical implications for children with uCP. Categorising into these subgroups might be useful in order to evaluate differential treatment response.

## **Practice change following an implementation study: The how and why of evidence adoption by occupational therapists working with children with cerebral palsy**

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**Background:** Delays in uptake of evidence into practice contributes to worldwide research waste. A recent implementation study targeting occupational therapy (OT) practice demonstrated modest changes in adopting “best evidence” to upper limb therapy for children with unilateral cerebral palsy (UCP).

**Aims:** To explore how and why OTs changed their practice.

**Method:** Three teams of OTs who participated in an implementation study were included. Of the original 9, 6 participated in the current study (Team A n=2 (50%) CP service; Team B n=2 (66%) paediatric rehabilitation service; Team C n=2 (100%) regional paediatric service). Semi-structured interviews conducted after completion of the a tailored multifaceted implementation intervention were audiotaped, transcribed verbatim and independently reviewed by two researchers. Content was mapped against four main outcomes of the study identifying what had changed, how, and why.

**Results:** Outcome 1 Goal setting: Formalised goal setting was implemented. OTs had increased awareness of its usefulness, perceived the process as feasible, with surprising and unexpected benefits. Outcomes 2 and 3 Use of contemporary motor learning approaches at adequate dose: OTs had greater awareness of the importance of increased repetitive task practice for motor learning. They experimented with constraint therapy, with observed benefits to patients which reinforced its continued use and increased therapist confidence. OTs developed group programs which were perceived as an easier context for constraint therapy (vs individual therapy). Therapists modified their views about home programs and felt more able to justify their importance based on increased knowledge of evidence. Outcome 4 Use of outcome measures: Formal measurement of upper limb outcomes remained limited.

**Conclusion:** Therapists had increased awareness and knowledge of evidence which enhanced confidence in delivering evidence-based interventions for children with UCP.

## **Distinction between pathological and functional muscle co-activation during active elbow extension in children with spastic unilateral cerebral palsy**

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**Background:** Children with spastic unilateral cerebral palsy (SUCP) have an involved upper limb (IUL) restricted in active range of motion (AROM) and in velocity when performing elbow extension, due to a combination of muscle impairments. One of them is excessive muscle co-activation (CA). CA usually has a functional role, particularly in joint stabilization. **Aim:** The aim of this study is to identify when pathological CA occurs during active elbow extension of the IUL to highlight its impact on movement restriction and to discriminate impaired muscles. **Methods:** 13 typically developing (TD) children and 13 children with SUCP performed active elbow extension/flexions at 3 externally paced frequencies. Elbow angle and velocity were computed using a subject-specific model tracking the position of 29 upper limb markers. With these data, the extension movement was decomposed into the Extension Acceleration Phase (EAP) (velocity increase) and the Extension Deceleration Phase (EDP) (velocity decrease). The percentage of CA for the brachioradialis(BR)/triceps and biceps/triceps couples for each phase was extracted from the surface electromyographic signals. Statistical analysis was conducted using linear mixed effects models. **Results:** During the EAP, excessive and positive frequency-dependent CA was found in the SUCP group, whereas CA in the TD group was low and invariant. These results point to pathological CA in the SUCP group, probably linked to restricted velocity. During the EDP, only excessive BR/triceps CA was found in the SUCP group. CA was positive frequency-dependent in both groups. These results point to mostly functional CA, for joint stabilization at the end of the movement. However, BR seems to stand out in its possible involvement in extension AROM restriction. **Conclusion:** This study provides insight into pathological CA in children with SUCP. Perspectives include individual clinical interpretation of the results, to assist in each child's therapeutic decision.

## **Head and trunk positions during sleep in adults with severe cerebral palsy and their relation to postural deformities**

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**Background:** Trunk deformities are commonly seen in adults with severe cerebral palsy. An asymmetric head position in daily life is a possible cause of these deformities.

**Aims:** To assess the head and trunk positions during sleep in adults with severe cerebral palsy and to test the association between the head-trunk symmetry and the direction of postural deformities, and the degrees of the deformities.

**Methods:** The participants were eight men and five women (ages 35–72 years) with severe cerebral palsy and postural deformities. Postural deformities are expressed as the direction of spinal curvature, the coronal Cobb angle, and the tilt and rotational angles of the trunk and pelvis, calculated using the 3D positions of body surface landmarks. The positions of the head and trunk during sleep were recorded using tri-axial accelerometers. Asymmetrical or symmetrical postures were identified whether the participant's head was rotated with reference to the trunk.

**Results:** The percentages of time spent in an asymmetrical position during sleep varied among the participants (mean: 45.5%, SD: 26.1%, min-max: 6%–98%). Eight of the participants spent more time in a symmetrical position than in an asymmetric position. No clear relationship was found between the head position (turned to the left or right) and the direction of spinal curvature (left or right), or between the head position and the direction of tilt and rotation of the trunk and pelvis. The period of time spent in an asymmetric position was not correlated with the coronal Cobb angle or the degrees of tilt and rotational angles of the trunk and the pelvis.

**Conclusions:** Head position during sleep was not related to the direction of postural deformities and/or degrees of the deformities in these 13 individuals with severe cerebral palsy.

## **"It has to be painful to be effective": experiences of children with cerebral palsy during physiotherapy**

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**Background :** Pain has a high prevalence in children and adolescents with cerebral palsy (CP). Recent studies exhibit that pain occurs during rehabilitation and especially during physiotherapy.

**Aim:** The purposes of this study were to identify the most painful rehabilitative procedures during physiotherapy, to analyse the pain management spontaneously developed by the children and therapists and to report the solutions proposed by the children.

**Methods :** 18 children/young adults with CP with a pain numerical scale of  $4.5/10 \pm 2.4$  (mean  $13.1 \pm 4.08$  years, 10 girls) during physiotherapy were interviewed using a "Focus Group" methodology. The questions followed a logical progression of an interview grid. The analysis was carried out from the verbatim to sub-themes and themes according to guidelines for qualitative studies. The themes were enriched gradually and inclusion were stopped when saturation were reached.

**Results:** Three themes emerged: (1) Experiences and emotional impact: Children reported notion of pleasure but stress and annoyance as well. (2) Pain occurrence and significance: Some children reported very painful experiences. For some children pain was a guarantee of effectiveness, for others it was not needed. Stretching of the adductors and triceps surae were reported to be the most painful. (3) Pain management: The relationship with the therapist was reported to have a great impact on pain perception. The children spontaneously developed adaptations to manage pain such as distraction or painkillers after the sessions.

**Conclusion:** This study confirms the reality of induced pain during physiotherapy. Stretching was clearly identified as the main painful procedure. Beliefs around pain shows that education is needed for children with CP and likely for therapists as well. New ways of stretching and improvement in communication between therapists and children may help in reducing the care-related pain during physiotherapy.

## **Which Measure Should I Use?: Content Analysis Using The ICF Core Sets For Children And Youth With Cerebral Palsy**

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**Background:** Selecting appropriate measure(s) for clinical or research applications for children and youth with Cerebral Palsy (CP) poses many challenges. The newly developed International Classification of Functioning (ICF) Core Sets for children and youth with CP serve as universal guidelines for assessment, intervention and follow up.

**Aims:**1) to identify valid and reliable measures used with children and youth with CP; 2) to compare the content of each measure to the ICF Core Sets CP.

**Methods:** Systematic review using multiple search engines to capture studies involving children with CP from 1998 to 2013. Interventional or observational studies published in English were included. All clearly defined measures were retrieved. Measures were classified as discriminative, predictive and evaluative. Psychometric properties were extracted when available. Construct of these measures were linked to the ICF. Subsequently, the content of each multiple-item measure was analysed using the ICF Core Sets as a reference.

**Results:** Out of 80 measures identified, 57 (72%) included reliability and validity testing. Most measures were discriminative, generic and designed for school-aged children. Measures with proven psychometric properties contained considerable variability in the degree to which their content represented the ICF Core Sets for CP. Primarily, measures covered the components of body functions and activities and participation. Overall, few categories from the ICF Core Sets were represented in the measures - between 2%-44%. One measure covered the majority of the environmental factors.

**Conclusions:** Results from this content analysis add novel information to characterize measures used with children and youth with CP. A combination of measures is needed to provide a comprehensive representation of the relevant areas of functioning included in the ICF Core Sets. Our results guide professionals seeking appropriate measures to meet their research and clinical needs.

## **Spatial localization skills in cerebral palsied children: how the presentation can influence children performances?**

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Spatial skills are requested for a large number of school learning and everyday life activities. These processes are known to be particularly vulnerable in cerebral palsied children who were found to be impaired in many visuospatial tasks such as pictures copy, visuospatial memory, construction with blocks, orientation and position in space and topology. However, the nature of their visuospatial deficit is still poorly specified. This study focus on the development of spatial localization processes in cerebral palsied children.

105 cerebral palsied children between 4 and 14 years old were tested with a spatial localization task (BEVPS) and were individually matched to typically developing children on chronological age. The tasks require participants to match a model (a blank matrix with 1 to 3 filled cells) with 3 responses possibilities. The size of the matrix, the presence of a grid and the position of filled cells were manipulated.

Results highlight that performances of 4 and 5 years children do not differ between groups. From 6 years, performances of CP children are significantly lower for all testing conditions (percentages of correct responses and reaction times) in comparison with the TD group. The presence of a grid does not improve children performances and even slows down CP children. Increasing the size of the matrix reduces significantly CP children performances. Analysis of errors highlights in control children the shifting of the global pattern more frequently than the shifting of a single element. However, CP children do not show the same pattern.

To conclude, spatial localization processing are deficient from the age of 6 in the CP group. Cerebral palsied children have no preference between local or global processing of the spatial components unlike TD children. At least, presence of spatial markers reduces CP children spatial skills.

## **Volumetric neonatal brain MRI and motor development in preterm infants at 11 years of age**

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**Background:** Preterm infants experience motor problems more often than children born at term. Regional brain volumes at term equivalent age are shown to predict motor development at 2 years of corrected age.

**Aim:** To study the prognostic value of regional brain volumes at term equivalent age (TEA) for motor outcome in very preterm infants at 11 years of age.

**Method:** A total of 98 very preterm infants were included. Volumetric brain magnetic resonance imaging (MRI) was done at TEA, and the Movement Assessment Battery for Children – Second Edition (The Movement ABC-2) and the Developmental Coordination Disorder Questionnaire 2007 (DCDQ'07) were assessed at 11 years of age. The presence of developmental coordination disorder (DCD) was determined by using the 5<sup>th</sup> percentile cut-off of the Movement ABC-2.

**Result:** The mean percentile of the total test score of the Movement ABC-2 examinations was 38.6 (SD 22.1, [0.5, 84.0]) in children without cerebral palsy (CP) (n=90). Only eight (8%) of all children had DCD, and 60% had regular after-school sporting activities. The results of the DCDQ'07 correlated with the results of the Movement ABC-2. Decreased volumes in all brain regions at TEA correlated with lower Movement ABC-2 total scores.

**Conclusion:** The majority of the preterm infants without CP had normal motor development at 11 years of age. Volumetric brain MRI at TEA provides an additional tool for predicting long-term motor outcome in preterm infants.



## THE RELATION BETWEEN TRUNK CONTROL AND GROSS, FINE MOTOR, COMMUNICATION AND EATING-DRINKING FUNCTIONS IN CHILDREN WITH CEREBRAL PALSY

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**Background:** Children with Cerebral Palsy (CP) have multiple problems such as motor, sensorial, communication and eating-drinking impairments. CP is caused by abnormal development or damage to the parts of the brain that control movement, balance, and posture. Some studies showed that postural control is important on these abilities.

**Aim:** We aimed that to investigate the relation between trunk control and gross, fine motor, communication oral motor abilities in children with CP.

**Method:** 43 children (4 to 17 years age) with CP [girl: 13 (30.2%), boy: 30 (69.8%)] In our study we classified levels of gross motor function, eating-drinking and communication abilities of children by respectively GMFCS, EDACS, CFCS. We evaluate trunk control with TIS. Spearman rank correlation was used to evaluate these assessments.

**Result:** Mean age was  $7.20 \pm 3.87$ . There was significantly relation between TIS and GMFCS ( $r_{static} = -0.89$ ;  $r_{dynamic} = -0.81$ ;  $r_{coordination} = -0.80$ ;  $r_{total} = -0.89$ ;  $p < 0.001$ ), TIS and MACS ( $r_{static} = -0.74$ ;  $r_{dynamic} = -0.66$ ;  $r_{coordination} = -0.67$ ;  $r_{total} = -0.77$ ;  $p < 0.001$ ). TIS and EDACS ( $r_{static} = -0.76$ ;  $r_{dynamic} = -0.52$ ;  $r_{coordination} = -0.53$ ;  $r_{total} = -0.77$ ;  $p < 0.001$ ), TIS and CFSC ( $r_{static} = -0.80$ ;  $r_{dynamic} = -0.65$ ;  $r_{coordination} = -0.67$ ;  $r_{total} = -0.83$ ;  $p < 0.001$ ).

**Conclusion:** Trunk control may be important for effective communication, eating-drinking abilities also better for gross and fine motor functions. Therefore speech therapists and physical therapists should focus on trunk control in rehabilitation programs and they may be make the decision together. We recommend to investigate the effect of trunk control impairment on children with different clinical types of CP separately in future studies.

## **Does the trunk control differ according to the limb influences in children with spastic cerebral palsy?**

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### **Background:**

Cerebral palsy (CP) is one of the causes of physical disability in children. Recent studies highlight importance of trunk control in children with CP.

### **Aim:**

We aimed that to investigate whether the trunk control differ in hemiplegic or diplegic children with CP.

### **Method:**

Eighteen children with CP (4-14 range years) were included in this study. Age, gender, CP classification according to Surveillance of Cerebral Palsy in Europe (SCPE), Gross Motor Function Classification System (GMFCS) were recorded by an experienced physiotherapist. Children were grouped in to extremity types of CP as hemiplegic and diplegic. The trunk impairment scale (TIS) was used to evaluate trunk control.

### **Result:**

Children age were  $7.50 \pm 1.49$  years in hemiplegic CP and  $6.60 \pm 0.89$  years in diplegic CP. Groups were similar about age ( $p > 0.05$ ). There were no significant difference in TIS all parameters (static, dynamic, coordination and total scores) among each groups ( $p > 0.05$ ). There was significant difference on trunk control between GMFCS levels ( $r = -0.89$ ;  $p < 0.001$ ).

### **Conclusion:**

Our study showed that the limb influence doesn't change trunk control in hemiplegic and diplegic children but GMFCS levels are strongly related with trunk control. Although hemiplegic children have unilateral impairment, but trunk control was effected as the same as diplegic children with CP. This study had small sample size. In future, it is needed to consider that larger sample size to investigate effects of unilateral and bilateral impairment on trunk control.

## **Predictivity of Assisting Hand Assessment on unimanual capacities and bimanual performances at preschool age**

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**Background.** AHA score at 18 months has been demonstrated predictive of assisting hand development in bimanual function at 8 years of age in children with congenital hemiplegia (Holmefur et al, DMCN 2010). Strong relationship between unimanual capacity and bimanual performance has been found at school age (Sakzewski et al, DMCN 2010). At our knowledge, predictive value of AHA score at early ages on unimanual capacities at school age has not yet been investigated.

**Aim.** Present study aims to evaluate the sensitivity of AHA to predict the unimanual capacities and bimanual performances at pre-school age in children with unilateral cerebral palsy.

**Method.** A sample of 11 children with congenital unilateral cerebral palsy were recruited at 2 years (T0) and assessed with AHA. The children were followed at preschool-age (5-6 years, T1) and re-assessed with AHA and MUUL. A rho Spearman correlation analysis was performed among the AHA percentage scores at T0 and those of AHA and MUUL at T1.

**Result.** A significant correlation among the values of AHA at T0 and values of AHA at T1 ( $r = .863$ ,  $p = .001$ ) and of MUUL at T1 ( $r = .829$ ,  $p = .002$ ) was found. Moreover, a positive correlation was found between AHA at T0 and MUUL at T1 ( $r = .862$ ,  $p = .001$ ).

**Conclusion.** These data show that the values of bimanual performances at 2 years could be predictive and influence the further development not only of bimanual performances but also of unimanual capacities. A larger study is needed to confirm these findings. This work was supported by Italian Ministry of Health-RF2012 GR-2011-02350053.

## RELIABILITY AND USABILITY OF THE TRANSLATED EATING AND DRINKING ABILITY CLASSIFICATION SYSTEM (EDACS) IN CHILDREN WITH CEREBRAL PALSY

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### BACKGROUND

Oromotor difficulties are common in individuals with Cerebral Palsy (CP) causing problems like growth limitation, malnutrition or other health problems influencing quality of life. A functional classification system for eating and drinking abilities has been developed in the UK, called the EDACS (Eating and Drinking Ability Classification System). The EDACS identifies key features of safety (choking, aspiration risk) and efficiency (duration, loss of food) linked with limitations to oral feeding skills. EDACS comprises 5 levels. The reliability has been studied in an English CP population and showed promising results (ICC 0.93)<sup>1</sup>.

### AIM

The aim of our study was to translate EDACS into Dutch, and to perform an interrater reliability and usability study with familiar, and non-familiar speech and language therapists (SLT's) in Dutch children with CP.

### METHOD

The EDACS was translated by Eremenco's method<sup>2</sup>. Children were classified on the EDACS by pairs of SLT's and parents. SLT1 knew the child well and SLT2 (not familiar with the child) just observed the child during mealtime(s). All therapists were specialized in working with children with CP. Correlation with other functional CP scales (like Gross Motor Function Classification System (GMFCS)) was determined.

### PRELIMINARY RESULTS

SLT's classified 149 children. The ICC between pairs of SLT's was 0.84 (95% CI 0.79-0.88), and between SLT1 and parents ICC 0.80 (95% CI 0.71-0.87). There was a significant but moderate correlation between EDACS and GMFCS (Kendall's tau 0.60). The usability study showed the EDACS was comprehensible for both parents and SLT's.

### CONCLUSION

The results of this study show good ICC's, so the Dutch EDACS is a reliable system for classifying eating and drinking performance by experienced, familiar and non familiar SLT's in children with CP.

(1) Sellers et al, Dev Med Child Neurol 2014; 56: 245-51

(2) Eremenco et al, Eval Health Prof 2005; 28: 212-232

## Children with Developmental Coordination Disorder show impaired local dynamic stability during gait

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**Background:** A recent meta-analysis on performance deficits in children with DCD suggests impaired dynamic control of gait, which may interfere with activities of daily. In a previous study we found increased trembling in static balance in children with DCD suggesting less effective automated spinal adjustments. This may influence gait control and stability. Local Dynamic Stability, defined as resilience to infinitesimal local perturbations naturally occurring during walking, could be a useful method of evaluating stability during gait. The aim of this study was to investigate if local dynamic stability in children with DCD is impaired.

**Methods:** 6 children with DCD ( $8.8 \pm 0.6$  years) and 10 typically developing children (TD) ( $9.1 \pm 0.4$  years) participated. Local dynamic stability was quantified as the short term Lyapunov exponent ( $\lambda_S$ ) from upper body accelerations during 4 min. treadmill walking at self-selected speed.  $\lambda_S$  was calculated from 0 to 0.5 stride using a fixed number of strides and expressed as logarithmic divergence per normalized stride-time [1]. A higher  $\lambda_S$  indicates a less stable gait.

**Results:** The DCD-group showed a tendency to a slower walking speed (DCD:  $3.2 \pm 0.2$  vs. TD:  $3.8 \pm 0.2$  km/h  $p=0.082$ ). A one way ANOVA showed a higher  $\lambda_S$  in the children with DCD ( $p \leq 0.01$ ), demonstrating poorer resilience to local perturbations during gait. Posthoc t-tests revealed that children with DCD had a higher  $\lambda_S$  in Medio-Lateral (DCD:  $2.04 \pm 0.10$  vs. TD:  $1.95 \pm 0.10$   $\lambda_S$ ;  $p=0.034$ ) and Anterior-Posterior directions (DCD:  $1.71 \pm 0.04$  vs. TD:  $1.41 \pm 0.06$   $\lambda_S$ ;  $p=0.001$ ).

**Conclusion:** The results showed a higher  $\lambda_S$  in children with DCD suggesting a less stable dynamic control of gait. The previously shown increased trembling in children with DCD indicates that less effective spinal adjustments could contribute to impaired local dynamic stability. This may have implications for future research in the effect of interventions.

[1]Stenum,J et al. J. of Biomechanics, vol 47, no. 15, pp. 3776-3779 (2014).

## **Ambulation level and walking performance in a total population of girls and women with Rett syndrome in Denmark**

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**Background:** Rett syndrome (RTT) is a rare neurodevelopmental disorder which mainly affects females. Approximately half of individuals with RTT are capable of walking 10 steps or more independently/with minimal support. More detailed information about level of ambulation and walking performance has not yet been reported in RTT. The Hoffer Ambulation Scale (HAS) categorizes individuals in five levels: Community ambulator(I), Household ambulator(II), Therapeutic ambulator(III), Stander(IV), Non-ambulator(V). The Functional Mobility Scale has previously been modified to persons with RTT (FMS-RS) and it assesses walking performance at 5m, 50m and 500m on a 0-4 scale (unable, maximal/moderate/minimal/no assistance).

**Aim:** To describe ambulation level and walking performance in the Danish population of girls and women with RTT.

**Methods:** All girls and women with RTT and a MECP2 mutation (n=95, age 3-60 years) were assessed with the HAS and the FMS-RS on the day of their visit at the Danish RTT Center or by telephone interview. As the HAS was a new tool to be used at the Center two physiotherapists administered this tool separately on n=66. Frequency tables were used to describe the distribution of scores on both tools. Inter-rater reliability for the HAS was assessed using intraclass correlation coefficient (ICC).

**Results:** The distribution of HAS levels were: I=47,4%, II=10,5%, III=13,7%, IV=15,8%, V=12,6%. With the FMS-RS 5m 40% were unable/required maximal assistance, 9,5% required moderate assistance and 50,5% required minimal/no assistance. For the FMS-RS 50m the percentages were 41,1%, 14,7% and 44,2%, respectively. Lastly, for the FMS-RS 500m the percentages were 62,2%, 6,3% and 31,5%, respectively. Agreement of HAS was excellent (ICC=0.98).

**Conclusions:** This is the first study to give a detailed picture of the daily walking performance in a total population of girls and women with RTT. The FMS-RS and the HAS offers complementary information about ambulation.

**Postural control intervention: a clinical study related to the efficacy of training balance in children from 2 to 6 years-old with spastic cerebral palsy**

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**Background:** Posture describes the relationship between the parts of the body Posture describes the relationship between the body and an external reference frame Posture also concerns the maintenance of the position of the body in relation to the reference frame

**Aim** To introduce an assessment and an intervention approach for babies and young children with cerebral palsy or developmental neurological impairment that focuses on treatment strategies for improving postural control inside the global rehabilitative approach

**Method:** We studied 20 children from 2 to 6 years-old with different types of CP through clinical baseline assessment of ecological interactive disability, specific reactive and proactive balance training and clinical assessment after intervention. GMFM, PEDI, Griffiths DS and specific balance skills tests were used in baseline and final assessments. Balance training for recovering from an unexpected external threat to stability during sitting or standing and for stabilizing posture in anticipation of a known threat to stability (voluntary movement) was performed using a moving platform bearing on a central pivot.

**Result** All the children trained with oscillating platform improved their postural control in post-training assessment.

**Conclusion** The study can be considered preliminary and was limited by the relatively small number of subjects included

## **Postural control in children, adolescents and young adults with congenital and childhood form of myotonic dystrophy type 1**

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**Background:** Myotonic dystrophy type 1 (DM1) is one of the more common neuromuscular diseases but with varying prevalence in different regions. Depending on the clinical symptoms and age at onset, DM1 is classified into subgroups. The disorder is multi-systemic with symptoms from the gastrointestinal system, muscular system, endocrine system, heart and central nervous system. Former studies have shown that contractures, muscle weakness and skeletal deformities are common and that motor skills are affected. Individuals with DM1 is also at higher risk of falling compared to healthy individuals. The knowledge of postural control in DM1 is still insufficient and needs to be further investigated.

**Aim:** To increase knowledge regarding postural control in children, adolescents and young adults with congenital and childhood form of DM1.

**Method:** Seventy-seven individuals, born 1981-2013, with congenital and childhood form of DM1 from southern and western Sweden were invited to participate in the study. Postural control was assessed with the Bruininks-Oseretsky Test of Motor Proficiency, using the subtest balance. The passive range of motion of ankle dorsiflexion and isometric muscle strength in ankle dorsiflexors were also investigated.

**Result:** Twenty-one female (7,1-28,9 years of age) and 23 male (8,2-28,8 years of age) completed the tests. The preliminary data show that postural control is decreased in a majority of the group. Degree of muscle weakness in the ankle dorsiflexors, range of motion in ankle dorsiflexion seem to be of importance for postural control as well. It also seems that the postural control deteriorates with age.

**Conclusion:** The knowledge of postural control in children, adolescents and young adults with congenital and childhood DM1 is important to improve the understanding of how daily life is affected and how to stimulate positive development.



## **The Canadian Occupational Performance Measure (COPM): How does it perform over a 3-year period for young children with cerebral palsy (CP)?**

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**Background:** The COPM is a reliable and valid outcome measure in which individual goals for occupational performance are identified and performance and satisfaction are rated on a scale of 1 to 10 (10 is the highest). It has become a popular outcome measure in pediatric rehabilitation research due to its responsiveness to change over a 3-6 month timeframe. However, the COPM's utility has not been evaluated over a longer follow-up period.

**Aim:** To determine the COPM's potential to change on individualized goals over 3 years.

**Method:** A prospective cohort study of ambulatory children with spastic CP, aged 2-6 years were recruited. Caregivers rated their child's performance and satisfaction on the goals at baseline & annually for 3 years. The COPM's ability to change was operationalized as performance scores less than 10 at both 1 & 2 year time points.

**Result:** 124 participants (age mean 3.9, SD 1.2y); GMFCS level I (62%), II (17%), III (20%) set 352 long-term COPM goals focused on gross motor activity & participation at baseline. 331(94%), 321(91%), 300(85%) goals were re-scored at 1-year, 2-years, and 3-years follow-up respectively. When evaluating the 331 goals with 1 year follow-up, 85% had performance scores less than 10. Using the 321 goals with 2 years follow-up, 77% had performance scores less than 10. At 1 year, 47(14%) goals had reached a maximum performance score of 10. Of those goals that reached a maximum score at year 1, 29 of 47(62%) goals were sustained at a score of 10 at 2 years. At 3 years, 21 (45%) of these goals were maintained at a score of 10.

**Conclusion:** Over 3 years, the majority had scores less than the maximum indicating they did not reach a ceiling and the COPM had the capacity to measure improvements in achieving individualized goals. Maintaining a maximum score over time was variable such that subjective perceptions may be susceptible to change. Overall, the COPM shows potential in its utility to measure change over a longer timeframe.

## **The Multilocomotor with pedaling system enhances mobility and the exploration in children with special needs.**

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**?Background?**For typically developing infants, the emergence of independent mobility via crawling and walking is associated with advances in motor, social, emotional, language, cognitive, and perceptual development. For children and adults with mobility impairments, such as those with significant cerebral palsy (CP), a power chair can provide both independent mobility and the associated improvement in quality of life. We developed Multilocomotor with pedaling system ('MPS'). MPS is power mobility device gets on by the standing position and the touch switch or the joystick can be operated. Our training uses an experimental power mobility device MPS that is small enough to be driven in the clinic.

**?Method?**One child, ages 7 male with spastic quadriplegic CP. GMFCS: level ? MACS: level ?. He began the MPS training from 4 years old for 40 minutes once a week. We did about 120 sessions in 3 years. There were three phases: a Baseline Phase consisting of 6 months the use of a MPS, a Trial Phase consisting of 18 months utilizing a MPS, and a Practice Phase consisting of 12 months utilizing a MPS. We videotaped MPS usage, later analyzing it with a behavior coding system. Moreover, we used and evaluated Assessment of Learning Powered mobility use.

**?Result?**In the evaluation of Assessment of Learning Powered mobility use, the Baseline Phase was Phase 2-Curious Novice. Trial Phase was Phase 4- Advanced beginner. Even Trial Phase required time to understand the position with the obstacle. Total time was measured to the directed word from the adult by about 30%. Practice Phase was Phase 6 -Competent.

**?Conclusion?**Child with severe CP becomes passive, and tends to lose the ability and independence. It is important for child with severe CP to use power mobility to enhance their social development.

## Reliability of manual muscle testing (MMT) for children with Spina Bifida

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**Background:** Manual muscle testing (MMT) is commonly used to monitor muscle strength and associated neurological status of children with spina bifida. For this to be clinically valid, a standardized and reliable MMT protocol for children with spina bifida is critical. Clinicians commonly use the Daniels and Worthingham (D&W) MMT protocol due to the extensive methodological information available. However, this protocol and its accompanying images is prepared for adults, and reliability has not been established for children with Spina Bifida.

**Aim:** Examine the inter-rater reliability of the D&W MMT protocol for children with spina bifida when applied by experienced and novice physiotherapists.

**Method:** 13 children with Spina Bifida (2 males) aged 6-12 years (mean 12 years 6 months, SD 2 years 9 months) were recruited from a Spina Bifida service in a state-wide tertiary children's hospital. Each child had strength of 19 lower limb muscles examined bilaterally using the D&W MMT protocol by one experienced and one novice physiotherapist. Examiner and limb order was counterbalanced. Fidelity was enhanced by (1) recreation of the D&W photo guide for each MMT test for each muscle with a child model; (2) development of a standardized recording form, (3) examiner training with children not in the study until agreement was reached on technique and scoring. Agreement between raters was examined with quadratic weighted kappa ( $\kappa_w$ ), percent exact agreement (%EA) and Bland-Altman limits of agreement (LoA). Minimal detectable change (MDC) was also calculated.

**Result:** The D&W MMT protocol shows excellent inter-rater agreement ( $\kappa_w = 0.950$ ; 95% CI: 0.935 - 0.962); good %EA = 72.29%; and appropriate LoA (-1.302 - 1.402) when results of experienced versus novice raters are compared. The MDC was 1.11 points on 6-point MMT scale.

**Conclusion:** The D&W MMT protocol, when used after standard training and with standard recording forms, is reliable for use with children with Spina Bifida.

**Does sensation change with age in children and adolescents? A systematic review.**

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**Background:** Somatosensory modalities, such as touch, proprioception and haptic ability greatly influence the achievement of developmental milestones for children. Describing somatosensory impairment, natural variability and typical or expected developmental changes across age groups will help establish frameworks for intervention in clinical populations.

**Aim:** This systematic review aimed to determine how different somatosensory modalities develop across childhood into adolescence to use as a point of reference for children at risk of somatosensory impairment.

**Methods:** Searches of 5 electronic databases were undertaken through EBSCO-host (MEDLINE, CINAHL, PsycINFO, SPORTDiscus and ERIC). Studies measuring at least one somatosensory modality in typically developing individuals between birth and 18 years and analysed by age were included. Characteristics of studies were collected including country of origin, sample size, demographics and outcome measure used. Quality assessment and data extraction were performed by two independent reviewers.

**Results:** Twenty three cross-sectional studies were included from a total of 188 articles retrieved: 8 examined aspects of touch, 5 proprioception, and 10 haptic ability. Variability of study designs and variation in outcome measurement tools precluded any formal meta-analysis.

**Conclusions:** Somatosensation matures through childhood into adolescence however, this review found the pattern of somatosensory development varied depending on the outcome measure used and the aspect of somatosensation being measured, making it difficult to describe expected performance. There is a need for comprehensive assessment batteries to measure the somatosensation, including touch, proprioception and haptic ability, of children at risk of somatosensory impairment to aid in the development of effective interventions.

## **To analyze the variability of the Jebsen-Taylor Test of Hand Function (JTTHF) outcomes as a result of Hybrid Constraint-Induced Movement Therapy (H-CIMT): a multiple single subject design**

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### **Introduction**

In this study children with Cerebral Palsy (CP) were subjected to Hybrid Constraint-Induced Movement Therapy (H-CIMT), i.e. a highly intense training camp of two weeks, for which Jebsen-Taylor Test of Hand Function (JTTHF) was used to quantify the dexterity of both hands before, during and after the intervention. It was expected that JTTHF outcomes showed a gradual improvement of arm-hand function as a result of the H-CIMT training camp.

### **Aim**

Aim of this multiple single subject study was to analyze effects of H-CIMT on JTTHF outcomes.

### **Methods**

Eight children with CP were included in this multiple single subject study (ABA-design). All children were tested with the JTTHF weekly for six weeks before (T1-T6) (A) and six weeks after (T11-T16) (A) and twice a week during H-CIMT (T7-T10) (B). Differences between all periods were analyzed by means of the Friedman Test, Wilcoxon Signed Rank test and the Coefficient of Variance (CV) of each child.

### **Results**

No significant changes were found between the three periods. Additionally, the CV values (%) of each child showed great variability between periods but also between children.

### **Conclusion**

JTTHF results did not show a training effect of H-CIMT. Regarding future research, the use of JTTHF should be reconsidered if it adequately represents arm-hand dexterity in children with CP.

**The Gait Outcomes Assessment List (GOAL): Validation of a new measure of gait function in ambulant children with cerebral palsy.**

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**Background:** Although a number of valid and reliable outcome measures have been described to measure aspects of gait function in children with cerebral palsy (CP), to date none have been developed with the input of children, their parents or caregivers. The Gait Outcomes Assessment List (GOAL) has been developed by a multidisciplinary team of researchers to reflect the aims and priorities of children and their parents. It has been designed to address all domains of the WHO-ICF.

**Aim:** The purpose of this study was to assess the validity of the GOAL as a measure of gait function in comparison with the “gold standard” three dimensional gait analysis (3DGA).

**Method:** A retrospective analysis of prospectively gathered data in 90 children and youth with CP, GMFCS levels I-III, mean age 12 years 1 month (3 years 5 months) with a range of 6-20 years, who attended a clinical gait analysis laboratory in 2014. During a full biomechanical assessment and 3DGA, parents completed the GOAL questionnaire. From kinematic data, the Gait Profile Score (GPS) and Gait Variable Scores (GVS) were calculated. Spearman Rank correlations were performed to compare total GOAL scores and GPS, and individual domain and item GOAL scores, with selected kinematic criteria and GVS scores.

**Result:** There was a strong negative correlation between total GOAL score and the GPS with a Pearson's correlation of  $r = -0.66$ , ( $p < 0.01$ ). The correlation between gait appearance domain and GPS was  $r = -0.56$ , ( $p < 0.01$ ). A moderate positive relationship was found between total GOAL score and gait velocity,  $r = 0.43$ , ( $p < 0.01$ ). Correlations between other kinematic criteria and gait appearance domains were less strong.

**Conclusion:** The GOAL shows strong correlations with the GPS suggesting that it is a valid approach to the assessment of gait function in ambulant children with CP, which addresses all domains of the WHO-ICF. Future studies are required to examine the responsiveness of the GOAL to change following intervention.

# **The Gait Outcomes Assessment List (GOAL): Discriminative Validity of a new measure of gross motor function for ambulant children with cerebral palsy.**

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**Background:** Current tools for measurement of gait and gross motor function in cerebral palsy(CP) provide objective information but may not include the child or family's priorities, expectations or views on function. The Gait Outcomes Assessment List(GOAL) may be the first outcome tool developed with direct input of children with CP, their parents or caregivers.

**Aim:** To investigate the discriminative validity of the GOAL as a measure of gross motor function in ambulatory children with CP.

**Method:** A retrospective analysis of prospectively gathered data on 105 children and youth; 65 boys, 40 girls, mean age 11y 11m, SD(3y 5m), range 6-20y with CP who attended a gait laboratory in 2014. Parents completed the GOAL during their child's gait analysis(3DGA). Total GOAL scores and domain scores were analysed. The discriminant validity of the GOAL was evaluated by comparison with standard instruments: GMFCS, Functional Mobility Scale(FMS), Gillette Functional Assessment Questionnaire(FAQ)

**Results:** Total GOAL followed a normal distribution with no floor/ceiling effects. Internal consistency was found with moderate-strong correlation between scores on all but one GOAL domain. Total GOAL discriminated between GMFCS levels ( $F(2,97)=42.4$ ,  $p<0.001$ ). Moderate-strong correlations were found between total GOAL, FMS and FAQ. Spearman's rho total GOAL and FMS were for 5 & 50m 0.59 ( $p<0.01$ ) and for 500m 0.66 ( $p<0.01$ ).

Pearson's correlation coefficients total GOAL were 0.75 ( $p<0.01$ ) and 0.74 ( $p<0.01$ ) with FAQ walking and activities scores respectively.

**Conclusion:** This study provides preliminary evidence that the GOAL is a valid measure of gross motor function in ambulant children with CP. It may improve understanding of child's and family's perspective of motor abilities, priorities and expectations. With 3DGA, it may provide a balanced assessment of outcomes across all domains of the WHO-ICF.

Further investigation should focus on the reliability and responsiveness of the GOAL.

## Real-time feedback to improve gait in children with cerebral palsy

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**Background:** Clinical gait analysis in children with cerebral palsy (CP) typically focuses on comfortable, regular walking. However, regular walking allows for compensations, which can make it difficult to unravel the causes of gait abnormalities. An alternative may be to challenge subjects out of their regular, deviant pattern using real-time feedback (FB). This may also be useful for targeted gait training. However, it is not known how children with CP respond to real-time FB.

**Aim:** To establish whether children with CP can adjust their gait pattern to real-time FB.

**Method:** 16 children with CP (age 6-16; GMFCS I, II and III) and a flexed-knee gait pattern walked on an instrumented treadmill in a virtual reality environment in 3 conditions: regular walking, feedback on the hip- (FBH) and on the knee angle (FBK). Hip and knee extension were calculated in real time and used to give FB on a bar plot. The aim was to maximize hip- or knee extension, while target values were presented at the top of the bar-plot. The gait profile score (GPS) [1] was calculated to see whether the overall gait improved.

**Results:** Peak hip and knee extension angles improved significantly in both FB conditions. In FBH, hip extension improved by  $5.1 \pm 5.9^\circ$  ( $p=0.01$ , 13/16 subjects) and knee extension by  $5.1 \pm 7.0^\circ$  ( $p<0.05$ ). In FBK, knee extension improved by  $7.7 \pm 7.1^\circ$  ( $p<0.01$ ; 15/16 subjects) and hip extension by  $3.7 \pm 6.2^\circ$  (ns). GPS did not improve, due to increased deviations in trunk, pelvis and ankle.

**Conclusion:** Almost all children were able to adapt their gait pattern and able to respond to real-time feedback, resulting in an improvement in peak hip and knee extension. The various compensation strategies used may indicate different underlying causes of the flexed-knee gait pattern. These findings show that real-time feedback is a promising tool for advanced gait analysis and might enable functional gait training in CP.

**References:** [1] Baker R et al. 2009 Gait Posture 30(3):265-9



## **What do people with severe disabilities communicate with the help of communication aids?**

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### **Background**

Functional communication can be described as the ability to receive and convey messages in a given context. It is important that assessment and intervention of communication take place in an individuals' everyday context. Thus, people in the professional and social network are important sources of information regarding individuals' communicative abilities. In this session, two survey studies will be presented.

### **Aim**

The overall aim of both studies was to investigate how people in the professional and social network of individuals with severe disabilities perceived that communication aids influenced the communication. The targeted populations were communication partners to children with Cerebral palsy (study 1) and Speech language pathologists (SLPs) to children and adults with Rett syndrome (study 2).

### **Method:**

Informants were primary caregivers (n=24), teachers (n=15) and personal assistants (n=18) (study 1) and SLPs (n=77) (study 2). The data was collected by questionnaires; distributed over the web, on paper or by telephone interviews. The studies covered aided communication in home and school settings.

### **Result:**

On the group level, the informants reported that the individuals with CP and Rett syndrome expressed a variety of communicative functions using aided communication. However at the level of the individual informants reported a narrower range of communicative functions.

### **Conclusion:**

Communication aids appear to facilitate communication with individuals with severe disabilities according to the professional and social network. There is a need for further knowledge on possibilities to widen the range of communicative functions that individuals with severe disabilities can express.

## SETTING GOALS WITHIN A REHABILITATION GROUP

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**Background.** Two child neurology units from university hospitals and three national learning and consulting centers have evaluated and developed their practices in Finland. One such development is the adoption of the GAS (Goal Attainment Scaling) which is an individualized, evaluative outcome measurement tool that rates the extent to which goals are attained.

**Aim.** The study evaluates the clinical practices of rehabilitation planning with an aim to examine and describe how rehabilitation goals are produced in a transdisciplinary team. In addition, the study seeks to answer the question of how rehabilitation goals are discussed within teams.

**Method.** The research data has been gathered by video-recording the activities of the teams in various working environments. The final collection of data consists of 13 rehabilitation planning meetings. The data was then analyzed with content analysis.

**Result.** The rehabilitation plan was always drawn up in cooperation with the child/youth and the parents. Two types of goal-related speech are produced within the teams: family-oriented and external-oriented. The family-oriented goals were ones presented by both the parents and the children. In some cases these goals were presented using GAS-method, in which cases the goals were related to the life of the family. A large amount of external speech, which revolved around various goals presented by different professionals that did not have a connection to the lives of the family, was also present within the activities of the teams.

**Conclusion.** Many types of goal-oriented speech was produced within the transdisciplinary teams. While many of the goals proposed by professionals are ones not attached to the life of the family and the child/youth, utilization of the GAS-method helps in redirecting goals in a manner where they are related to the life of the family. Utilizing the GAS within work groups must be developed into an integral part of a group's operation.

## **Computer Based Working Memory Training Initiated in a Hospital Setting for Children with Cerebral Palsy (CP) at Preschool Age – Pilot Project Protocol**

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### **Background**

Cognitive deficits e.g. impaired visual-spatial attention or working memory (WM) functions are common findings in children with cerebral palsy (CP). Working memory relies heavily on the fiber pathways of the brain linking the frontal and parietal parts of the brain. Studies show that the most common brain injury in children with CP is white-matter lesions.

### **Aim**

To evaluate the applicability of WM training and a chosen standardized neuropsychological test battery for preschool children with CP. At a later stage, we intend to carry out an effect study sampling a number of children with CP that will yield statistical power to evaluate training effects and near and far transfer effects of the training.

### **Method**

Six preschool children with CP will undergo the Cogmed Junior Memo (JM), computer based WM training program. Training will be initiated over one week in a hospital setting during participation in Program Intensified Habilitation (PIH) and completed at home with parents as training aides. The JM training consists of 25 daily sessions completed over a five week period. The children will be assessed with a standardized battery of neuropsychological tests while parents fill out questionnaires regarding behaviour difficulties, executive functioning and adaptive behaviour, directly before training, 10-12 weeks after completed training and six months after start of training.

### **Results**

Our primary outcome is the number of children that are able to complete the training. Secondary outcomes are parents' reports after training with their children and their subjective experiences with the effect and usability of the computer program itself.

### **Conclusion**

This pilot study is an important first step in designing a larger effect study, both in terms of technical and clinical considerations and when considering the ethical implications of assessing effect of a time consuming training task for young children and their parents.

## **Investigating the relationship between hypermobility and movement proficiency in children between 6-12yrs old**

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**Background:** Recent research has explored the potential overlap and co-occurrence of hypermobility and low movement proficiency (LMP), with a consistent deficit in proficiency seen in children with identified or symptomatic joint hypermobility syndromes. However, there is limited evidence to-date on the relationship between LMP and asymptomatic hypermobility measured via objective clinical assessments.

**Aim:** To investigate the relationship between joint hypermobility and motor proficiency in children aged 6-12 yrs.

**Methods:** 40 children with a mean age  $8.1 \pm 1.7$  yrs recruited from the community participated in the study. Movement proficiency was assessed via the Movement Assessment Battery for Children-2 (MABC-2). Measures of hypermobility included the Beighton score (BS; cut off scores  $\geq 5$  for 3-9yrs and  $\geq 4$  for 10-16 yrs), Lower Limb Assessment Score (LLAS; cut off score  $\geq 7$ ) and the Brighton Criteria.

**Results:** Partial correlations controlling for age demonstrated no significant relationship between the MABC-2 score, BS ( $r = -0.09$ ,  $p = 0.57$ ) or the LLAS ( $r = -0.15$ ,  $p = 0.38$ ). No participants met the criteria for joint hypermobility using the Brighton Criteria, however 64% of the sample was classified as hypermobile according to the standard BS cut-off compared to 28% via the LLAS. Using a revised BS cut-off of 7, 20% of the sample was classified as hypermobile. Of the total sample 50% were classified as at risk of movement difficulties according to the MABC-2 (below 16<sup>th</sup> percentile), with 32% and 42% also classified as hypermobile by the revised BS and LLAS respectively.

**Conclusion:** Contrary to the existing evidence in the field, these results demonstrate no relationship between movement proficiency and hypermobility in a community-based sample of 6-12 yr olds. Whilst hypermobility and movement proficiency appear to be distinct constructs those children experiencing greater mobility in addition to coordination difficulties warrant particular attention from clinicians.

## **Evaluation of the psychometric properties of the School Setting Interview (SSI) for students with cognitive difficulties in upper secondary school.**

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Evaluation of the psychometric properties of the School Setting Interview (SSI) for students with cognitive difficulties in upper secondary school.

**Background:** The School Setting Interview (SSI) is an assessment that investigates the student-environment fit. Evidence supports validity for the SSI concerning students with physical disabilities but the psychometric properties of the assessment has not yet been tested in regard to students with mainly cognitive difficulties.

**Aim:** The aim is to investigate the psychometric properties of the School Setting Interview (SSI) regarding students with cognitive difficulties in upper secondary school. I.e. whether or not the SSI measures a unidimensional construct, whether or not the students' response patterns are consistent, whether or not the SSI items are valid for students with cognitive difficulties, and whether or not the SSI rating scale is used in an appropriate manner.

**Methods:** Rasch analysis was used to examine the psychometric properties of the SSI. In total 509 SSI assessments were included in the analysis.

**Results:** The preliminary results of the Rasch analysis revealed that all except two of the sixteen items, "Social break activities" and "Accessing school", worked effectively to measure the underlying construct of student-environment fit. These two items were also found to be the easiest for this group of students. However, the overall validity of the SSI items was satisfactory. No Differential Item Functioning (DIF) was revealed in the analysis, i.e. the items measured the same ability in the same way across the group and were not influenced by gender. The response patterns of students were found to be consistent and the rating scale was used in a valid manner.

**Conclusion:** The findings support the use of the SSI for students with different cognitive difficulties in order to assess the person-environment fit of their school environment.

## **A comparison of Movement ABC-2 data from Italy and the UK**

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**Background.** The Movement Assessment Battery for Children (MABC-2) Test is widely used to identify children with motor problems. Ideally, any country using the test should produce national norms, which provide data on the performance of typically developing children and thus take into account cultural diversity in motor experiences. This helps to verify the validity of the test for local use.

**Aim.** To compare performance on Age Bands (AB) 1 (3-6 year olds) and 2 (7-10 year olds) of the MABC-2 in Italian children with data from the UK standardisation sample.

**Method.** Data from an Italian sample of 718 children (338 in AB1; 380 in AB2) were compared to data from 765 children from the UK standardisation sample (432 in AB1; 333 in AB2). Children were individually tested on the 8 items testing the three competence areas: Manual Dexterity (MD), Aiming and Catching (AC) and Balance (B).

**Results.** Multivariate analysis of variance revealed only a few significant country differences on individual items within the three competence areas and for single age years within the two age bands. Significantly better performance for the Italian sample was found in a timed manual dexterity task at 7 (MD1 preferred and non-preferred hand) and 9 years old (MD1 non-preferred hand) and on one task involving ball skills (AC1) at 9 and 10 year old. Significantly better performance for the UK sample was found in a non-timed drawing task (DM3) at 5 and 6 year old and a balance task (B2) for the ages of 3, 6 and 7 years.

**Conclusion.** Results suggest the test is suitable for use in Italy. Differences are discussed in relation to the school and sport experience at different ages and across the two countries.

## Evaluation of graphic and constructional praxis abilities in children through a digitizing tablet

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### Background

Paper and-pencil tests are commonly used in clinical practice for evaluation of motor and graphic constructional skills; analysis of planning and execution abilities through a cinematic analysis of performances (digitizing tablet) can be useful for a better definition in dysgraphia and dyspraxia diagnosis.

### Aim

1. Analyze kinematic parameters in graphic and constructional praxis tasks observing their modification in different age groups (7-10).
2. Define quantitative and qualitative index for a description of performances and for assessment of the effectiveness of specific interventions in rehabilitation
3. Show profiles in children with dysgraphia and dyspraxia

### Method

Neuropsychological tests (Visual Motor Integration, Rey-Osterrieth Complex Figure, Graphic motor fluency) have been proposed with a digitizing tablet; performances in 98 children have been analyzed through specific cinematic parameters (Total time, Total drawing duration, Total Pause Duration, Number of strokes, Maximum duration of a single stroke, Maximum Duration Single Pause, Total Drawing Area, Mean Stroke Speed, Total Strokes Length)

### Results

Significant changes are evident in the running time between the performance of 2<sup>nd</sup> and 5<sup>th</sup> class, in the total duration of the phases of not writing, in the maximum duration of each phase of not writing and in the total length of the lines.

### Conclusion

Digitizing tablet can be considered a useful tool in the analysis of graphic and-constructional praxis tasks in children.

Kinematic parameters allow a better definition of space-time characteristics related to graphic performance showing a trend that confirms the evolution of these skills with age.

Kinematic parameters generally do not correlate with the standard score to emphasize that these should be considered complementary to scores assessments test; specific and different profiles of patients with dysgraphia and dyspraxia disorders will be presented and discussed.

## **Addressing an urgent unmet need: creating evidence-based resources for community health workers to support children with neurodevelopmental disabilities in low-resource contexts.**

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### **Background**

Approximately 150 million children live with Neuro-developmental Disabilities (NDD), 90% of whom live in developing countries, however the paucity of specialized human resources to deliver services to these children remains a challenge in low and middle income settings. The WHO 2010 Community Based Rehabilitation Guidelines and 2011 World Report on Disability recommend a community based approach for children with NDD, however, the availability of trained community workers is variable and official guidelines on specific intervention strategies do not exist. Where community-based ‘rehabilitation’ is available, evidence of the effectiveness of the interventions is lacking.

### **Aims**

MAITS, a UK based charity involved in capacity-building of staff working in low-resource settings, was encouraged by an Indian non-governmental organization (NGO), Sangath, to develop a culturally sensitive resource using principles from evidence-based practice within therapies for children that could be implemented by community health workers.

### **Method**

The paper manual was developed using peer reviewed contributions from a range of experienced healthcare and education professionals from the UK and South Asia. The manual focuses on promoting functional everyday living skills, rather than impairment-based interventions. It has been piloted in Nepal, and is now being disseminated through NGOs in several countries. Parts of the manual have been developed into the ‘INFORM’ mHealth platform by Sangath, for ease of use, flexibility of upgrading and extending, and to enable remote interactive dialogue with supervisors as well as data gathering. This will be piloted in India next year.

### **Conclusion**

This project aims to support the delivery of evidence-based practices, at minimum cost, to support children with NDD by providing open-source paper-based and mHealth resources for generic community workers to maximize the quality of life of children and their families across the globe.



## **Defining the requirement for a system to enable the exploration of functional movement by children with dystonic cerebral palsy age 2 to 5 years.**

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### **BACKGROUND**

Whole body dystonia is a complex movement disorder that profoundly affects children and their families. Current seating systems are often inadequate due to their restrictive design. The research is being conducted as a partnership between families, therapists, paediatricians, and engineers.

### **AIMS**

To create a new functional postural support system that enables the exploration of functional movements, and also to identify appropriate functional outcome measures.

### **METHOD**

Consultation with new and experienced parent carers, children/young people, and clinicians was carried out to identify detailed information on the design requirements. Parents contributed their lived experience and expertise in managing everyday issues for disabled children; clinicians provided expertise on positioning children with complex disability; and work with disabled children enabled a range of support schemes to be evaluated.

### **RESULTS**

Parents and professionals highlighted the importance of floor play and table-top / tray activities in this population, as well as the need for simple adjustment, cleaning and transport. The need for beautiful design featured strongly in feedback from parents. Manual evaluation of support strategies showed that children should be able to be supported in side-lying, prone and seated positions, while allowing exploration of functional movement, and accommodating dystonic movements.

### **CONCLUSION**

Our collaborative work has shown that achieving functional floor-sitting is challenging in this population. We are designing a support system that works in multiple environments and contexts, using alternative positions and compliant support to accommodate dystonic movements, and allow children to explore functional movement strategies. Future work will include identifying appropriate and acceptable outcome measures of quality of life and functioning in physical and social domains.

Funded by Sparks Children's Charity and the Rooney Foundation.

## **Internet use among adolescents with intellectual disabilities in home and at school**

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**Background:** Today everyday life depends on having access to, understand and use internet in order to participate and take part in societal resources. This understanding can be complex for persons with intellectual disabilities (ID) due to their cognitive impairments. It is even stated that internet-use can be yet another part of daily life activities they are excluded from. Internet-use is claimed to involve risks, but also benefits for persons with ID, but there is a shortage in empirical studies with the target group's own opinion regarding this. Broader knowledge is acquired of internet-use in everyday life for adolescents with ID, as a precondition to participation.

**Aim:** This study aims to explore and describe internet-use and doing internet activities at home and at school among adolescents with mild and moderate intellectual disabilities.

**Method:** The study has a qualitative inductive design using observations and interviews in the two settings; at home and at school. Participants are six adolescents with mild and moderate ID, from special schools in the middle-region of Sweden, between the ages 13-20, that use internet to some extent. Data was collected at 2 occasions/participant for about 2 hours/participant/setting. The analysis was done using a qualitative content analysis.

**Result:** Preliminary results show that adolescents with mild and moderate ID use internet both at home and in school, to a greater extent than was expected, but the doings of internet-activities varies in the different settings. Both facilitating and hindering aspects are described by the participants. Pictures on the internet seem to be of support when using and navigating the internet.

**Conclusion:** Deeper knowledge regarding internet-use from the target groups own perspective has been gained. The results can be used in the different occupational settings and in further research to survey internet use and participation in internet-activities.

## **Empowering parents: Developing a digital tool to guide parents of children with disabilities to the right information**

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### **Background**

Parents of children with physical disabilities do a lot to support their child in daily life but also come across several challenges. They show a large scale of unmet needs (e.g. around financial issues, adaptations or finding suitable leisure activities). In the consultation process with physicians parents indicate a lack of information. Getting information about different aspects of care is difficult. Being informed is a major requirement for the process of empowerment and shared decision making. Parents who are better informed are able to prepare better for the consultation with different health care professionals, able to support each other and become equal partners in negotiating care or supporting child's participation

### **Aim**

In co-creation with parents, healthcare professionals, IT-professionals and researchers a digital tool will be developed, de WWW-wijzer (In English: WWW-roadmap) that will enable parents to explore their needs (What do you want to know?), help in their search for information (Where can you find information), and refer to appropriate professionals (Who can further assist you?).

### **Result**

The usability of the tool will be clinically evaluated by 80 parents of children with disabilities. Outcome measures include parental empowerment, use of the tool, family centeredness of care and patient and professional satisfaction.

### **Conclusion**

The tool is still under development. The objective of the (poster) presentation is (1) to describe the process of development of the tool, (2) describe the content of the tool, including pictures, and (3) share first experiences of parents with the tool. We hope a digital tool will help parents to explore their information needs and search for information.

## **Strategies of information seeking of parents of children with physical disabilities: An explorative qualitative study**

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### **Background**

Evidence suggests that parents of children with disabilities feel that not all their information needs are currently being met, but it is not yet clear how parents try to fill these information gaps. In this study we examine the way parents of children with a primarily physical disability search and value information from different sources.

### **Method**

Qualitative semi-structured interviews with parents were held to explore the strategies of participating parents concerning information needs. A thematic analysis approach was performed to analyse the interviews.

### **Results**

Fifteen interviews were conducted. Parents often started their search for information because of unmet information needs. Search strategies are adjusted depending on the type of information needed. The most important resources were healthcare professionals, peers, and institutions, such as hospitals and government authorities. Parents search for objective information from healthcare professionals' and institutions. Peers were the preferred resource for experience-based knowledge and support. Internet is a widely-used medium to search information and get into contact with different sources. There was a general preference for closed Internet communities for peer contact. Information evaluation is commonly done by comparing multiple resources.

### **Conclusion**

Parents search for different information needs at different sources. Information is valued through comparison of resources. Health care professionals should guide parents in their search for objective information and experience-based knowledge from peers.

## **ICF based functional goals in a context therapy program for children with cerebral palsy**

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**Background:** There is evidence that context therapy is an effective approach for children with cerebral palsy and a collaborative process for the definition of rehabilitation goals between family and professionals is essential for a successful intervention.

**Aim:** To describe ICF based functional goals established in a 6-month context therapy program.

**Method:** 41 children, aged 2-8 years, with cerebral palsy from west north part of Portugal were enrolled in the program. Once a week functional goals based in activities were defined using Canadian Occupational Performance Measure (COPM) with the active collaboration of parents/family in a home visit of two therapists. Goals were linked to ICF using established rules. Goal achievement was assessed with Goal Attainment Scale (GAS).

**Results:** ‘Self-care’ (26,8%), ‘mobility’ (26,5%) and ‘learning and applying knowledge’ (26,2%) were the ICF domains with the highest prevalence of functional goals defined. The lowest prevalence was found in the domain of ‘interpersonal interactions & relationships’ (0,6%). Goal achievement ranges between 56,1% for ‘learning and applying knowledge’ domain and 85,5% for ‘mobility’ domain. There was no association between GMFCS level and number of goals achieved or number of goals defined. An increase of performance satisfaction on COPM was reported by parents/family after 6 month intervention period.

**Conclusion:** Functional goals defined in a collaborative approach may improve the family-therapist relationship and contribute to reinforce the satisfaction with the rehabilitation process.

## **Effectiveness of robot-assisted gait training in children with cerebral palsy: A pragmatic, randomized, cross-over trial (PeLoGAIT)**

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**Background:** Walking ability is a priority for many children with cerebral palsy (CP) and their parents when considering domains of importance regarding treatment interventions. Robotic rehabilitation technologies are increasingly being implemented in the clinical setting to address this demand, but current evidence about the clinical effectiveness in pediatric rehabilitation is weak.

**Aim:** The aim of this study is to investigate the effectiveness of robot-assisted gait training (RAGT) on improvements of functional gait parameters in ambulatory children with cerebral palsy.

**Method:** Children aged 6 to 18 years with a bilateral spastic CP who are able to walk at least 14 meters with or without walking aids are recruited. Within a pragmatic cross-over design with randomized treatment sequences, they perform 5 weeks of RAGT (3 sessions per week) and 5 weeks of standard treatment, which is individually customized to the needs of the child. Both interventions take place in an outpatient setting. The dimension E of the Gross Motor Function Measure-88 (GMFM-88) as primary outcome as well as dimension D of the GMFM-88, 6-minute and 10-meter walking tests as secondary outcomes are assessed before and after each treatment sequence. Additionally, a 5-week follow-up is scheduled for the children who are assigned to the standard treatment first. Treatment, period, follow-up and carry-over effects will be analyzed.

**Results:** So far, 14 children (12 male, 2 female; mean age 11.3 years, range 6yrs – 15.3yrs) participated in the study. Adherence to the RAGT regime was very good. In average, the children participated in 14.3 trainings (range 10-15). First comparisons between RAGT and standard treatment revealed no significant differences. Detailed results of the first 14 participants will be presented at the conference.

**Conclusion:** Preliminary results do not suggest an improvement of functional gait measures in children with cerebral palsy after 15 outpatient sessions of RAGT.

## **The Dolphin Study: Optimising nutrition to improve growth and reduce neurodisabilities in neonates at risk of neurological impairment**

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**Background:** Docosahexaenoic acid (DHA), choline and uridine-5-monophosphate (UMP) are important brain nutrients which form phosphatidylcholine, the most abundant brain membrane phospholipid. DHA, choline and UMP supplementation increases rodent brain phospholipids, synaptic components, functional brain connectivity and cognitive performance. This novel pilot study supplemented infants at risk of neurological impairment (ARNI) with a nutrient combination containing these neurotrophic compounds.

**Aim:** In a double blind randomised control trial (RCT), investigate if intake of a specific nutrient combination improves neurodevelopmental outcome in infants ARNI.

**Method:** Recruitment was from UK neonatal units. Eligibility:  $\leq 31$  weeks, weight  $< 9^{\text{th}}$  percentile;  $< 31$  weeks with  $\geq$  Grade II intraventricular haemorrhage (IVH) or preterm white matter injury (PWMI); 31-40 weeks with  $\geq$  Grade II IVH or PWMI,  $\geq$  Sarnat Grade II hypoxic ischaemic encephalopathy or defined brain MRI abnormalities. Stratification was by gender, gestation and brain injury severity. Randomised infants received neurotrophic supplementation or placebo, for 2 years. Primary outcome was Bayley Scales of Infant Development III (BSID III) composite cognitive score (CCS) after 2 years. Secondary outcomes included BSID III composite language score (CLS) and BSID III composite motor score (CMS). Local Ethics Committee approval was granted.

**Results:** 62 neonates were recruited. After 2 years, mean CCS in the intervention group was 87.7 (SD 20.4) and 81.6 (SD 18.5) in the placebo group ( $\chi^2(1)=2.28$ ,  $p=0.13$ ; -0.2, 18.2). Mean CLS in the intervention group was 91.5 (SD 20.1) and 83.2 (SD 19.6) in the placebo group ( $\chi^2(1)=2.74$ ,  $p=0.1$ ; -2.4, 18.3). CMS was similar in both groups.

**Conclusion:** The difference in CCS and CLS between intervention and placebo groups represents a clinically significant effect size. Use of neurotrophic micronutrient supplementation in infants ARNI warrants exploration in a large multicentre RCT.

## **Financial Burden on Canadian Families Taking Care of a Child with Cerebral Palsy (CP): A Prospective Study**

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**Background:** Economic issues constitute an important component of child and family well-being. A child with impairments requires extra care; depending on their specific needs, they often require exceptional levels of services with additional costs.

**Aim:** This presentation reports personal costs incurred by families caring for a child with CP in Canada and identifies factors influencing the magnitude and share of costs borne solely by the families. This presentation will focus specifically on cost related to leisure.

**Method:** This presentation introduces some of the findings of a study identifying costs associated with taking care of a child with a disability in three Canadian provinces: Alberta, Ontario and Quebec. The study used a prospective research design with repeated measures. Study participants included 179 Canadian families caring for a child >18 years old with CP.

**Results:** There were differences in the proportion of costs paid by the family and reimbursed (public programs, insurance, and other sources) by age, Gross Motor Function Classification System (GMFCS) level and province of residence. For example, families with a child with more severe impairment (GMFCS level IV or V (47% of the study sample)), have 45% of these expenses reimbursed while the reimbursement percentage is between 11-19 % for families with a child in GMFCS levels I to III. Furthermore, more than 80% of these expenses are assumed solely by families of children aged 6 to 12 years old, in comparison of 52% for children 13 to 18 years old.

**Conclusion:** This presentation introduces data from a study identifying additional costs families face when caring for a child with CP. In future research, we should examine the personal and social dynamics that influence these costs to be able to inform policy-makers on the magnitude of cost and their determinants.



## **The effect of functional electrical stimulation on gait may vary between children with dystonic and spastic calf muscles – a pilot study**

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**Background:** Functional electrical stimulation (FES) is increasingly used to improve gait function in children with neurological disorders primarily by assisting paretic dorsiflexors in increasing dorsiflexion during gait.

**Aim:** The aim of this preliminary case-study was to examine if the effect of FES on dorsiflexion during the swing phase of gait was different between children with dystonic or spastic calf muscles.

**Method:** Seven children (mean age 11.1 yrs), referred to treatment with FES, were examined using 3D biomechanical gait analysis. Active and passive dorsiflexion range of motion, dorsiflexor strength in a 0-5 score and Ashworth score for spasticity of the plantarflexors were also measured during supine lying. Two subjects exhibited dystonia rather than spasticity (D), and the results from these two cases are presented in comparison with the group of children exhibiting spasticity (S).

**Results:** S group showed Ashworth scores between 0 and 2 in the plantarflexors. Mean strength of S was 3.4 (SD: 0.8), and 4 and 5 for D-subjects, respectively. Difference between maximal passive dorsiflexion and active dorsiflexion was 18° (SD: 13°) and 5 and 0° for D-subjects. Effect of FES showed a mean 2.8° (SD: 1.7°) higher dorsiflexion angles during swing phase in S, compared with 6.5° and 5.5° higher for the D-subjects.

**Conclusion:** All subjects showed higher degrees of dorsiflexion during swing phase of gait with FES. Subjects with dystonic muscles exhibit adequate dorsiflexor strength during a physical examination, however lacking selective, well-coordinated activation during gait. FES may have potential to improve the coordination of the dorsiflexor activation during the swing phase of gait, and thus improve gait in children with dystonic ankle muscles. This will be investigated further in a larger study.

# **Multi-dimensional efficacy of abobotulinumtoxinA injections on spasticity in children with dynamic equinus foot deformity due to cerebral palsy: 12-week efficacy results of a Phase III, randomized, controlled study**

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**Background:** Most trials evaluating botulinum toxin in cerebral palsy (CP) have been small and few have simultaneously assessed multi-dimensional areas of efficacy. Key efficacy analyses have shown the superiority of abobotulinumtoxinA (ABO) vs. placebo in improving muscle tone (Modified Ashworth Scale, MAS) and clinical status (Physician Global Assessment) at 4 and 12 weeks post-injection in CP children with dynamic equinus foot deformity.

**Aim:** To report up to 12-week efficacy of (ABO) in other endpoints.

**Method:** Phase 3 study in ambulatory CP children (aged 2–17) with dynamic equinus foot. Patients were randomized (N=241) to placebo, ABO 10U/kg/leg or 15U/kg/leg injected into the gastrocnemius-soleus complex. Multidimensional efficacy at weeks 4 and 12 was assessed by: Tardieu Scale (TS), Goal Attainment Scale (GAS) and Observational Gait Scale (OGS).

**Result:** Spasticity at the ankle joint was significantly improved with ABO (TS); the angle of catch ( $X_{V3}$ ) was increased vs. placebo at weeks 4 and 12 in the 15U/kg/leg group (both  $p < 0.01$ ) and at Week 12 in the 10U/kg/leg group ( $p < 0.05$ ); the spasticity grade (Y) was reduced for both doses at weeks 4 and 12 (all  $p \leq 0.0003$  vs. placebo). Reductions in spasticity appeared greater with the 15U/kg/leg dose than with 10U/kg/leg. Clinical relevance was confirmed by significantly superior effects for ABO (10U/kg/leg & 15U/kg/leg vs. placebo) on goal attainment (mean GAS T scores 51.5, 50.9 vs. 46.2; both doses  $p < 0.01$ ) and change from baseline in gait (OGS: 1.7, 1.3 vs. 0.2; both doses  $p \leq 0.01$  vs. placebo) at Week 4. Superiority was maintained at Week 12 for GAS (52.5, 50.5 vs. 45.8, both doses  $p < 0.01$ ) and for OGS at the 10U/kg/leg dose (1.4 vs. 0.5  $p < 0.05$ ). The most common treatment-related AE were injection site pain and muscular weakness (both ABO=2; placebo=1).

**Conclusion:** This large-scale pediatric study showed that a single dose of ABO reduces muscle tone/spasticity translating into improved patient functionality.

## **Parents' experiences when their children with severe physical impairments use gaze-based assistive technology in daily life**

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**Background:** Children with severe physical impairments without speech are dependent on assistance in all everyday activities. Gaze-based assistive technology (gaze-based AT) can be the only option for these children to perform activities. Focusing on parents' experiences of children's gaze-based AT use may give valuable knowledge in how gaze-based AT can be used in daily life. **Aim:** To describe and explore parents' experiences, when their children who have a severe physical impairment and are without speech, receive a gaze-based AT to use in daily activities. **Method:** Semi-structured interviews were conducted with parents to eight children with severe physical impairments (ages 5-15) who used gaze-based AT in daily life. The data analysis was guided by hermeneutical interpretation. **Results:** For the parents, the gaze-based AT usage meant that children gained a new impact in the situation which made a huge difference in daily life. It also provided children with opportunities to show personality and competencies and meant infinite possibilities for child development. Parents needed to handle the gap between children's abilities and all possibilities they saw with the gaze-based AT. The use of gaze-based AT shapes a hope of a better future for their children, when children use their inherent competencies and potential to develop, a future in which children can influence life. **Conclusion:** Understanding parents' view of children's gaze-based AT usage in daily life and what parents hope for is essential to be able for professionals to work together with parents in the same direction and by that be better prepared to support children in the use of gaze-based AT in daily life.

## Effectiveness of intensive therapy for children with cerebral palsy: a case report

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There is no consensus in the literature on intensity and frequency of services for children with cerebral palsy (CP). Currently, few studies have examined the effectiveness of intensive training for the development of children with CP. Aim: The study aimed to determine the effectiveness of intensive training for the improvement of gross motor function of a child with quadriplegic spastic CP, with 4 years and 10 months, classified as grade IV according to Gross Motor Function Classification System (GMFCS). Assessments on the participant's gross motor skills were carried out in all range of dimensions using Gross Motor Function Measure (GMFM - 88) in the first and last day of treatment. The sessions were carried out for 3 weeks, 3 hours per day, 5 days a week. Muscle strengthening exercises were performed in upper and lower limbs and trunk, aerobic exercises and gait training on the walker and parallel bar were also carried out during the intervention period. In the first hour of therapy, strengthening exercises were performed, then a half-an-hour interval was held for the patient to rest. After that, an hour and a half of aerobic exercises were carried out. For the strengthening exercises, a pre-established load of 50% of 10RM test for each muscle group was used. The number of series and repetitions were progressively increased, and the aerobic exercises were performed according to the patient's functional capacity. The parameter variation was obtained in percentage ( $\Delta\%$ ) and was calculated by the equation:  $\Delta j\% = (VjF - Vij) / Vji \times 100\%$ . Result: The results showed clinical improvement for the domain: Lying & Rolling (7.2%); Sitting (72.7%); Crawling & Kneeling (27.3%); Walking, Running & Jumping (99.8%) and Goal Total Score (27.5%). There was no improvement to the domain Standing (0%). Conclusion: The intensive training was effective for improving gross motor functions, especially for the domain Walking and Running.

## Access computer by children and young people with cerebral palsy

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**Background:** Children and youth with cerebral palsy who have upper limb motor deficits may struggle to access the computer. Use of technologies can help these difficulties. Do these people know and use technological resources? **Aim:** Identify the technological resources used for computer access by children and young people with cerebral palsy. **Method:** The study included 37 parents of children and youth with cerebral palsy, with level I to V MACS and GMFCS I to V, mean age 10 years ( $\pm 5$  years). Data collection was performed using a translated and adapted survey of Davies et al. (2010b) questioned about various technologies for computer access and access mode. Data were submitted to descriptive statistical analysis, and the chi-square test to assess the relationship between variables, was considered significant at  $p < 0.05$ . **Results:** Findings indicated there is no evidence of association between computer use and user gender ( $p = 0.286$ ), topographic distribution ( $p = 0.877$ ); GMFCS level ( $p = 0.1533$ ); and the level of MACS ( $p = 0.225$ ). About place to use computer, 35% use at home and at school; 23% non-use; 18% at school and at friends' houses; 15% only at home; 9% use only in school. Regarding computer access, 73% of respondents are using mouse and standard keyboard and only 27% have adapted devices. As for accessibility features in the operational systems only 24% knew about this information, however 65% of respondents were aware about devices can facilitate access computer. **Conclusion:** Although computer facilitate child and youth with cerebral palsy access information, there is still a portion of that population has no access to this equipment, and many families don't know the accessibility options available on the own computer.

## **Challenge and participation in youth with cerebral palsy – a follow up**

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The promotion of participation and self-determination of people with cerebral palsy through capacitation strategies, appears to be a key factors in the improvement of their quality of life. In this sense, it was developed a project whose aim was to increase participation of young people with cerebral palsy, through the involvement in decision-making processes in different areas and at different levels.

The aim is to evaluate the impact of this project in youth with cerebral palsy.

In this project, 7 youth with cerebral palsy, aged between 12 and 14 years, had the opportunity to share their life experiences related to sports activities and health with their peers from Newcastle. This project was developed during a year; including 20 group sessions, twice a month, to expand these topics and strengthening English language; and the participation in a workshop dedicated to young people with disabilities in Newcastle. The strategy was to put these young people sharing their life experiences regarding their experience as students, athletes and health care receptors, causing them to reflect on the interventions intended for them, with their peers and health professionals.

Participation, Self-determination, Life satisfaction and Hope were assessed before and after the workshop, using the Portuguese versions of LIFE-H, AIR Self-Determination Scale, Student's Life Satisfaction Scale, and Children's Hope Scale.

Results show that after the workshop it was notice an increase of Participation ( $6.5 \pm 1.6$ ;  $6.8 \pm 1.4$ ), Self-determination ( $101.2 \pm 13.2$ ;  $105.4 \pm 13.2$ ) and Life Satisfaction ( $29.7 \pm 2.0$ ;  $30.7 \pm 2.3$ ) and a decrease of Hope ( $29.0 \pm 7.0$ ;  $28.5 \pm 5.7$ ).

This show a positive impact of this approach, regarding the participation, socialization, self-acceptance and self-determination of these young people. The sharing and interaction in these contexts, the reflection and exchange provided appears to be crucial for the development and creation of new approaches in the field of disability.

## **Need, equality and sufficiency of psychological support to parents of children with disabilities in Sweden**

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**Background:** Parents of children with disabilities in Sweden report more psychological and physical health-problems than other parents and are more often absent from work due to ill health. In the general population health inequalities have been reported suggesting differences in care due to gender and immigrant background.

**Aim:** To investigate parents' report of need for and offer of psychological support in relation to (a) child age, (b) type of disability, (c) parent gender, (d) immigrant background and (e) living in a large city or small town.

**Method:** 47 fathers and 97 mothers of 110 children (aged 0-18 years) eligible for services, were randomly selected and interviewed via telephone. The children had diagnoses including autism, cerebral palsy and Down's syndrome. Parents answered 31 questions on their need for different kinds of support in relation to actual offer of such support. When parents expressed a need for a certain kind of support and indicated that they received such support it was categorized as a met support need and when they had not received it, it was categorized as an unmet support need.

**Results:** Parents of children aged 7-12 years reported most unmet psychological support needs, no relation was found between unmet support needs and type of disability or immigrant background. Mothers reported higher frequency of unmet psychological needs than fathers. Parents living in the small town had the least unmet psychological support needs.

**Conclusion:** Overall parents report a severe lack of psychological support. In quotes it can be seen how they feel abandoned by the welfare system, left to handle difficult life situations by them-selves.

## **Facilitating improvement and change in services for children with Cerebral Palsy in low resourced, rural hospitals without increasing costs**

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### **TITLE**

Facilitating improvement and change in services for children with Cerebral Palsy in low resourced, rural hospitals without increasing costs.

### **BACKGROUND**

In rural, low resourced hospitals serving large communities in South Africa and Lesotho, children attending Cerebral Palsy (CP) Clinics typically receive 30 minutes of therapy monthly and on average 4 hours of therapy annually. Passive movements are the mainstay of therapy. Sessions rarely involve individualised goal-directed therapy programmes.

### **AIM**

To establish if therapy time could be increased and a more comprehensive service offered to children with CP using existing resources at rural hospitals.

### **METHOD**

Over a 2 year period, teams of 3–4 specialist therapists spent five days at rural hospitals annually. The outreach programme included training of local therapists; group work with children; goal-setting; postural management; home visits; intensive therapy blocks; carer-to-carer training; therapy protocols; data management. Direct observation; a review of patient records and clinic statistics; as well as self-completed questionnaires and focus groups with therapists and caregivers were used to evaluate outcomes.

### **RESULTS**

28 outreach visits to 14 rural primary health facilities in South Africa and Lesotho involving 68 therapists and 714 children were conducted. On average, therapy contact time and number of new children accessing the services doubled. Intensive therapy blocks were introduced in 4 hospitals. Structured home visits are now standard at 9 hospitals; while 4 hospitals have electronic databases. Goal setting and individualised therapy plans are offered at 5 hospitals and carer-to-carer training is active at 80% of the sites. 90% of therapists felt more competent and confident.

### **CONCLUSION**

Through a short focused outreach programme by a team of therapists experienced in rural work, it is possible to improve quality of therapy services for children with CP without increasing resources or costs.



## **Parents' experience of participation in the implementation of Augmentative and Alternative Communication (AAC)**

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Recent research has increasingly focused on parents' experience of participation in the implementation of Augmentative and Alternative Communication (AAC); what a professional should consider in the encounter with the family and the effect this may have on the implementation of AAC.

The aim is to explore parents' experience of participation in the implementation of AAC.

A questionnaire, aimed for parents of children aged 1-17 years who have had an AAC-intervention, was developed and administered.

47 parents answered the questionnaire. A majority experienced participation in the implementation of AAC and felt they were being listened to concerning their opinion of the child's communicative ability. A majority also felt having sufficient knowledge concerning the AAC-mode, having been able to influence the choice of AAC-mode and having had the opportunity to watch it in use with the child. However, more than half of the parents hadn't had the opportunity to influence the content. Furthermore, the parents of the children who were the most experienced AAC-users wished to have more frequent follow-ups. The parents emphasised the necessity of the professionals being able to listen and to start from the families' starting-point.

The professionals have a large responsibility concerning the choice of AAC-mode and in seeing to that follow-ups are conducted. Parents who have experienced participation in the implementation of AAC with their toddlers may later experience that AAC is no longer being used, in spite of an actual need. In conjunction with an introduction of AAC, a more direct collaboration between speech- and language therapists, special needs teachers and psychologists probably would enhance the implementation when discussing AAC with the family. Yet another way of facilitating the AAC-implementation would be the introduction of an "accountable professional" who follows the child through transitions in life affecting the AAC-intervention.

## **The effect of Targeted Training on gross motor function in children with cerebral palsy using hypothetical matched controls**

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### **Background**

Targeted Training therapy is based on biomechanical principles and aimed at improving head, trunk and lower limb control in children with neuromotor disability. The Movement Centre (TMC), a clinical specialist Centre practising Targeted Training, has routinely collected clinical outcomes including GMFM for the past 6 years.

### **Aim**

This retrospective study aims to identify the effect of Targeted Training using a novel technique to control for inherent gross motor development in the study group.

### **Method**

All referrals of children with CP to TMC between 2009 and 2015 were included in the analysis.

The study included 82 children with a mean age of 4yrs 8 mths SD 2 yrs 8 mths and with CP with 3, 12, 20, 28 and 19 in GMFCS categories I-V respectively. The Targeted Training intervention had a mean duration of 11mths SD 2 mths. The change in GMFM for every child with CP treated at TMC was calculated together with GMFM change for an age and GMFCS matched hypothetical child using the Gross Motor Function Curves (Rosenbaum 2002). These hypothetical changes in GMFM were calculated using a method described by Yabunaka (2011). T-tests were used to identify differences in change scores between the Targeted Training and matched hypothetical control groups with five further analyses to examine change in the five GMFCS categories individually.

### **Result**

The hypothetical group increased on average 2.2 SD 2.4 GMFM points and the Targeted Training group increased 4.9 SD 4.6 GMFM points. The difference was highly significant ( $p < .001$ ). Further analysis showed significant differences for GMFCS III-V ( $p < .05$ ) but not for GMFCS I-II.

### **Conclusion**

Targeted Training would appear to be an effective therapy for improving gross motor function in children with cerebral palsy. The therapy appears to be especially effective for children with moderate to severe CP (GMFCS III-V).

## **Long stay patients : a review of children undergoing neuro-rehabilitation in a tertiary neurosciences unit**

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### **Background**

Neurorehabilitation for acquired brain injury at Great North Children's Hospital, Newcastle, UK is based alongside acute services on the paediatric neurology ward. This is a tertiary neuroscience centre providing for a population 2.8 million; area 14000km<sup>2</sup>. The duration of stay for each patient is highly variable; depending on injury (s) sustained, medical complexity, social and educational factors. There are cost implications; with respect to prolonged use of acute in-patient beds; and patient-centred reasons why rehabilitation may be better provided in a therapy led; specialist rehabilitation unit; when the patient no longer requires acute/ high dependency medical and nursing care.

A validated tool used in adults to assess level of need is the Rehabilitation Complexity Score (RCS-E v13). This is a 22 point scale which identifies care needs, risk, special nursing needs, therapy required and medical environment.

### **Aim**

To identify when young people who have had a prolonged admission for neurorehabilitation; could have been managed in a therapy led unit rather than an acute ward;

### **Method**

Case note review of children with stay duration >1 month in the paediatric neurology ward 2012-2014. RCS-E v13 was scored on admission and then at weekly intervals.. When medical and nursing needs were consistently minimal (RCS 1 or 0); it was concluded that these children could have been managed in a therapy led unit.

### **Results**

A total of 3044 in-patient bed days were analysed for 32 patients. 1361 days were classified RCS 0 or 1. 0-25% = 5 children. 25-50% = 15 children. 50-75% = 9 children. 75- 81% = 3 children.

### **Conclusion**

A total of 1360 bed days (42.5 days/patient), could have been delivered in a therapy led center in this cohort. This has implications for future service delivery in Newcastle.

## **SOCIAL PARTICIPATION IN CEREBRAL PALSY. CO-MORBIDITIES RELATIONSHIP**

Paola Diaz Borrego<sup>1</sup>, Francisca Cano Belmonte<sup>1</sup>, Beatriz Sanchez Cabrera<sup>1</sup>, Juan Andres Conejero Casares<sup>1</sup> and Belen Romero Romero<sup>1</sup>

<sup>1</sup>Physical Medicine And Rehabilitation, Virgen Macarena Hospital, Seville, Spain

### **BACKGROUND**

Through social and community participation, children and youth with cerebral palsy (CP) form friendships, gain knowledge, learn skills, express creativity, and determine meaning and purpose in life.

### **AIM**

This study aimed to determine the trajectories of social participation, by level of motor function and their relation to co-morbidities as intellectual disability, epilepsy, communication, deglutition and feeding, in a Spaniard population of individuals with cerebral palsy (CP).

### **METHOD**

Prospective cross-section analytic design survey. We collected CP individuals from our Children Rehabilitation Unit (Seville-Spain) over 3 months. Variables analyzed: demographic (gender, age), motor function (gross motor function classification system (GMFCS) and manual ability classification system (MACS)), social participation (child and adolescent scale of participation (CASP)), cerebral palsy association membership, intellectual disability, epilepsy, communication (communication function classification system (CFCS)), sialorrhoea (severity and frequency scale), and feeding (eating and drinking ability classification system (EDACS)).

### **RESULTS**

39 CP children, between 1-23 years old (mean: 9 years). Most common CP type: quadriplegia (56,4%). Motor function: GMFCS I-II 46,2%, III 5,1% and IV-V 48,8%. Severe communication disfunction: 25,7%. Mental disability and epilepsy: 56,4% and 53,8% respectively. Participation scale: severe limitation, more 20%. Older patients achieved less social participation. Worse motor levels were associated to lower participation. Mental retardation, communication disorders, epilepsy, feeding problems, and intensity/severity sialorrhoea proved to be independent characteristics associated with lower social participation with a statistical meaning.

### **CONCLUSIONS**

Better physical function is associated with a lesser impact of disability; however, the relationship between function, co-morbidities and participation is complex.

## **SOCIAL PARTICIPATION IN CEREBRAL PALSY. COMMUNICATION AND FEEDING RELATIONSHIP.**

Paola Djaz Borrego<sup>1</sup>, Belen Romero Romero<sup>1</sup>, Francisca Cano Belmonte<sup>1</sup>, Beatriz Sanchez Cabrera<sup>1</sup> and Juan Andres Conejero Casares<sup>1</sup>

<sup>1</sup>Physical Medicine And Rehabilitation, Virgen Macarena Hospital, Seville, Spain

### **BACKGROUND**

Children and youth with cerebral palsy (CP) experience a variety of functional limitations that impact on their participation in day-to-day activities.

### **AIM**

This study aimed to determine the trajectories of social participation in CP patients and its relation to communication function and feeding disorders, in a Spaniard population of individuals with cerebral palsy (CP).

### **METHOD**

Prospective cross-sectional analytic design survey. We collected CP individuals from our Children Rehabilitation Unit (Seville-Spain) over 3 months. Variables analyzed: demographic (gender, age), motor function (gross motor function classification system (GMFCS) and manual ability classification system (MACS)), social participation (child and adolescent scale of participation (CASP)), communication (communication function classification system (CFCS)), and feeding (eating and drinking ability classification system (EDACS)).

### **RESULTS**

39 CP children, between 1-23 years old (mean: 9 years). Most common CP type: quadriplegia (56,4%). Almost half of our patients were classified as GMFCS IV-V (48,8%) and MACS IV-V 41%. Severe communication dysfunction: 25,7% cases. Participation scale described severe limitation in more 20% patients. Worse motor levels were associated to lower participation and worse communication and feeding ability. Communication disorders and feeding problems proved to be independent characteristics associated with lower social participation with a statistical significance.

### **CONCLUSIONS**

Assessment of participation should enable the child and family to identify areas of life in which they want greater participation and so influence the choice of medical, therapeutic, and environmental interventions.

## **Gender differences in needs, received interventions and realization of individual goals in the rehabilitation of children with high-functioning autism spectrum disorder**

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Gender differences in needs, received interventions and realization of individual goals in the rehabilitation of children with high-functioning autism spectrum disorder

### **Background**

Autism spectrum disorder (ASD) is diagnosed about 5 times more often in boys than girls. Accordingly, both research and practices have long been biased towards the male presentation of ASD.

### **Aim**

This study aimed to investigate whether the gender disproportion in ASD is manifested in differences in interventions and realization of individual goals between boys and girls with high-functioning ASD within the child rehabilitation services in northern Sweden.

### **Method**

The study sample consisted of 46 children with high-functioning ASD between 7-18 years old (23 boys, 23 girls, mean age: 13 years). Data were obtained by systematic review of medical records and registers from 2011-2014 regarding needs within various domains, severity of problems, and associated interventions and goal achievements.

### **Result**

Girls with ASD displayed an evidently greater quantity of needs and goals within the domain Health and well-being than boys. In general, boys and girls with ASD received equal interventions with regard to quantity, type of intervention, and duration. However, more boys than girls met all their goals with principally satisfying results, as opposed to a greater proportion of the girls' goals being far from satisfied.

### **Conclusion**

Findings confirm previous reports regarding possible differential expressions of symptoms between boys and girls with high-functioning ASD. More research is warranted to explore whether gender-specific interventions can increase the possibility of equal treatment in clinical settings.

## **At home with autism: creating a communication enabling home environment to include a young child with autism.**

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### **Background**

A busy home environment may present communication barriers for a young child with autism. Yet, with limited access to professional support there is often a need for parents to take on the role of advocate and therapist; to become a specialist in their child's condition and needs.

### **Aim**

As a mother of a young boy with autism, the aim of my MA study was to create a communication enabling home environment and to document the real life context of this process.

### **Method**

Using analytical auto ethnography (Anderson 2006) this study explored methods which supported increased awareness and reflection on my interactions with my son with autism and explored the many barriers we as parents face in implementing strategies which promote communication. I set aside 1 hour per week over a period of 3 months to interact with my son. Taking lessons from intensive interaction (Caldwell 2002), Earlybird (Shields 2001) and More Than Words (Sussman 1999), I developed, videoed and reviewed sessions which used dance and movement to 'communicate' with my son. Video of sessions, a journal and interviews with the family provided insights into our communications.

### **Result**

Increased awareness of my son's communication motivations and interests allowed me to understand his 'language' better and to support his communication outside of the home.

### **Conclusion**

Reflecting on my interaction through the videos, my journal and family discussion suggested a wider impact from the study on the shared understanding of our family dynamics and all of our roles in creating an inclusive home. I believe that we as a family feel more effective in developing our relationships with my youngest son. In addition, through the process of recording and reviewing the data I found an increased resilience. My PhD study will develop this research further, including the participation of other families.

## **Cerebral palsy Africa exchanging experience and expertise with all who strive to enable children with cerebral palsy to reach their potential**

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Thousands of African children with cerebral palsy (cp) fail to reach their potential because the few therapists, teachers and community workers supporting them lack the appropriate expertise. Affordable assistive equipment supporting children in good positions is also mostly unavailable, preventing children participating in their communities and predisposing them to contractures & deformities.

Cerebral Palsy Africa Charity (CPA) provides specialist short training courses and follow up workshops for people working with cp children. Using tried and tested curricula CPA trains therapists as a resource, skilled in assessment and treatment of children; advising community based rehabilitation (CBR) workers about working with each child's family using everyday activities as therapy. CPA trains CBR workers in handling and management, working in partnership with caregivers using SMART goals to measure progress. The experienced trainers also train special needs teachers how to handle and manage children in school settings with the help from community groups to make supportive furniture.

Uniquely CPA trains mothers and others to make robust paper supportive furniture using Appropriate Paper-based Technology according to engineering principles. This gives children the possibility of learning to sit, stand, use their hands, and eat and drink safely. The equipment makers receive extra training so they become trainers themselves.

In order to achieve sustainability CPA sponsors key therapists to attend the 8 week Bobath/NDT course in South Africa and thereafter undertake training of trainers course and assist CPA until they can train the new therapy graduates in their own country.

Since 2005 CPA has provided 65 courses to Burkina Faso, Ghana, Kenya, Malawi, Tanzania, Uganda and Zambia. We are committed to delivering training, preparing professional and non-professionals to co-operate in bringing quality therapy to children with cp so they can be included education and society



## **Evaluation of treatment with hand orthoses for boys with Duchenne muscular dystrophy**

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**Background:** Duchenne muscular dystrophy (DMD) is a progressive neuromuscular disorder affecting boys. In early teens the progressive muscle weakness leads to loss of independent ambulation and most of them are then wheelchair users. They are then entirely dependent on their hand function for everyday activities. Contractures in the hands are common and together with muscle weakness the use of the hands in daily activities are ineffective and have a negative impact on the possibilities to participate in activities

**Aim:** To evaluate if treatment with hand orthosis in boys with DMD provide changes in joint mobility, muscle strength or fine motor skills and to identify and describe experiences of the treatment.

**Methods:** Eight boys with DMD with less than 50° of passive wrist extension with extended fingers participated. Additionally, in the interviews five parents were also included. The study had a mixed methods design; Three phases were carried out in a single subject design quantitative part; a baseline, phase A and an intervention, phase B during the boys used individual tailored hand orthosis every night for eight months. In both these phases range of motion, muscle strength and fine motor skills were measured every two months. Phase C was a follow up assessment. After phase B and at phase C the boy and their parents were interviewed in a qualitative part and their answers were analyzed with a Phenomenographical approach.

**Results:** The treatment decreased the progress of the contractures and also led to an increase in wrist extension. The qualitative interviews showed that treatment was experienced to make a difference as it decreased pain, slowed down the deterioration and instilled hope for boys with DMD and their parents.

**Conclusion:** The outcome is of paramount importance and suggests that hand orthosis should be recommended when passive wrist extension with extended fingers is decreased to less than 50°.

## Health-related quality of life and satisfaction with orthoses in a Swedish population of children with arthrogryposis

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**Background:** Lower functional exercise capacity has been reported in children with arthrogryposis multiplex congenita (AMC) than in healthy controls (HC). Orthoses are used to enable or facilitate walking.

**Aim:** To investigate health-related quality of life (HRQoL) and satisfaction with orthoses in a group of ambulatory children with AMC.

**Method:** Thirty-three children with AMC with a mean age 10.5 (SD 4.2) years participated in the study. Questionnaires measured HRQoL (CHQ-PF and EQ-5D-Y), functional capabilities (PEDI), and satisfaction with orthoses (QUEST 2.0). Children were divided into groups based on use of orthoses: Ort-D were dependent on orthoses for walking; Ort-ND used orthoses but were not dependent on them for walking; Non-Ort did not use orthoses. CHQ-PF (Parent Form) was compared between AMC and a Swedish reference group of 60 HC, mean age 12.9 (SD 1.5). Parametric and non-parametric statistics were performed with SPSS version 23.0.

**Result:** Children with AMC had significantly lower CHQ scores in nine of 12 subscales compared to HC. When comparing groups with AMC, Ort-D had lower CHQ physical functioning than Ort-ND ( $p=0.011$ ) and Non-Ort ( $p=0.002$ ). The children's reported perception of health with EQ-5D-Y did not show any difference between the groups. PEDI showed less mobility in Ort-D than Non-Ort ( $p=0.012$ ), whereas there was no difference in self-care. In total, both Ort-D and Ort-ND perceived satisfaction with their orthoses, however Ort-D was less satisfied with orthosis weight than Ort-ND ( $p=0.014$ ). As most important factor with the orthoses Ort-D preferred "comfort" and Ort-ND preferred "easy to use".

**Conclusion:** Children with AMC had lower physical HRQoL than HC, particularly in Ort-D. As confirmed with PEDI, mobility was lowest in Ort-D. With EQ-5D-Y, no difference was found in self-reported health between the groups. Satisfaction with orthoses was high but varied, emphasizing the importance of each child's opinion when prescribing orthoses.

## **Early powered wheelchair introduction in children affected by Cerebral Palsy: case-control study of the impact on the development of neuropsychological functions and quality of life**

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### **Background**

Clinical practice and literature data support the hypothesis that the introduction of powered wheelchair (PWC) in children with Cerebral Palsy (CP) could have a positive impact both on the development of neuropsychological functions and on the child's quality of life. However, there are few data about the introduction of PWC during the preschool period.

### **Aim**

The aim of the study is to assess the effects of early use (4-5 years) of PWC in children with CP, by evaluating changes in quality of life and in development of cognitive functions (i.e. visual attention, memory and visuospatial abilities).

### **Method**

In this case-control study, 16 children affected by CP (8 cases and 8 controls), of 4-5 years old, IQ  $\geq 50$ , with severe motor impairment (GMFCS: IV-V level), were investigated in neuropsychological functions with standardized scales. Evaluations on children quality of life and behavior were also performed (T0).

The group of the controls continued traditional rehabilitation and after six months (T1) was evaluated with the same protocol.

A personalized PCW was assigned to each patient of the case group. After a period of training (average 8 sessions for child), the device was delivered at home, to be used during the most common everyday activities (i.e. home, school). The use of the PCW was monitored through electronic devices located on the PCW and through questionnaires completed by parents, therapists, teachers. After 6 months children were re-tested (T1).

### **Results**

In the group of cases PCW has been well accepted; the training didn't show problems; electronic devices on PCW revealed widespread use.

Definitive data about quality of life and the neuropsychological functions are not yet available, because the study is in progress.

### **Conclusion**

Our preliminary data support the acceptability of PWC introduction during preschool age. The final results will show the impact on neuropsychological functions.

## **Trend Analysis of seven years data to demonstrate effectiveness of intervention**

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**Background:** Recently, more evidence of the theory supporting goal setting has emerged. Depending on the structure of the goal setting process this should contribute to the robustness of the results. An audit was carried out at a specialist cerebral palsy centre where goal setting is embedded into the service. Review of the process found that Goal Attainment Scaling (GAS) is combined with standardised measures when appropriate and carried out using the 4 stages of the G-AP framework. A collaborative family centred approach is central to the service and goals are developed jointly in this context, recognising families' circumstances (values/beliefs/priorities).

**Aim:** To demonstrate the effectiveness of a service through the use of GAS

**Method:** Retrospective analysis of raw data gathered from all children with cerebral palsy (GMFCS I-V) attending a specialist centre over a period of 7 years(2007-2014). Total of 2396 goals set by a multidisciplinary team.

**Results:** 78.9% of goals achieved or exceeded (score 0 to +2). 16.7% not achieved (-1 or -2). 4.4% no score. Results were analysed by GMFCS level and across years with similar results. Good outcomes demonstrated but no particular trend over time found.

**Conclusion:** Intervention success demonstrated at all GMFCS levels however further audit is needed to evidence the robust nature of the process and confirm GAS as a valid measure for children with cerebral palsy.

# **Intensive gait training in adults with cerebral palsy may lead to larger push-off velocity through increased contribution of sensory feedback to plantar flexor muscle activity.**

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**Background:** Toe walking associated with reduced push-off velocity and forward propulsion is common in persons with cerebral palsy (CP). Studies have shown that the contribution of sensory feedback to plantar flexor muscle activation is reduced in children with CP compared to normal peers. We hypothesized that this is also the case in adults with CP and that intensive gait training improves push-off velocity and power generation, partly due to improved contribution of sensory feedback to muscle activation.

**Aim:** The study investigated how the contribution of sensory feedback to activation of the soleus muscle is altered by intensive gait training in adults with cp.

**Methods** 32 adults with CP and 14 healthy subjects participated. The subjects walked on a treadmill during exposure to an unload perturbation applied at the ankle by a robotized ankle-foot orthosis. 3D gait analysis and electromyographic (EMG) activity of the tibialis anterior muscle and the soleus muscle was recorded. EMG from the Soleus muscle around push-off was compared between normal- and perturbed steps before and after 6 weeks of intensive gait training and with healthy subjects.

**Results:** The intervention group showed a significant larger push-off velocity during forced walking speed (mean diff 0.176 deg/sec,  $p = <0.001$ ) compared to the cp control group (mean diff 0,011 deg/sec,  $p = 0,844$ ). The intervention group showed increased forced gait speed (mean diff 0,335 km/hour,  $p = <0.001$ ) compared to the CP control group (mean diff 0,026 km/hour,  $p = 0,520$ ). Preliminary results suggest that contribution of the sensory feedback is lower in adults with CP compared to healthy subjects. The results indicate that the contribution of sensory feedback is improved after training.

**Conclusion:** Adults with CP may obtain more efficient muscle activation during push-off after intensive gait training. Improved contribution of the sensory feedback may partly explain some of the mechanisms involved in gait improvements.

## **Functional Outcomes using the Assessment of Motor and Process Skills (AMPS) following Deep Brain Stimulation (DBS)**

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**Background:** Young people with dystonia face significant challenges in independent living and the understanding of both motor and non-motor difficulties is important so that targeted interventions can be offered to maximise the potential to participate in society.

Objectively measured functional outcomes following DBS have not been previously reported.

**Objective:** This study aims to objectively evaluate activity of daily life outcomes following deep brain stimulation (DBS) in childhood dystonia and examine the relationship with dystonia reduction.

**Methods:** This is a prospective case series study involving 27 young people with hyperkinetic-dystonic movement disorders at least 1 year following DBS. Objective functional changes in daily life using a blind-rated AMPS assessment is reported. Comparison with dystonia reduction will also be reported.

**Results:** Significant changes in functional performance were seen at 1 and 2 years post DBS for AMPS. All young people showed motor skills below 2 logits and process skills below 1 at pre and post DBS, including primary dystonias.

No significant changes in dystonia were observed as measured by the Burke-Fahn-Marsden Dystonia Rating scale (BFM). No relationship was seen for any classification groups between dystonia impairment reduction as measured by the BFM and improvement in AMPS.

**Conclusions:** The Assessment of Motor and Process Skills significantly improved at 1 and 2 years after DBS for dystonia in children and young people.

Whether this improvement can be sustained or reach the normal AMPS range requires further study. More evidence is required to ascertain whether DBS plays a role in the management of secondary dystonia and for that, the use of robust and appropriate outcome measures is paramount.

## **Engaging children and adults as study advocates when designing research**

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**Background:** Within research there is a current drive for involving service users within study design. It was therefore important to involve individuals with Cerebral Palsy in the research design of a study looking at the experience of play for children with Cerebral Palsy.

This PhD research project aims to explore the experience of play for 6-12 year olds with high levels of physical disability due to Cerebral Palsy. 'Rose' (pseudonym) is an 8 year old with quadriplegic Cerebral Palsy, GMFCS 3, who uses direct access to an ipad to communicate. Tim is a 19 year old with quadriplegic CP, GMFCS 5, who uses a dynavox and head switches to communicate. Tim requested and provided written consent for his name to be used as a research advocate. Both study advocates participated in discussions with the researcher which significantly enhanced and informed the present study design.

**Aim:** This presentation aims to discuss the research literature underpinning the importance of engaging advocates within research design. It will then look at the practicalities of meeting both advocates and using discussions to inform the research.

**Method:** One meeting with Rose and two meetings with Tim for 1-2hrs enabled discussion of the present research study. The importance of play, the interview schedule and the design of participant posters and information sheets was discussed. These discussions were then used to inform the present research.

**Results:** Rose and Tim were helpful in informing the design of the present research. Discussions with the two advocates helped to pre-empt problems later within the research and also enabled the researcher to consider strategies that would gain in depth data during the study. Input in the design of participant information meant that this was much improved in preparation for recruitment.

**Conclusion:** The use of study advocates has been promoted within research literature and has led to improvements in the study design of the present project.

## Brain Plasticity in Unilateral Cerebral Palsy influence on outcomes following Intensive Bimanual Therapy

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**Abstract** Children with unilateral cerebral palsy (UCP) demonstrate poor bimanual skills. This study examined associations between neuroplasticity and hand skills following intensive bimanual therapy (BIT).

**Methods** Twenty children with UCP (11 boys, mean age 10y11m±1y9m) participated in a two-week BIT. The Assisting Hand Assessment (AHA), Childrens Hand Experience Questionnaire (CHEQ) and Jebsen Taylor Test of Hand Function (JTTHF) assessed hand skills at pre (T1), post (T2) and 6 weeks post (T3) BIT. MR imaging with diffusion tensor (DTI) and functional (fMRI) imaging was undertaken at baseline. A radiological score calculated brain injury. Eight children had serial MR imaging.

**Results** Progress was seen across hand function measures: AHA(p=0.04), JTTHF(p<0.001) and CHEQ(p<0.001). Baseline imaging parameters were associated with progress in hand function. T1 radiological scores correlated with bimanual progress (AHA r=0.475,p=0.034, CHEQ r=0.632,p=0.003) at T2 but negatively with unimanual (JTTFH r=-0.514,p=0.024) at T3. T1 fMRI showed negative correlations between contralesional voxel activation and progress on AHA at T2(r=-0.562,p=0.015) and T3(r=-0.479,p=0.052). T1 Fractional Anisotropy in affected posterior limb of the internal capsule correlated negatively to bimanual progress [CHEQ T2(r=-0.547,p=0.028); AHA T3(r=-0.656,p=0.008)]. Serial imaging showed increased white matter integrity in the corpus callosum and corticospinal tracts at T2. More unilateral activation patterns correlated with improvement in unilateral function of the affected hand.

**Conclusion** Bimanual intervention showed beneficial results. Baseline imaging parameters were associated with treatment in benefits with higher brain injury associated with bimanual improvement. Changes in WM integrity and pattern of activation to a more unilateral pattern corresponded to changes in hand skills. Results reflect considerable inter-individual differences in brain activation and intervention response.



## **Do new control modes that allow kinematic variability lead to increased activity during robot-aided gait training?**

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**Background:** Robot-aided gait training (RAGT) is increasingly used in pediatric neurorehabilitation with devices like the Lokomat (Hocoma AG, Switzerland). This device uses a position control strategy, i.e. exact positions of the knee and hip joint are prescribed throughout the ideal gait cycle. This has two disadvantages: Movement variability is restricted and patients tend to walk passively. Variability and active participation, however, are important for motor learning. Recently, two new control modes were developed. Path-control (PC) allows the patient to walk within a tunnel surrounding the ideal movement trajectory. The freeD (FD) mode is based on PC, while pelvis and leg cuffs are moveable in the mediolateral direction to allow weight shifting. The aim of this study was to evaluate whether leg muscle activity and heart rate (reflecting physical effort) increase from position control to PC to FD.

**Methods:** Thirteen adolescent patients with neurological disorders walked in the Lokomat with the three described conditions. We evaluated average EMG amplitudes of 5 leg muscles of the more affected leg. Simultaneously, the heart rate was recorded. Differences in EMG amplitudes and heart rate between the 3 conditions were tested with non-parametric tests (Friedman and Wilcoxon tests).

**Preliminary results:** Significant differences were observed for rectus femoris (stance phase) and the biceps femoris (BF) (swing phase). Heart rate showed a significant difference between the 3 conditions. Pair-wise comparisons showed that heart rate and muscle activity tended to be higher in the FD modus compared to the other conditions.

**Conclusion:** First results indicate that especially the FD mode seems promising for improving activity when training with the Lokomat, as it increases heart rate and proximal leg muscle activity. Therefore it may be a future solution to increase variability and activity during RAGT. Complete results will be presented at the meeting.

## **Can meta-cognitive training using the Cognitive Orientation to Occupational Performance Method improve executive functions?**

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**Background:** Executive functions is thought to be involved in the process of formulating, expressing and reaching a goal. Early brain injury may affect cognitive and executive development and function and have consequences for performance. Structured training and learning of meta-cognitive strategies may be useful to increase executive capacity. The Cognitive Orientation to Occupational Performance (CO-OP) is a client-centred method, based on a meta-cognitive approach. With support from a therapist the person is guided to find strategies for performance and goal-accomplishment during a ten weeks program. The CO-OP has shown promising results for reaching activity goals in everyday living.

**Aim:** To investigate how young people with a cerebral palsy or spina bifida experiences everyday problems related to executive functions before and 6 months after training with the CO-OP method.

**Method:** A pilot study with 10 young people (16-28 year) who completed the Dysexecutive Questionnaire (DEX) before and after a training period with the CO-OP method. The DEX is a self report scale, consisting of 20 items which captures various executive problems. A selection of neuropsychological tests from the Delis-Kaplan Executive Function System (D-KEFS) test battery was used for assessment of executive functions.

**Results:** There was a variability in how the participants experienced executive problems at baseline. At 6 months follow-up a majority reported improvement in executive functioning according to the DEX total score. The improvement was most prominent in planning ability. Participants also had less problems with distractibility and a better problem-solving capacity.

Results of the neuropsychological tests (D-KEFS) will be analysed and included in the presentation.

**Conclusion:** In this pilot study the CO-OP method was shown to enhance self-reported executive capacity, particularly planning ability. Results are preliminary and will be further explored in future research.

## **Gaze controlled computers for children with multiple disabilities – what factors influence to what extent the computer can be a benefit for the child? A qualitative study based on semi structured interviews with key persons**

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### **Background**

As children with severe multiple disabilities often use their eyes to communicate their intention, use of gaze controlled computers as a communication tool is interesting. It is both time consuming and requires specific competence to assess and introduce gaze controlled computers for children with severe cognitive and motor disorders and to prepare functional software grids. Professionals working in the area of Augmentative and Alternative Communication and Assistive Technology still lack the necessary competency. There is a need for more knowledge of how and for what these children use their systems, and furthermore of the factors that should be considered during both phases of assessment, implementation and future use.

### **Aim**

The aim of this study was to explore experiences to identify factors that may affect how children with severe multiple disabilities are able to influence and interact with their environment using a gaze controlled computer.

### **Method**

This study used method qualitative research approach. Semi-structured interviews with the children's key persons were analyzed using content analysis to identify both differences and similarities in the transcribed texts.

### **Results**

The children used their computers for a variety of activities. In some cases the gaze controlled computer could assist the child in expressing skills that haven't been possible before and so were unknown to the environment.

Time and expertise are needed in order to support the children use their computers effectively. There is also a need of frequent meetings in the child's network and to have follow-ups from service centres.

### **Conclusion**

Without the support needed, there is a risk that these children fail, and are considered not being able to use the computer functionally. This might lead to a lack of access to computers and a possibility to a more effective communication.

## **Gross Motor Outcome of Intensive Therapy in Children with Cerebral Palsy and Developmental Delay**

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**Background:** Many physicians and parents of children with developmental delay expect some effect of intensive rehabilitative treatment, though the evidence of intensive intervention is not well established. Indications of intensive therapy and factors that can have an influence on therapeutic effect are also not well known yet.

**Aim:** The aim of this study is to find out the short term effect of intensive therapy on gross motor function improvement in children with developmental delay.

**Method:** Retrospectively 89 patients were reviewed and total GMFM score percentage was analyzed.

**Results:** Mean age was  $36.49 \pm 16.96$  months (5 months-7 years 8 months) old and 47 children were boys. 72 children cerebral palsy (CP), 8 patients had genetic abnormality, and 9 patients had developmental delay of unknown origin. The GMFM score percentage was significantly increased after 8 weeks of intensive therapy ( $P < 0.001$ ). Improvement was significantly greater in the ambulatory group (GMFCS level I-III) than in non-ambulatory group (GMFCS level IV-V) and in the younger group (age  $\leq 36$  months old) than in older group (age  $> 36$  months old) ( $P < 0.001$ ). And children without seizure disorder showed better effect compared to children with seizure disorder.

**Conclusion:** Ambulatory status, age, and seizure disorder influenced on gross motor effect of 8 weeks of intensive rehabilitation therapy in children with cerebral palsy or developmental delay due to miscellaneous causes.

## Reaching kinematics on concrete and imaginary tasks in children with cerebral palsy

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### Background:

Underlying motor control strategies is important for treatment of upper limb dysfunction in children with cerebral palsy (CP). Reaching kinematics of concrete (object present) and imaginary tasks (object absent) were addressed for individuals without disabilities. However, no study attempted to investigate the reaching kinematics of the two conditions in children with CP.

**Aim** This study aims to investigate the reaching kinematics on concrete and imaginary tasks in children with CP.

### Methods:

Twenty-seven children with CP were collected and classified into 2 groups based on the manual ability classification system (MACS): level I (17) and level II (n=10). All children underwent assessment for reaching kinematics and upper limb function. Vicon system was used to measure the reaching kinematics of two tasks: concrete and imaginary reaching to ring a bell. The reaching kinematics were reaction time (RT), percentage of time to peak velocity (PPV), and peak velocity (PV). Upper limb function was assessed by Box block test (BBT).

**Results:** Children with MACS level I have greater BBT than those with level II ( $p<0.05$ ). Children with level I have lower nMT and nMU in concrete tasks than those with level II ( $p<0.01$ ). Children with level I have lower nMU in imaginary tasks than those with level II ( $p<0.05$ ).

**Conclusion:** Children with mild CP had smoother reaching pattern in concrete and imaginary tasks than those with severe CP. Furthermore, children with mild CP had quicker movement execution in concrete tasks than those with severe CP. Findings may allow clinicians understand the underlying motor control strategies of upper limb dysfunction in children with CP.

## **Disability Matters: creation of a suite of learning resources that challenge attitudes towards disabled children and young people**

Karen A Horridge<sup>1</sup>

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Presented on behalf of all the children, young people, parent carers and other experts who contributed.

### **Background**

In 2011, television journalists exposed the horrific abuse of people with learning disability and autism in a care home in Southern England<sup>1</sup>.

In 2013, a UK confidential inquiry revealed ongoing inequalities in access to healthcare and worse outcomes for people with learning disabilities<sup>2</sup>.

In 2014, only 5% Britons chose 'confidence' as one of the three terms that describe how they feel when they meet a disabled person<sup>3</sup>.

### **Aim**

In 2013, the Department of Health (England) funded Disability Matters to challenge and positively change attitudes in our society towards disabled children and young people.

### **Method**

A consortium of stakeholders led by the Royal College of Paediatrics and Child Health in the UK worked in full partnership at every stage with disabled children, young people, parent carers and other experts to produce and consult on a curriculum and design content for e-Learning and face-to-face training workshops.

### **Results**

58 sessions of e-Learning are now live online, freely accessible to everyone across all workforce sectors. Resources for face-to-face workshops are also available, to support understanding about disability and best practice in communication.

### **Conclusion**

Mutual respect and full partnership between children, young people, parent carers and professionals has been extremely productive. The published resources are full of authentic tips including audio and videos about how disabled children, young people and their families would like to be warmly welcomed, included and supported, to achieve the outcomes that matter most to them.

### **References**

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3. ComRes 2015. [www.comres.co.uk](http://www.comres.co.uk)

## **Impact of austerity measures on families with disabled children**

Karen A Horridge<sup>1</sup>

<sup>1</sup>Paediatric Disability, Sunderland Royal Hospital, Sunderland, UK

### **Background**

Contact a Family's Counting the Cost 2014 survey reported a sharp rise in families with disabled children going without the basics such as food, heating and days out as a family since last researched in 2012<sup>1</sup>.

### **Aim**

To obtain further evidence of the direct and indirect impact of austerity measures on families with disabled children.

### **Method**

An online survey was emailed on 20 November 2014 to all:  
Members of the British Academy of Childhood Disability (BACD)  
UK Child Development Team leads  
Members of the British Association for Community Child Health.  
This was closed 25 November 2014. A further survey was sent 8 January 2015 and analysed 16 January 2015.

### **Results**

134 responses were received from all four nations making up the UK with a spread from all regions.

Respondents reported:

Witnessing direct impact on families of austerity measures: 65%

Cuts to services for disabled children and their families: almost 80%

Paediatricians asked to write letters of advocacy, mostly about housing, impact of benefit cuts and to seek charitable funding for equipment or services previously provided by statutory services: >80%

More than 10% and up to 25% cuts across the board in services for disabled children and their families: 49%

Increased waiting times to see a paediatrician and/or therapist: 72%

Unable to meet national guidelines for timeliness of autism assessment: almost 80%

Referrals returned to general practitioners, including by non-clinicians: 30%

Increased thresholds to access services due to not being able to meet demand: 30%

### **Conclusion**

Cuts in services for disabled children and their families evidenced by these findings will inevitably lead to increased morbidity and mortality.

BACD and BACCH members have raised and continue to raise these findings with government officials and presented them on the BBC television news.

### **Reference**

1. <http://www.cafamily.org.uk/search-results/?s=counting+the+cost+findings>

## **Developing a Suite of Motion-controlled Games for Upper Extremities Training in Children with Cerebral Palsy**

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**Background:** Children with cerebral palsy (CP) usually have various impairment of their upper extremities (UE) function, UE function training is an important issue in CP rehabilitation. There is growing interest in exergaming as a rehabilitation tool. The Kinect system is a camera-based controller which a player can use to control a game through body movement. Scratch, the programming language for kids from the MIT Media Laboratory, had been widely used by non-programming professionals to write games. Stephen Howell had developed Kinect2Scratch, which allows data from Kinect controller to be sent to Scratch. Using the 3 tools therapists can customize exergames with less technical support.

**Aim:** To develop a suite of Kinect2Scratch games for children with CP and investigate the feasibility and effects of these games

**Methods:** Three games from the web (<http://scratch.saorog.com>) Hungry shark, Alien attack, and Hungry ant maths games were used as the base of game design. Children need to use their more affected UE doing up and down motion to control the shark to eat fishes, do multi-directional motion to control an ant to touch the numbers on the screen, do handclap (bilateral shoulder abduction-adduction) to shoot the Alien. When playing the games the children were asked to keep their elbow extension.

**Results:** Six children with cerebral palsy (2 boys, mean age  $8.5 \pm 2.67$  years) received 24 sessions of training (30 minutes per session, 10 minutes for each game). There was no adverse event during the study period. All children enjoyed the games. They had significant improvement in box and block test after intervention (pre-intervention  $14.833 \pm 16.82$ , post-intervention  $17.50 \pm 17.13$   $p=0.003$ .) Four parents reported improvement of the more affected UE function of their children, including more frequent use, more smooth motion, better reaching, and holding objects longer time.

**Conclusion:** The Kinect2Scratch games are feasible and effective for UE training of children with CP.



## **Effects of Occupational Therapy Home Programmes on Children with Cerebral Palsy**

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**Background:** Home-programmes can affect the level of function in children with cerebral palsy.

**Aim:** The aim of the study is to assess the effects of occupational therapy home programme, compared with control group on function and parent satisfaction with child function, participation, goal attainment, and quality of upper limb skill in school-aged children with cerebral palsy.

**METHOD:** Forty-two children with cerebral palsy (mean age: 8,6 years; Gross Motor Function Classification System: level I, 53%; level II, 15%; level III, 17%; level IV, 2%; level V, 13%; spasticity, 79%; dyskinesia, 19%; ataxia, 5%) were assigned to occupational therapy home programme for 12 or 8 weeks or to no home programme. Canadian Occupational Performance Measure scores were recorded 12 weeks after the baseline. Secondary measures were recorded at 3 and 6 weeks.

**RESULT:** Twelve weeks of home programme showed statistically significant differences in function and parent satisfaction with function, compared to no home programme group ( $p < 0,05$ ). No statistically significant difference was recorded between 3 week, 6 week and control group.

**CONCLUSION:** Occupational therapy is a evidence-based approach and occupational therapy home programmes implemented by parents at home were clinically effective if implemented at least 12 weeks.

## **Cross-cultural validation and reliability of the Chinese version of the Children's Assessment of Participation and Enjoyment (CAPE) for children with and without physical disabilities**

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### **Background**

The Children's Assessment of Participation and Enjoyment (CAPE) has been widely used worldwide with culturally appropriate translated versions to measure children's participation in leisure activities for children with typical development (TD) and physical disability (PD) aged 6 to 21 years.

### **Aim**

The aims of this study were to examine the cross-cultural validity of CAPE-Chinese version (CAPE-C), and to examine the reliability of the CAPE-C for school-children with TD and PD.

### **Method**

The CAPE, containing 55 items clustered into 2 domains and 5 activity types, was translated and adapted into traditional Chinese with the license agreement approved by the publisher. A total of 4 translators and 10 committee members joined the translation process. Data were collected by interviewing children with parents' assistance. Items with <10% of the sample doing the activities were considered not appropriate for Taiwanese culture. The study examined participation diversity and intensity. Internal consistency was examined for children with PD (n=105; mean age=7y10m) and children with TD (n=103; mean age=8y0m) using Cronbach's alpha, and test-retest reliability within 2 weeks (n=46 for TD; n=41 for PD) was examined using intra-class correlations (ICCs).

### **Result**

Forty-seven (85%) items were found to be applicable to the Taiwanese context, and 8 items may require revisions. The test-retest reliability (ICCs=0.55-0.87,  $p<0.05$ ) and internal consistency (Cronbach's alpha= 0.41-0.89) were mostly acceptable for children with TD and PD, except for the recreational activities (Cronbach's alpha= 0.25) for children with TD.

### **Conclusion**

The CAPE-C has acceptable test-retest reliability and internal consistency except for the recreational activities for children with TD. Cross-cultural validation of the CAPE enables international comparisons of children's participation in leisure activities. Further modification of the items will help to enhance the use of the CAPE-C in Taiwan.

## **Improving “Participation”: A systematic review of language, definitions and constructs used in intervention research with children with disabilities**

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**Background:** The ICF defines participation as “involvement in a life situation” and there is agreement that improving participation of disabled children is a priority. However, in reading the literature it appears there is no universal acceptance about how to operationalise the concept of participation. This is critical because, without clarity about the concept, defining outcome goals and developing scales and measures to assess participation outcomes will remain open to question as to whether the approaches are fit for purpose.

**Aim:** This systematic review investigated how researchers defined ‘participation’ and the language used in participation intervention research.

**Methods:** Nine health and education databases were searched for intervention studies of disabled children that included a participation outcome. Quantitative data were extracted using a customised form, and participation text data were extracted verbatim. Themes were derived using a thematic coding approach. These themes were applied to the outcome measures used in the included studies to compare participation language with the methods used to quantify participation changes.

**Results:** Of the 2257 articles retrieved, 25 were included in this review. Five participation themes and nine subthemes were distilled from the review. Two themes, Attendance and Involvement, were judged to be directly related to the participation construct. Three additional themes described related concepts: Preferences, Activity Competence and Sense of Self.

**Conclusion:** Attendance and Involvement seem to describe the essence of the participation concept. The related themes may provide important avenues to enhance participation outcomes and be important predictors of participation. This review highlights the need for researchers to define the construct under investigation clearly and to select measures carefully, as measurement choice is the mechanism through which the concept is operationalised in research.

## Effects of CareToy early home-based intervention on parental stress

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**Background.** Parenting an infant born preterm results in more challenges than infant born at term (Spielman V et al, 2009). Parents' involvement in Early Intervention (EI) programs seems to have a positive effect in some psychosocial aspects both on child and parent (Benzies et al, 2013). CareToy (CT) is a novel smart system that allows to provide an intensive, individualized, home-based and family-centered EI in preterm infants, aged 3-9 mths of corrected age (Sgandurra et al, 2014). An RCT study (Clinical Trial.gov NCT01990183), preceded by a pilot study, was recently carried out to evaluate the effects of CT intervention on neurodevelopmental outcomes respect to the standard care (SC).

**Aim.** The present study aims to evaluate the effects of CareToy EI on parenting stress in preterm infants.

**Method.** Parents (mother and father) of a subgroup of infants enrolled in the RCT study filled in a self-report questionnaire on parenting stress (Parental Stress Index-Short Form; PSI-SF) before (T0) and after (T1) the CT or SC period (4 weeks), according to the allocation of their preterm infant. For twins, an individual questionnaire for each one was carried out. Results obtained from mothers and fathers were separately analyzed with non parametric tests.

**Results.** 41 mothers and 41 fathers of 45 infants (24 CT/21 SC) filled in PSI-SF at T0 and at T1. CT intervention was mainly managed by the mothers. A significant ( $p < .05$ ) reduction in the Parental Distress subscale in the CT group versus SC was found in mothers. Any differences were found among fathers.

**Conclusion.** CT training seems to be effective in reducing parental distress in mothers, who spent more time in the CT intervention. These findings confirm the importance of the parents' involvement in EI programs. This work was supported by the CareToy EU project (GA: 287932; 7FP, ICT-2011-7).

## **Children, young people and family views on the usefulness of the health, functioning and wellbeing “Traffic Lights’ consultation communication tool**

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### **Background**

The Health, Functioning and Wellbeing Summary (HFWS) was developed by clinicians together with parent carers and disabled young people. It is a communication tool designed to:  
Assist families in gathering and relaying their concerns to inform medical consultation  
Help clinicians to focus on the issues that matter most to families.

### **Aims**

To determine if the HFWS:

Supported communication in consultations

Met communication standards set by the General Medical Council (UK) Good Medical Practice guidance: “You must listen to patients, take account of their views, and respond honestly to their questions”

### **Method**

Disabled children, young people and their families attending Sunderland paediatric disability clinics 14/01/2015-06/02/2015 were invited to answer questions about the HFWS after the consultation, independently from their clinical care.

### **Results**

All 60 participants fully completed the questionnaire: 58 parents, one carer and one young person.

All agreed that they had discussed everything they wanted to in the consultation and that all serious concerns had been addressed.

49/60 (82%) agreed that a consultation using the HFWS better addressed their needs than one that did not use it

54/60 (90%) scored the HFWS at least 8/10 for overall usefulness as a communication aid

### **Conclusions**

The HFWS supports effective communication during paediatric disability consultations in Sunderland and ensures that the issues that matter most to families on the day are adequately addressed. It could have wider utility in other settings and could be adapted for other specialties. Families view the HFWS as an effective communication tool.

**An exploratory study of the effect of Bobath therapy on the empowerment of caregivers attending Bobath Childrens Therapy Centre Wales (BCTCW).**

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**Background:** Families of children with CP face the difficulty of balancing the normal tasks of parenting with the provision of continuous care, therapy programs and the need to adjust emotionally to their child's difference from expectations. They therefore often face high levels of day-to-day stress. BCTCW uses family-centred practice (FCP), widely accepted as best practice for disabled children's services and their families. FCP acknowledges individual family differences, strengths and needs and that a child develops within the context of their family and community. It recognises that the family has the greatest influence over a child's health and well-being and are therefore specialists in their children's abilities and needs, and support to empower them to make decisions in partnership with professionals involved in their care.

**Aim:** To discover the impact of an initial block of therapy at BCTCW upon caregiver empowerment.

**Methods:** Mixed methodology; quantitative questionnaire (Family Empowerment Scale (FES)); qualitative in-depth interviews and focus group.

**Participants:** FES n= 44 parents/caregivers of children attending BCTCW for an initial block of therapy. Interviews: 4 mothers, 1 grandmother.

**Results:** Positive trend FES scores in all domains of empowerment (family:p=0.001, service system:p=0.0007, community/political:p<0.0001).

Strong themes emerged from interviews thematically analysed: Increased confidence (family and child); Managing expectations; Emotional impact of disability (family and child); Level of control; Impact of communicative behaviours; Looking to the future; Role of therapist as educator.

“made me feel as if someone else also cared about [] as much as we do”

“definitely changed my outlook on everything”

**Conclusions:** Within the study population an initial block of therapy at BCTCW was beneficial in empowering caregivers in all domains of the FES. Interviews provided insight into what aspects of practice at BCTCW empowered parents.

## **The Spider therapy changes the loading in sitting in children and adults with cerebral palsy.**

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### **Background:**

The Spider therapy was invented by Norman Lozinski in 1993. And it is part of the theasuit methods in USA. The Spider consists of a number of elastic cords from the lumber belt to the fence in four directions. The Spider can not only support body weight but also catch them from falling from front to back and from side to side. However, it is unknown about the change of the sitting balance in children and adults with cerebral palsy (CP) after the Spider therapy.

### **Aim:**

The purpose of this study is to clarify the effect of the Spider therapy for the sitting posture and balance.

### **Method:**

One Child and four adults with cerebral palsy (age:  $43.2 \pm 17.3$ , GMFCS ?) participated in this study. Subjects stood in the Spider and squatted for 10-20 minutes. Outcome measures are range of motion (ROM) of hip flexion, hip abduction, knee extension and ankle dorsiflexion, and the hip and ankle loading on sitting before and after the Spider therapy. The hip loading separated weighted side (WS) and anti-weighted side (AWS) before the Spider. The ankle loading was normalized with body weight.

### **Results:**

They achieve increase almost ROM, especially hip flexion ( $+5^\circ \sim +50^\circ$ ). The hip loading rate of WS before the Spider was  $63 \pm 10\%$  and has changed  $55 \pm 14\%$  after the Spider. The ankle loading increased from  $3 \pm 2\%$  to  $10 \pm 4\%$  of body weight.

### **Conclusion:**

In this study, children and adults with cerebral palsy increase ROM and less asymmetry in sitting after the Spider therapy. The Spider therapy can change the sitting balance in children and adults with cerebral palsy.

## **Toward Family-Centred Service – Do we need to identify the critical families?**

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### **Background**

Family Centred Service (FCS) is the recommended way of working within the rehabilitation field. The Measures of Processes of Care (MPOC) is a broadly focused instrument, valid, reliable and the most used instrument for evaluating the family-centredness of services from the parents' perspective.

### **Aim**

The aim of this study was to explore the degree to which parents' experience the service as being family-centred before and after professionals had participated in a collaboration project aiming to harmonise the national rehabilitation practice of children and youth with cerebral palsy (CP).

### **Method**

Parents of children diagnosed with CP visiting two university hospitals and parents of pupils in three learning and consulting centres participated in the study. The subjects were 53 parents who completed the MPOC-20 questionnaire with a 2-year interval (response rate 35%), with the majority (n=50) representing the learning and consulting centres. The scores of MPOC-20 were calculated as recommended by CanChild. Hierarchic and K-means cluster analysis was used for cluster affiliation.

### **Result**

The results identified two respondent cluster groups; one group was positive toward the FCS provided, and the other group more critical towards the service. The positive group scored a mean of 5-6 on the MPOC scale and the critical group 3-4. There were no significant differences between the groups and the different background variables. Both groups remained stable over time.

### **Conclusion**

There seems to be a group of families who experience the service more family-centred in general. This group was positive towards FCS before and after the collaboration project. Additionally there was a group who was more critical. Stability over time might be due to the fact that from the parent's point of view the collaboration project did not affect FCS quality. A further study with a qualitative approach could give a deeper understanding of the differences between the two groups.



## **Can an intensive indoor climbing therapy improve the trunk performance and upper limb functions in children with cerebral palsy?**

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### **Background**

Several literature postulates that climbing can improve coordination, articular mobility, endurance, muscle strength and upper limb functions in patients with different psychological, neurologic and orthopaedic diagnoses. At the C.D.N., an independent, regional, neuropsychiatric center for children, juveniles and adults with congenital or acquired brain damage, the climbing therapy occurs for years, as a combined therapy from physio- and occupational therapists. Research showed that intensive therapy can lead to progress in a short time. This can be encouraging for children with CP with slight progress after years of regular therapy.

### **Aim**

The purpose of this research was to assess the improvement of trunk performance and uni- and bimanual fine motor skills after a one week intensive indoor climbing therapy in children with CP.

### **Method**

The participants in this study were nine children in the ages five to 13 with CP (spastic unilateral CP: 3, spastic bilateral CP: 5, ataxic CP: 1). The cognitive ability was for all children in the normal range. All participants showed a low trunk tonus and deficits in trunk stabilization. The therapeutic intensive climbing week was undertaken two times during a period of four months. The therapy took place two hours per day. During the intensive weeks other therapies were paused. Pre and posttest were conducted within both weeks. Endurance of trunk performance was assessed using the Ayres' clinical observations. The upper limb outcomes were evaluated using M-ABC and BOT-2.

### **Result**

The trunk performance showed improvements in all participants, either in abdominal or supine position. No considerable changes were proved in the uni- and bimanual skills.

### **Conclusion**

In this study one week intensive climbing therapy has improved trunk performance. An improvement of uni- and bimanual skills cannot be detected with this study. A longer period of climbing therapy or more sensitive assessment could have more impact on upper limb functions.

## **Empowering parents to be parents in paediatric severe acquired brain injury using the “NIF-TY”: the Neuropsychological Integrated Formulation model**

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### **Background**

Parenting a child that has sustained a severe brain injury is replete with a multitude of challenges related to biopsychosocial changes (Wade, 2010).

Parents often feel enormously disempowered as they struggle to negotiate the interaction between their child's behavioural, emotional, neuropsychological needs with their own psychosocial needs.

### **Aim**

The objective was to devise an empowering transtheoretical integrative tool for comprehensive biopsychosocial formulation to use with parents.

This tool would allow them to understand their parenting dilemmas in a multifactorial model that then guided specific interventions.

### **Method**

A review of complex cases formed the basis of identifying improvements to existing methods.

It was imperative that our new model had the following features: (i) it allowed the impact of the brain injury to be explicitly acknowledged through the entirety of the child and family's biopsychosocial world, (ii) to be multifactorial & multisystemic, (iii) theoretically-based, (iv) developmental (primary and secondary impacts), (v) valuing of a strengths-based empowering approach, (iv) to be explicit enough as to have predictive qualities, and (vii) to be detailed enough to give rise to objective goal-setting.

### **Result**

The Neuropsychological Integrated Formulation “NIF-TY”, was devised that satisfied the above essential features.

It allows the development of a conceptual rationale for both individual and group working with parents to empower them to reconnect with their role as parents.

### **Conclusion**

“NIF-TY” is a clinical innovation that helps increase parental empowerment by allowing a comprehensive non-blaming understanding of their dilemmas and ways to address these.

## **Parents' perspectives of their children with CP and its management: a cross cultural view through the lens of the International Classification of Functioning, Disability and Health**

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**Background:** Parents perspectives strongly influence their behaviour towards the child's health condition and its management. Exploring parents' perspective can give us an insight into the prevalent perspectives and the factors shaping them. It will help to identify the areas of knowledge gaps and in designing the needed interventions to bridge the gap. **Aim:** To explore a) perspectives of parents' with different cultural and socio-economic backgrounds about their children with Cerebral Palsy (CP) and its management, b) parents' information needs to help in their child's management. **Methods:** using interpretive description approach, 18 English speaking parents having children with CP were selected from India and Canada (11 India and 7 Canada). Children were aged 2-10 years and had different Gross Motor Functional Classifications Levels. Semi-structured interviews were done using an interview guide, and data was analysed using thematic analysis. The domains of the ICF framework served as themes. **Results:** Body Structure and Function (BSF): Both children were seeking physiotherapy (PT) and speech therapy services to resolve similar problems. All Indian, and few Canadian parents were doing PT in the clinic and at home for correcting BSF problems. Canadian parents cared less about BSF problems and kept the child actively involved in various play activities. **Activity and participation:** many Indian children did not attend school compared to all Canadian children going to school. **Environmental factors:** both parents found families supportive. The negative attitude of doctors, society, beliefs and policies were barriers in child's rehabilitation. Parents needed comprehensive and centralised information resources to help in the child's rehabilitation. **Conclusion:** to achieve better rehabilitation outcomes, Indian society needs education and counselling regarding CP. In Canada, the funding process of receiving benefits from the ministries needs to be simplified.

## **A Challenging School Day in Move & Walk School, Where Conductive Education Meets Swedish National Curriculum**

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### **Background**

Move & Walk School in Sweden is an independent school running by a holistic approach of Conductive Education (CE). We have a permission for special schools with associated leisure activities from year 0 to 9 and special secondary school with individuals program from year 1- 4. The school follows The Swedish National Curriculum and it is free of charge to those who attend. The pupils learn on the basis of their own criteria and objectives according to the relevant curriculum. Today we have 15 pupils in Gothenburg and we have 9 pupils in Malmö, all of them live with moderate or severe multiply disabilities.

### **Method**

Conductive education is built on active learning linked to a specific purpose. By confirming the child's motivation and giving the individual pupil the time that needed in both physical and cognitive as well as communicative situations, we achieve an optimum learning situation. Pupils with neurological functional disabilities will be able to develop through active learning and experiences.

### **Leading question**

Which opportunities have Move & Walk School to integrate CE and the Swedish Curriculum in the special school program? In most cases of children who live with Cerebral Palsy we have to talk about multiple disabilities and that means shortly the whole personality and quality of life can be effected.

We are going to present 1 busy active school day on the poster how we organize and implement programs for the children by conductors.

### **Result**

By the complexity and the holistic approach of CE methodology lead the all areas development of our students. Satisfaction of families has got positives feedback and energy to our works.

### **Conclusion**

With consistence and flexibility in every second give the possible harmonization and fruitful collaboration between CE and the Swedish Curriculum. With the help of differentiation and the other possibilities of the pedagogy it is possible to take into account the individual needs and the age factor.

## Stepping Games for Training Motor Functions

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**Background.** Rehabilitation games that combine physical therapy exercises with computer games provide all prerequisites for effective motor learning – repeated practice of the same task with adjusted difficulty level and motivating feedback in safe environment. Encouraging future have stepping games that are using Dance Mat - flat electronic game controller with 3×3 matrix of square panels for the player to step on, to evoke actions within the game. Eight different stepping games with individually adjusted difficulty were available for home training. Results of each training session: time, duration and score were stored on the server and were available to the therapist for remote supervision.

**Aim.** The aim of the study was to evaluate influence of stepping games on walking abilities and balance of children with Cerebral Palsy.

**Method.** Preliminary assessment was done on ten patients with cerebral palsy, aged four to twelve years, GMFCS Level II - III. Patients followed two weeks home training program with daily 20 minutes gaming session. Every session includes 3 or 4 different games with individually adjusted difficulty parameters. Each patient was assessed before and after the training course by following tests: Timed Up and Go, Pediatric Balance Scale and Four Square Step Test.

**Results.** After two weeks of daily training, balance and walking improvements were noted. Pediatric Balance Scale improved on average by 1.5 points ( $p<0.05$ ), Timed Up and Go Test by 2.1 seconds, and the time in the Four Square Step Test was reduced on average by 1.7 seconds ( $p<0.05$ ). Results could have bias since the author participated in the creation of the rehabilitation games.

**Conclusion:** Rehabilitation computer stepping games may improve balance and walking skills in patients with cerebral palsy.

**Empowerment and quality of life among parents with young children with cerebral palsy**

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**Empowerment and quality of life among parents with young children with cerebral palsy**

**Background:** Family-centred service is considered to be best practice in early intervention and paediatric rehabilitation. Parental empowerment is one way to assess how professionals reinforce family confidence and competence in helping the child grow and develop. Moreover, parent's quality of life is associated with parent-child interactions and child development. However, these aspects of family functioning has yet to be adequately empirically examined.

**Aim:** To describe empowerment and QoL among parents with young children with cerebral palsy (CP), and assess associations between different dimensions of empowerment and QoL.

**Method:** Cross-sectional study with use of registry data from the Norwegian Cerebral Palsy Follow-Up Program and the associated research register, Habilitation trajectories and services for young children with CP. 61 children recently diagnosed with CP (59% of the cohort, mean age 29.9 mo, SD 12.1) participated. Empowerment and QoL data were collected from the Family Empowerment Scale (FES) and Quality of Life Scale (QOLS).

**Result:** Parental empowerment in the family and in service situations was high, though much lower in advocacy for improved services. The parent's QoL was in correspondence with a Norwegian reference population, or even better, except for the ability to do things on their own. Parents with low perceived empowerment appeared to have a significantly lower QoL than the other parents ( $p=0.032$ ).

**Conclusion:** High sense of parental control in managing the child and the child's services suggests family-centred behaviour among professionals, yet the systems seem to overlook working with families as an important source of knowledge to improve childcare services. The association between low perceived empowerment and poorer QoL, indicates that some families are in need of extra psychosocial support to strengthen parenting self-efficacy beliefs.

## **A follow-up study on reasons for the cessation of botulinum toxin-A therapy**

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### **<Background>**

Botulinum toxin-A (BoNTA) therapy for patients with spasticity is often repeatedly performed because its effective duration is limited. Once the therapy starts, it is difficult to expect when the therapy could be completed or stopped.

### **<Aim>**

To investigate main reasons for the cessation of the BoNTA therapy performed for patients with spasticity in our hospital.

### **<Method>**

Total 152 spastic patients treated with the BoNTA therapy between 2004 and 2012 were included in this study. Males were 88 and females were 64. The mean age was 13.9 years old and the range was 5 months to 59 years. The mean follow up period was 4.9 years and the range was a month to 125 months. No treatment over three years was defined as the cessation of the therapy. Reasons for the cessation were surveyed for all patients, and compared among groups based on the GMFCS classification.

### **<Result>**

Ninety-two patients (61%) were classified to the cessation of the BoNTA therapy, while 60 patients (39%) have continued to be treated with the therapy. The major reasons for the cessation in all patients were responder (patients maintaining improved: 25%), non-responder (23%) and altering to other treatments (24%). In the Level I+II group of the GMFCS classification, responder, non-responder and altering to other treatments were 22%, 28% and 39%, respectively. In the Level III group, 27% were responder, 23% were non-responder and 23% were altering to other treatments. Finally, the Level IV+V group demonstrated 25%, 21% and 19%, respectively.

### **<Conclusion>**

In this surveillance study for spastic patients treated with the BoNTA therapy, 61% of patients stopped receiving the therapy, and 25% of them could complete it with favorable results.

## **The effect of group art therapy on language development in children with cognitive impairment**

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### **Background**

Art therapy can be viewed as a form of alternative therapy that uses art to foster self-expression, increase self-esteem, manage emotions, and improve inter-subjective relationships. However, there is no research about the effect of art therapy on language development.

### **Aim**

The aim of this study is to evaluate the effectiveness of group art therapy on various domains of development, especially language development in children with cognitive impairment.

### **Method**

This study included forty one children with cognitive impairment who were recruited through outpatient clinic of pediatric rehabilitation from January 2011 to August 2015. The enrolled children received art therapy program in grouped with 4-6 children, for 60 minutes a day, once a week, for 6 months in each session, by experienced art therapist. The effects of art therapy were assessed by psychodevelopmental and language measurement scales which include Preschool Receptive-Expressive Language Scale(PRES), Denver Developmental Screening Test(DDST), Pediatric Evaluation of Disability Inventory(PEDI), and Box and Block Test(BBT) at baseline and after the completion of 6 months intervention. All outcomes were measured by well experienced assessors.

### **Result**

After 6 months of intervention, the enrolled children showed significant improvements in all domains of PRES compared with baseline levels. The scores increased in personal-social and fine motor-adaptive domains of DDST. Significant improvements were also found in self-care, mobility, and social function domains of PEDI and in BBT as well.

### **Conclusion**

Group art therapy program may have beneficial effects in not only fine motor and social function, but also language developments in children with cognitive impairment. Thus art therapy would be an one of adjuvant therapy to provide positive effects in management of children with cognitive developmental impairments.



## **Hand function in young children with cerebral palsy: current practice and parent-reported benefits**

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**Background:** Limited hand function is a common consequence of cerebral palsy (CP) and a strong predictor of restricted participation in daily activities. Substantial therapeutic resources aim to improve hand function, and research has shown that structured and intensive interventions can lead to functional changes in sub-groups of children with CP. Although pediatric rehabilitation services increasingly rely on the active involvement of parents, the characteristics of current practice have rarely been explored from the parents' perspective.

**Aim:** To explore characteristics of current interventions to improve hand function and factors associated with the likelihood of hand training and training benefits for a cohort of young children with CP.

**Method:** A cross-sectional design was used with parent-reported data and data from the Norwegian Cerebral Palsy Follow-up Program (CPOP). 102 children were included (53% of the cohort, mean age: 30.3 months, SD: 12.1). Children's hand function was classified according to the Mini-Manual Ability Classification System (Mini-MACS). Data were analyzed with descriptive statistics, cross-tables and logistic regression.

**Result:** The majority of the children performed hand training. The parents reported high amounts of training, and training was commonly integrated in natural activity settings. Both parents (OR=5.6,  $p<.011$ ) and OTs (OR=6.2,  $p<.002$ ) were more likely to report hand training for children at Mini-MACS levels II-III compared to level I. Parents reported larger child benefits when training was organized as a combination of training sessions and practice within daily activities (OR=7.090,  $p=.011$ ).

**Conclusion:** Describing the amount of interventions by the frequency of therapy sessions seems insufficient to capture current practice, as parents report a vast proportion of the training to be incorporated in daily activities. Variability in the organization of training seems likely to enhance parents' perceptions of child benefits.

## **On the way to the Russian Consensus on the botulinum toxin A (BTA) treatment in cerebral palsy (CP)**

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**Background:** BTA injections proved their efficacy and safety in the reduction of the spasticity in children with CP. Most of the muscles are injected “off-label” according to the scientific results and recommendations (European Consensus etc.) and national guidelines. In Russia many centers and doctors include BTA injections into CP rehabilitations but we still don’t have the consolidated recommendations for the “off-label” injections that could be used as a basic document for the specialists and the official authorities.

**Aim:** to prepare the Russian Consensus on the BTA treatment in CP based on the multicentral experience that could be used as a national guideline for the multilevel “off-label” injections and antispasticity treatment.

**Patients and methods:** we have already analyzed the results of the 382 multilevel BTA injections in the Scientific Centre of Childrens’ Health – the largest federal pediatric hospital in Russia. At least 4 other national CP centers will be included in the analysis of more than 500 patients since 2 to 18 years who received up to 14 repeated effective injections of the BTA. The total and per muscle dosages, the intervals between the injections, the age and GMFCS levels of the children, the use of the orthopedic procedures will be analyzed.

**Results:** according to the results of the different centers we plan to evaluate the situation with the BTA treatment of CP in our country and to bring out the problems and questions in this field as well as to prepare the national recommendations in pediatrics. The final results will be presented in the dates of the Conference.

**Conclusion:** the national multicentral guidelines of the BTA treatment in CP will become the basic reference document for the Russian pediatricians who deal with the spasticity and the scientifically based ground for the “off-label” use of the BTA in the country. Also this experience could be integrated into the international data on the efficacy of the spasticity treatment in CP.

## **Therapist's perceptions of factors that contribute to parents' satisfaction with intensive treatment for children with cerebral palsy**

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**Background** Intensive physiotherapy and occupational therapy may progress the skills of children with cerebral palsy (CP) (Arpino et al, 2010; Lee et al, 2015), but can be costly for families in time, financially, and may disrupt schooling (Odman et al, 2009). It is therefore important to audit such services.

**Aim** As a first step to better understanding the factors that can lead to parents being more satisfied or less satisfied with intensive treatment, therapist's views of this issue were explored.

**Method** Nominal group technique (NGT) is a structured multi-step procedure that elicits ideas and ranks responses from individuals within a group in response to a question, so gaining a diverse range of views (Potter et al, 2004). The views of therapists from three UK treatment centres were investigated through NGT. Questions investigated were "what factors do you believe contribute to parents being more (or less) satisfied with an intensive block of treatment?"

**Results** Twenty therapists participated. The 3 most important factors perceived to increase satisfaction were parents seeing meaningful positive change in their child, skilful and knowledgeable therapists and parent empowerment. Other factors related to communication, family centred services and liaison with team members. The most important factors thought to decrease satisfaction were lack of progression towards goals, the child being unhappy in therapy, insufficient information being given to parents and practical issues affecting families' ability to attend for therapy.

**Conclusion** Therapist's views of parental satisfaction with intensive therapy highlighted family-centred therapy focussing on family goals and good communication. The expertise of therapists was also thought to influence families' experience of therapy. Future audit using NGT will investigate and compare parents' views with those of therapists, to help establish which factors are important for effective service delivery.

## **ENABLING PARTICIPATION IN PHYSICAL PLAY IN CHILDREN WITH MOTOR IMPAIRMENTS: IDENTIFYING BIOPSYCHOSOCIAL TARGETS FOR INTERVENTIONS**

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**Introduction:** Evidence on how to enable participation in physical play in children with motor impairments is limited. The first step is to identify modifiable factors to target by interventions.

**Methods:** A mixed methods study using the integrated biopsychosocial framework. Participation was defined as “doing” physical play and “being” in the world through physical play.

**Participants:** children (6-8yrs) with motor impairments mobilising independently with/without equipment; their parents; and therapists. **Primary outcome:** self-reported participation (Children’s Assessment of Participation and Enjoyment [CAPE]). Data about modifiable impairment, activity, environmental, and personal factors were collected by therapists’ observations, parent questionnaires, and child-friendly interviews. CAPE, therapist, and parent data were analysed using linear regression. Interview data were analysed for emerging themes.

**Results:** Children’s (n=195) participation [median 18 times/week (IQR=11-25)] was mainly ‘recreational’ (e.g., pretend play, playing with pets) rather than ‘active physical’ (e.g. riding a bike/scooter). Parents (n=152) reported positive beliefs about children’s participation but varying levels of family physical participation. Therapists reported 23 unique impairments (e.g., muscle tone), 16 activity limitations (e.g., walking), and 3 personal factors (e.g., child’s confidence). Children (n=17) reported strong preference for physical play, but indicated that adults regulated their participation. Family physical participation, and impairment in child’s movement-related body structures, explained 18% of variation in child participation. Family participation explained the most variation.

**Conclusions:** Physical participation of families was a powerful influence on participation behaviour of children with motor impairments; interventions should focus on families. Current clinical data have limited utility in explaining these children’s participation.

## **PARTICIPATION IN PHYSICAL ACTIVITIES FOR CHILDREN WITH PHYSICAL DISABILITIES: FEASIBILITY AND EFFECTIVENESS OF PHYSICAL ACTIVITY REFERRALS**

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**Background:** Children with physical disabilities are at risk to develop cardiometabolic diseases because of inactivity. An active lifestyle with increased habitual physical activity and reduced sedentary behaviour is recommended. Physical Activity Referral (PAR) is an effective intervention to promote a lifestyle change in adults. There is a lack of knowledge about PAR in children with disabilities. **Aim:** To evaluate the feasibility and effectiveness of PAR for children with physical disabilities. **Method:** 14 children with physical disabilities, aged 7-12 years, and their parents participated in PAR, with assessments at baseline, 8 and 11 months. Sociodemographic, clinical and physical activity questionnaires were conducted at baseline; GMFM-66, physical activity and heart rate monitors and time use diaries were used at baseline and at 8 months. Motivational Interviewing and the Canadian Occupational Performance Measure (COPM) led to a written agreement between each child, its parents and the physiotherapist by using Goal Attainment Scaling (GAS). At 8 and at 11 months COPM and GAS were evaluated and PAR-evaluation, physical activity and costs & time spent questionnaires were completed. At 11 months feedback was given of measured physical activity levels and GMFM-66 scores. **Result:** Each child participated in 1-3 self-selected physical activities with support of the physiotherapist. PAR involved both everyday physical activities as biking to school and organised physical activities as wheelchair hockey due to individual preferences, opportunities and facilities. Measuring physical activity levels was motivating, COPM, GAS and GMFM-66 scores increased and several children made new friends. **Conclusion:** PAR seems to be feasible and effective. PAR promotes an active lifestyle through increased participation, motivation and engagement in physical activities and increased social participation. Further research is needed, preferably in a RCT including health economic analysis.

## **Combining clinic- and home-based virtual reality exercise programs for children with cerebral palsy**

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**Background:** Gross motor skills in children with cerebral palsy (CP) may be enhanced by clinic-based virtual reality (VR) applications. However, for home-based use, active video games such as the Kinect for Xbox 360 may be more accessible exercise options. We assessed the added value of combining a clinic-based VR intervention and home-based exergaming on motor skill acquisition in children with CP.

**Aim:** Compare changes in gross motor skills and functional mobility between children with CP at Gross Motor Function Classification System (GMFCS) levels I or II who undergo a 1-week clinic-based VR intervention combined with a 6-week home Kinect program to children who complete only the 6-week home program.

**Method:** Pilot non-randomized controlled trial. Five children received 1 hour of VR-based therapy for 5 days followed by a 6-week, 30 minutes/day home Kinect program. Six children completed only the 6-week home program. The Gross Motor Function Measure Challenge Module (GMFM-CM) and the Six Minute Walk Test (6MWT) were administered at baseline, after the 1-week VR intervention, following the 6-week program and at 1 and 2 months post-completion.

**Result:** There were no statistically significant changes in 6MWT or GMFM-CM scores following the 1-week VR training, or within or between groups at either time point following the 6-week Kinect program. All participants in the VR + Kinect group decreased their 6MWT distance above the minimally clinically significant difference (MCID) (mean 70.9m, SD 28.56m) following the Kinect training; in the Kinect-only group, 4/6 participants had a decrease in 6MWT distance below the MCID (mean 50.5m, SD 78.4m). All 6MWT scores returned to baseline at 2 months post-intervention.

**Conclusion:** No improvements were seen following a combined clinic and home-based VR intervention nor a home Kinect intervention alone in this small sample. The Kinect home program may have not been optimally targeted to challenge skill progression.

## **Using a website to facilitate therapist monitoring of a home-based video-gaming exercise program for children with cerebral palsy**

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**Background:** Adherence to a home-based Kinect video gaming exercise program may be challenged by lack of therapist monitoring. We explored the use of an interactive website as a communication tool.

**Aim:** To describe metrics of website use by participating children and therapists with respect to exercise program adherence, therapist-family interaction and usability.

**Method:** Evaluation occurred within a pilot non-randomized controlled trial. Web interfaces for young children and youth included interactive reporting and communication features. Qualitative interviews with parents and children explored website use following the study.

**Result:** Three physical therapists supervised eleven children with hemiplegic or diplegic CP at Gross Motor Function Classification System (GMFCS) levels I and II who completed a 6-week home Kinect program. Ninety-one percent used the website to report their Kinect and physical activities and respond to set questions for the full six weeks, logging in an average of 32.3 times (range 11-84 logins). Therapists logged in more frequently (range 32-84 logins per therapist) and updated exercise programs an average of 6.5 times per participant. There were no significant changes between weeks 1-6 in responses to enjoyment, challenge and fatigue questions. An average of 6.2 emails per participant were exchanged in which therapists provided positive reinforcement and families reported technical problems. Parents were the primary website users; they did not view the site as motivating children's Kinect adherence.

**Conclusion:** Parents more so than children used the website to record exercise program adherence, but required frequent reminders. Limited exchanges regarding exercise program difficulty and progression occurred between therapists and families. Study findings will inform improvements to website usability as well as to the content and format of weekly questions to better elicit information supporting treatment individualization.

## **The “SNAP” 2: Post-acute Systematic Neuropsychological Assessment Profile - using observations and participation in activities to compile a neuropsychological profile**

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### **Background**

It is difficult yet imperative to gain a person's neuropsychological profile in the post-acute stage of severe acquired brain injury (ABI) (Newby et al, 2013).

Due complex physical and psychological deficits, an individual may be unable to use standardised tests.

“SNAP 2” builds upon “SNAP 1” which is a tool for general information gathering based on clinical opinion.

### **Aim**

“SNAP” 2 aims to provide a pragmatic solution to collating meaningful information about cognitive functioning using systematic clinical observations of participation in everyday tasks/activities, to guide neurorehabilitation.

### **Method**

Knowledge regarding how cognitive functioning maps onto everyday functioning and tasks was given considerable thought. “SNAP 2” was developed in specialist residential rehabilitation settings that naturally provide opportunities of observing an individual's cognitive skills in a novel environment, thereby allowing unscaffolded skills to be observed in action.

### **Result**

“SNAP 2” was developed to help empower and guide clinicians when individuals cannot engage in formal neuropsychological assessment.

It is used cumulatively to build understanding of an individual, in line with their recovery.

It is a low cost pragmatic tool that systematically informs an individual's neuropsychological profile and avenues for intervention.

### **Conclusion**

“SNAP 2” can be used in early post-acute stages of severe ABI producing meaningful information regarding an individual's cognitive functioning when they are unable to engage in formal assessments.

Both “SNAP 1 and 3” empower clinicians to assess individuals early in rehabilitation thus avoiding unnecessary delays in developing interventions to increase quality of life of those affected by severe acquired brain injury.



## **Botulinum toxin A injections and occupational therapy in children with unilateral spastic cerebral palsy: a randomized controlled trial**

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**Background:** Children with unilateral spastic cerebral palsy (USCP) have often reduced bimanual performance of activities in daily life. One hand has often a reduction in the range and speed of movement, strength, sensation and muscle tone, which hampers the ability to grasp and manipulate with the impaired hand. Botulinum toxin (BoNT-A) in combination with occupational therapy has been proven effective in increasing the capacity of the upper limb in children with USCP. In contrast there are very few studies concerning repeated BoNT-A treatment and studies measuring capacity of hand function in all the domains of International Classification of Functioning, Disability and Health (ICF).

**Aim:** To investigate the effects of repeated BoNT-A combined with occupational therapy, including a splint, compared with occupational therapy alone on hand function in children with USCP, in all ICF domains.

**Method:** This study is randomized controlled, population-based, evaluator-blinded for primary outcome. Twenty children (14 males; median age 3y 1mo) with USCP, recruited at a rehabilitation centre in Sweden, were assigned to one of two parallel groups using concealed allocation. During one year, 10 children received occupational therapy, while 10 received repeated BoNT-A and occupational therapy. Primary outcome (Assisting Hand Assessment [AHA]), and secondary outcome measures (range of movement [ROM] and Canadian Occupational Performance Measure), were measured at baseline, 3, 6, 9 and 12 months.

**Results:** AHA revealed a superior effect in the BoNT-A/OT group at 12 months; 6 out of 10 improved compared with 1 out of 10 in the occupational therapy group ( $p < 0.03$ ). A 95% confidence interval for the difference in proportions is given as 0.01 to 0.81. Secondary outcomes improved in both groups.

**Conclusion:** Repeated BoNT-A/OT appeared superior to occupational therapy alone for bimanual performance in young children with USCP. Active ROM and goal performance improved in both groups.

**Evaluating functional outcomes of botulinum toxin type A injection combined with occupational therapy in the upper limbs of children with cerebral palsy: A 9-month follow-up from the perspectives of both child and caregiver**

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**Background:** Spastic type comprises about 80% of patients with cerebral palsy (CP). Literature supports the use of botulinum toxin type A (BoNT-A) as an adjunct to occupational therapy (OT) to facilitate the function of upper limbs in CP. Previous studies focused only on children's body functions and structures, without addressing perspectives of both child and caregiver.

**Aim:** To assess the effectiveness of combining BoNT-A with functional occupational therapy (OT) at 9-month follow-up in children with CP with bilateral upper limb impairments from the perspectives of both child and caregiver.

**Method:** Twelve children with CP and their caregivers were assessed across 5 time points in 9 months based on the ICF after BoNT-A injection and functional OT.

**Result:** Significant differences were found across 5 time points ( $p < .05$ ) for both grasp and visual-motor integration with small effects (effect sizes = 0.12 - 0.24) and the self-care capability and capability and performance of social function ( $p < .05$ ). However, based on the effect sizes (0.02 - 0.14), no significant effects were found at the 4 post-test time points. Small effects were found on the psychological domain (effect sizes = 0.25 - 0.37) and environmental domains (effect size = 0.27) at follow-ups.

**Conclusion:** Combining a BoNT-A injection with OT not only reduced the muscle tone and increased ROM but also improved the upper limb function and self-care capability in children with CP. More importantly, these effects persisted for up to 9 months. Functional OT extends the effectiveness of a BoNT-A injection.

## **Botulinum Toxin Injection to Improve Functional Independence and to Alleviate Parenting Stress in a Child with Advanced Pantothenate Kinase-Associated Neurodegeneration**

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**Background:** Pantothenate kinase-associated neurodegeneration (PKAN) is a rare autosomal recessive disease. Motor symptoms such as dystonia begin in early childhood and relentlessly become incapacitating later in life. Symptomatic treatment including anticholinergics and iron chelation is usually ineffective. Botulinum toxin type A (BoNT-A) is a safe and effective treatment in controlling the dystonia without major side effects. But it has been rarely reported to improve quality of life and to relieve the stress of caregiver in patients with PKAN.

**Aim:** We assessed the effect of botulinum toxin injection therapy for a patient with PKAN, especially in functional and societal domains, including Barry-Albright Dystonia Scale, quality of life, activities of daily living (ADL) and parenting stress of caregiver.

**Method:** We presented a 10-year-old girl with severe dystonia associated with PKAN, resulting in wheelchair-bounded status and severely impaired ADL function. She received injection with 180 units of Botox (onabotulinumtoxinA, Allergan Inc., Irvine, CA, USA), and was examined regularly after intervention. Each time, we evaluated the following parameters including dystonia pattern (by Barry-Albright Dystonia Scale, BADS), quality of life (by Cerebral Palsy Quality of Life for Children, CP QOL-Child, primary caregiver proxy-report form), activities of daily living (by the Functional Independence Measure for Children, WeeFIM) and parenting stress of caregivers (by Parenting Stress Index Short Form, PSI-SF).

**Result:** The therapeutic effect of BoNT-A injection was noted at four weeks after injection. BADS improved 25%. The total WeeFIM score increased (4%), and there was a reduction in PSI-SF score (3.8%) and "Pain and Impact of Disability" domain in the CP QOL-Child scores (8.3%)..

**Conclusion:** BoNT-A injection was effective to control dystonia, to improve functional independence, and to alleviate parenting stress of caregivers in our patient with advanced PKAN.

## **The relationship between prosthetic control and daily prosthesis use**

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**Background:** Myoelectric prostheses are often prescribed to children with arm deficiency and prosthetic training is given regularly by the prosthetic clinics. One goal of prosthesis fitting is to give the child an assistive tool to perform their daily activities. Our clinical experience told us that prosthetic fitting should be initiated at a young age but less is known whether the prostheses can ease the performance of their daily activities.

**Aim:** To evaluate the relationship between prosthetic control and the ease of performance in using the prosthesis to perform daily activities.

**Method:** During their clinic visits, pediatric prosthesis users (n=60, age 3 to 17) were asked to fill in a questionnaire 'Prosthetic Upper Extremity Functional Index' where the child (or the parent if the child is under 6) rated the ease of performance in using the prosthesis to perform 26-38 daily activities. Then the child performed a bimanual activity and an occupational therapist from the clinic (n=6) assessed the prosthetic control with an assessment tool 'Assessment of Capacity for Myoelectric Control'. Spearman rho was used to calculate the correlation between prosthetic control and ease of performance.

**Result:** A strong correlation between prosthetic control and the ease of performance in using the prosthesis to perform daily activities (Spearman rho 0.74). Children (n=34) that use their prostheses > 8 hours daily had less difficulty in performing the activities compared to children that use their prostheses < 8 hours.

**Conclusion:** The correlation between ease of performance and prosthetic control suggests that a myoelectric prosthesis can ease the performance of their daily activities if the child has a good prosthetic control.

**A feasibility study to evaluate the impact of postural support, constructed via appropriate paper-based technology (APT), on the participation and quality of life of young children with Cerebral Palsy in Kenya.**

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**Background-** The World Health Organization notes a lack of assistive devices for disabled people in Africa particularly children with Cerebral Palsy. Second-hand equipment from developed countries is not sustainable and may not be suitable for the individual child. APT using recycled cardboard for chairs and standing frames has been used mainly in Africa for thirty years, but not formally evaluated .

**Aim-** The Primary aim is to find out if APT assistive devices can improve the quality of life and participation of children with cerebral palsy in rural Kenya. The secondary aim is to see if APT devices are acceptable to children, families and their communities.

**Method –** Six months after an APT workshop in Nyahururu, Kenya, and once ethical approval was obtained, 6 children under seven years old are being recruited. After baseline measures of gross motor function, range of movement, Quality of life and participation, each child will be measured for a device which will be made from APT by workshop participants. Once complete, the devices will be issued with instructions on use and a recording booklet to document time used and any positive and negative effects. Monthly visits by local therapists, repeat assessments and interviews after six months will conclude the quantitative and qualitative data collection.

**Results -**The programme staff in Nyahururu are committed to the study, assisting with recruitment, translation of consent forms, information leaflets, assessment tools and explanations of usage to the participants. The workshop assistants will construct and issue the devices. Their usage and effect will be recorded with repeat assessments scheduled, providing results by May 2016.

**Conclusion –** It appears feasible to provide and study the effects of APT devices on young children with Cerebral Palsy in rural Kenya. A larger, multi-centre study will be required to demonstrate significant benefits and other factors needed to support more widespread implementation

**Immediate effects of Virtual Reality Training in Reaching of Children with Cerebral Palsy:**

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**Background:** Disability of upper limb function of children with Cerebral Palsy (CP) restricts their participation in social activities. Virtual reality (VR) has shown promising results in functional recovery of this population, however, few studies have evaluated its effectiveness in reaching movement of these children. **Aim:** To assess the immediate effects of training with VR in the range of motion of reaching of children with spastic hemiparetic CP. **Method:** We conducted a randomized crossover trial. Sample consisted of 12 children diagnosed with spastic hemiparetic CP of both genders, with a mean age of  $9.63 \pm 2.3$  years. Sample characterization was performed by assessing muscle tone, range of motion, grip strength, functional performance, handicraft and disability. Kinematic analysis of the upper limb was performed by Qualisys Motion Capture System®. Children were randomized to undergo initially the training A (using VR with Nintendo Wii®) or B (conventional physical therapy), constituting AB and BA sequences, with one day to each training and one week interval between trainings. Kinematics were performed immediately before and post-training and after a week (retention). Data were analyzed using a 5% significance level. Kinematic variables were analyzed by two-way ANOVA for repeated measures. **Result:** No significant changes were observed for angular and spatio-temporal variables between groups. Although training with VR had been highly motivating for children compared to conventional training, the time of intervention seems not to have been enough to promote changes in those variables. **Conclusion:** There were no gains using VR protocol in the current study. This protocol, however, was feasible and practicable, remaining the suggestion of his application for a longer period, considering the chronicity of the deficits presented by this population.

## IMMEDIATE EFFECTS OF TREADMILL TRAINING SESSION WITH ANKLE LOAD ON LOCOMOTOR KINEMATIC PARAMETERS OF CHILDREN WITH CEREBRAL PALSY

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**BACKGROUND** The literature reports that adding load to the lower limb results in adaptive responses in the locomotor pattern of healthy children and adults or with neurological diseases. The effects of disturbance on the gait of children with spastic hemiparetic cerebral palsy (SHCP) has not yet been investigated. **AIMS:** The study aimed to evaluate the immediate effects of treadmill training with leg weights on the locomotor kinematic parameters of paretic lower limb (PLL) and non-paretic lower limb (NPLL) in children with SHCP. **METHOD:** Quasi-experimental study. The sample consisted of 20 children with SHCP clinical diagnosis of both sexes (mean age was 8.8 years  $\pm$  2.39), and independent walk (GMFCS I-II) that walked with weight added on ankles in a single treadmill training session for 5 minutes. The main outcome was kinematic parameters of PLL and NPLL, evaluated by Qualisys Motion Capture System in three phases: before training (PRE); immediately after training (POST); and 5 minutes after the end of training (RET). **RESULTS:** No significant differences were observed when comparing angular variables of the LLP and LLNP. When comparing LLP and LLNP individually on three phases, using ANOVA test for repeated measures, both limbs showed similar behavior, demonstrating significant increase in range of motion on knee ( $F= 7.697$ ;  $P = .001$ ) and hip joint ( $F = 7.363$ ;  $P = .001$ ), maximum flexion in swing phase of knee ( $F= 11.896$ ;  $P < .001$ ) and hip joint ( $F = 15.055$ ;  $P < .001$ ) and the maximum height of the PLL during the swing phase ( $F = 15.144$ ;  $P < .001$ ). Bonferroni test identified that the differences occurred when comparing phases PRE x POST and POST x RET. **CONCLUSIONS:** The gait training with leg weights seems to be a disturbance which can modify the locomotor strategy for children with SHCP and that this population uses the same strategy in PLL and NPPL.

## **Using the ICF-CY to understand the experiences on participation in leisure activities of children and adolescents with cerebral palsy**

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**Background:** Leisure participation is vital to the growth and development of children and adolescents, as these activities promote development of skill competencies, peer interactions, and greater independence. However, children and adolescents with cerebral palsy (CP) are at risk for decreased participation in leisure activities, a key component for physical and mental health.

**Aim:** To explore CP children's views on participation in leisure activities and environmental factors that influenced these according to the International Classification of Functioning, Disability and Health - Children and Youth Version (ICF-CY).

**Method:** This study is part of a larger study about the validation of the Children's Assessment of Participation and Enjoyment (CAPE) test developed in Spain. Sixteen children and adolescents with CP (aged 7-18 years; 9 female and 7 male; GMFCS levels I-IV) participated in three focus groups. All groups were recorded, transcribed and analyzed thematically. Identified codes and themes were mapped to the domains of the ICF-CY.

**Result:** Despite the barriers experienced, children and adolescents with CP participated in a range of activities. Barriers and facilitators identified highlight aspects of the environment that could be modified through intervention to enhance participation in leisure activities (e.g. the support and attitudes of others, mobility and aspects of the physical environment).

**Conclusion:** Intervention aimed at improving participation may address the various physical, social and environment factors identified here as impacting on participation in leisure activities of children and adolescents with CP.



**LIFE CARRIES ON – Narrative research on the life stories of youth with CP and related speech disorders Acta Universitatis Lapponiensis 265**

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This research is based on my licentiate thesis titled “Story-telling of children using BLISS language” (2002). This study focused on the life narratives (narrative method) of youth with severe CP. The purpose was to determine how these youngsters perceived their childhood using the AAC method. This main research question was answered by focusing on the period of special education and its meaning as a separate phase of life. The second task was to investigate how youth with CP and related speech disorders experienced their own participation and possibility to influence their lives. And it was asked how challenging learning, communicating, moving, expressing feelings, and communal and social life have been for them.

Everyday life was studied using Susanne Scheibe’s Life Longing theory, in which the life course is considered to be directed by the presence of dreams.

According to the interviews, those school subjects providing skills and knowledge that they would need as young adults were regarded the most important ones. The most significant things to be learned were interaction skills, reading and writing skills, IT skills, having suitable aids and updating them, body management skills, independent movement with a wheelchair, and understanding of their rights and potential.

## **Effects of the standing Program with Hip abduction on Hip Acetabular Development in Children with Spastic Diplegia Cerebral Palsy**

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**Background:** Early identification and intervention with conservative measures are important to help manage hip dysplasia in children with a high adductor and iliopsoas tone and delay in weight bearing. **Aim:** The effect of a daily standing program with hip abduction on hip acetabular development in ambulatory children with cerebral palsy was studied. **Method:** The participants were 26 children with spastic diplegia cerebral palsy (CP), classified at Level III according to the Gross Motor Function Classification System (GMFCS). Thirteen children stood upright with hip abduction at least one hour daily from 12-14 months of age to 5.0 years with an individually fabricated standing frame with hip abduction. **Results:** At the age of 5.0 years, radiologic results of the study group were compared with a comparison group of thirteen children with spastic diplegia CP who had not taken part in standing program. The migration percentage in all children who stood with abduction remained within stable limits (13-23%) at the age of five years, in comparison to children who did not stand in abduction (12-47%) ( $p < 0.01$ ). **Conclusion:** The results indicate that a daily standing program with hip abduction in the first 5.0 years may enhance acetabular development in ambulatory children with spastic diplegia CP.

## **“Teen Academy” ~ Working with teenagers who have Cerebral Palsy: what goals do they set & what outcomes do they report?**

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### **Background**

Over recent years Bobath Scotland has run ‘Teen Academy’ groups for teenagers with Cerebral Palsy. Teen Academy provides a means of delivering therapy while simultaneously providing a social opportunity to increase self-confidence and develop new friendships. Groups are run over 1 to 2 weeks and involve 1 hour focusing on individually chosen goals followed by 1.5 hours working on group agreed goals.

### **Aim**

To review what goals teenagers set and the outcomes they report when they attend "Teen Academy".

### **Method**

Retrospective review of group reports, outcome measure results (Canadian Occupational Performance Measure – COPM) and non-standardised feedback from each Teen Academy group.

### **Results**

Between 2012-2015, five Teen Academy groups were organized: 20 different teenagers attended over this period.

Groups were typically attended by 4 to 5 teenagers aged between 12y3m-18y11m.

A total of 69 Individual goals were set :-

12% Body Structure & Function goals e.g. managing pain

87% Activity goals e.g. kitchen skills, grooming, dressing tasks

<1% Participation goals e.g. managing kerbs when out with family & friends

Collaborative goals set: managing in a cafe, organising a fashion show with refreshments, preparing a themed dinner party, producing short "How To Do Things" movies and performing a magic show.

COPM: Clinically significant positive changes were found in 86% of individual total scores.

Teenagers fed-back very positively regarding

- their group experience
- skill acquisition
- changes in how they felt about themselves

### **Conclusions**

Teenagers typically set themselves activity-level goals related to self-care and household tasks. Together they chose fun collaborative projects that involved application of their individual goals. Teenagers rarely set goals at Participation level. Clinically significant positive changes were reported for the majority of individual goals when using the COPM.

## **Influence of motor restrictions on representational momentum: a study in individuals with Cerebral Palsy**

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Previous studies suggest a slowdown of mental imagery (MI), in persons with Cerebral Palsy (CP). On the other hand, performance on Representational Momentum (RepMom) has been suggested to involve dynamic representations and to rely on MI. RepMom is the memory forward shift of the last perceived location of a moving target (more neutrally called M- or O-displacement, concerning horizontal or vertical). A slowdown of MI might, thus, be expected to impact on this mislocation, presumably by reducing its magnitude.

We investigated if this MI slowdown is reflected in RepMom tasks, in which MI is supposed to play a role. Studying this possibility might allow a clarification of the effect of motor impairments on MI, and it might, perhaps, contribute to a better characterization of these tasks concerning a possible relationship with MI.

The study involved 48 participants with CP (8-56y) and 49 typical individuals (8-55y). Videos of a blue square (1 cm<sup>2</sup>) moved horizontally at constant speed (left-right; right-left). After traveling a variable distance at different speeds, the square suddenly vanished. Participants were asked to localize target's last seen position, using a mouse cursor.

The forward error in both displacements was larger in CP sample than in typical participants (contrary to what an MI-based account would predict). Moreover, this forward shift increased with the severity of functional impairment as assessed by GMFSC and MACS.

This observed increase is suggested to rest on embodied motor anticipatory mechanisms, likely involved in the planning of actions towards moving objects. Findings suggest the deployment by CP participants of embodied compensatory strategies developed from prior experiences with dynamic objects, as interceptive actions. Limitations in activity may have an impact on dynamic representations underlying RepMom. It's important to enable experiences as wide as possible to CP individuals promoting their full participation in all activities.

## **Longitudinal comparison of rehabilitation services received by children with cerebral palsy and their leisure participation from 1.5 to 11 years age**

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**Background:** Physical (PT), occupational (OT), and speech (ST) therapy decisions for children with cerebral palsy (CP) are important for effectiveness and efficiency. **Aim:** Compare changes in amount/focus of therapy, rating of services meeting children's needs, and frequency of children's leisure activity participation as they age, and examine correlations of service amount, focus and meeting needs to participation. **Method:** 77 children with CP across functional levels and their parents from the USA and Canada participated. Parents answered questions about amount and focus of therapy in the past 12 months, completed the Child Engagement in Daily Life questionnaire, and rated the extent that services met their needs when children were 1.5-4.6 years old and when 6.3-11.1 years old, with M=5.8 years (SD=.6) between ratings. **Results:** Children when younger had more hours/year of PT, OT and ST than when older ( $p<0.001$ ). Therapy for children when younger focused more on primary impairments ( $p=0.01$ ) and play ( $p<0.001$ ) and when older focused more on secondary impairments ( $p=0.001$ ) and assistive devices/environmental adaptations ( $p=0.02$ ). Parents' rating of services meeting needs decreased from 3.9 to 3.4 for younger to older (4='to a great extent'; 3='to a moderate extent') ( $p<0.001$ ). Participation frequency increased slightly at older ages ( $p=0.001$ ). Correlations between therapy amounts/focus and rating of services meeting needs to participation at both ages were non-significant except for activity focus at the younger age ( $r=.27$ ,  $p=0.02$ ) and services meeting needs at both younger ( $r=.26$ ,  $p=0.02$ ) and older ages ( $r=.32$ ,  $p=0.01$ ). **Conclusions:** As children aged therapy amount decreased and focus shifted to secondary impairments and assistive devices/environmental adaptations, however parents' rating of services meeting needs decreased. Children's leisure participation improved with age, but only parent's rating of services meeting needs consistently correlated with participation.

## **SCOPE-IT model applied to a somatosensory discrimination intervention for children with cerebral palsy.**

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**Background:** To successfully modify an intervention from an adult population for use with children with CP it is important to understand the components that support a child's motivation and intervention effectiveness.

**Aim:** This qualitative study aimed to investigate the elements of a novel intervention that were engaging for children and parents.

**Method:** Ten children who had participated in the SENSE for kids intervention (mean age= 11yrs 2 m (SD= 2 yrs); 4 males; MACS level I=1, II=9) and their primary caregivers (N=11, 10 females) were interviewed. Semi structured interviews were audio recorded and transcribed verbatim. Transcripts were analysed using framework analysis in NVIVO 10. The framework used was the Synthesis of Child, Occupational Performance and Environment in Time (SCOPE-IT) model.

**Results:** Key themes were identified in the core domains of the SCOPE-IT model. Child factors: (i) reduction in verbal prompts to use assisting hand, (ii) awareness of the impact of altered sensation on function, (iii) increased confidence in sports. Motivation included autonomy: (i) goal setting for tailoring the intervention, (ii) caregivers value feedback on child's progress, (iii) caregivers need to allow children to attempt tasks; Competence: (i) experience and observation of success, (ii) success promoted engagement in novel tasks, (iii) greater accuracy in differentiating objects, textures and position in space; Relatedness: (i) rapport with the therapist, (ii) education about intervention, (iii) importance of functional translation of somatosensory training. The key themes in Environment included (i) therapy at home is beneficial for family routine, (ii) therapist preparation (iii) acceptability of equipment.

**Conclusion:** The SCOPE-IT model provided a useful framework for understanding those factors which did and did not enhance engagement of children with CP in the SENSE for kids intervention.

## **The classification of intervention approaches for children with Developmental Coordination Disorder (DCD) in systematic and meta-analytic reviews - a fundamental problem?**

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**Background:** When meta-analytic reviewers examine the effects of different intervention approaches, they attempt to cluster similar approaches into subgroups so that an aggregated effect size for each subgroup can be computed. On the basis of the highest effect size, they then recommend that type of intervention. Fundamental to this approach is the clarity of description of the main characteristics of a particular form of intervention and the subsequent reliability and validity of the reviewers' classification of each one. To date, little information is available on whether meta-analytic reviewers agree on the ways they classify and name intervention for children with DCD and what the sources of discrepancy are.

**Aim:** To examine the consistency with which intervention approaches are classified within 3 recent systematic and meta-analytic reviews of studies purporting to evaluate intervention outcomes on children with DCD and to address the problems encountered.

**Method:** Two authors independently assessed the consistency in classifying intervention approaches for children with DCD in three recent comprehensive systematic and meta-analytic reviews. Any discrepancies in their assessment were resolved by discussion.

**Result:** Five of the 20 intervention outcome studies (25%) contained in the reviews were not accorded the same classification by the authors.

**Conclusion:** Not all intervention approaches are clustered or labelled consistently between systematic and meta-analytic reviews. When future meta-analytic reviewers conduct a subgroup analysis, they should gain in-depth knowledge of each intervention approach and seek expert opinions widely to ensure the reliability and validity of the subgroups.

## **Functional electrical stimulation of the anterior tibial muscle during walking in spastic cerebral palsy: functional gain? A systematic review**

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**BACKGROUND** Spasticity often affects the ankle joint and interferes with mobility in children with spastic cerebral palsy (CP). Functional electrical stimulation (FES) could be useful in managing these problems.

**AIM** To assess the level of evidence for FES of the anterior tibial muscle during walking in children with spastic CP.

**METHOD** A systematic review was performed using American Academy of Cerebral Palsy and Developmental Medicine (AACPDm) and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methodology. Six databases were searched (Medline, EMBASE, PEDro, Web of Science, Cinahl and Cochrane Library). Studies in English, German or Dutch applying either direct or indirect stimulation of the anterior tibial muscle in children with spastic CP under the age of 20 years were included. Two reviewers scored level of evidence and conduct. Outcomes were classified according to the International Classification of Functioning, Disability and Health (ICF).

**RESULT** The search resulted in 744 abstracts. Thirthy-one articles were fully screened and finally 11 articles were used for analysis. Seven articles reported the GMFCS level of the participants, ranging from I to II. There is some evidence that FES has a positive effect on the ICF body structure and body function domain, i.e. on the ankle dorsiflexion angle and on gait kinematics in general. The evidence points to a decrease in gait velocity with the use of FES. For the ICF activity and participation domain there is no evidence that FES therapeutically improves functional walking ability. The level of evidence doesn't allow drawing conclusions on the effect of FES on ankle dorsiflexion strength, gastrocnemius spasticity, step length, cadence, ankle work and frequency of toe drag and falls.

**CONCLUSION** There is lack of evidence concerning the effects of FES. Future studies are necessary to clarify the effect of FES, especially in the ICF activity and participation domain.



## **Access of Autistic Children to Occupational Therapy Intervention in Bangladesh**

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### **Abstract**

**Introduction:** Autism Spectrum Disorders (ASD) is one of the fastest growing non-communicable diseases with a prevalence rate of 1 out of every 88 children.

**Objectives:** The study was carried out to find out the Occupational Therapy intervention access in different autism schools and centers in Bangladesh.

**Method:** A qualitative study design was chosen. An in-depth interview was taken among 13 Occupational Therapists from different autism schools/centers with their written consent. Only 8 (eight) caregivers' of autism children were selected for Focus Group Discussion (FGD).

**Results and Discussion:** The study revealed that visual (77%), gustatory (69.23%) tactile & auditory (61.54%) stimulations were used more commonly rather than proprioceptive (46.15%) and vestibular (38.46%) within the schools/centers with full facilities. Only a few schools/centers have the facilities to provide vestibular (61.54%), proprioceptive (53.85%) and visual (23.08%) stimulation. In this study, 69.24% therapists practiced self-care activities, 46.15% practiced productivity and more than half (61.54%) were involved in leisure activities. Almost sixty percent of children with autism were involved in social activities in their interventions. The study showed the significance of Occupational Therapy interventions areas from Focus Group Discussion (FGD) among caregivers of children with autism according to their needs. Among the respondents of FGD, sensory skills& play (87.50%), behavior therapy (75%), hand writing (62.50%) were thought to be very important Occupational Therapy areas in Bangladesh.

**Conclusion:** Nowadays, the caregivers believe that Occupational Therapy intervention is a 'heart of mind', an essential aspect, for children with autism. Organizational improvements, well set-up infrastructure, development of professional skills as well as intra and inter communication among relevant authorities are the urgent issues in Bangladesh

## **Two-week Intensive Program for children with Cerebral Palsy in Bangladesh**

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**Back ground:** Disability is a major concern issue in Bangladesh as well as all over the world. Centre for the Rehabilitation of the Paralysed (CRP), a well-known organization in Bangladesh is working for children with Cerebral Palsy (CP) and their primary caregiver/mother in Multi-Disciplinary Team (MDT). CRP works for the inclusion of people with disabilities into mainstream society. According to CRP's statistical report July 2012 to June 2013, CP is the most common condition amongst all of the other conditions. In the In-patient paediatric unit, 98% of clients had a diagnosis of CP. The outpatient unit had 1451 client of which 893 clients had diagnosed with CP. Two-week in-patient program for children with cerebral palsy of CRP highly focused on combination of educational and intervention program regarding physical, psychological, social and cultural aspects rather than only focused on intervention based program.

**Inpatient Paediatric Unit:** This residential program provides two-week intensive services for children with disabilities and their primary caregiver. Maximum 40 children get admission per 2 weeks program. Therapist (occupational therapist, physiotherapist & speech therapist) provides therapeutic interventions both in individual, group sessions and group therapy, like morning group therapy, hand therapy, feeding, dressing classes back care education, parents meeting, etc. Therapists educate the parents about the child's condition, and teach them how to take care of the child at home. Therapists also prescribe and provide assistive and adaptive devices according to the child's needs. On the discharge day of the program, the therapists provide a booklet of the overall treatment program for the parents. Discharge patients will return to outpatients for follow- up session.

**Conclusion:** The CRPs 2-week program is a unique program in Bangladesh. This is very effective for children with cerebral palsy to improve their quality of life and mainstreaming.

## **A “different ride” to an uncertain future – parent experiences of early diagnosis and GAME intervention**

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**Background:** Parent involvement in early intervention programs for children with disabilities is considered important to optimize developmental outcomes. Parents of newly diagnosed infants often feel overwhelmed and are at risk of poor psychological health. Little is known about the parent experience of early diagnosis of cerebral palsy and experience of engagement in intensive early intervention.

**Aim:** The aim of this study was to explore the parent experience of infants with or at high risk of cerebral palsy who were identified early and who participated in a home based early intervention program, GAME (Goals-Activity-Motor Enrichment).

**Method:** Nine mothers of infants who had been identified at 3-4 months as high risk of cerebral palsy and were involved in an early intervention randomised controlled trial (RCT), GAME, participated. Parents were interviewed face-to-face at the end of the RCT when their child was 12 months old. Semi-structured interviews were transcribed verbatim and coded to identify categories and themes using grounded theory.

**Results:** Themes identified by parents included; the importance of being taught ‘how to help’ their child; the value of ‘enriching the home environment’ and the most valued features of GAME, including the relationship with the therapist and the customization of the program to the infant and family. Parents voiced a strong preference for an early diagnosis despite the anxiety that accompanies prognostic uncertainty.

**Conclusion:** GAME intervention was highly valued by parents because they felt they learned how to help progress their child’s development. Although receiving a diagnosis was difficult, parents overwhelmingly preferred receiving the news early so they could focus on helping their child.

## **The short and long term effects of a prone standing program on muscle length in non ambulant children with cerebral palsy**

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### **Background**

Weight bearing program on a standing frame is routinely used in non-ambulant children with cerebral palsy (CP)[1,2]. The effect of this program on knee flexum (KF) in children with CP has not been previously studied.

### **Aim**

To evaluate the short and long term effects of a 7-week prone standing program on KF, hamstring and adductor lengths in non-ambulant children with CP.

### **Methods**

Eight non-ambulant children with spastic CP (GMFCS IV and V) with a mean age of  $11.6 \pm 2.5$ , presenting a KF of at least  $5^\circ$  bilaterally, stood on a prone standing frame for 1 hour, 5 days/week for 7 weeks. KF, popliteal angle (PA), and hip abduction while the knee is extended (HAbd) were assessed using a manual goniometer at the baseline assesement (T1), after 7 weeks (T2) and 3 months later (T3). Intra and inter-rater reliability of goniometer measurements were tested for the calculated parameters. Two operators performed the measurements twice each on 5 children with CP with 2-week intervals between measurements. Mean values of calculated parameters at T1 T2 and T3 were compared using Friedman test was. Intra and Inter repeatability was evaluated by calculating the Intraclass Correlation Coefficient (ICC).

### **Results**

KF, PA and HAbd did not differ significantly between measurements by either the same or different raters. The ICC values showed very high repeatability for all the parameters (0.92 for PA, 0.87 for KF and 0.97 for HAbd). Our results showed a significant decrease of KF between T1 and T2 ( $-14^\circ \pm 8$  vs  $-7^\circ \pm 9$ ,  $p=0.004$ ) and between T1 and T3 ( $-14^\circ \pm 8$  vs  $-6^\circ \pm 14$ ,  $p=0.003$ ). Moreover, The PA decreased between T1 and T2 ( $58^\circ \pm 12$  vs  $48^\circ \pm 12$ ,  $p=0.009$ ) and between T1 and T3 ( $58^\circ \pm 12$  vs  $46^\circ \pm 12$ ,  $p=0.012$ ). No significant difference was found for the HAbd.

### **Conclusion**

Daily standing program could reduce the knee flexum and improve the hamstrings length for a long term period in non ambulant children with CP.

[1] Paleg et al. *Pediatr Phys Ther* 2013, [2]Marcias et al. *Pediatr Phys Ther*.2015

## **Interval hypoxic training in rehabilitation of children with cerebral palsy**

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**INTRODUCTION.** The method of interval hypoxic training (IHT) is widely used around the world to increase physical endurance of athletes and to treatment the different diseases. Such producers as, «HYPOXICO», «GO2ALTITUDE», «Bio Nova 204" offer special equipment for IHT. The aims of the study is research the effectiveness of IHT in rehabilitation of children with cerebral palsy (CP).

**METHODS.** Clinical study was carried out at 128 children (aged 1-7 years), who received kinesiotherapy at the rehabilitation center for 2 weeks. Patients were divided into two groups: 1 group (+IHT) – 96 patients, 2 group – 32 patients. IHT have conducted on the certified installation of mountain air "BOREY" (Ukraine). Initial inspired gas contained atmospheric O<sub>2</sub> (21%). The inspired O<sub>2</sub> fell to 12% O<sub>2</sub> during 3-4 days. Every session consists of for 5-7 min period of 12% O<sub>2</sub> inspiration with 5 min interval period of room air inspiration. IHT procedure is formed of 3-4 sessions. Total course of IHT consisted of 10-15 procedures duration 30-40 min.

Methods of evaluation: clinical, laboratory, instrumental methods, quality of life evaluation (PedsQL).

**RESULTS.** All children easily tolerated the hypoxia periods without any side effects. The best physical activity is observed in the first group, children complained less on fatigue during kinesiotherapy. The physiological responses IHT are to increase the transport of oxygen to cells by improving the function of the respiratory and cardiovascular systems, the development of biologically active substances (HIF-1 factor, VEGF-factor, erythropoietin), normalization of heart rate variability, improving blood flow to tissues.

**CONCLUSION:** IHT is recommended in the complex rehabilitation of children with CP for increasing of exercise tolerance during the activity, such as kinesiotherapy, ergotherapy, etc. The further development of the methodology will allow IHT to emerge as an important method for improving of the adaptive capabilities of the patients.

## **The digital schoolbag : user experiences**

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### **Background**

Children with motor disabilities affecting upper limb use and/or motor coordination often encounter limitations in handwriting and graphomotor performance that may interfere with school participation and learning.

### **Aim**

To assess the experiences of users of the digital schoolbag (DS), a digital setup and environment, that allows students to access and work on all of the written media necessary in school, from their laptop computer.

### **Method**

An e-mail invitation to an online survey, based on semi-structured interviews with key stakeholders, was sent to all users in the service provider's database. The questionnaire included 24 affirmations exploring user profile, DS utilization, DS efficacy, and environmental facilitators/obstacles. Responses were graded on a 5-point Likert scale from total agreement to total disagreement.

### **Result**

52/119 users took part (participation 44%). Mean age was  $12.0 \pm 2.8$  years, with 70% boys; the diagnoses were: developmental coordination disorder (DCD) 59%, neuromuscular diseases 18%, cerebral palsy 8%, other 18%. 76% of users were in mainstream schools, 24% in special needs schools.

Participants strongly agreed (>80%) that the DS increased their legibility, their neatness and their writing endurance. They substantially agreed (>60%) that the DS increased their working speed, improved their working organization and decreased their fatigue. They moderately agreed (>40%) that the DS improved aspects of self-esteem and empowerment. A majority of teachers were reported as supportive of the use of the DS (68%).

Users with DCD were more likely to use their DS for schoolwork ( $P=0.02$ ) and less likely to use it to play ( $P=0.04$ ) compared to users with other diagnoses, and also reported higher efficacy with the DS in completing their homework ( $P=0.04$ ).

### **Conclusion**

The DS allows students to overcome handwriting difficulties and increase their performance in tasks that require written media, and for certain may improve inclusion.

## THE EFFECTS IN UPPER EXTREMITIES FUNCTION USING A HEADPOD IN A CHILD WITH CEREBRAL PALSY

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**Background:** The Headpod is a device used to encourage upright position of the head, keeping it vertically aligned with the thoracic spine while promoting physiological activation of the neck muscles. It is designed for children with low muscle tone, weakness and lack of head control. **Aim:** The purpose of this case study was to determine whether it was feasible for a boy with cerebral palsy (CP) to use a headpod to promote upper-extremities (UUEE) movement initiation for manipulative purposes. **Method:** A four years-old boy diagnosed of CP, level 5 at GMFCS and level 3 at Level of Sitting Scale (LSS). Manual Ability Classifications System (MACS) did not provide a level for his ability due to severity of CP. A moulded pelvic seat (PS) was made to provide the child with postural support from pelvis to shoulders to facilitate movements and activities that involved reaching. A Headpod was added to the PS to give dynamic head support through suspension, over a month-period. The child was videotaped twice a week while he was encouraged to perform UUEE voluntary movements to attempt participation in planned activities. **Results:** Before intervention he required total assistance to perform UUEE activity. After adding the Headpod, voluntary movements of UUEE improved and his level of attention and participation increased. As long as the PS and the Headpod were provided, the child was able to perform simple functional UUEE movements. Therefore, after intervention he could be classified as level 5 at MACS. **Conclusion:** Adding the Headpod to the PS of a child with GMFCS level 5 can facilitate the use of his UUEE because it provides head postural support, giving more corporal stability and limiting dystonic movements. Specific tests for measuring function of UUEE in children with level 5 at GMFCS have not been found. The Quality Upper Extremity Skills Test is not useful for this population. MACS was employed to assess the effect of Headpod, knowing that it is not an assessment tool.

## **CPUP Family Faculty” - to invite and involve Users and their Families in a Secondary Prevention Health Programme**

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“CPUP Family Faculty” - to invite and involve Users and their Families in a Secondary Prevention Health Programme.

**Background:** CPUP is a national registry and follow-up program that includes approximately 95 percent of children and youth, and more recently adults, with a diagnosis of cerebral palsy (CP) in Sweden. User involvement in healthcare is receiving more attention both for those with disability and without and we are in the process of creating and implementing a so called “CPUP Family Faculty” to assist and advise the program.

**Aim:** The overall goal is to establish and make into routine practice a “partnership paradigm” where persons with CP and their families and other CPUP users have more opportunities to strengthen the program, in order to maximize their own benefit of being enrolled by proactively working in collaboration with the board of CPUP and healthcare professionals.

**Method:** To explore, describe and evaluate the contextual effects on the process of developing and implementing a CPUP Family Faculty in a well-established follow up program that has been in existence since 1994. The structure, mission, vision, and work process of the Faculty will be developed in collaboration between the stakeholders and the professionals and the process of how this will be accomplished will be actively studied.

**Result:** Aims and goals of the new faculty as well as challenges and opportunities are discussed.

**Conclusion:** We believe the CPUP Family Faculty is the initiation of a fruitful collaboration between healthcare providers (professionals) and stakeholders (individuals with CP and their families) and offers a potential of significant impact for many individuals.



## EFFECT OF TRUNK TRAINING ON GROSS MOTOR FUNCTION, TRUNK CONTROL AND SPASTICITY IN CHILDREN WITH BILATERAL SPASTIC CEREBRAL PALSY

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**BACKGROUND:** Many children with cerebral palsy (CP) has both trunk and extremity impairment but during therapy sessions many therapists focus on extremities. **AIM:** The aim of this study was to analyze the effect of trunk training on spasticity, gross motor function and trunk control of children with bilateral spastic CP. **METHOD:** 21 children participated in this study. We used stratified random sampling according to the Gross Motor Function Levels. There was 11 children (3 girls and 8 boys) in the Trunk Training Group (TTG) with  $7,59 \pm 2,41$  years mean age. And 10 children (2 girls and 8 boys) in control group (CG) with  $9,50 \pm 4,4$  years mean age. TTG received a therapy program targeted trunk including strengthening and neurodevelopment approach. CG received regular physical therapy targeted extremities. All the children assessed with Gross Motor Function Measurement (GMFM), Trunk Control Measurement Scale (TCMS) and Modified Tardieu Scale (MTS) before and after 8 week intervention. **RESULTS:** When we compared first and second assessments with The Wilcoxon Signed-Rank Test there wasn't significant difference between values of MTS for both groups ( $p > 0.05$ ). Only for left soleus muscle of the TTG there was significant difference ( $p = 0,016$ ). There was significant difference in total GMFM score, GMFM sitting, crawling and kneeling, walking dimensions, total TCMS scores, TCMS Static Sitting Balance (SSB), Dynamic Sitting Balance (DSB) and Dynamic Reaching (DR) sub scores in the TTG ( $p < 0.05$ ). There wasn't significant difference in CG. When we compare the groups with and Mann Whitney U test there was significant difference between groups for GMFM total scores, GMFM sitting dimension, TCMS total scores, TCMS DSB and TCMS DR in favor of TTG. **CONCLUSION:** According to results of our study trunk training is effective for improving gross motor function and trunk control of the children with bilateral spastic CP. But doesn't changes muscle spasticity.

## **Change in pulmonary function after incentive spirometer exercise in children with spastic cerebral palsy: a randomized controlled study**

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**Background:** Children with cerebral palsy (CP) have lower pulmonary function compared to normal, healthy children. Poor chest mobility, trunk extensibility, and weak respiratory muscle strength are related to poor respiratory function in children with CP. Incentive spirometer exercise (ISE) is simple respiratory training by sustaining maximal inspiration for a prolonged period using slow inspiration and deep breaths.

**Aim:** To investigate the effect of ISE on pulmonary function and maximal phonation time (MPT) in the children with spastic CP.

**Method:** Fifty children with cerebral palsy were randomly assigned to two groups: the experimental group and the control group. Both groups underwent comprehensive rehabilitation therapy. The experimental group underwent additional ISE. The forced vital capacity (FVC), forced expiratory volume at one second (FEV1), FEV1/FVC ratio, peak expiratory flow (PEF) and MPT were assessed as outcome measures before and after 4 weeks of training.

**Result:** There were significant improvements in FVC, FEV1, PEF and MPT in the experimental group, but not in the control group. In addition, the improvements in FVC, FEV1, and MPT were significantly greater in the experimental group than in the control group.

**Conclusion:** The results of this randomized controlled study support the use of ISE for enhancing pulmonary function and breath control for speech production in children with CP.

**The Drooling Reduction Intervention (DRI) trial: Is hyoscine or glycopyrronium more effective and acceptable for the treatment of drooling in children with neurodisability?**

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**Background:** Drooling saliva is a common problem in children with neurodevelopmental disorders. The consequences of drooling include skin breakdown, dehydration, and damage to clothing/equipment. Hyoscine and glycopyrronium are most commonly used to reduce drooling, but there is little evidence about their relative effectiveness, or side effect profiles.

**Aims:** In a single blind randomised controlled trial, investigate whether hyoscine or glycopyrronium is more effective and acceptable for the treatment of drooling in children with non-progressive neurodisability.

**Methods:** Children age 3-15 years who had never received medication to treat drooling were recruited from 15 UK centres and randomised to hyoscine or glycopyrronium; stratification was by centre and drooling severity. Dose adjustment and side effect monitoring were undertaken weekly by the trial team over 4 weeks to identify the most effective dose for each child in the context of any side effects. Primary outcome data were gathered with the standardised Drooling Impact Scale (DIS) at 4 weeks by a researcher blind to treatment group status.

**Results:** 92 children (median age 4.9 years) were randomised (49 hyoscine and 43 glycopyrronium). 48 children commenced hyoscine treatment, and 38 started glycopyrronium. By 4 weeks, 35/48 children (73%) remained on hyoscine and 33/38 (87%) on glycopyrronium; the remainder had stopped trial medication due to side effects. At 4 weeks there was no significant difference in DIS scores between the treatment groups suggesting both medications were equally effective at the maximum tolerated dose. However, hyoscine was associated with more problematic side effects than glycopyrronium and parents were more likely to stop using hyoscine.

**Conclusions:** Hyoscine and glycopyrronium are equally effective in treating problematic drooling in children with neurodisability. However, hyoscine is associated with more problematic side effects and is less likely to be tolerated.

## **Augmented Reality face game in early oral motor treatment: single case study**

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**Background and aim:** Augmented Reality (AR) allows the user to interact with the real world with any desired graphic and it is often used in rehabilitation giving useful dynamic visual cues to enhance motor learning. In this study the AR is based on live face motion tracking and we assume that it's a perfect tool for an interactive oral-motor treatment. Oral-motor ontogeny follows a stepwise progression and each oral-motor milestone is also dependent upon maturation and practice, medical illness can interrupt this process. Tube-fed children report high risk for impaired development of normal oral-motor patterns: oral hypersensitivity, facial defensiveness, less mature coordination, food refusal and speech delay are commonly observed in such children, months to years after cessation of tube feeding.

**Case study and Method:** We present a single case study of a pre-term two-year-old girl prolonged incubated in neonatal intensive care unit, nasogastric and then peg feed. Schedule for Oral-Motor Assessment (SOMA) was used to evaluate the preverbal oral-motor skill. The little girl has carried out a three week treatment aimed on classic dysphagic approach, traditional oral-motor child exercise and three basic AR face games. These games work like a simple video-switch based on AR mouth triggered in a growing demanding path. Games are: Big Mouth (basic "open-close" switch), Duck Feed ("close-open-close" switch- based on rhythmic time related feedback), Lion Jaws ("close-open-roar" switch- based on mouth and voicing detection).

**Result and Conclusion:** The girl has reported an improvement in all the oral motor activity assessed, especially in the hypersensitivity reduction, motor coordination and sound production. AR face games give useful results mainly in the early days of training compliance. The contactless approach, mouth visual cues and engagement feedback related are the main advantage of this treatment.

## PARENT AS A THERAPIST: THEIR VIEW

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**Introduction:** Rehabilitation method according to Stojcevic Polovina is developed for rehabilitation of children with cerebral palsy. It is a family based method where rehabilitation of children is performed by educated and trained parents. This approach enables rehabilitation to be highly intensive and reduces the time spent in institutions. According to previous research and long-lasting experience, such intensity increases the chances of changing natural course of cerebral palsy.

**Aim:** to present different views of parents conducting intensive rehabilitation with their children with cerebral palsy.

**Method:** a structured, filmed interview was conducted with three different parents of children with cerebral palsy, of different age, different GMFCS level and different expectation/prognosis.

**Results:** In their own words, parents explain reasons for conducting intensive rehabilitation for several hours a day, for many months or years. They give us their view on rehabilitation performed at home. They explain the impact it has on a family life, but they also explain why they keep on going, what are their hopes and expectation.

**Conclusion:** Although all parents agree that it is not easy to be a parent who also is a kind of a therapist for your own child, the benefits for the child outnumber the hardships for a parent. It also gives a parent the most active role in the life of his child by which he/she tries to give a child the best possible chance for a smallest possible disability.

## **Environmental barriers and facilitators for children with cerebral palsy in India: a cross sectional survey**

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### **BACKGROUND**

Cerebral palsy (CP) is the most common type of movement and posture disorder in children leading to activity limitations. Environmental factors may restrict or facilitate participation in children with CP.

### **AIM**

The aim of the study was to identify the environmental barriers and facilitators in children with CP.

### **METHODS**

This study was a cross sectional survey, carried out among the caregivers of children with CP. Sixty caregivers of persons with CP aged between 8 to 20 years participated in the study satisfying the inclusion criteria. The survey was conducted using Craig Hospital Inventory of Environmental Factors (CHIEF) questionnaire which contains a total of twenty-five items on environmental factors. These items are categorized into five subscales: policies, physical and structural, work and school, attitudes and support, and services and assistance. Each item is scored for both frequency and magnitude which determines how often and how much the barriers are faced. Demographics of child and caregiver and clinical data were also collected.

### **RESULTS**

Overall, girls (58%) reported more barriers compared to boys on the CHIEF total scores. The most common environmental barriers reported were physical / structural (72%), attitude / support (56%), policies (52%), services / assistance (35%) and policies (26%). The CHIEF total scores were correlated positively with GMFCS. As the severity of GMFCS levels was more, barriers reported were also higher. The FMS were correlated negatively as the mobility status was better, the barriers reported were lesser.

### **CONCLUSION**

Findings from this study indicate that presence of multiple environmental barriers to participation of children with CP. Enhancing participation of children with CP by altering barriers and increasing facilitators requires further research concerning these factors. This study suggested that people with lower function in gross motor require further support to participate in social activities.

## **Longitudinal assessment of gait quality in children with diplegia following serial lower limb intramuscular Botulinum Toxin-A injections**

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**Background:** Serial lower limb intramuscular Botulinum toxin-A (BoNT-A) injections are administered to children with diplegia to reduce spasticity, improve walking ability and functional mobility, and delay the need for orthopaedic surgery.

**Aim:** To determine the effect of multiple treatment cycles of lower limb intramuscular BoNT-A injections and post-injection physiotherapy on gait quality in children with spastic diplegia.

**Method:** Sixteen children with diplegia (mean (SD) 3 years 8 months (1 year 6 months) at first BoNT-A treatment; male n=8; GMFCS II) who had undertaken pre- and post-treatment 2D video gait assessments for first to third BoNT-A treatment cycles were assessed on 2D gait videos using the Edinburgh Visual Gait Score (EVGS). Intramuscular BoNT-A injections were administered to a maximum total dose 4-6 U/kg body weight Botox<sup>®</sup> per limb to the hamstrings or adductors and/or gastrocnemius, soleus and tibialis posterior muscles. Children received, on average, six one-hour physiotherapy strengthening and mobility training sessions per BoNT-A treatment cycle. Mixed-effects linear regression was performed assessing the change from baseline to each subsequent assessment ( $p < 0.05$ ).

**Result:** The EVGS score for both lower limbs improved significantly from baseline to each subsequent assessment. The greatest improvement occurred after the second BoNT-A treatment cycle (fifth assessment) with a decrease of 3.07 points from baseline (95% CI -4.59 to -1.55;  $z = -3.96$ ,  $p < 0.001$ ), which approaches the least significant difference value for EVGS of 3.2 points.

**Conclusion:** Serial lower limb intramuscular BoNT-A injections combined with physiotherapy lead to significant improvements in gait quality over time in children with spastic diplegia which may prolong the time before orthopaedic surgery is required.

## **How to communicate with children with profound (intellectual) (and) multiple disabilities? Evaluation of a systematic intervention method**

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### **How to communicate with children with profound (intellectual) (and) multiple disabilities? Evaluation of a systematic intervention method.**

#### **Background**

At our centre, an outpatient treatment centre for multiple impaired children in The Hague, we provide education and treatment. Many of these children are not able to communicate verbally.

A programme (COCP) to optimize communication between the severely impaired child and its communication partners was developed in the Netherlands. Around each child a communication group is formed out of all communication partners, both from home and our centre. All members of the group are involved in all phases of the treatment and take joint decisions on individual intervention goals and plans.

#### **Aim**

Aim of the study was to evaluate the effectiveness of the programme in a group of children and their communication partners.

#### **Method**

In the last 10 years the programme was applied in 17 children and their communication partners. The programme was evaluated by interviews with the communication partners, video evaluation and scored on a list of communication items. The list contains 12 items on method of communication, such as facial expression, sign language, pictures etc. In addition, communication functions such as making a choice between items, asking for information, joking/pretending.

#### **Result:**

The questionnaire was completed in six children. There was an improvement on the method items in four out of six children and in the function items in five out of six.

Items with the most improvement in communication functions were taking turns during activity, asking for an object or activity which is in close range, and joking / pretending. In the method items pointing, using pictures and graphic symbols showed the most improvement.

#### **Conclusion**

Based on the results of all these evaluations we can show a positive effect of the communicative interaction programme between nonspeaking children and their communication partners.



## **Can we demonstrate the clinical utility of modified Constraint Induced Movement Therapy (mCMIT) as an intervention for children and young people following an acquired brain injury in a residential rehabilitation setting?**

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### **Background**

There is strong empirical evidence for the effectiveness of constraint induced movement therapy (CIMIT) improving upper limb function in children with cerebral palsy (CP). Children with acquired brain injuries (ABI) can present with similar difficulties to those with CP, suggesting CIMIT could be useful for this group. However, there is limited research investigating use of mCIMIT in pediatric ABI rehabilitation.

### **Aim**

To investigate whether mCIMIT is useful, accessible, practical and acceptable for children with unilateral upper limb impairment following ABI, in residential rehabilitation.

### **Method**

Pilot study using mixed methods. Two weeks of mCIMIT (1 hour/day, 5 days/week) alongside usual rehabilitation. Glove constraint of unaffected limb used during targeted activities with affected limb. Outcome measures pre/post intervention (MACS, QUEST, COPM and CHEQ), clinical observations and feedback from children, parents and clinical team collected.

### **Results**

Data will be collected for 6 months. Results thus far indicate all children (n=4) demonstrated measurable change on one or more outcome measures. Statistical analysis will be completed on full sample. All children completed the protocol, with positive feedback from all parties.

### **Conclusion**

mCIMIT can be clinically useful for children with ABI in residential rehabilitation. The successful implementation of this pilot, shown through clinical observation and positive feedback, demonstrated the accessibility, practicality and acceptability of the intervention protocol. Clinical change in upper limb function also indicated that mCIMIT is an appropriate intervention for children who meet inclusion criteria. However, high prevalence of cognitive and behavioral issues in early stage of recovery necessitates consideration of inclusion criteria, and structure and content of programme. Further research to determine the efficacy of mCIMIT compared to usual rehabilitation for children with ABI should be conducted.

## **Reconstructing gaze - problems of communication partners and children using gaze control for a communication aid**

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**Background:** Children with severe motor impairment - through cerebral palsy or other disabilities - and dysfunctional speech profit from gaze control as an access method for voice-output communication aids (VOCA). Gaze control is often much easier than other access methods for this group of users. Augmentative and alternative communication offers support for children and their environment using a communication aid.

**Aim:** Through observation, we investigate the every-day experience of children using gaze control: How do the interaction and communication with a gaze controlled VOCA look like?

**Method:** Participant observation offers the possibility to participate in the practice of using a gaze controlled VOCA. The researcher can interact with the child while observing the situation. Through this inclusion of the researcher in the situation, participant observation facilitates the discovery of practical knowledge of user and communication partners.

**Results:** One result of our observations is that gaze control is a hardly visible way of accessing a VOCA. Compared to the fingers of a person touching keys or a touch screen, the gaze of a user is rather invisible. As a consequence of this invisibility, it is difficult to model and/or demonstrate the use of gaze control for the child. This is especially a problem when the eyes are occasionally not recognised by the device. The direction of the gaze has to be computed, and if this fails, special attention by the environment is needed to reconstruct the direction.

**Conclusion:** We identified two helpful strategies to deal with problems when a child uses a VOCA with gaze control: 1) A change of perspective helps to see whether a child is trying hard but the device currently does not recognise the eyes (reconstructing the gaze). 2) It is important to offer alternative ways of communication to the child (e.g. body gestures), so that she can communicate if she perceived a disturbance in eye recognition (communicating the gaze).

## **New guide to planning and implementing the use of gaze control for a communication aid**

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**Background:** Children with severe motor impairment – through cerebral palsy or other disabilities – and dysfunctional speech profit from gaze control as an access method for voice output communication aids (VOCAs). Gaze control is often much easier than other access methods for this group of users. However, these devices are complex. If family and/or professional helpers think about introducing gaze control to a child, they might ask: what is relevant to know, and how should the decision process be planned? The presented guide offers assistance for answering these questions, for planning and implementing the use of a gaze controlled VOCA. It has been developed in Germany (as part of university research), because there was a need for such a document in the German community of augmentative and alternative communication (AAC). Recently, it has been translated and adapted for international use.

**Aim:** The aim of the guide is to assist family members and professional staff working in the field of AAC to decide if gaze control is appropriate for a particular child to control a VOCA.

**Method:** We conducted interviews with AAC experts and observed children who use a gaze controlled VOCA. Based on the results of this qualitative research and on current literature on gaze control, we developed the guide.

**Results:** The guide contains four parts: 1) analysis of needs and wishes of the user and her family / environment; 2) survey of individual capabilities of the user; 3) tutorial for testing and assessment; 4) tips for the first steps with a gaze control.

**Conclusion:** The new guide is a very helpful tool if you are to decide whether gaze control is appropriate for a child who uses a AAC. It empowers professional and family helpers to work with gaze controlled VOCAs and to plan the process of needs assessment, testing, selecting, and implementing a new device.

## **Impact of multi-modal web-based rehabilitation on occupational performance and upper limb outcomes: randomized trial in children with acquired brain injury**

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**Background:** Children with acquired brain injury (ABI) experience persistent difficulties across broad domains of cognition, motor function and behaviour.

**Aim:** To determine whether a multi-modal web-based rehabilitation program, “Move it to improve it” (Mitii™) is more effective than usual care (UC) to improve occupational performance, upper limb function and visual perception in children with ABI.

**Method:** Sixty children were randomly allocated, 58 (53% males, mean age 11y11mo, SD 2y6mo, MACs equivalent I=32; II=24; III=2) received either 20 weeks of Mitii™ (n=29) or UC (n=29). Mitii™ comprised upper limb, cognitive, visual perception and gross motor tasks, aimed to be completed for a total dose 60 hours. Outcomes were the Assessment of Motor and Process Skills (AMPS), Melbourne Assessment of Unilateral Upper Limb Function (MUUL), Jebsen Test of Hand Function (JTHF), Test of Visual Perceptual Skills (TVPS-3) and Canadian Occupational Performance Measure (COPM) assessed at baseline and 20 weeks.

**Results:** Groups were equivalent at baseline. Most children presented with minimal upper limb impairments, 14 (24%) scored below 90% on the MUUL for their impaired/non-dominant hand. Participants completed on average 17.6, SD 14.9 hours of Mitii™, substantially less than recommended. Mitii™ achieved significantly greater gains on TVPS-3 Complex Processes compared to UC (Estimated mean difference EMD 10.1, 95%CI 1.3, 18.8; p<0.001) and figure ground perception (EMD 3.0, 95%CI 0.6, 5.4; p=0.01). There were no differences between groups on upper limb and occupational performance outcomes.

**Conclusion:** Mitii™ led to changes in visual perception skills but not upper limb function or occupational performance. Maintaining engagement of children with an ABI with Mitii™ over 20 weeks was problematic and impacted dose of training. Mitii™ should be considered as an adjunct to augment and increase the training dose of regular therapy, rather than a stand-alone intervention.

**Five-days of intensive hands-on therapy improves motor and functional performance in children with CP living in a rural African setting: a randomized controlled trial**

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**BACKGROUND** Ethical considerations of withholding therapy make it difficult to establish evidence for “hands-on” therapy for children with Cerebral Palsy (CP). Resource-constrained settings offer an opportunity to address this dilemma as standard care often comprises limited therapy (e.g. 30 minutes monthly, equating to five hours annually).

**AIM** To establish whether therapeutic handling conferred any advantage on the functional performance of children with CP living in a poor rural South African district.

**METHOD** Children aged 1 to 17 years across all GMFCS levels attending a rural CP Clinic were randomized into one of three study arms based on geographical clustering: (i) a once off two hour caregiver training session (no intervention group); (ii) a daily three hour caregiver training workshop over five days (caregiver training group) or (iii) a daily two hour caregiver training workshop plus 75 minutes of daily hands-on therapy for five days (therapy group). All children were given equipment and continued with their monthly therapy appointments. Child and caregiver related outcomes were assessed at baseline, immediately pre- and post-intervention, and eight weeks later using validated tools.

**RESULTS** Sixty-eight children were enrolled. At 8 week follow-up, GMFM scores were significantly better for the therapy group compared to the other two groups (mean difference therapy group 1.9 [95%CI 0.05–3.8]; caregiver training group -0.64 [95%CI -1.3–2.8]; no intervention group 0.76 [95%CI -1.3–2.8]. Similarly, modified PEDI scores increased significantly in the therapy group (3.92 [95% CI -0.29–8.12] but not in the other groups. In contrast, caregiver related changes were greatest in the caregiver training group.

**CONCLUSION** A five day intensive course of hands-on therapy significantly improved functional performance in children with CP living in low-resourced settings. Maximum gains can best be achieved through a combination of caregiver training and hands-on therapy.

## **Helping helpers help: A program for supporting non-governmental organizations working with disabled children**

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**Background.** In many countries children with disabilities and their families are dependent on non-governmental organisations (NGOs) for receiving services. These organisations, in turn, often have scarce resources and little organisational support. When dealing with families under great stress and children with comprehensive needs, while receiving little societal support, these organisations are at risk of experiencing internal problems.

**Aim.** To develop and trial a concept for supporting NGOs and their leaders in preventing or managing organisational problems affecting their services to families.

**Method.** Building on program theory and quality improvement, we have developed a program with five components, running during a 12-month period. 1/ Assessing the current situation using interviews with all stakeholders and a questionnaire about group dysfunction; 2/ Executive coaching for the leader focusing on leadership style, communication, and co-production of services; 3/ Group meetings without the leader, focusing on team building, communication, and co-production of services; 4/ Constant reassessment of the identified problem areas; and 5/ Development of new goals and measures of quality in the services together with the leader and the team.

**Results.** The project is ongoing in its 8<sup>th</sup> month. The working climate has improved considerably, but there has also been some personnel turnover. The leader has developed considerable skills in communication and promoting co-production of services. The one-year follow up will provide feedback on current group functioning and sense of involvement from parents.

**Conclusion.** If the concept proves useful this could be a way of providing organisational support to non-governmental agencies working with children with disabilities and their families. The program components are a framework that allow for flexible tools to be used, depending on the background and expertise of those involved in delivering the Helping Helpers Help program.

## **Building the bridge of parent-professional partnership**

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**Background.** For the effective use of augmentative and alternative communication (AAC) in children, partnership between the family and the practitioner is required. In Hungary, many parents of children with disabilities had encountered services that were unhelpful or even hostile and authoritarian rather than working in partnership with the family. Therefore, services with the explicit idea of developing parent-professional partnership face challenges.

**Aim.** To elicit the experiences of parents and professionals at a non-governmental organisation in Hungary regarding their communication about the child's AAC with each other.

**Method.** Three focus groups were conducted: two with parents and one with professionals. The text was analysed using qualitative content analysis.

**Results.** An overarching metaphor of building a bridge was identified with four subthemes linking in to this theme. 1. Alone at each side of the gap; 2. Balancing hope and realism; 3. What are we building, anyway?; 4. Should we, can we, aim for more? In sum, professionals and parents both had a sense of being alone in their endeavour, not quite agreeing with or trusting each other on AAC. Parents were both unrealistic in their hopes for the development of the child and wanted more advanced technical aids, but several of them also felt they understood their child well enough and had no real need for AAC. Professionals, on the other hand, wanted small, but reliable improvements in the child's AAC use to build on later. Both parents and professionals were aware of their differences, but they nevertheless felt frustrated.

**Conclusions.** Partnering in AAC can be compared to building a bridge. Both sides need to agree on what should be built, how, and why. When building in an unsafe setting, engineers and builders will have to collaborate even harder on getting it right. Being open about differences between professionals and parents, building trust, and agreeing on common goals seem to be a way forward.

## **Are two-year old children who underwent Therapeutic Hypothermia for neonatal Hypoxic Ischaemic Encephalopathy at increased risk of behavioural problems?**

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**Background:** Therapeutic Hypothermia (TH) for neonatal Hypoxic Ischaemic Encephalopathy (HIE) reduces severe neurodevelopmental morbidity in early childhood. However, little is known on behavioural outcomes.

**Aims:** (1) To describe two-year behavioural outcomes in children who underwent TH for HIE; (2) To explore associations of behavioural measures with cognitive and neurological function, and neonatal Magnetic Resonance Imaging (MRI) findings.

**Methods:** Cross-sectional study in a tertiary hospital-based cohort of children who underwent TH for HIE. Forty-four children (25 boys) were assessed at mean age 26.9 months (SD 3.8) with structured neurological examination, Bayley III Scales, Child Behavior Checklist 1.5-5 (CBCL), and Quantitative Checklist for Autism in Toddlers (QCHAT). Neonatal MRI was assessed using the Barkovich scoring system (Barkovich et al., 1998). Data were analysed descriptively; Spearman's correlation coefficients were calculated.

**Results:** Normal neurological examination was present in 77%, non-specific signs in 9%, cerebral palsy in 14%. A relatively high proportion scored in the sub-clinical and clinical range on the CBCL for internalising (19%) and externalizing (26%) problems, in particular on the attention subscale (26%). Mean QCHAT scores were not significantly higher than published norms. Neonatal MRI was associated with neurological status ( $r=.593$ ;  $p<.01$ ), but not with Bayley scores. CBCL and QCHAT scores were neither associated with MRI nor with neurological status. However, lower cognitive Bayley scores were associated with higher QCHAT ( $r=-.448$ ,  $p=.015$ ), CBCL internalizing ( $r=-.446$ ,  $p=.017$ ), externalizing ( $r=-.485$ ,  $p<.01$ ), and total problems ( $r=-.478$ ,  $p=.01$ ) scores. Lower Bayley language scores were associated with higher QCHAT scores ( $r=-.573$ ,  $p<.01$ ).

**Conclusion:** Our data suggest that children who underwent TH for HIE are at risk for behavioural, in particular attention problems. These are associated with cognitive development.



## **Depression in adolescence: the perspectives of patients and their caregivers on relevant areas of functioning**

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### **Background**

Depression is one of the leading causes of disease burden and disability across all age groups. Due to the complex clinical presentation of depression, patients require different therapy strategies. Functioning and the International Classification of Functioning, Disability and Health for Children and Youth (ICF) are increasingly taken into account for the diagnoses and evaluating the effectiveness of treatments.

### **Aim**

The aim of this study is to identify relevant aspects of functioning associated to unipolar depression of adolescent patients and their caregivers by using the ICF.

### **Method**

We conduct(ed) semi-structured (dyadic) interviews with 10 in-patients, aged 13-18 years, diagnosed to have depression (ICD criteria) and 10 of their caregivers. Interviews were audio-taped, transcribed verbatim and coded in f4analyse using the ICF coding system. The study runs until december 2015.

### **Result**

Preliminary results show that patients and caregivers named a variety of different ICF categories. Most of them were represented by the ICF components activities, participation and contextual factors.

### **Conclusion**

Patients and their caregivers described many of the same areas of functioning, but provided unique perspectives. Since depression is a mental disorder, it is not surprising that disturbed mental functions were described. However, patients and their caregivers, focussed on activity, participation and contextual factors. This preliminary results highlight the need to explore both perspectives, patients and caregivers, when characterizing the functional profile and planing therapeutical interventions. The ICF can be helpful in the description of the health status and for planning patient-centered interventions.

## **EFFECTS OF NEURODEVELOPMENTAL TREATMENT ON DESBUQUOIS SYNDROME: A CASE REPORT**

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**Aim:** Desbuquois syndrome (DS) is an uncommon, autosomal recessive disorder characterised by short stature, generalised skeletal dysplasia and severe bone maturation. Our aim was to describe a case of DS with delayed gross motor function in a two years old boy and to show neurodevelopmental treatment results.

**Method:** A two years old boy patient applied our department due to sitting problem by his family. Clinic and demographic data were collected from hospital records and his family. He had bilateral patellar chondroplasia on X-ray and knee flexion deformity, joint laxity and malalignment on hands dominantly fingers and feet on physical examination. The Gross Motor Function Measurement (GMFM) and the Bayley Scales of Infant Development (BSID) were used to evaluate gross motor, fine motor, language and cognitive abilities and Alberta Infant Motor Scale (AIMS) was used to evaluate postural control before and after the treatment period. Neurodevelopmental treatment was performed three times a week for six months.

**Result:** After six months GMFM-C and GMFM-D and AIMS scores were increased. There was a change in BSID gross and fine motor, language and cognitive subtests.

**Conclusion :** DS is a complex disorder which requires interdisciplinary team work. Physiotherapy and rehabilitation support is important to prevent deformities, to decrease secondary complications, to provide activity and participation.

## Effects of the CareToy training on grasping forces in preterm infants

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**Background** Infants born preterm explore object less in the first 6 months (Lobo et al, 2015) but little is known about their grasping forces. Specific goal-directed activities can promote their object exploration development. CareToy System (CT) is a new technological tool with embedded sensors to provide an intensive, individualized, home-based and family-centred early intervention, remotely monitored from the rehabilitation staff (Sgandurra et al, 2014).

**Aim** Present study aims to assess the grasping pressure applied on a kit of sensorized toys by a sample of preterm infants and the impact of CareToy training on it.

**Method** 26 preterm infants (aged 3-6 months of corrected age) performed daily 4 weeks of training with the CT platform. Infants were divided in three groups (low, medium and high) according to their motor competencies according to Infant Motor Profile values. A kit of four sensorized toys (ring, u-shaped toy and mickey [Sgandurra et al, 2014; Cecchi et al, 2015]) with an embedded pressure sensor were used as part of the training for the promotion of the grasping activities on midline ( $53 \pm 28$  vs  $683 \pm 174$  minutes). One of the toy was placed on the midline while the infant was in supine position.

**Result** In the first week of training, data show no differences in the grasps intensity among the three groups. Data across the CT training show a positive trend in the first two groups with a significant increase of grasp intensity. Moreover, at the end of the CT training, the first group reached significantly higher values with respect to the medium group showing an anticipation of the expected increase of the grasping intensity.

**Conclusion** Sensorized toy allowed to measure the grasping activity. The number of grasps in the first week of CT training could represent a neurodevelopmental index. The CT training seems to promote grasping activities in terms of grasping force. This work was supported by the CareToy EU project (GA: 287932; 7FP, ICT-2011-7).

## **A comparative study on the effectiveness of mirror therapy versus modified constrained induced movement therapy in upper extremity function among children with hemiplegic cerebral palsy post orthopaedic selective spasticity surgery**

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### **BACKGROUND**

Mirror therapy (affected limb is masked inside the mirror box) and modified constraint induced movement therapy (unaffected limb is constrained during therapy hours) are well established effective therapies in the upper extremity functioning of children with cerebral palsy (CP). But comparing their effectiveness is a gap in the available literature.

### **AIM**

To compare the effectiveness of mirror therapy (MT) with modified constraint-induced movement therapy (mCIMT) in the rehabilitation of children with hemiplegic CP post orthopaedic selective spasticity surgery (OSSCS).

### **METHODS**

A prospective clinical trial was conducted among 36 children with hemiplegic CP, who underwent orthopaedic selective spasticity surgery of forearm flexors and pronators of affected upper limb were randomly divided into two groups: Group A (n=18; 12 boys, 6 girls) with mean age of  $8.54 \pm 3$  years received MT and Group B (n=18; 8 boys, 10 girls)  $7.8 \pm 3.45$  years received mCIMT. Study duration was 6 weeks with 1 hour per day of MT for Group A and 1 hour per day of mCIMT for Group B was performed under therapist supervision. Both groups received regular intensive physiotherapy program also. The Besta scale and Melbourne assessment of upper extremity function (MAUULF) scale were performed at baseline, 6 weeks after the treatment and follow ups at 1 month and 3 months later.

### **RESULTS**

After six weeks of treatment, the mCIMT group showed significant improvements than the MT groups in both Besta ( $p < 0.01$ ) and MAUULF ( $p < 0.01$ ) scores for hemiplegic upper extremity who underwent orthopaedic selective spasticity surgery. The obtained outcomes were maintained at 1 month and 3 months follow up also.

### **CONCLUSION**

Modified CIMT showed better improvement than MT in the upper extremity function of children with hemiplegic CP, which suggests the inclusion of mCIMT in the post operative rehabilitation for children with hemiplegic CP who underwent orthopaedic selective spasticity surgery.

## **Effectiveness of low level laser therapy on post operative pain after single event multilevel surgeries among children with cerebral palsy**

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### **BACKGROUND**

Low level LASER therapy (LLLT) is one of the commonly used pain management modality. Several advancements have been made since its arrival and one of the latest is the use of all four radiant energies (Infrared LASER, Light Emitting Diode, Magnetism, Ultra sound) as a coherence effect on the body tissues for therapeutic effect.

### **AIM**

To investigate the effectiveness of low level laser therapy on post-operative pain after a type of single event multilevel surgery called Single Event Multilevel Lever Arm Restoration Anti Spasticity Surgery (SEMLARASS) among children with cerebral palsy (CP).

### **METHOD**

Sixty five children with CP of age group between 6 to 20 years who reported pain after SEMLARASS were included in the study. They were randomly divided into two groups: Group A (n=34) received LLLT along with conventional pain management techniques (CT) and Group B (n=28) received only CT. The LLLT was given in the following parameters: 1 minute at 1000Hz per every 10cm<sup>2</sup> for 6 days per week for 2 weeks at the pain site. No other medications were given during this phase. Both the groups received other CT for 30 minutes per day for the same period. Visual analog scale was used for the pain measurements prior to and 2 weeks after the treatment. Follow up was done after 1 month.

### **RESULT**

After 2 weeks of treatment the group A which underwent LLLT showed better reduction of pain than the group B which underwent only conventional therapy in children with CP. Significant difference was found in the VAS ( $p < 0.01$ ) scores of group A compared to group B. The obtained progress was also maintained in the 1 month follow up.

### **CONCLUSION**

LLLT can be used as a therapeutic modality in reduction of post-operative pain following single event multilevel surgery among children with CP. But large scale studies are still needed to prove its effectiveness on various groups of children with CP.

## **Combining Constraint Induced Movement Therapy and Action Observation Training: A Study Protocol of a Randomized Controlled Trial in Children with Unilateral Cerebral Palsy**

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### **Background**

Problems in upper limb (UL) function in children with unilateral cerebral palsy (UCP) are traditionally trained with motor execution treatment models, such as Constraint Induced Movement Therapy (CIMT). However, these children also present deficits in motor planning, which could be tackled with Action Observation Training (AOT). However, whether combining both training models would have additional effects on UL function still remains unknown.

### **Aim**

The aim of this study is to investigate the effects of an intensive treatment model consisting of CIMT and AOT compared to CIMT alone on UL function in children with UCP. Secondly, we will study the predictive value of neurological factors on treatment outcome.

### **Methods**

A randomized, controlled, evaluator-blinded trial (RCT) is conducted in 60 children between 6 and 12 years old. Before randomization, children are stratified according to their House classification, age and type of cortical reorganization assessed by Transcranial Magnetic Stimulation (TMS). A 9-day camp model is set up in which children have 54h of intensive therapy including AOT/placebo (15h). The experimental group watches goal-directed video sequences for three minutes, followed by the motor execution of these actions for three minutes. The control group performs the same actions after watching computer games. The assessment consists of clinical measures at the body function, and activity level, participation and quality of life, as well as 3D UL movement analysis. Brain imaging techniques include TMS, Diffusion Kurtosis Imaging (DKI), structural MRI and resting state functional MRI.

The timeline for the assessment is T1 (1-1.5 month before the camp onset), T2 and T3 (before and after the intervention) and T4 (6 months after the intervention).

### **Discussion**

This paper describes the methodology of an RCT evaluating the combined effect of AOT to CIMT in children with UCP across the ICF and defining the characteristics of best responders.

## **Long term results of early myoelectric prosthesis fitting- a prospective case-control study**

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**Background:** Children with upper limb reduction deficiency (ULRD) are recommended to be fitted with hand prosthesis at an early age because it encourages motor learning and prosthetic integration into the body scheme. Early fitting of a passive prosthetic hand is supported by the literature but the age for introducing an active, myoelectric, hand varies and is more controversial. In Scandinavia the myoelectric hand prosthesis is introduced to the child at the age of 3 years, but in North America it is recommended that the fitting takes place as early as 10-15 months of age.

**Aim:** The aim of this study was to compare ability to operate the myoelectric hand, prosthesis use and risk for rejection among two different age groups for paediatric myoelectric prosthesis fitting.

**Method:** A prospective case-control study design was chosen. Thirty-six children participated; 9 were fitted with myoelectric prosthesis early, before 3 years of age (cases), and 27 after 3 years of age (controls). Ability to operate the hand was measured with Skills Index Ranking Scale (SIRS) ranging from 1-14 with higher score indicating higher ability.

**Results:** The children fitted early demonstrated ability to operate the hand voluntarily, SIRS level 5, at md 24 (inter-quartile range 12 – 39) months of age, whereas in conventional fitting the corresponding age for this was md 36 (inter-quartile range 33 – 45) months. However, at 42 months of age, the median SIRS level in cases was 7 and in controls 8, showing a catch up in the controls ( $p=0.604$ ). Prosthesis use varied over the years and between the groups. Cases demonstrated a higher rejection rate than controls but the difference in risk was not statistically significant.

**Conclusion:** There is no additional advantage for the long term function of fitting a myoelectric prosthetic hand to children at very early age. The recommended age is around 3 years, with further consideration taken to the individual psychosocial and motor development.

## **Possibilities with the quality registry HabQ – the view of parents.**

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### **Background**

Parents today are expected to act as informed partners, forming the habilitation for their children together with the professionals. This requires that parents have access to reliable information. A quality registry may be an important tool for sharing information with parents.

HabQ is a quality registry run in collaboration between Föreningen Sveriges Habiliteringschefer and 17 county councils (out of 21 in Sweden) and Linköping university. The registry evaluates parents' views of the habilitation process and effects on health and functioning such as grossmotor function, activity performance, cognition, speech, eating and swallowing as well as self-rated health. The registry is now developing methods to share information with parents. In this process it is necessary to have information about what kind of information parents need and how it's best presented .

### **Aim**

To describe how a quality registry could be useful for parents with children with disabilities.

### **Method**

Two groups of parents (8 persons) to children with Cerebral Palsy were interviewed on two occasions. The interviews aimed at gaining information on the parents' views of how the registry may be useful to the parents and what may be important data to receive from the registry. The interviews were recorded and transcribed verbatim. Data was analysed using qualitative content analysis.

### **Result**

The analysis yielded five themes: The registry is already important to the parents in an indirect way. The registry may become important in a direct way. Parents want to share their data with the registry in a comfortable way. Parents want to get information from the register in various ways. Parents perceive there might be risks with being part of a registry.

### **Conclusion**

Being part of the HabQ quality registry is of importance to the parents and the advantages of receiving information from the registry will be helpful and outweigh possible risks/disadvantages.



**Socioeconomic Disadvantage and Spastic Cerebral Palsy: a matched case-control study, Michigan, USA**

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**Background:** Socioeconomic position (SEP) is highly correlated with the health, development, and wellbeing of children. To date, only a handful of studies have examined the relationship between socioeconomic disadvantage and the risk of cerebral palsy (CP).

**Aim:** To investigate the association between indicators of socioeconomic disadvantage and the risk of CP and whether gestational age (GA) mediates the association.

**Methods:** Using a 1:1 matched case-control study design, we matched 124 children with spastic CP to 124 children without CP on birth year, GA grouping (<28, 28-32, 33-36, >37 weeks'), and child's sex. Conditional logistic regression was used to assess the association between each SEP indicator (low maternal education: <high school vs. >some college, and total annual household [HH] income: <25,000 US dollars vs. >25,000 US dollars) and the odds of spastic CP. Covariates included in the multivariate regression models included maternal age, maternal marital status, parity, and public/private health insurance, and late entry or no prenatal care.

**Results:** In bivariate analyses the odds of spastic CP was significantly associated with low maternal education (Odds Ratio [OR]=1.94, 95% Confidence Interval [CI]: 1.13-5.11); this association persisted even after adjustment for covariates (adjusted OR=2.40, 95%CI: 1.04-4.98). In stratified analyses low maternal education was only significantly related to spastic CP among term-born children (adjusted OR=9.42, 95% CI=1.29-68.87). In bivariate analysis HH income <25,000 US dollars was significantly associated (OR=2.56, 95% CI: 1.18-5.52) with spastic CP; however, in multivariate models this association was marginally significant (OR=2.20, 95% CI: 0.82-5.92). HH income <25,000 US dollars was not significantly associated with spastic CP when stratified by GA.

**Conclusion:** This study suggests low maternal education is associated with the odds of spastic CP among term-born children.

## **Acceptability of intensive speech therapy delivered via Skype to children with dysarthria and cerebral palsy**

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### **BACKGROUND**

An intensive therapy focussing on breath control, phonation and speech rate has been shown to increase the speech intelligibility of children with dysarthria and cerebral palsy. To date the therapy has been provided face to face. A current phase II study is investigating the feasibility of providing the therapy via Skype.

### **AIM**

This study explored the acceptability of Skype-delivered therapy to children with cerebral palsy and their parents.

### **METHOD**

Eleven children aged 5 -17yrs were allocated to the Skype therapy group in the feasibility study. Each child received individual dysarthria therapy via Skype three times per week for six weeks. Sessions usually took place after school, with children Skyping from home. Qualitative interviews with children and parents were conducted one week prior to therapy, three weeks into therapy and six weeks post therapy. Children and parents were asked about their experiences of participating in the study and the impacts of therapy. Transcripts of the interviews were analysed thematically.

### **RESULTS**

Preliminary analysis of transcripts identified that the key themes which support the acceptability of Skype-delivered therapy were therapy taking place in a consistent, familiar environment; confidence in the therapist; therapy outcomes and convenience, with a relatively short time-scale for delivery. When asked what stood out for them about the therapy delivery parents consistently stated that not having to travel to appointments was a positive factor, whereas the children described their enjoyment of the activities within the therapy sessions. Negative responses have been minimal but included minor technical difficulties and scheduled appointments disrupting normal routines.

### **CONCLUSION**

Skype delivery of therapy is acceptable to families; the short time frame of therapy and positive outcomes for children outweigh the temporary disruption to usual routines.

## **Adolescents with cerebral palsy sharing their participation experiences: Everything about us with us!**

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**BACKGROUND** School, sports and healthcare are important participation areas for adolescents with cerebral palsy (CP). To be able to truly understand and optimize their participation, it is necessary to switch our perspective: let the adolescent with CP be the starting point. This perspective implies qualitative research with a focus on their experiences. But that is not all: it also implies research in which adolescents themselves play an active role in determining design and outcomes. **AIM** To let adolescents with CP share their personal experiences in a qualitative, participatory research project with a focus on participation at school, at sports, and in healthcare. **METHOD** This study is a 10-year follow-up of children with CP who previously, aged 2-7 yrs, enrolled in a large longitudinal research program in The Netherlands (PERRIN). Now, as they are 12-17 yrs, 50 of them (various severity levels) will share their experiences concerning school, sports and healthcare. Qualitative research methods are used, including open interviews. The study is further characterized by participatory research methods: adolescents with CP are significantly and actively involved as partners in all stages, i.e. from research questions to practical recommendations. **RESULTS** Main outcomes are 1) experiential knowledge by adolescents with CP about school, sports and healthcare; and 2) their own practical recommendations in these three domains. Secondary outcomes are insights in the process of executing qualitative participatory research with adolescents with CP. First results are expected in spring 2016. **CONCLUSION** In this study, adolescents with CP share their experiences and provide recommendations in important participation domains. The study is not only executed for them, but rather with them: they are regarded as experts and are the face of the ongoing study. An important added value is that such a role may empower them and, in the long term, may benefit their participation in society.

## **Effect of a 5 day Hybrid CIMIT program in children with Unilateral Cerebral Palsy in the age of 5-12 years**

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## **Effect of a 5 day Hybrid CIMIT program in children with Unilateral Cerebral Palsy in the age of 5-12 years**

### **Background**

Modified Constraint-Induced Movement Therapy(m-CIMT) supplemented with bimanual intensive therapy(BIT) (together defined as hybrid CIMIT) have shown promising results in improving bimanual performance in children with unilateral cerebral palsy(CP). No optimal dosage of Hybrid CIMIT is known. Many Hybrid CIMIT interventions have longer duration than 5 days.

### **Aim**

The aim of this study is to determine the effect of a short Hybrid CIMIT program on bimanual skills in children with unilateral CP.

### **Method**

During the period 2013–2014, children with unilateral CP who attended the hybrid CIMIT intervention during a day-camp(circus Revanti) were included in this study. The intervention lasted for five consecutive days. All children daily received 3,6 hours of m-CIMT, followed by 4,85 hours of bimanual training. m-CIMT consists of shaping and repetitive tasks(S&R). Bimanual training includes goal directed training and age related play activities. During follow-up(between t1 and t2) the children received homework instructions.

Data collection occurred in three different moments, two weeks before the intervention(t0), at the final day of the Hybrid CIMIT intervention(t1) and three months after(t2).

Outcome measures are the AHA(assisting Hand Assessment), GAS(Goal Attainment Scaling) and Abilhands Kids.

The Wilcoxon signed rank test was used to determine differences between t0 and t2.

### **Result**

Twenty children(50%boys) with unilateral CP(aged from 4.11 to 11.10 years; mean age: 8.3 years) participated in this study.

Results showed a significant difference in bimanual performance for all three measurements.(p<0.05) between t0 and t2. In addition, the majority of the children showed a clinical important change on all three outcome measures.

### **Conclusion**

Based on data obtained it is concluded that the five day Hybrid CIMIT program increases bimanual skills and functional performance.

## **Modern approaches to the rehabilitation of children with disabilities.**

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### **Aim**

The aim is to increase the efficiency of rehabilitation of children with disabilities by implementation of innovative approaches to activity-based therapy.

### **Method**

Analysis of the rehabilitation efficiency of 700 children has been conducted. The results of the techniques aimed at stimulation of children's activity: Sensory integrative therapy, Occupational therapy and massage, physiotherapy were evaluated.

### **Results**

It has been established that passive rehabilitation techniques are chiefly aimed at correcting the structure and functional capacity of the patient. Application of these methods had an influence upon prevention or reduction of the contractures, different strains, muscle force increasing and functional capacity support.

Attainment of maximal functionality was assured by the application of the child's activity-based techniques followed by participation of the trained family members. SI-therapy and Occupational therapy makes it possible to realise the main goal of rehabilitation - acquisition of the highest possible functional capacity, autonomy and independence of the child with disability.

From the standpoint of evidence-based medicine of the EACD, a list of efficient methods of rehabilitation for children has been compiled. These include: activity-based therapy, constraint induced movement therapy (CIMT), bimanual intensive training and domestic occupational therapy programs.

Rate, regularity and duration of the above techniques intensive courses have been presented with the follow-up application in daily activities of the skills acquired.

### **Conclusion**

1. Efficiency improvement in rehabilitation of children with disabilities depends on application of the techniques aimed at the patient's activity in conditions of micro social environment (family centered care).

2. Further introduction of modern techniques in conformity with evidence-based medicine positions will allow achieving the highest possible level of patient adaptation.

**Effects of botulinum toxin A injections and/or bimanual task-oriented therapy on hand functions and bimanual skills in children with unilateral Cerebral Palsy: a clinical trial.**

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**Background.** This study reports on the effects of botulinum toxin A (BoNT-A) in the upper extremity (UE) in children with unilateral Cerebral Palsy (uCP) and/or bimanual task-oriented therapy (BITT) on UE range of motion, spasticity, (functional) strength, bimanual activities (the AHA, the ABILHand-Kids questionnaire (AK), the Observational Skills Assessment Score (OSAS)) and goal achievement (GAS and COPM).

**Methods.** Thirty-five children, mean age 7.14y (SD 2.63), 11 Manual Ability Classification Score (MACS) I, 15 MACS II and 9 MACS III, participated. Study groups were: BoNT-A-only (n=5), BITT-only (n=11), BoNT-A+BITT (n=13), and control (n=6). Twenty-two children were randomised, 13 children received their parents' preferred treatment (BoNT-A+BITT or BITT-only). Analysed comparisons: BITT (BoNT-A+BITT and BITT-only; n=24) versus no BITT (BoNT-A-only and control; n=11), BoNT-A (BoNT-A-only and BoNT-A+BITT; n=18) versus no BoNT-A (BITT-only and control; n=17), and additional effect BoNT-A (BoNT-A+BITT versus BITT-only). Follow-up time: 24 weeks.

**Results.** BoNT-A increased active thumb abduction, decreased finger flexion tone and negatively affected key grip strength and unilateral functional strength. BITT had positive effects on functional grip strength. No significant group differences were found on the AHA. BoNT-A showed significant improvement in quality of grasping and holding of the wrist on the OSAS. BITT improved significantly on the AK and the COPM. BITT, more than BoNT-A+BITT, showed positive effects on the GAS at 12 (significant), 18 and 24 weeks.

**Conclusions.** BITT has a clear positive effect on functional strength, goal achievement and bimanual performance, even up to 6 weeks after therapy had stopped. BoNT-A has a positive effect on thumb abduction, finger flexor tone and quality of movement of the affected UE during working time, but a negative effect on strength. BoNT-A has no additional effect on bimanual performance and goal achievement.

## Upper extremity serial casting: Clinical audit supports further good quality research

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**Background:** Serial wrist casting is used, with or without BoNT-A injections, to manage passive range of motion aiming to improve orthoses tolerance, delay the need for surgery and reduce pain. As minimal evidence exists to support casting intervention, good quality research is required to confirm or change practice.

**Aim:** Present pilot data on wrist casting outcomes to prepare for future research.

**Method:** Audit of 60 children with cerebral palsy having wrist casting (76 wrists). Mean age (SD) was 13y0m (3y3m); 29 males; 48 spastic quadriplegia, 12 spastic hemiplegia; MACS Level I=0, II=10, III=3, IV=10, V=37; 43 had upper limb BoNT-A injections. Outcome was passive wrist extension (PROM). Clinically important change was determined a priori to be 20°.

**Results:** Goals for casting were to increase PROM and improve orthosis tolerance. Mean increase in PROM was 24.3° (14.9); 9 wrists achieved no change; 52 (68%) achieved a clinically important increase in PROM. Increase in PROM following and without BoNT-A was 21.8° (14.7) and 27.8° (14.8) respectively, there was no clinically or statistically significant difference between groups ( $p=0.08$ ). There was no difference in amount of change in PROM across GMFCS and MACS Levels, or diagnosis of hemiplegia vs quadriplegia. Seven (9%) temporary adverse events were reported. There were no differences in age, number of casts, baseline PROM or change in PROM for children who did or did not have BoNT-A injections. Children who had BoNT-A injections wore casts for statistically, but not clinically, significantly longer (mean difference 0.4 days; 95%CI=0.03 to 0.80 days,  $p=0.04$ ).

**Conclusion:** Casting appears to increase passive range of wrist extension for many children with cerebral palsy, whether implemented following BoNT-A injections or not. These data provide justification for pursuit of approvals and funding to implement larger studies providing higher level evidence to inform effective and efficient practice.

## THE RELATIONSHIP BETWEEN RESPIRATORY DISTRESS SYNDROME OF INFANTS AND USING MEDICATION AND SUBSTANCE ABUSE IN PREGNANCY

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**Background:** Infants born preterm account for a substantial part of neonatal morbidity, with respiratory distress syndrome (RDS) being a dominating clinical problem.

**Aim:** RDS is the most common respiratory problems in premature, so in our study we aimed to find out the relationship between RDS and using medication, substance abuse and medication+substance abuse during pregnancy.

**Method:** 132 premature infants with LBW included in the study. Gestational ages, corrected ages and birth weights of infants were recorded. Risk factors such as birth trauma, postnatal intensive care unit hospitalization duration, respiratory distress, hypoxia, asphyxia, intracranial/intraventricular bleeding and glisemic impairment histories of infants were investigated. Correlations between RDS and using medication, substance abuse and medication+substance abuse during pregnancy of infants mothers' were analyzed.

**Result:** Corrected and gestational ages of premature infants were mean  $7.81 \pm 4.47$  months and  $31.40 \pm 3.08$  weeks, respectively. Birth weight of infants were  $1695.05 \pm 720.30$  gram. 57 (42.54%) of 132 infants mothers' using medication, 15 (11.19%) substance abuse and 8 (5.97%) both using medication plus substance abuse. Fourty-six (34.59%) of 132 infants have RDS. There were positive, moderate correlations between RDS scores and using medication ( $r=0.421$ ;  $p<0.01$ ); substance abuse ( $r=0.346$ ;  $p<0.01$ ); and both of them ( $r=0.346$ ;  $p<0.01$ ).

**Conclusion:** Although there is no known exact cause of the mother's drug prematurity, drug use and drug + substance abuse are listed among the causes of prematurity RDS also seen in the prematurity has an effect on mortality and morbidity. Therefore, especially during pregnancy, we think that the mother's should pay attention to using medication, substance and drug abuse.



## Teaching aided communication: self-report and intervention by SLPs

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### Background

Children with severe motor disability and intellectual disability (e.g. children with cerebral palsy or Rett syndrome) typically have complex communication needs (CCN). These children can communicate by using communication aids (e.g. communication boards and speech generating devices (SGDs) provided that the communication partners use partner techniques. Speech and language pathologists (SLPs) have a central role in teaching aided communication.

### Aim

The aim was: (1) to examine how SLPs instructed parents and school personnel in aided communication with individual with Retts syndrome and (2) to evaluate an intervention directed towards physiotherapists working with children with cerebral palsy

### Method

(1): Informants were SLPs (n=77) working at Swedish habilitation centers with individual with Retts syndrome. Data was collected by a web-based questionnaire and analyzed by descriptive statistics. (2): Six physiotherapists working at Swedish habilitation centers participated in a communication partner instruction program suggested by Kent-Walsh and McNaughton (2005). Interactions between physiotherapists and children with CP were video recorded. Data was analyzed by descriptive statistics and conversational analysis.

### Result

The main finding from the self-reported data showed that communication partner techniques to a large extent were given informally and orally. The main finding of the intervention showed an increased use of partner technique which resulted in extended communication by the children.

### Conclusion

SLPs report often teaching aided communication informally and orally. Physiotherapists' use of partner techniques increased after participating in a course using the instructional approach of communication partner instruction program suggested by Kent-Walsh and McNaughton (2005).

## **Understanding parental attitudes towards early screening for autism spectrum disorders**

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**Background:** Little is known about parents' reactions towards a potential early screening tool for autism spectrum disorders (ASD). It has been suggested that a diagnosis of ASD does not only affect the child but it also affects the parents. Therefore, it is important to investigate the opinions of parents about early screening for ASD. **Aim:** The current study examined what parental factors (demographics, temperament, personality) may influence parents' reaction towards a potential early screening tool and what they would require in order to be more positive towards this tool. **Method:** Parents (n = 64) were asked to complete a questionnaire in an electronic or pen and paper format. Both formats contained a structured interview questionnaire with questions about early screening, a demographics questionnaire, a temperament questionnaire and a personality questionnaire. **Results:** The majority (86%) of the participants agreed that early screening is worthwhile and that they (92.2%) would like to choose whether their child would take the test. Most participants reported that a non-distressful test (82.2%), further educational and social support (54.9%), and having friends and family with knowledge about ASD (62.5%) would encourage them to have the test for their child. It was also found that participants' age, gender, level of socioeconomic status, education level, number of children and personality were significant factors that had an affect on participants' opinions about early screening for ASD. **Conclusion:** These findings add to the limited literature about parents' feelings and reactions towards early screening for ASD, as this theme has not previously been explored. Age, gender, socioeconomic status, education level, the number of children and personality were related to how parents perceived the introduction of early screening for ASD. This work has provided valuable insights into parents' potential reactions to ASD diagnostic screening in early childhood.

## **A Case report of a child with HIV infection and Glutaric Aciduria Type 1**

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Title: A Case report of a child with HIV infection and Glutaric Aciduria Type 1

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Background: We present a South African child with HIV and Glutaric Aciduria type 1. Outcomes have been good despite many challenges. He was enrolled onto a HIV research study at six weeks of age and commenced on antiretroviral therapy (Zidovudine, Lamivudine and Ritonavir/Lopinavir). He presented with focal seizure at sixteen months of age and a MRI was done that showed significant brain atrophy and asymmetrical hyperintensities in white matter and a focal area of haemosiderosis in R Sylvian fissure region. Since these finding were not in keeping with HIV encephalopathy, metabolic screening confirmed Glutaric aciduria type 1. A293T mutation, which is common in the African population, was detected.

Aim: To share a case of dual diagnosis but with favourable outcome.

Method: We present a single case report.

Result: He was started on L-carnitine and a low protein and lysine free tryptophan reduced diet, along with antiretroviral therapy. He was diagnosed with pulmonary tuberculosis at 21 months which resolved after 6 months of anti -tuberculosis treatment. At 7 ½ years he developed lipoatrophy and Zidovudine was substituted with Abacavir. On serial neurodevelopmental and neurocognitive testing scores were similar to healthy neighbourhood controls except for mild language delay.

Conclusion: Despite many health challenges he faced, early detection was pivotal in a favourable outcome. In this case the concomitant use of antiretroviral therapy and anti -tuberculous therapy in a child with Glutaric aciduria type 1 appears to be safe.

## **Is it possible to measure AAC-effects physiologically? A pilot study within a pediatric care setting**

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### **Background**

Many children with a communicative disability are frequent consumers of hospital care. The United Nations Convention on the Rights of People with Disabilities (CRPD) and the Child Convention guarantee the right to communicate using the preferred means of communication, including augmentative and alternative forms (United Nations, 2006). In spite of this, hospital staff most often trust in the parents to act as interpreters, and have little knowledge about communicative disability and AAC. A working model using the principle of universal design and augmentative and alternative communication (AAC) methods was developed within the project KomHIT- communication support in paediatric and dental care.

### **Aim**

This pilot study focuses on the possible effects of the KomHIT AAC intervention on a group of children with varying degrees and types of communicative disability, undergoing day (outpatient) surgery. The unique purpose was also to see if this could be assessed using a physiological measure, namely salivary cortisol.

### **Method**

All staff were educated and AAC strategies were used at home prior to admission and during the hospital stay. Twenty-five children (7 in the intervention group, 18 in the control group) and their parents were asked about their emotional state using the State-Trait Anxiety Inventory (STAI), and samples of saliva were collected. Premedication was also checked.

### **Result**

The children in the KomHIT AAC intervention group showed somewhat lower levels of cortisol and none were in need of premedication compared to five children in the control group. No statistical differences between groups were seen on the STAI.

### **Conclusion**

The combined results in this study give a weak indication that AAC can decrease stress and anxiety in children with a communicative disability undergoing day surgery and that salivary cortisol level may be a feasible measure in AAC studies. More research is needed.

## Selective Dorsal Rhizotomy a “Learning Journey” Do the changes post SDR, as perceived by the parents, indicate gaps in the objective clinical assessment including GMFM-66/-88, 2/6 Minute Walk Test and CP-QoL?

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**Background:** SDR demonstrated to reduce spasticity, and increase motor function. No study has investigated parental observations of changes post-SDR.

**Aim:** Exploring parental perception and quantitative outcome measures, enlightening understanding of everyday values of changes post-SDR.

**Methods:** A mixed methods design using quantitative data; GMFM-66/-88, 2/6 MWT, CP-QoL, and qualitative data, parental focus group post-SDR, was conducted. Non-parametric tests were used for pre, 6 and 12 month post-SDR analysis of the quantitative data. Following separate analysis, quantitative and qualitative results were merged.

**Results:** 14 datasets were used and 3 parents attended the focus group discussion.

**Qualitative:**

6 themes emerged: 1)Preparation for SDR; 2)More important things than walking; 3)Therapy is key; 4)Improved Quality of family life; 5)Bringing up a child with a disability; 6)What helps parents through the SDR process.

This provided in depth insight into everyday values of post-SDR changes, their impact on quality of life for the child and family, and identified areas not recorded by the quantitative measures.

**Quantitative:**

GMFM showed statistically significant improvements at 6month for 66total(p=0.011), 88total(p=0.001), B(p=0.006), C(p=0.012), and D(p=0.007), and at 12 months for 66 total (p=0.028), 88total(p=0.002), B(p=0.012), C(p=0.007), D(p=0.042), and E(p=0.028).

CP-QoL:“Feeling about Functioning”(p=0.038) and “Pain and impact of disability”(p=0.021) showed statistically significant improvements from pre to 6month post-SDR.

2/6MWT:A non-significant increase in walking distance was found.

**Conclusion:** Quantitative data showed improvement as described by parents. However quality of functionality, safety, and appearance of the child were not captured. Parents described increased confidence, independence, better sleep and toileting ability, as the most important. Not addressed by the used outcome measures were emotional impact of surgery on family life and issues at school

## **Effects of a goal directed intensive bicycle skills group program for children with cerebral palsy: a case series**

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**Background:** Learning to ride a two wheel bike is a common childhood milestone and bike riding is a popular means of physical activity, yet most cycling research for children with cerebral palsy (CP) has been on stationary bikes.

**Aim:** This pilot study aims to investigate the effect of a goal directed intensive group bike skills program for children with CP on self perceived performance and satisfaction with bike specific skills, skill acquisition and health-related quality of life (HRQOL).

**Method:** 5 children with CP (ages 9-12, Gross Motor Function Classification System I-II) participated in a goal directed bike skills group program for 2 hours/day over 3 consecutive days. The primary outcome measure, the Canadian Occupational Performance Measure (COPM), measured bike-specific self perceived performance and satisfaction. Secondary outcomes included bike-specific skill level and HRQOL as measured by the PedsQL (generic v4.0). The COPM and bike skills were measured at baseline, immediately post and at 3 months post-intervention. HRQOL was reported by parents at baseline and at 3 months post-intervention

**Result:** Clinically significant improvements in self perceived performance and satisfaction scores immediately post-intervention were seen in all participants, with improvements maintained at 3 months post-intervention. No participant could ride a two wheel bike at baseline. Of the 5 participants, 3 learned to ride independently, while all acquired bike specific skills which were maintained at 3 months post-intervention. There was no obvious change in HRQOL.

**Conclusion:** A goal directed intensive skill specific group program appears to be a promising method for improving self perceived performance and satisfaction and learning to ride a two wheel bike for children with CP. Future research is warranted and could examine the effect of skill acquisition on participation in physical activity, a growing challenge in this population.

## Early Physiotherapy and Down Syndrome: Does this Improve Age of Walking?

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### Background:

Children with Down syndrome have delayed motor development relative to their peers, with many possible causes implicated. Estimates vary from 40% of children walking independently by 24 months, to 50% of children walking by 1 year.

Early physiotherapy is popular with parents and recommended, partly for future benefit, in Down Syndrome guidelines in the UK, Europe and the USA. However, there is increasing opinion that children may not benefit from routine physiotherapy, and it is not routinely offered to all children in the UK by all departments.

### Aim:

The aim of this retrospective study was to identify whether children with Down syndrome who received physiotherapy had an earlier age of independent walking than those who did not.

### Methods:

The database of children attending the Down syndrome clinic at St George's Hospital (United Kingdom) was reviewed. Motor outcome was measured by the age at which healthy children achieved independent walking; comparative testing was performed between the group that received physiotherapy versus those who did not.

### Results:

Results did not demonstrate any significant difference in walking age between the physiotherapy group (n= 11) who walked at a mean of 27.7 months whilst the non-physiotherapy group (n= 18) walked at mean average of 22.6 months (p=0.09). When measuring the number of patients who were mobile at the age of 2 years, 55% of patients who received physiotherapy were walking independently, versus 66% of patients who did not receive physiotherapy.

### Conclusion:

Early physiotherapy was not associated with better motor outcome in children with Down syndrome, supporting current practice that this should not be offered routinely. Although our sample was small, the observation from this study shows the need for a multicentre study.

## **Systematic review about the efficacy of treadmill interventions with partial body weight support in children under six years of age at risk of neuromotor delay**

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**Background:** Delayed motor development may occur in children with Down syndrome (DS), cerebral palsy (CP) or children born preterm, which may limit the child's opportunities to explore the environment. Early intervention literature suggests that task-specific training facilitates motor development. Treadmill intervention (TM) is an example of task-specific locomotor training. **Aim:** To update a previous review from September 2011 that assessed effectiveness of TM intervention on motor development in pre-ambulatory infants and children under six years of age at risk for neuromotor delay. **Methods:** In July 2014 we searched Ovid MEDLINE, CENTRAL, PsycINFO, CINAHL, EMBASE, Science Citation Index, PEDro, CPCI-Science and LILACS. **Results:** We identified two additional trials, resulting in a review of six trials (151 participants). Of the 151 children, 92 were allocated to TM intervention groups, with the other children serving as controls. When comparing TM versus no-TM intervention, meta-analysis was conducted for three variables: 1) age of onset of independent walking: TM intervention appeared effective in promoting earlier independent walking in children with DS (effect estimate -4.00; 95%CI: -6.96, -1.04); 2) age of onset of walking with assistance: TM intervention had positive effects in infants with DS (effect estimate -74.0; 95%CI: -135.40, -12.60) and 3) GMFM: TM intervention did not affect total GMFM scores in children with DS or CP (effect estimate 0.88; 95%CI: -4.54, 6.30); but one high dosage study reported improvement in dimensions D and E in children with CP. **Conclusions:** Treadmill interventions have been studied in small controlled trials in children with DS, CP and children with moderate risk for developmental delay. Current evidence indicates that TM intervention may accelerate the development of walking in children with DS. There is emerging evidence that intensive TM intervention may accelerate developmental skill attainment in children with CP.



**Development and evaluation of a model for intervention using the method "My time" and time aids for children with disabilities. Pilot study.**

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**Background:** Difficulties with management of time are frequently observed in children and youth with disabilities. Methods for early intervention needs to be developed.

**Aim:** To develop and evaluate a model for early intervention to support children with disabilities to get an increased ability for time perception.

**Method:** Data collection included the Kit for assessment of Time processing ability (KaTid), self-ratings of Autonomy, Parent scale of children's daily time management and Adaptive Behavior Assessment System (ABAS) measuring children's everyday functioning.

Preschool children (n=20), 4 children with disabilities or special needs and 16 typically developed children were given the same intervention for 8 weeks with the method "My Time" and time aids. Data was analysed by using Wilcoxon Ranks Test.

**Results:** There was a significant increase in Time Processing Ability (TPA measured with Ka-Tid) and in the parts Cognition and General Adaptive Behavior (ABAS). Children with disabilities/special needs start at a lower level of TPA (Mn=11.5) compared to typically developing children (Mn=27.6).

**Conclusion:** By the use of "My Time" it is possible to help preschool children with disabilities or special needs to develop skills in managing time and thereby increase their everyday functioning. Which components in "My Time" that are most effective and for whom should be further examined by the use of a RCT study design.

## Perspectives of Dutch physiotherapists towards self-management support: a Q-methodology study

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**Background:** Improving the individual's capacity for self-management is essential to optimize health of people with chronic conditions, and to face the challenge of increasing healthcare costs. It is unclear how physiotherapists (PTs) view self-management support.

**Aim:** To determine perspectives towards self-management support among Dutch PTs.

**Method:** A cross-sectional study with mixed-methods design was conducted in the Netherlands using the Q-methodology. 39 PTs were locally recruited in various working settings. They were asked to rank order 37 validated statements about self-management support in a standardized distribution (ranging 'most disagree' to 'most agree'). To determine different perspectives towards self-management support a by-person centroid factor analysis with varimax rotation was performed with PQmethod, to reveal the highest explained variance ( $R^2$ ). The qualitative analyses of the verbal motivation of PTs supported interpretation of the results.

**Result:** PTs (51% Female) were aged between 22 and 64 years (mean 41.3y; SD: 12.3y) and working in a primary (n=15), secondary (n=5) tertiary (n=16) physiotherapeutic care, or other settings (n=3). Although a general opinion towards self-management support was discovered, nuances could be identified in the PTs' role (educating or coaching) and drive (internal or external) for providing self-management support, as well as the collaboration between the individual and PT (partners or no partners). Four different perspectives were identified, labelled as the 'clinician' ( $R^2=14\%$ ), 'supervisor' ( $R^2=9\%$ ), 'client-centered coach' ( $R^2=13\%$ ), and 'innovative coach' perspective ( $R^2=15\%$ ).

**Conclusion:** Self-management support already seems to form part of PTs' work. Each perspective contains valuable elements of self-management support. Post-graduate training for PTs should be tailored to the needs of the perspectives to optimize self-management support.

## **Death in children with severe physical disability; can we improve care by looking at the last two years of life?**

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**Background:** Despite having an increased mortality compared to unaffected children, it remains a challenge to identify when children with severe physical disability are approaching death. There is increasing consensus that palliative care can enhance the experience and satisfaction of patients and families of children with life-limiting conditions, however, when do children with severe neurodisabilities become terminal?

**Aim:** To identify key clinical changes that occur during the two years prior to death that may indicate approaching end of life in children with severe physical disability.

**Methods:** Retrospective cohort analysis of children aged 1 to 18 years with severe physical disability, who attended RCH, and died between 1 January 2013 and 1 January 2015. Data was grouped into four six-monthly time periods in the two years before death. Key clinical features were extracted from medical records, and descriptive and comparative analyses were performed.

**Results:** Forty-eight eligible children were identified. Twenty children had a progressive cause of severe physical disability, and they were more likely to die earlier, compared to children with non-progressive aetiologies ( $p=0.06$ ). Children with progressive causes may have resuscitation limitations formalised earlier ( $p=0.09$ ). Information about respiratory support provided at home was infrequently available. There was an increasing proportion of children requiring artificial feeding closer to death. There was an increase in median number of days in hospital, and in admissions with respiratory presentations in the six-months before death.

**Conclusion:** Clinicians are more comfortable with end of life care in children with known progressive causes of severe physical disability. Although there are identifiable group trends, comparison with a cohort of surviving children with severe physical disability will identify whether there are predictors of death in children with severe physical disability.

## **Parenting stress and optimism among mothers and fathers of preschool children with cerebral palsy**

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### **Background**

Having a preschool child with cerebral palsy (CP) affects parents' everyday coping. Program Intensified Habilitation (PIH) is designed to strengthen children's motor, communication and cognitive skills, and to assist parents in reducing stress and optimize everyday function.

### **Aim**

To evaluate the level of stress and optimistic view in general among parents of preschool children with CP and to examine whether participating in PIH has a beneficial effect on stress levels and optimism.

### **Method**

Parents of preschool children (n= 42) with CP participating in PIH have filled out the Parenting Stress Index (PSI) and Life Orientation Test (LOT) before and after attending the program.

### **Results**

Having a preschool child with CP was associated with increased level of stress for about 1/3 of the parents, at the start of the program. A total of 36 % of the mothers and 23% of the fathers scored above normative clinical level. Mothers and fathers' stress levels as groups differed. They experienced similar patterns of stress related to their child, but not to their own life situation. Mothers experienced significantly more stress than fathers in the areas Health, Role Restrictions, Depression and Relation to Spouse. After participating in PIH mothers' levels of stress were reduced, their level of optimism increased, and fathers' level of stress were more similar to mothers.

### **Conclusion**

Participating in an intensified habilitation program reduces stress levels and increase optimism among mothers. In addition, participation seems to align mothers' and fathers' experience of their situation. Based on clinical experience with the program, this is likely due to deeper insight into the child's challenges and increased empowerment among parents.

## **PARENT-LED WORKSHOPS CAN CREATE A POSITIVE THERAPEUTIC ENVIRONMENT AND DISPEL MISPERCEPTIONS IN RESOURCE-CONSTRAINED SETTINGS**

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### **Background**

Whilst working with children with Cerebral Palsy (CP) and their caregivers in rural, low-resourced settings we observed that most were ill-informed and confused about CP, despite attending therapy and consequently carry-over and care was sub-optimal.

To address this need for information, a parent-led training programme comprising five workshops was designed in consultation with 20 parents. These parents were then trained as workshop facilitators.

### **Aim**

To evaluate the impact of parent-led training workshops on caregivers of children with CP.

### **Method**

Over a two year period, trained Parent Facilitators from ten rural areas in South Africa and Lesotho ran a series of five workshops for caregivers in their own communities. Caregivers completed a questionnaire after each workshop. Following translation into English, the data was analysed thematically.

### **Results**

During the two years 564 caregivers attended all five workshops. Prior to the workshops, caregivers expressed being in a state of confusion, hopelessness and darkness. They struggled to accept their children, felt alone and blamed themselves.

After the workshops caregivers expressed feelings of confidence, pride and hope – “my heart is now relieved.” They conveyed how the workshops helped them overcome the struggle of accepting their child, which allowed them to love them and feel confident to take them out in public.

Caregivers stated that two misperceptions: that their child will not live for a long time and that therapy would “fix” the child, resulted in them not listening to what therapists tell them. Furthermore caregivers wanted to help others and tell them that “their child is not sick.”

### **Conclusion**

Providing caregivers of children with CP with information in their own language, presented in a way that is simple to understand and by a parent who has lived the same journey is a powerful tool in dispelling misperceptions and creating a positive environment for therapy.

## **Effect of Inter-manual training on hand shaping during grasp in children with Unilateral Spastic Cerebral Palsy**

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### **Background**

The ability to shape the hand in anticipation of object shape is essential for efficient grasp and manipulation. Children with USCP, demonstrate impairment in shaping ability that is limited to the affected side and may benefit from an intervention that uses the unimpaired hand to provide input to the affected side.

### **Aim**

To test the effect of an inter-manual training protocol on hand-shaping in children with USCP. We hypothesized that children with USCP will demonstrate increased hand posture differentiation to object shape following a single session of inter-manual training compared to a control group

### **Methods**

2 groups of children (n=20, ages 7-14) with USCP grasped 3 differently-shaped objects while fitted with reflective markers. Each shape was lifted in a reciprocal fashion with the less impaired hand followed by the impaired hand (25 trials per shape). (The control group alternated lifts with a sham object). To quantify hand shaping during reach a visuomotor efficiency index score (VME) was calculated (a score of 100 reflects perfect discrimination). The VME is derived from all hand joint angles at multiple intervals throughout reach and provides temporal and spatial information on the evolution of hand posture to object shape. To measure the effect of inter-limb training on hand posture differentiation, kinematic and VME variables were analyzed.

### **Results**

Results of 6/10 projected subjects per group are reported. Subjects in the intervention group demonstrated an increased max VME (average differential =  $9 \pm 2.5$ ,  $p=0.01$ ), and a higher VME at deceleration (average differential =  $16 \pm 9$ ,  $p=0.003$ , and were able to differentiate more finger joints to object shape (average =  $2 \pm 0.5$ ,  $p=0.001$ ) compared to controls. A higher VME is reflective of increased ability to shape the hand.

### **Conclusion**

Preliminary results suggest that inter-manual training may be a useful paradigm to increase hand shaping ability in children with USCP.

## **One, two, three, towards self-responsibility?! Exploring intentions for self-management of parents of children with a chronic condition and rehabilitation professionals**

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### **Background**

Within Dutch pediatric rehabilitation services self-management increasingly is acknowledged as critical basis of successful interventions, characterized by substantial responsibility, active participation and partnership with professionals. For many parents and their children indeed self-management is applicable, but there are others for whom it is a problem. Although rehabilitation professionals in general value self-management, they can strongly differ in their opinions about parent involvement. Better comprehension of intentions of parents and professionals is needed to accommodate and achieve more optimal self-management.

### **Aim**

This study aims to explore intentions and motivations for self-management of parents and professionals.

### **Method**

In a survey motivation, perceived support, attitudes and competency for self-management were measured among parents and professionals within 5 pediatric rehabilitation teams.

### **Result**

Analysis with 71 parents and 36 professionals indicated that 72% of the parents report they perform self-management, although 45% have difficulties to sustain this under stress. 28% of the parents believe self-management is important, but are not active themselves. Parents and professionals have both intrinsic- and also considerable extrinsic motivations for self-management. Almost all professionals believe parents should be active members of the care team. Although most parents feel supported, 15% are less satisfied with the support offered by the professionals. Intrinsic motivation was significantly correlated with more perceived support ( $r=.23$ ) and higher competency for self management ( $r=.40$ ).

### **Conclusion**

There is no optimal match between intentions of parents and professionals with regard to self-management. Further research on the underlying perceptions of parents and professionals about self-management, as well as perceived barriers and facilitators can help professionals to better tune in to the needs and expectations of parents.

## Effects of rhythmic auditory stimulation walking training on gait in children with cerebral palsy: A pilot study

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### Background

Recently, several research studies on the effects of rhythmic auditory stimulation (RAS) walking training on gait in adults with cerebral palsy (CP) have been reported. However, owing to the lack of a control group, the possibility of detecting a learning effect would be caused by repeated walking. From this point of view, the effect of RAS walking training has not been clarified fully.

### Aim

The aim of this pilot study was to investigate the immediate effects of RAS walking training on gait in comparison to the changes induced by repeated walking training in children with CP.

### Method

A convenience sample of 6 children (4-10 years old) with CP (3 with spastic diplegia and 3 with spastic hemiplegia) was included in this study. This research study was conducted with the approval from the research ethics committee of Osaka Prefecture University (2014-112). The participants randomly performed 15 minutes both RAS and repeated walking training. Then, each participant walked 10 m at their comfortable walking speed before and after each training session. Temporal data were obtained by using a floor-based photocell gait analysis system. To compare the sampled data, Wilcoxon signed-rank test was used. Statistical significance was set at  $P = 0.05$ .

### Result

Temporal gait measures revealed that RAS walking training significantly increased walking velocity, stride length, and step length ( $P < 0.05$ ), whereas repeated walking training did not induce significant changes in temporal gait measures.

### Conclusion

These findings indicate that RAS walking training would lead to a faster gait and improve temporal measures in individuals with CP.



## **To do and participate - Enhancing participation in daily life through Cognitive Orientation to daily Occupational Performance in young persons with spina bifida or cerebral palsy**

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**Background:** Participation occurs in the interaction between the person and the environment in activity. Performing an activity requires both motor function and executive function (planning, and performing goal-directed actions). Research shows that persons with spina bifida (SB) as well as with cerebral palsy (CP) have activity and participation restriction due to both motor- and (often disregarded) executive dysfunctions. The Cognitive Orientation to daily Occupational Performance (CO-OP) approach aim to guide the persons to master their own activity goals. Strategies for performance and problem-solving are discovered by the person with guidance from the therapist.

**Aim:** To investigate if the CO-OP approach is effective for achievement of self-identified goals and improvement in self-perceived community participation for young adults with SB or CP.

**Method:** Pilot project with 10 young persons (16-28 year) participated in a 10 week treatment with the CO-OP; 5 with CP (MACS I-III) and 5 with SB. Goal achievement was evaluated with the COPM. Evaluations was carried out on baseline, directly after and 6 month after the treatment period with outcome measures on all ICF-levels. Participant's experience of the CO-OP approach was captured with interviews.

**Result:** Preliminary results show considerable improvement in self-rated performance of the goals for all participants, with a median of 5 levels increase on a 10-level scale. Both self-rated participation and executive ability to plan and to stay focused was rated higher by the majority. In the interviews the participants expressed feelings of higher self-efficacy as their problem-solving ability increased; "If I have a problem to do something that is not a failure- I just make a new plan". The outcome of the treatment period was well worth the effort.

**Conclusion:** This study shows that the CO-OP is a promising approach to achieve personal goals and enhance participation through strategy use in young persons with SB or CP.