



## **Fatigue and quality of life seven years after severe childhood traumatic brain injury: results of the TGE prospective longitudinal study**

Mathilde Chevignard, Hugo Câmara-Costa, Leila Francillette, Marion Opatowski, Hanna Toure, Dominique Brugel, Anne Laurent-Vannier, Philippe Meyer, Georges Dellatolas, Laurence Watier

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## Oral Presentations

### Oral presentation 1

#### Rethinking trajectories and outcomes in autism

S GEORGIADES<sup>1</sup>, C KASARI<sup>2</sup>, S BISHOP<sup>3</sup>, T FRAZIER<sup>4</sup>

<sup>1</sup>McMaster University, Hamilton, Canada; <sup>2</sup>University of California Los Angeles (UCLA), Los Angeles, CA, USA; <sup>3</sup>University of California, San Francisco (UCSF), San Francisco, CA, USA; <sup>4</sup>Autism Speaks, USA

Within the interrelated themes of 'Innovation for Participation, Assessment, and Treatment', we propose a new way of thinking about trajectories and outcomes in autism. The traditional concept of 'optimal outcome' describes only individuals who, over time, stop meeting diagnostic criteria for autism. However, changing our notion of meaningful outcomes, and how and when those outcomes are measured, moves us toward a more inclusive spectrum approach. Redefining 'optimal outcomes' as the 'best possible outcomes considering a child's history' better captures the variability in the way children with autism grow and develop. It allows use of the child's own history to examine intra-individual growth, and considers outcomes across a spectrum of domains. The concept of 'chronogeneity' - the study of autism heterogeneity in relation to the dimension of time - is an innovative research approach that takes into account variability in change over time at the group and individual level while examining how, when, and why some individuals may deviate from group trajectories. We are at a juncture in autism research where variability no longer needs to be considered 'statistical noise' but rather 'informative variance' that can help form a more precise and dynamic picture of autism. That can in turn help inform the ways we adapt interventions to meet the diverse and changing needs of all children with autism. Rethinking what 'optimal outcomes' mean, including variables and domains identified as meaningful by those living on the spectrum, is a step toward advancing participation in research, clinical care, education, and the larger community.

### Oral presentation 2

#### Neurological pathology in children with autism spectrum disorders

T VOLOSHYN, V KOZYAVKIN

International Clinic of Rehabilitation, Truskavets, Ukraine

**Introduction:** Autism spectrum disorders (ASD) although coded in ICD-10 as psychiatric disorders are not singly related to a psychiatry. Often changes of motor development and neurological condition occur that worsen socialization of these patients and their quality of life. Frequently, patients do not communicate with other kids because they cannot fulfil tasks that typically developing peers are able to do.

**Patients and Methods:** In total 189 patients with ASD (F84.0) were examined using Autism Comorbidity Interview, parent's questionnaires, neurological examination, dynamometry,

Box and Blocks test, and the 9-hole peg test. Patients were aged 5 to 14 years (mean age 7.2y).

**Results:** It was found that only 28.9% of children with ASD were without comorbid neurological pathology. In total, 34.8% had uni/bilateral pyramidal tract insufficiency, 21.9% had perinatal lesion of the central nervous system (F82), 9.9% had cerebral palsy (G80), and 9.9% had epilepsy (G40). 25.7% of patients had an increase of muscle tone in distal parts of lower/upper limbs, 18.8% had a decreased range of passive motions in the joints of the lower limbs. Fine hand function was impaired in 45.9% of patients, both manipulative and grasping abilities were worse in comparison to mean norms.

**Conclusion:** Changes in neurological state in patients with ASD are common and there is an acute necessity to identify and code them accordingly. This will benefit complex treatment approaches for those patients based on a multidirectional influence.

### Oral presentation 3

#### Reliability of single-day gait performance measures using inertial sensors in children with cerebral palsy

C GERBER<sup>1,2</sup>, L CARCREFF<sup>2,3,4</sup>, A PARASCHIV-IONESCU<sup>4</sup>, S ARMAND<sup>3</sup>, CJ NEWMAN<sup>2</sup>

<sup>1</sup>CHUV, Lausanne, Switzerland; <sup>2</sup>Paediatric Neurology and Neurorehabilitation Unit, Department of Pediatrics, Lausanne University Hospital, Lausanne, Switzerland; <sup>3</sup>Laboratory of Kinesiology Willy Taillard, Geneva University Hospitals and University of Geneva, Geneva, Switzerland; <sup>4</sup>Laboratory of Movement Analysis and Measurement, Ecole Polytechnique Fédérale de Lausanne, Lausanne, Switzerland

**Introduction:** Long-term measurement with inertial measurement units (IMUs) could be an objective tool to evaluate daily-life gait performance (GP) and physical activity (PA) in children with cerebral palsy (CP). Our aim was to investigate the reliability of such measurement.

**Patients and Methods:** IMUs data was collected during two school-days of the same week and one weekend-day in 15 children with CP and 14 controls. Additionally, 10 children with CP were measured on the same weekday 2–4 weeks apart. Reliability of PA and GP was evaluated using Intraclass Correlation Coefficients (ICC) and Minimal Detectable Change (MDC95).

**Results:** For CP groups, ICCs were high (0.70–0.98) for GP comparisons of two school days. ICCs were lower when comparing two school days of controls and lowest comparing a school day with a weekend day for CP and controls. PA showed ICCs of 0.90–0.91 when measuring the same school day 2–4 weeks apart, but very low ICCs when comparing two school days of the same week or a school day with a weekend day. MDC95 were high for both groups and all comparisons, but comparable with findings of in-lab studies looking at similar parameters.

**Conclusion:** Our IMUs and algorithm setup appears to be a reliable tool to measure daily life GP in children with CP

when repeatedly measured on two school days. PA is also reliably assessed but by measuring the same school day some weeks apart. The high MDC95 values question whether the setup is a responsive outcome measure of intervention.

## Oral presentation 4

### How is daily physical activity associated with gross motor capacity in children with cerebral palsy?

C GERBER<sup>1,2</sup>, L CARCREFF<sup>2,3,4</sup>, A PARASCHIV-IONESCU<sup>4</sup>, S ARMAND<sup>3</sup>, CJ NEWMAN<sup>2</sup>

<sup>1</sup>CHUV, Lausanne, Switzerland; <sup>2</sup>Paediatric Neurology and Neurorehabilitation Unit, Department of Pediatrics, Lausanne University Hospital, Lausanne, Switzerland; <sup>3</sup>Laboratory of Kinesiology Willy Taillard, Geneva University Hospitals and University of Geneva, Geneva, Switzerland; <sup>4</sup>Laboratory of Movement Analysis and Measurement, Ecole Polytechnique Fédérale de Lausanne, Lausanne, Switzerland

**Introduction:** Technological progress allows the use of inertial measurement units (IMUs) to objectively measure children's daily performance. Our aim was to quantify physical activity states (PAS) using IMUs as a measure of performance in children with cerebral palsy (CP), and explore the association with motor capacity.

**Patients and Methods:** 15 children with CP wore IMUs during a school-day. Six PAS were calculated; (1) sitting/lying, (2) standing, (3) active short, (4) active moderate, (5) active long, and (6) active very long duration. Children were divided into achiever and non-achiever of PAS 5 and 6. Participants' capacity was measured with the Gross Motor Function Measure (GMFM-66).

**Results:** PAS 1 correlated negatively, PAS 2, 5, and 6 correlated positively, and PAS 3 and 4 did not correlate with GMFM scores. Children attaining PAS 5 and 6 had higher GMFM scores than non-achievers. Referring cut-off levels (value of best proportion of specificity and sensitivity for group discrimination) were GMFM scores of 73.4 (PAS 5) and 82.6 (PAS 6).

**Conclusion:** Children with lower levels of capacity spent more time sedentary than those with higher levels who spent more time standing and achieved longer durations of active states. The differences in GMFM scores between achiever and non-achiever of PAS 5/6, implies that a minimal level of capacity is needed to achieve high levels of activity. Nevertheless, our results show that one cannot directly infer children's daily performance from capacity, and that not all children fully use their motor capacity in daily life.

## Oral presentation 5

### Quality of motor behaviour in infancy is associated with neurological and cognitive function at school age

YC WU<sup>1</sup>, KR HEINEMAN<sup>1,2</sup>, M HADDERS-ALGRA<sup>1</sup>

<sup>1</sup>Institute of Developmental Neurology, Department of Paediatrics, University Medical Center Groningen, Groningen, the Netherlands; <sup>2</sup>Stichting Epilepsie Instellingen Nederland (SEIN), Zwolle, the Netherlands

**Introduction:** Movement quality and milestones are essential parameters of infant motor development. This study aimed to evaluate associations between the quality of infant motor behaviour, measured with the Infant Motor Profile (IMP), and neurological and cognitive function at school age.

**Patients and Methods:** Participants were 249 children born to sub-fertile couples with or without assisted reproductive technique. Motor behaviour was assessed at 4, 10, and 18 months with the IMP, a video-based assessment with five domains (variation, adaptability, fluency, symmetry, and performance). Neurological optimality score (NOS) and IQ were measured at 9 years with the minor neurological dysfunction assessment and Wechsler Abbreviated Scale of Intelligence respectively. Latent class growth modelling was used to distinguish infant developmental trajectories. Multivariable regression analyses were applied to assess contribution of developmental motor trajectories to 9-year outcomes.

**Results:** Children with a slow developmental trajectory in adaptability ( $n=13$ ) had a 3.5 points lower NOS (95% confidence interval [CI]: -6.3, -0.8), a 11.4 points lower verbal IQ (95% CI: -20.1, -2.7), and a 11.5 points lower performance IQ (95% CI: -20.1, -2.9) than children with typical adaptability development. Children with a slow developmental trajectory in performance (milestones;  $n=60$ ) had a 6.3 points lower performance IQ than children with a typical performance development (95% CI: -10.9, -1.7). The other IMP-domains were not associated with 9-year outcomes.

**Conclusion:** Motor behaviour in infancy, in particular adaptability, was associated with neurological and cognitive outcome at school age.

## Oral presentation 6

### Intra-detrusor injections of botulinum toxin type A in children with spina bifida: a multicenter study

C OLIVARI-PHILIPONNET<sup>1,2</sup>, J HASCOET<sup>3</sup>, B PEYRONNET<sup>3</sup>, V FORIN<sup>4</sup>, M BARON<sup>5</sup>, G CAPON<sup>6</sup>, T PRUDHOMME<sup>7</sup>, G KARSENTY<sup>8</sup>, A MANUNTA<sup>2</sup>, X GAME<sup>7</sup>

<sup>1</sup>Centre de Référence Spina Bifida - Dysraphismes, CHU de Rennes, Rennes, France; <sup>2</sup>Spina Bifida - Dysraphismes Referral Centre, University Hospital of Rennes, Rennes, France; <sup>3</sup>Department of Urology, University Hospital of Rennes, Rennes, France; <sup>4</sup>Department of Pediatric Physical Therapy and Rehabilitation, Trousseau Hospital, Paris, France; <sup>5</sup>Department of Urology, University of Rouen, Rouen, France; <sup>6</sup>Department of Urology, University of Bordeaux, Bordeaux, France; <sup>7</sup>Department of Urology, University of Toulouse, Toulouse, France; <sup>8</sup>Department of Urology, University of Marseille, Marseille, France

**Introduction:** Intradetrusor injections of botulinum toxin type A (IDBTX-A) are the criterion standard in adults for treatment

of neurogenic detrusor overactivity refractory to anticholinergics. Data regarding IDBTX-A in pediatric patients with spinal dysraphism are scarce. The objective was to assess the effectiveness of IDBTX-A in this population.

**Patients and Methods:** All patients under 16 years who underwent IDBTX-A between 2002 and 2016 at six institutions were included in a retrospective study. Our primary endpoint was the injection's success defined as both clinical improvement (no incontinence episodes between intermittent catheterizations [CIC], no urgency, less than 8 CIC per day) and urodynamic improvement (no detrusor overactivity, normal bladder compliance for age) lasting approximately 12 weeks.

**Results:** In total 53 patients (mean age 8.5y) were included. Of these 33 (62.3%) had repeated injections (2–8 injections) resulting in a total number of 141 IBTX-A. The global success rate of the first injection was 30%, significantly better for patients with closed spinal dysraphism than with myelomeningocele ( $p=0.002$ ). Clinical success rate was 66% and was significantly associated with maximum urethral closure pressure (34 vs 54.4cm H<sub>2</sub>O;  $p=0.02$ ). The urodynamic success rate was 34%. Patients with closed spinal dysraphism had higher success rate versus patients with myelomeningocele (48.2% vs 17.4%;  $p=0.02$ ). After a mean follow up of 3.7 years, 23 patients (43.4%) required augmentation cystoplasty.

**Conclusion:** Despite IBTX-A enabled clinical improvement in most patients (66%) urodynamic outcomes were poor resulting in a low global success rate.

## Oral presentation 7

### A simple screening test for elementary visuo-spatial perception deficit

L PISELLA, C VUILLEROT, S GONZALEZ

Lyon Neuroscience Research Center, Bron, France

**Introduction:** Reliability and validity of a screening test for a deficit in elementary visuo-spatial perception (EVSP) are evaluated.

**Patients and Methods:** This prospective study collected norms from 210 typically developing individuals (aged 4–40y) and evaluated the internal consistency of the EVSP screening test. Test–retest reliability was examined on 25 individuals. Validity also involved retrospective clinical data collected from 225 children consulting for suspicion of neurodevelopmental disorder. Since EVSP matures through childhood, we classified the EVSP screening test scores using the norms by age category and performed Pearson correlations with standard clinical tests scores.

**Results:** Test–retest reliability (intraclass correlation coefficient=0.76) and internal consistency (Cronbach's  $\alpha=0.76$ ) were satisfactory. Construct validity included correlation with the subtests of the Wechsler Intelligence Scale for Children, Fourth Edition (WISC-IV) involving visuo-spatial analysis (Matrix Reasoning and Block Design:  $p<0.01$ , Symbol Search and Coding:  $p<0.05$ ) and was reinforced by the expected non-correlation between the Verbal Comprehension Index and EVSP. EVSP correlated with manual dexterity of the Movement Assessment Battery for Children ( $p<0.05$ ) and the

Working Memory Index ( $p<0.05$ ) of the WISC-IV including the subtest Arithmetic ( $p<0.01$ ).

**Conclusion:** This screening test is reliable and valid to evaluate EVSP before more complex cognitive or motor assessment.

## Oral presentation 8

### Dorsal rhizotomy for spastic diplegia using enlarged interlaminar openings and monitoring of ventral and dorsal roots for checking topography and testing excitability. Prospective study in 28 cases

M SINDOU<sup>1</sup>, G GEORGOULIS<sup>2</sup>, A JOUD<sup>3</sup>

<sup>1</sup>University of Lyon, Lyon, France; <sup>2</sup>Medical School, University of Athens, Greece; <sup>3</sup>Neurochirurgie Pédiatrique, CHRU, Nancy, France

**Introduction:** Dorsal rhizotomy, a well-established method for treating spastic diplegia, is still controversial regarding technical modalities. To achieve optimal accuracy for identifying roots and minimal aggressiveness onto spine, a new technique, named 'keyhole inter-laminar dorsal rhizotomy' (KIDr) was developed.

**Patients and Methods:** In total 28 patients underwent the following protocol. First, bilateral intradural access to all L2–S2 ventral (VR) and dorsal roots (DR), at exit to/entry from their dural sheaths, through (usually 3) inter-laminar enlarged openings. Second: intraoperative neuro-monitoring (ION) with EMG-recordings under stimulation of VR (0.2mA/2Hz) to verify myotomal distribution and DR (1mA/50 Hz) to test excitability of metameric circuitry. Third: microsurgical (partial) sectioning of the selected DRs, according to preoperative planning, adjusted after ION.

**Results:** Pluri-level enlarged inter-laminar approaches allowed accurate identification of all roots with their corresponding myotomes and quantification of the degrees of DR excitability. ION led to modify the preoperative planning established by the multidisciplinary team in 90% of the patients. There was no complication, excepted one pseudo-meningocele that resolved spontaneously. Surgery did not generate any secondary spine instability. Postoperative pain was limited in time so that rehabilitation program could start on average as soon as the 10th postoperative day. Objectives of surgery were attained in all but one patient.

**Conclusion:** The study shows KIDr reliability to individually access all lumbo-sacral roots and stimulate separately VR for anatomical mapping and DR for physiological testing, allowing accurate tailored surgery. By respecting the posterior architecture of vertebrae, the postoperative period is short and instability reduced.



## Oral presentation 9

### Reliability and validity of a novel 3D bimanual protocol in children with unilateral palsy

M CACIOPPO<sup>1,2</sup>, F GAILLARD<sup>2,3</sup>, B BOUVIER<sup>3</sup>,  
G BOUZILLE<sup>4,5</sup>, C NEWMAN<sup>6</sup>, T PASQUET<sup>2</sup>,  
A CRETUAL<sup>3</sup>, H RAUSCENT<sup>2</sup>, I BONAN<sup>2</sup>

<sup>1</sup>CHU Rennes, Service Médecine Physique et Réadaptation, Rennes, France;

<sup>2</sup>Department of Physical Medicine and Rehabilitation, Rennes University Hospital, Rennes, France; <sup>3</sup>M2S Laboratory (Mouvement Sport Santé), Rennes 2 University, ENS Rennes, UEB, Campus de Ker Lann, Bruz, France;

<sup>4</sup>CIC Inserm, Centre de Données Cliniques, Rennes University Hospital, Rennes, France; <sup>5</sup>INSERM U199, Rennes, France; <sup>6</sup>Paediatric Neurology and Neurorehabilitation Unit, Lausanne University Hospital, Nestlé Hospital, CHUV, Lausanne, Switzerland

The 'Be an Airplane Pilot' (BE-API) protocol is a novel 3D clinical protocol developed to study the bimanual performance of children during a game. Following the validation performed in typically developing children (TDC), this study aims to assess the reliability and validity of this protocol in children with unilateral cerebral palsy (uCP). The angular waveforms (WAVE), the maximum angles (MAX), and the range of motion (ROM) of the trunk, shoulder, elbow, and wrist joints were collected in 20 children with uCP (mean age 12.0±3.2y) and 20 TDC (mean age 11.9±3.4y) during bimanual tasks exploring specific degrees of freedom (DoF). In children with uCP, the bimanual performance was scored with the Assisting Hand Assessment (AHA) and ABILHAND-Kids, to explore relations between clinical measures and kinematic parameters. A high reliability was found for a large majority of kinematic parameters (WAVE: CMC ≥0.82; MAX & ROM: ICC≥0.85, SEM≤4.7°). Children with uCP had significantly lower elbow extension, forearm supination, wrist adduction, and higher wrist flexion than TDC ( $p<0.02$ ). In children with uCP, correlations were found between MAX & ROM values and clinical assessments (AHA score:  $r=0.48-0.65$ ; ABILHAND-Kids score:  $r=0.48-0.49$ ). The high reliability of the protocol and its ability to highlight differences between children with uCP and TDC, in bimanual situation is very promising. To complete its validation, the between day reliability and sensitivity to change will be assessed before its deployment as a clinical routine.

## Oral presentation 10

### Training to enhance family-centered care: an intervention effectiveness study

L GAFNI LACHTER, A BEN-SASSON, N JOSMAN

University of Haifa, Haifa, Israel

**Introduction:** Family-centered care (FCC) is widely recommended as best practice in pediatric healthcare settings, yet it is often insufficiently implemented. Effective training can minimize the gap between FCC theory and practice. The goal of this study was to measure the effectiveness of an innovative training program to enhance practitioners' skill and confidence in FCC practices.

**Materials and Methods:** 61 healthcare providers participated in a 30-hour training. The training included direct instruction

on best practices together with learning activities to promote application into practice. Training effectiveness was evaluated by pre-post changes in the Measure of Processes of Care, Service Provider form (MPOC-SP) and a confidence questionnaire developed for the study. Qualitative information was derived from participants' reflective assignments and feedback survey.

**Results:** A repeated measures multivariate analysis of variance identified significant changes in pre-post MPOC-SP and confidence scores with a large effect size ( $F[1,7]=13.54$ ,  $p<0.00$ ,  $I^2=0.89$ ), and indicated significant changes in two of the four MPOC-SP factors and on all confidence scales. Changes in FCC application were significantly and positively correlated with confidence scores. Qualitative analysis revealed that experiential learning and reflection were key learning tools for promoting confidence and implementing knowledge and skills. **Conclusion:** Carefully designed evidence-based training programs can advance the skills and confidence needed for translation of FCC theoretical principles into practical application. The findings provide important evidence which informs best practices in professional training for healthcare providers.

## Oral presentation 11

### Multidisciplinary diagnostic settings for children with a neurobiological developmental delay or disorder in Flanders: comparison of governmental regulations

E CLOET<sup>1,2,3</sup>, L DE MEIRLEIR<sup>3</sup>, M LEYS<sup>2</sup>

<sup>1</sup>Vrije Universiteit Brussel, Jette, Belgium; <sup>2</sup>Department of Public Health, Research Group OPIH, Vrije Universiteit Brussel (VUB), Jette, Belgium;

<sup>3</sup>Department of Pediatric Neurology, University Hospital Brussels, Jette, Belgium

**Introduction:** Diagnosis of a neurobiological developmental delay or disorder (NDDD) should be made as early as possible by a specialized multidisciplinary team to improve the child's future social and emotional development, wellbeing, and social participation. However, major organizational and work process differences between diagnostic settings potentially impact the care provided. This research aims to map the regulative frameworks at the federal and community levels for specialized multidisciplinary diagnostic teams for children with suspected NDDD in Flanders, that may impact organization and work processes.

**Patients and Methods:** Document analysis of policy documents and legal frameworks of the centers for ambulatory rehabilitation (CAR), centers for developmental disorders (CDD), student guidance centers (SGC), ambulatory mental health care centers (MHC), and autism reference centers (ARC).

**Results:** For diagnostics at a CAR or MHC, patients have to be referred. The regulations on target group facility for the CAR, ARC, and MHC is pathology-based, regulations on CDD and SGC are more general. In a CAR and MHC diagnostics aim at support and rehabilitation. Diagnostics at SGC are action-oriented and aim at support, referral, and coordination. ARC and CDD make clinical classifying diagnostics, referral, and further coordination. The ARC uses a standardized protocol for diagnostics. The regulations on team

composition (numbers and disciplines) are set for the CDD and MHC, more detailed rules are set for ARC, CAR, and SGC.

*Conclusion:* Federal regulations are more detailed than community regulations. Regulations impact on organization of clinical practice. The type of diagnostics is influenced by the mission of the setting.

## Oral presentation 12

### Children conceived by in vitro fertilization: cognition and behaviour at 9 years

K HEINEMAN<sup>1,2</sup>, D KUIPER<sup>2</sup>, S LA BASTIDE-VAN GEMERT<sup>3</sup>, MJ HEINEMAN<sup>4</sup>, M HADDERS-ALGRA<sup>2</sup>

<sup>1</sup>University of Groningen, University Medical Center Groningen, Groningen, the Netherlands; <sup>2</sup>University of Groningen, University Medical Center Groningen, Department of Paediatrics, Division of Developmental Neurology, Groningen, the Netherlands; <sup>3</sup>University of Groningen, University Medical Center Groningen, Department of Epidemiology, Groningen, the Netherlands; <sup>4</sup>University of Amsterdam, Academic Medical Center, Department of Obstetrics and Gynaecology, Amsterdam, the Netherlands

*Introduction:* Currently, almost three percent of children are born with the help of assisted reproductive technologies (ART) such as in vitro fertilisation (IVF) or intra cytoplasmic sperm injection (ICSI). This raises the important question whether ART influences developmental outcome. The aim of this study was to evaluate cognitive and behavioural outcome at 9 years in children conceived with ART.

*Patients and Methods:* The Groningen ART cohort study has a prospective design. The cohort consists of children born following IVF or ICSI with conventional controlled ovarian hyperstimulation (COH-IVF/ICSI), children born following IVF/ICSI in the modified natural cycle (MNC-IVF/ICSI) and children born after natural conception to subfertile couples (Sub-NC group). At 9 years 57 COH-IVF, 46 MNC-IVF, and 66 Sub-NC singleton children were assessed. Cognition was assessed with the Wechsler Abbreviated Scale of Intelligence (WASI), behaviour was assessed with the Child Behaviour Checklist (CBCL) and Teacher Report Form (TRF). Univariable analyses and multiple linear regression models were used.

*Results:* There was no significant difference in IQ scores between ART groups ( $p=0.746$ ). Multivariable analyses did not show influence of ART group on total, verbal and performance IQ. CBCL and TRF scores did not differ significantly between ART groups ( $p=0.090$  and  $p=0.507$ ). Multivariable analyses did not show influence of ART group on CBCL and TRF total, internalizing and externalizing T-scores.

*Conclusion:* ART did not influence cognitive and behavioural outcome at 9 years. These are reassuring results for both parents and clinicians involved in ART.

## Oral presentation 13

### Development and validation of a risk severity score identifying patients with cerebral palsy at high-risk for developing surgical site infection after spinal surgery

H MATSUMOTO<sup>1,2</sup>, M CAMPBELL<sup>2</sup>, B ROYE<sup>2</sup>, D ROYE<sup>2</sup>, L LENKE<sup>2</sup>, P SPONSELLER<sup>3</sup>, J FLYNN<sup>4</sup>, D SKAGGS<sup>5</sup>, M GLOTZBECKER<sup>6</sup>, M VITALE<sup>2</sup>

<sup>1</sup>APANDID, New York, USA; <sup>2</sup>Columbia University Medical Center, New York, USA; <sup>3</sup>Johns Hopkins Medical Institute, Baltimore, Maryland, USA;

<sup>4</sup>Children's Hospital of Philadelphia, Philadelphia, Pennsylvania, USA;

<sup>5</sup>Children's Hospital of Los Angeles, Los Angeles, California, USA; <sup>6</sup>Boston Children's Hospital, Boston, Massachusetts, USA

*Introduction:* Surgical site infection (SSI) following pediatric spinal instrumentation and fusion (PSIF) occurs with higher incidence in patients with cerebral palsy (CP). The purpose of this study is to develop and validate a risk severity score (RSS) to predict SSI in patients with CP undergoing PSIF.

*Patients and Methods:* Consecutive pediatric patients with CP undergoing PSIF at four academic hospitals between 2006 and 2011 were included in the development phase. In the validation phase, pediatric patients with CP who underwent PSIF between 2008 and 2017 enrolled in a prospective registry were included. Patients' clinical data were collected by reviewing charts. SSIs within 90 days postoperatively were recorded.

*Results:* The risk of SSI was 11% in the original data set. Final prediction model included non-ambulatory status (OR 4.0), diaper dependent (OR 2.5), age <12 years (OR 2.5), major coronal curve magnitude >90 degrees (OR 1.3), behavioral disorder/delay (OR 1.3), and revision surgery (OR 1.3) with a predictive ability of 73.4% indicating good ability to predict SSI. This model was then applied to 390 patients from a large multicenter registry. 8.2% of patient experienced SSI. The model again demonstrated excellent predictive ability (74.3%) in a novel data set. Discrimination was 0.743 and calibration was  $p=0.435$ .

*Conclusion:* This RSS has demonstrated excellent operating characteristics, implying that it will be useful for perioperative decision making. This will allow better informed consent, guide efforts for perioperative optimization, and will be a useful research tool, allowing outcome comparisons among medical centers.

## Oral presentation 14

### 3D printing and assistive devices: from patient to designer

H LE TALLEC DE CERTAINES, W ALLEGRE, E CAOUSSE, AM EVAÏN, V BERNIER FRANCOIS, JP DEPARTE, M CREUSAT, V TSIMBA

Centre de Rééducation et Réadaptation de Kerpape, Ploemeur, France

Kerpape Rehabilitation Center provides care for children with congenital or acquired neurological disorders. Since 2016, a Fab-Lab called 'REHAB-LAB' has been fully integrated in this center. It allows one volunteer patient to become the designer of his/her own assistive device, by using the innovative technology of 3D printing, in collaboration with an

occupational therapist and with the help of a technological facilitator. Case 1: a 16-year-old with a severe Charcot-Marie-Tooth disease, who developed a passion for philately. During a two weeks stay, he designed a clip to let him hold and move stamps alone. This case report is about illustrating the different steps 'from scratch' in the design process. Case 2: a 17-year-old with cerebral palsy, who decided to create an assistive device to clean his glasses alone. This case report is about illustrating how a patient can be involved in the design from an existing wooden prototype. These two case reports, which give patients feedbacks through a testimony, show the benefits of 3D printing in the field of rehabilitation, especially for patient involvement. Global issues behind the REHAB-LAB are: (1) patient involvement leading to a better motivation and appropriation of the assistive device, (2) digital fabrication which change the way to create assistive devices leading to change professional practices, and (3) sharing assistive devices, experiences and organization around the world leading to a community of REHAB-LAB structures.

### Oral presentation 15

#### Reduced plasma brain-derived neurotrophic factor (BDNF) concentration in children with severe cerebral palsy (CP) is related to suboptimal nutrition and low physical activity level

S HANSEN<sup>1,2,3</sup>, J LORENTZEN<sup>1,3</sup>, L PEDERSEN<sup>2</sup>, F HENDRICH<sup>2</sup>, M JOSAL<sup>3</sup>, J PINGEL<sup>1</sup>, JB NIELSEN<sup>1,3</sup>, B KIENS<sup>2</sup>

<sup>1</sup>Department of Neuroscience, Panum Institute, University of Copenhagen, Copenhagen, Denmark; <sup>2</sup>Molecular Physiology Section, Department of Nutrition, Exercise and Sports, Department of Neuroscience, University of Copenhagen, Copenhagen, Denmark; <sup>3</sup>Elsass Institute, Charlottenlund, Denmark

**Introduction:** Brain-derived neurotrophic factor (BDNF) is a mediator of exercise- and nutrition-induced neural plasticity. In children with cerebral palsy (CP), neuromuscular deficits and mobility impairment have a negative impact on the physical activity level and nutritional status, but whether this leads to decreased BDNF concentration is unknown. The aim of the present study was to investigate the plasma BDNF concentration, nutritional status, and physical activity level in children with mild to severe CP.

**Patients and Methods:** Children with mild CP (Gross Motor Function Classification System [GMFCS] level I–II,  $n=31$ , age  $10.6 \pm 0.6$ y), severe CP (GMFCS level IV–V,  $n=14$ , age  $10.9 \pm 1.1$ y), and typically developing (TD) children ( $n=22$ , age  $10.9 \pm 0.6$ y) completed blood sampling, dietary registration, and questionnaires.

**Results:** Children with severe CP had approximately 40% lower plasma BDNF concentration than TD ( $p<0.05$ ). Furthermore, children with severe CP had lower daily physical activity level compared to TD ( $p<0.01$ ) and a daily intake of energy, n-3 fatty acids and dietary fibres which were only approximately 50% of TD ( $p>0.001$ ).

**Conclusion:** Reduced plasma BDNF concentration was observed in children with severe CP. This may be of

significance for optimal neural growth and plasticity. Underlying mechanisms may be low physical activity level and suboptimal intake of energy, n-3 fatty acids, and dietary fibres. Individually-based dietary counselling should be recommended for children with severe CP with focus on n-3 fatty acids supplementation and sufficient intake of energy and dietary fibres.

### Oral presentation 16

#### TranXition: A new rehabilitation paradigm to enhance social participation of youth with disabilities transitioning to adulthood

I CORMIER<sup>1,2</sup>, V COUSINEAU<sup>1,2</sup>, C ROBILLARD<sup>1,2</sup>, G CHABOT<sup>1,2</sup>, S CLOUTIER<sup>1,2</sup>, P HARRISON<sup>1,2</sup>, E SCAZZOSI<sup>1,2</sup>, M BÉTOURNAY<sup>1,2</sup>, G DE ROUSSAN<sup>1,2</sup>, L AUCOIN<sup>2,3</sup>

<sup>1</sup>MAB-Mackay Rehabilitation Center, Montreal, Canada; <sup>2</sup>CIUSSS du Centre-ouest-de-l'île-de-Montréal, Montreal, Canada; <sup>3</sup>CR Constance-Lethbridge, Montreal, Canada

**Introduction:** Transition to adulthood represents a challenge for youth with disabilities and their families, often experienced as 'hanging over a cliff'. The continuum from pediatric to adult services is limited and lacks consideration for community participation. The MAB-Mackay Rehabilitation Centre has developed the TranXition program to address these needs by helping youth maximize their potential through exposure to real life experiences.

**Patients and Methods:** The service delivery approach includes community group-based interventions with youth (15–25y with motor and sensory disabilities) over a period of 8 months, supported by an interdisciplinary team. Activities chosen by and with the youth are means to develop their life skills, including completing a final trip/adventure. The program aims to assess the impact of their interventions using measures such as the Assessment of Life Habits; the Goal Attainment Scaling; the Engagement questionnaire. In addition, the evaluation includes a digital assessment (Photovoice 2.0) to measure the process of change as experienced by the participants.

**Results:** We anticipate that exposure to real life challenges will contribute to the development of self-awareness and self-determination necessary to break isolation and foster community participation. It will thus support the youth's identification of the means to nurture healthy living habits and maintain an overall sense of well-being.

**Conclusion:** The TranXition program contributes to the development of an innovative evidence-based rehabilitation approach inclusive of patient's eXperiences outside of institutional walls. It propels youth's development of autonomy by recognizing their strengths as active participants to society.

## Oral presentation 17

### The effectiveness of Task Oriented Arm Strength Training on body function, arm hand activity, and participation level

E RAMECKERS, R SMEETS, I TELGENKAMP,  
L BRAUERS, M GEIJEN, Y YANSSEN-POTTEN

Adelante Center of Expertise, Valkenburg, the Netherlands

**Introduction:** Muscle weakness is an important limiting factor of upper limb function in children with cerebral palsy (CP). A functional strength training program, called Task Oriented Arm Strength Training in children with CP (TOAST-CP) has been developed, using loaded objects from daily life, to ensure the specificity of the neural adaptation to the trained activities. In contrast, usual care with specific manual skill learning program, without any embedded strength training was performed. The effect of TOAST-CP on strength and the performance of daily activities was compared with the effect of manual skill learning.

**Patients and Methods:** This was a multicentre randomized controlled trial. Fifty children with unilateral CP (11 [3] years), were randomly assigned to TOAST-CP (intervention) ( $n=25$ ) or manual skills training group (controls) ( $n=25$ ). Grip strength (Kg), crate task (Kg), Jebsen Taylor Test for Hand Function Test (JTTHF) (Sec), Assisting Hand Assessment (AHA) (logit), and Goal Attainment Scale (GAS) were measured. Baseline, direct, 3 months, and 6 months follow-up measurements were performed. The treatment period was 16 weeks, 3 times per week, 30 minutes per session. General linear model, repeated measures, and post hoc tests were used.

**Results:** In total 111 goals were practiced in both groups. The TOAST-CP group showed significant improvement on grip, crate task, JTTHF, AHA, and GAS score, and significant interaction effect on all scores except for GAS, because the manual skills group showed equal improvement.

**Conclusion:** With these results it can be concluded that the TOAST-CP approach seems to be effective at all levels of the ICF-CY and should be advised for implementation.

## Oral presentation 18

### Parcellation analysis of language areas of the brain and its clinical association in children with autism spectrum disorder

B KOSHY<sup>1</sup>, R LIVINGSTONE<sup>2</sup>, C DEVARAJAN<sup>1</sup>,  
R BEULAH<sup>1</sup>, A VARGHESE<sup>2</sup>, S MANI<sup>1</sup>

<sup>1</sup>Developmental Paediatrics, Christian Medical College, Vellore, India;

<sup>2</sup>Radiology, Christian Medical College, Vellore, India

**Introduction:** Children with autism spectrum disorder (ASD) are reported to have atypical language brain volume and symmetry patterns. Brain morphometric analysis in children with ASD was evaluated for language area volumes and left-right asymmetry; and compared with clinical information.

**Patients and Methods:** Drug-naïve children with ASD who visited the Developmental Paediatrics Unit, aged 3 to 12 years of age were recruited for the study after obtaining informed consent. The diagnosis was by a multidisciplinary team. All

children underwent assessments and MRI brain scan. Post-processing included cortical reconstruction and volumetric segmentation of unimodal and higher order association areas related to language. Quantitative neuroimaging results for both volumes and left-right asymmetry were compared with both autism severity and ability test scores.

**Results:** Initial analysis has been done on 32 children with ASD. Detailed post-processing analysis of 10 children aged 36 to 99 months has been completed. Autism severity score ranged from 30.5 to 40 on CARS. Unimodal association areas of pars opercularis and planum temporale and higher association area of supramarginal gyrus had left asymmetry; while pars triangularis displayed right asymmetry. The supramarginal gyrus indicated a left asymmetry in males, while it showed right asymmetry in females. Children who had higher autism symptoms had significant lower left frontal opercular volume compared to those with lower autism symptom severity. An updated analysis will be presented during the conference.

**Conclusion:** Asymmetry patterns of language areas of brain in children with ASD and low left frontal opercular volumes in children with higher autism symptomatology indicate anomalous fronto-temporal grey matter development.

## Oral presentation 19

### The relationship between skeletal muscle morphology and gait and function in ambulant children with cerebral palsy

C BLACK<sup>1</sup>, J NOBLE<sup>2</sup>, A MCNEE<sup>3</sup>, N FRY<sup>2</sup>,  
A SHORTLAND<sup>1</sup>

<sup>1</sup>King's College London, London, UK; <sup>2</sup>Guy's & St Thomas' Foundation

Hospital Trust, London, UK; <sup>3</sup>Chelsea and Westminster Hospital, London, UK

**Introduction:** The aims of this project were: (1) to evaluate the relationship between muscle volume (MV) and the product of maximum anatomical cross-sectional area (aCSA) and muscle belly length in children with cerebral palsy (CP), and (2) to assess the relationship between MV and measures of gait and function in this group. We hypothesised that (1) MV could be predicted from the product of aCSA and muscle belly length, and (2) MV would be predictive of a measure of global gait abnormality and of functional walking ability.

**Patients and Methods:** Data from a sample of 18 children with CP (range 7–16y) were analysed. Volumes of the medial and lateral gastrocnemii were calculated from 3D ultrasound 3DUS using a 2D scanner (Aloka SSD1000) and a commercial freehand compacter (Tomtec GmbH). We calculated the product of aCSA and the length of the muscle belly measured from 3DUS. The Gait Profile Score (GPS) was calculated from 3D kinematic data. We assessed participants using the Timed Up and Go and the Functional Mobility Score. The relationships between variables were assessed using linear regression.

**Results:** There was a strong linear relationship between the aCSA-length product and the MV ( $R^2>0.891$ ). MV had weak and insignificant correlations with gait and functional measures.

**Conclusion:** Our results suggest that estimates of MV may be made from the product of aCSA and muscle length (which



could be acquired using 2D ultrasound). Morphological measurements of the gastrocnemii do not predict the gait pattern of children with CP.

## Oral presentation 20

### Raising the bar: sports-focussed gross motor assessments for ambulant children with cerebral palsy

G CLUTTERBUCK<sup>1,2</sup>, M AULD<sup>3</sup>, L JOHNSTON<sup>2</sup>

<sup>1</sup>Charles Sturt University, Port Macquarie, Australia; <sup>2</sup>University of Queensland, Brisbane, Australia; <sup>3</sup>CPL – Choice, Passion, Life, Brisbane, Australia

**Introduction:** Sports-specific gross motor assessment is critical when identifying sporting opportunities for children with disabilities. This study investigated performance and concurrent validity for ambulant children with CP on the mainstream Test of Gross Motor Development (TGMD-2) with cerebral palsy (CP)-specific Gross Motor Function Measure-Challenge (GMFM-Challenge) and field tests of running, jumping, and throwing.

**Patients and Methods:** Sports-specific gross motor assessment is critical when identifying sporting opportunities for children with disabilities. This study investigated performance and concurrent validity for ambulant children with CP on the mainstream Test of Gross Motor Development (TGMD-2) with cerebral palsy (CP)-specific Gross Motor Function Measure-Challenge (GMFM-Challenge) and field tests of running, jumping, and throwing.

**Results:** Children in GMFCS level I demonstrated higher locomotor ( $z=-4.489$  to  $-3.120$ ,  $p<0.001$ ) and TGMD-2 Object Control scores ( $z=2.081$ ,  $p=0.037$ ) compared to GMFCS level II. Children with higher overall motor scores scored higher on individual running (MPST and 10x5mST,  $r(54)=-0.516$  to  $-0.816$ ,  $p<0.001$ ), jumping (Vertical Jump and Broad Jump,  $r(54) 0.499-0.774$ ,  $p<0.001$ ) and throwing (Seated Throw,  $r(54) =0.341-0.500$ ,  $p=0.012$ ,  $p<0.001$ ) tests. Age was associated with performance for children at GMFCS level I but not GMFCS level II.

**Conclusion:** Tests were achievable and appropriately challenging for ambulant children with CP. Scores discriminated between performance and were strongly associated with GMFCS. Concurrent validity was established between the TGMD-2, GMFM-Challenge, and locomotor field tests. The TGMD-2 and GMFM-Challenge effectively assess multiple sports-focussed skills while field tests provide time efficient targeted assessments and estimate global sports skills.

## Oral presentation 21

### Quality of life vs discrimination, autonomy, and inclusion in day centers for adults with cerebral palsy

M CARVALHO<sup>1</sup>, D ALBERGARIA<sup>1</sup>, F LUZ<sup>1</sup>, A LAGES<sup>1</sup>, J ALVARELHÃO<sup>2</sup>

<sup>1</sup>Cerebral Palsy Association of Porto, Porto, Portugal; <sup>2</sup>School of Health Sciences, University of Aveiro, Aveiro, Portugal

**Introduction:** Quality of life (QoL) as an outcome measure is essential in services for adult persons with cerebral palsy (CP). The aim of this study was to investigate the association between QoL measures in adults with CP attending Cerebral Palsy Association of Porto day centers.

**Patients and Methods:** Cross-sectional study including 31 participants (16 proxy, 15 self-report), 58.1% males, mean age 41 years (SD 10y 8mo). Data were obtained on demographic variables, GMFCS, BFMF, and Viking Speech Scale. Participants reported QoL through WHOQOL-BREF, and WHOQOL-DIS (0–100 score).

**Results:** The mean scores for WHOQOL-BREF domains (proxy vs self-report) were: 'physical health', 68.1 (SD=10.1) vs 73.6 (SD=16.4); 'psychological', 60.9 (SD=21.7) vs 66.4 (SD=21.5); 'social relationships', 37.5 (SD=9.4) vs 52.0 (SD=14.7); 'environment', 64.5 (SD=13.0) vs 77.3 (SD=12.4). For WHOQOL-DIS domains the mean scores were (proxy vs self-report): 'discrimination', 34.2 (SD=19.6) vs 69.7 (SD=12.1); 'autonomy', 44.1 (SD=19.1) vs 36.0 (SD=9.8); inclusion, 59.1 (SD=18.9) vs 32.8 (SD=8.7). For self-report respondents WHOQOL-BREF 'physical health' and 'psychological' domains were correlated with both WHOQOL-DIS 'discrimination' and 'autonomy' domains ( $p<0.05$ ). A negative association was found between speech production and 'inclusion' domain ( $p<0.05$ ). No associations were found for proxy respondents.

**Conclusion:** WHOQOL-BREF and WHOQOL-DIS are useful outcome measures for CP services. WHOQOL-DIS includes important dimensions not present in other QoL tools.

## Oral presentation 22

### Participation seven years after severe childhood traumatic brain injury: results of the prospective longitudinal study

M CHEVIGNARD<sup>1,2,3</sup>, H CÂMARA-COSTA<sup>2,4</sup>, L FRANCILLETTE<sup>2</sup>, M OPATOWSKI<sup>5</sup>, H TOURE<sup>3</sup>, D BRUGEL<sup>3</sup>, A LAURENT-VANNIER<sup>3</sup>, P MEYER<sup>6,7</sup>, D DELLATOLAS<sup>4</sup>, L WATIER<sup>5</sup>

<sup>1</sup>Hôpitaux de Saint Maurice, Saint Maurice, France; <sup>2</sup>Sorbonne Université, Laboratoire d'Imagerie Biomédicale, LIB, Paris, France; <sup>3</sup>Rehabilitation Department for Children with Acquired Brain Injury, Groupe de Recherche Clinique Handicap Cognitif et Réadaptation (HanCre), Sorbonne Université, Paris, France; <sup>4</sup>Université Paris-Saclay, Université Paris-SUD, UVSQ, CESP, INSERM, Paris, France; <sup>5</sup>Biostatistics, Biomathematics, Pharmacoepidemiology and Infectious Diseases (B2PHI), INSERM, UVSQ, Institut Pasteur, Université Paris-Saclay, Paris, France; <sup>6</sup>Paediatric Anesthesiology Department, Hôpital Necker Enfants Malades, Paris, France; <sup>7</sup>Faculté de Médecine René Descartes Paris 5, Paris, France

**Introduction:** Participation in home, school, and community activities is considered the ultimate goal of rehabilitation. The

aims of this study were to examine participation 7 years after severe childhood traumatic brain injury (TBI).

**Patients and Methods:** Children (0–15y) consecutively admitted in a single trauma center following severe accidental TBI were included in a prospective longitudinal study (TGE cohort). Among the 65 survivors, 37 participated in the seven-year post-injury follow-up (62% males, mean age 15.4y [SD=4.4; one third had become adults], mean length of coma 6.68d [SD=4.96]). There was no significant difference between participants and non-participants regarding demographics, TBI severity, or intellectual ability measured 2 years' post-injury. A group of 33 individually-matched controls was included. Participation was measured using parent- and self-report forms of the Child and Adolescent Scale of Participation (CASP).

**Results:** Parent/proxy reports indicated significantly lower participation among patients with TBI compared to controls, but the self-reports did not. In the TBI group, parent/proxy-reported participation was variable, with 22% of the TBI group clearly showing greater restrictions than controls. Participation restrictions were significantly associated with injury severity, poor functional outcome one-year post-injury, executive and behavioral difficulties and higher fatigue levels seven years' post-injury, but not with pre-injury nor family factors.

**Conclusion:** Several years after severe childhood TBI, participation appears to depend more on injury-related factors than on environmental factors. In the CASP self-report assessments of participation by children and adolescents, there could be some ambiguity between capacity and performance.

## Oral presentation 23

### Comprehensive assessment of executive functioning following childhood severe traumatic brain injury: validation of the newly developed French FEE battery

M CHEVIGNARD<sup>1,2,3</sup>, L SALAH<sup>3</sup>, E PINEAU-CHARDON<sup>3</sup>, J ROCHE JEANNE<sup>3,4</sup>, C HUON<sup>4</sup>, D LE GALL<sup>3</sup>, M ER-RAFIQI<sup>4</sup>, N FOURNET<sup>5</sup>, JL ROULIN<sup>5</sup>, A ROY<sup>4,6</sup>

<sup>1</sup>Hôpitaux de Saint Maurice, Saint Maurice, France; <sup>2</sup>Sorbonne Université, Laboratoire d'Imagerie Biomédicale, LIB, Paris, France; <sup>3</sup>Rehabilitation Department for Children with Acquired Brain Injury, Groupe de Recherche Clinique Handicap Cognitif et Réadaptation (HanCre), Sorbonne Université, Paris, France; <sup>4</sup>Laboratory of Psychology of Pays de la Loire, Angers, France; <sup>5</sup>Univ. Grenoble Alpes, Univ. Savoie Mont Blanc, CNRS, LPNC, Grenoble, France; <sup>6</sup>Neurofibromatosis Clinic and Learning Disabilities Reference Center, Nantes University Hospital, France

**Introduction:** Executive functions are frequently impaired following childhood traumatic brain injury (TBI), and they are difficult to assess. The aims of this study were to perform a comprehensive assessment of executive functioning following moderate-to-severe childhood TBI, and to study demographic and severity factors influencing outcome, using a newly developed test battery (Childhood Executive Functions - FEE Battery).

**Patients and Methods:** A convenience sample of 43 patients aged 7 to 16 years and 86 matched population norm controls underwent assessment using the FEE battery (12 subtests, designed to assess flexibility, inhibition, working memory, and

planning). The parent- and teacher-ratings of the Behavior Rating Inventory of Executive Function (BRIEF) questionnaire were collected.

**Results:** In the TBI group (65% males; 93% severe TBI; mean age at injury 9.12y [SD=4.1], Glasgow coma scale 5.85 [SD=2.06]; length of coma 6 days [SD=11.21]; time since injury 1.02 [SD=2.67] years), relatively to the control group, performance was significantly impaired in most of the FEE subtests (all time measures and most error measures) and in the BRIEF parent- and in teacher-reports, with moderate to large effect sizes. Univariate correlations in the TBI group did not yield significant correlations between the FEE subtests or the BRIEF questionnaires on one hand, and socio-economic status, TBI severity, or age at injury on the other hand.

**Conclusion:** Executive functioning is severely impaired following severe childhood TBI, and is best assessed using a combination of neuropsychological tests and behavioural ratings.

## Oral presentation 24

### Using kinematic analyses to explore sensorimotor control impairments in children with 22q11.2 Deletion Syndrome

LJB HILL<sup>1</sup>, AC CUNNINGHAM<sup>2</sup>, M MON-WILLIAMS<sup>3</sup>, KJ PEALL<sup>2</sup>, DEJ LINDEN<sup>2</sup>, J HALL<sup>2</sup>, MJ OWEN<sup>2</sup>, M VAN DEN BREE<sup>2</sup>

<sup>1</sup>University of Leeds, Leeds, UK; <sup>2</sup>MRC Centre for Neuropsychiatric Genetics and Genomics, Cardiff University School of Medicine, Cardiff, UK; <sup>3</sup>School of Psychology, University of Leeds, Leeds, UK

**Introduction:** The 22q11.2 deletion is a chromosomal abnormality associated with increased risk of mental disorders, developmental delay and a variety of physical health problems. Recent research also suggests impaired development of coordination skills may also be a feature of 22q11.2 Deletion Syndrome (22q11.2DS). This study aimed to characterize sensorimotor control abilities in children with 22q11.2DS and investigate their relationship with co-occurring IQ impairments and psychopathology.

**Patients and Methods:** 54 children with 22q11.2DS and 24 unaffected sibling controls, comparable in age and sex, underwent kinematic analysis of their hand movements, whilst performing a battery of three visuo-manual coordination tasks that measured their tracking, aiming and steering abilities. Additionally, standardized assessments of full-scale IQ (FSIQ), attention deficit hyperactivity disorder (ADHD), indicative autism spectrum disorder (ASD) and anxiety disorder symptomatology were conducted.

**Results:** Children with 22q11.2DS showed deficits on seven of nine kinematic descriptors of their movement quality across the three coordination tasks, compared to sibling controls. Within 22q11.2DS cases the extent of impairment on only one kinematic descriptor was significantly related to their FSIQ, after correction for multiple testing. Equally, only movement quality whilst visuo-manually tracking was nominally associated with ADHD symptom count.

**Conclusion:** Impairments in sensorimotor control are seen on a range of visuo-manual tasks in children with 22q11.2DS but these impairments appear to be largely unrelated to the

severity of other psychopathological and intellectual impairments commonly found in children with 22q11.2DS. This work strongly suggests neurodevelopmental disorders of movement should be considered

## Oral presentation 25

### Developing an ICF Core Set for adults with cerebral palsy

S NOTEN<sup>1,2</sup>, J BENNER<sup>1,2</sup>, C LIMSAKUL<sup>3</sup>, W VAN DER SLOT<sup>1,2</sup>, H STAM<sup>1</sup>, M SELB<sup>4</sup>, R VAN DEN BERG-EMONS<sup>1</sup>, M ROEBROECK<sup>1,2</sup>

<sup>1</sup>Dept of Rehabilitation Medicine, Erasmus University Medical Center, Rotterdam, the Netherlands; <sup>2</sup>Rijndam Rehabilitation, Rotterdam, the Netherlands; <sup>3</sup>Department of Orthopedic Surgery and Physical Medicine, Prince of Songkla University, Songkhla, Thailand; <sup>4</sup>ICF Research Branch, WHO-FIC Collaborating Centre (at DIMDI) and Swiss Paraplegic Research, Nottwil, Switzerland

**Introduction:** Cerebral palsy (CP) is one of the most common motor developmental disorders in childhood. So far research and care in CP have mainly focused on children, whereas nowadays 75% of persons with CP are adults. With adulthood, new perspectives arise and other health issues become relevant. A universal language to describe their levels of functioning and disability is lacking. Developing an International Classification of Functioning, Disability and Health Core Set (ICF-CS) for this population would provide a firm scientific base to select outcome measures for clinical practice and international research and would complement the recent ICF-CS for children. This study aims to develop an ICF-CS for adults with CP.

**Patients and Methods:** The preparatory phase collects evidence from four different perspectives: a systematic literature review (researcher's perspective), a qualitative study (patients' perspective), an empirical study (clinical setting), and an expert survey (experts' perspective). Collected data will be linked to ICF categories. The final phase includes an international consensus meeting with experts and health professionals to decide which ICF categories will be included in the ICF-CS.

**Results:** We will present in detail the multi-method study design to develop the ICF-CS for adults with CP.

**Conclusion:** Combined study results will establish a common language to improve communication across disciplines, countries, health care systems, and services. The ICF-CS for adults with CP will provide essential categories that can guide research, clinical care, and routine outcome monitoring in this population.

## Oral presentation 26

### Impact of early brain lesions on the retrogeniculate visual pathway in children with cerebral palsy: a diffusion tensor imaging study

R ARANEDA<sup>1</sup>, L DRICOT<sup>1</sup>, R KUPERS<sup>2</sup>, D EBNER-KARESTINOS<sup>1</sup>, G ICKX<sup>1</sup>, SM HATEM<sup>3</sup>, KM FRIEL<sup>4</sup>, AM GORDON<sup>5</sup>, Y BLEYENHEUFT<sup>1</sup>

<sup>1</sup>Institute of Neuroscience, Université catholique de Louvain, Brussels, Belgium; <sup>2</sup>Department of Neuroscience and Pharmacology, Panum Institute, University of Copenhagen, Copenhagen, Denmark; <sup>3</sup>Physical and Rehabilitation Medicine, Brugmann University Hospital, Brussels, Belgium; <sup>4</sup>Burke-Cornell Medical Research Institute, White Plains, New York, USA; <sup>5</sup>Department of Biobehavioral Sciences, Teachers College, Columbia University, New York, USA

**Introduction:** After an early brain lesion, children with unilateral spastic cerebral palsy (USCP) present important changes in gray and white matter affecting, among other, motor and visuospatial functions. The type and side of the lesion may likely have an influence on the integrity of white matter tracts. We aimed to investigate white matter characteristics of the optic radiation (OR) in children with USCP, regarding the type and the side of the lesion. Additionally, we aimed to assess the relationship between possible OR changes and the visuospatial neglect described in this population.

**Patients and Methods:** Using diffusion tensor imaging, we measured the characteristics of the OR in 40 children with USCP. After the OR reconstruction from anatomical landmarks, fractional anisotropy (FA) and the voxel number were used to assess the quality of fibers originating from the lesional and the nonlesional hemisphere. We compared these measures regarding the lesion type and side and we correlated them with a visuospatial assessment.

**Results:** We observed alterations in the OR of children with USCP on the lesional hemisphere compared with the nonlesional hemisphere in the FA and the voxel number. These differences were influenced primarily by the type of lesion and, to a lesser degree, by the side of the lesion. A correlation was also observed between the voxel number and the visuospatial assessment.

**Conclusion:** Our results indicate an important role of the timing of the lesion in the resulting features of these children's OR and probably in the compensation resulting from neuroplastic changes.

## Oral presentation 27

### Pain coping strategies in children with cerebral palsy

E CHALEAT-VALAYER<sup>1</sup>, F ROUMENOFF<sup>1</sup>, R BARD-PONDARRE<sup>1</sup>, A LUCET<sup>2</sup>, JC BERNARD<sup>1</sup>

<sup>1</sup>CMCR des Massues - CRF, Lyon, France; <sup>2</sup>CMPRE de Bois Larris - CRF, Lyon, France

**Introduction:** The types of coping strategies used to deal with chronic pain influence emotional distress, disability, and quality of life. Pain-coping strategies have been extensively studied in 'typically developing' (TD) children, but few studies have explored the experiences of children with physical disabilities.

Children with cerebral palsy (CP) have a high probability of developing chronic pain. The primary aim of this work was to describe coping strategies in children with CP as a function of age, and to compare with TD children.

**Patients and Methods:** Individuals were prospectively recruited from two pediatric rehabilitation centers in France. The PPCI-F (Pediatric Pain and Coping Inventory - French) and SPQ (Structured Pain questionnaire) were completed with each child.

**Results:** 142 children with CP were included (median age: 12.5–19y; 57% males). They generally used fewer coping strategies than TD children (seeks social support: 12.47 vs 12.85,  $p=0.24$ ; cognitive self-instruction: 9.28 vs 10.90,  $p=0.00018$ ; distraction: 4.89 vs 7.00,  $p<0.0001$ ; problem solving: 4.43 vs 5.19,  $p=0.00019$ ). In the CP group, seeking social support decreased with age  $p=0.0022$  and cognitive self-instruction increased  $p<0.0001$  with age. Problem solving and distraction did not change. Coping strategies were influenced by GMFCS level ( $p=0.022$ ) and history of surgery ( $p=0.0019$ ).

**Conclusion:** Children with CP generally use fewer coping strategies than TD children and tend to rely on social support. Use of active strategies increased with age, but later and fewer than in TD children.

## Oral presentation 28

### The best combination of diagnostic tests for cerebral palsy in high risk infants: a case control study

A GUZZETTA<sup>1</sup>, D ROMEO<sup>2</sup>, O CHORNA<sup>3</sup>, C MORGAN<sup>4</sup>, C GALEA<sup>4</sup>, S DEL SECCO<sup>3</sup>, I NOVAK<sup>4</sup>

<sup>1</sup>Stella Maris Scientific Institute, Pisa, Italy; <sup>2</sup>Fondazione Policlinico A. Gemelli, IRCCS, Rome, Italy; <sup>3</sup>Department of Clinical and Experimental Medicine, University of Pisa, Italy; <sup>4</sup>Cerebral Palsy Alliance Research Institute, Brain Mind Research Centre, University of Sydney, Sydney, Australia

**Introduction:** International clinical guidelines recommend the use of neuroimaging, Prechtl's General Movements Assessment (GMA), and Hammersmith Infant Neurological Examination (HINE) to diagnose cerebral palsy (CP) early in infancy. Previous studies provided excellent sensitivity and specificity for the use of each of the tests, but no study has examined the predictive power of the combined use of GMA, neuroimaging, and HINE in the early diagnosis of CP.

**Patients and Methods:** We conducted a retrospective case-control study of 441 high risk infants born between 2003 and 2014, from three hospitals in Italy. Three groups of infants with either a normal outcome, mild disability or CP at two years, were matched for birth year, sex and gestational age. Three-month HINE, Fidgety GMA and available neuroimaging were retrieved from medical records. Logistic regression was conducted with log-likelihood used to determine model fit and Area Under the Curve (AUC) for accuracy.

**Results:** Sensitivity and specificity for detecting CP were respectively, 88% and 62% for 3-month HINE (cut-off score 57), 95% and 97% for absent fidgety GMs and 79% and 99% for neuroimaging. The combined predictive power of all 3

assessments gave sensitivity and specificity values of 97.86% and 99.22% respectively (PPV 98.56% and NPV 98.84%).

**Conclusion:** CP can be detected early in high risk infants when findings from these tests triangulate. Clinical implementation of these tools is likely to reduce the average age when CP is diagnosed, and intervention is started, with great advantage for infants with CP and their families.

## Oral presentation 29

### Validity of semi quantitative scale for brain MRI and visual function in children with periventricular leukomalacia

F TINELLI<sup>1</sup>, S FIORI<sup>1</sup>, G PURPURA<sup>1</sup>, R PASQUARIELLO<sup>1</sup>, A GUZZETTA<sup>1,2</sup>, G CIONI<sup>1,2</sup>

<sup>1</sup>Department of Developmental Neuroscience, Laboratory of Vision, IRCCS Fondazione Stella Maris, Pisa, Italy; <sup>2</sup>Department of Clinical and Experimental Medicine, University of Pisa, Pisa, Italy

**Introduction:** Periventricular leukomalacia (PVL) is the main causes of cerebral palsy (CP) in children born preterm, often associated with impairment of different aspects of visual function. The aim of the current study is to systematically examine the relationship between type and severity of brain lesion on MRI and visual function in a large cohort of children with PVL.

**Patients and Methods:** 94 children with CP due to PVL were recruited at Stella Maris Scientific Institute in Pisa. We included only individuals (70) who had at least one MRI after the age of 3 years and an evaluation of visual function including fixation, following, saccades, nystagmus, acuity, visual field, stereopsis and color perception. Brain lesion location and extent were assessed by using a semi-quantitative MRI-scale for children with CP. We evaluated the correlation between total visual score (TVS) and three global indexes at MRI. After that we compared the extension of the lesions between individuals with impaired visual function and those without impairment in each specific item to understand the role of cortical and subcortical structures on vision.

**Results:** The three global indexes correlated with TVS in a statistical significant way ( $p<0.0001$ ). Visual acuity, visual field, and colour impairment was present in children with more extensive lesion to occipital lobes and thalami while fixation and saccade impairment was linked to internal capsule.

**Conclusion:** Structural MRI has a value for understanding the relationship between brain lesion severity and visual function in children with CP.



## Oral presentation 30

### Update on evidence for interventions to improve participation in physical activities and habitual physical activity level in children with cerebral palsy

S REEDMAN, R BOYD, L SAKZEWSKI

Queensland Cerebral Palsy and Rehabilitation Research Centre, Faculty of Medicine, The University of Queensland, Brisbane, Australia

**Introduction:** Physical training interventions improve activity capacity but do not improve participation in physical activities (PAs) in children with cerebral palsy (CP).

**Patients and Methods:** A published systematic review was updated with evidence from subsequently eligible trials until July 2018. Included studies were controlled/comparison trials including children with CP 5 to 18 years. Qualitative analysis utilized the Downs and Black Scale. Quantitative analyses utilized RevMan 5.3.5. Two raters evaluated intervention components against the Behaviour Change Technique Taxonomy. **Results:** Twelve studies (9 RCTs) of physical training ( $n=7$ ), physical training + personal factor-focused ( $n=1$ ), environment/personal factor-focused ( $n=2$ ), and participation-focused ( $n=2$ ) interventions were included. Methodological quality was poor ( $n=1$ ) moderate ( $n=3$ ), and high ( $n=8$ ). There was a strong effect of environment/participation-focused interventions to increase PA participation goal performance (Canadian Occupational Performance Measure,  $n=2$ , participants=37, MD=4.11, 95% CI: 3.07–5.15,  $p<0.001$ ). There was a weak effect of any intervention to increase moderate-to-vigorous PA (MVPA) ( $n=4$ , participants=165, SMD=0.30, 95% CI: -0.06 to 0.67,  $p=0.11$ ). Subgroup analysis excluding physical training revealed a moderate, significant effect on MVPA ( $n=3$ , participants=83, SMD=0.52, 95% CI: 0.07–0.96,  $p=0.02$ ). Participation-focused interventions demonstrated a wider variety of behaviour-change techniques.

**Conclusion:** Participation-focused interventions improve PA participation and have the potential to improve MVPA in children with CP. Clinicians should incorporate behaviour-changing strategies to improve participation in PAs.

## Oral presentation 31

### Measuring motor fatigability in the upper limb in subjects with neurological disorders: a systematic review

L BRAUERS<sup>1,2</sup>, E RAMECKERS<sup>1,2,3</sup>, D SEVERIJNS<sup>1</sup>, P FEYS<sup>1</sup>, R SMEETS<sup>2</sup>, K KLINGELS<sup>1</sup>

<sup>1</sup>REVAL - Rehabilitation Research Center, Faculty of Rehabilitation Sciences, Hasselt University, Hasselt, Belgium; <sup>2</sup>Department of Rehabilitation Medicine, Research School CAPHRI, Maastricht University, Maastricht, the Netherlands; <sup>3</sup>Center of Expertise, Adelante Rehabilitation Center, Valkenburg, the Netherlands

**Introduction:** Motor fatigability has been suggested to be important for upper limb function in patients with a neurological disorder. However, research on motor fatigability is limited due to the diverse use of definitions, assessment protocols, and outcome measures. This review aims to provide an

overview of the present literature on definitions, assessment protocols, and outcome measures for motor fatigability in neurological patients and to shed light on the known clinimetric properties according to the COSMIN criteria.

**Patients and Methods:** Two databases were consulted for studies published between January 2003 and April 2018.

**Results:** 33 studies were included which described 15 definitions, 41 assessment protocols, and 9 outcome measures on motor fatigability. Protocols were mostly situated on ICF body function level and were most often performed on individuals with multiple sclerosis. On ICF body function level, protocols including maximal, submaximal, isometric, concentric, and eccentric contractions were used with a variable duration between 8.3 seconds and 3 minutes. On ICF activity level, most protocols included wheelchair related tasks.

**Conclusion:** This review proposes a definition of motor fatigability for use in neurological populations. Based on neurophysiological fundamentals, recommendations are made on the protocol and outcome measures of motor fatigability on ICF body function level. On ICF activity level, too little is known to make a sound statement on the use of protocols in neurological populations. Last, clinimetric properties, such as reliability, validity, and responsiveness to change should be investigated for the protocols of motor fatigability per neurological population.

## Oral presentation 32

### The relationship between very early brain microstructure at 32 and 40 weeks postmenstrual age and 12-month motor outcome in very preterm born infants: a diffusion MRI study

J GEORGE<sup>1</sup>, K PANNEK<sup>2</sup>, J FRIPP<sup>2</sup>, M CHATFIELD<sup>1</sup>, R WARE<sup>3</sup>, S ROSE<sup>2</sup>, P COLDITZ<sup>1</sup>, R BOYD<sup>1</sup>

<sup>1</sup>The University of Queensland, Queensland Cerebral Palsy and Rehabilitation Research Centre, Child Health Research Centre, Faculty of Medicine, Brisbane, Australia; <sup>2</sup>Health and Biosecurity, The Australian e-Health Research Centre, CSIRO, Brisbane, Australia; <sup>3</sup>Menzies Health Institute Queensland, Griffith University, Brisbane, Australia

**Introduction:** Brain microstructure using diffusion MRI at 30 to 32 weeks postmenstrual age (Early MRI, PMA) and 40 to 42 weeks PMA (Term MRI) in brain regions known to be associated with motor function was examined, and its relationship with motor outcomes at 12 months corrected age (CA) was evaluated.

**Patients and Methods:** Infants born <31 weeks' gestational age (GA) in this prospective cohort study underwent 3T Early and Term MRI. Regional fractional anisotropy (FA) and mean diffusivity (MD) were calculated in 3 regions of interest (JHU neonate atlas; automatic segmentation): the posterior limb of the internal capsule (PLIC), corpus callosum (CC), and cerebral peduncles. Mixed effects linear regression was conducted for Bayley Scales of Infant and Toddler Development, 3rd Edition and the Alberta Infant Motor Scale (AIMS), acknowledging correlation between siblings, with adjustment for sex, PMA at MRI, age at 12-month assessment ( $p<0.05$ ).

**Results:** Eighty-nine infants (median GA 28+5weeks, 53 males, Early MRI median 32+2weeks PMA), and 91 infants (median

GA 28+2weeks, 56 males, Term MRI median 40+5 weeks PMA) had useable diffusion images and 12-month outcome data. Early MRI FA and MD were not associated with motor outcomes. Term MRI FA in the PLIC and cerebral peduncles were positively associated with both motor outcomes. Term MRI MD in the right cerebral peduncle was negatively associated with the AIMS.

**Conclusion:** Term but not Early MRI microstructure in this very preterm cohort was associated with motor outcomes at 12 months corrected age.

### Oral presentation 33

#### The impact of timing of the brain lesion and corticospinal tract organization on mirror movement characteristics in children with unilateral cerebral palsy

C SIMON-MARTINEZ<sup>1</sup>, L DECREAENE<sup>1</sup>, E VAN HOOF<sup>1</sup>, I ZIELINSKI<sup>2,3,4</sup>, B HOARE<sup>5,6</sup>, B STEENBERGEN<sup>2,3,7,8</sup>, E ORTIBUS<sup>9</sup>, L MAILLEUX<sup>1</sup>, H FEYS<sup>1</sup>, K KLINGELS<sup>1,10</sup>

<sup>1</sup>KU Leuven - University of Leuven, Department of Rehabilitation Sciences, Leuven, Belgium; <sup>2</sup>Behavioural Science Institute, Radboud University Nijmegen, Nijmegen, the Netherlands; <sup>3</sup>Clinic for Pediatric and Adolescent Psychiatry, Psychosomatics, and Psychotherapy, Uniklinik; <sup>4</sup>RWTH Aachen, Germany; <sup>5</sup>Monash University, Department of Paediatrics, Melbourne, Victoria, Australia; <sup>6</sup>La Trobe University, School of Occupational Therapy, Melbourne, Victoria, Australia; <sup>7</sup>School of Psychology, Australian Catholic University, Melbourne, Australia; <sup>8</sup>Centre for Disability and Development Research, Australian Catholic University, Melbourne, Australia; <sup>9</sup>KU Leuven - University of Leuven, Department of Development and Regeneration, Leuven, Belgium; <sup>10</sup>Rehabilitation Research Centre, BIOMED, Hasselt University, Diepenbeek, Belgium

**Introduction:** Mirror movements (MM) in unilateral cerebral palsy (uCP) negatively impact upper limb function, although the underlying mechanisms of MM occurrence are unknown. We investigated the combined impact of type of the brain lesion and the corticospinal tract (CST) organization on MM characteristics in uCP.

**Patients and Methods:** Forty-six children with uCP (mean age 10y 5mo, 18 Manual Ability Classification System [MACS] level I, 16 MACS II, 12 MACS III) performed the Windmill-task to quantitatively evaluate MM, providing MM-strength (mirror activity strength) and MM-coupling (mirror activity similarity). Type of the lesion was classified into periventricular (PV) ( $n=29$ ) and cortico-subcortical lesion ( $n=17$ ). CST-organization was determined using Transcranial Magnetic Stimulation, identifying 16 as contralateral, 15 ipsilateral, and 15 bilateral. Interaction and main effects of lesion type and CST-organization were investigated with a two-way-ANOVA ( $\hat{I}<0.05$ ).

**Results:** The CST-organization was the main factor influencing MM-strength in the paretic ( $p=0.01$ ) and non-paretic hand ( $p=0.03$ ), showing stronger MM in ipsilateral compared to contralateral CST-organization. MM-coupling in the non-paretic hand, when moving the paretic hand, was influenced by the interaction between lesion timing and CST-organization ( $p=0.01$ ), whereby children with PV lesion showed higher coupling if they were ipsilaterally or bilaterally organized.

Neither lesion type nor CST-organization influenced MM-coupling in the paretic hand ( $p>0.05$ ).

**Conclusion:** MM-strength is mainly determined by the CST-organization whilst MM-coupling in the non-paretic hand is influenced by lesion type and CST-organization. Our results suggest distinct mechanisms in each lesion type, contributing to underpinning the underlying mechanisms of MM.

### Oral presentation 34

#### Surface EMG is essential for distinguishing overactive pronator(s) during active supination in children with unilateral spastic cerebral palsy

A SARCHER<sup>1</sup>, S BROCHARD<sup>2</sup>, B PERROUIN-VERBE<sup>1</sup>, M RAISON<sup>3</sup>, G LETELLIER<sup>4</sup>, F LEBOEUF<sup>5</sup>, R GROSS<sup>1</sup>

<sup>1</sup>Motion Analysis Laboratory, Physical Medicine and Rehabilitation, University Hospital of Nantes, Nantes, France; <sup>2</sup>Laboratory of Medical Information Processing (LaTIM), INSERM UMR 111, University Hospital of Brest, Brest, France; <sup>3</sup>Pediatrics, Sainte-Justine University Hospital and Ecole Polytechnique de Montréal, Montréal, Canada; <sup>4</sup>Pediatric Rehabilitation Center ESEAN, Nantes, France; <sup>5</sup>College of Health and Social Care, University of Salford, Salford, UK

**Introduction:** Active elbow supination is frequently limited in children with unilateral spastic cerebral palsy. This limitation can be due to excessive activation of the pronators during active supination, resulting in spastic coactivation. However, it is unclear which (if any) pronator is overactive for each child. The most common treatment for spastic coactivation is injection of neuromuscular blocking agents. As this treatment may also increase paresis, it is essential to identify for each child which pronator presents an excessive activation during active supination.

**Patients and Methods:** Twenty-five children with unilateral spastic cerebral palsy (mean age 10.6y SD 3.0) and 12 typically developing children (mean age 11.0y, SD 3.0) performed active pronation-supination cycles at 0.50Hz. Upper limb kinematics and surface electromyography of the pronator teres and pronator quadratus were measured. Muscle activation of each pronator was defined as 'excessive' or 'typical' using a previously published statistical analysis of the EMG signals.

**Results:** Of the 25 children with unilateral spastic cerebral palsy, 9 had only one overactive pronator (pronator teres  $n=7$  and pronator quadratus  $n=2$ ). Ten children had overactivity of both pronators and 6 had no pronator overactivity. The presence of spastic coactivation was related to the severity of the supination deficit but not to the clinical grading of spasticity.

**Conclusion:** The number of pronator muscle(s) with an excessive activation during active supination varied between children. Using electromyography to identify which pronator is overactive could increase the accuracy of treatment of muscle overactivity.

## Oral presentation 35

### Implementation of a clinical upper limb movement analysis for children with elbow movements' disorders

A SARCHER<sup>1</sup>, R GROSS<sup>1</sup>, B PERROUIN-VERBE<sup>1</sup>, M RAISON<sup>2</sup>, G LETELLIER<sup>3</sup>, S BROCHARD<sup>4</sup>

<sup>1</sup>Motion Analysis Laboratory, Physical Medicine and Rehabilitation, University Hospital of Nantes, Nantes, France; <sup>2</sup>Pediatrics, Sainte-Justine University Hospital and Ecole Polytechnique de Montréal, Montréal, Canada; <sup>3</sup>Pediatric Rehabilitation Center ESEAN, Nantes, France; <sup>4</sup>Laboratory of Medical Information Processing (LaTIM), INSERM UMR 111, University Hospital of Brest, Brest, France

**Introduction:** Gait analysis is a commonly used tool for patients with movement disorders. The association of kinematics and EMG data helps the clinician in the treatment decision and in the follow-up of the patient. Elbow movements can be affected in neurological disorders such as cerebral palsy, stroke, spinal cord injury, etc. The objective is to present an upper limb movement analysis implemented in a clinical context for patients with elbow movements' disorders.

**Patients and Methods:** 37 children with unilateral spastic cerebral palsy (including 2 with dystonia) and 3 children with stroke followed the upper limb movement analysis so far. The reference group is composed of 25 typically developing children. This analysis focuses on detecting abnormal muscle activations during active analytical elbow movements of flexion/extension and pronosupination, performed at different speeds.

**Results:** Inter-session and inter-trial variability of elbow kinematics and EMG signals of shoulder and elbow muscles has been quantified, and a statistical method has been developed to detect differences between EMG signals. The analysis report computes for each child: their active ranges of motion; their compensatory movements; their movement variability; the presence of muscle overactivity, with its relation to the movement speed.

**Conclusion:** This elbow movements' analysis provides relevant information on the active motor function of each patient. In particular, it can help the clinician targeting which (if any) muscle(s) to inject with botulinum toxin A to improve the motor function. A perspective is to evaluate the sensitivity to change of this analysis after a treatment or therapy.

## Oral presentation 36

### Managing to learn bimanual activities as life unfolds in unilateral spastic cerebral palsy: a grounded theory approach

G LIDMAN<sup>1,2</sup>, K HIMMELMANN<sup>1,2</sup>, M PENY-DAHLSTRAND<sup>1,2</sup>

<sup>1</sup>Regional Rehabilitation Centre for Children and Adolescents, Queen Silvia's Children's Hospital, Sahlgrenska University Hospital, University of Gothenburg, Gothenburg, Sweden; <sup>2</sup>Institute of Neuroscience and Physiology at the Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

**Introduction:** Children and adolescents with unilateral spastic cerebral palsy (USCP) often have impaired hand function. This makes it difficult for them to deal with everyday

activities requiring the use of both hands. This study aimed to explore and describe the experiences of children and adolescents with USCP when it comes to learning and dealing with activities requiring the use of both hands.

**Patients and Methods:** Ten children and adolescents (10–18y) with USCP took part in semi-structured interviews. Grounded Theory was used for qualitative analysis.

**Results:** The learning of bimanual activities was described as a process taking place in interaction with the dynamics of everyday situations and with life as it unfolds. The study identified five categories, with thirteen subcategories describing the participants' approach to learning. The importance of these categories varied depending on degree of disability, age and the general setting. This was summarized in a multi-dimensional theory.

**Conclusion:** The in-depth perspective used means that the findings and the theory are based on the participants' subjective experiences. The findings described yielded a theoretical understanding of factors that could exert a positive or negative effect on a successful learning of bimanual activities.

## Oral presentation 37

### Co-construction of child personas in the development of a digital communication support system for increased participation in pediatric habilitation

B TELEMANN<sup>1</sup>, C CARLSSON<sup>1</sup>, P SVEDBERG<sup>1</sup>, E VINBLAD<sup>2</sup>, I LARSSON<sup>1</sup>, J NYGREN<sup>1</sup>

<sup>1</sup>School of Health and Welfare, Halmstad University, Halmstad, Sweden;

<sup>2</sup>The Child and Youth Rehabilitation Centre, Region Skåne, Sweden

**Introduction:** Digital communication support systems have great potential to facilitate the provision of child-centered care where children and young people are allowed and enabled to participate in planning and decision-making in their own habilitation. The aim of this study was to co-construct child personas together with children and young adults from pediatric habilitation for the design of a digital communication support system.

**Patients and Methods:** The child, parent and practitioner perspectives on goals, needs, and behaviours in relation to participation in pediatric habilitation were characterized based on interviews with 20 children (6–17y) and 8 young people (18–30y) with intellectual disabilities, physical disabilities, or autism spectrum disorders, 17 parents (aged 31–62y) and 10 practitioners. Data were interpreted and explained together with children from the interviews ( $n=14$ ) in two explorative design workshops and a validation workshop.

**Results:** We present findings and insights on how to co-construct child personas in the context of pediatric habilitation. The work resulted in three personas with different priorities that model the behaviors, attitudes, and goals of three user archetypes tailored for developing digital communication support systems in this particular use context.

**Conclusion:** By applying our progressive steps of data collection and analysis, we arrive at authentic child-personas that are now used to design and develop a digital communication support system for the particular goals, needs and behaviors of children in pediatric habilitation.

## Oral presentation 38

### Development of a porcine model of cerebral palsy: first step before a study on the efficacy of a stereotactic stem cell therapy

E MAZERAND<sup>1,2</sup>, C GALLET<sup>1,2</sup>, L LE FOURNIER<sup>1,2</sup>,  
M DINOMAI<sup>3</sup>, C MONTERO-MENEI<sup>4</sup>, P MENEI<sup>1,2</sup>

<sup>1</sup>CHU Angers, Angers, France; <sup>2</sup>Neurosurgery Department, Angers University Hospital, Angers, France; <sup>3</sup>Rehabilitation Department, Angers University Hospital, Angers, France; <sup>4</sup>CRCINA-INSEERM UMR1232 Angers University Hospital, Angers, France

**Introduction:** Cerebral palsy is the main cause of motor impairment in children, with no curative treatment available. Before assessing the efficacy of a stem cell therapy, we first wanted to develop an animal model of cerebral palsy. Porcine model was chosen because of the anatomic similarities between human and porcine brains.

**Patients and Methods:** An injection of endothelin-1 was performed under stereotactic conditions in the periventricular white matter of ten 15-days-old piglets. An MRI was performed before, just after, 4 weeks, and 16 weeks after the injection. The clinical evolution was recorded and an histologic analysis was performed after their euthanasia.

**Results:** Fifty percent of injected piglets died immediately after the injection, highlighting the well-known frailty of piglets and the anaesthetic complexity of this model. The surviving piglets did not have any persistent neurological deficit. In all animals, an immediate postoperative MRI showed a well-located lesion in the periventricular white matter. In the surviving animals, brain lesions tended to be less visible on further T2 weighted MRI scans. Histologic data (hematoxylin eosin safran staining) showed small porencephalic cavities surrounded by a glial reaction. Complementary analysis with lugol staining (assessing demyelination), and further MRI are under process and scheduled.

**Conclusion:** The model of cerebral palsy developed is complex due to its frailty. Until now, only neonatal brain lesion models without survival study are available. Our study is the first, to our knowledge, to develop a cerebral palsy model associated to a survival study, with a view to develop repairment strategies.

## Oral presentation 39

### The management of sleep problems in children with neurodisabilities: what does existing research tell us, and what should be the next steps for research?

B BERESFORD<sup>1</sup>, A PARKER<sup>1</sup>, A SCANTLEBURY<sup>2</sup>,  
C FAIRHURST<sup>1</sup>, C HEWITT<sup>1</sup>, C MCDAID<sup>1</sup>

<sup>1</sup>University of York, York, UK; <sup>2</sup>Newcastle University, Newcastle, UK

**Introduction:** Sleep problems are more prevalent and tend to be more entrenched among children with neurodisabilities compared to typically developing children. Considering the impact sleep problems have on children's and parents' outcomes, practitioners need access to a synthesis of existing evidence to inform clinical decision-making.

**Patients and Methods:** A systematic review and meta-analyses of RCTs of pharmacological interventions, and a 'sister' a systematic review of evaluations of non-pharmacological interventions. For both, reviews only concerned the management of non-respiratory sleep disturbance. Sixteen databases, grey literature, and reference lists of included papers were searched up to February 2017. Data were extracted and quality assessed by two researchers.

**Results:** Over 70 child and parent outcomes were measured across all studies reviewed. Thirteen RCTs of pharmacological interventions (all melatonin) were included. All except one were at high or unclear risk of bias. Whilst there was evidence of benefit and safety of melatonin compared with placebo, the extent of this benefit is unclear. Twenty-six studies of non-pharmacological interventions were included, all were at high or unclear risk of bias. Most were parent-directed psychoeducational interventions. None had been subject to more than one evaluation. Clinical heterogeneity and poor study quality meant it was not possible to draw definitive conclusions on intervention effectiveness.

**Conclusion:** Work to establish a core outcomes dataset for sleep management interventions is required and must incorporate identification of what are meaningful changes in outcomes from children's and parents' perspectives. High quality evaluations of pharmacological and non-pharmacological interventions are needed.

## Oral presentation 40

### Corticospinal connectivity patterns and motor outcome in infants with early brain injury

J KOWALSKI<sup>1</sup>, S NEMANICH<sup>1</sup>, T NAWSHIN<sup>1</sup>,  
E SUTTER<sup>1</sup>, M CHEN<sup>2</sup>, C PEYTON<sup>3</sup>, E ZORN<sup>4</sup>, R RAO<sup>4</sup>,  
M GEORGIEFF<sup>4</sup>, B GILICK<sup>1</sup>

<sup>1</sup>Department of Rehabilitation Medicine, University of Minnesota, Minneapolis, MN, USA; <sup>2</sup>Department of Psychiatry, University of Minnesota, Minneapolis, MN, USA; <sup>3</sup>Department of Physical Therapy and Human Movement Sciences, Northwestern University, Chicago, IL, USA; <sup>4</sup>Department of Pediatrics, University of Minnesota, Minneapolis, MN, USA

**Introduction:** Perinatal stroke often leads to cerebral palsy (CP) and atypical development of the corticospinal tracts (CST). Assessment of CST development via transcranial magnetic



stimulation (TMS) may provide information enabling earlier diagnosis of CP, promoting earlier intervention and improved functional outcomes. Here we established the feasibility and safety of TMS to characterize CST development in infants with perinatal stroke.

**Patients and Methods:** Participants: seven infants with unilateral or asymmetric bilateral perinatal stroke. Motor outcomes were assessed with the General Movement Assessment (GMA) and Bayley Scales of Infant and Toddler Development-III (BSID-III). TMS was applied to each motor cortex and motor evoked potentials (MEPs) were measured from bilateral wrist flexors. Connectivity patterns (contralateral, bilateral, ipsilateral, or absent) were analyzed based on presence/absence of MEPs from each hemisphere.

**Results:** Participants' mean corrected age was 8.68 months, range 3 to 14 months. Five of seven infants demonstrated atypical motor development with GMA and BSID-III. To date, three of the five infants with atypical motor development received a CP diagnosis; the GMA demonstrated 100% accuracy in predicting infants at risk of CP. TMS revealed primarily absent CST circuitry patterns from the more affected hemisphere (five absent, two contralateral) and heterogeneous CST patterns of the less affected hemisphere (two absent, three contralateral, one ipsilateral, one bilateral).

**Conclusion:** TMS assessment of CST organization patterns is safe and feasible in infants as young as 3 months of age. Additional data collection could inform whether a relationship exists between CST organization pattern, motor outcome, and diagnosis of CP.

## Oral presentation 41

### A new concept in the treatment of neuro muscular scoliosis: the progressive correction by a minimally invasive fusionless technique using a self-expanding device

L MILADI, N KHOURI, V TOPOUCHIAN, C GLORION

Necker Hospital, Paris, France

**Introduction:** Conventional treatment of spinal deformities involves bracing, followed by spinal instrumented fusion. Growing rod techniques are more frequently used but have a high rate of complications. We report the results of a minimally invasive fusionless technique using a new self-growing rod allowing a spontaneous progressive correction of spinal deformities.

**Materials and Methods:** Included were 18 cases of neuromuscular scoliosis, from various etiologies with an operating age of 11 years and a minimum follow-up of 2 years. All patients were non-ambulatory and operated with a bilateral fusionless construct from T1 to the pelvis, using self-expanding rods, by a minimally invasive approach. No additional postoperative maneuvers were applied. Spinal segments length as well as the amount of rod elongation was analyzed, in addition to the clinical and radiographic data.

**Results:** The rods expanded spontaneously in 16 cases from 18. Mean Cobb angle improved from 78° preoperatively to 30° after index surgery then to 26° at last follow-up. The pelvic obliquity went from 31° preoperatively to 12° postoperatively

then to 3° at last follow-up. There were three complications in two patients (11%): two infections, one bulkiness of a crosslink.

**Conclusion:** The preliminary results of the self-growing rod are promising in neuromuscular scoliosis, thanks to its spontaneous expansion and a low rate of complications. In contrast with other types of growing rods, our device can be left permanently which makes us hope to avoid final arthrodesis. More follow-up is needed.

## Oral presentation 42

### A wearable pediatric exoskeleton for progressive reduction of crouch gait in individuals with cerebral palsy

D DAMIANO, T BULEA

National Institutes of Health, Bethesda, USA

**Introduction:** Crouch gait in CP is energetically costly and associated with pain, joint degeneration, and ambulatory decline. Current treatments temporarily alleviate crouch but successful long-term solutions remain elusive. We aimed to conduct the first clinical study of our pediatric wearable rehabilitation exoskeleton for progressive crouch reduction using a novel control strategy. Most gait-assist devices utilize impedance control which constrains motion. Ours tracks leg motion and provides short bursts of knee extension motor assistance during mid-stance and/or late swing.

**Patients and Methods:** Seven patients with CP (5–19y, GMFCS levels I–II) and crouch gait were given a custom exoskeleton, with assistance levels optimized to maximize knee extension without compromising stability. Each performed five practice sessions walking with the exoskeleton. Electromyography (EMG) of the vastus lateralis and semitendinosus and kinematic analyses of overground walking without and with the exoskeleton were performed. Primary outcome was maximum knee extension during stance. Paired *t*-tests used to compare conditions.

**Results:** Mean stance knee extension increased in the exoskeleton by 13.5° ( $p=0.020$ ) in more and 6° ( $p=0.047$ ) in less affected limbs, with stance + swing assist most effective. EMG in all showed increased or maintained vasti activity with device with some showing increased hamstring activity during swing.

**Conclusion:** This first reported wearable pediatric exoskeleton for gait rehabilitation reduced crouch magnitude similar to surgical outcomes. Refinement of control strategies underway to reduce hamstrings co-activity. The ultimate goal is to provide home-based intensive task specific practice to strengthen and train patients to walk more upright even without the device.

## Oral presentation 43

### Level of disability and participation and the readiness of transition to adulthood for youth with cerebral palsy

Z ROŽKALNE<sup>1,2</sup>, A VĀTRA<sup>2</sup>, M MUKĀNS<sup>1</sup>

<sup>1</sup>Rīga Stradins University, Riga, Latvia; <sup>2</sup>Rīga Stradins University, Children's Clinical University Hospital, Riga, Latvia

**Introduction:** Participation is considered a fundamental goal of rehabilitation and plays a significant role in the readiness of transition to adulthood. For transition aged youth with cerebral palsy, it is crucial to identify the level of disability in participation and the impacting factors.

**Patients and Methods:** Participants were searched through the Children's Clinical University Hospital database. Assessments were made using the Rotterdam Transition Profile (RTP) and WHO Disability Assessment Schedule (WHODAS). Mental state was tested with Mini-Mental State Examination (MMSE) and the physical functioning with Gross Motor Function Classification System (GMFCS).

**Results:** Eighty-one individuals aged 16 to 21 years (40 males, 41 females; mean 18y, IQR=17–20) participated. Levels of GMFCS: level I 44.4%, level II 29.6%, level III 16.1%, level IV 9.9%. Most significant correlations were found between: WHODAS area Mobility and RTP areas of Transportation:  $rs=-0.64$  and Intimate Relationships:  $rs=-0.34$  ( $p<0.01$ ); WHODAS area Self-care and RTP areas of Sexuality:  $rs=-0.46$  and Intimate Relationship:  $rs=-0.44$  ( $p<0.01$ ) and WHODAS area Participation and RTP areas of Transportation:  $rs=-0.51$  and Leisure:  $rs=-0.39$  ( $p<0.01$ ). Higher score of MMSE (29–30) compared to lower (24–28) showed higher score in the RTP section Participation: mean 10.0 (IQR=7.3–16.0) vs mean 8.0 (IQR=5.5–9.5),  $p<0.001$ .

**Conclusion:** Preparation for adulthood and improving participation for youth with cerebral palsy should address fields of transportation, self-care, leisure, intimate relationships, and sexuality. Mental state should also be taken into account.

## Oral presentation 44

### Cognitive-motor dependencies in the development of developmental coordination disorder

P WILSON<sup>1</sup>, S RUDDOCK<sup>2</sup>, J PIEK<sup>3</sup>, D SUGDEN<sup>4</sup>, B STEENBERGEN<sup>5</sup>

<sup>1</sup>Australian Catholic University, Melbourne, Australia; <sup>2</sup>La Trobe University, Melbourne, Australia; <sup>3</sup>Curtin University, Perth, Australia; <sup>4</sup>University of Leeds, Leeds, UK; <sup>5</sup>Radboud University Nijmegen, Nijmegen, the Netherlands

**Introduction:** Children with developmental coordination disorder (DCD) also commonly show deficits in executive function (EF). An important empirical and clinical question is how strongly EF deficits predict DCD over childhood, and vice versa. Here we traced the codevelopment of EF and motor skill in a large cohort. We predicted, first, that DCD expressed in early childhood would predict later EF issues and, second, that young children below the threshold for

DCD but with EF deficits, would show a heightened risk of DCD in later childhood.

**Patients and Methods:** 200 children (aged 6–12y) were tested every 6 months over a 2-year period; 40 children were diagnosed with DCD at time zero. EFs were assessed using the Groton Maze Learning Task (GMLT), 1-back memory, and anti-reach task. Growth trajectories were analysed.

**Results:** EF deficits were a risk factor in the later development of DCD, both for those who met diagnosis of DCD at time zero and for those above threshold. Intriguingly, there was a sub-group of children with very poor EF (but not DCD) who showed little change in both domains over time.

**Conclusion:** We conclude that EF deficits are a risk factor for the development of DCD. However, there is a sub-group that presents with cognitive issues but who go on to develop age-appropriate motor skills. These data support the view that EF should be a compulsory part of the assessment suite for DCD. Results are discussed in terms of a hybrid-ecological model of DCD, together with clinical implications.

## Oral presentation 45

### The relationship with pain and sleep problems among children with cerebral palsy

P KARLSSON, I HONAN, C GALEA, E WRIGHT, N BADAWI

Cerebral Palsy Alliance, Discipline of Child and Adolescent Health, The University of Sydney, Sydney, Australia

**Introduction:** Three in four children with cerebral palsy (CP) experience pain and one in five has a sleep difficulty. These significantly impact on the individual's daily functioning as well as that of their family. This study aims to increase our understanding of the relationship between pain and sleep in children with CP.

**Patients and Methods:** Children aged 3 to 17 years with complete classifications, pain, and sleep data were included in this prospective cohort study. Caregiver proxy was used to report child pain. Sleep was assessed using the Sleep Disturbance Scale for Children. Logistic and multiple logistic regression was used to examine the relationships between pain and sleep using odds ratios, and to investigate associated impairments: child age, GMFCS E&R, vision and epilepsy.

**Results:** Mean age 5.5 years (3.2 SD); GMFCS E&R levels I to III=85%; IV to V=15%; 36% had a vision impairment; 19% epilepsy; 44% of children experienced pain. When adjusting for age, children with pain were 4.0 times (95% CI 1.9–8.6; AUC 69%) more likely to have sleep difficulties; and a 13% decrease in risk of sleep difficulties as age increased by each year. When adjusting for age, children with sleep difficulties were 4.0 times (CI 1.9–8.4; AUC 67%) more likely to have pain; and a 16% increase in risk of pain as age increased each year.

**Conclusion:** To better support children with CP, understanding the relationship between pain and sleep and providing screening and interventions are imperative.

## Oral presentation 46

### A comprehensive investigation of major congenital anomalies in children with pre/perinatally acquired cerebral palsy: an international data linkage study

S GOLDSMITH<sup>1</sup>, S MCINTYRE<sup>1</sup>, LG ANDERSEN<sup>2</sup>, K HIMMELMANN<sup>3</sup>, C GIBSON<sup>4</sup>, N BADAWI<sup>1</sup>, G GARCIA JALON<sup>5</sup>, E BLAIR<sup>6</sup>, M HANSEN<sup>6</sup>, E GARNE<sup>7</sup>

<sup>1</sup>Cerebral Palsy Alliance Research Institute, University of Sydney, Sydney, Australia; <sup>2</sup>The Cerebral Palsy Register of Norway, Vestfold Hospital Trust, Tønsberg, Norway; <sup>3</sup>University of Gothenburg, Queen Silvia Children's Hospital, Gothenburg, Sweden; <sup>4</sup>Women's and Children's Health Network, Adelaide, Australia; <sup>5</sup>Queen's University Belfast, Belfast, UK; <sup>6</sup>Telethon Kids Institute, Perth, Australia; <sup>7</sup>Hospital Lillebaelt Kolding, Kolding, Denmark

**Introduction:** Congenital anomalies occur in 3% to 6% of the general population. Previous investigations of anomalies in children with cerebral palsy (CP) have been hampered by sample size, methodological variation, and the heterogeneity of CP and anomalies. This study will determine what proportion of children with CP have major congenital anomalies, and compare their function to children with CP without anomalies.

**Patients and Methods:** Data on children with CP, born 1991 to 2009, registered with population-based CP registers of Europe (6) and Australia (3) were linked with congenital anomaly registers. Data were pooled, EUROCAT definitions of congenital anomalies applied, and descriptive analyses conducted of children with and without anomalies.

**Results:** Of 8226 children with pre/perinatally acquired CP, 1879 had a congenital anomaly (22.8%, 95% CI 22.0–23.8). While children with CP and anomalies had similar proportions of males to those without anomalies, they had greater proportions of singletons, term births, and spastic bilateral motor types. Children with anomalies had greater impairment on all measures: GMFCS levels IV/V (40 vs 25%), moderate-profound intellectual impairment (48 vs 25%), severe vision impairment (13 vs 6%), severe hearing impairment (5 vs 2%), severe speech impairment (40 vs 22%), epilepsy (47 vs 30%), and death (8 vs 4%).

**Conclusion:** One in four children with CP in this large, international linkage study had major congenital anomalies. These children have more severe functional outcomes than their peers with CP. Future research will investigate pathways to CP via specific anomalies, with a view to identifying opportunities for primary prevention.

## Oral presentation 47

### People with cerebral palsy and their family's opinion regarding genomics research and international data sharing

Y WILSON<sup>1</sup>, S MARMONT<sup>2</sup>, M THORNTON<sup>2</sup>, S VAN OTTERLOO<sup>2</sup>, S MCINTYRE<sup>1</sup>

<sup>1</sup>Cerebral Palsy Alliance Research Institute, University of Sydney, Sydney, Australia; <sup>2</sup>CP Quest, Australia

**Introduction:** Genomic research in cerebral palsy (CP) will rely upon large-scale international enrollment and data sharing.

To understand how people with CP and their families view these studies we conducted an online survey.

**Patients and Methods:** Participants were recruited via the NSW/ACT CP Register, Reaching for the Stars, Cerebral Palsy Alliance, CP Research Network, and CP Now Foundation/CP Daily Living. Survey responses included yes/no and multiple choices. Chi-squared tests were used to compare groups and explore associations.

**Results:** 166 individuals participated with a mean age of 42 years (SD, 10y 4mo). 16% were individuals with CP, 87% were females, 65% were Australian residents, and 72% had completed tertiary education. Overall, 66% of respondents were willing to participate in a genomics study. Education ( $\chi^2=4.679$ ,  $p=0.031$ ,  $\phi=0.181$ ), previous genetic testing ( $\chi^2=4.801$ ,  $p=0.028$ ,  $\phi=0.197$ ), awareness of genomics ( $\chi^2=4.275$ ,  $p=0.039$ ,  $\phi=0.186$ ), and trust in the international research community ( $\chi^2=12.847$ ,  $p=0.002$ ,  $\phi=0.406$ ) were associated with a willingness to participate. Trust was also associated with willingness to biobanking ( $\chi^2=12.972$ ,  $p=0.002$ ,  $\phi=0.410$ ), and willingness to share deidentified data ( $\chi^2=19.639$ ,  $p=0.002$ ,  $\phi=0.508$ ).

**Conclusion:** People with CP and their families are willing to participate in genomics studies; however, these data demonstrate the importance of facilitating trust between the research community and participants.

## Oral presentation 48

### 'Mum, for the first time, I feel like I belong somewhere': strength-based computer coding groups for adolescents with autism

M JONES<sup>1</sup>, M FALKMER<sup>1</sup>, B MILBOURN<sup>1</sup>, T TAN<sup>2</sup>, S BOLTE<sup>3</sup>, S GIRDLER<sup>1</sup>

<sup>1</sup>School of Occupational Therapy, Social Work and Speech Pathology - Curtin University, Perth, Australia; <sup>2</sup>Department of Mechanical Engineering, Curtin University, Perth, Australia; <sup>3</sup>Division of Neuropsychiatry - Karolinska Institutet, Stockholm, Sweden

**Introduction:** Many individuals with autism spectrum disorder (ASD) demonstrate strengths and abilities that are well suited to the Information and Communication Technology (ICT) sector. Despite this, the employment rate for individuals with ASD remain low internationally. It has been proposed that a strength-based approach could be used to prepare adolescents with ASD for employment. Computer-coding clubs have been proposed as one way of developing pathways to future employment for adolescents with ASD. This study aimed to define the essential components of a strength-based computer coding program for adolescents with ASD.

**Patients and Methods:** A realist evaluation approach triangulated ethnographic data collected methods including participant observations, focus groups, and interviews. Observations were undertaken during eight sessions of computer coding groups for 17 adolescents with ASD and five program facilitators. Focus groups and interviews were conducted with 67 participants, consisting of 23 adolescents, 20 facilitators, and 24 parents. Interviews and focus group discussions were transcribed verbatim and coded to determine the essential components.

**Results:** Strength-based coding clubs for adolescents with ASD had three main components: facilitators, activities, and environment. Facilitator factors related to the techniques employed by the facilitators, including applying an individual approach. Activity factors related to the design of the activities, and included the special interests of adolescents. Environment factors relate to both sensory preferences and creating a safe environment.

**Conclusion:** This study highlights the essential components of strength-based computer coding clubs for adolescents with ASD. These findings can inform a framework for the design and evaluation of future strength-based programs.

## Oral presentation 49

### Fascicular motor neurotomy associated to single event multilevel surgery in cerebral palsy: a long-term review with gait analysis

B ZAGORDA<sup>1</sup>, E HADDAD<sup>2</sup>, B BAYLE<sup>1</sup>, V GAUTHERON<sup>1</sup>, B DOHIN<sup>2</sup>

<sup>1</sup>Physical Medicine and Rehabilitation, Saint-Etienne hospital, Saint-Etienne, France; <sup>2</sup>Pediatric Surgery, Saint-Etienne hospital, Saint-Etienne, France

**Introduction:** Gait disorders in cerebral palsy benefit from single event multilevel surgery (SEMLS) but recurrence may occur related to remaining spasticity. The aim of this study was to assess SEMLS associated with selective partial proximal neurotomies (SN).

**Patients and Methods:** We collected in patients who had both SEMLS and SN between 2009 and 2016. Indication for SN was dynamic spasticity on RF and MH. Clinical data: range of motion, Modified Ashworth Scale (MAS), and Gross Motor Function Measure (GMFM). Gait analysis kinetic and kinematic data were collected. Gait deviation index (GDI) and Gait profile score (GPS) were calculated.

**Results:** 34 patients were included. The average time assessment after surgery was 33.35 months. GDI and GPS were improved, (respectively 74.2 to 79.7 [ $p=0.010$ ] and 11.54 to 9.5 [ $p=0.005$ ]). Knee flexion decreased at body weight acceptance phase: 30.8° to 24.7° ( $p=0.006$ ). Maximum joint moments were closer toward normality: knee: 55% of gait cycle ( $p=0.003$ ), hip: 10% of gait cycle ( $p=0.004$ ) and for knee flexion at 95% of gait cycle ( $p=0.005$ ). GMFM (E item) increased from 75.39% to 78.84% ( $p=0.009$ ). Spasticity (MAS) decrease: RF 1.3 to 0.33, MH 1.95 to 0.05.

**Conclusion:** Surgical procedure demonstrated clinical and functional benefits. GDI and GPS were improved. Moreover, kinematics is improved particularly at the beginning of gait cycle. Authors advocate association of SEMLS and SN.

## Oral presentation 50

### Bimanual intensive training with or without a lower extremity component: are the changes in upper extremities affected?

G SAUSSEZ<sup>1</sup>, M BRANDÃO<sup>2</sup>, A GORDON<sup>3</sup>, Y BLEYENHEUFT<sup>1</sup>

<sup>1</sup>Institute of Neurosciences, Université catholique de Louvain, Brussels, Belgium; <sup>2</sup>Federal University of Minas Gerais, Belo Horizonte, Brazil;

<sup>3</sup>Teachers College, Columbia University, New York, NY, USA

**Introduction:** Hand-arm bimanual intensive therapy (HABIT) promotes hand function using intensive practice of bimanual functional tasks. This intervention has shown to be efficacious to improve upper extremity (UE) function in children with unilateral spastic cerebral palsy (USCP). Recently, a new intervention has been introduced in which the lower extremity (LE) is simultaneously engaged during HABIT (Hand-arm bimanual intensive therapy including lower extremities; HABIT-ILE). It is unknown whether the addition of a LE component attenuates UE improvements. This study aims to compare UE improvements in HABIT versus HABIT-ILE.

**Patients and Methods:** This study consisted of retrospective analysis of 86 children with USCP who received 90 hours of HABIT ( $n=42$ ) or HABIT-ILE ( $n=44$ ) as participants in previous studies. Primary outcomes were ABILHAND-Kids and the Assisting Hand Assessment. Secondary measures included the Jebsen-Taylor Test of Hand Function, Pediatric Evaluation of Disability Inventory (PEDI), and Canadian Occupational Performance Measure (COPM).

**Results:** Both groups showed similar significant improvements for all tests except the PEDI and COPM. Larger improvements on these tests were found for the HABIT-ILE group. These larger improvements may be explained as a consequence of the constant simultaneous UE-LE stimulation during HABIT-ILE intervention. LE and, more specifically, UE-LE coordination are often used during daily living activities included in the PEDI and potentially in the COPM.

**Conclusion:** UE improvements in children with USCP are not attenuated by a LE component. In addition, systematic LE stimulation during bimanual intensive intervention (HABIT-ILE) leads to larger functional improvements in activities of daily living involving the LE.

## Oral presentation 51

### Reliability and validity of functional bimanual and unimanual strength in children with unilateral cerebral palsy

M GEIJEN<sup>1</sup>, R SMEETS<sup>1</sup>, C BASTIAENEN<sup>2</sup>, A GORDON<sup>3</sup>, L SPETH<sup>4</sup>, E RAMECKERS<sup>5</sup>

<sup>1</sup>Maastricht University, Research School CAPHRI, Department of Rehabilitation Medicine, Maastricht, the Netherlands; <sup>2</sup>Maastricht University, Research School CAPHRI, Department of Epidemiology, Maastricht, the Netherlands; <sup>3</sup>Department of Biobehavioral Sciences, Teachers College, Columbia University, New York, USA; <sup>4</sup>Adelante, Centre of Expertise in Rehabilitation and Audiology, Hoensbroek, the Netherlands; <sup>5</sup>Pediatric Rehabilitation and Physiotherapy, Hasselt University, Hasselt, Belgium



**Introduction:** Clinical relevant information about the use of strength and strength measurement during daily activities in children with unilateral cerebral palsy (CP) is lacking. Therefore, an instrument to measure task-oriented arm-hand strength for cross-sectional and evaluation purposes (TAAC) was developed. Both newly developed functional bimanual (lifting a crate) and unimanual tasks (lifting a pitcher) can be measured with the affected hand (AH) and non-affected hand (NAH). This study focuses on some clinimetric properties of the TAAC.

**Patients and Methods:** In 105 children with unilateral CP (6–18y) test-retest reliability of the TAAC was investigated. For construct-validity, TAAC outcomes were compared to grip and pinch strength and Jebsen-Taylor Hand Function Test (JTHFT).

**Results:** Good test-retest reliability was shown for the crate task (ICC=0.888) and pitcher task NAH (ICC=0.893), and moderate reliability for the pitcher task AH (ICC=0.670). Crate task showed moderate correlation with grip strength AH ( $r=0.493$ ) and NAH ( $r=0.528$ ). The pitcher task AH showed moderate correlation with pinch strength AH ( $r=0.441$ ), and JTHFT AH ( $r=0.387$ ). A low correlation was shown for the pitcher task NAH with JTHFT NAH ( $r=0.271$ ), and a moderate correlation with pinch strength NAH ( $r=0.479$ ).

**Conclusion:** The results suggest that the test-retest reliability for both task are moderate to good. The construct validity has moderate correlations, indicating that the TAAC measures related but also different constructs. Therefore, the TAAC is a good addition to the existing methods.

**Results:** Children with CP had significantly smaller peak-passive and functional ROM compared to TD children ( $p<0.001$ ). Children with CP used more of their passive wrist extension ROM to complete functional tasks ( $86\pm48\%$ , TD:  $51\pm9\%$ ). Typically developing children completed the tasks wholly in extension, using  $-10\pm7\%$  of their passive flexion ROM (CP:  $30\pm25\%$ ). There was no correlation between passive and functional wrist ROM in either group ( $r=-0.535$  to  $0.367$ ;  $p>0.05$ ).

**Conclusion:** Findings raise the question of the suitability of passive ROM measurement as a clinical indicator of upper limb function. In addition to measuring peak-passive ROM, clinicians should consider the amount of functional ROM needed to complete specific tasks, and aim to incorporate goal-oriented

## Oral presentation 52

### Passive range of motion - is it useful?

#### Understanding the relationship between passive and functional range of motion at the wrist in children with cerebral palsy

E FERNANDO<sup>1</sup>, C WALMSLEY<sup>1</sup>, C WILD<sup>1</sup>,  
T GRISBROOK<sup>1</sup>, S WILLIAMS<sup>1,2</sup>

<sup>1</sup>Curtin University, Perth, Australia; <sup>2</sup>University of Auckland, Auckland, New Zealand

**Introduction:** While measurement of passive wrist range of motion (ROM) using a goniometer is used to evaluate the effectiveness of interventions in children with cerebral palsy (CP), it may not reflect the ROM used during functional tasks. This study aimed to (1) describe the relationship between functional and peak-passive wrist ROM, and (2) compare functional and passive wrist ROM of children with CP to typically developing (TD) peers.

**Patients and Methods:** Thirteen children with CP (Manual Ability Classifications System levels I–IV; 8y 4mo±2y 4mo) and 14 TD children (9y 9mo±2y 11mo) had measurements of passive wrist ROM (goniometry), and functional wrist ROM (three-dimensional motion analysis) during upper limb tasks taken. Peak-passive ROM was compared to functional ROM (paired *t*-tests), and values between groups were cross-compared (independent *t*-tests).

### Oral presentation 53

#### Assessment of a tele-diagnosis experimentation of autism spectrum disorders

C DOYEN<sup>1</sup>, E DESAILLY<sup>2</sup>, V GOUPIL<sup>2</sup>, K KAYE<sup>1</sup>

<sup>1</sup>Centre Hospitalier Sainte Anne, Paris, France; <sup>2</sup>Fondation Ellen Poidatz, Saint Fargeau-Ponthierry, France

**Introduction:** Diagnosis of autism spectrum disorders (ASD) is often incomplete while it is known as a key factor to success of the care process. Because of the unequal access to specialized care and of the potential bias introduced by the effect of the children going to the Diagnosis Center, telemedicine for ASD is hypothesized as relevant to improve diagnosis and medical care.

**Patients and Methods:** Clinical and functional evaluations were conducted in 16 children aged 12±4 years. The remote evaluation is a 4-step teleconsultations process led by the psychiatrist: first, medical history and observation; second, ADI-R interview with parents; third, Childhood Autism Rating Scale and the Vineland Adaptive Behavior Scales assisted by a psychologist; fourth, feedback to parents about the results of the observations of the team. Feasibility and parents, children and professional satisfactions are assessed. Completeness of the former medical follow-up is measured.

**Results:** The program is well-accepted and the use of validated instruments for diagnosis or functional evaluation has been feasible in 94% of the children. Former medical data were incomplete for 56% of cases. Complementary genetic or medical investigations were prescribed for 50% of cases. Medical advice about psychotropic or vitaminic medication was given for 31% of cases. Mean duration of the evaluation was 11±9 weeks.

**Conclusion:** This experimentation empirically validates the concept of remote evaluation for children and adolescents with ASD. The need to extend the use of telemedicine to tele-expertise for medicine monitoring or behavioral disorder management has been noted.

### Oral presentation 54

#### Nutritional status of children with cerebral palsy in remote Sumba Island of Indonesia

I JAHAN<sup>1,2</sup>, T KARIM<sup>1,2,3</sup>, M MUHIT<sup>1,2</sup>, D HARDIANTO<sup>4</sup>, M HASSAN AL IMAM<sup>1,2</sup>, M CHANDRA DAS<sup>1,2</sup>, H SMITHERS-SHEEDY<sup>3,5</sup>, N BADAWI<sup>3,5</sup>, G KHANDAKER<sup>1,2,3,6</sup>

<sup>1</sup>CSF Global, Dhaka, Bangladesh; <sup>2</sup>Asian Institute of Disability and Development (AIDD), University of South Asia, Dhaka, Bangladesh;

<sup>3</sup>Discipline of Child and Adolescent Health, Sydney Medical School, The University of Sydney, Sydney, Australia; <sup>4</sup>CSF Indonesia, Waikabubak, Indonesia; <sup>5</sup>Cerebral Palsy Alliance Research Institute, The University of Sydney, Sydney, Australia; <sup>6</sup>Central Queensland Public Health Unit, Central Queensland Hospital and Health Service, Rockhampton, Queensland, Australia

**Introduction:** A gap in evidence regarding childhood malnutrition among children with cerebral palsy (CP) specially from low and middle-income countries (LMICs) makes it difficult to design and implement cost effective nutrition interventions. We aimed to assess the burden and underlying factors of malnutrition among children with CP in a remote island in Indonesia.

**Patients and Methods:** We conducted a community-based key informant method survey of children with CP in the southwest regency of Sumba Island, Indonesia. Children with suspected CP were identified by trained key informants and were assessed by a multidisciplinary medical assessment team. Anthropometric measurements (e.g. weight, height) were taken, z scores were calculated, and nutritional status was determined for each of the children with CP following WHO guidelines. WHO Anthro and WHO AnthroPlus softwares were used to calculate the z scores.

**Results:** 130 children with CP were included in the study. The majority of them were severely underweight (78.8%) and severely stunted (85.9%). Children <5 years, in Gross Motor Function Classification System (GMFCS) levels III to V, tri/quadruplegia, at least one associated impairment, intellectual impairment, speech impairment, and swallowing difficulties had more a severe form of malnutrition. GMFCS level was significantly associated with height-for-age z score when adjusted for covariates (e.g. epilepsy, intellectual impairment).

**Conclusion:** Malnutrition among children with CP is substantially high in remote parts of Indonesia (i.e. Southwest Sumba). There is an urgent need for nutrition rehabilitation services to avert poor health related outcomes among children with CP in LMICs like Indonesia.

### Oral presentation 55

#### Parental burnout among parents with child with chronic condition

S PERIER, S CALLAHAN, N SÉJOURNÉ

Université Toulouse II – Jean Jaures, Toulouse, France

**Introduction:** Parents of children with disabilities or disease are likely to face daily difficulties. The parental ideal refers to many goals identified by the parents, which causes stress and exhaustion.

**Patients and Methods:** In this study, 125 parents (mean age=36.24y; SD=7.44) of children with a chronic disability or disease (e.g. learning difficulties, genetic disease, asthma) filled in sociodemographic information about themselves and their child. Questions about mental load, parental burnout, and self-compassion were also answered.

**Results:** Significant correlations are negative between the parental burnout and all dimensions of self-compassion ( $p<0.001$ ). Also, there were significant positive correlations between parental burnout and six out of seven items of mental load ( $p<0.05$ ). Three regression analyses were used to produce the final model which explains 40.7% of the variance in the Parental Burnout score ( $F[5.119]=18.04$ ;  $p<0.00$ ). The variables that belong to the model were the presence of health and/or psychological problems ( $t=3.80$ ;  $p<0.001$ ), the self-kindness ( $t=-4.31$ ;  $p<0.001$ ), the organizational fatigue at the end of the week ( $t=2.92$ ;  $p<0.05$ ), and the ability to execute all planned tasks ( $t=-3.17$ ;  $p<0.05$ ).

**Conclusion:** Further to previous studies about parental burnout, other factors explain this phenomenon in this study. In parenthood, burnout is recently developed and would deserve to be incorporated in devices of parental support.

## Oral presentation 56

### Gait parameters of the independent walking onset of children with unilateral cerebral palsy

A GRIGORIU<sup>1</sup>, M LEMPEREUR<sup>2</sup>, S BOUVIER<sup>3</sup>,  
L PADURE<sup>1</sup>, S BROCHARD<sup>2</sup>

<sup>1</sup>National Center of Rehabilitation for children "Dr. N. Robanescu", Bucharest, Romania; <sup>2</sup>CHRU, Service de Medecine Physique et Readaptation, Université de Bretagne Occidentale, Brest, France; <sup>3</sup>Lab. de Traitement de l'Information Médicale, (INSERM UMR 111), Brest, France

**Introduction:** Knowledge on the development of the independent gait development for infants with cerebral palsy is limited. This study aimed to compare the gait biomechanical parameters (spatiotemporal and kinematics) during the first six months of independent walking of toddlers with unilateral cerebral palsy (UCP) with those of typically developing (TD) infants matched for walking experience.

**Patients and Methods:** Fifteen TD toddlers and twelve UCP children, with a maximum walking experience of six months, were recorded using a 3D optoelectronic system. The groups were matched from larger groups regarding the averages of walking experience and 'velocity divided by the leg length'. Data on spatiotemporal parameters and kinematics were collected. Statistical parameter mapping was used for kinematic comparison.

**Results:** Significant between group differences were observed for the single support phase (shorter on the affected side of UCP children). At the group level, the unique significant kinematic difference seen in UCP infants compared to TD children was the external rotation of the pelvis on the hemiplegic side (13,25 degrees). There were no other differences at the hip/knee/ankle level.

**Conclusion:** The dominant biomechanical modification in infants with UCP during the first six months of independent walking is proximal. At this age, the excessive pelvic retraction

of the affected side is likely to be due to abnormal initial motor control disorders more than compensatory mechanisms. These findings provide evidence for early motor interventions focusing on the proximal level in order to optimize gait development at the earliest stages of children with UCP.

## Oral presentation 57

### Improving epilepsy control among children with cerebral palsy in rural Bangladesh

T KARIM<sup>1,2,3</sup>, MC DAS<sup>1,2</sup>, M MUHIT<sup>1,2</sup>, N BADAWI<sup>3,4</sup>,  
G KHANDAKER<sup>1,2,3,5</sup>, SS MOHAMMAD<sup>3</sup>

<sup>1</sup>CSF Global, Dhaka, Bangladesh; <sup>2</sup>Asian Institute of Disability and Development (AIDD), University of South Asia, Dhaka, Bangladesh;

<sup>3</sup>Discipline of Child and Adolescent Health, Sydney Medical School, The University of Sydney, Sydney, Australia; <sup>4</sup>Cerebral Palsy Alliance Research Institute, University of Sydney, Sydney, Australia; <sup>5</sup>Central Queensland Public Health Unit, Central Queensland Hospital and Health Service, Rockhampton, Queensland, Australia

**Introduction:** Poorly controlled epilepsy is a risk factor for increased morbidity among children with cerebral palsy (CP). We aimed to define the prevalence, clinical phenotypes, and barriers to optimum epilepsy control among children with CP.

**Patients and Methods:** We used the Bangladesh CP Register (BCPR), an ongoing population-based surveillance to identify children with CP and epilepsy. Specialist assessments were conducted led by a paediatric neurologist with intervening follow-ups. Details of seizure/event type, frequency, and medication compliance were collected. Antiepileptic drugs (AED) were prescribed based on seizure type, family income, comorbidity, and availability.

**Results:** 23.4% (171/726) of the BCPR cohort had a clinical diagnosis of epilepsy. Of which 166 were assessed between December 2016 and January 2018. Of these, 110 had seizures (64/110 generalized tonic clonic seizures and 28/110 focal seizures) including 28.2% (31/110) with seizures >30 minutes and a robust emergency seizure management plan was unavailable. 18.1% (30/166) had non-epileptic events. AED changes consisted of dose alteration ( $n=34$ ), medication change ( $n=11$ ), and treatment initiation ( $n=42$ ). On follow-up, 69.2% (54/78) were taking prescribed medications. 75.9% (41/54) showed improvement and 14 were seizure free. Inconsistent medication due to affordability was the main reason for poor seizure control.

**Conclusion:** Epilepsy is prevalent and poorly managed among children with CP in rural Bangladesh. Epilepsy management can be improved with regular follow-up, education on common seizure types and mimics, use of commonly available affordable AED, and guidelines for prolonged seizure management.

## Oral presentation 58

### Three-dimensional upper limb movement characteristics in children with brachial plexus birth palsy

C PONS<sup>1</sup>, M LEMPEREUR<sup>2</sup>, K ALTER<sup>3</sup>, M THEPAUT<sup>4</sup>, D DAMIANO<sup>3</sup>, S BROCHARD<sup>5</sup>

<sup>1</sup>Pediatric rehabilitation department, Fondation ILDYS, Brest, France; <sup>2</sup>LaTIM, INSERM U 111, Brest, France; <sup>3</sup>Functional and Applied Biomechanics Section, Rehabilitation Medicine Department, National Institutes of Health, Bethesda, USA; <sup>4</sup>Pediatric surgery department, CHRU de Brest, Hopital Morvan, Brest, France; <sup>5</sup>PMR department, CHRU de Brest, Hopital Morvan, Brest, France

**Introduction:** Obstetrical brachial plexus birth palsy (OBPP) is an upper limb paresis secondary to brachial plexus injury during birth delivery. We aimed to investigate which kinematic and spatiotemporal parameters differentiate upper-limbs movements in children with OBPP from age-matched typically developing children (TDC).

**Patients and Methods:** 12 children with unilateral OBPP (mean age=11.7y [SD 4.2]) and 11 TDC (10.9y [SD 2.5]) participated. 3D motion of both upper limbs of children with OBPP and of the non-dominant limb of TDC were collected during 5 shoulder amplitude tasks and 3 functional tasks. Spatio-temporal parameters, 3D upper-limb joint kinematics, and Arm Profile Score (APS) were calculated and compared between upper-limb groups.

**Results:** Spatio-temporal parameters did not differ between groups for most of the tasks. Statistically significant changes were found during all the tasks at the gleno-humeral joint, especially in the rotation plane, but also on all the other joints (trunk, scapulo-thoracic, elbow, wrist). For all tasks, children with OBPP had significantly higher APSs compared to TDC. In the unimpaired side of children with OBPP, significant kinematic differences compared to TDC were found, especially in the shoulder rotation plane.

**Conclusion:** Effective movements with good motor control but with atypical patterns of movements were highlighted on the impaired upper limb of children with OBPP. The major involvement of the gleno-humeral joint was confirmed, large compensatory movements were found on the other joints. Differences were also found on the unimpaired limb, in favor of a bimanual evaluation of children with OBPP.

## Oral presentation 59

### Fatigue and quality of life seven years after severe childhood traumatic brain injury: results of the TGE prospective longitudinal study

H CÂMARA-COSTA<sup>1</sup>, L FRANCILLETTE<sup>2</sup>, M OPATOWSKI<sup>3</sup>, H TOURE<sup>4</sup>, D BRUGEL<sup>4</sup>, A LAURENT-VANNIER<sup>4</sup>, P MEYER<sup>5</sup>, G DELLATOLAS<sup>1</sup>, L WATIER<sup>3</sup>, M CHEVIGNARD<sup>6</sup>

<sup>1</sup>Centre de recherche en Épidémiologie et Santé des Populations Université Paris-Saclay, Université Paris-SUD, UVSQ, CESP, INSERM, Paris, France; <sup>2</sup>Sorbonne Université, Paris, France; <sup>3</sup>Biostatistics, Biomathematics, Pharmacoepidemiology and Infectious Diseases (B2PHI), INSERM, UVSQ, Institut Pasteur, Université Paris-Saclay, Paris, France; <sup>4</sup>Rehabilitation Department for Children with Acquired Brain Injury, Hôpitaux de Saint Maurice, Saint Maurice, France; <sup>5</sup>Paediatric Anesthesiology Department, Hôpital Necker Enfants Malades, Paris, France; <sup>6</sup>Sorbonne Université, Laboratoire d'Imagerie Biomédicale (LIB), Rehabilitation Department for Children with Acquired Brain Injury, Hôpitaux de Saint Maurice, Saint Maurice, France

**Introduction:** To investigate fatigue and health-related quality-of-life (HRQoL) seven years following severe childhood traumatic brain injury (TBI).

**Patients and Methods:** Self- ( $n=34$ ) and/or parent/proxy ( $n=25$ ) reports on the Multidimensional Fatigue Scale and the Pediatric Quality-of-Life Inventory were collected 7 years after severe childhood TBI (ages 7–22y). The data collected included socio-demographic characteristics, injury severity, overall disability (Glasgow Outcome Scale, GOS Peds), and functional outcome (Pediatric Injury Functional Outcome Scale) 1-year post-injury, and clinical assessments of disability (GOS Extended Peds), motor impairment and intellectual ability 7-years post-injury. A control group ( $n=33$ ) had data on fatigue, HRQoL, and intellectual ability.

**Results:** Participants with severe childhood TBI and parents/proxies reported higher levels of fatigue ( $d=0.95$  and  $1.2$ ) and poorer HRQoL ( $d=0.80$  and  $0.63$ ) than controls. Fatigue was significantly associated with HRQoL in self- ( $r=0.75$ ) and parent/proxy-reports ( $r=0.80$ ). Correlations between self- and parent/proxy-reported fatigue were significant ( $r=0.72$ ), as were associations between self- and parent/proxy-reports of HRQoL ( $r=0.56$ ). Female sex was associated with poorer self-reported fatigue and HRQoL. Older age at injury and longer coma duration were linked to poorer self-reported fatigue. Functional outcome 1-year post-injury was associated with self-reported fatigue and HRQoL, and 1-year post-injury overall disability was related to self-reported HRQoL. Overall disability 7-years post-injury was associated with self- and parent-proxy reports of fatigue.

**Conclusion:** Subjective fatigue is related to injury severity and functional outcome 7-years post-severe TBI and has a strong impact on reported HRQoL.



## Oral presentation 60

### A quantification of the visuoperceptual profile of children with cerebral visual impairment (CVI) based on the Flemish CVI questionnaire

N BEN ITZHAK<sup>1</sup>, K VANCLEEF<sup>2</sup>, J WAGEMANS<sup>3</sup>, I FRANKI<sup>1</sup>, E ORTIBUS<sup>1,4</sup>

<sup>1</sup>Department of Development and Regeneration, University of Leuven, Leuven, Belgium; <sup>2</sup>Department of Experimental Psychology, University of Oxford, Oxford, UK; <sup>3</sup>Department of Brain & Cognition, University of Leuven (KU Leuven), Leuven, Belgium; <sup>4</sup>Centre for Developmental Disabilities, Leuven, Belgium

**Introduction:** Cerebral visual impairment (CVI) is a deficit in visual information processing without ocular disease and is a most prominent cause of severe childhood visual impairment. The heterogeneous deficits seen in CVI are reflected in the responses on the Flemish CVI questionnaire. However, it is unclear which deficits correlate or group together, therefore, the questionnaire's underlying factor structure was investigated.

**Patients and Methods:** Caretakers of 419 (258 males) children (178 with a CVI diagnosis, 224 without CVI diagnosis, 17 without definitive diagnosis; mean age 6.1y) completed a total of 485 questionnaires at several time points between 2008 and 2018. An exploratory factor analysis (EFA) was conducted to determine the underlying questionnaire structure followed by a Mann-Whitney *U* (MWU) test to compare the factor results between CVI and no CVI.

**Results:** The EFA resulted in a 5-factor (Object and face perception, Visual interest, Clutter and distance viewing, Moving in space, and Anxiety-related behaviours) biologically and clinically plausible model, retaining 35 items (56.13% variance). MWU tests indicated that all factor scores were significantly higher in CVI compared to no CVI (*p*-values ranged from 0.000 to 0.001; *r* values ranged from 0.17 to 0.40). Object and face perception showed the largest difference between CVI and no CVI.

**Conclusion:** The Flemish CVI questionnaire has five underlying factors on which more deficits were reported in CVI compared to no CVI. Profiling via this factor structure can help identify CVI and allow for individualized and adaptive therapy.

## Oral presentation 61

### Effectiveness of a novel task-specific approach for attaining two-wheel bicycle related goals: a randomised controlled trial

R TOOVEY<sup>1</sup>, AR HARVEY<sup>1</sup>, JL MCGINLEY<sup>2</sup>, KJ LEE<sup>1</sup>, STF SHIH<sup>3</sup>, AJ SPITTLE<sup>1</sup>

<sup>1</sup>Murdoch Children's Research Institute, Royal Children's Hospital, The University of Melbourne, Melbourne, Australia; <sup>2</sup>The University of Melbourne, Melbourne, Australia; <sup>3</sup>Deakin University, Melbourne, Australia

**Introduction:** Innovative ways of engaging children with cerebral palsy (CP) in meaningful physical activities are required. This study aimed to determine if a novel task-specific training approach is more effective than a parent-led home programme for attaining individualised two-wheel bicycle related goals in

children with CP (Gross Motor Function Classification System [GMFCS] levels I and II) aged 6 to 15 years.

**Patients and Methods:** An assessor-blinded trial was conducted across two paediatric rehabilitation centres. Children were randomised to a task-specific centre-based group programme (intervention) or parent-led home programme (comparison). Goal attainment, defined as attainment of a goal to an expected or greater level on the Goal Attainment Scale, was assessed one week (T1, primary) and three months (T2) following the intervention period. Complete case analysis was conducted using logistic regression, adjusted for site.

**Results:** Sixty-two children; 33 males (54%), mean age 9y 6mo (SD 2y 6mo), GMFCS levels I *n*=35 (56%) and II *n*=27 (44%) were allocated to the intervention (*n*=31) or comparison (*n*=31). Children in the intervention group were more likely to achieve goal attainment at both T1 (odds ratio [OR]=17.8, 95% confidence interval [CI] 4.2–75.1, *p*<0.0001) and T2 (OR=4.2, 95% CI=1.1–15.6, *p*=0.03) than those allocated to the comparison.

**Conclusion:** The task-specific group programme was more effective for goal attainment compared to the parent-led home programme in the short to medium term. Longer-term follow-up would provide further support for this intervention in children with CP.

## Oral presentation 62

### Social and cognitive sequelae of Sturge-Weber Syndrome

J SLONEEM<sup>1</sup>, J MOSS<sup>2</sup>, H RICHARDSON<sup>1</sup>, C HAWKINS<sup>1</sup>, T FOSI<sup>1,3</sup>, S POWELL<sup>1</sup>, S AYLETT<sup>1,3</sup>

<sup>1</sup>Great Ormond Street Hospital, London, UK; <sup>2</sup>Cerebral Centre, University of Birmingham, Birmingham, UK; <sup>3</sup>Developmental Neurosciences, University College London, Institute of Child Health, London, UK

**Introduction:** Sturge-Weber syndrome (SWS) is a rare neurocutaneous condition caused by a mutation in the *GNAQ* gene giving rise to anomalies affecting the skin, eye, and brain. Those diagnosed commonly have a facial port-wine stain and suffer from varied degrees of epilepsy, hemiplegia, and/or glaucoma. A high prevalence of social and cognitive difficulties has also been documented which significantly impacts on the lives of those affected, however, research has yet to be conducted to delineate the phenomenology of these in detail.

**Patients and Methods:** A clinical case note review has been undertaken for the largest known cohort of children and young people (0–18y) with SWS (*N*>140). Results from standardised cognitive assessments (e.g. Bayley scales and Wechsler Scales of Intelligence) and standardised measures of social communication are described alongside medical characteristics and risk markers known to predict varied social and cognitive outcomes. Statistical analysis allows comparison of children with SWS to other groups to determine how typical their presentation is.

**Results:** Data analysis is ongoing. Preliminary analysis suggests that those with SWS show atypical social communication profiles. Cognitive profiles are expected to be uneven with variable trajectories (i.e. static, fluctuating, or deteriorating) and may be predicted by key risk markers associated with the condition.

*Conclusion:* Children with SWS are at increased risk of developing social and cognitive deficits. Their atypical presentation means timely and thorough assessment of difficulties is required to ensure adequate support to be put in place to help individuals reach their potential.

### Oral presentation 63

#### Surgery outcome prediction in cerebral palsy using supervised machine learning

O GALARRAGA<sup>1</sup>, V VIGNERON<sup>2</sup>, N KHOURI<sup>3</sup>, B DORIZZI<sup>4</sup>, E DESAILLY<sup>5</sup>

<sup>1</sup>Coubert Rehabilitation Center (UGECAM IDF), Coubert, France; <sup>2</sup>University of Evry, Evry, France; <sup>3</sup>Necker - Enfants Malades Hospital, Paris, France; <sup>4</sup>TELECOM SudParis Institute, Évry, France; <sup>5</sup>Ellen Poidatz Foundation, Saint Fargeau-Ponthierry, France

*Introduction:* Surgery among children with cerebral palsy (CP) often gives good results, but the functional outcomes are hardly predictable. The objective of this work is to utilize machine learning to simulate the effect of surgery on CP gait. *Patients and Methods:* Clinical gait analysis and physical examination data of children with CP before and after surgery were considered. Regression models were optimized for each surgical procedure (9 in total), using ensemble learning with feed-forward neural networks. In order to give a unique output per surgical combination, the models outputs were combined depending on the statistical significance of each procedure. Leave-one-out cross-validation was utilized for performance assessment. Prediction root-mean-square error (RMSE) was compared to a naive predictor that predicts the average post-operative data of the non-tested patients.

*Results:* Data of 183 children with CP were included. Depending on the nine considered gait angles, the average prediction RMSE varied between 3.8° (pelvic obliquity) and 9.4° (hip rotation and foot progression). The prediction error of the proposed system was between 4.3% (ankle dorsiflexion) and 16.4% (pelvic tilt) smaller than the naive predictor error for all the considered gait angles ( $p < 0.05$ ).

*Conclusion:* The proposed system shows the most likely post-operative gait kinematics for every patient, potentially allowing a better discussion between clinicians and patients. The likely contribution of each procedure is also showed. If validated externally, the proposed system could be used for treatment decision-making in CP.

### Oral presentation 64

#### Factors influencing parent and caregiver decisions to enroll children to participate in perceived high-risk brain research

T NAWSHIN<sup>1</sup>, M BEHAN<sup>2</sup>, S NEMANICH<sup>1</sup>, J KOWALSKI<sup>1</sup>, E SUTTER<sup>1</sup>, M BOXRUD<sup>1</sup>, J DUBINSKY<sup>3</sup>, B GILLICK<sup>1</sup>

<sup>1</sup>University of Minnesota Twin Cities, Department of Rehabilitation Medicine, Minneapolis, MI, USA; <sup>2</sup>Winona State University, Marketing, Winona, MI, USA; <sup>3</sup>University of Minnesota Twin Cities, Department of Neuroscience, Minneapolis, MI, USA

*Introduction:* Participant enrollment is crucial for robust results in human research. Parents may hesitate about their child's participation in research perceived as high-risk. We combined a consumer behavioral science approach with recruitment protocols in our pediatric neuromodulation laboratory. Conducting a survey at the Minnesota State Fair 2018, we identified factors influencing parental decisions about pediatric participation in perceived high-risk neuromodulation studies.

*Patients and Methods:* Adult parents and caregivers completed an anonymous 28-question iPad-questionnaire regarding factors that might influence enrolling their children in neuromodulation research.

*Results:* A total of 622 participants completed the questionnaire, with 11.3% having a child with a disability. Using a Likert scale, parents considered health benefit (63.2%) and evidence of safety (61.9%) as significant factors when enrolling children in research. Parents of children with a disability were more likely to involve their children in research (45.5%) than those with typically developing children (19.7%). Over other options, parents were more likely to choose a blue-colored environment, the term 'non-invasive brain therapy', and seeing a child engaged in rehabilitation while receiving brain stimulation.

*Conclusion:* Consumer behavior theory posits that many variables influence consumer decision-making process, including how the receiver encodes and decodes information. Specific to neuromodulation, we found that parents of children with brain injury were hesitant to enroll children in neuromodulation research due to perceived risk, potentially based on poorly-encoded messaging. We share a series of preferred encoded messages in parental decisions regarding perceived high-risk research participation to incorporate in future neuromodulation studies.

## Oral presentation 65

### Resting-state functional MRI brain connectivity changes predict clinical outcome after early focal lesions: the example of neonatal arterial ischemic stroke (NAIS)

L HERTZ-PANNIER<sup>1</sup>, D BEKHA<sup>1</sup>, D GERMANAUD<sup>1</sup>, L DRUTEL<sup>2</sup>, E PEYRIC<sup>3</sup>, C RENAUD<sup>3</sup>, M KOSSOROTOFF<sup>4</sup>, S CHABRIER<sup>3</sup>, M DINOMAS<sup>2</sup>, SN GUYEN THE TICH<sup>5</sup>

<sup>1</sup>UNIACT-Neurospin-CEA Saclay/inDEV-UMR NeuroDiderot, Paris, France;

<sup>2</sup>Dept MPR and LUNAM, CHU Angers, Angers, France; <sup>3</sup>CR National AVC enfant, CHU St Etienne, St Etienne, France; <sup>4</sup>CHU Necker-Enfants Malades, Paris, France; <sup>5</sup>CHU Lille, Lille, France

**Introduction:** Neonatal arterial ischemic stroke (NAIS) is an exquisite model to study brain plasticity after early focal lesions. Follow-up in childhood shows inconstant cerebral palsy, good language outcome in half of cases, and frequent executive/visuospatial impairments. We explored whether underlying inter- and intra-hemispheric functional connectivity (studied with resting state-fMRI) correlates with language outcome at school-age.

**Patients and Methods:** From 100 newborns with NAIS (AVCnn cohort) followed until age 7 years, 38 patients with a middle cerebral artery stroke (and 29 controls) underwent a 3T resting state-fMRI connectivity protocol and language fMRI (sentence production, exploitable in 19 patients/26 controls). After correction of motion/distortion artifacts, Rs-fMRI data was exploitable in 32 patients/26 controls. Connectivity between 72 ROIs grouped into 10 functional networks was compared across groups according to clinical language assessment, language fMRI lateralization, lesion size, and sex.

**Results:** Strongly reduced inter-hemispheric connectivity was found in patients, mainly in auditory, language, and attentional/visuospatial networks, with a high correlation with clinical language performances, and no sex nor lesion size effect. Surprisingly, we found no connectivity changes within the contralesional hemisphere, despite high prevalence of contralesional language organization. Finally, ipsilesional connectivity was increased in patients with normal language outcome, when compared to both controls and patients with impaired language, suggesting overcompensation.

**Conclusion:** Widespread inter-hemispheric dysconnectivity is a leading abnormality after an early stroke, that strongly correlates with language outcome. Increased ipsilesional connectivity is associated with normal language outcome while contralesional is not. Functional connectivity is useful to understand global consequences of early focal lesions.

## Oral presentation 66

### Investigating the role of sleep, pain and associated impairments in predicting maternal and paternal mental health among children with cerebral palsy

P KARLSSON<sup>1</sup>, I HONAN<sup>1</sup>, C GALEA<sup>1</sup>, E WRIGHT<sup>1</sup>, N BADAWI<sup>1,2</sup>

<sup>1</sup>Cerebral Palsy Alliance, Discipline of Child and Adolescent Health, The University of Sydney, Sydney, Australia; <sup>2</sup>Grace Centre for Newborn Care, The Children's Hospital at Westmead, Sydney, Australia

**Introduction:** Parents of children with cerebral palsy (CP) experience mental health difficulties at higher rates than the general population. However, little is known about factors that predict parental mental health in CP. This study aimed to examine the role of child sleep, pain, and associated impairments in predicting parental mental health.

**Patients and Methods:** This is a prospective cohort study of 172 children aged 3 to 17 years. Parental mental health was assessed via the Depression, Anxiety, Stress Scale-21, and child sleep via the Sleep Disturbance Scale for Children. Logistic and multiple logistic regression was used to investigate predictors of parental depression, anxiety and stress, including: child age, pain, GMFCS level, vision, CP type, CFCS, and epilepsy.

**Results:** Of the 168 mothers and 50 fathers, 22% and 24% experienced depression; 22% and 16% anxiety; and 29% and 26% stress respectively. Mean age of children was 5.5 years (3.2 SD). When adjusting for associated impairments, mothers of children with sleep difficulties were 3.6 times (95% CI, 1.7–7.8) more likely to report clinically elevated stress levels and 3.2 times (95% CI, 1.4–7.3) more likely to report anxiety. Once adjusting for associated impairments, child sleep difficulties did not significantly predict maternal depression nor father depression, anxiety, or stress.

**Conclusion:** Clinicians should consider the impact of sleep difficulties, pain, and associated impairments on both child and mother and provide appropriate supports. This will ensure mothers can remain effective carers, supporting their children to reach their full potential.

## Oral presentation 67

### Marfan syndrome in adolescents: perspectives on restrictions in daily functioning and participation - barriers, facilitators and support needs

J WARNINK-KAVELAARS<sup>1</sup>, A BEELEN<sup>1,2,3,4</sup>,  
T GOEDHART<sup>1</sup>, F NOLLET<sup>1</sup>, M ALSEM<sup>1</sup>, L MENKE<sup>5</sup>,  
R ENGELBERT<sup>1,6</sup>

<sup>1</sup>Amsterdam UMC, University of Amsterdam, Rehabilitation, Amsterdam Movement Sciences, Amsterdam, the Netherlands; <sup>2</sup>Center of Excellence in Rehabilitation Medicine, Brain Center Rudolf Magnus, University Medical Center Utrecht, Utrecht, the Netherlands; <sup>3</sup>De Hoogstraat Rehabilitation, Utrecht, the Netherlands; <sup>4</sup>Department of Rehabilitation, Physical Therapy Science & Sports, Brain Center Rudolf Magnus, University Medical Center Utrecht, the Netherlands; <sup>5</sup>Amsterdam UMC, University of Amsterdam, Pediatrics, Amsterdam, the Netherlands; <sup>6</sup>ACHIEVE, Center of Applied Research, Amsterdam University of Applied Sciences, Faculty of Health, Amsterdam, the Netherlands

**Introduction:** Marfan syndrome (MFS) is a rare heritable connective tissue disease affecting multiple organs and tissues. Understanding the impact of MFS on daily functioning and participation is essential to provide optimal (medical) support to adolescents with MFS.

**Patients and Methods:** To explore the perceived restrictions of MFS on daily functioning and participation and adolescents support needs we interviewed 19 adolescents with MFS in a qualitative study. Audio-recordings were transcribed, coded, and linked to categories of the International Classification of Functioning, Disability and Health for Children and Youth. Restrictions, barriers, and facilitators of daily functioning and participation and support needs were indicated and interpreted.

**Results:** The adolescents reported activity limitations in mobility, self-care, and domestic life. Participation was restricted in school, work, friendships, relationships, sports, play, and other leisure activities. Reported participation barriers were physical impairments, pain, fatigue, activity limitations, unsupportive attitudes from others and personal factors such as low self-esteem, and the feeling of not fitting in their peer-group. Reported participation facilitators were physical fitness, having balanced schedules, positive support from others and personal factors such as a positive mindset, living day by day, feeling self-confident, disease acceptance, and having perseverance. Furthermore adolescents reported support needs on sports, education, work, treatments to improve physical fitness, fatigue and pain, and psychological support programs.

**Conclusion:** We showed that MFS in adolescents restricts daily functioning and participation by multiple physical, personal, and environmental barriers and facilitators warranting awareness, adolescent empowerment, tailored treatments, and (medical) support programs.

## Oral presentation 68

### Improving body functions of youth with physical disabilities through participation in community activities: an evaluation

D ANABY<sup>1</sup>, J W GORTER<sup>2</sup>, M LEVIN<sup>1</sup>, R TEPLICKY<sup>2</sup>,  
L TURNER<sup>2</sup>, L AVERY<sup>3</sup>, I CORMIER<sup>4</sup>, J COULTER<sup>5</sup>,  
J HANES<sup>2</sup>

<sup>1</sup>McGill University, Montreal, Canada; <sup>2</sup>CanChild, McMaster University, Hamilton, Canada; <sup>3</sup>Avery Information Services Ltd, Orillia, Canada; <sup>4</sup>MAB-Mackay Rehabilitation Centre, Montreal, Canada; <sup>5</sup>Women's Sledge Hockey of Canada, Canada

**Introduction:** Emerging personalized interventions implemented in the natural environment are considered recommended practice for improving youth participation. It is unclear, however, whether enhancing participation can simultaneously improve both body functions and activity performance - key outcomes of rehabilitation programs. We examined the effectiveness of youth engagement in a self-chosen 8-week community-based activity (e.g., swimming, playing piano) on 3 relevant body functions (motor, cognitive and affective), as well as on the performance of the selected activity.

**Patients and Methods:** A 20-week interrupted time series design with multiple baselines across 7 youth with physical disabilities aged 15 to 25 years (median=18y) was employed. Change in three relevant body functions, underpinning the specific chosen activity, including motor (e.g., Functional Reach Test), cognitive and affective (Behavior Assessment System for Children), and activity performance (Canadian Occupational Performance Measure) were measured repeatedly, providing individual outcome trajectories. Linear regression was used to test each of the 106 trajectories and mixed-effect models estimated the overall intervention effect across participants and outcomes. Effect size was also calculated.

**Results:** Significant improvements were observed for: affect (5/7 youth), cognition (3/3 youth), motor (6/6 youth), and performance (7/7 youth). Significant immediate changes were observed with respect to anxiety, hyperactivity and performance, and significant change throughout the intervention was observed for performance. Notable effect sizes were observed for: anxiety (0.31), attention (0.82), hyperactivity (1.73), and performance (3.20).

**Conclusion:** Findings illustrate the multiple benefits resulting from participation-based interventions, emphasizing the merit of meaningful youth-engaging 'real-life' therapies.

## Oral presentation 69

### A users guide to imaging and measuring muscle change in children with cerebral palsy: a scoping review of the evidence

S WILLIAMS<sup>1</sup>, S REID<sup>2</sup>, J VALENTINE<sup>3</sup>, C ELLIOTT<sup>1</sup>,  
S STOTT<sup>4</sup>

<sup>1</sup>Curtin University, Perth, Australia; <sup>2</sup>University of Western Australia, Perth, Australia; <sup>3</sup>Kids Rehab WA, Perth Children's Hospital, Perth, Australia; <sup>4</sup>University of Auckland, Auckland, New Zealand

**Introduction:** Understanding of musculoskeletal impairments associated with cerebral palsy (CP) has advanced considerably



due to innovative imaging technology. This scoping review aimed to synthesise the literature to determine the most appropriate approach to imaging for the purposes of comparing to typical muscle development, or to measure change in CP muscle.

**Patients and Methods:** Articles utilising ultrasound (US), three dimensional US (3DUS), and/or Magnetic Resonance Imaging (MRI) to determine morphology of lower limb skeletal muscle in children with CP were included. Searches of all original articles up to September 2018 were conducted in the following databases: Medline, Embase, Scopus, Web of Science, PubMed, and PsycInfo.

**Results:** Forty-three articles spanning 2003 to 2018 were identified: US (18), 3DUS (10), and MRI (18). Muscle volume was most commonly reported ( $n=25$ ), followed by muscle thickness ( $n=12$ ), fascicle length ( $n=12$ ), anatomical cross-sectional area ( $n=11$ ), muscle length ( $n=9$ ), and pennation angle ( $n=8$ ). Only seventeen studies reported validity/reliability of their data collection method, while 11 referred to previous literature. Twenty-two studies reported on a single muscle ( $n=16$  medial gastrocnemius), while 21 reported on multiple muscles. Only four studies reported estimates of muscle growth over time. Eleven used musculoskeletal imaging as an outcome measure following intervention. Few studies compared data to the functional mobility of the child with CP.

**Conclusion:** More work needs to be done to understand changes in lower limb muscle morphology with growth and how these changes align to the functional ability of the child with CP.

## Oral presentation 70

### Does spasticity at the ankle differ in children with hereditary spastic paraplegia and bilateral spastic cerebral palsy?

N DE BEUKELAER<sup>1</sup>, L BAR-ON<sup>2</sup>, S-H SCHLESS<sup>1</sup>, B HANSEN<sup>1</sup>, N PEETERS<sup>1</sup>, E ORTIBUS<sup>3</sup>, K DESLOOVERE<sup>1</sup>, A VAN CAMPENHOUT<sup>4</sup>

<sup>1</sup>Department of Rehabilitation Sciences, KU Leuven, Leuven, Belgium;

<sup>2</sup>Amsterdam UMC, Vrije Universiteit Amsterdam, Department of Rehabilitation Medicine, Amsterdam Movement Sciences, Amsterdam, Netherlands; <sup>3</sup>Department of Development and Regeneration, KU Leuven, Leuven, Belgium; <sup>4</sup>Department of Orthopedic Surgery, UZ Leuven, Leuven, Belgium

**Introduction:** HSP is caused by heterogeneous group of genetic disorders varying in age of onset, whereas SCP is caused by perinatal non-progressive brain lesion. Despite differences in etiology, spasticity at the ankle joint is treated similarly, resulting in various success. We aimed to explore whether an instrumented spasticity assessment differentiates between HSP, SCP and typically developing (TD) children.

**Patients and Methods:** Children with HSP and SCP (10 per group, 6–15y) were matched for Gross Motor Function Classification System level (I–III) and compared to TD children. Surface electromyography (sEMG) from the medial gastrocnemius and joint torque were synchronously collected during manually applied passive ankle movements at low (LV) and high velocity (HV). sEMG (normalized to maximum voluntary contraction) and torque at LV and the change in these

between LV and HV were compared between groups with Kruskal-Wallis tests.

**Results:** Compared to TD, both HSP and SCP had significantly higher sEMG at LV ( $p=0.030$  and  $0.004$  respectively) and at HV-LV ( $p=0.006$  and  $p<0.001$  respectively). The latter was also higher in HSP compared to SCP. However, only in SCP was the ankle torque significantly higher than in TD ( $p=0.037$ ).

**Conclusion:** Spasticity parameters in HSP and SCP differed from TD reference values. While HSP showed a higher neural component (sEMG) compared to SCP, this was not accompanied by pathological torque values. Hence, increased torque in SCP is likely to be partially caused by non-neural alterations, which may be absent in HSP due to later onset.

## Oral presentation 71

### Eye-tracking technology in children with dyskinetic cerebral palsy: the efficacy of a five-week intervention on eye-tracking performance, quality of life and participation

S BEKTESHI<sup>1</sup>, I VANMECHELEN<sup>1</sup>, L VERLINDEN<sup>2</sup>, S BOSCHART<sup>2</sup>, J DEKLERCK<sup>2</sup>, E ORTIBUS<sup>3</sup>, J-M AERTS<sup>4</sup>, H HALLEZ<sup>5</sup>, P KARLSSON<sup>6</sup>, E MONBALIU<sup>1</sup>

<sup>1</sup>KU Leuven, Bruges, Belgium; <sup>2</sup>KU Leuven, Leuven, Belgium; <sup>3</sup>KU Leuven, Department of Development and Regeneration, Leuven, Belgium; <sup>4</sup>KU Leuven, Department of Biosystems, Leuven, Belgium; <sup>5</sup>KU Leuven, Computer Science Technology TC Campus Bruges, Bruges, Belgium; <sup>6</sup>University of Sydney, Cerebral Palsy Alliance, Sydney, Australia

**Introduction:** Children with dyskinetic cerebral palsy (DCP) lack fine motor control and are restricted in using conventional computers. Eye-tracking technology is a promising computer interface in severe disabilities, however, evidence-based knowledge in DCP remains scarce. This study aims to investigate the impact of a five-week eye-tracking intervention on performance, quality of life (QOL), and participation.

**Patients and Methods:** Ten participants with DCP, 4 to 13 years old (mean age 8y 4mo, SD 3y 1mo) were recruited. The Tobii PCEye Mini eye-tracker was used for data collection and the Sensory Guru Eye-Fx software to assess performance. Success rate was computed by the sum of obtained targets. Questionnaires investigated the impact of eye-tracking on QOL and participation. Non-parametric statistics were used to report pre- and post-intervention differences.

**Results:** The significant increase in success rate from baseline to follow-up ( $p=0.014$ ) implies an improvement of eye-tracking performance over time. Median values of the success rate increased after the five-week intervention both at a sample ( $p=0.046$ ) and participant ( $n=9$ ) level. Clinicians reported a positive impact of eye-tracking technology on QOL and participation. Increased levels in confidence, self-esteem, social well-being, and active participation during therapy were observed post-intervention.

**Conclusion:** Eye-tracking performance improved after a five-week intervention. This technology shows the potential to be a successful computer interface for children with DCP. Additionally, the use of eye-tracking assistive technology can lead to a better QOL and higher participation of the target group.

Future eye-tracking intervention studies including a larger sample size are warranted.

## Oral presentation 72

### The gap between the needs of young adults with cerebral palsy and attention of professionals on participation in mealtimes

L REMIJN<sup>1</sup>, L VAN DEN ENGEL-HOEK<sup>2</sup>, B DE SWART<sup>1,2</sup>

<sup>1</sup>HAN University of Applied Sciences, Nijmegen, the Netherlands; <sup>2</sup>Radboud Medical University Center, Radboud University Nijmegen, Nijmegen, the Netherlands

**Introduction:** The impact of difficulties with eating and drinking in young adults with cerebral palsy (CP) in daily life seems not a regular topic in rehabilitation. A first study showed that this target group experience (1) difficulties in eating and drinking ability; (2) many restrictions in eating and drinking situations, leading to; (3) negative feelings; and (4) lower participation levels, while little attention is directed towards these difficulties. The purpose of the ongoing study is to find out to what extent professionals acknowledge this gap.

**Patients and Methods:** In the first study, we collected data from ten participants with CP, aged 16 to 23 years. For the ongoing study, we included several professionals in the Netherlands. We used a qualitative study design with a conventional content analysis. Semi-structured in-depth interviews were used. After the transcription of the interviews, we coded relevant phrases and clustered and synthesized them into categories related to the four topics derived from the first study.

**Results:** The interviews of the professionals are currently running and these results will be derived at the end of this year.

**Conclusion:** We expect to find differences between the knowledge of professionals and the experiences of young adults with CP concerning eating and drinking. Both studies intensify our opinion to recommend adaptation of regular multidisciplinary rehabilitation programs in order to increase social participation and self-management, regarding eating and drinking ability.

## Oral presentation 73

### Facilitators of participation in the home, school, and community environments for children with disabilities participating in an all abilities community sport program

S WILLIAMS<sup>1</sup>, L JENSEN<sup>1</sup>, M GODDING<sup>1</sup>, J HITCH<sup>1</sup>, B KOOIMAN<sup>1</sup>, N GIBSON<sup>2</sup>

<sup>1</sup>Curtin University, Perth, Australia; <sup>2</sup>Ability Centre, Perth, Australia

**Introduction:** Community sports offer meaningful opportunities for participation for children and their families. 'Starkick' is a community run Australian rules football program for children of all abilities, with children wearing the same team uniform, playing on the same field at the same time as their typically developing peers.

**Patients and Methods:** Thirty-seven parents of children with developmental disabilities (5–13y) participating in Starkick

completed the Participation and Environment Measure - Children and Youth (PEMCY). In addition, 20 parents completed a semi-structured telephone interview answering questions pertaining to their child's participation in Starkick.

**Results:** Parents listed 268 strategies to facilitate participation in the PEMCY: 95 for home, 88 for school and 85 for community. Ten themes in four categories were identified: child (social skills, emotional self-agency), task (environment modification, coaching, physical modification) family (function, competence, finances), and service providers (advice/resources, communication). The most frequent themes were family functioning (70%), task coaching (40%), child emotional self-agency (35%), and child social skills (32%). Children had the highest frequency of participation and involvement in the home environment and the lowest frequency and involvement in the community. Following Starkick the frequency and involvement in school and community increased significantly. Parent interviews revealed six key points. Their child experienced a sense of belonging, team fellowship, having fun, making friends, acceptance, and social support. Coaches' and volunteers' attitudes and skills were important.

**Conclusion:** Opportunities for participation in community sporting programs have the potential to effect change for children with disabilities in home, school, and community environments.

## Oral presentation 74

### Disorders of anticipatory turning strategies and trajectory formation in spastic diplegic cerebral palsy

V BELMONTI<sup>1</sup>, G CIONI<sup>1</sup>, A CASTILLA<sup>2</sup>, A BERTHOZ<sup>3</sup>

<sup>1</sup>IRCCS Fondazione Stella Maris, Pisa, Italy; <sup>2</sup>Institut de Médecine Expérimentale, Paris, France; <sup>3</sup>Collège de France, Paris, France

**Introduction:** Population norm adults show consistent trajectory geometry and anticipatory head orientation in goal-oriented locomotion, whose typical development has been recently described. The aims of this study were: (1) to describe trajectory formation in children with spastic diplegia. (2) To identify specific subgroups. (3) To envisage new intervention strategies.

**Patients and Methods:** Thirteen patients with spastic diplegia (5–23y) were enrolled and compared with 26 controls from a previous study. Whole-body trajectories and orientation of body segments during turning were extracted by an optoelectronic system (SMARTA<sup>®</sup>, BTS). Trajectory variability, head-heading deviation, and head anticipation time (cross-correlation with heading) were analysed.

**Results:** Trajectory variability was higher in patients than controls ( $t=2.50$ ,  $p=0.017$ ). Head anticipation was present in patients but highly variable, sometimes lacking, sometimes exaggerated. Three sub-groups of spastic diplegic patients could be identified: those who differed completely from typical behaviour (high trajectory variability and abnormal head orientation); those with minor abnormalities; and those who did not differ from controls.

**Conclusion:** This is the first account of trajectory formation and anticipatory orientation disorders in CP. Findings support

the modelling of goal-oriented locomotion as an intrinsically double task: trajectory formation versus gait control. Abnormal gait due to spasticity and musculoskeletal problems does not account for difficulties in trajectory formation. Top-down factors must be taken into account for tailored rehabilitation programmes.

## Oral presentation 75

### Therapy disguised as fun: How an adaptive bungee trampoline programme hid the physical therapy for children with cerebral palsy

S WILLIAMS<sup>1</sup>, A GERMAIN<sup>2</sup>, N GIBSON<sup>2</sup>,  
M BLACKMORE<sup>2</sup>, B NEWELL<sup>3</sup>

<sup>1</sup>Curtin University, Perth, Australia; <sup>2</sup>Ability Centre, Perth, Australia; <sup>3</sup>Kids in Motion Physiotherapy, Perth, Australia

**Introduction:** Underpinnings of the concept of the 'F-words' of childhood disability suggest a need for more recreational opportunities for all children with disabilities, even if not therapeutic. Trampolines are a fun leisure-time activity, and an adaptive set up can provide opportunities for participation for children with cerebral palsy (CP).

**Patients and Methods:** Four children with CP (6–11y, mean=8y 3mo; SD=1y 10mo), Gross Motor Function Classification System levels I to V, participated in this single subject research study to assess the outcomes of a trampoline programme. Participants completed two 30-minute sessions weekly for 12 weeks using an adaptive setup. A harness and bungee cords connect to a support frame allowing for adjustment to body weight support and effort required for jumping. Weekly assessments (including function, strength, balance, and enjoyment) were recorded, and parent interview was undertaken at the completion of the study.

**Results:** Attendance was high (82–100%), mirrored by the children's self-ratings of enjoyment. The three ambulant children had significant improvements in lower limb muscle strength, and two improved in balance and functional strength. The non-ambulant participant increased supported standing and sitting, and observations of neck and head control were evident. Most improvements were maintained at follow-up. Parent interviews revealed themes of improved strength, fitness, and endurance, increases in participation in other activities, and emotional and social benefits. There were no adverse events.

**Conclusion:** Opportunities for participation in 'fun' activities can provide enjoyable therapeutic options to improve lower limb strength and functional mobility in children with a range of functional levels.

## Oral presentation 76

### Initial validation of a new assessment instrument and protocol for assessing autism in children with visual impairment (DAiSY Project)

N DALE<sup>1,2</sup>, E SAKKALOU<sup>2</sup>, M ERIKSSON<sup>1</sup>,  
R BLEKETIANE<sup>1</sup>, A SALT<sup>1</sup>

<sup>1</sup>Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK; <sup>2</sup>UCL Great Ormond Street Institute of Child Health, London, UK

**Introduction:** Children with visual impairment (VI) are at high risk of developing autism spectrum disorder (ASD). We present initial validation of the VISCOS, a novel observational schedule for the identification of social communication difficulties/ASD, drawing on principles of the ADOS but specifically designed for VI.

**Patients and Methods:** 100 4 to 7-years-olds (mean=5.4y), with severe VI (mean=0.98 logMAR) participated. Presented are preliminary data from 67 children, who engaged in social interaction and play using standard presses and were rated by the assessor using VISCOS. A clinician, expert in VI and ASD, independently scored children using the video assessments and the parent-reported DAWBA to reach diagnostic formulation according to DSM-5 criteria.

**Results:** The internal consistency of VISCOS-Total items was good ( $I\pm=0.87$ ). Inter-rater reliability was excellent ( $ICC=0.95$ ,  $p=0.0001$ ). Significant positive associations were found between VISCOS-Total and the parent-rated questionnaire (Social Responsiveness Scales, SRS-2) suggesting good criterion validity. Clinician formulation showed: Low Risk=66%; Borderline=19%, and ASD=13%. A ROC analysis revealed excellent predictive discriminant validity ( $AUC=0.92$ ) with a sensitivity/specificity of 0.86 for clinician ratings leading to a VISCOS threshold score for High Risk or Low Risk for ASD. Large effect sizes were found between the High Risk and Low Risk group on SRS-2 subscales ( $p=0.005$ ,  $I\pm=0.122$ ).

**Conclusion:** Results suggest a reliable instrument depicting strong internal coherence, construct validity, inter-rater reliability, and predictive discriminant validity. A diagnostic algorithm is being developed for more efficient accurate clinical diagnoses.

## Oral presentation 77

### Relationship between neonatal MRI, clinical assessment scores and neurodevelopmental outcomes at 2 years corrected age in very preterm born infants

J GEORGE<sup>1</sup>, R WARE<sup>2</sup>, M CHATFIELD<sup>1</sup>, S FIORI<sup>3</sup>,  
J FRIPP<sup>4</sup>, K PANNEK<sup>4</sup>, S ROSE<sup>4</sup>, P COLDITZ<sup>5</sup>,  
RN BOYD<sup>1</sup>

<sup>1</sup>The University of Queensland, Queensland Cerebral Palsy and Rehabilitation Research Centre, Child Health Research Centre, Faculty of Medicine, Brisbane, Australia; <sup>2</sup>Menzies Health Institute Queensland, Griffith University, Brisbane, Australia; <sup>3</sup>Stella Maris Scientific Institute, Department of Developmental Neuroscience, The University of Pisa, Pisa, Italy; <sup>4</sup>Health and Biosecurity, The Australian e-Health Research Centre, CSIRO, Brisbane, Australia; <sup>5</sup>The University of Queensland, Centre for Clinical Research, Brisbane, Australia

**Introduction:** To identify which combination of structural MRI and clinical assessment scores (1) early (30–32wks

postmenstrual age), (2) at term equivalent age (TEA), and (3) at 3 months corrected age (CA) best predict motor and cognitive outcomes at 2 years CA.

**Patients and Methods:** Ninety-eight very preterm born infants in this prospective cohort study underwent early MRI at median 32 weeks PMA ( $n=59$  males; median gestational age 28+5wks) and a second MRI at TEA. Clinical assessment early and at TEA included Hammersmith Neonatal Neurological Examination (HNNE), NICU Neonatal Neurobehavioural Scale (NNNS), and General Movements Assessment (GMs). Premie-neuro was performed early and Test of Infant Motor Performance (TIMP) and a visual assessment were performed at TEA. At 3 months CA infants underwent GMs, TIMP, and a visual assessment. Motor and cognitive development outcomes were assessed using Bayley Scales of Infant and Toddler Development, 3rd Edition. Multivariable models were developed using mixed effects linear regression.

**Results:** The motor and cognitive outcome models both included three variables. The motor model consisted of 3-month CA GMs score, TEA deep grey matter MRI score, and early HNNE reflexes subscale score. The cognitive model included 3-month CA GMs score, TEA GMs score, and 3-month CA visual assessment score.

**Conclusion:** A combination of MRI scores and clinical assessment findings were more strongly associated with motor outcome than either MRI or clinical measures alone. Visual assessment at 3 months CA complements GMs trajectory to predict cognitive outcome at 2 years CA.

## Oral presentation 78

### Bilateral alterations in muscle size and quality of the medial gastrocnemius muscle in unilateral spastic cerebral palsy

S OBST<sup>1</sup>, R BOYD<sup>2</sup>, F READ<sup>2</sup>, L BARBER<sup>1</sup>

<sup>1</sup>School of Health, Medicine and Applied Sciences, Central Queensland University, Bundaberg, Australia; <sup>2</sup>Queensland Cerebral Palsy and Rehabilitation Research Centre, Child Health Research Centre, Faculty of Medicine, The University of Queensland, Brisbane, Australia

**Introduction:** Bilateral alterations of muscle structure in children with unilateral spastic cerebral palsy (USCP) could reflect systemic causes for impaired muscle growth. 3D ultrasound (3DUS) has been used to evaluate muscle volume and may also be used to assess muscle quality using ultrasound grey scale parameters.

**Patients and Methods:** Twenty-six children with USCP (age  $6.0 \pm 2.4$ y; GMFCS I=17, II=9) and 10 age-matched typically developed (TD) children participated. 3DUS images of the medial gastrocnemius (MG) of both limbs in children with CP, and the right limb in TD children, were analysed to determine muscle volume and echo intensity and pattern.

**Results:** Normalised MG volume of the more-involved limb was smaller ( $1.2 \pm 0.5 \text{ cm}^3/\text{kg/m}$ ) than the less-involved limb ( $1.6 \pm 0.5 \text{ cm}^3/\text{kg/m}$ ) and TD group ( $2.5 \pm 0.6 \text{ cm}^3/\text{kg/m}$ ), the latter of which was significantly larger than less-involved limb. Large and significant differences in all echo parameters were found between TD and CP children. Small, but significant

differences, were found between limbs for some echo intensity (mean, median, skewness) and pattern measures (energy).

**Conclusion:** The MG of both limbs in children with USCP is smaller and, on the basis of quantitative 3DUS structurally different to TD children. Both limbs in children with USCP had ultrasound findings consistent with disruption of muscle architecture. These findings may indicate bilateral muscle impairment in children with USCP. It may be inappropriate to use the less-involved limb as a control group in USCP muscle research.

## Oral presentation 79

### How participation-focused is usual care in paediatric neurodisability in New Zealand?

F GRAHAM, J WILLIMAN, E TIMOTHY

University of Otago, Christchurch, New Zealand

**Introduction:** Goal oriented and participation focused therapy are criterion standards of care in rehabilitation with children. We aimed to identify the extent of collaborative participation focused therapy, and to understand rehabilitation clinicians' beliefs about practices.

**Patients and Methods:** Participants were health professionals working with children with neurodisability. This was a cross-sectional study (retrospective case-note audit and questionnaire to clinicians). Case-notes were randomly selected and audited for goal examples and interventions. Subgroup analysis by service and profession were undertaken using weighted mean differences and chi-square analyses. Questionnaire data were analysed descriptively.

**Results:** Five services were recruited ( $n=46$  clinicians) with 220 case-notes audited. Only half (368/660, 56%) of the anticipated goals were identified. Goals targeted participation ( $n=225/660$ , 34%); activities ( $n=107$ , 16%); tasks ( $n=23$ , 3.5%); environment factors ( $n=11$ , 1.7%) or were uncodeable ( $n=2$ , 0.3%). Physiotherapists  $\chi^2=29.14$ ,  $p<0.001$  and one of two public health services  $\chi^2=20.48$ ,  $p=0.030$  were significantly less likely to target participation compared to other professions and services. Family involvement was high across all sectors (87–95%). Clinicians reported valuing children's participation and family involvement but reported limitations of skill, self-monitoring, and professional/workforce cultures that did not support these practices.

**Conclusion:** Participation focused practice is unusual care in paediatric rehabilitation in New Zealand, with limited use of goal-setting in some sectors. Basic goal setting training is a quality improvement priority before advancing skills in participation-focused rehabilitation.



## Oral presentation 80

### A randomized cross-over design evaluating the effects of using a rehabilitation-specific gaming software platform for the achievement of individual physiotherapy goals of children with severe spastic cerebral palsy

S DECAVELE<sup>1</sup>, E ORTIBUS<sup>2</sup>, A VAN CAMPENHOUT<sup>1</sup>, B JANSEN<sup>3</sup>, L OMELINA<sup>3</sup>, I FRANKI<sup>2</sup>

<sup>1</sup>CP Reference Centre, UZ Pellenberg, Pellenberg, Belgium; <sup>2</sup>Department of Development and Regeneration, University of Leuven (KU Leuven), Leuven, Belgium; <sup>3</sup>Department of Electronics and Informatics, Vrije Universiteit Brussel, Brussels, Belgium

**Introduction:** Cerebral palsy (CP) is the most common cause of permanent neurological disabilities in children. Many children require long-term daily physiotherapy (PT) and video-gaming is a promising tool to increase motivation in rehabilitation. The effects of an intervention with rehabilitation specific video-games were evaluated on individually defined therapy goals, gross motor function, and motivation. Additionally, we evaluated the effects after three months.

**Patients and Methods:** Thirty-two children (bilateral spastic CP, Gross Motor Function Classification level III–IV, 6–15y) were randomized using a cross-over design into an intervention group (regular PT and gaming) or a control group (regular PT). The effects of both training periods (each 12wks) were compared using the Goal Attainment Scale (GAS), Trunk Control Measurement Scale (TCMS), Pediatric Balance Scale (PBS), Gross Motor Function Measure-88 (GMFM-88), and Dimensions of Mastery Motivation Questionnaire (DMQ).

**Results:** The GAS estimated marginal mean change scores (EMC) were significantly higher after the intervention compared to the control period (8.5 and 2.4,  $p=0.00$ ). The EMC for standing exercises (3.85% and 0.22%,  $p=0.04$ ) and dynamic sitting balance (5.9% and -1.7%,  $p=0.00$ ) were also significantly higher. After three months follow-up the results were not maintained for the total GMFM scores (-1.1%) and for static sitting balance (-3.2%) ( $p=0.04$ ).

**Conclusion:** A combined approach of 'regular' PT and rehabilitation specific gaming showed significant results on individually defined therapy goals, dynamic sitting balance, and standing exercises. However, follow-up results show that continuous physiotherapy is needed.

## Oral presentation 81

### The acceptability, usability and comprehensibility of ENVISAGE: a program to empower parents of children newly diagnosed with a neurodisability

G NICKSON<sup>1</sup>, L MILLER<sup>1</sup>, C IMMS<sup>2</sup>, D KHAN<sup>3</sup>

<sup>1</sup>Australian Catholic University, Brisbane, Australia; <sup>2</sup>Australian Catholic University, Melbourne, Australia; <sup>3</sup>Children's Health Queensland, Brisbane, Australia

**Introduction:** Parents raising children with a neurodisability experience major challenges. Despite substantial evidence attesting to poor parent physical and mental health, the preventability of these impacts has not been explored. ENabling

VISIONS and Growing Expectations (ENVISAGE) is a parent, clinician, and researcher collaboration developed to integrate research evidence, clinical experience and parent expertise to support and empower parents to improve family outcomes as well as their child's. ENVISAGE comprises five workshops developed with parents, for parents, based on best practice in childhood disability. The aim of this study was to explore the comprehensibility, acceptability, and usability of ENVISAGE for caregivers of children with a neurodisability and refine content and delivery based on caregiver feedback.

**Patients and Methods:** This mixed methods study included parents of children with a neurodisability (>12mo post-diagnosis). In phase one, parents reviewed ENVISAGE workshop materials and completed surveys. In phase two, parents participated in interviews and a focus group.

**Results:** Five parents completed phases one and two. More than 80% of parents reported the ENVISAGE workshops were understandable, relevant, and meaningful to their family. Themes from qualitative data revealed ENVISAGE was empowering; facilitated a change in focus from disability to abilities; and provided families with tools to connect, communicate and collaborate. Recommendations regarding format and media support was also discussed.

**Conclusion:** ENVISAGE successfully addresses the key issues and concerns reported by parents at the time of diagnosis. Refinement of workshop materials based on parent feedback will improve the accessibility of the program to all families.

## Oral presentation 82

### Empowerment trajectories among parents of young children with cerebral palsy

R KALLESON<sup>1</sup>, S OSTENSJO<sup>1</sup>, R JAHNSEN<sup>2,3</sup>

<sup>1</sup>Faculty of Health Sciences, Oslo Metropolitan University, Oslo, Norway;

<sup>2</sup>CPOP, Department of Clinical Neuroscience for Children, Oslo University Hospital, Oslo, Norway; <sup>3</sup>CHARM, Institute of Health and Society, University of Oslo, Oslo, Norway

**Introduction:** Family empowerment is considered a desirable process and outcome when aiming to improve services for children with disabilities and their families. This study describes family empowerment from enrolment in a follow-up program and throughout the following three years, and the associations with child, family and service characteristics.

**Patients and Methods:** The study has a longitudinal cohort design, including a population-based sample of 58 families having a child with CP approximately 4 years-old registered in the Norwegian CP register between 2012 and 2014. Empowerment in the context of the family, service situations, and community was assessed using the Family Empowerment Scale (FES). Mean scores of the three subscales at six time points were calculated, and associations between FES scores and child, family, and service characteristics were assessed using a linear mixed model.

**Results:** Empowerment ratings in family and service situations were high and stable (mean 4.1 SD=0.5–4.3 SD=0.4), while lower in the community subscale (mean 2.4 SD=0.7–2.7 SD=0.8). In the family domain, empowerment was associated with family characteristics (education, employment, quality of

life), in service situations with both child (GMFCS level), family (education, quality of life) and service characteristics (multidisciplinary team), and in the community domain with child (age, GMFCS level) and service characteristics (multidisciplinary team, intensive training).

**Conclusion:** Parental empowerment in the community differed from empowerment in family and service situations. Associations between empowerment and child, family and service characteristics varied between the subdomains.

### Oral presentation 83

#### **Eat, sleep, play, connect: a systematic review of participation outcome measures for children aged under 3 years**

L JOHNSTON<sup>1</sup>, C MOBBS<sup>1</sup>, A SPITTLE<sup>2</sup>

<sup>1</sup>The University of Queensland, Brisbane, Australia; <sup>2</sup>The University of Melbourne, Melbourne, Australia

**Introduction:** Assessment of participation is important for guiding treatment of infants and older children, however little is known about assessments for young populations. The aim of this study was to identify and examine psychometric properties of participation outcome measures for children aged under 3 years.

**Patients and Methods:** We performed a systematic review according to PRISMA Guidelines. Four electronic databases were searched to identify assessments that (1) measured participation 'attendance' or 'involvement' according to the Imms et al 'Family of Participation Related Constructs'; (2) with psychometric data for children aged under 3 years; (3) in English in full text. Two reviewers independently evaluated quality of psychometric evidence using The Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) Checklist.

**Results:** Searches identified 1249 articles. Fourteen met the inclusion criteria. They included seven outcome measures: the Assessment of Preschool Children's Participation, Canadian Occupational Performance Measure, Child Engagement in Daily Life Measure, Children's Assessment of Participation with Hands, Daily Activities of Infants Scale, Test of Playfulness and Young Children's Participation and Environment Measure. All measures quantified 'attendance' through diversity and/or frequency. Three also measured 'involvement'. There was limited psychometric data for all tests for children under 3 years. Over half (4/7) the measures were limited to children older than six months.

**Conclusion:** Participation assessments are becoming available for young children, however assessment scope and psychometric data are limited. Research is needed to develop valid, reliable and responsive measures of 'attendance' and 'involvement' especially for infants.

### Oral presentation 84

#### **In vivo ankle joint kinematics from dynamic MRI using a registration-based framework: towards spastic equinus deformities**

K MAKKI<sup>1,2</sup>, B BOROTIKAR<sup>1,3</sup>, M GARETIER<sup>1,4</sup>, S BROCHARD<sup>1,3</sup>, D BEN SALEM<sup>1,3</sup>, F ROUSSEAU<sup>1,2</sup>

<sup>1</sup>LaTIM, INSERM, U1101, Brest, France; <sup>2</sup>IMT Atlantique, Brest, France; <sup>3</sup>CHRU de Brest, Brest, France; <sup>4</sup>Hôpital d'Instruction des Armées Brest, Brest, France

**Introduction:** Cerebral palsy, responsible of ankle and foot deformities, is the leading cause of child motor disabilities. Management of spastic equinus deformity remains a challenge and requires better biomechanical understanding. Dynamic MRI is a non-invasive method providing spatio-temporal in-vivo information of the joint. Acquired MRI data usually consist of a high-resolution (HR) static scan and a series of low-resolution (LR) dynamic scans. We propose a method for measuring 3D in-vivo kinematics of the ankle joint from dynamic MRI acquisition of a single range-of-motion cycle.

**Patients and Methods:** MRI data was acquired using a 3T MR scanner as part of a clinical study for children with spastic equinus deformity. One HR static scan ( $0.26 \times 0.26 \times 0.8\text{mm}$ ), and three LR dynamic scans (15 time frames,  $0.57 \times 0.57 \times 8\text{mm}$ ) were acquired. The proposed approach relies on an intensity-based registration method to estimate motion from multi-plane dynamic MRI data. First, a rigid motion of each ankle bone was estimated. Second, a four-dimensional (3D+time) high-resolution dynamic MRI sequence was estimated through a log-euclidean framework for the computation of temporal dense deformation fields. The method was applied on dynamic MRI data acquired for six healthy pediatric cohort to establish in-vivo normative joint biomechanics.

**Results:** Results demonstrate the robustness of the proposed pipeline, quantification of in-vivo ankle joint kinematics and a HR visualization of the ankle joint.

### Oral presentation 85

#### **Sensorimotor synchronization and continuation is partially impaired in children with cerebral palsy**

C CHERRIERE<sup>1</sup>, Y LAGARRIGUE<sup>1</sup>, C DONSKOFF<sup>2</sup>, M LEMAY<sup>3</sup>, P MARQUE<sup>1</sup>, J TALLET<sup>1</sup>

<sup>1</sup>ToNIC, Toulouse NeuroImaging Center, Université de Toulouse, Inserm, UPS, Toulouse, France; <sup>2</sup>Paul Dottin pediatric rehabilitation Center, Ramonville Saint-Agne, France; <sup>3</sup>University of Québec à Montréal UQAM, Montréal, Canada

**Introduction:** The natural tendency to synchronize movements to rhythmic auditory stimulations (RAS) is used in rehabilitation. RAS has shown motor benefits in population with CP. However, little is known about the capacity of children with CP to intentionally synchronize to RAS and continue to produce the required rhythm.

**Patients and Methods:** 10 children with CP, 9 typically-developed (TD) children, and 9 TD adults: (1) produced spontaneous tempo with their dominant hand tapping on a buzzer; (2) synchronized tapping of their dominant hand with RAS

specifying a tempo Similar (700ms) or Different (1300ms) than their spontaneous tempo; (3) continued to produce the specified tempo after the withdrawal of the RAS. Two trials were required for all conditions. ANOVAs Group x Tempo x Continuation were performed on the mean tempo error and its variability.

**Results:** Spontaneous tempo of all groups did not differ from 700ms. The mean tempo error for the Different tempo was larger in Continuation than Synchronization for all Groups ( $p=0.001$ ) and larger for the group of children with CP than for TD children ( $p=0.002$ ).

**Conclusion:** Despite a preserved ability to intentionally synchronize and continue with a tempo similar to their spontaneous tempo, children with CP seem to present an impaired ability to synchronize and continue with a different tempo. These results suggest a specific sensorimotor adaptation mechanism impairment, that should be considered for future rehabilitation programs.

### Oral presentation 86

#### With CO-OP 'I'm the boss' - experiences of the Cognitive Orientation to daily Occupational Performance approach as reported by youth and young adults with spina bifida or cerebral palsy

A-M ÖHRVALL<sup>1</sup>, L BERGQVIST<sup>2</sup>, C HOFGREN<sup>3</sup>, M PENY-DAHLSTRAND<sup>2</sup>

<sup>1</sup>Karolinska Institutet, Department of Neurobiology, Care Sciences, Huddinge, Sweden; <sup>2</sup>University of Gothenburg, Sahlgrenska Academy, Institution of Neuroscience and Physiology, Gothenburg, Sweden;

<sup>3</sup>Habilitation and Health, Västra Götalandsregionen, Gothenburg, Sweden

**Introduction:** Restrictions to activity and participation in persons with cerebral palsy or spina bifida are often due to both motor and executive dysfunction. Hence methods focusing solely on motor issues are not enough to enhance participation. The Cognitive Orientation to daily Occupational Performance (CO-OP approach) is a performance-based and problem-solving approach which gives the clients the opportunity to find their own way to solve problems when performing activities. Through an interactive process, between the client and therapist, during strategy use and guiding with questions the client chooses their own goals, is actively involved in the process of problem-solving, identifies strategies to improve skill acquisition, and evaluates the activity performance. The aim was to explore and describe the experiences of the CO-OP approach as reported by youth and young adults with cerebral palsy or spina bifida.

**Patients and Methods:** Semi-structured individual interviews conducted post-intervention and at 6 months follow-up after a CO-OP intervention period with ten participants, five with each condition, aged 16 to 28 years. Qualitative content analysis was used.

**Results:** The participants described how the CO-OP approach enhanced their problem-solving in daily life by using meta-cognitive thinking skills. Four categories describing the participants' experiences emerged: 'CO-OP is a different way of learning', 'CO-OP sometimes puts a strain on me', 'CO-OP

supports my way of thinking and doing' and 'CO-OP boosts me'.

**Conclusion:** The youth and young adults expressed that the CO-OP approach provided them with an opportunity to master everyday-life problems by using meta-cognitive thinking, which enhanced their self-efficacy.

### Oral presentation 87

#### Is more frequent physical therapy a success factor for enhanced gross motor progress in children with cerebral palsy? A national prospective cohort study

GV STØRVOLD<sup>1</sup>, RB JAHNSEN<sup>2,3</sup>, K-AI EVENSEN<sup>4</sup>, G H BRATBERG<sup>5</sup>

<sup>1</sup>Nord-Trøndelag Hospital Trust, Levanger, Norway; <sup>2</sup>CPOP, Department of Clinical Neuroscience for Children, Oslo University Hospital, Oslo, Norway; <sup>3</sup>CHARM, Institute of Health and Society, University of Oslo, Oslo, Norway; <sup>4</sup>Department of Clinical and Molecular Medicine and Department of Public Health and Nursing, Norwegian University of Science and Technology, Trondheim, Norway; <sup>5</sup>Faculty of Nursing and Health Sciences, Nord University, Levanger, Norway

**Introduction:** As children with cerebral palsy (CP) often spend considerable time in physical therapy, the aim of this study was to investigate the association between physical therapy frequency and gross motor improvement in children with CP.

**Patients and Methods:** This was a prospective cohort study of 442 children aged 2 to 12 years, in Gross Motor Function Classification System levels I to V, from the Cerebral Palsy Follow-up Program and the Cerebral Palsy Register of Norway. Outcome was change in reference centiles for the Gross Motor Function Measure (GMFM-66) between two subsequent assessments ( $n=1056$ ) analyzed in a Linear Mixed Model.

**Results:** We found a dose response association between physical therapy frequency and gross motor improvement. Mean change was 4.2 (95% CI: 1.4–7.1) centiles larger for physical therapy 1 or 2 times per week and 7.1 (95% CI: 2.6–11.6) centiles larger for physical therapy >2 times per week, compared to less frequent physical therapy when analyzed in a multivariable model including multiple child and intervention factors. The only statistically significant confounder was number of contractures, which was negatively associated with gross motor improvement.

**Conclusion:** When gross motor improvement is a goal for children with cerebral palsy, more frequent physical therapy should be considered.

### Oral presentation 88

#### Co-development of a new tool to enhance children's participation: The CMAP-Book

N VÄNSKÄ, S SIPARI

Helsinki Metropolia University of Applied Sciences, Helsinki, Finland

**Introduction:** To ensure the child's best interests in rehabilitation the child's right to participation according to the UN

Convention on the Rights of the Child need to be secured. The purpose of the co-development project (LOOK) was to create tools that enhance children's participation and active human agency in rehabilitation and in everyday life.

**Patients and Methods:** Overall 351 participants took part in different phases of the co-development (2015–2017). The evidence found from literature review and results from individual interviews with children ( $n=6$ ), focus group interviews with rehabilitation professionals ( $n=24$ ), and parents ( $n=4$ ), and future workshop ( $n=6$ ) were utilized as base for the development process. The co-development included: (1) designing the tool's first version in collaborative workshops, (2) piloting the tool, (3) collecting feedback and reflection, (4) generating the tool's final version.

**Results:** The co-development produced a tool called the CMAP-Book, which is an electronic book made with an app. The CMAP-Book enables the identification and description of meaningful activities, participation, and environmental factors in daily life from child's perspective with videos, photos, pictures, recordings, and writing. The tool enables the child, family, and professionals to prepare for the collaboration in rehabilitation with flexibility according to child's and family's needs. Theoretical background base on the ICF-framework and the construct of child's active human agency.

**Conclusion:** The CMAP-Book was co-developed as an accommodating and innovative tool that is used in collaboration with child as an active partner.

## Oral presentation 89

### Content validity and feasibility of ActiveYou-1: a new web-based instrument for mapping activity preferences in children and adolescents with disabilities

LK DALEN<sup>1</sup>, L SHIELDS<sup>2</sup>, D STANLEY<sup>3</sup>, A NYQUIST<sup>1</sup>, R JAHNSÉN<sup>4</sup>, A ULLENHAG<sup>5</sup>

<sup>1</sup>Beitostolen Healthsport Center, Beitostolen, Norway; <sup>2</sup>Charles Sturt University, Bathurst, Australia; <sup>3</sup>University of New England, Armidale, Australia; <sup>4</sup>Oslo University Hospital, Oslo, Norway; <sup>5</sup>Malardalen University, Västerås, Sweden

**Introduction:** A main goal for health and service providers is to optimize participation for children with disabilities. Children's preferences seem to be one of the most important predictors of participation. Currently no web-based measure of children's preferences exists.

**Patients and Methods:** Content validity and feasibility of a new web-based measure of children's preferences for physical activities are investigated. The instrument was developed in several steps. A review of 149 children with disabilities' preferred goal activities was performed to identify relevant activities to be included. A pilot version of ActiveYou-1 was sent to 341 children with disabilities who participated in a rehabilitation stay at the Beitostolen Healthsports Centre (BHC) in Norway. Semi-structured group interviews were conducted with therapists working at BHC to identify potential problems that may arise when answering ActiveYou-1. Finally, qualitative interviews were conducted with six children with disabilities in order to validate the new version.

**Results:** Based on the analysis of the 149 children's preferred goal activities, 19 physical activities were identified to be included. The results from the pilot trial resulted in three activities being excluded, a new sorting of activities on snow was done and play computer games/virtual reality was added. The interviews with therapists and children with disabilities showed that ActiveYou-1 included relevant physical activities and was easy to understand and answer in a web-based version.

**Conclusion:** ActiveYou-1 is a valid and feasible, web-based instruments for mapping activity preferences in children and adolescents with disabilities.

## Oral presentation 90

### Importance of stakeholder involvement in the creation of digital platforms for people with cerebral palsy and their families

T PICKAR<sup>1</sup>, R BYRNE<sup>1</sup>, P ROSENBAUM<sup>2</sup>, D ROYE<sup>3</sup>

<sup>1</sup>Cerebral Palsy Foundation, New York, USA; <sup>2</sup>McMaster University, Hamilton, Canada; <sup>3</sup>Columbia University, New York, USA

**Introduction:** Semi-structured focus group interviews were conducted to gain data and narrative feedback about the information gathering habits of people with cerebral palsy (CP), parents of children with CP, and healthcare providers as they tested and reviewed new digital platforms.

**Patients and Methods:** Participants were recruited for individual and group interviews. 78 individuals were interviewed in 15 groups for 90 minutes, parents (38), individuals with CP (11), and healthcare providers (29). At least two researchers attended each session and took notes on nonverbal behavior, group dynamics, and emergent themes. Four key content domains were explored: available information about CP, methods for information gathering, website and app behavior and usage, social isolation, and ability to connect with others through technology. All sessions were audio-recorded and then transcribed.

**Results:** Five major themes emerged from focus groups: lack of credible information about CP (100%), desire to connect to other people (91%), need for local resources (72%), lack of developmental milestones tailored to individuals with CP (43%), absence of websites with easily digestible information about CP (44%). Participants felt disempowered by the lack of CP specific knowledge and wanted a one-stop shop with a broad range of content. Recommendations included creation of videos, patient checklists, and evidence based resources.

**Conclusion:** Challenges to accessing reputable information about CP were identified by all participants, specifically how to identify verified information and absence of a central information clearinghouse. The stakeholder perspective is essential when creating and vetting new resources to address barriers to information access.



## Oral presentation 91

### A small step program in a randomised controlled trial for infants at risk of developing cerebral palsy or other neurodevelopmental disorders

K LÖWING, L HOLMSTRÖM, K TEDROFF, A-  
L WEILAND, B-M ZETHRAEUS, C FURMARK,  
H FORSSBERG, A-C ELIASSON

Karolinska Institutet, Stockholm, Sweden

**Introduction:** The primary objective was to evaluate the effects of the newly developed Small Step Program (SSP) on general development in children at risk for developing cerebral palsy (CP) or other neurodevelopmental disorders.

**Patients and Methods:** A randomised, controlled study comparing the SSP with usual care (UC). Infants at risk at between 3 and 8 months of age (corrected age, CA), were recruited from the clinical follow-up program at the hospital. The intervention was a 40 weeks homebased program focusing on gross motor skills, fine motor skills, or communication during distinct time-periods. The Peabody Developmental Motor Scales, Second Edition (PDMS-2) was used as the primary outcome measure. For statistical analysis a multiple regression model was used with outcome on PMDS-2 as dependent variable, and age at inclusion, HINE at baseline, PMDS-2 at baseline, as independent variables.

**Results:** Thirty-nine infants were randomised to SSP ( $n=19$ , age 6.3 CA [1.62]) or UC ( $n=20$ , age 6.7 CA [1.96]). CP or other neurological disorders were diagnosed in 38 of the 39 children at 2 years. There was no group difference on PDMS-2 at the end of treatment. When PMDS-2 was used at the end of treatment as outcome, an interaction between group and PMDS-2 at baseline was significant.

**Conclusion:** All children in this study developed positively over time. In the UC group, the baseline status was predictive of outcome. The development in the SSP was not explained by the baseline status, indicating that the intervention influenced children's development positively.

## Oral presentation 92

### Impact of motor function on connectivity between motor areas in children after arterial ischemic stroke

S GRUNT<sup>1</sup>, S WINKELBEINER<sup>2</sup>, A FEDERSPIEL<sup>2</sup>,  
S KORNFELD<sup>3</sup>, R EVERTS<sup>3</sup>, S KAMAL<sup>3</sup>, J DELGADO<sup>3</sup>,  
L STEINER<sup>3</sup>, N SLAVOVA<sup>1</sup>, M STEINLIN<sup>1</sup>

<sup>1</sup>Institute of Diagnostic and Interventional Neuroradiology, University Hospital, Inselspital, University of Bern, Bern, Switzerland; <sup>2</sup>Division of Systems Neuroscience, Translational Research Center, University Hospital of Psychiatry and Psychotherapy, Bern, Switzerland; <sup>3</sup>Division of Neuropaediatrics, Development and Rehabilitation, Children's University Hospital, Inselspital, Bern, Switzerland

**Introduction:** The mechanisms regulating motor recovery after arterial ischemic stroke (AIS) in children are widely unknown. The aim of this study was to examine alterations in the motor network after childhood AIS using resting-state functional MRI (rsfMRI) and to investigate their relationship to motor recovery.

**Patients and Methods:** Patients with AIS (diagnosed <16y, >2y after diagnosis) and an age and sex matched control group of population norm volunteers were recruited within the Swiss Neuropediatric Stroke Registry. Hemiparesis was diagnosed according to the Pediatric Stroke Outcome Scale. Upper limb function was assessed with the Melbourne Assessments of Unilateral Hand Function. Functional ROI-to-ROI connectivity was analyzed with rsfMRI within the motor network including the primary motor cortex, prefrontal cortex (PFC), dorsal premotor cortex, supplementary motor area (SMA), precuneus, and the superior parietal lobus.

**Results:** Seven AIS patients with and 10 without hemiparesis as well as 12 population norm volunteers were included. The three groups differed significantly in dexterity and fluency of movements and in the connectivity strength between the ipsilesional PFC and the ipsilesional SMA. In AIS patients, motor performance was inversely correlated to the connectivity strength within the motor network. Controls showed a positive relation between motor performance and connectivity strength within the motor network.

**Conclusion:** The connectivity strength within the motor network after childhood AIS is related to motor outcome. These findings can help to better understand the mechanisms of motor recovery after childhood AIS.

## Oral presentation 93

### Researchers and parents: essential partners in participatory childhood disability research

M NOVAK PAVLIC<sup>1</sup>, P ROSENBAUM<sup>1</sup>, A CROSS<sup>1</sup>,  
L MILLER<sup>2</sup>, C IMMS<sup>2</sup>, R MARTENS<sup>1</sup>, K POZNIAK<sup>1</sup>,  
J ZIVIANI<sup>3</sup>, G NICKSON<sup>2</sup>

<sup>1</sup>CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, Canada; <sup>2</sup>Australia Catholic University, Melbourne, Australia; <sup>3</sup>The University of Queensland, Brisbane, Australia

The focus of early intervention in pediatric research has traditionally been on the child's well-being and helping them reach their developmental potential. Pediatric researchers are beginning to expand their focus to explore both children's and families' strengths and needs. An integrated Canadian-Australian research team (including parents and health services researchers) is now partnering together to develop a caregiver-focused online intervention program: 'ENVISAGE: ENabling VISIONS And Growing Expectations'. ENVISAGE aims to foster a best start for parents by providing a platform for knowledge sharing and exchange on evidence-based contemporary themes in childhood disability. Through a five-week online workshop series parents are introduced to five themes: (1) The WHO's ICF Framework and the 'F-Words in Childhood Disability'; (2) Child, sibling, and family development; (3) Parenting; (4) Taking care of oneself; (5) Connecting, communicating, and collaborating. All these workshops have been co-developed with parents and all will be co-led by both parents and researchers. In this presentation, we will outline the path of the development of the ENVISAGE project, and will highlight our main lessons learned thus far from working together as an international integrated research team.

## Oral presentation 94

### Machine learning based prediction of ambulatory versus non-ambulatory motor function in children with cerebral palsy

I ESPEN<sup>1</sup>, R STØEN<sup>2</sup>, T FJØRTOFT<sup>3</sup>, D GAEBLER-SPIRA<sup>4</sup>, M MSALL<sup>5</sup>, C PEYTON<sup>5</sup>, R-A DEREGNIER<sup>6</sup>, I E SILBERG<sup>7</sup>, NT SONGSTAD<sup>8</sup>, L ADDE<sup>2</sup>

<sup>1</sup>Department of Neuromedicine and Movement Science, Norwegian University of Science and Technology, Trondheim, Norway; <sup>2</sup>Department of Clinical and Molecular Medicine, Norwegian University of Science and Technology, Trondheim, Norway; <sup>3</sup>Clinic of Clinical Services, St. Olavs Hospital, Trondheim University hospital, Trondheim, Norway; <sup>4</sup>Shirley Ryan AbilityLab, Chicago, USA; <sup>5</sup>Department of Pediatrics, University of Chicago Comer Children's Hospital, Chicago, USA; <sup>6</sup>Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, USA; <sup>7</sup>Division of Pediatric and Adolescent Medicine, Department of Neonatology, Oslo University Hospital, Oslo, Norway; <sup>8</sup>Department of Paediatric and Adolescent Medicine, University Hospital of North Norway, Tromsø, Norway

**Introduction:** Early identification of cerebral palsy (CP) and severity of later motor function could optimize early intervention. Recently, computer-based assessments of general movements from video recordings have shown potential for early prediction of CP. However, no machine learning methods have been able to predict later gross motor function in children with CP. The aim of this study was to evaluate the ability of a machine learning procedure to predict ambulatory/non-ambulatory function at 4 years age in children with CP.

**Patients and Methods:** A prospective study of 378 high-risk infants from 6 hospitals in Norway and the USA. All infants were video recorded between 9 and 15 weeks post-term age. The movement frequencies and covariance of legs, arms, trunk, and head were used to develop a CP-score between -1 and 1 of infant movements by a supervised machine learning procedure. The CP-score was compared to the Gross Motor Function Classification System (GMFCS) in the children with CP.

**Results:** The sample comprised 41 children with CP (27 [66%] males, median birthweight 1420g [range 385–4800g], median gestational age 29wks [range 23–42wks]) at a median age of 3.7 years [range 0.7–6.0y]. Twenty-one and 20 children had ambulatory (GMFCS levels I–III) and non-ambulatory function (GMFCS levels IV–V) respectively. The CP-score was significantly higher ( $p < 0.001$ ) for ambulatory (median CP-score -0.026) than non-ambulatory function (CP-score -0.221).

**Conclusion:** The CP-score may be a feasible tool for the prediction of ambulatory versus non-ambulatory function in children with CP.

## Oral presentation 95

### Preferred posture in lying and its relation to scoliosis and windswept hips in adults with cerebral palsy

A AGUSTSSON<sup>1</sup>, E RODBY-BOUSQUET<sup>2</sup>, T SVEINSSON<sup>3</sup>

<sup>1</sup>Endurhaefing - Centre of excellence, Kopavogur, Iceland; <sup>2</sup>CPUP, Department of Orthopaedics, Lund University, Lund, Sweden; <sup>3</sup>Research Centre for Movement Sciences, University of Iceland, Reykjavík, Iceland

**Introduction:** The aim of this study was to clarify the association of scoliosis and windswept hips with immobility, lying position, and time in lying, in adults with cerebral palsy.

**Patients and Methods:** This cross-sectional study included 830 adults (469 males and 361 females) with a diagnosis of CP. Gross motor function classification system level, presence of scoliosis, hip and knee joint range of movement, lying position, postural ability in lying, and time in lying were used to identify connections between them.

**Results:** Adults who are immobile in the lying position have higher odds of both scoliosis and windswept hips. Spending more than 8 hours daily in the same lying position, increased the odds of having scoliosis, while lying solely in a supine position, resulted in higher odds of windswept hips.

**Conclusion:** The preferred posture frequently observed in immobile adults with CP, leads to established deformation of their body shape. The results indicate the need for early introduction of appropriate posture control, in immobile individuals with CP, from a young age. Implications for rehabilitation the preferred posture, observed in immobile adults with cerebral palsy, leads to a distortion of their body shape. One in four adults with cerebral palsy use only one position when in bed. The results indicate the need for early introduction of appropriate posture control in individuals unable to change position. This is associated with instructional course on Posture and Postural Ability Scale (PPAS).

## Oral presentation 96

### Autism spectrum disorder and attention-deficit/hyperactivity disorder in children with cerebral palsy - more common than we think?

M PÅHLMAN<sup>1</sup>, K HIMMELMANN<sup>2</sup>, C GILLBERG<sup>1</sup>

<sup>1</sup>Gillberg Neuropsychiatry Centre, Institute of Neuroscience and Physiology, University of Gothenburg, Gothenburg, Sweden; <sup>2</sup>Department of Pediatrics, Institute of Clinical Sciences, University of Gothenburg, Gothenburg, Sweden

**Introduction:** Associated impairments are common in children with cerebral palsy (CP) and can sometimes be more limiting than the motor disorder. There is a growing awareness that autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD) are more common in CP than in the general population. We described the occurrence of ASD and ADHD, and the associations with CP type, gross motor function, and intellectual level in children with CP.

**Patients and Methods:** A population-based group of 264 children, born 1999 to 2006, from the CP Register of western Sweden, were studied at the age of 10 to 17 years.

Information from all available records were retrieved regarding ASD, ADHD, intellectual level, and other associated impairments. Parents were asked to fill a comprehensive combined screening questionnaire for ASD and ADHD, and responded in 230 of 264 cases. But 19 in the most disabled group could not be assessed, resulting in 211 analyzed questionnaires.

**Results:** ASD was diagnosed in 18% (47/264) and ADHD in 21% (55/264). Positive screening for ASD was found in 35% (74/211) and ADHD in 50% (105/211); of which 29% (61/211) for both disorders. Positive screening was found in children with all CP types, and at all levels of gross motor function, and more likely with increasing intellectual disability (except for profound intellectual disability).

**Conclusion:** ASD and ADHD are common in children with CP, and may still be underdiagnosed. Assessment of ASD and ADHD is needed in all types of CP and functional levels.

### Oral presentation 97

#### Cortical visual function at preschool age in very preterm infants

C BROGNA<sup>1</sup>, D ROMEO<sup>1</sup>, M MALLARDI<sup>1</sup>, C VELLI<sup>1</sup>, F GALLINI<sup>2</sup>, F TINELLI<sup>3</sup>, E MERCURI<sup>1</sup>, D RICCI<sup>1,4</sup>

<sup>1</sup>Pediatric Neurology Unit, Catholic University, Fondazione Policlinico A. Gemelli, IRCCS, Rome, Italy; <sup>2</sup>Neonatal Intensive Care Unit, Catholic University, Fondazione Policlinico A. Gemelli, IRCCS, Rome, Italy;

<sup>3</sup>Department of Developmental Neuroscience, IRCCS Stella Maris Scientific Foundation, University of Pisa, Pisa, Italy; <sup>4</sup>National Centre of Services and Research for Prevention of Blindness and Rehabilitation of Visually Impaired, Rome, Italy

**Introduction:** Very preterm (VPT) children are at high risk for neurological, visual, visuo-spatial, and visuo-cognitive difficulties due to brain lesions or retinopathy of prematurity (ROP). Much less is known on the development of these competences in low-risk VPT children. Aims of this study were to verify the influence of preterm birth per se on the development of visual/motor-perceptual impairment and a possible correlation between visual and motor impairment.

**Patients and Methods:** Inclusion criteria: GA 32 weeks, normal cranial ultrasound scans, ROP stage 2, typical neurodevelopment at 24 months corrected age. Assessment (age 4–5y): WPPSI; visuo-perceptual tests: Stereopsis, Crowding effect, FORM and Motion Coherence test; motor perceptual tests: ABC movement, VMI, ABCDEFV battery.

**Results:** One hundred and nine children (44 males, 65 females) were enrolled; 98 had normal IQ (mean  $98.1 \pm 11.43$  SD), 11 borderline (mean  $77.5 \pm 7.5$  SD). Most children had normal results in both visual and motor-perceptual assessments but for ABCDEFV battery (60% had abnormal results). Not surprisingly, most children with borderline IQ showed abnormal results in all the assessments. Crowding effect and stereopsis significantly correlated with ABC (total-manual), VMI (including the motor coordination subtest), and ABCDEFV battery scores.

**Conclusion:** Our results showed a specific influence of preterm birth per se on the development of visual, visuo-perceptual, and motor-perceptual competences in the absence of brain and ocular pathologies. Interestingly presence of visual

impairment correlated for specific visuo and motor perceptual impairment on different tests this confirming a closer link between dorsal and ventral stream vulnerability.

### Oral presentation 98

#### Pain, fatigue, and sleep disturbances in young adults with cerebral palsy

M VAN GORP<sup>1,2</sup>, L VAN WELY<sup>2</sup>, A DALLMEIJER<sup>2</sup>, W VAN DER SLOT<sup>1,3</sup>, V DE GROOT<sup>2</sup>, H STAM<sup>1</sup>, M ROEBROECK<sup>1,3</sup>

<sup>1</sup>Erasmus University Medical Center, Rotterdam, the Netherlands;

<sup>2</sup>Amsterdam University Medical Center, Amsterdam, the Netherlands;

<sup>3</sup>Rijndam Rehabilitation, Rotterdam, the Netherlands

**Introduction:** Adults with cerebral palsy (CP) often report pain and fatigue, but insight is lacking regarding these health complaints in younger adults compared to references, and associations with sleep disorders and perceived health.

**Patients and Methods:** Young adults with CP ( $n=97$ , 28y 6mo [3y 9mo], 51% GMFCS level I, no intellectual disability) participated. Pain was assessed with a numeric rating scale, and fatigue, sleep disturbance, and global physical and mental health using PROMIS (Patient Reported Outcome Measurement Information System) short forms. Regression analyses were used to evaluate differences in the prevalence of health issues, interrelationships, and associations with perceived health between individuals with CP and age-matched references.

**Results:** Young adults in GMFCS levels II to V reported more pain and fatigue (54%, 46%) compared to references (26%, 37%), whereas individuals in GMFCS level I reported less pain and fatigue (8%, 6%). Proportions of persons with sleep disturbances (28%) were similar to references (34%). Pain and fatigue were more strongly associated in persons with CP (std beta 0.81) than in the references. In persons with CP these health issues correlated most strongly to perceived mental health (std beta  $-0.83$ ,  $-0.74$ ).

**Conclusion:** Individuals with CP in their twenties in GMFCS levels II to V report more pain and fatigue than references, while those in GMFCS level I report these less often. Pain and fatigue are notably interrelated in young adults with CP and affect their perceived mental health. Health professionals should monitor pain and fatigue in individuals in GMFCS levels II to V, and may consider treatment options for both issues in combination.

### Oral presentation 99

#### Machine learning to support 'shared' multilevel surgery decision

E DESAILLY<sup>1</sup>, O GALARRAGA<sup>2</sup>, N KHOURI<sup>3</sup>

<sup>1</sup>Fondation Ellen Poidatz, Saint Fargeau Ponthierry, France; <sup>2</sup>Coubert Rehabilitation Center (UGECAM IDF), Coubert, France; <sup>3</sup>Hôpital Universitaire Necker Enfants Malades, Paris, France

**Introduction:** Clinician's experience is decisive in planning a 'tailor-made' single event multilevel surgery but the objectivity

of this empiricism is not absolute. Gait improvement expectations of the patients with cerebral palsy (CP) may sometimes differ from the surgeon's target outcome. One way to address these considerations is to develop an objective tool for comparing the patient to be operated with those that have already been operated.

**Patients and Methods:** 183 operated children with CP having had clinical gait analysis before and after surgery are included. Spatio-temporal parameters, kinematic angles of both lower limbs, and clinical examination data were considered. For each patient, similar patients are searched by a k-nearest neighbor algorithm. Two options are then possible: the analytical study of the nearest neighbor's outcomes and prediction of the most likely kinematic outcome if the intended surgical strategy has already been performed on the neighbors. Ethical dilemmas are discussed with a sample of users.

**Results:** Average preoperative kinematic root mean square error (RMSE) between the nearest pairs of patients was  $8 \pm 2^\circ$ . Post-operative predictions were possible for 57 patients (31%) with an average RMSE of  $11 \pm 3^\circ$ .

**Conclusion:** The results highlight the need to introduce surgeon's and patient's specific weighting of the different parameters used in the algorithm. Ethical reasoning concerning the usage of this system to support 'shared' multilevel surgery decision will be developed.

## Oral presentation 100

### Does self-perceived gait relate to objective gait assessment in young adults with cerebral palsy?

A BONNEFOY-MAZURE<sup>1</sup>, G DE COULON<sup>2</sup>, S ARMAND<sup>1</sup>

<sup>1</sup>Willy Taillard Laboratory of Kinesiology, Geneva University Hospitals, Geneva, Switzerland; <sup>2</sup>Pediatric Orthopaedic Service, Department of Child and Adolescent, Geneva University Hospitals and Geneva University, Geneva, Switzerland

**Introduction:** Different gait scores can be used to summarise the gait quality of CP patients. Nevertheless, it appears that the perception of the patient about his gait disorder is often neglected. This study explored how CP patients perceive their gait and the relationships between gait perception with gait parameters but also with age, SF36, endurance, pain, and fatigue.

**Patients and Methods:** Fifty-six patients (mean age:  $19.5 \pm 4.7$ y) with CGA were included. Gait scores and gait speed were calculated. Subjective gait score was assessed with the question: 'On a scale from 0 (worst) to 10 (optimal), how you would describe your walk today?' using a visual analogue scale. Endurance 6 minute walking test (6MWT) was also done. Quality of life was evaluated using the SF-36 questionnaire. T-test, Pearson correlations, and the backward stepwise model were used to compare and find relationships between data of interest.

**Results:** The subjective gait score was  $7.2 \pm 1.7$  and was only significantly higher for the group in GMFCS level I compared to GMFCS II to III (respectively:  $7.6 \pm 1.4$  vs  $5.7 \pm 1.8$ ). Positive correlations were found between subjective gait score with: gait speed, distance of 6MWT, SF36 Mental score, physical function, general health, vitality and social function,

and negative correlation with the age. Only age, SF36 mental score and vitality were significant predictors of subjective gait score.

**Conclusion:** Our results demonstrate that subjective gait perception is influenced by level of impairments but has no links with gait scores. CP is a multifactorial disorder with complex interrelation between motor impairments and function.

## Oral presentation 101

### Early infant upper limb assessment: interrater reliability of the Mini-Assisting Hand Assessment for young children with unilateral cerebral palsy

EO NEILL<sup>1</sup>, S GREAVES<sup>2</sup>, L KRUMLINDE SUNDHOLM<sup>3</sup>

<sup>1</sup>Central Remedial Clinic, Dublin, Ireland; <sup>2</sup>Department of Occupational Therapy, The Royal Children's Hospital, Melbourne, Australia; <sup>3</sup>Karolinska Institutet, Department of Woman's and Children's Health, Neuropediatric unit, Stockholm, Sweden

**Introduction:** Early intervention targeted at the affected hand in bimanual play is of critical importance to the development of upper limb skills for children with unilateral cerebral palsy (uCP). To determine if such interventions are effective, the use of valid and reliable assessment tools is of paramount importance. Here, we evaluate the interrater reliability of the Mini-Assisting Hand Assessment (Mini-AHA) in young infants with uCP. Validity has been established but the reliability, with which scores can be consistently reproduced, has yet to be investigated.

**Patients and Methods:** 20 infants with clinical signs of uCP (16 males, 4 females; mean age 13mo [SD 3mo]) were assessed on one occasion using the Mini-AHA. This is an assessment instrument that measures and describes how effectively children with uCP use their affected hand during bimanual play performance. It can discriminate different levels of ability and evaluate change over time. Two raters scored all 20 infants, and in addition, 3 raters each rated a combination of ten infants. Interrater reliability was evaluated using intraclass correlation coefficients (ICCs) for total scores (Mini-AHA units). **Results:** ICC's for the Mini-AHA unit scores were excellent in both the two-rater trial 0.97 (CI: 0.92–0.99) and the combined rater trial 0.98 (CI 0.97–0.99).

**Conclusion:** This study demonstrated excellent interrater reliability for the Mini-AHA. It is a reliable assessment for measuring early infant bimanual hand use in children with uCP, and such findings permits confident use in both clinical and research settings.



## Oral presentation 102

### Constraint-induced movement therapy in children with unilateral cerebral palsy: a Cochrane review update

B HOARE<sup>1,2,3,4</sup>, M WALLEN<sup>5,6</sup>, M THORLEY<sup>7</sup>,  
M JACKMAN<sup>8</sup>, L CAREY<sup>2</sup>, C IMMS<sup>4</sup>

<sup>1</sup>Monash Children's Hospital, Melbourne, Australia; <sup>2</sup>La Trobe University, Melbourne, Australia; <sup>3</sup>Monash University, Melbourne, Australia; <sup>4</sup>Australian Catholic University, Melbourne, Australia; <sup>5</sup>School of Allied Health, Australian Catholic University, Sydney, Australia; <sup>6</sup>Cerebral Palsy Alliance, The University of Sydney, Sydney, Australia; <sup>7</sup>Queensland Paediatric Rehabilitation Service, Brisbane, Australia; <sup>8</sup>John Hunter Children's Hospital, Newcastle, Australia

**Introduction:** Constraint-induced movement therapy (CIMT) aims to improve unimanual capacity and bimanual performance.

**Materials and Methods:** This was a Cochrane systematic review. Randomised controlled trials comparing CIMT with a low dose, high dose, dose-matched comparison or a different form of CIMT in children with unilateral CP, aged 0 to 19 years were included. The search strategy was undertaken in March 2018. Risk of bias was assessed using Cochrane's tool and GRADE used to rate the overall quality of evidence.

**Results:** We included 36 randomised controlled trials including 1264 participants; mean age 5.96 years (SD 1.82), range 3 months to 19.8 years; 53% males; 47% left hemiplegia. Mean total number of hours of CIMT provided was 129 hours (range 20–504hrs). We judged the risk of bias as moderate to high across the studies. Low-quality evidence indicates that CIMT is more effective than a low dose comparison for improving bimanual performance immediately following intervention (mean difference [MD] 5.44 AHA units, 95% CI 2.37–8.51). CIMT was not more effective for improving bimanual performance immediately following intervention when compared with high dose (MD –0.39 AHA units, 95% CI –3.14 to 2.36) or dose-matched intervention (MD 0.80 AHA units, 95% CI –0.78 to 2.38).

**Conclusion:** For children with unilateral CP, there is low to very low evidence that CIMT results in improved bimanual performance and unimanual capacity when compared to a low dose comparison, but not when compared to a high dose or dose-matched comparison.

## Oral presentation 103

### Emerging evidence for accelerated aging through longitudinal evaluation of cardiovascular disease risk factors in individuals with cerebral palsy

P MCPHEE<sup>1,2</sup>, MJ MACDONALD<sup>2</sup>, JL CHENG<sup>2</sup>,  
EC DUNFORD<sup>2</sup>, JW GORTER<sup>1</sup>

<sup>1</sup>Department of Pediatrics, McMaster University, Hamilton, Canada;

<sup>2</sup>Department of Kinesiology, McMaster University, Hamilton, Canada

**Introduction:** The objectives of this study were: (1) to examine longitudinal changes in traditional and non-traditional cardiovascular disease (CVD) risk factors in individuals with cerebral palsy (CP); and (2) to investigate relationships between Gross

Motor Function Classification System (GMFCS) level, age, and CVD risk factors.

**Patients and Methods:** Twenty-eight individuals with CP (GMFCS levels I–V) participated in a longitudinal study. Traditional CVD risk factors included waist circumference and systolic blood pressure. Non-traditional CVD risk factors included carotid artery intima media thickness (cIMT) and distensibility, carotid-femoral pulse wave velocity (cfPWV), and flow mediated dilation (FMD). Repeated measures ANOVA were performed to compare variables at baseline and follow-up. Multiple linear regressions were performed to assess the relationship between age and GMFCS level with traditional and non-traditional CVD risk factors.

**Results:** Follow-up time was 4.0±1.2 years (follow-up mean age=35.1±14.4). Absolute (0.31±0.13 vs 0.22±0.08mm,  $p=0.045$ ) and relative FMD (9.9±4.7 vs 7.5±2.6%,  $p=0.049$ ) decreased while cIMT (0.52±0.17 vs 0.67±0.33mm,  $p=0.041$ ) increased from baseline to follow-up. Age at baseline was a significant independent predictor of cIMT change ( $R^2=0.261$ ,  $p=0.031$ ).

**Conclusion:** Individuals with CP experienced significant changes in non-traditional CVD risk factors over four years, despite no change in traditional risk factors. Age was strongly associated with change in cIMT in this cohort and this relationship should be considered in the surveillance of CVD in young adults with CP and continue throughout the lifespan.

## Oral presentation 104

### Parent, child and clinician experience with a child-engaged approach to rehabilitation goal setting: a qualitative study

L PRITCHARD-WIART<sup>1</sup>, A MCKILLOP<sup>1</sup>, J ANDERSEN<sup>2,3</sup>,  
S PHELAN<sup>1</sup>, S MAH<sup>3</sup>, M BULAT<sup>3</sup>

<sup>1</sup>Faculty of Rehabilitation Medicine, University of Alberta, Edmonton,

Canada; <sup>2</sup>Faculty of Medicine and Dentistry, University of Alberta,

Edmonton, Canada; <sup>3</sup>Glenrose Rehabilitation Hospital, Edmonton, Canada

**Introduction:** Despite a focus on family-centred service delivery and collaborative decision-making, children are rarely optimally engaged in identifying their own rehabilitation goals. Increased child engagement may enhance child and parent motivation and improve meaningful child outcomes. The objective of this study was to explore child, parent, and clinician experiences with a child-engaged approach to rehabilitation goal setting.

**Patients and Methods:** Interpretive description was used to guide data collection and analysis. Children with cerebral palsy aged 5 to 12 years ( $n=7$ ), their parents ( $n=8$ ), therapists ( $n=2$ ), nurse practitioner ( $n=1$ ), and physician ( $n=1$ ) participated in individual interviews about their experiences with a child-engaged approach to rehabilitation goal setting. Goal setting for inpatient and outpatient rehabilitation was guided by four main principles: (1) child first, (2) goal setting is a collaborative process, (3) goals guide intervention, and (4) goals and knowledge of goal progress nurture motivation. Strategies included use of child/parent videos and pictures for goal discussion and goal setting tools designed for children. Goal identification discussions were grounded in the goals identified

by children. Thematic analysis was conducted as described by Knafl and Webster (1988).

**Results:** Three themes were identified: (1) it is crucial for children to have a voice, (2) child identified goals are rewarding and motivating for children, and (3) families value and want professional input in goal setting.

**Conclusion:** The results suggest that a child-engaged goal setting approach is meaningful for children, their parents, and clinicians. Collaborative approaches to goal setting that optimize child engagement should be further evaluated and considered in practice.

## Oral presentation 105

### Walking speed in children with cerebral palsy: laboratory versus daily-life

L CARCREFF<sup>1,2,3</sup>, CN GERBER<sup>1</sup>, A PARASCHIV-IONESCU<sup>3</sup>, K AMINIAN<sup>3</sup>, CJ NEWMAN<sup>1</sup>, S ARMAND<sup>2</sup>

<sup>1</sup>Paediatric Neurology and Neurorehabilitation Unit, Department of Pediatrics, Lausanne University Hospital, Lausanne, Switzerland; <sup>2</sup>Laboratory of Kinesiology Willy Taillard, Geneva University Hospitals and University of Geneva, Geneva, Switzerland; <sup>3</sup>Laboratory of Movement Analysis and Measurement, Ecole Polytechnique Fédérale de Lausanne, Lausanne, Switzerland

**Introduction:** Walking speed is considered as the sixth vital sign. We aimed at comparing the walking speed in laboratory and in daily-life (DL) of children with cerebral palsy (CP) as compared to children with typical development (TD).

**Patients and Methods:** Fifteen children with CP and 14 children with TD wore inertial sensors during in-laboratory gait assessments and during 3 consecutive days in DL. In-laboratory and DL speeds were compared using Wilcoxon paired tests in each group. We also compared the proportion of children in the three following categories: 'DL<Laboratory', 'DL=Laboratory' and 'DL>Laboratory', based on the comparison of median DL speed and the range of in-laboratory speed.

**Results:** DL speed was found lower than in-laboratory speed within the overall CP group ( $p=0.018$ ), whereas no difference was found for the TD group ( $p=0.153$ ). None of the children with CP were in the 'DL>Laboratory' category, 47% were in the 'DL=Laboratory' and 53% were in the 'DL<Laboratory'. Half of the children with TD were in the 'DL>Laboratory' category, 21% in the 'DL=Laboratory', and 29% in the 'DL<Laboratory'.

**Conclusion:** Gait assessed in laboratory and DL settings, which can be associated to capacity and performance respectively, as described by the International Classification of Functioning, does not correlate. This result supports the need to complement laboratory assessment with performance evaluation to improve the understanding of the patient's difficulties. Moreover, children with CP seem not to fully exploit their gait capacities in DL.

## Oral presentation 106

### Prediction of gait impairment in children born very preterm from near-term brain microstructure assessed with diffusion tensor imaging, using exhaustive feature selection and cross-validation

K SCHADL<sup>1,2</sup>, K CAHILL-ROWLEY<sup>1,3</sup>, K SCHADL<sup>1,2</sup>, R VASSAR<sup>1</sup>, K YEOM<sup>4</sup>, DK STEVENSON<sup>5</sup>, J ROSE<sup>1,3</sup>

<sup>1</sup>Department of Orthopaedic Surgery, Neonatal Neuroimaging Research Lab, Stanford University School of Medicine, Stanford, USA; <sup>2</sup>Semmelweis University School of Medicine, Budapest, Hungary; <sup>3</sup>Motion & Gait Analysis Lab, Lucile Packard Children's Hospital, Stanford, USA; <sup>4</sup>Department of Radiology, Lucile Packard Children's Hospital, Stanford University School of Medicine, Stanford, USA; <sup>5</sup>Division of Neonatal and Developmental Medicine, Stanford University School of Medicine, Stanford, USA

**Introduction:** The aim of this study was to predict gait impairment in toddlers born preterm with very-low-birthweight (VLBW), from near-term white-matter microstructure assessed with diffusion tensor imaging (DTI), using exhaustive feature selection and cross-validation.

**Patients and Methods:** Near-term MRI and DTI of 48 bilateral and corpus callosum regions were assessed in 66 VLBW preterm infants; at 18 to 22 months adjusted-age. 52/66 participants completed follow-up gait assessment of velocity, step length, step width, single-limb support (SLS), and the Toddler TDI. Multiple linear models with exhaustive feature selection and leave-one-out cross-validation were employed in this prospective cohort study: linear and logistic regression identified three brain regions most correlated with gait outcome.

**Results:** Logistic regression of near-term DTI correctly classified infants high-risk for impaired gait velocity (93% sensitivity, 79% specificity), right and left step length (91% and 93% sensitivity, 85% and 76% specificity) and SLS (100% and 100% sensitivity, 100% and 100% specificity), step width (85% sensitivity, 80% specificity), and Toddler TDI (85% sensitivity, 75% specificity). Linear regression of near-term brain DTI and toddler gait explained 32–49% variance in gait temporal-spatial parameters. Traditional MRI methods did not predict gait.

**Conclusion:** Near-term brain microstructure analyzed using DTI and statistical learning methods predicted gait impairment and explained substantial variance in toddler gait. Single-limb-support was most accurately predicted.

## Oral presentation 107

### Relationship between early visual functions and brain lesion characteristics in congenital hemiplegia

A BANCALE<sup>1</sup>, A GUZZETTA<sup>1,2</sup>, F ABBATE<sup>1</sup>, G CIONI<sup>1,2</sup>, S FIORI SIMONA<sup>1</sup>

<sup>1</sup>Department of Developmental Neuroscience, IRCCS Stella Maris Foundation, Pisa, Italy; <sup>2</sup>Department of Clinical and Experimental Medicine, University of Pisa, Pisa, Italy

**Introduction:** Visual deficits are common in children with unilateral brain lesions. However, the impact of type and timing of the brain insult are unclear. We assessed cerebral visual

disorders (CVD) with a detailed new clinical tool in infants with hemiplegia during the first two years of life. We explored the relationship between CVD and brain lesion timing and characteristics.

**Patients and Methods:** Multiple visual assessment of 30 infants were grouped according to age at evaluation (total assessments 47: 0–4mo=5; 5–12mo=21; 13–24mo=21) and type/timing of brain lesion (stroke,  $n=23$  and venous infarction,  $n=7$ ). Brain MRI performed before 24 months (mean  $9.6 \pm 10.35$ ) was assessed by a semi-quantitative MRI (sqMRI) scale for brain lesion severity. Visual functions (VF) were assessed with a new scale testing the following areas: spontaneous visual behaviour, ocular motility, primary visual perception, and early visual adult-infant interaction. Within each subgroup, Spearman's Rho was used to test the correlation between sqMRI and VF.

**Results:** A significant correlation was found between sqMRI scores and CVD in the first year of life, in particular with the area of primary visual perception. Higher correlations were found in infants with perinatal stroke as compared to those with periventricular lesions. No correlation remained in the second year.

**Conclusion:** In children with unilateral brain lesions, the severity of visual disorders correlates with the lesion characteristics when vision is assessed during the first but not during the second year. This might be related to maturation and adaptive neuroplasticity.

## Oral presentation 108

### Synergy weights are similar between different gait patterns in children with cerebral palsy

M GOUDRIAAN<sup>1</sup>, E PAPAGEORGIOU<sup>1</sup>, BR HUMAN<sup>2</sup>, KM STEELE<sup>2</sup>, G MOLENAERS<sup>3</sup>, K DESLOOVERE<sup>1</sup>

<sup>1</sup>Department of Rehabilitation Sciences, University of Leuven, Leuven, Belgium; <sup>2</sup>Mechanical Engineering, University of Washington, Seattle, WA, USA; <sup>3</sup>Department of Development and Regeneration, University of Leuven, Leuven, Belgium

**Introduction:** In cerebral palsy (CP) complexity of motor control from synergy analysis is related to the gait deviation index. However, the contribution of individual muscles within a synergy may differ per single joint gait pattern. The aim of this study was to assess differences in synergy weights for individual joint patterns in CP.

**Patients and Methods:** We collected electromyography of rectus femoris (REF), medial hamstring (MEH), tibialis anterior (TIA), medial gastrocnemius (GAS), and gluteus medius (GLU) during gait in 106 children with CP (4–15y; GMFCS levels I–III). We calculated synergies with non-negative matrix factorization. The number of synergies explaining 95% of the variance (N95) was extracted. We used k-means cluster analysis ( $k=5$ ) to find similar synergies and classified knee (minor, increased flexion, or stiff knee) and ankle (minor, equinus, or calcaneus) patterns during stance and swing. Weight differences were assessed with a Kruskal-Wallis and post-hoc Mann-Whitney  $U$  test ( $\hat{I} \pm 0.005$ ).

**Results:** No significant differences in weights, nor in N95, were found between the patterns. For the whole group, median (interquartile range) of N95 was 3 (1). The first synergy was

characterized by high activity of the MEH (0.57 [0.28]) and GLU (0.50 [0.32]), the second by GAS (0.70 [0.27]), and the third by REF (0.51 [0.30]) and TIA (0.66 [0.23]).

**Conclusion:** With synergy analysis, the contribution of muscles to the whole gait pattern is assessed instead of on a joint level. Comparison of synergy weights and activations between total patterns (e.g. crouch vs jump gait) might give new insights.

## Oral presentation 109

### Potentials of lung ultrasound for the assessment of feeding-related aspiration in infants: a pilot study

S FIORI<sup>1</sup>, E MORETTI<sup>1</sup>, G CIONI<sup>1,2</sup>, L GARGANI<sup>3</sup>, A GUZZETTA<sup>1,2</sup>

<sup>1</sup>Department of Developmental Neuroscience, IRCCS Stella Maris Foundation, Pisa, Italy; <sup>2</sup>Department of Clinical and Experimental Medicine, University of Pisa, Pisa, Italy; <sup>3</sup>Institute of Clinical Physiology, National Research Council, Pisa, Italy

**Introduction:** Children with neurological impairment (CNI) often show abnormal ingestion functions, which predispose to aspiration-induced acute and chronic lung disease, malnutrition, further neurodevelopmental disturbances, and disorders of carer-infant interaction. Our aim was to test the hypothesis that lung ultrasound (LUS) is effective in detecting meal-related pulmonary abnormalities in CNI.

**Patients and Methods:** LUS examinations were performed in 10 CNI (mean age  $18.5 \pm 8.6$ mo; GMFCS level II–V, median=4) and in 4 controls (mean age  $17.2 \pm 7.8$ mo) before and immediately after a meal (within 10min). We established a dedicated LUS score according to previous literature (score range=0–18). Feeding ability was assessed with an adapted version of the eating and drinking ability classification system (EDACS). **Results:** Changes in LUS score before and after meal were detected only in CNI (pre-meal  $1.8 \pm 2.5$  vs post-meal  $4.5 \pm 2.7$ ,  $p=0.001$ ), with very large effect size (Cohen's  $d=2.1$ ). A correlation emerged between pre- and post-meal LUS differences and GMFCS ( $p=0.03$ ,  $r=0.49$ ). Furthermore, a correlation emerged between pre- and post-meal LUS differences and EDACS levels ( $p=0.009$ ,  $r=0.62$ ). Notably, the LUS score pre-meal was already worse in CNI compared to controls ( $1.8 \pm 2.5$  vs  $0.2 \pm 0.5$ ).

**Conclusion:** These preliminary data are the first observation of LUS changes before and after a meal in CNI and correlations with clinical measures. These results make LUS extremely promising as a versatile tool to monitor meal-related pulmonary aeration changes in CNI.

## Oral presentation 110

### Assessment of Motor Repertoire predicts neurodevelopmental outcomes in very preterm infants

C PEYTON<sup>1</sup>, J MARKS<sup>2</sup>, C EINSPIELER<sup>3</sup>,  
M SCHREIBER<sup>2</sup>, M MSALL<sup>2</sup>

<sup>1</sup>Northwestern University, Chicago, IL, USA; <sup>2</sup>University of Chicago, Chicago, IL, USA; <sup>3</sup>University of Graz, Graz, Austria

**Introduction:** Prechtl's General Movement Assessment (GMA) is the most sensitive tool for detecting cerebral palsy in infancy, but is less accurate in predicting non-motor dysfunction that is more prevalent in very preterm infants. The Assessment of Motor Repertoire (AMR), details GMA scoring and measures additional spontaneous infant behaviors including posture, movement character, motor repertoire, and movement quality. Our aim was to evaluate if the AMR predicted language, cognitive, and non-cerebral palsy motor dysfunction in very preterm infants better than GMA alone.

**Patients and Methods:** 123 infants born approximately 31 weeks and <1500g were assessed with the GMA and AMR (between 10–15wks corrected age), and the Bayley Scales of Infant and Toddler Development at 2 years corrected age. For each Bayley subscale we used multiple regression to include GMA alone and AMR as predictors of Bayley subscales.

**Results:** The GMA and the AMR were significantly associated with all Bayley subscales at 2 years. The inclusion of AMR substantially increased the contribution of these assessments to the proportion of variance in the language (R<sup>2</sup> GMA=0.11, R<sup>2</sup> AMR=0.16) motor (R<sup>2</sup> GMA=0.12, R<sup>2</sup> AMR=0.20) and cognitive (R<sup>2</sup> GMA=0.11, R<sup>2</sup> AMR=0.23) Bayley subscales.

**Conclusion:** The additional spontaneous infant behaviors measured by the AMR may be an early and important indicator of cognitive, language and motor performance in VLBW infants. The AMR may be a useful tool in directing motor and developmental delays requiring early intervention supports in high-risk infant populations.

## Oral presentation 111

### Structural neural networks in adolescents with periventricular leukomalacia: evidence for perceptual visual impairments

C BAUER<sup>1,2</sup>, E BAILIN<sup>1,2</sup>, C BENNETT<sup>1,2</sup>, P BEX<sup>3</sup>,  
L MERABET<sup>1,2</sup>

<sup>1</sup>Harvard Medical School, Boston, MA, USA; <sup>2</sup>Massachusetts Eye and Ear, Boston, MA, USA; <sup>3</sup>Northeastern University, Boston, MA, USA

**Introduction:** Perceptual visual impairments are reported in the majority of individuals with periventricular leukomalacia (PVL), yet the underlying neural correlates are unknown. The observed visual impairments often include difficulties with motion perception, complexity/simultanagnosia, and attention. This study uses diffusion tractography methods to determine the potential neurophysiological mechanism underlying perceptual visual dysfunctions associated with PVL.

**Patients and Methods:** A cohort of adolescents with PVL and typically developing controls were enrolled. Participants with

PVL were also diagnosed with spastic diplegia and cerebral visual impairment (CVI). Each participant completed a battery of psychophysical assessments, including motion perception and visual search. Tractography was performed using data obtained on a Philips 3T Achieva using a high angular resolution diffusion imaging (HARDI) protocol. The inferior fronto-occipital (IFOF), superior longitudinal (SLF), and inferior longitudinal fasciculi (ILF) were reconstructed for the neural correlates of the dorsal and ventral streams. Metrics of network integrity (including node strength and degree) were also examined across the whole brain.

**Results:** Significant impairments in motion perception and visual search were observed in individuals with PVL compared to controls ( $p<0.05$ ). Volumes of the SLF, ILF, and IFOF were significantly reduced ( $p<0.05$ ), while anisotropy was increased. Node strength and degree were significantly decreased throughout the brain in individuals with PVL, particularly in the nodes surrounding the lateral ventricle.

**Conclusion:** These data indicate that alterations in the white matter connectivity of the dorsal and ventral visual streams may correspond to the visual perceptual impairments observed in individuals with PVL.

## Oral presentation 112

### The perceived effects of taking part in RaceRunning on health and wellbeing

M VAN DER LINDEN<sup>1</sup>, M VERHEUL<sup>2</sup>, N TENNANT<sup>3</sup>,  
R BYRNE<sup>1</sup>, F VON WALDEN<sup>4</sup>

<sup>1</sup>Queen Margaret University, Edinburgh, UK; <sup>2</sup>University of Edinburgh, Edinburgh, UK; <sup>3</sup>RaceRunning Scotland, Ayr, UK; <sup>4</sup>Karolinska Institutet, Stockholm, Sweden

**Introduction:** RaceRunning allows people with moderate-to-severe disability to take part in an aerobic activity involving some weight bearing. The aim of this study was to explore the perceived benefits and risks associated with RaceRunning.

**Patients and Methods:** A survey containing 25 questions was distributed to RaceRunning coaches and athletes in the UK and Sweden. Completing and returning the survey implied informed consent. Completion by proxy was allowed.

**Results:** Sixty-five athletes (38 females) completed the survey (Sweden  $n=40$ , UK  $n=24$ , USA,  $n=1$ ). Median age was 16 years (range 5–63y) and the majority relied on a wheelchair (50%) or walker (20%) over a distance of 50m. Most athletes had been involved with RaceRunning for more than one year (83%) and trained once a week (64%). Only one athlete reported a RaceRunning related injury that lasted more than 4 weeks. The majority had made new friends through RaceRunning (93%) and felt taking part in RaceRunning had increased their confidence (96%). Respondents who had been involved in RaceRunning for 3 months or more reported to be a lot less (18%) or a bit less (23%) out of breath during their usual mobility tasks. The majority also felt that their functional mobility was improved (23%: 'a lot', 45%: 'a bit') and reported decreased muscle tightness (15%: 'a lot', 37%: 'a bit'). Only six respondents (10%) reported increased muscle tightness. Sleep quality was perceived to have improved (31%: 'a lot', 31%: 'a bit').



*Conclusion:* Athletes perceive a variety of benefits from taking part in RaceRunning. These results also confirm the feasibility of this activity and the importance of stretching.

### Oral presentation 113

#### Sports participation in children with neonatal brachial plexus palsy

M VAN DER HOLST<sup>1</sup>, F HARBERTS<sup>2</sup>, D STEENBEEK<sup>3</sup>, W PONDAAG<sup>3</sup>, R NELISSEN<sup>3</sup>, T VLIET VLIELAND<sup>1</sup>

<sup>1</sup>Basalt Rehabilitation, Leiden University Medical Center, Leiden, the Netherlands; <sup>2</sup>Basalt Rehabilitation, The Hague, the Netherlands; <sup>3</sup>Leiden University Medical Center, Leiden, the Netherlands

*Introduction:* Children with neonatal brachial plexus palsy (NBPP) may have life-long impaired upper extremity function. Exercise and sports is important for them to prevent an inactive lifestyle. To date it is not known to what extent children with NBPP participate in sports, in what kinds of sport, and if this influences health-related quality-of-life (HR-QoL).

*Patients and Methods:* To quantify and characterise sports participation and HR-QoL in children with NBPP, all children aged 8 to 19 years seen at our NBPP clinic were asked to complete the Short Questionnaire to Assess Health and Activity for Adolescents and the Pediatric Outcome Data Collection Instrument (PODCI). Sports participation and PODCI scales were compared between children with different treatment history: surgical (i.e. greater lesion extent/severity) or conservative treatment.

*Results:* One-hundred-eighty-four children participated (median age 12y, IQR 10–14y), of which 71.4% underwent surgery. One-hundred-forty-one (77%) participated in sports, with no differences between treatment groups. Ninety-three children provided information on sports selection: 40 (43%) were active in predominantly-lower extremity sports, 34 (36%) in sports which require active use of one arm, and 22 (21%) in sports necessitating active use of two arms. In the surgery group, significantly less children played sports involving two arms (9% vs 38%,  $p=0.007$ ). Those involved in sports scored significantly higher on the PODCI Sports and Happiness scales, irrespective of treatment history ( $p<0.05$ ).

*Conclusion:* Most NBPP children participated in sports and sport-selection was associated with lesion extent and severity. Those involved in sports reported significantly higher HR-QoL than those that do not.

### Oral presentation 114

#### Early prediction of unilateral cerebral palsy in infants with asymmetric perinatal brain injury: model development and internal validation

UC RYLL<sup>1</sup>, N WAGENAAR<sup>2</sup>, C VERHAGE<sup>3</sup>, M BLENNOW<sup>4</sup>, L DE VRIES<sup>2</sup>, A-C ELIASSON<sup>1</sup>

<sup>1</sup>Department of Women's and Children's Health, Karolinska Institutet, Stockholm, Sweden; <sup>2</sup>University Medical Center Utrecht, Department of Neonatology, Utrecht, the Netherlands; <sup>3</sup>University Medical Center Utrecht, Child Development and Exercise Center, Utrecht, the Netherlands; <sup>4</sup>Department of Clinical Science, Intervention and Technology, Karolinska Institutet, Stockholm, Sweden

*Introduction:* Early diagnosis of unilateral cerebral palsy is important after asymmetric perinatal brain injury (APBI). Our objective is to estimate the risk of unilateral cerebral palsy (UCP) in infants with APBI during the first months of life using neuroimaging and clinical assessment.

*Patients and Methods:* Prognostic multivariable prediction modelling study including 52 infants (27 males), median gestational age 39.3 weeks with APBI from Sweden ( $n=33$ ) and the Netherlands ( $n=19$ ). Inclusion criteria: (1) neonatal MRI within one month after term-equivalent age (TEA), (2) Hand Assessment for Infants (HAI) between 3.5 and 4.5 months of age. UCP was diagnosed approximately 24 months of age. Firth regression with cross-validation was used to construct and internally validate the model to estimate the risk for UCP based on the predictors corticospinal tract (CST) and basal ganglia/thalamus (BGT) involvement, contralesional HAI Each hand sum score (EaHS), gestational age, and sex.

*Results:* UCP was diagnosed in 18 infants (35%). Infants who developed UCP more often had involvement of the CST and BGT on neonatal MRI and had lower contralesional HAI EaHS compared to those who did not develop UCP. The final model showed excellent accuracy for UCP prediction between 3.5 and 4.5 months (area under the curve=0.980; 95% CI 0.95–1.00).

*Conclusion:* Combining neonatal MRI, the HAI, gestational age, and sex accurately identify the prognostic risk of UCP at 3.5 to 4.5 months in infants with APBI.

### Oral presentation 115

#### Critical reflection on walking devices for children with cerebral palsy and introducing an innovative walking aid providing alignment and enabling individually adjusted support

R CUPPERS<sup>1</sup>, D WENMAKERS<sup>2</sup>, J SEYLER<sup>3</sup>

<sup>1</sup>University of Antwerp, Mechelen, Belgium; <sup>2</sup>DWEN, Dilsen-Stokkem, Belgium; <sup>3</sup>VIGO, Hasselt, Belgium

*Introduction:* Walking aids are widely used by children with cerebral palsy (CP). Unfortunately, this often comes at the cost of poor alignment which can increase the risk for musculoskeletal deformities and even loss of walking in the long term. An optimal walking device should maintain a balance between body structure and function on the one hand and activity and participation on the other. A multidisciplinary

team developed a new walking device based on the clinical need for better alignment, proper muscle activity, weight bearing (i.e no saddle) and walking handsfree.

**Patients and Methods:** Next to developing a new walking device, PubMed and parallel databases were searched for 'walking aids' and 'cerebral palsy' including related terms. This resulted in 1815 articles of which 27 were selected based on inclusion criteria and the Oxford levels of evidence.

**Results:** Walking devices can be classified into handheld-walkers, gait trainers, and robotic devices. These differ regarding the degree of support provided to body segments, the quantity of weight-bearing, and self-initiated or actuated movements. No clear evidence-based recommendations regarding the use of walking devices in CP are currently available. Based on clinical experience, the innovative walking device might provide better alignment by having an individually adjustable amount of support and the possibility to walk hands-free.

**Conclusion:** Selecting an appropriate walking aid for the individual child may not only affect the child's activity and participation but also the body structure and function. The developed device might strike a better balance to address this issue, but further research is necessary.

## Oral presentation 116

### Cognition and bimanual performance in children with unilateral cerebral palsy: a multicentre, cross-sectional study

B HOARE<sup>1,2,3,4</sup>, A CRICHTON<sup>1</sup>, M DITCHFIELD<sup>1</sup>, M THORLEY<sup>5</sup>, M WALLEN<sup>6,7</sup>, J BRACKEN<sup>8</sup>, A HARVEY<sup>9</sup>, I NOVAK<sup>7</sup>, C ELLIOTT<sup>10</sup>, S-M GWINI<sup>11,12</sup>

<sup>1</sup>Monash Children's Hospital, Melbourne, Australia; <sup>2</sup>La Trobe University, Melbourne, Australia; <sup>3</sup>Monash University, Melbourne, Australia; <sup>4</sup>Australian Catholic University, Melbourne, Australia; <sup>5</sup>Queensland Paediatric Rehabilitation Service, Brisbane, Australia; <sup>6</sup>School of Allied Health - Australian Catholic University, Melbourne, Australia; <sup>7</sup>Cerebral Palsy Alliance, The University of Sydney, Sydney, Australia; <sup>8</sup>Royal Children's Hospital, Melbourne, Australia; <sup>9</sup>Murdoch Children's Research Institute, Melbourne, Australia; <sup>10</sup>Curtin University, Perth, Australia; <sup>11</sup>School of Public Health & Preventive Medicine - Department of Epidemiology - Monash University, Melbourne, Australia; <sup>12</sup>University Hospital Geelong - Barwon Health, Geelong, Australia

**Introduction:** Motor outcomes of children with unilateral cerebral palsy (CP) are clearly documented, yet few studies describe the cognitive functioning in this population, and the associations between the two is poorly understood.

**Patients and Methods:** This was a prospective, cross-sectional multi-centre observational study. A convenience sample of 78 children (46 males, 37 left hemiplegia, mean age 9.0y, SD 1.9y; MACS I [ $n=24$ ], MACS II [ $n=54$ ]) with unilateral CP and without intellectual impairment were recruited. We examined associations between cognition, namely executive functions (EF), and bimanual performance. Primary outcomes included: Bimanual performance – the Assisting Hand Assessment (AHA) and Cognition (EF) – information processing (NEPSY – semantics total score); attention control (Test of Everyday Attention for Children (TEA-Ch) – time/target scores); cognitive flexibility (Neuropsychology Assessment for Children-II (NEPSY) – inhibition combined scores); and goal

setting (Tower of London – total z-scores). Data were analysed using linear regression models. The model was adjusted for unimanual capacity and general cognitive ability.

**Results:** Prior to adjusting for covariates, all 4 domains of EF including information processing ( $p=0.006$ ), attention control ( $p=0.015$ ), cognitive flexibility ( $p<0.001$ ), and goal setting ( $p=0.015$ ) significantly impacted bimanual performance (AHA). After adjusting for general cognitive ability and unimanual capacity, only a significant effect for cognitive flexibility on bimanual performance remained ( $p=0.04$ ).

**Conclusion:** This data partially supports our hypothesis that high-level cognitive function (particularly cognitive flexibility) may impact how children with unilateral CP, without intellectual impairment, perform bimanual tasks.

## Oral presentation 117

### Survival and mortality in cerebral palsy: observations to the sixth decade from a data linkage study of a total population register and national death index

K LANGDON<sup>1</sup>, E BLAIR<sup>2</sup>, K LANGDON<sup>1</sup>, S MCINTYRE<sup>3</sup>, D LAWRENCE<sup>4</sup>, L WATSON<sup>5</sup>

<sup>1</sup>Perth Children's Hospital, Perth, Australia; <sup>2</sup>Telethon Kids' Institute, Perth, Australia; <sup>3</sup>Cerebral Palsy Alliance, Sydney, Australia; <sup>4</sup>University of Western Australia, Perth, Australia; <sup>5</sup>King Edward Memorial Hospital, Perth, Australia

**Introduction:** Patterns of survival in people with cerebral palsy (CP) is of interest to individuals with CP, their families, health professionals, health economists, and insurers. We describe patterns of survival and mortality to the sixth decade in a geographically defined population of people with CP stratified by clinical description of their impairments in early childhood.

**Patients and Methods:** Children with CP born in Western Australia (WA) from 1956 to 2011, and registered on the WA Register of Developmental Anomalies, were linked to the Australian National Death Index in December 2014. Patterns of mortality were investigated using survival analysis methods.

**Results:** Of 3185 eligible persons, 436 (13.7%) had died. 37% of the sample with the mildest impairment had survival patterns reflecting the general population. For the remainder, mortality increased with the severity of impairment. Of 349 (75%) with cause of death available, 58.6% were attributed to respiratory causes including 171 (49%) due to pneumonia at mean age 14.6 years (SD 13.4). For the most severely impaired, early childhood mortality increased in succeeding decades of birth cohorts from 1950s to 1990 however it then decreased for subsequent birth cohorts. Notably, in the cohort of children born from 1991 to 2000 with the most severe impairments, mortality by 20 years of age exceeded that of all other birth cohorts.

**Conclusion:** For individuals with CP and mild impairment survival is similar to that of the general population. Since 1990 mortality for those with severe CP in WA has shifted from childhood to young adulthood.

## Oral presentation 118

### The Hammersmith Infant Neurological Examination: predicting outcomes other than cerebral palsy?

D ROMEO<sup>1</sup>, F SINI<sup>1</sup>, C VELLI<sup>1</sup>, F COWAN<sup>2</sup>,  
L HAATAJA<sup>3,4</sup>, S SIVO<sup>1</sup>, G LEO<sup>1</sup>, D RICCI<sup>1</sup>, E MERCURI<sup>1</sup>

<sup>1</sup>Pediatric Neurology Unit, Fondazione Policlinico A. Gemelli, IRCCS, Rome, Italy; <sup>2</sup>Department of Paediatrics, Imperial College, London, UK; <sup>3</sup>Pediatric Neurology, Children's Hospital, University of Helsinki, Helsinki, Finland; <sup>4</sup>Helsinki University Hospital, Helsinki, Finland

**Introduction:** The Hammersmith Infant Neurological Examination (HINE) is recommended for the early prediction of cerebral palsy (CP). However, no data are reported using the HINE to detect a high-risk for other atypical outcomes.

**Patients and Methods:** We conducted a retrospective study on 1626 high-risk infants (term  $n=665$ , preterm  $n=961$ ). The HINE was performed sequentially between 3 and 12 months corrected age. At 2 years the Bayley Scales of Infant Development and a neurological assessment were undertaken, when infants were classified as typical or atypical (CP or an MDI <70). The predictive validity of the HINE was calculated for two different outcomes (atypical outcome with/without CP) using specific cut-off scores according to the age at assessment.

**Results:** Of the 1626 infants, 1150 had a typical outcome whereas 475 were found atypical (154 with CP, 321 without CP). At 3 months, a cut-off score of 59/78 showed a sensitivity and specificity of 65% and 97% respectively, for detecting atypical outcome, and of 52% and 97% for atypical outcome without CP. A progressive improvement in the predictive power was observed up to 12 months (cut-off score 70/78) with a sensitivity and specificity respectively of 81% and 94%, for atypical outcome, and of 76% and 94% for atypical outcome without CP.

**Conclusion:** In high-risk infants the HINE proved to be a good tool for detecting infants with atypical neurodevelopmental outcome without CP. Its predictive power progressively improved during the first year after birth.

## Oral presentation 119

### Speech and language features of bilateral perisylvian polymicrogyria: a systematic review

RO BRADEN<sup>1,2</sup>, R LEVENTER<sup>1,2,3</sup>, A JANSEN<sup>4,5</sup>,  
IE SCHEFFER<sup>3,6,7,8</sup>, AT MORGAN<sup>1,2</sup>

<sup>1</sup>Murdoch Children's Research Institute, Melbourne, Australia; <sup>2</sup>Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne, Melbourne, Australia; <sup>3</sup>Royal Children's Hospital, Melbourne, Australia; <sup>4</sup>Neurogenetics Research Group, Reproduction Genetics and Regenerative Medicine Research Cluster, Vrije Universiteit Brussel, Brussels, Belgium; <sup>5</sup>Pediatric Neurology Unit, Department of Pediatrics, UZ Brussel, Brussels, Belgium; <sup>6</sup>Epilepsy Research Centre, Department of Medicine, The University of Melbourne, Austin Health, Melbourne, Australia; <sup>7</sup>Department of Paediatrics, The University of Melbourne, Melbourne, Australia; <sup>8</sup>The Florey Institute of Neuroscience and Mental Health, Melbourne, Australia

**Introduction:** Bilateral Perisylvian Polymicrogyria (BPP) is a malformation of cortical development characterised by

excessive microscopic gyration and abnormal cortical lamination of the Sylvian fissures and surrounding cerebral cortex. Confusion in terminology exists due to the multiplicity of terms used to describe what is now defined as BPP based on imaging findings. Despite communication impairment being frequently reported in BPP, no studies have comprehensively evaluated the speech, language, or oral functional phenotype. Here, we systematically review the communication phenotype of BPP, and examine the association between severity of speech, language, and oral functional impairment, and topography of polymicrogyria.

**Patients and Methods:** A systematic search of MEDLINE, EMBASE, and PubMed databases using MeSH terms synonymous with BPP and speech, language, or oral motor impairment was completed in October 2017. 2411 papers were identified and 48 met inclusion criteria.

**Results:** Speech, language, and oral structural and functional impairments are frequent in BPP. Expressive language deficits are frequently more severe than receptive. Only one study used formal assessments to demonstrate the presence of speech disorder, namely dysarthria. Diffuse BPP was associated with more severe language impairment than posterior BPP in eight studies.

**Conclusion:** Expressive and receptive language impairments are common in BPP, though assessment of the specific speech phenotype has not been reported in detail. The paucity of studies detailing the communication phenotype of BPP highlights the need for further investigation. It is critical that these domains are thoroughly characterised in order to improve understanding of prognosis and the development of targeted therapies.

## Oral presentation 120

### Top curricular priorities for pediatric residents in the care of children with medical complexity: a Delphi study

L GLADER, L NEWMAN, K HUTH  
Boston Children's Hospital, Boston, MA, USA

**Introduction:** Previous studies of pediatric residents have identified educational gaps and lack of comfort caring for children with medical complexity (CMC). A standardized curriculum with defined core competencies in the care of CMC is needed. The purpose of this study is to identify essential topics for a complex care curriculum for pediatric residents.

**Patients and Methods:** An initial topic list was generated through literature review and proceedings of national complex care special interest group meetings. Expert panelists were identified based on experience in complex care and residency education. Using the Delphi method to determine group consensus, an electronic survey was developed asking panelists to identify 10 to 15 curricular topics essential for pediatric residents. An iterative approach was used with feedback to participants and a maximum of three rounds. Consensus was defined as >70% identifying a topic as essential.

**Results:** Sixteen experts were approached and agreed to participate. Response rate was 100% for all three rounds. Experts were from the USA (44%) and Canada (56%), most were

affiliated with an academic center (96%) and practiced in both inpatient and outpatient settings (69%). Eleven topics were identified as essential: feeding difficulties and nutritional concerns, pain and irritability, transition, feeding tube management/trouble-shooting, difficult discussions, team management/care coordination, dysmotility, aspiration, safety/emergency planning, neuromuscular and skeletal issues, and advocacy for patients/families.

**Conclusion:** The Delphi method effectively led to the identification of eleven curricular priorities in the care of CMC, providing an innovative guide for standardized curriculum development in complex care.

## Oral presentation 121

### Parents' and professionals' views about parent-delivered interventions for eating and drinking difficulties for young children with neurodisability

L PENNINGTON<sup>1,2</sup>, H TAYLOR<sup>2</sup>, C BUSWELL<sup>3</sup>, J CADWGAN<sup>4</sup>, A COLVER<sup>2</sup>, D CRAIG<sup>2</sup>, D GARLAND<sup>5</sup>, E MCCOLL<sup>2</sup>, H MCCONACHIE<sup>2</sup>, JR PARR<sup>2</sup>

<sup>1</sup>Institute of Health and Society, Newcastle University, Newcastle, UK;

<sup>2</sup>Newcastle University, Newcastle, UK; <sup>3</sup>Newcastle Upon Tyne Hospitals NHS Foundation Trust, Newcastle, UK; <sup>4</sup>Guys' and St Thomas's NHS Foundation Trust, London, UK; <sup>5</sup>National Autistic Society, London, UK

**Introduction:** Eating, drinking, and swallowing difficulties (EDSD) are common in young children with neurodisability. It is not known which interventions are commonly used by parents, which are considered effective, or how intervention success should be measured. This survey aimed to: (1) identify current UK provision for young children with neurodisability and EDSD; (2) determine parents' and professionals' views of the effectiveness of interventions and the outcomes that are important to measure.

**Patients and Methods:** Questionnaires were completed by: Parents/carers of children with neurodisability and EDSD aged under 13 years ( $n=361$ ); healthcare professionals ( $n=449$ ) and education staff ( $n=59$ ) working with children with EDSD. Recruitment was through parent and professional networks, UK child development teams, specialist schools, and their networks.

**Results:** Many different interventions are used by healthcare professionals and families. The interventions most commonly reported by parents were food or drink modification, food desensitisation, and strategies to enhance communication. Healthcare professionals thought that the interventions parents reported using were effective. Professionals also frequently recommended positioning, sharing information with parents/carers to increase their understanding of the child's EDSD, and waiting for children's feeding cues during mealtimes. Improved nutrition and better general health were the most highly rated outcomes by both parents and professionals; parents also highly rated weight gain and professionals better quality of life for the child.

**Conclusion:** A wide range of interventions are used at home by UK parents of children with neurodisability. There was

substantial agreement between parents and professionals regarding important outcome areas.

## Oral presentation 122

### Long-term functional outcome following severe childhood traumatic brain injury: results of the prospective longitudinal follow-up of the TGE cohort

S NEUMANE<sup>1</sup>, H CÂMARA-COSTA<sup>2,3</sup>, L FRANCILLETTE<sup>2</sup>, H TOURE<sup>1</sup>, D BRUGEL<sup>1</sup>, A LAURENT-VANNIER<sup>1</sup>, P MEYER<sup>4,5</sup>, G DELLATOLAS<sup>3</sup>, L WATIER<sup>6</sup>, M CHEVIGNARD<sup>1,2</sup>

<sup>1</sup>Rehabilitation Department for Children with Acquired Brain Injury, Hôpitaux de Saint Maurice, Saint Maurice, France; <sup>2</sup>Sorbonne Université, Laboratoire d'Imagerie Biomédicale, LIB, 756 Paris, France; <sup>3</sup>INSERM CESP, Villejuif, France; <sup>4</sup>Paediatric Anesthesiology Department, Hôpital Necker Enfants Malades, 757 Paris, France; <sup>5</sup>Faculté de Médecine René Descartes Paris, France; <sup>6</sup>Biostatistics, Biomathematics, Pharmacoepidemiology and Infectious Diseases B2PHI, INSERM, UVSQ, Institut Pasteur, Université Paris-Saclay, Paris, France

**Introduction:** The aims of this study were to study functional outcome over 24 months following childhood severe traumatic brain injury (TBI); and to determine how initial functional status predicts 7-year intellectual and academic outcomes.

**Patients and Methods:** Children (0–15y) consecutively admitted in a single trauma center, following severe accidental TBI, were included in a prospective longitudinal study (TGE cohort). At 3, 12, 24 months, and 7 years, disability, functional, intellectual, and educational outcomes were assessed (paediatric Glasgow Outcome Scale; GOS-Ped, Paediatric Injury Functional Outcome Scale; PIFOS; Wechsler scales; mainstream school vs special education).

**Results:** 65 children survived (66% males; mean age at injury 8.1y [SD=4.6]; lowest Glasgow Coma Scale 6.1 [1.8]; length of coma 6.6d [4.8]). GOS-Peds indicated severe impairments at 1 month (vegetative state: 8%, good recovery: 6.5%), with significant improvement over time (25% 'good recovery' by 24mo). Functional impairments were severe initially, improved by 3 and 12 months ( $p<0.0005$ ), without subsequent significant progress. At each time-point, PIFOS score was highly correlated to TBI severity (length of coma [ $p<0.0004$ ]) and to GOS-Ped scores ( $p<0.0001$ ). 12-month PIFOS score was highly correlated to full-scale IQ at 12, 24 months ( $p<0.0001$ ), and 7 years ( $p<0.004$ ), and significantly predicted the type of education ( $p<0.0001$  at 12 and 24mo;  $p<0.002$  at 7y).

**Conclusion:** Functional status at 1 and 2 years significantly predicts long-term intellectual and educational outcomes. Systematic personalised long-term follow-up should be organised, with increased attention for those with persistent functional impairment 12-months post-injury.



## Oral presentation 123

### Locomotor training improves functional mobility in children with bilateral spastic cerebral palsy

D POOL<sup>1</sup>, J VALENTINE<sup>1</sup>, C ELLIOTT<sup>2</sup>

<sup>1</sup>Perth Children's Hospital, Perth, Australia; <sup>2</sup>Curtin University, Perth, Australia

**Introduction:** Effective motor intervention options to improve functional mobility for children with bilateral spastic cerebral palsy (CP) in GMFCS levels III, IV, and V are limited. Locomotor training (LT) is an activity based rehabilitation approach that has the potential to improve mobility in children with CP with more severe mobility restrictions. We aimed to examine the feasibility of intensive LT in children with bilateral spastic CP in GMFCS levels III, IV, and V.

**Patients and Methods:** Forty children were enrolled (mean age 8.1y SD 2.1y; GMFCS level III [ $n=16$ ]; GMFCS IV [ $n=10$ ]; GMFCS V [ $n=14$ ]). All children received three LT sessions/week for 6 weeks. Each LT session involved step retraining with both facilitated and independently generated steps on the treadmill and overground training in the child's own walking frame. Mixed models were used to determine the changes from post treatment (6wks) and follow up (6mo) compared to baseline in WeeFIM, GMFM-66, COPM, 10 metre walk test (10mWT), and Goal Attainment Scale (GAS).

**Results:** There were significant improvements ( $p<0.05$ ) and clinically meaningful changes at post-treatment and follow-up compared to baseline for WeeFIM scores, COPM performance and satisfaction scores, GMFM-66, 10mWT, and GAS. There were no adverse events.

**Conclusion:** Our results support LT as a feasible, acceptable, potentially efficacious, and practical intervention to improve functional mobility for children with CP. LT can be provided safely to children even with severe mobility restrictions to facilitate meaningful improvements for activity and participation.

## Oral presentation 124

### Outcomes from the Zurich Center for Spina Bifida following fetal surgery repair for myelomeningocele?

B PADDEN<sup>1,2</sup>, DA WILLE<sup>2,3</sup>, B LATAL<sup>2,4</sup>, M MEULI<sup>2,5,6</sup>

<sup>1</sup>University Children's Hospital, Rehabilitation Center, Zurich, Switzerland; <sup>2</sup>The Zurich Center for Spina Bifida, University Children's Hospital Zurich, Zurich, Switzerland; <sup>3</sup>Division of Pediatric Neurology, University Children's Hospital Zurich, Zurich, Switzerland; <sup>4</sup>Child Development Center, University Children's Hospital Zurich, Zurich, Switzerland; <sup>5</sup>Department of Pediatric Surgery, University Children's Hospital Zurich, Zurich, Switzerland; <sup>6</sup>The Zurich Center for Fetal Diagnosis and Therapy, Zurich, Switzerland

**Introduction:** The Zurich Centre for Fetal Diagnosis and Therapy is one of the few centres worldwide to offer open fetal surgery on the unborn child. This highly specialized and innovative technique is mainly used to repair myelomeningocele. In order to facilitate the long-term care of these patients, we opened the Zurich Center for Spina Bifida in 2018. We will introduce our unique program and comprehensive model

for the postnatal care of patients after fetal surgery repair for myelomeningocele and present clinical outcomes.

**Patients and Methods:** To date, 97 open, fetal surgery repairs have taken place in our center. One quarter of these patients reside in Switzerland. We compared our results for functional level in relation to anatomical level, ambulation at 30 months, and cognition at 24 months with the MOMS-Trial outcomes. The MOMS-Trial results, published in 2011, are currently the benchmark for fetal surgery outcome in spina bifida aperta.

**Results:** Compared to the MOMS-Trial data, level gain in our cohort is comparable; there is less level loss and less foot deformity. Cognitive outcomes are comparable at 24 months.

**Conclusion:** The Zurich Centre for Fetal Diagnosis and Therapy has been offering fetal surgery repair for MMC since 2010. These patients are followed with a specific treatment protocol in the Zurich Center for Spina Bifida from birth until transitioning into adult care. Our favorable clinical outcomes, when compared to the MOMS-Trial Data, provide the necessary incitement to continue fetal surgery repair for MMC.

## Oral presentation 125

### 'Here we are together, at home you are alone': the social processes of a group based intensive rehabilitation program for young adults with disabilities

M MIKLOS<sup>1</sup>, R JAHNSEN<sup>1,2</sup>, A NYQUIST<sup>1</sup>, H HANISCH<sup>3</sup>, S GIRDLER<sup>4</sup>

<sup>1</sup>University of Oslo, Beitostølen Healthsports Center, Beitostølen, Norway;

<sup>2</sup>CHARM, Inst. of health and society, University of Oslo, Oslo, Norway;

<sup>3</sup>Work Research Institute, Oslo Metropolitan University, VID Specialized University, Oslo, Norway; <sup>4</sup>Curtin Autism Research Group, School of Occupational Therapy, Social Work and Speech Pathology, Curtin University, Perth, Australia

**Introduction:** Young adults with disabilities often report feeling alone in their experience of disability and group-based rehabilitation approaches provide opportunities for the young adults to meet and share their experiences. The Beitostølen Healthsports Center (BHC) in Norway provides a residential group based rehabilitation program underpinned by adapted physical activity (APA), with a stay ranging in duration from 19 to 26 days. The aim of the study was to identify the key social processes and outcomes of this intensive APA rehabilitation intervention involving young adults with disabilities.

**Patients and Methods:** 54 young adults attending four young adults groups at BHC (age 17–34y) participated in this study. A grounded theory methodology employing ethnographic data collection methods enabled in-depth exploration of the social processes of the rehabilitation stay.

**Results:** The social environment was centrally important to the outcomes of a stay at BHC. Fundamental to the social processes of rehabilitation was the role of the staff in fostering a culture defined by opportunities, competence, and involving the young adults. This underpinned a rehabilitation context in which the participants felt safe and free to challenge themselves. Being with peers with disabilities was defined by a shared understanding of the experience of disability, with

opportunities for exchanging experiences and having fun. Peers improved motivation to actively engage in the rehabilitation stay, built courage, and promoted self-reflection.

**Conclusion:** While many rehabilitation approaches fail to consider the influence of social context on rehabilitation outcomes they appear fundamental to the outcomes of a stay at BHC.

## Oral presentation 126

### Translating the outcomes of robotics-based versus virtual reality-based interventions for children and young people with autism into everyday functioning: a systematic review

S CASTRO

Roeampton University, London, UK

**Introduction:** Research shows that both robotics-based and virtual reality-based interventions generate positive outcomes for children with autism. It is argued that robot-assisted interventions can be perceived as less-challenging than human-led interventions, and virtual reality-based interventions replicate social situations in a less anxiety-generating context. However, limited evidence is available on how these interventions compare and on how they translate into positive everyday functioning outcomes. This study aims to first, systematically review studies on robotics-based and virtual-reality based interventions for children with autism, comparing outcomes between the two types of intervention; and second, to map both interventions' outcomes to the International Classification of Functioning, Disability and Health (ICF), in order to document how they translate into improved Body Functions or Activities and Participation.

**Patients and Methods:** Empirical studies, including case studies and experimental studies, targeting children and young people up to 25 years, were included in the review, which followed the Joanna Briggs Institute method for systematic review search.

**Results:** Both intervention outcomes map onto the Activities and Participation domain, but the majority of the studies result in improved Body Functions. Frequencies of specific aspects of functioning within these domains were computed and differences by age of participants were analysed.

**Conclusion:** Currently, research on technology-based interventions for autism seems to neglect the translation of discrete body-function outcomes into everyday life participation. Future research should focus on a longitudinal follow-up of technology-based interventions for autism and on embedded interventions.

## Oral presentation 127

### Mitochondrial oxidative capacity in children with cerebral palsy is independent of mitochondrial content and similar across functional levels

S DAYANIDHI<sup>1</sup>, A RUDOFSKI<sup>1</sup>, J LARSON<sup>2</sup>,  
V SWAROOP<sup>2</sup>, R LIEBER<sup>1</sup>

<sup>1</sup>Shirley Ryan AbilityLab, Chicago, IL, USA; <sup>2</sup>Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL, USA

**Introduction:** Children with cerebral palsy (CP) require significantly increased energy expenditure and demonstrate fatigability during functional tasks. Muscle mitochondria are the primary sources for oxidative capacity and energy production. Unfortunately, mitochondrial oxidative capacity in children with CP and its association with different functional levels is not known.

**Patients and Methods:** Sixteen children (6–16y, 10 males, 6 females, GMFCS level II: 5, III: 5, IV: 3, V: 3), undergoing surgical correction for muscular contractures participated in this study. Twenty-four biopsies were obtained from adductors, vastus lateralis, gastrocnemius, and semimembranosus. Carbohydrate and fatty acid protocols were performed on permeabilized muscle fibers to test all the complexes of the electron transport chain and muscle homogenate tested for citrate synthase assays.

**Results:** Surprisingly, maximal mitochondrial phosphorylation capacity was similar across different GMFCS levels (II:  $75.7 \pm 19.3$ , III:  $68.8 \pm 21.4$ , IV:  $98.2 \pm 18.8$ , V:  $87.9 \pm 16.3$  pmol O<sub>2</sub>/s/mg). This was uncorrelated with mitochondrial content ( $p > 0.1$ ), as measured by citrate synthase. Counterintuitively, functional ambulators; GMFCS II+ III, had lower mitochondrial capacity than minimal ambulators; GMFCS IV+V, ( $72.7 \pm 19.9$  vs  $93.0 \pm 17.2$  pmol O<sub>2</sub>/s/mg,  $p < 0.05$ ). Furthermore, mitochondria preferentially used carbohydrates over fatty acids.

**Conclusion:** Mitochondrial function and content are typically associated with activity levels and endurance training leads to improved mitochondrial health. Surprisingly, children with CP had similar mitochondrial function across different functional levels and might even be lower in functional ambulators. Importantly, mitochondrial respiration capacity is dictated by the electron transport chain capacity rather than by mitochondrial content. Developing therapies to increase mitochondrial activity and thus functional capacity would be an important goal for children with CP.

## Oral presentation 128

### Content validity testing of the Autism Classification System of Functioning: Social Communication (ACSF:SC) with toddlers and school-aged children with autism

B DI REZZE<sup>1</sup>, P ROSENBAUM<sup>2</sup>, S GENTLES<sup>3</sup>, C RONCADIN<sup>4</sup>, L ZWAIGENBAUM<sup>5</sup>, MJC HIDECKER<sup>6</sup>, S GEORGIADIS<sup>3</sup>, O HLYVA<sup>1</sup>, H VIVEIROS<sup>2</sup>

<sup>1</sup>School of Rehabilitation Science, McMaster University, Hamilton, ON, Canada; <sup>2</sup>Department of Pediatrics, McMaster University, Hamilton, ON, Canada; <sup>3</sup>Offord Centre for Child Studies, McMaster University, Hamilton, ON, Canada; <sup>4</sup>Ron Joyce Children's Health Centre, Hamilton, ON, Canada; <sup>5</sup>Department of Pediatrics, University of Alberta, Edmonton, AB, Canada; <sup>6</sup>Department of Communication Disorders, University of Wyoming, Laramie, WY, USA

**Introduction:** The Autism Classification System of Functioning: Social Communication (ACSF:SC) classifies 5 levels of social communication abilities of children with ASD. Currently it is used with preschoolers (3–6y), with whom it has undergone testing. This study examines ACSF:SC validity with toddlers (2–3y) and school-aged (>6y) children with ASD.

**Materials and Methods:** We used mixed-methods to test ACSF:SC age expansions. We conducted cognitive interviews and focus groups with parents and clinicians. Transcripts were analyzed using qualitative content analysis. (International stakeholders' [n=50] data will be collected and analysed through an online survey prior to this presentation.)

**Results:** Ten parents and 17 clinicians working with toddlers or school-aged children with ASD participated, and three themes emerged: applicability, clarity, and usability of the tool. Applicability captured respondents' observations on developmental appropriateness of the level descriptions, and their ability to 'see' an individual child in one ACSF:SC level. Most found the ACSF:SC relevant, but in the toddler group it was important to consider the educational and emotional needs of parents of newly diagnosed children. Clarity captured respondents' understanding of the ACSF:SC, its explicit and underlying constructs, level descriptions and distinctions. Usability helped to identify areas that needed to be more user-friendly.

**Conclusion:** Through various validation processes, these results indicated that ACSF:SC constructs were applicable to both toddlers and school-aged children with ASD, as well as being understood by most parents. Several recommendations need to be considered before proceeding with its final revisions and field testing.

## Oral presentation 129

### The effect of different walking devices on body functions, activity and participation in children with cerebral palsy: a systematic literature review

J LEBEER, R CUPPERS, E CELENS, L WEYENBERG, C CAVENS, L TAEYMANS, C VAN DE RECK, K CEULEMANS, F EGO, S TRUIJEN

Department of Physiotherapy and Rehabilitation, University of Antwerp, Antwerp, Belgium

**Introduction:** Walking aids are widely used in children with cerebral palsy (CP), but carry a risk for musculoskeletal deformities. The aim of the study is to determine the effect of walking aids on gait kinematics, trunk and pelvic control, hand function, activities, and participation.

**Patients and Methods:** Electronic databases (PubMed, Web of Science) were searched using pre-defined terms, excluding meta-analyses, systematic reviews, and comments. Risk of bias was evaluated using 'Cochrane risk of bias tool', 'QUADAS-2' and 'QUIPS'. Quality of evidence was assessed using EBRO.

**Results:** 30 studies were included, covering 1360 children. Motor function and participation improved after training with Lokomat, robotic-assisted training with task-oriented physiotherapy, multi-positional walking sticks, and hands-free mobility devices. Effects are small. Posterior are better than anterior walkers as regards stride length, stability, and alignment. Most studies have low evidence level because of heterogeneity, low numbers, and lack of control groups. Negative effects include wrist deviations in anterior and posterior walkers; daily life activities may be disrupted when using adaptive equipment. Pooled data analysis was not possible due to heterogeneity.

**Conclusion:** Robotic walking aids are promising as to improving body functions (lower extremity kinematics), but are limited to therapy rooms. Rare is the literature comparing different walking aids between each other. With supported pelvis, there is better trunk control and synergy with lower extremities. Results on activities and participation are scarcely researched. There is a need for innovation in developing walking aids, facilitating a functionally useful gait pattern, proper trunk control, activities and participation yet without hindering hand function.

## Oral presentation 130

### Associations between brain volumes, myelin, and upper-limb kinematics in children born preterm

L RÖNNQVIST<sup>1</sup>, E DOMELLÖF<sup>1</sup>, A-M JOHANSSON<sup>1</sup>, K RIKLUND<sup>2</sup>, MJB WARNTJES<sup>3</sup>, N LENFELDT<sup>4</sup>

<sup>1</sup>Department of Psychology, Umeå University, Umeå, Sweden; <sup>2</sup>Department of Radiation Sciences, Umeå University, Sweden; <sup>3</sup>Department Centre for Medical Image Science and Visualization, Linköping University, Linköping, Sweden; <sup>4</sup>Department of Pharmacology and Clinical Neuroscience, Umeå University, Umeå, Sweden

**Introduction:** Long-term outcomes linked to preterm (PT) births have generally found an increased amount of neuromotor-developmental delays and/or disabilities. Few studies have

addressed how upper-limb kinematics associates with brain volumes and myelination. This study aimed to investigate such possible relationships within children born PT compared with term-born controls at early school age, in relation to gestational age (GA) and birthweight (BW).

**Patients and Methods:** This sub-study, part of a multidisciplinary project exploring long-term effects of PT births, included 27 children (mean age=8.2y) born PT (mean GA=32wks, range 22–35wks), and 33 age-matched born at term. Kinematics of task-specific head and bi-/uni-manual upper-limb-movements was measured by a 3D-registration system (ProReflex). Brain volumes and myelin content were investigated by a 3-Tesla, magnetic resonance imaging (MRI)-scanner with a 7 minute Synthetic MRI (SyMRI) acquisition-sequence.

**Results:** Significantly ( $p<0.05$ ) less efficient upper-limb kinematics with more segmented and longer movement paths was found in PT-born compared with term-born infants, particularly evident for those extremely-/very PT-born ( $<32$ wks GA). Smaller total brain volumes and regional white-matter reduction with less myelin were significantly correlated with more segmented and longer arm- and head-trajectories, and with lower GA and BW.

**Conclusion:** The present findings show that an extremely- and very-PT-birth may cause long-term effects on neuromotor-mechanisms involved in goal-directed movements and that these effects are associated with generally delayed brain development and myelination. Additionally, SyMRI stands out as a suitable and cost-effective method for longitudinal/follow-up of brain development and changes, reducing distress in children due to a decreased scan time.

### Oral presentation 131

#### Parents' experience of undertaking an early upper limb home training program with a video coaching approach for babies and toddlers with (a high risk of developing) unilateral cerebral palsy

A VERHAEGH<sup>1,2</sup>, N NUIJEN<sup>2</sup>, J VRIEZKOLK<sup>2</sup>, P AARTS<sup>2</sup>, M WILLEMSSEN<sup>3</sup>, M NIJHUIS-VAN DER SANDEN<sup>3</sup>

<sup>1</sup>Sint Maartenskliniek, Venlo, the Netherlands; <sup>2</sup>Sint Maartenskliniek, Nijmegen, the Netherlands; <sup>3</sup>Radboud University Medical Center, Nijmegen, the Netherlands

**Introduction:** Since 2014 we have delivered a uni- and bimanual home training program with video coaching for infants and toddlers (8–36mo) at high risk of developing unilateral cerebral palsy to increase the use of the affected arm and hand in bimanual activities. This qualitative study aims to explore parents' experiences.

**Patients and Methods:** Parents of 13 children participated in a face-to-face semi-structured interview. Interviews were transcribed verbatim and analysed using a thematic content analysis approach. Two researchers independently analysed the transcripts and themes were discussed in the research group until consensus was reached.

**Results:** Two overarching themes were identified: factors influencing the organization of the program and factors influencing the impact of the program for parents. Organization related factors included content and delivery issues; (high) training intensity, (difficulty with) planning by parents and (lack of) support by family and health professionals. Parent related factors included the attitude and motivation of the parent towards the program. Being creative in thinking of new play activities and keeping the program fun for the child were perceived as challenging but important. Although three parents perceived no effect on hand function, all parents mentioned that the program had made them aware of stimulating the affected arm and hand and that it had become part of their daily routines.

**Conclusion:** Overall, parents were very satisfied with the program and video coaching approach. All parents would recommend the program to others. The interviews provided valuable information that will be used for improving the home training program.

### Oral presentation 132

#### Uneven learning patterns in medically complex children evaluated from toddlerhood to school age

M WEISSBOURD, A RUSSOW, L BOSWELL, MK SANTELLA, M WECK, A-R DEREGNIER

Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL, USA

**Introduction:** High-risk children may show normal cognitive abilities, but require extensive therapy or educational support due to uneven learning patterns that are not apparent with summary measures of outcomes. The purpose of this study was to evaluate patterns of uneven learning in high-risk children.

**Patients and Methods:** Children ( $n=95$ ) were enrolled in this prospective longitudinal study for extreme prematurity, significant neurologic problems, neonatal cardiac surgery, or prolonged hospitalization. Children were assessed at 18 to 24 months and 3.5 to 5 years corrected age using the Bayley Scales of Infant Development, Third Edition (Bayley-III) and the Differential Abilities Scale, Second Edition (DAS-II). Uneven abilities were defined as composite/cluster score differences of  $>15$  points (one standard deviation).

**Results:** There was a significant correlation between the Bayley-III cognitive scores and the DAS-II General Conceptual Ability (GCA;  $r=0.568$   $p<0.001$ ), but more children had low cognitive scores at preschool (14/91) than at 18 to 24 months (4/95,  $p<0.001$ ). Uneven patterns of learning ( $>1$  standard deviation difference between composite or cluster scores) occurred in 52/95 (54.7%) of children tested with the Bayley-III and 42/95 (44.2%) of children tested with the DAS-II. Children with uneven learning at 18 to 24 months had a trend toward lower preschool GCA scores than children with evenly-developed 18 to 24 month skills ( $94.8\pm4.5$ ,  $101.5\pm5.5$ ,  $p=0.057$ ).

**Conclusion:** In this group of medically complex children, uneven patterns of learning were common and cognitive delays emerged over time, emphasizing that it is important to



follow children longitudinally and present each child's pattern of strengths and weaknesses to help identify children's needs and target appropriate therapeutic intervention prior to school entry.

### Oral presentation 133

#### Mini-EDACS: Eating and Drinking Ability Classification System for young children with cerebral palsy

D SELLERS<sup>1</sup>, L PENNINGTON<sup>2</sup>, E BRYANT<sup>1</sup>, K BENFER<sup>3</sup>, K WEIR<sup>4</sup>, C MORRIS<sup>5</sup>

<sup>1</sup>Chailey Clinical Services, Sussex Community NHS Foundation Trust, Lewes, UK; <sup>2</sup>Institute of Health and Society, Newcastle University, Newcastle, UK;

<sup>3</sup>Queensland Cerebral Palsy and Rehabilitation Research Centre, Child Health Research Centre, Faculty of Medicine, University of Queensland, Brisbane, Australia; <sup>4</sup>Gold Coast Campus, Griffith University, Southport, Australia; <sup>5</sup>University of Exeter, Exeter, UK

**Introduction:** The Eating and Drinking Ability Classification System (EDACS) was developed to classify function of people with cerebral palsy (CP) in 5 levels from 3 years. This study aimed to develop and test Mini-EDACS to describe developing eating and drinking abilities of children with CP between 18 and 36 months.

**Patients and Methods:** EDACS was applied to existing longitudinal videoed standardised feeding evaluations of children with CP aged 18 to 36 months ( $n=130$ ). EDACS content was modified to describe distinct levels of ability and mealtime performance for younger children with CP from video assessments. The content validity of Mini-EDACS was established through an international Delphi survey; consensus was defined as >80% agreement. Mini-EDACS classifications were made by parents using personal knowledge of their children, and speech and language therapists (SLT) from video recordings ( $n=50$ ). Inter-observer reliability was assessed by comparing levels assigned by expert observers.

**Results:** Mini-EDACS contains age-appropriate descriptions of eating and drinking ability for children 18 to 36 months with CP, including suitable drinking methods, and descriptions indicating learning of biting, chewing, swallowing, and drinking skills. 89 stakeholders including parents, health professionals, and care staff participated in the Delphi survey. Levels of agreement for 21 out of 22 questions were between 95% and 100%. One question received 92% agreement. Reliability data will be reported for SLTs vs SLTs and SLTs vs parents.

**Conclusion:** Mini-EDACS describes 5 distinct levels of eating and drinking ability for children with CP age 18 to 36 months. Use of Mini-EDACS by parents and professional enables systematic sharing of information about children's abilities. EDACS, with expanded descriptions of function in Mini-EDACS, can facilitate working in partnership with families across the lifespan. Mini-EDACS will broaden the focus of population-based research.

### Oral presentation 134

#### Comparing participation levels of children with cerebral palsy according to use of orthosis and assistive devices

M KEREM-GÜNEL<sup>1</sup>, A NUMANOĞLU-AKBAŞ<sup>2</sup>, M KEREM-GÜNEL<sup>1</sup>, O ÇANKAYA<sup>1</sup>, K SEYHAN<sup>1</sup>, C ÖZAL<sup>1</sup>, M TUNÇDEMİR<sup>1</sup>, S ÜNEŞ<sup>1</sup>, H ÖZCEBE<sup>1</sup>, U ARSLAN<sup>1</sup>

<sup>1</sup>Hacettepe University, Ankara, Turkey; <sup>2</sup>Cumhuriyet University, Sivas, Turkey

**Introduction:** The use of orthosis and assistive devices is quite common in children with cerebral palsy (CP). The aim of this study is to investigate whether there is any difference in participation between the children with CP, who are classified as level III according to Gross Motor Function Classification System (GMFCS), who use and do not use orthosis and assistive devices.

**Patients and Methods:** The study included 48 (25 males, 23 females) children with CP, classified as GMFCS level III, with a mean age of  $7.28 \pm 4.15$  years between the ages of 2 and 18. Demographic characteristics of the children and the use of ankle foot orthosis (AFO), standing frames, and walkers were recorded. The participation levels of the children included in the study were evaluated with Assessment of Life Habits (Life-H) scale.

**Results:** According to the results of our study, it was found that there was a difference in Life H Fitness scores ( $p=0.031$ ) among children who use and do not use AFO. Children who did not use AFO had higher Fitness scores. There were differences in Nutrition ( $p=0.008$ ), Interpersonal Relationships ( $p=0.021$ ), Daily Activities Total ( $p=0.032$ ), Social Role Total ( $p=0.012$ ), and Total Life-H ( $p=0.012$ ) scores among children who use and do not use walkers. It was found that children who use walkers had higher scores.

**Conclusion:** Our study showed that participation levels are better in children with CP, who are classified in GMFCS level III that use walkers.

### Oral presentation 135

#### Chewing training in children with cerebral palsy: combining motor and functional exercises

S GHANEM, J EL KHOURY, C SCHLINK, C SALAMEH, S ANDARI, C SALAMEH, M BAKHOS, A MASSAAD SESOBEL, Service Social pour le Bien Etre de L'Enfant atteint de Handicap, Kesrouan, Lebanon

**Introduction:** Chewing alterations are often described in cerebral palsy (CP). While oral-motor exercises (OME) are recommended to improve swallowing function and physiology, the current level of evidence on the effect of OME on chewing is poor. Passive and active exercises are used to treat chewing alterations, however, oral-motor programs, including functional exercises where food is introduced, have never been described. We aimed to evaluate the effect of a treatment protocol combining passive, active, and functional exercises on chewing.

**Patients and Methods:** 13 children with CP (age:  $5 \pm 1$  y, GMFCS IV:  $n=9$ , GMFCS level V:  $n=4$ ), presenting chewing alterations according to the Mastication Observation and Evaluation instrument (MOE) were enrolled. The sensory profile 2, showed normal oral-sensory processing for all participants. A 4-step treatment protocol was applied: passive, active, and functional exercises, where food was introduced, were performed during the same session. MOE total score as well as the score of each parameter were compared before (T0) and 9 months (T1) after the application of the protocol using paired t-test or Wilcoxon-Signed-Rank test.

**Results:** MOE total score increased in T1 ( $20.5 \pm 2$ ) vs T0 ( $19 \pm 2$ );  $p=0.025$ . While all the scores attributed to each parameter tend to increase in T1 compared to T0, only one parameter (lateral tongue movement) showed a significant increase:  $T1=2.8 \pm 0.4$  vs  $T0=2.3 \pm 0.4$ ;  $p=0.014$ .

**Conclusion:** Combined active, passive, and functional exercises could be helpful to improve chewing in CP.

## Oral presentation 136

### Reduced structural connectivity after neonatal arterial ischemic stroke: a whole brain analysis

P PRETZEL<sup>1</sup>, M DINOMAI<sup>2</sup>, L HERTZ-PANNIER<sup>3</sup>, T DHOLLANDER<sup>4</sup>, S CHABRIER<sup>5</sup>, S GROESCHEL<sup>1</sup>

<sup>1</sup>Experimental Pediatric Neuroimaging, Department of Child Neurology, University Children's Hospital of Tübingen, Tübingen, Germany;

<sup>2</sup>Département de Médecine Physique et de Réadaptation and LUNAM, Université d'Angers, Angers, France; <sup>3</sup>Neurospin, Institut Frédéric Joliot, Paris, France; <sup>4</sup>Florey Institute of Neuroscience and Mental Health, Melbourne, Australia; <sup>5</sup>CHU Saint-Etienne, Inserm, University of Lyon, Saint-Etienne, France

**Introduction:** Neonatal arterial ischemic stroke (NAIS) can lead to long-term functional deficits, especially for contra-lesional motor function. It is more and more recognized, that this early focal lesion can have more widespread effects on the development (and reorganization) of the whole brain network. We investigated the whole brain structural connectivity in children after NAIS, hypothesizing that a widespread network of pathways remote from the lesion is affected.

**Patients and Methods:** 33 children with NAIS of the middle cerebral artery were investigated at the age of 7.3 years (6.9–7.9y) using 3T MRI, and compared to 31 typically developing children of the same age (7.6y, 6.9–8.8y). Diffusion-weighted MRI scans were processed using the MRtrix software package. Advanced whole brain analysis of fibre density and cross section (FDC) was used, based on fibre orientation distributions (FOD) within each voxel. An FOD template was created and a common lesion mask was used.

**Results:** Children after NAIS showed reduced FDC in the ipsilesional cortico-spinal tract, thalamo-cortical pathways, corpus callosum, association pathways (superior longitudinal and arcuate fasciculus, and in temporal lobe), and parts of the optic radiation ( $p<0.05$ , FWE-corrected). The contra-lesional hemisphere was affected via commissural pathways.

**Conclusion:** Children after NAIS showed reduced structural connectivity in widespread brain networks remote from the lesion. Several projection, association, and commissural pathways were affected, involved in different functional networks.

These results underline the global structural effects of NAIS on the developing brain by influencing structural networks remote from the infarct.

## Oral presentation 137

### Mental disorders in 8- to 16-year-old children with cerebral palsies in Denmark: a register-linkage study

G RACKAUSKAITE<sup>1</sup>, N BILENBERG<sup>2</sup>, B HAMMER BECH<sup>3</sup>, J ROSENDAHL ØSTERGAARD<sup>1</sup>

<sup>1</sup>Aarhus University Hospital, Aarhus, Denmark; <sup>2</sup>University of Southern Denmark, Odense, Denmark; <sup>3</sup>Aarhus University, Aarhus, Denmark

**Introduction:** Cerebral palsy (CP) is an umbrella-term for children with motor disability due to the brain lesion early in life. Data regarding psychiatric comorbidity in CP is sparse. We hypothesized that prevalence of mental disorders will be associated to the clinical type of CP (unilateral or bilateral spastic, dyskinetic, and ataxic types).

**Patients and Methods:** A register-linkage study between the Danish Cerebral Palsy Registry and the National Patient Registry (NPR) included 881 children and adolescents with registered CP-type, who were alive at follow-up (8–16y). The outcome was at least one diagnosis of mental disorder in NPR, defined as ICD-10 codes F06.0–F99.9 or R41.8. Descriptive analyses were performed in order to compare the prevalence of mental disorders in different types of CP. Logistic regression analyses are planned in order to adjust for severity of CP.

**Results:** Right-sided spastic CP had the lowest prevalence of mental disorders (15.7%, CI 11.0–21.6%), followed by the left-sided unilateral CP (17.4%, CI 15.0–27.8%). Mental disorders were most common in the bilateral spastic CP (27.3%, CI 23.1–31.9%). Results of logistic regression analyses will be available in January 2019.

**Conclusion:** Association between the clinical type of CP and prevalence of mental disorders indicates that the risk of mental disorder differs between the different types of early brain damage. Therefore, we suggest that further etiological studies of mental disorders in CP focus on brain-imaging.

## Oral presentation 138

### Is adapted cycling training achievable in children with cerebral palsy with poor motor function?

C DUSSAULT-PICARD, A POULIOT-LAFORTE, J LACHAPPELLE, M LEMAY, L BALLAZ

Sainte-Justine UHC, Research Center, Montreal, Canada

**Introduction:** In children with cerebral palsy (CP), lower muscle strength and cardiorespiratory fitness are associated with lower locomotion capacities, especially in children with poor gross motor function (GMFCS levels II–IV). Cycling exercise could be a promising approach to improve walking efficiency, due to its potential impact on these physiological systems. The objectives of this study were: (1) to assess if cycling exercise is in accordance with Verschuren's recommendations, in terms of

intensity and duration, and (2) to report the physical limitations which could impact training feasibility.

**Patients and Methods:** Fifteen children with spastic CP, who were able to ride an adapted tricycle (Trivel, Montreal, Canada) were included (aged 5–11y; GMFCS levels II–IV). A 9-week training program (2 sessions/week) was implemented on stationary tricycle in a school for children with motor disabilities (Victor-Doré, Montreal, Canada). Three bouts of 5-minute exercise, with standardized encouragement, were planned for each session. Intensity and duration of exercise were evaluated during each session. Lower limb range of motion, muscle strength, and spasticity were assessed before training.

**Results:** The intensity and duration of the training sessions were  $45.7 \pm 9.5\%$  of reserve heart rate and  $16.6 \pm 4.4$  min respectively. Children performed  $12.8 \pm 2.8$  training sessions. Four participants were not able to achieve the targeted minimal exercise recommendations (two in GMFCS level II and two in GMFCS level III). Muscle strength, spasticity, and GMFCS level were not related to exercise intensity and duration.

**Conclusion:** The achievement of adapted cycling training is possible in children with poor motor function, even in those with low muscle strength.

### Oral presentation 139

#### An evidence-based model for decision making in augmentative and alternative communication: findings from the I-ASC project

J GOLDBART<sup>1</sup>, J MURRAY<sup>1</sup>, Y LYNCH<sup>1</sup>, L MOULAM<sup>1</sup>, N RANDALL<sup>2</sup>, S JUDGE<sup>2</sup>, S MEREDITH<sup>1</sup>, E WEBB<sup>3</sup>, H WHITTLE<sup>1</sup>, D MEADS<sup>3</sup>

<sup>1</sup>Manchester Metropolitan University, Manchester, UK; <sup>2</sup>Assistive Technology Service, Barnsley Hospital NHS Trust, Barnsley, UK; <sup>3</sup>University of Leeds, Leeds, UK

**Introduction:** Children whose speech is insufficient for their day-to-day needs may benefit from augmentative and alternative communication (AAC) ranging from symbol boards to high-tech computer-based approaches. High-tech devices are expensive, yet there is evidence that children may not be getting full benefit because the devices do not meet their educational, social, or personal needs.

**Patients and Methods:** Three systematic reviews, six focus groups, 76 interviews with children and young people who use AAC, their families and their AAC teams, Best-Worst scaling, and a Discrete Choice Experiment (involving 248 professional) were used to explore clinical decision making in AAC prescription and to identify good practice.

**Results:** Synthesis of the data has generated a dynamic clinical decision-making model which comprises two global themes: Competing Considerations, made up of access features, communication aid attributes, and child characteristics, and Cultural and Contextual Influencers, made up of available resources, transitions, and ways of working.

**Conclusion:** AAC decision-making is a complex, dynamic, multifactorial process. Understanding competing priorities and making the process explicit has enabled team to produce

materials to support decision-making, with the aim of enhancing the quality of decisions and the provision of AAC which best meets the needs of children and young people.

### Oral presentation 140

#### Objective measurement of sitting, using pressure mapping

MN EEK<sup>1</sup>, A BLOMKVIST<sup>1</sup>, K OLSSON<sup>1</sup>, K LINDH<sup>1</sup>, K HIMMELMANN<sup>2</sup>

<sup>1</sup>Regional Rehabilitation Centre, Queen Silvia Children's Hospital, Sahlgrenska University Hospital, Gothenburg, Sweden; <sup>2</sup>Department of Pediatrics, Institute of Clinical Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

**Introduction:** Sitting balance is a problem for patients with severe motor problems. There is a lack of objective methods to assess balance and the effect of interventions. The aim of the study was to explore measurable variables from pressure mapping measurements.

**Patients and Methods:** Measurements from 50 typically developing children and 35 children with cerebral palsy (CP; 4–18y), sitting on a bench with a pressure mat, were analyzed for seat load symmetry, sway and hip abduction.

**Results:** Reliability regarding sway and hip abduction angle showed moderate to excellent intra class correlations. Children with CP were compared to typically developing children with statistically significant differences for all sway variables, with higher values for children with CP. Children with CP also had a more asymmetric seat load, which increased with age. For hip abduction angle, 45% of the children with CP were outside the 2 SD values for typically developing children. An asymmetric position was frequent in children with CP.

**Conclusion:** Pressure mapping can give objective measurable data on several aspects of importance for sitting and sitting function, such as symmetry, sway, and hip abduction. Finding an objective measurement for sitting function will increase our knowledge and the possibility to optimize sitting, a well-needed function in children with severe CP. Secondary gains with an optimized sitting position may be increased participation and quality of life.

### Oral presentation 141

#### Effect of a trunk-targeted rehabilitation on trunk control deficit and gait disorders in children with cerebral palsy

J PIERRET<sup>1</sup>, S CAUDRON<sup>1</sup>, J PAYSANT<sup>2</sup>, C BEYAERT<sup>1</sup>

<sup>1</sup>EA 345 Développement, Adaptation et Handicap, Université de Lorraine, Nancy, France; <sup>2</sup>Institut Régional de Médecine Physique et de Réadaptation, Nancy, France

**Introduction:** Children with cerebral palsy (CP) usually have both locomotor disorders including excessive braking of ankle dorsiflexion during loading response (EBAD-LR) and trunk control deficit. While EBAD-LR is usually thought to be related to triceps spastic dysfunction, this behavior could be due to a trunk control deficit. Thus we tested if trunk control

improvement in CP children, via an enhanced axial rehabilitation, could lead to a reduction in EBAD-LR.

**Patients and Methods:** 15 CP children (8±2y) followed a cross-over study with two successive phases of 3 months, one with usual rehabilitation (UR) and one with rehabilitation targeting the control of axial segments (enhanced axial rehabilitation, EAR). Axial segments control was assessed by both specific unstable sitting posturography and trunk control measurement scale (TCMS). EBAD-LR was assessed by the negative ankle power peak at loading response during a 3D clinical gait analysis. In CP children, the first assessment before rehabilitation was compared to values in 16 typically developing children (TD) and repeated after each phase of rehabilitation for comparisons.

**Results:** CP children before rehabilitation had significant lower axial segments control compared to TD children (lower score on TCMS and greater COP sway area on unstable sitting). Both axial segments control and EBAD-LR improved after EAR while UR had no significant effect in both therapeutic subgroups.

**Conclusion:** Enhanced axial rehabilitation, incorporating many activities challenging axial segments, not only improved axial segments control but also EBAD-LR. EBAD-LR, that mechanically controls trunk anterior progression during gait, is suggested to contribute to postural adaptation to trunk control deficit in CP children.

## Oral presentation 142

### Supportive care in children with spinal muscular atrophy type 1: results from a french multicentric study

M HULLY<sup>1</sup>, C BARNERIAS<sup>1</sup>, B CHABROL<sup>2</sup>, C VUILLEROT<sup>3</sup>, P SABOURAUD<sup>4</sup>, J-M CUISSET<sup>5</sup>, C CANCES<sup>6</sup>, J ROPARS<sup>7</sup>, F RIVIER<sup>8</sup>, A ISAPOFF<sup>9</sup>, I DESGUERRE<sup>1</sup>

<sup>1</sup>APHP-Necker Enfants Malades Hospital, Paris, France; <sup>2</sup>APHP-La Timone Hospital, Marseille, France; <sup>3</sup>University Hospital of Lyon, Bron, France;

<sup>4</sup>University Hospital of Reims, Reims, France; <sup>5</sup>Roger Salengro Hospital, Lille, France; <sup>6</sup>Children Hospital, Toulouse, France; <sup>7</sup>University Hospital, Brest, France; <sup>8</sup>University Hospital of Montpellier, Montpellier, France; <sup>9</sup>APHP-Trousseau Hospital, Paris, France

**Introduction:** This National Hospital Clinical Research Program (PHRC) was conducted in France between 2012 and 2016 to depict palliative practices in spinal muscular atrophy type 1 (SMA-I). New drugs (Nusinersen) have been developed and may modify its natural history. We thus present data about supportive care for patients included in that PHRC, comparing them to patients not included concomitantly.

**Patients and Methods:** Supportive care data (enteral nutrition, non-invasive ventilation [NIV], sedation), age and place of death were collected prospectively from a specific health-book and a survey about conditions of death for the patients included in the PHRC and retrospectively by questioning physicians of the French Pediatric Neuromuscular Network for the other patients, some of them receiving Nusinersen.

**Results:** In 18 centres, 38 patients were included in the PHRC, 43 were not; including 7 receiving Nusinersen. Mean age at diagnosis was 3.9 months (SD 2.4). 77 patients died at 7.5

months (SD 4.96), 32% at home, 8% in an intensive care unit. 85% patients received enteral nutrition, some through a gastrostomy (8%). 16% had a NIV. 70% received sedative treatment. No statistical difference was found between the two groups. However only all 3 patients (4%) receiving Nusinersen had both a gastrostomy and a NIV, without any sedation.

**Conclusion:** Our data confirm that palliative care is essential in the management of ASI-I patients, that is so far still a fatal disorder. Our data suggest that Nusinersen treatment was accompanied by more invasive supportive care, claiming for a standardization of practices in the children and caregivers' best-interest.

## Oral presentation 143

### Evaluation of motor skills and independency in activities of daily living in children with speech impairments: a pilot study

BB SANLI<sup>1</sup>, Z GUVEN<sup>1</sup>, AS SAHLI<sup>2</sup>, V YILDIZ KABAK<sup>1</sup>, F IPEK<sup>1</sup>, S ATASAVUN UYSAL<sup>1</sup>

<sup>1</sup>Faculty of Health Sciences, Department of Physiotherapy and Rehabilitation, Hacettepe University, Ankara, Turkey; <sup>2</sup>Hacettepe University Vocational School of Health Services Hearing and Speech Training Center, Ankara, Turkey

**Introduction:** To investigate motor skills (MS) and independency level in activities of daily living (ADL) in children with speech impairment (SI) and to analyze the relationship between these parameters.

**Patients and Methods:** The present study was designed as a pilot study. This study included 18 children (5 females, 13 males, mean age: 6.72±1.60y) who were diagnosed with SI including stutter, articulation disorder, speech delay. To evaluate motor skills, Bruinsky-Oseretsky Test of Motor Proficiency, Second Edition Short Form (BOT-2) was used, while Functional Independence Measure for Children (WeeFIM) was used to determine independency level in ADL.

**Results:** Manual dexterity and bilateral coordination subtests of BOT-2 showed a positive correlation with WeeFIM scores. It has been found that there is a moderate positive correlation between self-care and manual dexterity (MD) ( $r=0.47$ ,  $p=0.04$ ). WeeFIM total point score and bilateral coordination (BC) indicated high positive correlation ( $r=0.6$ ,  $p=0.008$ ), also moderate positive correlation between social cognition (SC) and BC ( $r=0.54$ ,  $p=0.02$ ).

**Conclusion:** This study showed that children with SI who scored better MD and BC due to their participation in more social activities (with their peers and relatives etc.) had higher SC scores than others. Since upper extremities are used more often in self-care, we think upper extremity functions were associated with independency in ADL. In order to develop independency in ADL, implementations aiming to increase upper extremity functioning should be performed.



## Oral presentation 144

### Innovation in stakeholder engagement in research: a Canadian network perspective

K SHIKAKO-THOMAS<sup>1</sup>, J WEISS<sup>2</sup>, C PUTTERMAN<sup>3</sup>

<sup>1</sup>McGill University, Montreal, Canada; <sup>2</sup>York University, York, UK; <sup>3</sup>Canada/Israel Autism Research Initiative, Toronto, Canada

**Introduction:** The CHILD-BRIGHT Network is a pan-Canadian network that aims to improve life outcomes for children with brain-based developmental disabilities and their families. The Knowledge Translation Program is developing methods to: better engage stakeholders in research, identify the optimal strategies to communicate research findings, measure the impact of research on clinical, systems, and community.

**Patients and Methods:** Rapid review of iKT measurement tools and selection in partnership with patients. Longitudinal data collection from all network activities (research projects, programs and services) using a mixed method (quantitative and qualitative) approach to identify barriers and consolidate best practices in stakeholder engagement. Webinars and KT Cafés for research projects looking to further engage the public in the development of their research projects; web-based Community Matching Tool, fostering innovative knowledge translation strategies through annual KT Innovation Incubator competition.

**Results:** Engagement growth as measured by increased trust and higher levels of engagement in the research process, engagement of patient-partners to develop, evaluate and implement knowledge translation projects in partnership with researchers across Canada, parent mentor program supporting understanding and engagement of parents.

**Conclusion:** The KT program has started the process of studying how to engage vulnerable populations, such as families in low socio-economic status and other minorities. By measuring trust and direct impacts in the community longitudinally we expect to improve engagement strategies and building the methods infrastructure for a Policy Response Unit, which will identify key policy-makers in childhood disabilities to participate in the design and needs assessments to broaden the scope of stakeholders engaged and possible impacts of our research.

## Oral presentation 145

### Urgently needed: improved harmonization of visual impairment reporting in cerebral palsy registers worldwide for increased participation

E ORTIBUS<sup>1,2</sup>, I FRANKI<sup>2</sup>, L JONNAERT<sup>1</sup>, K DE LA CRUZ<sup>3</sup>

<sup>1</sup>University Hospitals Leuven, Leuven, Belgium; <sup>2</sup>KU Leuven, Department of Development and Regeneration, Leuven, Belgium; <sup>3</sup>Imas12-Hospital 12 de Octubre-ISCIII SAMID, Madrid, Spain

**Introduction:** Visual impairment (VI), whether from ocular or cerebral origin, impacts largely on participation of children with cerebral palsy (CP). In 1998, the Surveillance of CP in Europe (SCPE) agreed on two items to report (any VI and severe VI). However, CVI was not clearly part of the criteria. Therefore, we wanted to document the way in which (1) CP

registries have access to VI data, and (2) their clinical network performs the visual assessment of children with CP.

**Materials and Methods:** Two cross-sectional surveys: (1) questionnaire Q1 was addressed to CP registry leaders (RL) throughout Europe, the US, Canada, Australia, and Bangladesh ( $n=26$ ), concerning access to and classification of VI data; (2) questionnaire Q2 (disseminated through RL) was addressed to allied clinicians ( $n=39$ ), detailing VI assessment and reporting.

**Results:** All (16) European RL reported having VI data on more than 80% of their registered CP cases, compared to only 30% of the other registries (10). In four out of five of the RL, the presence of CVI was classified either consistently as any or as severe VI, or as either one depending on the degree of CVI. Although 64% to 73% of the clinicians in/outside Europe, respectively, performed a standardized visual assessment in children with CP, only one in three assessed CVI. Functional vision evaluation was performed in 44%.

**Conclusion:** There is room for improving harmonization of visual (perceptual) assessment and classification of VI in children with CP worldwide, in order to accurately estimate its impact on participation.

## Oral presentation 146

### Innovative robotic walker promotes exercise and participation in adolescents with cerebral palsy

A MCCORMICK<sup>1</sup>, H ALAZEM<sup>1</sup>, C HUNT<sup>2</sup>, C DIXON<sup>2</sup>, S ZAIDI<sup>1</sup>

<sup>1</sup>Children's Hospital of Eastern Ontario, Ottawa, Canada; <sup>2</sup>Grandview Children's Centre, Oshawa, Canada

**Introduction:** As youth with cerebral palsy (CP) age, options for mobilization are limited and many individuals lead sedentary lives. Research assessing robotic walkers (RW) identifies advantages, including the ability to walk hands-free and promote daily physical fitness. Using a newly designed RW modified for youth with CP, study goals looked at enhancing opportunities for physical fitness, gait training, and participation for our clients.

**Patients and Methods:** Data for this pilot study was collected on CP patients between the ages of 15 and 24 years ( $n=5$ ) in GMFCS levels III to IV enrolled at the Children's Hospital of Eastern Ontario and Whitby Abilities Centre. Videos demonstrate walker function. Distance walked, steps taken, and heart rate were documented during the 6 minute walk test and gym-based activities. Semi-structured interviews were administered to collect qualitative feedback.

**Results:** The RW, with automated lift, permitted youth with mixed tone and spastic quadriplegia to safely transfer from sit to stand, walk, and perform athletic activities in standing hands-free positions. During fitness activities, heart rate moved into expected ranges for moderate to intense exercise.

**Conclusion:** Upon successful study completion, there were no further recommendations for changes to the RW. Collaborative research is planned to further test this RW with a larger cohort of expanded ages at the Whitby Abilities Centre and Ottawa Hospital Rehabilitation Centre.

## Oral presentation 147

### Severe visual impairment in children with cerebral palsy: trend over time and determinants. A SCPE network population-based study

J DE LA CRUZ<sup>1</sup>, E SELLIER<sup>2</sup>, I FRANKI<sup>3</sup>, P TEJADA-PALACIOS<sup>4</sup>, V HORBER<sup>5</sup>, E ORTIBUS<sup>6</sup>

<sup>1</sup>Health Research Institute Imas12, Madrid University Hospital '12 Octubre'-SAMID-ISCIII, Madrid, Spain; <sup>2</sup>Pôle Santé Publique - Département de l'Information Médicale, CHU de Grenoble, France; <sup>3</sup>KU Leuven, Department of Rehabilitation Sciences, Leuven, Belgium; <sup>4</sup>Department of Ophthalmology, Madrid University Hospital '12 Octubre', Madrid, Spain; <sup>5</sup>Paediatric Neurology and Developmental Medicine, University Children's Hospital, Tübingen, Germany; <sup>6</sup>KU Leuven, Department of Development and Regeneration, Leuven, Belgium

**Introduction:** There is increasing awareness that systematic functional vision assessment and follow-up can lead to enhanced participation. The objectives of this study were: (1) to test the presence of a trend over time in the proportion of severe visual impairment (sVI), and (2) to estimate the association of neonatal, brain lesion morphology, and function determinants with sVI.

**Patients and Methods:** Cross-sectional register study. Surveillance of Cerebral Palsy in Europe database (JRC-SCPE) includes case data on children with cerebral palsy born in 1980 to 2009 and registered at 5 to 8 years old in 30 registers from 26 European countries ( $n=19950$ ). sVI is defined as 'blind or no useful vision after correction'. SCPE MRICS was used to classify neuroimaging findings.

**Results:** Visual impairment was reported in 7085 children (35%), and known sVI in 2032 (10%). There was no significant trend in sVI for the birth-period 1995 to 2009,  $p=0.19$ . sVI was significantly more frequent in children with bilateral spastic CP (14%) and dyskinetic CP (16%), GMFCS V (32%), BFMF V (32%), severe intellectual impairment (25%), active-epilepsy (24%). Neuroimaging (MRICS) predicted significantly higher risk of sVI with the following findings: brain malformations (A, 14%), combined sequelae of periventricular leukomalacia and intraventricular haemorrhage (B3, 21%) or cortico/subcortical lesions only (C2, 20%).

**Conclusion:** sVI is present in at least one in ten children with cerebral palsy. Level of motor function limitation, severity of intellectual impairment, and brain lesion type contribute to identify children at higher risk of sVI. Future research may benefit from using a classification that considers CVI features in the definition of visual impairment.

## Oral presentation 148

### Determinants of satisfaction with motor rehabilitation in persons with cerebral palsy: a national survey in France (ESPaCe)

G CORNEC<sup>1</sup>, J DE LA CRUZ<sup>2</sup>, I DESGUERRE<sup>3</sup>, P TOULLET<sup>4</sup>, J BOIVIN<sup>4</sup>, G DREWNOWSKI<sup>5</sup>, M BODORIA<sup>6</sup>, S BROCHARD<sup>1</sup>

<sup>1</sup>Brest University Hospital, Pediatric Physical Medicine and Rehabilitation, Brest, France; <sup>2</sup>Madrid University Hospital '12 Octubre' - ISCIII SAMID, Health Research Institute i+12, Madrid, Spain; <sup>3</sup>Hôpital Necker - Enfants Malades, Pediatrics - Radiology - Genetics, Paris, France; <sup>4</sup>Institut Motricité Cérébrale - Cercle de Documentation et d'Information pour la rééducation des Infirmités Motrices Cérébrales, Paris, France; <sup>5</sup>Expert patient, Lyon, France; <sup>6</sup>La Fondation Motrice / Fondation Paralysie Cérébrale, Paris, France

**Introduction:** User satisfaction is a key indicator of health-care quality. The aim of this study was to identify factors associated with satisfaction with motor rehabilitation (MR) in children and adults with cerebral palsy (CP).

**Patients and Methods:** This study was part of a national survey coordinated by La Fondation Motrice aimed at documenting the views of persons with CP on the provision of MR. A steering committee, that included persons with CP, patient and family organisations, professional and scientific societies, developed a questionnaire on MR. The 8-items Client Satisfaction Questionnaire (CSQ-8) was the study primary outcome. The questionnaire was disseminated nationally through advocacy groups, professional and social networks. It was answered online or on paper by the person with CP or by the main carer. Data analysis included generalized linear modelling and multiple imputation for missing data.

**Results:** From June 2016 to June 2017, 1010 validated participants (354 children, 145 adolescents, and 511 adults) responded to the questionnaire and 750 completed the CSQ-8. Determinants selected through univariate analysis and intermediary models were included in a final model predicting 40% of the variance of satisfaction ( $R^2=0.4$ ). Identified independent determinants of satisfaction with MR were: (1) person with CP characteristics (GMFCS, MACS, pain) (2) organisation of MR (coordination of health care, CP training of health professionals), (3) content of physiotherapy sessions (management of pain by the physiotherapist, information and goal-setting).

**Conclusion:** Focusing on pain management, therapeutic alliance, coordination, and training of health professionals should lead to improved perceived care quality for persons with CP.

## Oral presentation 149

### Delivering evidence-informed intensive motor focussed intervention in partnership with parents, community and hospital-based therapists for children with brain injury

A GORDON, D MINEHANE, J MASSEY, B SIEGLE, T ARICHI

Evelina London Children's Hospital, London, UK

There is now compelling evidence for specific modalities of individualised, protocolised, goal-directed intensive interventions to make lasting improvements in motor function for

children with hemiparesis. Despite this, few children and families have access to such interventions. We have developed a service model, through collaboration with parents, which aims to be both cost and clinically effective and is co-delivered by parents, and community and hospital therapists. The intervention service, based at Evelina London Children's Hospital centres on a partnership model of delivery, where parents/young people are coached by occupational therapists to deliver a prescribed modality and dose of intervention. Defined modalities and prescribed intensity of intervention are delivered. The assessment protocol includes standardised measures of adaptive behaviour, bimanual function, child-centred GAS goals, and parental/young person rating of performance and satisfaction with functional tasks requiring two hands. The children/young people are assessed 6 weeks and immediately prior to the intervention, immediately after, and 6 weeks, and 6 months after the intervention to evaluate retention of benefit. We present the findings of the first 35 children who have been enrolled in the programme ranging in age from 5 months to 10 years (predominantly pre-schoolers). We report the findings of our standardised assessments, individualised goals, parent ratings of outcome, community therapist feedback, and describe the service model and protocol. We make the case for a partnership model being feasible, clinically effective, and having benefits to parents beyond those measured in their child/young person.

## Oral presentation 150

### Implementation science decreases age at cerebral palsy diagnosis below 12 months in a multicenter clinical network

N MAITRE<sup>1</sup>, J BURTON<sup>2</sup>, A DUNCAN<sup>3</sup>, S IYER<sup>4</sup>,  
B OSTRANDER<sup>5</sup>, R BYRNE<sup>6</sup>

<sup>1</sup>Nationwide Children's Hospital, Columbus, OH, USA; <sup>2</sup>Kennedy Krieger Institute, Johns Hopkins University, Baltimore, MD, USA; <sup>3</sup>McGovern

Medical Center, University of Texas, Houston, TX, USA; <sup>4</sup>UCLA Medical Center, Los Angeles, CA, USA; <sup>5</sup>University of Utah, Salt Lake City, UT, USA; <sup>6</sup>Cerebral Palsy Foundation, New York, NY, USA

**Introduction:** In the US, diagnosis of cerebral palsy (CP) occurs at around 2 years in most clinical settings despite an evidence-base for earlier diagnosis. Implementation science (IS) allows rigorous, feasible and scalable knowledge translation.

**Patients and Methods:** This was a Phase 3 (multi-site) study using standardized IS to decrease age at CP diagnosis to 12 months throughout a network of 5 geographically and socio-economically diverse high-risk infant follow-up programs (combined total >10 000 annual visits). Four stages included: (1) Exploration: concept design, IRB, site visits, SWOT analyses; (2) Installation: database construction, staffing, training, process flow design; (3) Initial implementation: data collection, parent perception questionnaires (Edinburgh and Ways of Coping), repeated PDCA cycles, monthly site-specific; and all-site calls; (4) Full implementation: monitoring of fidelity of process flow, site/parent data, scale-up, and improvement projects.

**Results:** Mean age at CP diagnosis decreased from 22.7 to 10.9 months in 9 months compared to the same period 1 year prior. Standardized 3 to 4 month visits increased from 499 to 1143, high-risk for CP diagnoses from 34 to 190 and new CP diagnoses from 152 to 213. No parent experienced resulting depression. Opportunities for improvement were: sitting while giving diagnosis (50%), provision of 'just-right' information (42%), action plans (50%), and community resources (64%). Regional scale-up and addition of psychological support for parents are ongoing. Results informed an international dissemination conference.

**Conclusion:** IS facilitates early diagnosis of CP below 12 months of age in diverse clinical settings. Repeated cycles of improvement allow scaling up to multiple sites and regions and incorporation of parent feedback.