#### Poster presentation 1

#### The development and content validity of the selfreported Youth and Young-adult Participation and Environment Measure (Y-PEM)

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Introduction: Transitioning to adulthood can be a challenging process. This study aimed to refine and validate a self-reported measure of participation and environment, named Youth, Young-adult Participation and Environment Measure (Y-PEM), to comprehensively capture participation at home, school, and community, and to develop a new section to evaluate workplace participation for transition-aged individuals.

Patients and Methods: A multi-phase sequential mixed-method design was employed, guided by the Flowchart for Instrument Development, the cultural equivalence framework, and elements of COSMIN. Specifically, consecutive rounds of cognitive interviews among 24 participants aged 12 to 33 (mean = 21; n=19 with physical disability) and consultation with experts in the field of employment (n=15) were conducted for item development and validation. Relevancy and clarity of items in each setting were further assessed using the 10-cm Visual Analogue Scales (VASs).

Results: Youths recommended adding mature roles specific to this age group such as dating, caring for others, preparing meals, driving, and work participation. Newly developed work-related items were perceived important by experts (mean 3.4/out of 4) and young-adults (3.1/4) with average clarity of 8.8/10 and relevancy of 8.4/10 on the VASs. Across the remaining settings, on average, clarity and relevancy of items were rated respectively 8.7 and 8.1 in the community; 8.3 and 8.1 in the school/educational setting, and 6.9 and 7.4 in the home (out of 10). No suggestions were made to modify environmental items. Conclusion: Results suggest the content of the Y-PEM is clear, relevant, and comprehensive for, and can be completed by,

#### Poster presentation 2

individuals aged 12-30.

## Improving participation of youth with physical disabilities during COVID-19 using the PREP approach: Initial evaluation

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Introduction: This study examined the feasibility and initial effectiveness of the Pathways and Resources for Engagement and

Participation (PREP) intervention in improving participation of youth with physical disabilities during COVID-19. Specifically, unique participation goals and strategies used to address them are reported along with changes in participation levels.

Patients and Methods: A 22-week individual-based interrupted time series design was employed among seven youth (4 females) with physical disabilities aged 17–24 (median = 22). PREP intervention forms completed by therapists were reviewed and common intervention strategies were extracted. Performance of and satisfaction with the activity were measured weekly using the Canadian Occupational Performance Measure (COPM) and individual trajectories of change were visually analyzed.

Results: All participants identified a non-virtual participation goal and started engaging in their selected activity with another individual. Four participants have completed the intervention participating in their leisure activity for 8 weeks. A range of activities were chosen including singing, cooking, playing board games, horseback riding and badminton. Common strategies in accordance with health guidelines included: creating 1:1 opportunities, matching same-age peers with similar interests, structuring informal activities, being flexible, having an alternative plan, and consulting with the disability community. Visual inspection of completed COPM data (n=4; 8 trajectories) indicated an improvement in performance and satisfaction for all participants. Median scores increased by at least 2 points on the COPM scales in 6/8 trajectories, suggesting a clinically significant improvement.

Conclusion: Improving participation during the pandemic appears feasible and requires creative and flexible intervention strategies to address existing barriers.

#### Poster presentation 3

### Physical therapy goals of children with cerebral palsy in Qatar: An ICF-CY perspective

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*Introduction*: The primary aim of this study was to classify physical therapy (PT) goals for children with cerebral palsy (CP) attending an outpatient setting, against ICF-CY codes.

Patients and Methods: One-hundred and fifty PT goals of 75 children were studied. Sixty-four percent were male, aged 2–14 (mean: 6.8±3.2 years), 16% GMFCS levels I and II, 27% GMFCS level III and 57% GMFCS levels IV and V, with Arab (61%) and Asian (39%) ethnicity.

Results: One-hundred forty-eight of 150 motor-goals had 248 ICF-CY linking. The distribution of goals were: Body structure 0%, Body function (BF) 27% (66 linking), Activities and participation (AP) 67% (166 linking), and Environmental factors (EF) 6% (16 linking). Seventy-four percent children had AP-codes, 28% BF-codes and 11% EF-codes. Thirty-three, 2-level classification codes were identified within 12 chapters across BF, AP and EF domains. The prominent chapter-wise linking per domain were, neuro-musculoskeletal-movement-related-functions (*n*=60 linking-BF), mobility (*n*=150 linking-AP), and support-relation-ships (*n*=9 linking-EF). Among two-level classification codes, most

frequent were: maintaining-basic-body-position d415 (n=56 linking) and walking d450 (n=20 linking) from the AP-domain, and muscle-power-functions b730 (n=22 linking) from BF-domain. AP and BF domains showed higher linking in the age category 4-5 years, while EF in the age category 6-7 years. Severity levels showed significant associations with EF (p=0.009), while child age showed significant associations with BF (p=0.010) and AP (p=0.028) domains.

Conclusion: Motor-goals of children with CP reveal a higher representation in the mobility chapter of AP domain. However, it mirrors major representation gaps, in the rest of the participation chapters of AP and in personal and environmental factors.

#### Poster presentation 4

#### Early lexical development measurements by the Language Development Survey: A feasibility study in Italian-learning children with autism spectrum

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Introduction: English-learning children with autism spectrum disorder (ASD) have delayed lexical development on the Language Development Survey, a parent-reported expressive vocabulary checklist (LDS; Rescorla, 2013). We tested the Italian-version of the LDS to measure early lexical development in Italian children with ASD. We also aimed to address possible cross-linguistic similarities in early lexical acquisition in ASD.

Patients and Methods: Total vocabulary score (total number of acquired words/310) and semantic category scores across 14 semantic categories (number of words acquired per class/words per class) were computed in children with ASD (n=30, 73% males) and in typically developing (TD) children (n=43, 70% males). Results were compared between groups matched for nonverbal developmental age (DA): (ASD: median DA 24; range: 6-43 months. TD median DA 24; range:15-33 months) (*p*=0.743). Semantic category scores were compared after controlling for vocabulary size.

Results: The TD group was significantly younger (median chronological age (CA) 25; range 18-30 months) than the ASD group (median CA 60; 22-89 months) (p< 0.0001). LDS total vocabulary score was significantly lower in ASD (0.07; range 0.02-0.98) compared to TD children with equivalent DA (median 0.41; range 0.02–0.95) (p< 0.0001). Semantic category scores were all significantly decreased in the ASD group compared to the TD group (p< 0.001). When controlling for vocabulary size, children with ASD and TD children did not differ significantly in semantic cat-

Conclusion: LDS measurements in a sample of Italian-learning children with ASD concur with delayed but not-deviant lexical development informing cross-linguistic similarities in language acquisition and early intervention programs.

#### Poster presentation 5

#### Family-centered care in rehabilitation for children with cerebral palsy from the perspective of multiprofessional team of specialists

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Introduction: The study aim was to research self-esteem and understanding of the family-centered services for children with cerebral palsy from the perspective of multi-professional specialists.

Patients and Methods: Study design: convergent parallel mixedmethods study. In the quantitative part of the research, self-assessment of employees of four rehabilitation centers was performed using the questionnaire 'Measure of processes of care for service providers'. There were six interviews with service providers in the qualitative part of the study. The interviews were individual and semi-structured. Data processing was performed using deductive content analysis.

Results: According to the participants, the services were provided using the principles of family-centered care, and the lowest rating was given for providing general information to families. The selfesteem of professionals for family-centered principles is not related to the age, experience, level of education, qualification of the participants. The study identified understanding of familycentered care and its principles; experience in providing services using principles of family-centered care; factors that affect this approach in providing services.

Conclusion: The participants' understanding of family-centered care is related to the importance of providing information, respecting families and involving in rehabilitation, but lack of understanding of formal and informal support. Participants face different challenges in providing family-centered services. Specialists identified the lack of time, indifference of parents, negative experience as barriers in family-centered care. Participants consider that improving the coordination of rehabilitation services and reducing the number of patients for a specialist could improve the provision of family-centered services.

#### Poster presentation 6

Executive function profile in children with mild CP M BLASCO<sup>1,2,3</sup>, M GARCÍA-GALANT<sup>1,2,3</sup>, A BERENGUER-GONZÁLEZ<sup>1</sup>, O LAPORTA-HOYOS<sup>1,2,3</sup>, J BALLESTER-PLANÉ<sup>1,2,3</sup>, X CALDÚ<sup>1,2,3</sup>, J MIRALBELL<sup>1,2,3</sup>, F GIMENO<sup>4</sup>, E TORO-TAMARGO<sup>5</sup>, M MELÉNDEZ-PLUMED<sup>5</sup>, R PUEYO<sup>1,2,3</sup>

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Introduction: People with cerebral palsy (CP) often present executive dysfunctions, which play an important role in behaviour regulation, social abilities, and daily life activities. This study aims to examine the multiple domains of executive function (EF) to identify specific executive function profiles in children with mild CP. Patients and Methods: Fifty-three children with CP from 8 to 12 years of age (mean age 9.9, SD 1.6 years, 30 males), MACS I to III, and mean intelligence quotient (IQ) of 99.5 (SD 11.5) were included. Working memory, inhibition, cognitive flexibility and planning were assessed with the following tests: Digit Span backwards (Wechsler Intelligence Scale for Children - Fifth Edition, WISC-V), Auditory attention and response set (Developmental NEuroPSYchological Assessment-II, NEPSY-II), and Tower test (Delis-Kaplan Executive Function System). Performance in the different EF domains was compared by using  $\gamma^2$  tests (Fisher's exact test).

Results: Frequency of impairment varies across all four EF domains (p< 0.005). Thirty-eight percent of participants showed impairment in cognitive flexibility, 30% in working memory, 24% in inhibition, and finally, 16% presented planning impairment. Conclusion: Children with CP and with mild motor ability and average IO show an uneven profile of EF. Executive dysfunction is present in 16% to 38% of participants, depending on the EF domain assessed. This variability indicates the need for assessing all EF domains when using interventions targeting EF.

#### Poster presentation 7 Management of pain and sleep difficulties in children with cerebral palsy - A quality improvement audit

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Introduction: Children and young people with cerebral palsy commonly experience difficulties with pain and sleep. The NICE guidelines on 'Cerebral Palsy in under 25s' recommend that pain and sleep difficulties are assessed and addressed at each clinical encounter.

Patients and Methods: An audit of our practice in the Multidisciplinary Cerebral Palsy clinic in 2018 demonstrated poor compliance with NICE guidelines, therefore a pain assessment tool for non-verbal patients and a clinic proforma were introduced in order to standardise care. A prospective re-audit of all patients seen in the Cerebral Palsy MDT clinic was carried out over a 6 month period in 2019.

Results: Re-audit showed excellent compliance with pain assessment, increasing from 50% to 98% of patients. The cause was considered in 93% of those with pain, rising from 78%. 86% of those with pain received pain management plans, increasing from 15%. 39% of non-verbal children's carers perceived them to have pain and the assessment tool was only employed in these cases. Using a clinic proforma improved the assessment of sleep difficulties from 63% to 98%, with 87% of patients receiving a clear management plan for sleep difficulties. Conclusion: The audit cycle demonstrated significant improvement in multidisciplinary care of pain and sleep difficulties, in line with national standards. Onward recommendations include using a pain assessment tool for all non-communicating patients, even if pain is not identified by carers at initial assessment. We also encourage consistent provision of sleep and pain management plans, including a step-wise analgesic approach, where difficulties are identified.

#### Poster presentation 8

#### Neurodevelopmental outcome of preterm very low birth weight infants from a single Italian tertiary center over an eleven-year period

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Introduction: Preterm very low birth weight infants (VLBWi) are known to be at greater risk of adverse neurodevelopmental outcome. Identifying early predictors of poor outcome is essential in order to start early intervention. Few studies have investigated neurodevelopmental outcome in Italian VLBWi.

Patients and Methods: This was a single-center longitudinal cohort study including all consecutive VLBWi admitted to the Neonatal Intensive Care Unit of Policlinico San Matteo between January 1st 2005 and December 31st 2015. Neurodevelopmental outcome was assessed at 24 months of corrected age using Griffiths' Mental Developmental Scales and was classified as: normal, minor sequelae (minor neurological signs, GQ between 76 and 87), major sequelae (cerebral palsy; GO <75; severe sensory impairment). To identify independent neonatal risk factors for adverse outcome a multivariate ordered logistic regression model was performed.

Results: 502 VLBWi completed the follow up. 75.3% showed a normal outcome, 13.9% minor sequelae and 10.8% major sequelae (3.8% cerebral palsy). Male gender (OR 1.59 CI 95% 1.0-2.5; p = 0.043), bronchopulmonary dysplasia (OR 1.7 CI 95% 1.1–2.9; p value 0.026), abnormal neonatal neurological assessment (OR 2.1 CI 95% 1.3–3.4; p = 0.002) and severe brain ultrasound abnormalities (OR 6.1 IC 95% 2.4-15.1; p < 0.001) were independent predictors of poor outcome on multivariate analysis. Conclusion: The rates of major sequelae are in line with international studies, as is the prevalence of developmental delay over cerebral palsy. Analysis of perinatal complications and the combination of close cUS monitoring and neurological examination are

#### Poster presentation 9

#### Oral melatonin as a new tool for neuroprotection in preterm newborns: Study protocol for a randomized controlled trial

useful in early identifying infants with adverse outcome.

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Introduction: To date, there are few neuroprotective molecules available for prevention of neonatal brain damage. Melatonin has been shown to reduce brain injury in term infants with hypoxicischemic encephalopathy trough anti-oxidant effects. We aim to assess the neuroprotective role of melatonin in preterm infants who lose the maternal supply and are also unable to produce it during the first weeks of extrauterine life.

Patients and Methods: This was a prospective, multicenter, doubleblind, randomized vs placebo study. 60 preterm newborns with a gestational age <30 weeks will be recruited and will received oral melatonin or placebo for 15 days starting within 96 h after birth. After the administration period, an early plasma marker of melatonin efficacy will be measured (malondialdehyde). At term-equivalent age neurological examination, general movements and visual function assessments will be performed. The incidence of bronchodysplasia and sepsis will be registered. Neurodevelopmental outcome will be assessed at 4-6 months using the modified Fagan Test of Infant Intelligence and at 24 months using Griffiths Mental Development Scales.

Results: A statistically significant decrease in malondialdehyde concentration in the treated group (primary aim). We will also analyze if there are statistically significant differences in preterm health complications and in neurodevelopmental outcome between placebo and treated group.

Conclusion: This is the first pilot study about the role of melatonin in preterm newborns. Considering the amount of morbidities related to preterm birth and the financial and social costs of the care of preterm infants, melatonin could be a neuroprotectant leading to considerable saving of resources.

#### Poster presentation 10

Goal attainment following treatment with abobotulinumtoxinA and an intensive home therapy program in children with upper-limb spasticity J CARRANZA<sup>1</sup>, E DABROWSKI<sup>2</sup>, N DURSUN<sup>3</sup>, A TILTON<sup>4</sup>,

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Introduction: In children with upper-limb spasticity, botulinum toxin injections are often used to produce a selective reduction in muscle tone while optimising the potential for occupational therapies to enhance motor ability and functional skills. Primary endof analysis this phase 3 study confirmed abobotulinumtoxinA (8 U/kg and 16 U/kg) significantly reduced hypertonia versus the 2 U/kg low-dose control. We have also assessed effect of treatment on goal achievement.

Patients and Methods: This was a double-blind, repeat-cycle study (NCT02106351). During Cycle 1, children (2-17 years) with CP and spasticity in ≥1 upper-limb were randomized to receive abobotulinumtoxinA at doses of 2 U/kg, 8 U/kg and 16 U/kg in the elbow/wrist flexors and other upper-limb muscles followed by an individualised home-exercise therapy program (HETP). Goals were chosen at baseline and goal attainment was assessed at weeks 6 and 16.

Results: Active rather than passive goals were more commonly selected. High proportions of children achieved their goals at least as expected (rated as ≥0), with no significant differences in goal achievement between groups. Responder rates for primary goal (2 U/kg, 8 U/kg, 16 U/kg) were 70.6%/75.8%/74.3% at week 6, increasing to 86.4%/82.1%/81.2% at week 16. Responder rates for individual goals at week 16 were: Reaching (n=20/23/25): 100%/91.3%/80.0%; Grasp and Release (n=17/20/14): 70.6%/ 75.0%/78.6%; Involving the arm more (n=31/28/31): 77.4%/ 89.3%/80.6%; Using limb as helping hand (n=16/18/18): 87.5/ 61.1%/88.9%; Dressing (n=12/14/7): 66.7%/85.7%/71.4%; Range of movement (n=8/16/7): 87.5%/68.8%/85.7%; Donning/tolerating splints (N = 2/4/3): 50.0%, 75.0%, 100%; Ease of care (n=2/4) 1/1): 100%/100%/0; Hygiene (n=0/1/4): -/100%/75.0%.

Conclusion: Treatment with abobotulinumtoxinA plus a HETP was associated with high levels of goal achievement.

#### Poster presentation 11

Sensitivity and responsiveness of a modified Jebsen-Taylor Test of Hand Function scoring for children with unilateral cerebral palsy

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Introduction: The Jebsen-Taylor Test of Hand Function (JTTHF) is one of the most used test to assess manual dexterity of children with unilateral cerebral palsy (UCP) in research and clinics. The original version of this test only assesses the time to complete the test (speed), disregarding the amount of objects handled (accuracy). However, speed and accuracy are often interdependent, i.e., faster movements may be performed to the detriment of reduced accuracy (and conversely). The use of a modified version of scoring, considering speed and accuracy, could increase the sensitivity of the JTTHF to characterize motor performance, but could also modify its psychometric properties. The aim of this study was to implement a measure of the speed-accuracy trade-off function in the JTTHF. Patients and Methods: This retrospective study included 169 typically developing children (TDC) (1 assessment) and 28 children with UCP assessed before and after an intensive intervention. Results: The original score showed an age-related improvement up to 8-10 years old. After this age, the values tend to reach a plateau with no major improvements. For the modified score, the values showed a continuous age-related improvement. Significant

Conclusion: This study provided a modified score, considering speed and accuracy, which maintained the responsiveness after an intervention and could be more representative of the motor performance of children with UCP. In addition it produced reliable norms for the JTTHF.

differences were observed after the intervention for the less and

more affected hand in children with UCP for both scores.

#### Language delay in San Filippo syndrome

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Introduction: San Filippo syndrome is a mucopolysaccharidosis characterized by language delay, sleep disturbances, irritability/aggressivity, and motor delay. At the end of the first decade, there is a gradual loss of the acquired capacities even leading to postration.

Patients and Methods: A 27 month old boy with San Filippo syndrome referred to a phoniatrician because of language delay. Background: 13 months: non-referential bisilables; 18 months: some onomatopoeias; 26 months: symbolic game; 35 months: Brunet Lezine test's result. 18 months with the worst punctuation at language item. He has received treatments by a logotherapist and he has been taught bimodal language. Examination: A poor range of vocabulary, 2 words phrases, altered articulation of some phonemes, slow rhythm bimodal language. Normal oral praxies. No feeding alterations. Good level of attention and impulsivity control. Sociable and kind.

Results: He received gene therapy with an adenovirus vector at 36 months old and has continued with a logotherapist and stimulation therapy. Follow up at 42 months: vocabulary has widened, 2-3 word phrases with little variety. Better use of bimodal language. He goes to an ordinary school with pedagogical support. No behavioral disturbances.

Conclusion: Having a periodic follow-up in order to prescribe treatment with a logotherapist, stimulation therapy, or pedagogical support whenever the patient may require it could help to diminish the burden of disease as well as keeping the family informed about the prognosis of this disease.

#### Poster presentation 13

#### Association between muscle strength and functioning in children and adolescents with cancer - Preliminary study

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Introduction: In Brazil, childhood cancer represents of 3% of all malignant tumors. According to the International Classification of Functioning (ICF), muscle strength represents one of the functions in the domains of body structure and function and its maximum measurement can predict a participant's capacity. The term functioning encompasses all body structures and functions, activities, and participation, therefore, it must be understood as the result of the dynamic interaction between the individual's health conditions and the contextual factors that surrounds him.

Patients and Methods: Children and adolescents, from 5 to 21 years of age, diagnosed with cancer, were invited for outpatient followup, supported by Ricardo Moysés Junior Cancer Foundation (Juiz de Fora, MG, Brazil). These are preliminary results of a cross-

sectional observational study, approved by the University's Ethics Committee (opinion: 28699920.2.0000.5147). The data collection was initially carried out remotely, by video call (WhatsApp), in which personal, environmental information and application of the functioning instrument (Pediatric Evaluation of Disability Inventory - computer adaptive-test - PEDI-CAT) were collected. Secondly, face-to-face data collection was carried out, and the strength of the knee flexors and extensors, and handgrip was measured using a handheld dynamometer. Pearson's correlation coefficient was used for data analysis.

Results: A strong correlation (r > 0.75) was observed between muscle strength and functioning for all measurements performed. Conclusion: This study suggests that there is a strong association between functioning and knee flexors, knee extensors, and handgrip strength, and these measures can be performed in clinical practice as informative for these ICF constructs.

#### Poster presentation 14

#### Association between calf circumference, muscle strength and functioning in children and adolescents with cancer - Preliminary study

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Introduction: Childhood cancer can be impacted by antineoplastic drugs, which can cause loss of low-fat body mass. The interpretation of sarcopenia in infant-juvenile population is limited to skeletal muscle mass deficiency, and the use of immunosuppressive drugs, nutritional status of the patient, and lifestyle (diet and physical inactivity) are factors that can influence sarcopenia and loss of skeletal muscle mass of this population.

Patients and Methods: Children and adolescents, from 5 to 21 years of age, diagnosed with cancer, in outpatient follow-up, supported by the Ricardo Moysés Junior Cancer Foundation (Juiz de Fora, Minas Gerais, Brazil) were invited to participate. These are preliminary results of a cross-sectional study, approved by University's ethics committee (opinion: 28699920.2.0000.5147). Data collection was initially performed remotely, by video call (WhatsApp), and application of the functioning instrument (Pediatric Evaluation of Disability Inventory - Computer Adaptive Test-PEDI-CAT). Secondly, a face-to-face collection was performed, where the calf circumference was measured with a tape, and strength of knee flexors and extensors and palmar grip, were measured with a manual dynamometer. Pearson's Correlation Coefficient was used for data analysis.

Results: A strong correlation was observed (r≥0.75) between calf circumference, muscle strength in lower limbs, and functioning for all measurements performed.

Conclusion: The study suggests that there is a strong correlation between calf circumference, functioning, knee flexors, and knee extensors. In clinical practice the measurement of calf circumference may predict both deficits in lower limb strength and functioning, possibly indicating a beginning of sarcopenia in the youths under childhood cancer treatment.

#### PARTICIPA BRAZIL — Engaging families of children with cerebral palsy in research: Registration of Brazilian participants

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Introduction: To create cerebral palsy (CP) motor trajectories for children and adolescents in Brazil, it is essential families' contribute to research, sharing their detailed experience and knowledge about their children. Thus, this study aims to report the strategies used by PARTICIPA BRAZIL to reach families of children and youths with CP and to characterize this population. Patients and Methods: We used the social media app Instagram to publicize the National Multicentered Study Project (PartiCipa Brazil), present the researchers, and announce the National CP Registry in Brazil. We aimed to reach families interested in participating in the study with a brief Google forms survey. This study was approved by the ethical committee (CAAE: 28540620.6.1001.5133).

Results: The Instagram page was launched on January 22nd, 2021. In 10 days, we had 632 followers, and 206 families filled the Google forms for the National Registry of CP for the PartiCipa Brazil Research. The mean age of the children is 5.25 (3.98) years; 49% of families use both public (21.8%) and private assistance (29.1%); participants subscribed from all 5 regions of Brazil: North (5.4%), Northeast (8.3%), Central-west (7.3%), Southeast (63.6%), and South (15.5%).

Conclusion: This first attempt to use social media to reach families to become involved with the PartiCipa Brazil Research has worked well. We still want to reach more families, especially in the North and Northeast of the Country, to follow-up and create functioning trajectories for these youths in Brazil.

#### Poster presentation 16

#### Children and adolescents with cancer assisted in a Support Institution in Juiz de Fora, Minas Gerais, Brazil – Preliminary study

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Introduction: The most frequent tumors in childhood are leukemias, central nervous system tumors, lymphomas, and neuroblastoma. According to Brazilian National Institute of Cancer (INCA), these patients should maintain follow-up with a multidisciplinary team for early recognition and appropriate care of possible late complications.

Patients and Methods: Children and adolescents, from 3 to 21 years of age, diagnosed with cancer, in outpatient follow-up, supported by the Ricardo Moysés Junior Cancer Foundation (Juiz de Fora, Minas Gerais, Brazil) were invited to participate. These are preliminary results of a cross-sectional observational study, approved University's ethics committee 28699920,2,0000,5147). The data collections were performed remotely (WhatsApp), with personal and environmental information and application of physical activity level instruments. Descriptive Frequency Analysis was performed for data analysis. Results: Nineteen participants participated in this preliminary study. Of these, 57.9% are female; mean age 11.37 years (5.84). The diagnosese were: 36.8% acute lymphoid leukemia, 10.5% chronic myeloid leukemia, 21.1% Hodgkin lymphoma, 5.3% neuroblastoma; 52.6% of the participants were in intermediate phase of treatment, 42.1% in control phase and 5.3% in palliative care; 36.8% of the participants in chemotherapy treatment; 26.3% chemotherapy and radiotherapy and 10.5% surgical approach. The participants were mostly physically inactive (78.9%). Regarding the follow-up with professionals from the multidisciplinary team, 57.9% had nutritional follow-up and 42.1% received physiotherapy.

Conclusion: The study suggests that the prevalence of cancer in the assisted population agrees with INCA estimates. More attention and care are needed regarding nutritional care of the participants and guidelines for physical inactivity.

#### Poster presentation 17

#### Absence of neutralising antibody formation during incobotulinumtoxinA treatment of spasticity in botulinum toxin-naïve children with cerebral palsy: Phase 3 analysis

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Introduction: Neutralising antibodies (NAbs) have been linked to secondary non-response to botulinum neurotoxin type A (BoNT-A) injections, a controversial and concerning issue when treating paediatric spasticity. We investigated NAb formation in three Phase 3 studies of incobotulinumtoxinA, a BoNT-A without complexing proteins, for the multipattern treatment of spasticity in children/adolescents with cerebral palsy (CP).

Patients and Methods: Patients with lower-limb (LL), upper-limb (UL) or combined LL/UL spasticity (2-17 years; uni- or bilateral CP; Ashworth Scale score ≥2 in clinical patterns for treatment) were enrolled. Patients received total body incobotulinumtoxinA doses of ≤16-20 U/kg (maximum 400-500 U) depending on the study (TIM: NCT01893411; TIMO: NCT01905683; XARA: NCT02002884) and Gross Motor Function Classification System level I to V, for <6 injection cycles (ICs). NAb formation against BoNT-A was investigated in patients ≥21 kg at screening and end of study. Blood samples were analysed for antibodies using a fluorescence immunoassay (FIA), and positive samples were tested for NAbs using a hemidiaphragm assay.

Results: Overall, 907 patients (59.6% male, mean [SD] age 6.7 [4.2] and bodyweight 23.3 [13.9] kg) received treatment. Patients ≥21 kg were tested using FIA at screening (386/403 [95.8%]) and end of study (318/422 [75.4%]), of which 150/403 (37.2%) and 167/422 (39.6%) were toxin-naïve. Eleven patients tested positive for NAbs at screening and/or end of study; all had previously received other BoNT-As. None developed secondary non-response to incobotulinumtoxinA. No toxin-naïve patients developed NAbs after incobotulinumtoxinA treatment.

Conclusion: NAb formation was absent in toxin-naïve children/adolescents with CP treated with ≤6 ICs of incobotulinumtoxinA.

#### Poster presentation 18

#### The feasibility of an adapted sports program in a middle income country

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Introduction: Sport and physical activity programs for people with motor impairments are increasing. However, in low- and middle income countries, including Suriname, opportunities for adapted sports are lacking. Therefore, a weekly adapted sports program 'Mi Kan Du Sport', was set up in Suriname. This study aims to assess the feasibility of the weekly program in terms of adherence, volume and effectiveness.

Patients and Methods: Ambulant children, aged 7-15 years, with motor impairments participating in the adapted sports program are recruited to participate. The adherence (measured by the number of attended sessions), the volume and effectiveness of the training program are measured throughout 8 weeks of training. To measure volume, participants wear heart rate monitors during the entire session. Physical activity levels are measured using activity monitors one week before and one week after the 8-week program. Effect on mobility and strength is assessed by the 1-Minute Walk Test, modified Timed Up and Go, hand grip strength, Bilateral Step-up, Sit-to-Stand and Sit Up Test.

Results: Fifteen children are currently participating in the feasibility study. Results will be presented during the 33rd Annual EACD Conference.

Conclusion: We expect adherence to be around 80%. We expect fairly low volumes of the activities during the program as well as fairly low intensity activities. Regular sporting programs offered once a week may not be sufficient to expect changes in physical activity, strength and mobility due to low volumes. An active physical lifestyle needs to be promoted throughout daily life.

#### Poster presentation 19

#### Children and young people's perspectives on decision-making and their experiences around selective dorsal rhizotomy

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Introduction: Selective dorsal rhizotomy (SDR) is an irreversible neurosurgical procedure to reduce spasticity in children with cerebral palsy (CP). Little information exists on the extent to which children and young people (CYP) participate in decision-making around SDR. This study explored the experiences, expectations and CYP involvement in the decision-making for SDR surgery, post-operative physiotherapy treatment and outcomes.

Patients and Methods: A qualitative study using 1:1 interviews utilising creative methods was conducted. Five CYP (2 girls and 3 boys) participated, and interviews lasted between 45 minutes to 2 hours. Data were analysed using thematic analysis.

Results: CYP are heavily reliant on their parents to make decisions and inform them of the process. Their focus remains on the social issues, the psychological and physiological challenges of CP that they experience in their daily lives. The CYP involvement in the SDR process changes from being a passive onlooker during the decision-making process to becoming an active participant after the surgery. Individual characteristics and attributes of CYP have an impact on how they cope with the rehabilitation burden, adjust to their changing levels of function and participation.

Conclusion: Although SDR offered CYP the benefit of 'freedom to choose' and improved participation in daily life, further consideration is required to meet their psychosocial needs, particularly when preparing for SDR and adjusting afterwards. Providing ageappropriate information, resources to help parents and psychological support for CYP are integral to facilitate them through the decision-making process and post-operative intensive rehabilita-

#### Poster presentation 20

Functional mobility in ambulatory children with bilateral spastic cerebral palsy at two years following single-level selective dorsal rhizotomy D CHUGH<sup>1</sup>, S CAWKER<sup>1</sup>, K AQUILINA<sup>1</sup>, A GANDEKAR<sup>1</sup>

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Introduction: A primary goal of selective dorsal rhizotomy (SDR) is improvement in functional mobility. Outcomes at 2 years after

single-level SDR and rehabilitation are presented for ambulatory children (Gross Motor Function Classification System [GMFCS] levels II and III) with bilateral spastic cerebral palsy.

Patients and Methods: Data from 82 children, GMFCS level II (n=26) and III (n=56) who underwent SDR and 2 years follow-up were analysed. Mean age (SD; range) at SDR surgery was 6 years 7 month (2 years 2 months; 2 years 9 months to 13 years 8 months). Functional mobility outcomes were the 6-minute walk test (6MWT) and two parent-reported measures, the Functional Mobility Scale (FMS) and the Gillette Functional Assessment Questionnaire (FAQ).

Results: 6MWT distance, mean (95% CI), improved by 119.8 m (86.1–153.4 m, p < 0.001) in GMFCS level II, and by 49.6 m (17.7–81.6 m, p = 0.003) in GMFCS level III. Ratings on the 1–6 FMS 5 m, 50 m, 500 m improved by at least 1 in 46.2%, 73.1% and 59.3% (p=0.008) in GMFCS level II and 56.1%, 53.4% and 35.1% (p=0.005) in GMFCS level III. Ratings on the 1–10 FAQ improved by at least 1 in 52% (n=25, p = 0.004) and 55.6 % (n=45, p = 0.015) of children in GMFCS level II and III respectively. Deterioration in all scores was observed in 2/82 children. Conclusion: Data show significant improvements in functional mobility in the majority of children in both GMFCS level II and III at 2 years after SDR. Further study is required to identify how these changes impact habitual physical activity in daily life.

#### Poster presentation 21

### Strengths and Difficulties Questionnaire for estimation of prevalence of mental health problems in 8 to 10 year old Georgian children

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Introduction: Mental health problems are frequent among children and seem to predict mental disorders in adulthood. The study aimed to assess whether the gender of the child affects the difference between the Strengths and Difficulties Questionnaire (SDQ) assessments performed by parents and teachers in the Republic of Georgia.

Patients and Methods: In 2019 a cross-sectional survey in four main cities of Georgia was conducted. In total 16,654 8 to 10 year old children from 211 public schools were included. SDQ completed by parents and school teachers was used to determine emotional and behavioral problems among Georgian children.

Results: 16,654 (74%) parents out of 22,553 agreed to participate in the study. 1565 (9.39%) children were screen rated positive in the top five percentile by either parent or teacher or both. Cutoff scores for 99–95 percentiles (top 1–5%) was defined. Boys were more likely to be screen rated positive than girls, especially by teachers: parents rated screen positive 7.5% of females, teachers 7.2%, while males 9.4% and 11.5% respectively. Pairwise correlation coefficients (0.53) revealed moderate correlations according to p-values (<0.05) between scores and all correlations were statistically significant.

Conclusion: The study defined the cut-off scores of SDQ for 8–10 year old children and a gender difference in prevalence of mental health problems in Georgia. The SDQ could be used in

primary healthcare and school settings to identify children with special needs.

#### Poster presentation 22

#### Remodulation of clinical interventions for neurodevelopmental disorders during the Covid-19 Pandemic in a public neuropsychiatric service for childhood and adolescence

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Introduction: In this study, we present the use of telemedicine during the first lockdown period (March–June 2020) of the Covid-19 pandemic, in our public service for mental health and rehabilitation in childhood and adolescence (UOC Neuropsichiatria Infantile e dell'Adolescenza ASL Taranto, Polo Occidentale), describing the reorganization of the clinical and therapeutical interventions delivered for our patients.

Patients and Methods: We specifically analyze the efficacy of direct, indirect, synchronous, asynchronous and hybrid tele-practice (i.e. language and speech therapy, neuropsychomotor treatments and educational interventions) for a sample of 55 children with neurodevelopmental disorders attending our service using two assessment tools: a questionnaire to evaluate parent/caregiver satisfaction and a clinical tool for operators to investigate the perception of effectiveness and efficiency of remote treatments.

Results: Our results describe benefits linked with higher sociocultural status, availabilty of internet connection and electronic devices and level of collaboration of families involved, such as with a lower degree of severity of the disorders (i.e. absence of comorbidity with emotional and behavioural issues).

Conclusion: These findings suggest the need for more active involvement of families in the care process and activation of policies aimed at allowing access to internet sources and digital devices for families. Further investigations are needed to better evaluate the feasibility and efficacy of tele-rehabilitation in the broad spectrum of neurodevelopmental disorders.

#### Poster presentation 23

### Young people's perceptions of participation – A qualitative study

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Introduction: Research on lay perceptions is constantly increasing. Yet, young people's perceptions of participation are barely examined until now, which is surprising considering the importance of regarding knowledge for practice and science. Information about individuals' understanding of concepts as participation is necessary to perform suitable counselling, therapy, research and consequently political and societal changes. This especially applies for people in the transition phase, which comes with a broad variety of life situations.

Patients and Methods: Using the qualitative method of group discussions, twenty young adults with and without cerebral palsy (CP) from northern Germany were asked about their perceptions of participation. In addition, proxy interviews were conducted with three parents and an attendant of a sheltered workshop to indirectly include young adults with more severe CP who were not able to take part in a discussion. The interviews were transcribed and analysed using qualitative content analysis.

Results: Young adults have complex and individually different perceptions of participation. The interviews showed six types of definitions: Togetherness, Social inclusion & Participation in society, Open-mindedness & Interest, Equal opportunities & treatment, Freedom of choice & Autonomy and To have a voice. Furthermore, eight areas of participation were mentioned as important for young adults: Social environment, Work & Education, Leisure, Media, Mobility, Habitation & Household, Politics and Finances & Self-administration.

Conclusion: Young adults have their very own concepts of participation which are not sufficiently reflected in scientific definitions. This should be considered in research, clinical work as well as politics and society.

#### Poster presentation 24 From COVID networks to global partnerships M DEMPSEY1, K ŚWIECZKOWSKA2

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Introduction: In March 2020, two occupational therapists from Poland and Ireland joined the EACD COVID-19 Global Task Force. They were involved in collating information to offer support to clinicians and families during the pandemic. This poster will look at the experience of this involvement and celebrate the developments that have grown from this initial collaboration.

Patients and Methods: Children with disabilities and their families. Results: Through discussions for this collaborative work, partnerships and alliances developed that might otherwise never have happened. These networks are continuing and will benefit children and families both for Covid and non-Covid supports and interventions. Examples will be illustrated in the poster.

Conclusion: Networking and building informal relationships can support the development of 'bottom-up' approaches to child and family support. While recognising the importance of academic research and dissemination of knowledge this poster highlights the importance of the human element that truly connects the research with people.

#### Poster presentation 25 Assistance impact in child rehabilitation unit by COVID-19

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Introduction: The pandemic has had an important impact on the

rehabilitation activity, changing the organization and healthcare model. The objective is to describe the alternative models developed for child disability assistance and their results.

Patients and Methods: Prospective study from March 15, 2020 to May 15, 2020 in a Rehabilitation Unit of a level III hospital. An organizational structure is selected with different roles among the unit staff: rehabilitation doctors, physiotherapists, occupational therapists, speech therapists, clinical assistants and administrative assistants. The structure includes a head of service, a secretary, a safety reference responsible for supervising good practice in safety of professionals, patients, environment, spaces, circuits. Qualitative and quantitative analysis is carried out.

Results: Protocols are developed in healthcare, communication, human resources, logistics, monitoring and evaluation. In healthcare, we developed 13 new graphic protocols, updated 19, videoedited 3, for the most prevalent pathologies. Hospitalization medical consultations decreased by 45%; 100% of consulted patients received physiotherapy or/and occupational therapy. In the outpatient area, the 679 scheduled in-person medical visits were transformed into telematics consulting: phone-call 74%, video-calls 15.66%; contact was not possible in 10.34%. Telephone followup was carried out for the 227 patients whose treatment was suspended: physiotherapy 71.8%, occupational therapy 59%, with video calls 10.2% and 12% respectively. The satisfaction survey of perceived quality with the attention to patients, parents and caregivers, reflects 95% as very satisfied.

Conclusion: A contingency plan with organized structures and defined roles allows maintaining virtual care with high degree of satisfaction in childhood disability.

#### Poster presentation 26 Rehabilitative intervention in a pediatric intensive

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Introduction: The rehabilitation programs in pediatric intensive care units (PICUs) are increasingly more sought after by pediatricians and parents alike, backed by growing evidence in efficacy. However, there is little information regarding patient eligibility, components of the rehabilitation team, optimal time of intervention, viability, safety, efficiency and profitability of said programs. Objectives: Identify the profile of patients in PICUs included in the rehabilitation program, therapies used and safety of the interventions.

Materials and methods: Descriptive retrospective study characterizing admitted patients in the PICU at Gregorio Marañon General University Hospital included in the rehabilitation program, from July to December of 2020.

Results: Of 167 patients admitted to the PICU, 28 rehabilitative interventions were performed (17%). 15 were males (54%), with a median age of 7 months (SD: 1.23-2.09). The main admission diagnosis was heart disease (39%). Mean stay in the PICU was 72.57 days. 3 patients died during admission (10%). 22 were treated with motor therapy (76%), 12 with respiratory physiotherapy (43%), 13 with occupational therapy (46%) and 15 with speech therapy (52%). No adverse effects were reported during treatment. Continuity of care was performed to all of them after their transfer to the ward.

Conclusion: The critical patient profile is an infant with congenital heart disease and prolonged stay in the PICU. They benefit from a multidisciplinary intervention, without adverse effects.

#### Poster presentation 27

#### Portuguese National Surveillance of Cerebral Palsy (PVNPC): Feasibility of the reassessment of adolescents with cerebral palsy, born 2001 to 2003 T FOLHA<sup>1</sup>, AJ SANTOS<sup>1</sup>, J ALVARELHÃO<sup>2</sup>, A CADETE<sup>3</sup>, D VIRELLA<sup>1</sup>

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Introduction: The Portuguese National Surveillance of Cerebral Palsy (PVNPC) effectively registers clinic, epidemiologic and functionality data of children with cerebral palsy born since 2001, at the recommended age of 5-year-old. For PVNPC to provide useful, up-to-date indexes, data on the evolution of cerebral palsy later in life are required.

Patients and Methods: Therefore, it was planned to reassess during adolescence those individuals registered as a child (Project for Reassessment of Adolescents) and a feasibility study was designed, on a 'best scenario' approach. Regular notifiers for PVNPC in two of the regions with the best adherence were invited to reassess in 2016-2019 those participants born in 2001-2003, which had been registered to PVNPC.

Results: The target sample includes 34% of the national 2001 to 2003 birth-cohort. Information about 77% of the participants born in 2001 to 2003 was obtained. The participants with the best odds for reassessment in adolescence were those that had registered more complex conditions as a child.

Conclusion: The study highlights the need to design strategies to reduce participation and identification bias. We conclude that it is feasible to reassess adolescents registered as a child to PVNPC but actions to promote participation and to control bias are required.

#### Poster presentation 28

#### Parent-reported daily activities and mobility changes in ambulatory children with cerebral palsy one year after selective dorsal rhizotomy

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Introduction: Selective dorsal rhizotomy (SDR) is a neurosurgical procedure used to reduce spasticity in the lower limbs in children and young people (CYP) with cerebral palsy (CP). The main goals are to improve gross motor function, independence, activity level and participation. This study aimed to evaluate changes in the Daily Activities and Mobility domains of Paediatric Evaluation of Disability Inventory- Computerised Adaptive Test (PEDI-CAT) one year after SDR in ambulatory children with CP.

Patients and Methods: PEDI-CAT data of 28 children (19 male, 9 female) were analysed. Preoperative Gross Motor Function Classification System (GMFCS) levels were II (n=10) and III (n=18). The mean age (range) at surgery was 7 years 2 months (3 years 9 months, 13 years 8 months). The PEDI-CAT was administered at baseline and one year after SDR by the occupational therapist. Results: There was a significant improvement in both PEDI-CAT Daily Activities (p=0.001) and Mobility scores (p=0.043) for the whole group (n=28). Children in GMFCS level III demonstrated significant improvement in the Daily Activities scores (p=0.001) but not in the Mobility scores (p=0.19). Children in GMFCS level II showed no significant improvement in the Daily Activities (p=0.47) or Mobility scores (p=0.12).

Conclusion: These results indicate that SDR and subsequent rehabilitation may improve daily activities and functional mobility in some CYP with CP one year after SDR. Children in GMFCS level III showed more functional gains compared to children in GMFCS level II. The reasons for these differences between the two GMFCS levels needs further exploration.

#### Poster presentation 29 Analysis of the situation of school-based physiotherapy services in Spain

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Introduction: Students with special educational needs may need the specific and specialized support of Physiotherapy in order to facilitate the development of their maximum potential and help in their educational inclusion. The information about school-based physical therapy development in Spain is very scarce. The objective of this study is to describe the situation of physiotherapy in educational centers and compare it among the different autonomous communities.

Materials and methods: A descriptive and cross-sectional study was carried out through the elaboration of an online survey, designed together with a panel of experts using the Delphi method. Five thematic blocks were included related to the provision of the physiotherapy service, working conditions and the met of the students' needs.

Results: 178 responses were obtained. Their geographical distribution was homogeneous, although large differences were detected among the autonomous communities. Most of the participants work in special education centers and there are autonomous communities in which physical therapists do not work in ordinary centers. Only 28.4% answered that the physiotherapist is integrated into the educational orientation teams of their autonomous community and has the function of determining the need for the resource.

Conclusion: School-based physiotherapy services to support students with special educational needs is unequal among the autonomous communities, and in some of them it is considered insufficient.

#### Performance-based test versus behaviour-rating scales to measure executive functioning impairment in children with cerebral palsy

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Introduction: Children with cerebral palsy (CP) may present executive dysfunction that persists into adulthood and which has been associated with quality of life. There are different approaches to assess executive functions. The aim of the present study was to compare executive function outcomes obtained by performancebased tests with those obtained from behaviour-rating scales. Patients and Methods: Forty-six children with CP from 8 to 12 years of age (mean age 9.93, SD 1.5, 28 males) were included. Digit span backwards from the Wechsler Intelligence Scale for Children - Fifth Edition (WISC-V), Auditory attention and response set from Developmental NEuroPSYchological Assessment-II (NEPSY-II) and Tower test from Delis-Kaplan Executive Function System were used for the performance-based assessment of the four main executive functioning domains. The Behavior Rating Inventory of Executive Functioning (BRIEF-2) was the rating scale used. Differences between performance-based tests and behaviour-rating scale outcomes were examined using Wilcoxon signed-rank tests.

Results: Children with CP showed a significantly better performance in the global executive index of the BRIEF-2 than in the global executive function composite score (Z = -5.016; p = 0.000) of the test performances. A better performance in cognitive and emotional regulation indexes of the BRIEF-2 than in the tests that assess similar functions of planning and working memory (Z = -2.995; p = 0.003), and cognitive flexibility (Z = -2.093;p = 0.036), respectively, was found.

Conclusion: Children with CP have better executive function outcomes when assessed by behaviour-rating scales than by performance-based tests. To properly assess executive functioning in children with CP, both measures provide complementary information.

#### Poster presentation 31

#### Impact of covid-19 on people with cerebral palsy in the process of ageing

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Introduction: Confinement presents a challenge for people with cerebral palsy who are aging. The health alert caused by the coronavirus has led to restriction of movement, interruption of routines and reduction of social interactions that have led to changes in daily life. The aim is to analyse the impact of confinement

through the demands made by elderly people with cerebral palsy and the prevention and coping strategies offered to the group and their families.

Patients and Methods: The Federation of Cerebral Palsy Associations of a Spanish community offers Covid-19 counselling and support service to people with cerebral palsy and their families. From March to May 2020, various requests were received, specifically thirty requests made by elderly people. The causes, effects and recommendations are analysed.

Results: It was found that many of the difficulties are a consequence of not attending, working and participating in centres and services, breaking their routines, with families taking charge of the necessary support throughout the day. Requests for general accompaniment are collected: information, training and advice; as well as requests about specific conditions: due to age, support needs, special characteristics, area in which they live, economic level, loss of a family member and being infected by covid-19.

Conclusion: The physical, mental and social effects suggest the design of new supports that respond to the needs and fulfil the confinement measures from a personalized, safe and quality attention to manage the confinement and face these events in the future

#### Poster presentation 32

#### Difference in participation between young adults with cerebral palsy and young adults from the general population: Cross-sectional multicentre **European study**

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Introduction: Studies already show less participation in most areas of life in children and adolescents with disabilities compared to the general population. This study addresses young adults (YA) with cerebral palsy (CP) compared to persons the same age in the general population.

Patients and Methods: A cross-sectional study was conducted in four European regions, targeting YA [19-28 years] identified from CP registries and multiple sources, or recruited online for the general population (GP). The QYPP-YA measured participation on six domains from high to low participation. Standardized differences between populations were estimated using WLSMV

Results: YA with CP showed higher scores than the GP in all domains with the largest gap on intimate relationships. This large gap was reduced in big cities. Women in big cities showed greater differences than men on independence in life choices, but narrower than in smaller towns. Men in big cities showed higher freedom of decision than the GP. Parental level of education moderated the difference on online communication. Difference on social life domain was country-dependent. Students had lower interpersonal relationships score than non-students. Less severely

motor impaired and self-respondent youth showed no difference with the GP on interpersonal relationships and social life, and higher freedom of decision.

Conclusion: Participation in young adults is much impaired especially in intimate relations when these individuals are affected by CP. Particular attention should be paid to the population of young people with CP living in the countryside or small towns, and more generally to young women.

#### Poster presentation 33

#### Improvement of spasticity-related pain with incobotulinumtoxinA treatment in children/ adolescents with cerebral palsy: Pooled analysis of three Phase 3 studies

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Introduction: Spasticity-related pain (SRP) in children/adolescents with cerebral palsy (CP) is common and reduces quality of life. The effect of incobotulinumtoxinA on SRP was assessed using pooled data from three Phase 3 studies.

Patients and Methods: Ambulant/non-ambulant patients (2– 17 years; uni- or bilateral CP; Ashworth Scale score ≥2 in clinical patterns for treatment) were enrolled. Patients received total body incobotulinumtoxinA doses of ≤16 U/kg (≤400 U) for lower-limb (LL) treatment in two injection cycles (ICs) in TIM (NCT01893411). In TIMO (NCT01905683), TIM completers and new recruits received four ICs with 16-20 U/kg (<400-500 U) for LL or combined LL/upper-limb (UL) treatment. In XARA (NCT02002884), patients received four ICs with 16 to 20 U/kg (≤400-500 U) for UL or combined LL/UL treatment. Changes in self-reported/observed SRP were assessed using the Questionnaire on Pain caused by Spasticity (QPS).

Results: Assessments for 849 patients with LL and 454 patients with UL treatment were included. Of these, 340 (40.0%, LL: 61.2% male, mean [SD] age 9.3 [3.8], bodyweight [BW] 32.6 [14.8] kg) and 160 (35.2%, UL: 61.9% male, mean [SD] age 10.3 [3.7], BW 36.8 [16.5] kg) assessed SRP by QPS. Most (81.9% LL; 69.7% UL) reported pain at baseline for ≥1 activity. Complete SRP relief was seen at week 4 in each IC (25.0-54.8%, highest in IC4). Observed and self-reported SRP frequencies were consistent (all p < 0.001 for responder rates).

Conclusion: Repeated incobotulinumtoxinA injections led to sustained pain reduction in children/adolescents with spasticity, with ≤54.8% experiencing complete pain relief in the injected limb during activities.

#### Poster presentation 34

#### Pooled efficacy analysis of incobotulinumtoxinA in the multipattern treatment of upper- and lower-limb spasticity in children/adolescents with cerebral palsy

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Introduction: Efficacy of incobotulinumtoxinA for lower-limb (LL) and upper-limb (UL) spasticity in children/adolescents with cerebral palsy (CP) was assessed using data from the first controlled injection cycle of two Phase 3 studies, TIM (NCT01893411) and XARA (NCT02002884).

Patients and Methods: Ambulant/non-ambulant patients (2-17 years; uni- or bilateral CP; Ashworth Scale [AS] score ≥2 in clinical patterns for treatment) were enrolled. Patients were randomised (2:1:1) to three incobotulinumtoxinA dose groups: 8, 6, 2U/kg bodyweight (BW), maximum 200, 150, 50U per LL clinical pattern in TIM and per UL in XARA. Additional multipattern treatment was permitted (total body doses ≤16-20 U/kg [≤400-500 U]) depending on study/Gross Motor Function Classification System (GMFCS) levels I to V. Changes from baseline in AS score and Global Impression of Change Scale (GICS) scores at Week 4 were assessed for LL (TIM; XARA) and UL treatment (XARA).

Results: 603 patients with LL treatment (58.9% male, mean [SD] age 6.8 [4.2] years, BW 23.6 [13.5] kg, 27.2% GMFCS IV-V) and 350 patients with UL treatment (62.9% male, mean [SD] age 7.3 [4.4] years, BW 25.0 [15.0] kg, 30.9% GMFCS IV-V) were included. Significant improvements in AS score for main LL/UL clinical patterns were seen across doses at Week 4 (all p < 0.0001vs baseline except adducted thigh, 8 U/kg). Significant improvement in AS score for main UL clinical pattern was noted with 8 versus 2 U/kg (p=0.004). GICS confirmed improvement in LL/ UL spasticity at week 4.

Conclusion: IncobotulinumtoxinA provides effective multipattern treatment of LL/UL spasticity in children/adolescents with CP.

#### Poster presentation 35

#### The association between self-efficacy and autonomy in young people with cerebral palsy

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Introduction: Autonomy as one domain of participation is an important goal in the lives of young people, both with and

without disabilities. Self-efficacy can be seen as a participation-related construct, but little is known about the association between the two. The aim of this work was to explore the distribution of self-efficacy and autonomy regarding different clinical and socioeconomic factors as well as their association in young people with cerebral palsy.

Patients and Methods: This research was part of the European study 'Trans-Disab'. We included 357 young adults with cerebral palsy aged 19-28 (mean 24 years, 200 males) in our analysis. In addition to sociodemographic information, self-efficacy was measured with the General Self-Efficacy Scale (GSES-10) and autonomy with the domain 'autonomy' of the participation instrument 'Questionnaire of Young People's participation for Young Adults (QYPP-YA)'. Questionnaires were filled in by the participants themselves if possible, otherwise by a close carer. The distribution of self-efficacy and autonomy in different clinical and socioeconomic levels was assessed via boxplots respectively. Spearman's rank correlation was performed between self-efficacy and autonomy.

Results: There are differences in the levels of self-efficacy and autonomy regarding varying clinical and socioeconomic levels. Overall, severe impairments are associated with low levels of selfefficacy and autonomy. A strong association was found between self-efficacy and autonomy.

Conclusion: Self-efficacy and autonomy are associated. Further studies should explore the direction of the association. By empowering young adults with impaiments in one of these variables, a virtuous circle of both constructs might occur.

#### Poster presentation 36

#### Action preparation, performance and motor imagery in children with autism spectrum disorder

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Introduction: Motor anomalies are frequent in autism spectrum disorder (ASD). Effective and efficient motor acts rely on the formation of motor plans that serve as predictive models or blue-prints of upcoming actions. We studied movement initiation latencies (MILs) and movement durations in a peg-rotation (PR) task and response times (RT) in a motor imagery (MI) task in children with ASD.

Patients and Methods: Thirteen 7-8 year-old children with ASD (4 girls) and 17 typically developing (TD) children (9 girls) participated. MILs and PR task duration, extracted from 3D kinematic recordings, and RTs on a MI task (hand laterality judgement task) was compared between children with ASD and TD. The PR-task varied in constraints and the possibility to pre-plan actions was experimentally controlled.

Results: Nine of the ASD children passed the MI task showing biomechanical constraints effect but the error rate was however higher than in TD. The MILs on the PR-task were shorter when pre-planning was possible, indicating a time cost for movement planning. This cost was highest for the children who failed the MI task, specifically for the PR-task with the highest constraint where task durations also were the highest. Overall, TD children had shorter PR-task durations than ASD.

Conclusion: MI ability was highly varied for the ASD children. Interestingly, the children with ASD failing the MI task showed the greatest increase in MILs in relation to task difficulty indicative of pre-planning. They also had increased task durations, specifically for the most difficult condition, suggestive of poorer on-line control.

#### Poster presentation 37

#### Pooled efficacy/safety analysis of incobotulinumtoxinA for upper-/lower-limb spasticity in children with severe cerebral palsy (GMFCS level

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Introduction: Efficacy/safety of incobotulinumtoxinA for lowerlimb (LL)/upper-limb (UL) spasticity were assessed in children/ adolescents with severe cerebral palsy (CP) (Gross Motor Function Classification System [GMFCS] level IV-V) using data from the first injection cycle of two Phase 3 studies, TIM (NCT01893411) and XARA (NCT02002884).

Patients and Methods: Non-ambulant patients (GMFCS IV-V; 2-17 years; uni- or bilateral CP; Ashworth Scale [AS] score ≥2 in clinical patterns for treatment) were analysed. Patients were randomised to three incobotulinumtoxinA doses: 8, 6, 2 U/kg bodyweight, maximum 200, 150, 50 U per LL clinical pattern in TIM, and per UL in XARA. Additional multipattern treatment was permitted (total body doses ≤16 U/kg [≤400 U]). Changes from baseline in AS score and Global Impression of Change Scale (GICS) scores at Week 4 were assessed for LL (TIM; XARA) and UL treatment (XARA). Adverse events (AEs) were assessed.

Results: Of patients with GMFCS IV and V, 164 and 108 had LL and UL treatment, respectively. Statistically significant improvements in AS score for the pes equinus and flexed elbow/wrist and investigator's GICS were seen with all doses at week 4 (p< 0.0001 vs baseline, greatest: 8 U/kg). Efficacy was largely similar in patients with GMFCS I to III. AE frequency was generally <30.0% across doses and GMFCS I to V. Most common AEs for GMFCS IV and V were nasopharyngitis (7.0%) and pharyngitis (3.2%); few treatment-related AEs (n=1), serious AEs (n=5) or AEs of special interest (n=2) occurred.

Conclusion: In children with severe CP (GMFCS IV-V), incobotulinumtoxinA is effective, safe and well-tolerated for multipattern treatment of LL/UL spasticity.

### Oral baclofen in children with cerebral Palsy, is it really effective? A 10 year retrospective study

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Introduction: Spasticity is most commonly associated with cerebral palsy in children and currently there are variable treatment options and ways of assessing it. We audited our practice against the current NICE guidance and reviewed the effectiveness of Baclofen.

Patients and Methods: 44 children meeting criteria were identified from the electronic database to have received oral baclofen for cerebral palsy over the last 10 years. Data was taken from clinic letters and notes for patient sex, age, GMFCS, co-morbidities and presence of dystonia. A score was designed to assess Baclofen effectiveness.

Results: Baclofen was started in 61% because of spasticity. 70% had documented reviews of their response to treatment. Only 4 children had documented side effects from the use of baclofen. Children with documented dystonia all had baclofen in their treatment but more than 50% required additional medications. Correlation analyses were used to estimate the relationships between the treatment outcomes and other independent factors. A weak positive correlation showed males had better effectiveness. A negative but weak correlation was noted with regard to comorbidities, dystonia, GMFCs level and age started.

Conclusion: Since the introduction of the NICE guideline in 2012, our use of baclofen has more than doubled. Introduction of a memory aid is taking place to prompt complete documentation when seeing a child on baclofen. The correlations were statistically insignificant; however, they give good indicators. Perhaps with a larger sample size, statistically significant results can be obtained.

## Poster presentation 39 Measurement of trunk control in children with neurological impairements

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Introduction: Children with neurological impairments, such as cerebral palsy (CP), acquired brain damage (ABD) or spinal cord injury usually present alterations in trunk control that cause functional and performance limitations. Although improving trunk control is a habitual aim in rehabilitation programs, its clinical evaluation is not always objective. Trunk control measures must have demonstrated good psychometric properties and been validated in target population. To our knowledge, the last review about trunk control measures dated in 2014.

Our aim was to describe the clinical tools that have been validated for the assessment of the trunk in children with CP and other neurological impairments.

Patients and Methods: Two reviewers independently search in three databases: Pubmed, CINAHL and Web of Science, with the terms 'balance' or 'postural control' or 'trunk control' or 'postural stability'; 'assessment' or 'test'; and 'sitting' and 'child'. Only studies in English published between 2013 and 2021 with full text

available that describe psychometric properties of balance tools were selected.

Results: Nine clinical balance tools, from 15 articles, were identified to asses trunk control in children with neurological impairments. Of those, three assess balance in sitting and standing. Six of nine had at least one study informing about validity and reliability, supporting their use in clinical practice. Details on responsiveness remain scant.

Conclusion: Trunk Control Measurement Scale (TCMS) and Segmental Assessment of Trunk Control (SATCO) are the most evidenced and used tools to measure trunk control in neurological impairments. More research is needed to provide evidence on responsiveness for clinical balance tools.

#### Poster presentation 40

### Psychometric properties of the spanish version of the Trunk Control Measurement Scale (TCMS)

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Introduction: Children with cerebral palsy (CP) often show poor trunk control, leading to a great functional impairment. Despite its relevance, there is not a validated tool to measure trunk control in children with CP in Spain. Our aim was to develop the Spanish version of the Trunk Control Measurement Scale (TCMS).

Patients and Methods: A translation and back-translation process were performed to obtain the Spanish version of the TCMS. Children with CP from 8 to 15 years of age, able to sit without support and who had not undergone surgery in the previous six months were recruited. Children were evaluated one time and recorded on video. To determine the intra-rater reliability, the same physical therapist assessed the videos at least fifteen days apart. For inter-rater reliability, a second physical therapist rated independently the video recordings. Intra class coefficient (ICC) was calculated. Cronbach's alpha was used to determine the internal consistency. To examine construct validity, Pthe ediatric Balance Scale (PBS) was administrated and the Pearson's rank calculated.

Results: Twenty children (mean age 11 years 2 months; range 9–13 years 2 months) met the inclusion criteria. Intra-rater ICC ranged from 0.84 to 0.98. Inter-rater ICCs ranged from 0.83 to 0.99. Cronbach's alpha coefficients ranged from 0.83 to 0.94. Pearson's Rank correlation with the PBS was 0.68 (p=0.005).

Conclusion: The Spanish version of the TCMS appears to be a reliable and valid tool for trunk control evaluation in children with CP, but further studies are required.

#### Improvement of muscle flexibility in children with spastic diplegia by using a low-cost Flexi-standing in natural environments

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Introduction: Children with spastic diplegic CP commonly have muscle shortening and decreased of range of motion (ROM) of the lower limb muscles with growth. The focus of CP rehabilitation in children has shifted towards approaches that emphasize goal-oriented activity, and task practice in optimal environments. The aim of this study is to show the effects of low-cost Flexi-standing (LC-FS) in maintaining muscle flexibility during early stages of development.

Patients and Methods: Six children with spastic diplegia GMFCS level II, used a LC-FS for a period of 3 months and between the age of 30 and 38 months. It has been used in their home as play activity with parent's instruction. Hamstrings and gastrocnemius ROM were goniometrically assessed at baseline and at 4 years. The GMFM was used to assess what impact it had on their motor

Results: The ROM of the hamstrings increased on average in all children but in gastrocnemius the initial ROM was maintained. Four children increased the GMFM percentile from 50% to 75%, while in the other two children there was no significant change. Conclusion: In this small study we found that it was possible to increase the flexibility of the spastic muscles that contributed to gain speed of gait and better ability for posture transitions. The perception of the parents was that they had fun with their child with the use of the LC-FS and improved the functional goal management empowerment for their child.

#### Poster presentation 42 **Knowledge of the Gross Motor Function** Classification System (GMFCS) among Spanish pediatric physical therapists

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Introduction: To learn where the pediatric physical therapists in Spain are in the knowledge and use of the Gross Motor Function Classification System (GMFCS)

Patients and Methods: A link from a survey was distributed electronically and across social networks.

Results: All 257 respondents reported hearing and use the GMFCS, 98% agreed it was useful, 70% worked in pediatrics for more than 6 years, 65% of physical therapists confirmed that they use the GMFCS to predict gross motor function in clinical decision-making, to set realistic goals and to anticipate need for assistive technology. Although 47% of the physical therapists used GMFCS with the family to help them understand gross motor functioning, to a lesser extent it was used with the family to discuss frequency, duration of services, and goal setting.

Conclusion: Although all responding therapists used GMFCS to better understand the specific functioning of children and allows them better communication between professionals, they did not use it consistently with the family. Pediatric PTs might need more training on how to effectively communicate prognostic information to families using the GMFCS and set realistic goals together.

#### Poster presentation 43

#### Early upper limb interventions in infants with unilateral cerebral palsy: A systematic review L MAILLEUX<sup>1,2</sup>, N DE BEUKELAER<sup>2,3</sup>, MARIA BELÉN CARBONE<sup>2</sup>, E ORTIBUS<sup>1,4</sup>

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Introduction: It has been proposed that the benefits of early, activity-based motor interventions could be larger than the same intervention after two years of life, due to the greater neuroplastic potential of the infant brain. Hence, studies investigating early motor intervention programs in infants with unilateral cerebral palsy (CP) are rising.

Patients and Methods: We performed a systematic literature search in five electronic databases (PubMed, Embase, Cochrane Central Register of Controlled trials, CINAHL and Web of Science) following the PRISMA-statement guidelines. Clinical trials were critically appraised with the PEDro scale.

Results: Four single blinded randomized controlled trials, three non-randomized controlled trials, one participatory design and one cross-sectional survey were included, all reporting on upper limb interventions. In total, this review included 229 infants with uCP, 193 professionals and nine parents of infants with uCP. Modified constraint-induced movement therapy was most frequently performed, which appeared to be effective and safe to increase the function of the upper limb. Modified constraint-induced movement therapy and bimanual training were equally effective. The eTIPS (i.e. early Therapy In Perinatal Stroke) is a new early intervention program delivered by the parents, that has been shown to be well-accepted by the parents. This review could not identify clear clinical nor neurological predictors of treatment

Conclusion: Early upper limb intervention programs seem effective, feasible and safe to perform in infants with unilateral CP, emphasizing the importance to refer to diagnostic-specific centers facilitating the start-up of such early interventions.

#### Poster presentation 44

#### Adopting the Questionnaire of Young People's Participation for Young Adults (QYPP-YA) — A validation study

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Introduction: The original Questionnaire of Young People's Participation (QYPP) was developed for use with children and adolescents. To track participation throughout the transition, a new version was developed measuring participation in young adults with and without disabilities, adopting existing items, and generating new ones using focus groups. The aim of this study was to validate this measure.

Patients and Methods: Within a multicenter European observational study (France, Germany), we recruited young 'emerging' adults with cerebral palsy (CP) and a representative sample of the general population (GP) of the same age. We split the GP-sample into two equivalent subsamples, the first part was used to identify the factor structure via exploratory factor analysis and to exclude items with low/multiple factor loadings. The resulting model was tested using confirmatory factor analysis. Reliability and different forms of validity were investigated: Quality of Life (WHOQOL-Bref) was used to analyze divergent validity, participation (WHO-DAS 2.0) for convergent validity, and comparisons of QYPP-YA scores between CP and GP to assess known-group validity.

Results: The final QYPP-YA includes 17 items assigned to 6 domains (Autonomy, Independency, Intimate Relationships, Interpersonal Relationships, Social Life, Online Communication). Scales show satisfying internal consistencies in the CP-sample  $(\alpha = 0.67 - 0.81)$  and in the GP-sample  $(\alpha = 0.71 - 0.80)$ , except for 'Online Communication'. Convergent, divergent, and knowngroup validity were confirmed.

Conclusion: The QYPP-YA instrument features promising psychometric characteristics to assess and compare key domains of participation in healthy and disabled young adults. It provides a multi-dimensional, economic, and sound assessment for use in population surveys and clinical trials.

#### Poster presentation 45

#### Evaluation and follow-up of NF-Walker technical aid during the transition to adult life

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Introduction: The technical aids in the field of disability need a cost-benefit analysis. The purpose of our study is to determine the characteristics of the Norsk Funktion-Walking Orthosis (NF-Walker) user, know the level of satisfaction, the effectiveness and the degree of adherence over time.

Patients and Methods: Observational longitudinal study starting in 2012 of 26 patients using the NF-Walker, with reassessment in 2021. Collected data: epidemiological and clinical data (GMFCS), continuity of use or causes of abandonment and degree of satisfaction using The Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST 2.1)

Results: In 2012, 26 patients were evaluated with a mean age of 10.2 years. The main diagnosis was cerebral palsy, with GMFCS IV and V. Mean weekly use 8.5 h. The QUEST score 4.29 (SD: 2.4-6.3). In 2021, we continue to monitor 73% of them and only 1 patient still use it. The main reasons of abandonment were: increasing deformities (72.2%), need of size change (16.7%), clinical improvement (11.1%) and lack of parents' time (5.26%). The mean use of the walker was 5.4 years (SD: 2-9). The QUEST score in 2021 was 3.12 (DE: 1.2-5.3). 80% of parents consider the use 'very satisfactory' in all items.

Conclusion: NF-Walker users are children with cerebral palsy at more severe functional levels. The dropout rate is very high in adolescence, the progressive deformities being the main cause. In spite of the abandonment, there is a high level of satisfaction of parents and caregivers with the walker.

#### Poster presentation 46

#### Caudal regression syndrome: Our experience

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Introduction: Caudal regression syndrome (CRS) is a group of very rare congenital defects dependent on the embryonic caudal region that includes abnormal development of the sacrum and lumbar vertebrae. It can be associated with open or closed dysraphism and urogenital, gastrointestinal and musculoskeletal malformations. The objective of our study is to know the prognosis of gait, bisphincteric control and associated malformations of patients diagnosed with CRS controlled by the Neural Tube Defects Unit (NTDU) of our hospital.

Patients and Methods: Descriptive, retrospective study of patients under 18 years of age who are periodically controlled in the NTU with a 2-year follow-up. We collected, among others, demographic variables, gait level, neurological deficit and bisphincteric control. Results: Sample of 12 patients (6 women and 6 men) with a mean age of 8 years (2-14 years). 11 patients (92%) have community ambulation. 25% (3 patients) present motor neurological deficit due to conus medullaris malformation. 50% (6 patients) have a neurogenic bladder. 8 (66%) performed physiological fecal evacuation while 4 were carriers of ileoscolostomy. 75% of the cases present urogenital and gastrointestinal malformations.

Conclusion: (1) Most patients with CRS present community ambulation. (2) Only one third of our patients presented neurological deficits related to malformations of the conus medullaris. (3) Bisphincteric function is frequently affected. (4) The most frequent associated malformations are gastrointestinal and urogenital.

#### Poster presentation 47

#### Promoting language skills in children with neuromotor and intellectual disorders: Telepractice at the time of SARS-CoV-2

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Introduction: The aim of this study is to gather preliminary results on the effectiveness and feasibility of intensive, parent-centred telepractice-based intervention to improve language and communicative skills in preschool children with neuromotor and intellectual disorders. Patients and Methods: Nine preschool children (5 females, mean age 63 months, SD 8.7 months) underwent a telepractice program four times a week designed to promote speech, lexical and syntactic skills. Families were remotely connected from home with the therapists, who controlled the rehabilitation procedures from the hospital. The number of stable phonemes, of understood and repeated words, and of understood and repeated sentences were evaluated as outcome measures three months (pre-baseline) and one week (baseline) before the intervention, at the end of the intervention (T1) and at a three-month follow-up (T2).

Results: An increase in the number of stable phonemes was detected after the treatment, even if it was not statistically significant. After the intervention program, there was a significant increase in the number of understood words (ratio T1 vs baseline: 1.33; 95% CI: 1.03-1.71) and repeated words (ratio T1 vs baseline: 1.39; 95% CI: 1.00-1.92), as well as of understood sentences (ratio T1 vs baseline: 1.80; 95% CI: 1.24-2.35) and repeated sentences (ratio T1 vs baseline: 4.23; 95% CI: 1.96-9.12). No significant differences were found when comparing all the outcome measures at pre-baseline and at baseline.

Conclusion: An intensive parent-oriented telepractice-based intervention has the potential to increase scores of lexical and syntactic tasks in children with neuromotor and intellectual disorders.

#### Poster presentation 48

#### Reliability and validity of the Dutch version of the **Communication Function Classification System and** Viking Speech Scale in Flanders, Belgium

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Introduction: This research aimed to investigate the reliability and validity of the Dutch version of the Communication Function Classification System (CFCS-NL) and Viking Speech Scale (VSS-NL) in Flanders, Belgium and to analyze the correlation between both scales and other functional classification scales for children with cerebral palsy (CP).

Patients and Methods: 20 children with CP (15 males, mean age 6.9 years [4.5-10.9 years]) from the CP-reference centre of the University Hospitals Leuven (Belgium) participated. The interand intrarater reliabilities of the CFCS-NL and VSS-NL between parents, a teacher, a medical professional, two experienced speech-language pathologists (ESLP), and a student SLP were analyzed using weighted Kappa. The Pediatric Education Disease Inventory - NL was used to examine the validation.

Results: The interrater reliabilities of the CFCS-NL and VSS-NL were fair to excellent (k = 0.56-0.97, k = 0.51-0.96, respectively), with mostly fair reliability between medical and non-medical professionals (CFCS-NL) and between one ESLP and the others (VSS-NL). The intra-rater reliability for both was excellent (k = 0.94-0.97; k = 0.96-1.00) for the ESLPs. The validity was strong for the CFCS-NL and strong to very strong for the VSS-NL. Both scales correlated very strongly. Furthermore, both were strongly related with the GMFCS and MACS, and moderate to strong with the EDACS.

Conclusion: The Dutch versions of the CFCS and VSS are reliable and valid for classifying respectively communication skills and speech intelligibility in children with CP in Flanders, Belgium. To improve the reliability of both scales, it might be useful to adapt the manual of the CFCS and VSS.

#### Poster presentation 49

#### Home-based exercise programs vs active video gaming and virtual reality to improve motor outcomes in children with disability: Systematic review

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Introduction: Tele-rehabilitation has become a hallmark in children rehabilitation during the Covid-19 pandemic, and motor interventions as home-based exercise programs, active video gaming and low-cost virtual reality play a fundamental role in it. Even though they have been previously described in contexts where a continuous face-to-face follow-up is not possible, they have reached a new height in this global health situation where its opportunities and challenges have to be analyzed.

Patients and Methods: Four electronics databases were systematically searched (PubMed, OTseeker, PEDro and Cochrane). Included studies were randomized clinical trials during the five last years (from 2016 to 2021) for children and adolescents with motor impairments. Exclusion criteria were studies that did not report motor skills outcomes and which were not related to neurological disorders.

Results: Despite having the potential to increase the intensity and frequency of motor training, home programs—developed as home-based exercises (bimanual therapy, lower-extremity functional training, etc.) and active video gaming including virtual reality (Mitii<sup>TM</sup>, Wii<sup>TM</sup>, Xbox<sup>TM</sup>, PlayStation<sup>TM</sup>, combination of portable accelerometers and sEMG)—have common elements and differences. Likewise, parameters as adherence, participation with other children, enabled to choose 'when' to participate could be different. Therefore, it is necessary to clarify which telerehabilitation approach could be more effective depending on motor goals —of the child, family and professional—impact on ICF domains, age, motor developmental disorder, natural environment or socioeconomic resources.

Conclusion: The Covid-19 pandemic has provided an opportunity for telerehabilitation. This systematic review aims to describe and compare these different approaches, highlighting their opportunities and challenges.

#### Poster presentation 50

#### 'NE@R': A new tool for promoting parents involvement in follow-up program for preterm infants during COVID-19 pandemic

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Introduction: Prevention of neurodevelopmental disorders in preterm infant represent a major health challenge. Moreover, the COVID-19 emergency lead to services reorganization and the development of new care strategies. We created a free-access

digital resource to support neurodevelopment of babies at neurological risk included in our follow-up programs and to be used to overcome the restrictions imposed by the pandemic situation. We aim to assess acceptability and feasibility of this new platform and to evaluate its potential use also after the COVID-19 period.

Patients and methods: From October 2020 to January 2021 we recruited a sample of at risk preterm newborn (g.a. <32 weeks and birthweight <1500 g) included in our follow-up program. At each follow-up visit the access to the age-specific platform is given to the parents with a QR Code. It contains information, videos and play activities suitable for the developmental phase and applicable in everyday life at home. Parents' feedback was assessed by an 'ad hoc' on line questionnaire.

Results: The platform was proposed to 31 families. The majority of parents gladly accepted the project and reported feeling more confident in promoting their children's development through play. All parents found the advices useful and would recommend it to other families and for using it in the future.

Conclusion: 'NE@R' is a handy and effective support for preterm born families to enhance proximity during everyday play and promote development in high-risk conditions; it helps enhancing connection between experts, child and family, contributing to a family-centered approach.

#### Poster presentation 51

## Effectiveness of construct induced movement therapy (CIMT) in the rehabilitation of children with cerebral palsy and stroke

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Introduction: Ukraine has been training specialists in occupational therapy for the last five years. At present, occupational therapy methods, such as CIMT, bimanual training are widely implemented in the Ukrainian rehabilitation institutions. The aim of this study is to investigate the effectiveness of CIMT in children with hemiplegia.

Patients and Methods: Clinical study was carried out at 42 children (mean age 7.5 years), without severe intellectual and behavioral disorders. Among them 33 children were with CP, 9 – with stroke, GMFCS levels I to III. The following scales were used to assess hand functionality and CIMT effectiveness: MACS, Van Heest, ABILHAND, Sollerman test, goniometry, dynamometry. Motor training consisted of the development of grasping, coordination, strength, speed of movements; perception and stereognosis; bimanual skills; training of household skills. A modified Taube glove was used to restrict a healthy hand. CIMT therapy was performed according to a modified protocol from 45 min to 1 h per day, 20 days, 3–5 times a week (age depending). Parents were given recommendations on the involvement of the affected limb in everyday self-care skills.

Results: Improvement in the functional activity of the affected limb was observed in children with CP and stroke. But according to the assessment scales, the best results were observed in children with stroke.

Conclusion: Implementation CIMT in rehabilitation centers improving self-care skills, writing, independence children with hemiplegia in daily activities. Preliminary results suggest a better

recovery of lost function in children with stroke compared with the group of children with CP.

#### Poster presentation 52

### Cognition, brain pathology and mutation type in three patients with a COL4A1 mutation

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Introduction: COL4A1 encodes  $\alpha$  1 chain of type IV collagen. Mutations in the COL4A1 gene cause vascular basement membrane disruption leading to hemorrhage in utero or later in life. Mutations can lead to variable clinical features reflecting the location and severity. The neurologic phenotypes in children can consist of cerebral palsy, epilepsy and intellectual impairment. In previous studies the developmental state in patients with a COL4A1 mutation has been described in various degrees.

Patients and Methods: We describe the cognitive and neuropsychological skills of three pediatric patients. Standardized psychological tests were used in the neuropsychological assessment. MRIs and COL4A1 mutations are presented. Information about the phenotypes of the affected family members is also included.

Results: Our patients' intellectual impairments varied from severe intellectual disability to mild learning difficulties. In the MRIs porenchepahly, periventricular leucomalasia and signs of hemorrhage is described. One of the mutations was a de novo, one was inherited from affected parents and in one the inheritance pattern is not known yet. None of the three mutations has been described before in the medical literature or databases.

Conclusion: According to our study, the cognitive skill level and neuropsychological profile vary with the extent of the hemorrhagic event. We also describe three new mutations in COL4A1. The etiological diagnosis in COL4A1 mutation is important for genetic counselling, for considering whether anticoagulation or thrombolysis is needed or not and for advising patients to avoid high impact sports.

#### Poster presentation 53

## Dosing from a phase 3, pivotal study of abobotulinumtoxinA injection in upper-limb muscles in pediatric patients with cerebral palsy

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Introduction: We report dosing data from a phase 3 study of repeat, upper-limb abobotulinumtoxinA injections in children with CP.

Patients and Methods: This was a double-blind, repeat-treatment study (NCT02106351). In Cycle 1, children were randomized to abobotulinumtoxinA 8 U/kg, 16 U/kg or 2 U/kg control dose

groups. Doses were divided between the primary target muscle group and additional muscles tailored to clinical presentation.

Results: 212 children were randomized, of which 210 received ≥1 abobotulinumtoxinA injection. Per the protocol, the elbow and wrist flexors were the most commonly injected upper-limb muscles. Across all 4 cycles, the brachialis was injected in 89.5% of children (dose range 0.8-6 U/kg), the brachioradialis in 83.8% (0.4-3 U/kg), the flexor carpi ulnaris in 82.4% (0.5-3 U/kg) and the flexor carpi radialis in 79.5% (0.5-4 U/kg). The next most frequently injected muscle was the pronator teres, which was targeted in 70.0% of children (0.3-3 U/kg). Other frequently injected upper-limb muscles were the adductor pollicis (54.3%, 0.3-1 U/kg), pronator quadratus (44.8%, 0.1-2 U/kg), flexor digitorum superficialis (39.0%, 0.5-4 U/kg), flexor digitorum profundus (28.6%, 0.5-2 U), flexor pollicis brevis/opponens pollicis (27.6%, 0.3-1 U/kg) and biceps (27.1%, 0.5-6 U/kg). AbobotulinumtoxinA was generally well-tolerated at these doses; muscular weakness was reported in 4.3% of children in the 8 U/kg group and 5.7% in the 16 U/kg group.

Conclusion: These data provide information on the dose ranges used during this phase 3 study, which were well-tolerated. In line with the protocol, most children received injections into the elbow and wrist flexors. However, there was a wide variety of other upper-limb muscles injected as physicians tailored injection patterns.

#### Poster presentation 54 Effectiveness of therapeutic exercise in children with cerebral palsy: A systematic review

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Introduction: Therapeutic exercise in children with cerebral palsy (CP) is considered a cornerstone within the therapies that aim to improve functionality and gross motor skills. Nevertheless, the effectiveness of the intervention is likely to be influenced by the different approach in terms of type of exercise (aerobic, strength and balance training), age of participants or level of GMFCS, among others. In this sense, this systematic review analyzed the current literature and the highest levels of evidence to examine the effects of therapeutic, individualized and protocolized exercise in children with CP.

Patients and Methods: Three electronics databases were systematically searched (PubMed, PEDro and WOS) and 18 studies met the inclusion criteria: randomized clinical trials; published in the last five years; exercise-based intervention; training program over six weeks; not surgery in the last year; children with CP between 0 to 18 years and GMFCS level I, II, III. The methodological quality assessment was performed with PEDro scale, and all the articles included were scored as 'high quality' (6/10).

Results: Therapeutic exercise in children with CP could have positive effects on strength, aerobic endurance, balance and different gross motor skills. This systematic review showed a lack of consensus in training methodology and standardization of assessment tools used in children with CP, which could compromise the generalizability of the results in the target population.

Conclusion: Despite its possible positive effects for some functional and motor outcomes, this systematic review found opportunities and challenges for a consensus in therapeutic exercise for children with CP.

#### Poster presentation 55

#### Modified constraint-induced movement therapy at home to improve the affected upper limb functionality in infantile hemiplegia with moderatemanual-ability: Case series

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Introduction: Children with hemiplegia have lower spontaneous use and quality of movement in the affected upper limb. Thus, the children's participation in their daily activities is reduced. Modified constraint-induced movement therapy (mCIMT) is applied to improve the affected upper limb function. The objective of this study was to assess the functionality of the affected upper limb in children diagnosed with hemiplegia aged between 4 and 8 years after applying low-intensity mCIMT.

Patients and Methods: Prospective case series study. A mCIMT protocol was applied at home for five weeks, with two hours of containment per day. Four measurements were performed, using the quality of upper extremity test (QUEST) scale, the Shriners Hospital for Children Upper Extremity Evaluation (SHUEE) Evaluation, a hand dynamometer.

Results: The sample was composed of eight children with moderate manual ability. Statistically significant differences were detected in all the studied variables (p< 0.05) between the pretreatment and post-treatment results (week 0-week 5), except for upper limb dressing, putting on splints and buttoning up. The greatest increase occurred in spontaneous use from Assessment 1 to Assessment 4 (p=0.01), reaching 88.87% active participation in bimanual tasks. The quality of movement of the upper limb exhibited a significant value due to the increase in dissociated movements and grasp (p=0.01).

Conclusion: A low dose (50 h) of mCIMT increased the functionality of children diagnosed with congenital hemiplegia between 4 and 8 years of age with moderate manual ability.

#### Poster presentation 56

#### Experience of families and children on constraintinduced movement therapy into the natural environment

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<sup>1</sup>University of Castilla-La Mancha, Ciudad Real, Spain; <sup>2</sup>University of Málaga, Malaga, Spain; <sup>3</sup>University of Sevilla, Sevilla, Spain Indroduction: Modified constraint-induced movement therapy (mCIMT) is efficient at improving upper limb non-use. The experiences of families and children with mCIMT could allow researchers to understand how it influences their day-to-day life and to improve the function of the affected upper limb without altering family life and avoiding frustration. The objective was to collect the experiences of parents and their children (aged 4-8 years) who did mCIMT at home. Patients and Methods: Individual semi-structured interviews were performed to obtain insights into their experience with mCIMT. The experiences of parents and children were described in thematic sections. Eight children with hemiplegia (six years, standard deviation, SD: 1.77) and their parents were asked about their experiences after applying 50 h of mCIMT at home.

Results: Three main themes emerged from the children's interview data: (1) the experience of wearing the containment in the mCIMT intervention, (2) the reaction to performing the therapy at home with his/her family, and (3) learning of the affected upper limb. In the parents' interview data, there were two main themes: (1) the difficulty of executing an intensive therapy protocol (mCIMT: 50 h) at home and (2) the feeling of not wanting to finish the intervention. Conclusion: The experiences of the parents and their children regarding mCIMT allowed us to understand the facilitators and barriers that affect the execution of mCIMT at home, and this understanding allows us to improve its future application.

#### Poster presentation 57

# Single-case experimental design to study short-term effects of transcranial direct-current stimulation in cerebral palsy: How do we select optimal methodology?

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Introduction: There have been promising reports of the use of brain stimulation techniques such as transcranial direct current stimulation (tDCS) in the management of children with cerebral palsy. However, marked interindividual response variability can be expected. Therefore we wondered which single case experimental design (SCED) might be useful for pilot studies of short-term effects of tDCS on cognitive and motor function in this population. Patients and Methods: We studied various combinations of phases for SCED for their discrimination potential for the placebo effect, variability of discrete distribution of results, individual response variability, training effect, interference of fatiguability, and paradigm duration, as analysis criteria. In addition to classical baseline 'phase A' during which no intervention is performed, and the intervention 'phase B' (tDCS), we considered a 'phase C' with sham intervention allowing blinding. We studied thus the following SCED combinations: CB, AB, ABA, CBC, ABCA, CBCBCB, ACABA using discrete optimality scores for each analysis criterion. Randomisation of the occurrence of 'phase B' and 'phase C' was also computed for the latter three combinations.

Results: The highest compound optimality score was associated with the ABCA combination, followed by CBCBCB.

Conclusion: The ABCA combination with randomisation may be an appropriate SCED approach to study the short-term effect of tDCS as it allows evaluation of placebo effect, takes account of individual variability, training effect, and interference from fatiguability, while being theoretically feasible. Its power would be enhanced if repeated two or three times with 2-week intervals.

## Poster presentation 58 Development of a guide for teaching infants how to use the Explorer Mini

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Introduction: Millions of children worldwide are born with disabilities such as cerebral palsy, spina bifida, or Down syndrome and

may benefit from the introduction of multimodal mobility options as a part of early intervention. The Explorer Mini by Permobil is a powered mobility device intended for young children between 12 and 36 months of age who experience mobility limitations. This device, the result of collaborative global efforts, is the first of its kind to be designed for infants for self-initiated mobility and environmental exploration.

Patients and Methods: There is currently no standardization of how to teach/introduce infants or children to use power mobility devices. While the theory is available, no documented practice guide currently exists. An international and multidisciplinary research team engaged in an extensive review of current evidence and a Delphi consensus study, with input from over 40 clinicians and caregivers, regarding training priorities and strategies for the introduction of powered mobility to infants.

Results: This global partnership has resulted in the development of an evidence-based practice guideline to introduce powered mobility to infants safely and effectively, as one means of a multimodal approach to empower mobility and exploration for all children. Conclusion: Using an evidence-based, stakeholder-driven approach to teach infants with disabilities how to explore their environment will allow for consistent intervention strategies to facilitate mobility successes and develop more robust mobility outcome measures. This project can aid in empirical data acquisition to support mobility technology design and intervention in an effort to advance mobility options and strategies for infants with disabilities worldwide.

#### Poster presentation 59 Children with disabilities in Las Segovias, Nicaragua: The voice of protagonists

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Introduction: Children with disabilities (CwD) in developing countries are living in a complex situation, with difficult access to basic resources and low consideration of their fundamental rights. Rural context and extreme poverty of people living in Las Segovias worse the situation.

Patients and Methods: (1) To describe the social, educational and healthcare context of CwD in Las Segovias, and (2) to determine factors conditioning their wellbeing, by exploring families and professionals' perspectives. This was a qualitative descriptive study, with a phenomenological approach, through semi-structured interviews following COREQ guidelines. 20 families of CwD and 20 professionals working with them were interviewed, audio recorded, transcribed and verbatim encoded. Transcripts were analysed using thematic analysis.

Results: The informant's speeches were categorized into thematic categories and subcategories. Verbatims provided insight into the main problems that CwD and their families have: the care is assigned to women. Having CwD is a social stigma and leads to social exclusion, which is worsened by rural living, mother migration and poverty. Women haven't basic care information to support CwD. The main care resources come from NGOs, informal

social leaders' actions and volunteers. Professionals and families demanded for specialized training and more human resources.

Conclusion: The main concerns are related to family household, health and educational approach to disability, social and community care. The healthcare system does not cover basic needs and public services do not provide support to entities working with CwD. A need for awareness programs and specific training for caregivers and professionals were identified to empower families and children.

#### Poster presentation 60

#### Exploring the use of Halliwick aquatic therapy in the rehabilitation of children with disabilities: A scoping review

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Introduction: Halliwick aquatic therapy is a rehabilitation intervention that is gaining popularity for people with disabilities. This scoping review provides an overview on the state of research about the impact of Halliwick aquatic therapy for children with disabilities

Patients and Methods: Four electronic databases were searched to obtain research on the use of Halliwick for pediatric rehabilitation: Medline, CINAHL, Embase and PsycINFO. Potential citations were first screened by title and abstract, and full texts were then examined on the second round. We analyzed demographics, how therapy was implemented, and the measurements used, with measured variables mapped onto the domains of WHO's International Classification of Functioning, Disability and Health (ICF). Results: Twenty-four publications met the inclusion criteria. The majority of research included children with cerebral palsy (n=12) or autism spectrum disorder (n=8), with very few studies including other disabilities (n=5). There was a wide variation in the number of lessons per study and how each lesson was structured. Fourteen studies lacked a control group. Looking at ICF domains, all 24 articles measured variables pertaining to body structure and functions; four looked for changes in performance of daily activities, four into ability to participate in social roles, and seven into personal factors.

Conclusion: There is no consensus on how the Halliwick method should be structured, leaving a gap for future research on program implementation. To shift our viewpoint beyond what a disability prevents to what one's level of functioning allows, it is important to broaden the scope of research into the other ICF domains.

#### Poster presentation 61

**Evaluation of quality of life in early intervention** RP ROMERO-GALISTEO1, E PINERO-PINTO2, IC JEMES-CAMPAÑA¹, R PALOMO-CARRION³

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Introduction: Early intervention (EI) programs have traditionally focused on needs of the child, ignoring the environmental and family context that surrounds them. However, this approach has changed in recent decades, moving to a model that assesses

perceptions from family and proposing changes aimed at improving their quality of life (OoL). The objective of this study was to assess the QoL of families who attend EI Centers in Andalusia (South of Spain).

Patients and Methods: A total of 91 families who attended an EI Center in Andalusia answered a QoL questionnaire (CdVF) for the children under 18 years old. This assessment instrument is made up of 61 items arranged on a Likert scale.

Results: The sample consisted of a total of 67 women and 24 men aged between 20 and 52 years. The average scocre of the respondents was 4.05 out of 5. The items with the lowest score showed the need of the family members to receive some psychological attention service. On the contrary, the best valued ítems corresponded to the well-being perceived in relation to the family member with developmental deficits.

Conclusion: QoL has become a reliable indicator to guide service quality improvement strategies and evaluate their effectiveness. In general, EI Centers are not inmune to the growing interest in measuring the QoL, the support received and the perceptions of their users. The need to integrate the study on QoL within health management practice is evident.

#### Poster presentation 62

#### Is it easy to evaluate the quality of service in early intervention? Yes, it is...with a good instrument

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Introduction: Almost fifty years have passed since early intervention (EI) services have been provided in Spain. Until today it was important to demonstrate the effectiveness of the intervention. Today, it is essential to determine the quality of these services and families are fundamental in the current perspective of EI. The objective of this study was to evaluate the quality of service perceived by families in EI Centers and its relationship with satisfaction and future intention.

Patients and Methods: A measurement model of 50 items was used in a sample of 233 families users of EI services in two centres in Andalusia (south of Spain). A confirmatory factor analysis (CFA) and a regression analysis were conducted.

Results: The model showed a satisfactory fit and the regression analysis indicated that the treatment romos ( $\beta = -0.28$ ) and adaptation of activities ( $\beta = 0.27$ ) have greater weight with respect to satisfaction, whereas for future intention, the factors of greater weight were adaptation of activities ( $\beta = 0.23$ ) and location  $(\beta = 0.20)$ 

Conclusion: The current study offers a wide perspective of the perception of the service with an active participation of families in the treatment within the EI service. This will allow professionals in EI, service providers and researchers to consider the families as capable agents and making decisions

# Poster presentation 63 Impact of level in health and disability on independency in healthcare transition for young adults with cerebral palsy

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*Introduction*: Young adults with cerebral palsy are at risk of insufficient knowledge and skills of proper health monitoring. Identification of factors associated with an impact on transition are at significance.

Patients and methods: Participants were searched through Children's Clinical University Hospital data base. Level of health and disability was measured using WHO Disability Assessment Schedule (WHODAS 2.0) and the level of independency in healthcare transition with the Transition Readiness Assessment Questionnaire (TRAO).

Results: Eighty-one participants (16–21 years) with no or mild cognitive deficits were assessed. Managing medications correlated with cognition rs –0.47, self-care rs –0.54, life activities rs –0.44 and total score of WHODAS 2.0 rs –0.53; appointment keeping with cognition rs –0.43, self-care rs –0.53, life activities rs –0.42 and total score of WHODAS 2.0 rs –0.52; talking with providers with getting along rs –0.41; managing daily activities with cognition rs –0.40, mobility rs –0.51, self-care rs –0.60, participation rs –0.53 and total score of WHODAS 2.0 rs –0.68; overall score of TRAQ correlated with cognition rs –0.50, self-care rs –0.56, life activities rs –0.45 and total score of WHODAS 2.0 rs –0.56, all correlations were p < 0.001, if rs  $\geq \pm 0.40$ . Binary regression analysis revealed the most impacting factors were: level of self-care OR = 0.23 (95% CI = 0.07–0.73), p = 0.01 and cognition OR = 0.27 (95%, CI = 0.08–0.96), p = 0.04.

Conclusion: When preparing young adults with cerebral palsy to adult healthcare, level of cognition should be considered, and skills of self-care improved.

#### Poster presentation 64

## Feasibility of the Lower Limb Sensorimotor Training (LoSenseT) for children and adolescents with cerebral palsy

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Introduction: Sensorimotor impairments are common in individuals with cerebral palsy (CP). However, available training protocols for this population are mostly directed to the upper limbs and focused on motor impairments. To address this gap, the Lower Limb Sensorimotor Training (LoSenseT) was developed. Here we report its feasibility.

Patients and Methods: Eight individuals with uni- and bilateral CP (mean age 12.3 years, 7 males, all GMFCS level I), were enrolled in the LoSenseT protocol after informed consent and assent. The LoSenseT is delivered in a game format for 60 min each session, being composed of proprioceptive (imitation game) and tactile (guessing game) activities that involve the lower limbs and are performed during three consecutive days, with increasing difficulty levels across days. LoSenSeT principles include (1) patient-clinician feedback during active tasks; (2) repetitive presentation

of stimuli within and between sessions; (3) stimulus exploration using vision (intermodality calibration); (4) stimulus exploration using the sensory component being trained (intramodality calibration) and (5) activity execution without the aid of vision. A qualitative feedback questionnaire assessed protocol feasibility. *Results*: No adverse events were reported. Satisfaction and engagement levels were acceptable: four participants reported interest in taking the training during regular rehabilitation and four were neutral. Two participants wanted to have more time to perform the activities during the sessions and one found it difficult to understand the rules.

Conclusion: The LoSenseT training protocol seems to be feasible in practice, being a novel approach targeting lower limbs sensorimotor impairments of individuals with CP.

#### Poster presentation 65

### Reorganization of 'the intensive and early diagnosis and treatment service' for children with ASD: The Messina NPIA UOC ASP5 experience

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Introduction: The restrictive measures imposed during the Covid-19 lockdown required a reshaping of the management of Health Services, with the launch of innovative pathways and good practices. The Messina NPIA UOC ASP 5 has set up the 'S.O.S Autism' Service, which is dedicated to children with autism spectrum disorder (ASD) and their families and whose aim is the management of daily problems and routines.

Patients and Methods: Sample A 118 children with ASD (age 0–6). Sample B 21 children with ASD being treated with ESDM and ABA methods. The services and tools used were: S.O.S. Autism desk, e-mail, supervision of video recordings, PEP3, ABBLS-R, VINELAND-II, satisfaction questionnaires, combined distance and in presence modalities.

Results: The new NPIA assistance was organized as follows: Sample A: PHASE1: (1) activation of the S.O.S. Autism Desk for all 118 patients; (2) remote modalities for rehabilitative prescriptions and didactic support certifications. PHASE 2: resumption of NPIA activities maintaining the remote and in-person modalities. PHASE 3: resumption of NPIA activities totally in presence. Sample B: PHASE1: (1) telephone support; (2) involvement of parents in remote by sending home data sheet for problem behaviors resolution and by structuring of daily routines and individual goals; (3) telephone monitoring and analysis of video recordings. PHASE 2: home health care treatment through specialized staff. PHASE 3: return to all-in presence activities.

Conclusion: The NPIA assistance reorganization during Covid-19 phases 1 and 2, allowed the continued rehabilitation and habilitation pathways and guaranteed the NPIA territorial services for population with ASD.

#### Management and specialist care for users with autism spectrum disorder in day-care centers during the Covid-19 health emergency

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Introduction: The restrictive measures imposed during the Covid-19 lockdown required a reshaping of the management of Health Services, with the launch of innovative pathways and good practices. The day-care centers for autism spectrum disorder affiliated to ASP 5 of Messina were forced to find alternative tools and strategies to guarantee the continuity of therapeutic and assistance activities. Therefore, telehealth has become an excellent tool. Patients and Methods: The sample was composed of 59 users with ASD, aged 6-18 years. The activities included: Ouestionnaires administered to parents; Telephone and video calls with families (more contacts during the week) to carry out structured and laboratory skills; Remote guidance for parents on the compilation of data sheet; Analysis of video recordings of the activities carried out by parents and users; Parent training/coaching through telephone support; Remote team meetings for planning and verification purposes. Results: The reorganization of telehealth services showed that: The users of the three day-care centers, despite some initial difficulties, have adapted to new routines and ways of interacting with parents and therapists; Parents, thanks to their good compliance, developed a greater sense of self-efficacy and good management of stress.

Conclusion: The reorganization of the services with remote tools adopted by the three day-care centers has proved to be a supplementary tool for the habilitation and psychoeducational activities in presence. The most positive outcome was recorded for those users with ASD in which the involvement of families was greater in the pre-Covid era.

#### Poster presentation 67

#### Mental health and quality of life of young adults with cerebral palsy compared to young adults in the general population

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Introduction: While evidence concerning quality of life (QoL) in youth with cerebral palsy (CP) in comparison to the general population has been accumulating, there is a lack of studies exploring differences on a wider range of positive and negative mental health outcomes in emerging adulthood.

Patients and Methods: In this binational population-based cross-sectional study as part of the Sparcle cohort, we assessed QoL (WHOQOL-Bref), self-efficacy (GSE), depression (PHQ-9), and anxiety (GAD-7) in 198 young adults with CP and 593 young adults from the general population matched regarding French or German country of residence as well as age and gender. All levels of impairment were included in the CP sample. Analyses were based on independent t-tests and ANCOVAs with impairment and pain as covariates.

Results: Similar levels of QoL were found in both samples, except for the QoL domain 'environment', with higher QoL for young adults with CP as compared to the general population. There were significant descriptive differences regarding depression with lower levels in the CP sample, but also lower levels of self-efficacy. However, pain as a covariate had a significant negative impact on all mental health outcomes, decreasing self-efficacy while increasing depression and anxiety. Impairment as a covariate had a significant decreasing impact on physical QoL and self-efficacy only.

Conclusion: Similar expressions of positive and negative mental health outcomes in young adults with cerebral palsy and the general population point to the adaptive capacity of young adults with cerebral palsy.

#### Poster presentation 68

#### Parental distress in the frame of COVID-19 Italian quarantine: A cohort study on pediatric patients with neuropsychiatric conditions

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Introduction: In Italy, the national COVID19-related quarantine had adverse psychological effects on children and parents. While parenting became essential for positive development, increased parental distress interfered with children wellbeing. Thus, we aimed to identify clinical and demographic predictors of parental distress in families of children with neuropsychiatric disorders during lockdown.

Patients and Methods: Seventy-seven parents of children with neuropsychiatric disorders (1-1.5 years) have been asked to fill out three online questionnaires - a socio-demographical questionnaire (http://edu.eacd.org/eacd-covid-19-surveys-initial-report), Child-Behavior-Checklist (CBCL 1.5-5 years/6-18 years) and the Parental-Stress-Index fourth-edition short-form (PSI-4-SF) - to explore the relationship between parental distress, emotional/behavioral problems in children and quarantine-related factors. Univariate analyses and multiple mediation models were performed to identify significant independent predictors of parental distress and their reciprocal interplay.

Results: Significant positive associations between CBCL internalizing problems and all PSI-4-SF subscales, and between CBCL externalizing problems scale and 'Difficult Child' subscale were

found. On the other hand, the 'Parent-Child Dysfunctional Interaction' subscale and quality of teachers-child relationship were negatively associated as well as the 'Difficult Child' subscale and quality of peers-child relationship. The effect of teachers-child relationship quality on 'Parent-Child Dysfunctional Interaction' was mediated by internalizing problems of children, while the effect of peers-child relationship quality on 'Difficult Child' by both internalizing and externalizing problems.

Conclusion: Internalizing problems in children with neuropsychiatric disorders were among the strongest predictors of parental stress during lockdown mediating the indirect effects of quarantine-related factors, thus suggesting the importance of their detection during and after emergency situations to provide assistance and reduce parenting pressure.

#### Poster presentation 69 A framework for parent-focused eHealth research

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Introduction: eHealth is an emerging field concerned with how technology is used to deliver effective health care services and how to develop emerging technology that optimises health and health behaviours. The Covid-19 pandemic has increased the use of digital technologies supporting parents and children with disabilities at home. However, it is not yet clear how eHealth interventions are best designed to support parents with their children's therapy home programmes.

Patients and Methods: A scoping review was undertaken to explore how parent-focused eHealth is being used to support children with chronic health and disability needs. Data was summarised using thematic analysis organised around models of behaviour change (COM-B model) and persuasive technology (Fogg Model). Results: A systematic search identified 9405 peer-reviewed publications reporting parent-focused eHealth interventions. Forty-two articles representing 23 distinct interventions were included. Three themes capturing the functional relationships driving eHealth interventions were derived: (1) Engagement-for-Motivation, (2) Implementation-for-Ability, and (3) Interaction-for-Sustained Engagement. The third theme was the least well represented, despite the need for parents to sustain engagement with health services, and for health services to provide long-term support in chronic childhood disabilities. A conceptual framework to visualise how these themes fit within the context of the technology, the family, the health professional, and the intervention approach was developed.

Conclusion: Findings explain how intervention principles and technology interact to support parents with their children's therapy home programmes. The conceptual framework clarifies the functional relationships between intervention components and contexts, critically informing future design and research in parentfocused eHealth.

#### Poster presentation 70

#### Motor coordination patterns in children with developmental coordination disorder and spastic cerebral palsy

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Introduction: Impaired motor performance significantly impacts participation and emotional wellbeing in both developmental coordination disorder (DCD) and cerebral palsy (CP). The diagnosis of both conditions is based on clinical features, and it is sometimes challenging to distinguish between them. The aim of this preliminary study is to test the feasibility of an approach generating objective parameters of motor coordination in DCD and

Patients and Methods: Six children aged 9 or 10 years with DCD (n=2), bilateral spastic CP (n=2, GMFCS levels I and II) or typical development (n=2). Full body 3D-kinematics was recorded using VICON Nexus 2.11.0 with 35 markers while the child repeatedly performed the jumping in place-opposite sides synchronized task from the BOTMP-2. Intersegmental coordination was analysed with continuous relative phase plots. Mean absolute relative phase (MARP) was calculated to quantify the relationship between body segments.

Results: In the typically developing children MARP was (as expected) out-of-phase between left and right humerus (LH-RH), and humerus and ipsilateral femur (H-IF). MARP was in-phase between humerus and contralateral femur (H-CF). In children with DCD MARP was more in-phase for LH-RH and H-IF, and more out-of-phase for H-CF. The child with CP in GMFCS level I showed even more in-phase relations for LH-RH and H-IF; and an even more out-of-phase relationship for H-CF. The child with CP in GMFCS level II was not able to perform a representative jump.

Conclusion: We present a feasible method to quantify differences in motor coordination in children who can perform the task.

#### Poster presentation 71

#### Satisfaction with health care services and unmet health care needs in young adults with cerebral palsv

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Introduction: Health care services play an important role in improving autonomy and self-efficacy in people with disabilities.

We assumed that poor availability and accessibility of health care services are associated with dissatisfaction with health care.

Patients and Methods: Within a European multicenter observational study 303 young adults with cerebral palsy aged 19-28 (mean 24 years, 168 males, Germany n=110, France n=88, and Portugal n=105) were included. We assessed reported unmet health care needs and satisfaction with health care (YHC-SUN-SF), as well as environmental and social variables of these participants based on a self- or proxy-reports. We used Pearson correlation analyses to explore associations between satisfaction and unmet health care

Results: The indicator for unmet health care needs was 5.1 with a standard deviation of 3.2 (range 0-12). We found no association of sociodemographic variables on unmet health care needs. The YHC-SUN global score indicated moderate to high levels of satisfaction with health care. Unmet health care needs were not associated with the general satisfaction with health care.

Conclusion: Young adults with CP reports of unmet health care needs varied largely but showed substantial deficits in some aspects. This does not impact on the satisfaction with health care people currently receive and we conclude that these are two different constructs to evaluate the quality of health care.

#### Poster presentation 72

#### Does a feeding ability scale help describing the diversity of cerebral palsy in a population-based registry?

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Introduction: The Portuguese National Surveillance of Cerebral Palsy (PVNPC) registers clinic, epidemiologic and functionality data of children with cerebral palsy born since 2001, at the recommended age of 5-year-old. We explore if a feeding ability scale helps describing the diversity of cerebral palsy at a populationbased registry level.

Patients and Methods: Data from the PVNPC birth-cohorts 2001-2013 were analysed. PVNPC shares common methodology, definitions and tools with SCPE, in addition to some specific classification and description tools. The agreement between the functional severities described by Viking Speech Scale (VSS) and by Feeding Activity Scale (FAS) was explored. Both scales were collapsed to 3 levels for analysis.

Results: The overall severity classification agreement was 82.3% (Kappa 0.681); while 84.2% of those classified as FAS I or II also classified as VSS I or II, 79.5% of those classified as VSS IV also classified as FAS IV or V. The agreement was mostly reduced when adjusting to BMFMCS (Kappa 0.294-0.397), GMFCS (Kappa 0.299-0.536) and IQ (Kappa 0.395-0.533), as well as when adjusting to the complexity of cerebral palsy, using either the PVNPC (Kappa 0.317-0.557) or the SCPE (Kappa 0.285-0.523) systems. The severity classification agreement remained stable when adjusting to either visual (Kappa 0.602-0.693) or hearing (Kappa 0.437–0.672) impairment.

Conclusion: The complexity of cerebral palsy needs to be addressed when describing important daily activities, as verbal communication (speech intelligibility) and feeding ability, which affect inclusion and participation and may require early intervention and technical aids.

#### Poster presentation 73

#### Parental decision-making around selective dorsal rhizotomy - A family participatory research

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Introduction: Selective dorsal rhizotomy (SDR) is an irreversible neurosurgical procedure used to reduce spasticity while aiming to improve sensorimotor function for children with cerebral palsy (CP). Little research has explored the complexity of parental decision-making experiences surrounding SDR surgery and required rehabilitation.

Patients and Methods: Qualitative methods using in-depth, semistructured interviews were used. Eighteen parents (11 mothers and 7 fathers) participated whose child had SDR and completed two-year post op rehabilitation. Data was analysed using thematic analysis.

Results: Results showed the burden of responsibility lies heavily with parents when making decisions around the SDR process. Decision making focuses on having to balance facts with their own emotions, which is heavily influenced by their aspirations for their child and 'wanting no regrets'. Parents identified specific gaps that would have aided their decision-making, including: lack of balanced information in a timely and accessible manner to make a fully informed choice; limited support from local teams; lack of psychological support in managing hopes and expectations, level of preparedness in dealing with pre- and post-op eventualities. These parents, two years post-surgery, reflected that they felt the need to recalibrate the reality [of outcome] against the media 'miracle cure' portrayal of the intervention.

Conclusion: Although all parents reported that they had no regrets on their decision for their child having SDR, many felt a mismatch between their expectations and the outcomes of the surgery. Further work is needed to support parents and professionals making decisions on behalf of the child by providing well-balanced accessible information.

#### Poster presentation 74

#### Assessing visual spatial processing in cerebral visual impairment (CVI) using a virtual reality based visual search task

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Introduction: Children with cerebral visual impairment (CVI) report difficulties with finding a target of interest within a

complex scene. It remains unknown as to how varying task demands and other visual factors influence performance.

Patients and Methods: We developed a novel virtual reality (VR) based search task combined with eye tracking called the Virtual Toy Box. Participants (CVI n=11, mean age 12.9 years; controls n=33, mean age 17.5 years) were instructed to search for a preselected 3-D toy presented among a varying number of surrounding distractor toys (1-15). In three separate experiments, the effect of manipulating set size, field of view (FOV), and object spacing was assessed

Results: Overall, children with CVI showed impaired performance compared to controls with respect to success rate. Furthermore, manipulating FOV had a greater effect on worsening performance than the spacing between objects. With respect to reaction time, CVI participants showed greater impairment with increasing distractor set size, suggestive of less efficient visual processing. Finally, gaze error was largest during trials with the largest FOV. Conclusion: Results are consistent with clinical reports of impaired visual search performance in CVI, with a general trend of worsening performance with increased visual task demands. Furthermore, varying FOV had a greater effect on performance than object spacing. This novel VR based approach offers good experimental control while maintaining a high degree of ecological validity and participant engagement. This may also have important clinical applications in assessing factors that affect higher order visual spatial deficits in this condition.

#### Poster presentation 75

#### Identification of autism spectrum disorders in 8 to 10 vear old Georgian children by using the Autism Spectrum Screening Questionnaire

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Introduction: Rising prevalence of autism spectrum disorders (ASD) highlights the importance of research on the development of effective screening procedures for school age children. This study aimed to identify the prevalence of ASD among 8-10 year old school children in the Republic of Georgia.

Patients and methods: In 2019 a cross-sectional survey in four main cities of the Republic of Georgia was conducted. In total, 16,654 3rd and 4th grade (8-10 years) children from 211 public schools were included. The Autism Spectrum Screening Questionnaire (ASSQ), completed by parents and school teachers, was used to determine children at risk for ASD.

Results: 16,654 (response rate 74%) parents agreed to participate in the study. Parents and teachers rated 770 (5.0%) and 669 children (4.9%), respectively, as screen positive (in the top five percentile). Cut-off scores for 99-95 percentiles (top 1-5%) was defined. Boys were more likely to be rated screen positive than girls. The share of boys rated in the top 5% by parents is 5.6% compared to 4.3% of girls. Teachers place boys in the top 5% even more frequently - 6.4% versus 3.4% girls. Pairwise correlation coefficients (0.53) revealed moderate correlations between scores and according to p-values (<0.05) all correlations were statistically significant.

Conclusion: The study defined the cut-off scores of ASSO for 8-10 year old Georgian children and gender differences in prevalence of risk for ASD. The ASSQ was a successful tool to identify children with special needs.

#### Poster presentation 76

#### Early prediction of cerebral palsy by remote General Movement Assessment in hospital follow-up after covid-19 closure

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Introduction: The General Movement Assessment (GMA) is implemented in hospital high-risk follow-up programs in the Central Norwegian Regional Health Authority for detection of cerebral palsy before 5 months age. Infants are filmed by health care personnel at the hospital outpatient clinic. The covid-19 pandemic hampers today's hospital visits for families. The main objective of this study is to investigate a health-care model with home-based video recordings for remote GMA applied in hospital follow-up programs.

Patients and Methods: This is an ongoing observational study, that includes two home-based video recordings taken at 12+1 to 14+6 and 15+1 to 17+6 weeks post term age and uploaded to a hospital server. High-risk infants admitted to three Norwegian hospital follow-up programs is screened for inclusion before discharge from the NICU. A total of 100 infants/families, able to understand Norwegian and willing to sign informed consent, will be included. The healthcare model sends teaching material to the parents on how to perform video recordings fulfilling GMA standards. Remote GMA are performed on received videos, and 'risk of CP' diagnosis are documented into the medical records. Healthcare model feasibility is evaluated by calculating the number of incoming videos, the number of videos fulfilling required GMA standards, and by applying interviews and surveys for parents and paediatricians about their experiences.

Results: Recruitment commenced January 2021. So far, 15 patients have been included at St. Olavs University Hospital (n=8), Ålesund Hospital (n=6) and Levanger Hospital (n=1). Parental surveys are being collected continuously.

Conclusion: The health-care model study will continue to August 2022.

#### From cerebral palsy to hereditary spastic paraplegia D AMROM, J SOBLET, C VILAIN, G SMITS

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Introduction: Cerebral palsy (CP) is a clinically and etiologically heterogeneous condition. The observation of little change in CP prevalence despite progress of medical interventions suggests individual predisposing causes are playing a role. Among inherited factors, hereditary spastic paraplegia (HSP) can be difficult to distinguish from CP, especially if there is only one affected patient in the family and/or a suggestive pre/perinatal history.

Patients and Methods: We studied our cohort of 250 CP patients and selected patients of the diplegic spastic type. We carried out detailed review of medical records, phenotyping of their specific clinical and neuroimaging features. We explored a potential constitutional cause by genotyping with comparative genomic hybridization (CGH) array, targeted gene sequencing and/or next generation sequencing with mendeliome.

Results: One family encompassed two siblings with intracranial calcifications conferring them a pseudo-TORCH phenotype but without lymphocytosis, CGH array and mendeliome were negative, additional next generation sequencing is ongoing. All other patients were sporadic. Single gene pathogenic or likely pathogenic variants included L1CAM (SPG1, X-linked), SPG11 (SPG11, autosomal recessive), KIF1A (SPG30, autosomal recessive), ERLIN1 (SPG62, autosomal recessive), RNASEH2B (type 1 interferonopathy/Aicardi-Goutières Syndrome 2 [AGS2], autosomal recessive).

Conclusion: Cerebral palsy is a clinical description. We characterized a number of HSP types as the final diagnosis of diplegic spastic CP, and one patient with a type 1 interferonopathy (AGS2). An etiologic work-up of CP patients is always necessary and may be updated, to allow specific treatment and appropriate genetic counseling. Next generation sequencing is still carried out in the unsolved patients.

#### Poster presentation 78 **Complementary and alternative therapies in autism** spectrum disorders

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Introduction: A child with autism spectrum disorder (ASD) need an array of medicines and therapies. The former may cause side effects, the latter are time and money intensive and less accessible in the Indian set ups. Parents are often lured by the promise of 'cure' by alternative therapies.

Patients and Methods: We interviewed 40 parents of autistic children, with an aim to find the awareness and spectrum of alternative or complementary treatment methods accessed by them.

Results: Of those interviewed, 80% visited a speech therapist, 65% occupational therapist, 12.5% were receiving behavior therapy and 37.5% were receiving drugs (mostly resperidone). About 50% of parents used homeopathy, 22.5% used GFCF diet, 15% used camel milk, 17.5% used Ayurveda treatment and carnosine each, 2% used probiotics and 10% took vitamin supplements. Upto 5% of parents mentioned using osteopathy and massages with essential oils. Only 20% of parents mentioned improvements with homeopathy, one each mentioned improvements with probiotics, osteopathy and massage. A majority of parents observed no improvements in behavior with any of the alternative or complementary therapies. One parent mentioned an improved bowel habit with GFCF diet. None of the parents observed any untoward side effects. The most common source of information was parents of other children with ASD in 32.5%, followed by therapists/doctors, families and internet in one case. The cost of alternative medicines was generally reported to be nominal (less than 500 INR or 5 GBP per month). 37.5% parents were interested in continuing the treatments.

Conclusion: This research highlights the need for research on evidence of usefulness of alternative therapies for autism.

#### Poster presentation 79

A European survey of professionals' training needs in wearable lower limb robotic assistive technology (LLRAT) for children with neurological conditions

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Introduction: MOTION (motion-interreg.eu) is a four year, cross-Europe project involving clinical, technical and academic partners in the UK, France, Belgium and The Netherlands. MOTION aims to design innovative wearable, lower limb robotic assistive technology (LLRAT) for children with neurological conditions and to develop training for its use in healthcare practice. Wearable LLRAT includes devices such as powered ankle foot orthoses (AFOs) and exoskeletons, which support standing, walking and rehabilitation

Patients and Methods: An online survey was designed by the project team, informed by the research literature, and covering four main areas: LLRAT experiences, knowledge, attitudes, and training needs. Paediatric occupational therapists, physiotherapists and other related healthcare professionals were invited to complete the survey- available in English, French and Dutch-with an overall sample target of 200+ respondents.

Results: Preliminary results from 137 respondents showed that while only 5% of paediatric healthcare professionals had been trained in the use of wearable LLRAT with children, the majority held positive views towards the benefits of its use. Most respondents (99%) would like more training and information, including both online and in-person learning. The main perceived benefits of wearable LLRAT were: gait retraining (93%); extended independent walking (84%); clinical impacts, e.g. impacts on cardiovascular health (83%) and muscle strength (75%); and psychosocial benefits, e.g. self-esteem and quality of life (92%).

Conclusion: Paediatric health care professionals recognise the benefits of wearable, LLRAT for children but more information and training is needed.

#### Corticospinal tract (re)organization in children with bilateral cerebral palsy correlates with upper and lower extremities function

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Introduction: Early brain injury may disrupt the connectivity of corticospinal tracts (CSTs) producing life-long impairments in fine dexterity and gross motor functions, thus impacting a person' s autonomy. We aimed to describe the (re)organization of CSTs of children with bilateral cerebral palsy (BCP), to determine the white matter characteristics of the upper and lower extremity tracts separately and to relate these to behavioral outcomes.

Patients and Methods: Diffusion tensor imaging (DTI) was performed in twenty-nine children with BCP; 23 data sets were successfully analysed. Task fMRI-guided tractography from motor cortex to brainstem was performed, separating the fibers associated with upper and lower extremities. Then, fractional anisotropy (FA), mean (MD), radial (RD), and axial (AD) diffusivities were quantified. In addition, manual dexterity, gait endurance and everyday activities were assessed.

Results: Children either maintained a contralateral CST organization (n=13) or had a CST bilateral (re)organization (n=10). Comparisons between these two connectivity patterns showed better FA, AD and RD metrics (p< 0.01) favoring the contralateral organization, mainly in the lower extremity tracts. Similar results were observed when comparing the same parameters between the tracts of the dominant and non-dominant hemisphere (MD, AD and RD = p < 0.05), favoring the dominant one, mainly in the lower extremity tracts. Correlation analyses showed an association between manual dexterity, gait endurance and everyday activities with the FA, MD, AD and RD ( $r \ge 0.45$ ; p < 0.05).

Conclusion: Two CST organisation patterns were observed, with different DTI metrics. Moreover, metric's observed for upper and lower extremity tracts were associated with children' motor function and daily activities.

#### Poster presentation 81

#### Talus and calcaneus morphologies and its determinants in children with unilateral cerebral palsy and equinus gait

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Introduction: To compare the volumes of talus and calcaneus bones of children with unilateral cerebral palsy and equinus gait to typically developing children, and to define predictive factors for variations in the volume of ankle short bones.

Patients and Methods: MRI data were used to provide the ankle short bone morphology of children with cerebral palsy and fixed equinus and typically developing children. Manual segmentation of the entire talus and calcaneus was performed to compute mean statistical shape models of the talus and calcaneus for each group. Strength, spasticity, and amplitude of dorsiflexion were measured for children in both groups and were used for regression analysis. Results: Eleven children with unilateral cerebral palsy (CP) and fixed equinus (Equinus, n = 11) and ten typically developing children (Control, n = 10) were included in this study. The volume of the talus (-23%, p = 0.036) and the calcaneus (-25%,p = 0.051) were lower in children with CP and fixed equinus compared to controls. A statistical model including group (Equinus or Control), age, overall spasticity index, overall strength index, and ankle dorsiflexion amplitude as factors explained 64 and 67% of the variation in the talus and calcaneus volume, respectively.

Conclusion: This study demonstrates impairment of the talus and calcaneus volumes in children with unilateral cerebral palsy and with equinus gait. These results are crucial to adjust individualized rehabilitation and surgical programs in order to stimulate children's short bone development with fixed equinus.

#### Poster presentation 82

#### Functional communication, speech intangibility and motor speech difficulties among children registered into the Bangladesh CP register (BCPR)

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Introduction: Evidence on communication and speech difficulties among children with cerebral palsy (CP) are limited in low- and middle-income countries. We aimed to assess the communication, speech intelligibility, and motor speech disorders among children with CP in rural Bangladesh.

Patients and Methods: Children with CP aged <18 years registered into the Bangladesh Cerebral Palsy Register were recruited following purposive sampling method. Each child underwent detailed neurodevelopmental assessment by multidisciplinary team including pediatrician, physiotherapist, speech and language therapist. Data were collected on socio-demographic characteristics, functional communication (i.e. Communication Function Classification System [CFCS], Functional Communication Classification System [FCCS]), motor speech disorder (i.e. Viking Speech Scale [VSS]), speech intangibility (i.e. National Technical Institute for the Deaf [NTID]), and gross motor skills (i.e. Gross Motor Function Classification System [GMFCS]). Descriptive and bivariate analyses were conducted.

Results: Between Sep and Oct 2020, 147 children were included (mean [SD] age: 6.4 [4.1] years, 37.4% female). 49.7% were in

CFCS level V. 61.9% were in FCCS level V. 58.5% were in VSS level IV, and 61.2% were in NTID level 1. A significant positive association between GMFCS level and VSS, CFCS, FCCS, NTID level was observed (p< 0.001, p < 0.001, p = 0.004 and p < 0.001 respectively). Significant positive association between VSS level and CFCS, FCCS, NTID level was also observed (p < 0.001 for all).

Conclusion: The majority of children had severe motor speech impairment, poor functional communication and poor speech intangibility. The severity of communication and speech difficulties increased with severe gross motor function impairment and motor speech disorder. Early intervention focusing gross motor function limitation and speech and communication difficulties could improve the outcome.

#### Poster presentation 83

A new way of supporting visually impaired children and their families during the Covid-19 pandemic

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Introduction: The arrival of the Covid-19 pandemic strongly impacted the daily routine of children, but especially those with developmental disabilities. The Robert Hollman Foundation (RHF) wanted to continue its work supporting the development of visually impaired children and their families even during the lockdown period and so it was obliged to change some aspects of its ways of working. The use of online methods became necessary and the RHF-Distance Support Project was born.

Patients and Methods: Laptops were made available to all RHF professionals, who were trained in the use of e-platforms and allowed online access to the clinical database. Weekly team meetings followed for planning and problem-solving and shared drives were created for data and multimedia storage. Audio-video calls, videos and tailored-made multisensory materials were created specifically for each child. Educational, rehabilitative, psychological, recreational and therapeutic activities were offered. Everything was designed to be shared on-screen with children and their families and was very easy for them to reproduce for use at home. At the end of July 2021, a questionnaire was sent to parents and professionals to obtain feedback regarding the Project.

Results: The questionnaire highlighted the strengths and weaknesses of this new approach proposed in the project. Both parents and professionals expressed high satisfaction levels with it overall. Conclusions: From the results of both parents and professionals the idea of using something new was considered, a combined approach, a mix of traditional care methods in presence and online tailor-made activities.

#### Poster presentation 84

Dystonia and choreoathetosis related to heart rate and accelerometry-based activity index during powered wheelchair mobility in dyskinetic cerebral palsy

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Introduction: Head and/or foot steering systems support people with severe dyskinetic cerebral palsy (DCP) in independent mobility. Mobility is a physically demanding task, however, exerciseload and activity-intensity during powered mobility in DCP are unknown. Additionally, an intention to move exacerbates dystonia and choreoathetosis which interfere with functioning. Insights on exercise-load, activity-intensity, dystonia and choreoathetosis may increase mobility training efficiency.

Patients and Methods: Ten participants with DCP, aged 6-21 years old were included. Participants performed four mobility tasks: independent driving, driving through a corridor, a 360° turn to the right/left, and a slalom. Presence and severity of dystonia and choreoathetosis in the head and arms was assessed using the Dyskinesia Impairment Mobility Scale. Heart rate (HR) assessed exercise-load measured using the Scotsche Rhythm+. The accelerometry-based activity index (AI) determined activity-intensity, measured using three Inertial Measurement Units placed on the forehead and on each wrist. Descriptive statistics and Spearman's rho (rs) described and assessed any associations.

Results: Neck- and distal arm dystonia showed significant correlations with HR (0.65 < rs < 0.95; <0.001 < p < 0.040), whereas proximal arm choreoathetosis (0.67 < rs < 0.90, 0.001 < p < 0.036). HR was significantly associated to the arms AI (0.66 < rs < 0.78, 0.008 < p < 0.030).

Conclusion: Exercise-load was associated only to dystonia and activity-intensity only to choreoathetosis, especially of the arms. Increased activity-intensity often leads to higher fatigue levels, so therapists should attempt to decrease the arm choreoathetotic movements for an increased movement efficiency during training. Findings highlight the difficulties in measuring exercise-load and activity-intensity in DCP due to the involuntary hypertonic and/ or hyperkinetic hallmark of dystonia and choreoathetosis.

#### Poster presentation 85

Heart rate variability during rest and eve-tracking gaming performance in children with dyskinetic cerebral palsy and typically developing children S BEKTESHI<sup>1</sup>, P KARLSSON<sup>2</sup>, I VANMECHELEN<sup>1</sup>, T VAN CRIEKINGE<sup>3</sup>, M KONINGS<sup>1</sup>, P HELLIN<sup>4</sup>, H HALLEZ<sup>5</sup>, JM AERTS<sup>6</sup>, E ORTIBUS<sup>7</sup>, E MONBALIU<sup>1</sup>

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Introduction: Eye-tracking devices could support children with severe dyskinetic cerebral palsy (DCP) in gaining computer access. Stress and effort levels of using an eye-tracking device are however yet unclear. In this respect, heart rate variability (HRV) is used often as a measure for effort and/or stress. This study explored HRV while using eye-tracking devices in children with DCP and typically developing (TD) children.

Patients and Methods: This study included 23 TD children (9 years 4 months  $\pm$  2 years 7 months) and 7 children with DCP (8 years 3 months  $\pm$  2 years 3 months). Participants played ten standardized eve-tracking games using the Tobii X3-120 eve-tracker. HRV was measured during rest and eye-tracking performance using the Bittium Faros 360° Holter device. Kubios Premium was used to analyze HRV parameters such as parasympathetic nervous system (PNS) index and sympathetic nervous system (PNS) index. Descriptive statistics and t-tests described and assessed any differ-

Results: Significantly lower PNS-index (t[22] = 2.691, p = 0.013) with higher SNS-index (t[22] = -3.241, p = 0.002) were recorded from rest to gaming in TD children, but not in children with DCP (t[6] = 0.064, p = 0.951 and t[6] = 0.240, p = 0.818 respectively). A lower PNS-index combined with higher SNS-index is an indication of increased stress and effort.

Conclusions: TD children, but not children with DCP, show a significant change in autonomic response between rest and gaming performance. Thus, using an eye-tracking device appears to increase stress and effort levels in TD children, possibly attributed to the unfamiliarity with the device. On the contrary, children with DCP show comfort and ease in interacting with an eyetracker and should therefore be given the opportunity to benefit from it in daily-life activities.

#### Poster presentation 86

#### The speed-accuracy tradeoff in using an eyetracking device in children with dyskinetic cerebral palsy and typically developing children

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Introduction: Being able to communicate, possibly with the help of assistive communication devices, is of utter importance for children with severe dyskinetic cerebral palsy (DCP). In this respect, speed-accuracy tradeoff (Fitts' Law) in using an eye-tracking device shows the user's ability to interact with point-and-select operations, used to create efficient interfaces to increase communication rate. This study explored the speed-accuracy tradeoff in using an eye-tracking device in DCP and typically-developing (TD) children.

Patients and 15 TD children Methods: (10 years 11 months  $\pm$  2 years 6 months) and 7 children with DCP (8 years 8 months  $\pm$  2 years 2 months) were included. Tobii PCEye Mini eye-tracker and FittsStudy software were used to perform tasks with four indices of difficulty (ID). Movement time (MT), Errors, Average Throughput (TPave), effective ID (IDe), effective width (We) and effective amplitude (Ae) were calculated for both groups using descriptive statistics.

Results: MT (s) was  $4.02 \pm 2.08$  for TD children and  $12.8 \pm 8.66$ for children with DCP. Errors during performance were 23% for TD and 42% for DCP, with a TPave (bits/s) of 0.57  $\pm$  0.32 and  $0.28 \pm 0.39$ , respectively. IDe (bits) was  $1.66 \pm 0.42$  with We  $(173 \pm 80)$  and Ae  $(332 \pm 61)$  for TD and IDe  $(1.48 \pm 0.66)$ with We (219  $\pm$  97) and Ae (338  $\pm$  104) for DCP.

Conclusion: Compared to TD children, children with DCP had a longer MT, made more errors, and had a lower speed-accuracy tradeoff performance as measured by the TPave. Whereas Ae (distance between targets) is similar between groups, the difference in We (target width) may indicate the importance of larger computer icons in screens used by children with DCP to facilitate faster and more accurate selection.

#### Poster presentation 87

#### The effect of medial versus medial and lateral hamstrings lengthening on transverse gait parameters in cerebral palsy

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Introduction: Isolated medial hamstrings lengthening may cause a relative external rotation moment on the tibia due to preserved lateral hamstrings activity. We compared transverse plane kinematic alignment following isolated medial (MHL) versus medial and lateral hamstrings lengthening (MLHL).

Patients and Methods: A retrospective cohort with cerebral palsy was treated with hamstrings lengthening as part of SEMLS at a tertiary referral center. Concurrent osteotomies or tendon transfers, GMFCS IV or V preop, absent gait analysis (GA) within 12 months preop or after one year postop were excluded. Kinematic changes with MHL versus MLHL were compared, on a per-limb basis, between preop and short term (ST) (1-2 years), and long term (LT) (3+ years). One way ANOVA, post-hoc Bonferroni, and unpaired t-tests were calculated.

Results: 150 children (110 MHL, 124 MLHL) evaluated at age  $9.4 \pm 4.1$ ,  $12.2 \pm 4.9$  and  $13.8 \pm 4.1$  (pre-op/ST/LT), GMFCS levels I (21% MHL, 15% MLHL), II (52%, 44%), and III (27%, 40%). Tibial external rotation increased, greater with MHL compared to MLHL, statistically significant in ST (change of 8.93° [SD 15.9°] vs  $4.35^{\circ}$  [14.5°], p = 0.045), diminishing in LT (change of 8.20° [14.7°] vs 9.29° [17.6°], p = 0.71). Hip, ankle rotation, foot orientation also increased, with no statistical difference between MHL and MLHL.

Conclusion: Tibial external rotation increased in isolated medial hamstrings lengthening compared to medial and lateral hamstrings lengthening. While the mean effect diminished in longterm follow up, it could delay or mitigate the need for tibial osteotomy in some patients. There was no detectable relative impact on hip or pelvis rotation.

#### Constraint-induced movement therapy and bimanual training in children with hemiplegic cerebral palsy mainstreamed in regular school: A randomized controlled study

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Introduction: This study aimed to compare the effects of modified constraint-induced movement therapy (mCIMT) and bimanual training (BIT) based on the International Classification of Functioning, Disability, and Health's conceptual framework.

Patients and Methods: Thirty-two children (mean age 10.43 years [SD 2.9 years]; 15 females, 17 males) whose functional profiles associated with Manual Ability Classification System (MACS), Gross Motor Function Classification System (GMFCS) and Communication Function Classification System (CFCS) changed between level I-III, were randomly distributed to one of the mCIMT or BIT groups with equivalent dosing frequency and intensity (10 weeks/3 days per week/2.5 h per day). Upper extremity body structure/functions, activity, and participation outcomes were assessed before and after treatment, and at 12 weeks post-intervention.

Results: Overall, mCIMT produced more significant improvements in all outcomes than BIT at the immediate post-intervention period (T2), which were maintained better in the mCIMT group throughout the 12-week follow-up period (T3) (Cohen'd-effect size: dmCIMT>dBIT). However, effect size (ES) for the quantity of bimanual use was found to be larger in BIT group than mCIMT group (dBIT = 1.41 and dmCIMT = 1.23), while the immediate effect of mCIMT for quality of bimanual use parameters was observed better than BIT (ranges of dmCIMT = 0.91-0.96 and ranges of dBIT = 0.63-0.77).

Conclusion: With significant differences between study groups in all outcomes except from quantity of bimanual use, favouring mCIMT, both intervention approaches were found to be effective on all measured parameters

#### Poster presentation 89 Interventions to improve visual perception in cerebral palsy: A systematic review

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Introduction: Cerebral Palsy (CP) is a motor function disorder often accompanied by cognitive impairments, such as deficits in visual perception abilities that might have an impact on quality of life. The aim of this study was to systematically review the interventions focused on visual perception in children and adults with

Patients and Methods: A general systematic electronic search was conducted in PubMed, PsycINFO, Central Register of Controlled Trials (CENTRAL), CINAHL and ERIC from September 2010 to September 2019. A qualitative evaluation of the studies was performed according to the 2011 Oxford Centre for Evidence Based Medicine Levels of Evidence (LOE). Among all studies that were identified, those considering visual perceptual abilities are presented in this abstract.

Results: Among the 8 studies focused on visual perception, three were randomized controlled trials (RCT) (level 2 of LOE), and five were level 4 of LOE. Interventions were multi-modal (n=4), cognitive (n=1), and physical (n=3). Among studies at the level 2 of LOE, 2 identified effective interventions at improving visual perceptual abilities and one did not reach a significant improve-

Conclusion: Taking into account that visual perceptual abilities are the main cognitive impairment in CP, it urges to find interventions to target them. At the moment, multi-modal interventions seem to be the best option to improve visual perception. It remains undetermined whether physical interventions in CP have an effect on visual perceptual functioning.

#### Poster presentation 90 The progression of BMI status over time in Irish ambulant children with cerebral palsy

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Introduction: An increasing prevalence of overweight and obesity in children has been reported globally. Most studies examining the trajectory of BMI of children over time have tended to focus on children with typical development. Our group previously reported prevalence rates in a paediatric cerebral palsy cohort. However, the trajectory of BMI was not examined. It was therefore the purpose of this study to follow the same children over two assessments and examine the changes in BMI as children with CP age and determine the severity of obesity.

Patients and Methods: A retrospective analysis was conducted of the National Movement Laboratory database yielding 574 participants that met inclusion criteria. BMI was calculated retrospectively, and age adjusted BMI centiles were used for analysis. A chi-square test for homogeneity was used to compare differences in proportions. Differences between assessments were assessed using a Kruskal-Wallis one-way analysis of variance with Bonferroni adjustment for post-hoc comparisons.

Results: No statistically differences were present in proportions for any BMI classifications between first and repeat assessment (p=0.05). Small non-statistically significant increases were evident in both the obesity (7.8% to 11.5%) and overweight (10.8% to 12.4%) categories. A rise in the severity of obesity was also evident. Eighty percent of children remained in a healthy bmi category between assessments whilst 56% remained either overweight or moved into a category of obesity.

Conclusion: The results of this study highlight the importance of maintaining a healthy bmi status with the apparent difficulty in reversing overweight and obesity, moving into adolescence and young adulthood.

## Association between frequency and involvement at participation at home and parent's availability of time during the COVID-19 pandemic

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Introduction: The COVID-19 pandemic period (PP) changed the families' daily routine, especially ones with children with neuromotor impairments (NI). Spending more time at home during PP, children's participation at home (PH) assumed a different perspective, which might be associated with a child's personal interests and caregiver's attitude. We investigated the association between children's frequency and involvement at PH and parent's availability of time to incentivated PH.

Patients and Methods: Following ethical approval, 92 parents of children with NI (47% Down syndrome, 13% cerebral palsy, 20% autism, 20% others) (8.17  $\pm$  3.93 years) were remotely surveyed during PP about: 1-frequency in PH; 2-involvement of PH; 3-parent's perception of time availability to incentivated PH of their child using Participation and Environment Measure for Children and Youth. We used multivariate linear regression analysis. Child's involvement during the PH and the parent's availability of time were used as independent variables and frequency of PH was dependent variable. Statistical analyses used SPSS-V24 with significance level at p < 0.05.

Results: The child's involvement and parent's perception of time availability can explain 51.2% of variance in the child's frequency of PH.

Conclusion: Children and adolescents that get involved more in PH may feel more motivated in PH, which favors them to participate more frequently. Parents who believe having less time to support their child's PH can provide more opportunity for their child to participate because it can minimize how much the parents anticipate to do for the child, that reinforces the importance of the family and can guide therapeutic goals.

#### Poster presentation 92

### Ambulatory performance, motor function and gait capacity in young adults with cerebral palsy

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*Introduction*: Youths with cerebral palsy (CP) have reduced levels of ambulatory performance (AP). The aim was to investigate the contribution of motor function, and gait capacity on AP.

Patients and Methods: Patients with CP older than 15 years who underwent a Clinical Gait Analysis (CGA) and accepted to wear an ActiGraph GT3X+ at sacrum level during 7 days were included. AP was assessed through the number of steps/day from ActiGraph measures, gait capacity through the 6-min-walking test (6MWT), and motor function through CGA outcomes such as a modified Gait Profile Score (mGPS), the Gait Variable Scores (GVS) and self-selected walking speed. The patients were

dichotomised in two categories regarding their levels of AP: occasional walkers (<5000 steps/day) and regular walkers (≥5000 steps/day). Mean, 95% CI and T-tests were used to compare the two categories of patients.

Results: Thirty-four youths with CP were included (20.7  $\pm$  4.9 years, 14 girls), 27 in GMFCS I and 7 in GMFCS II, 20 unilateral and 14 bilateral CP. Twenty-two patients were classified as occasional walkers (14 unilateral CP, 16 GMFCS I). Occasional walkers had reduced 6MWT distance (486.0 [401.2–570.9] vs 621.3 [547.6–695.1] m), reduced walking speed (0.9 [0.9–1.1] vs 1.2 [1.1–1.3] m/s), reduced hip flexion-extension GVS (5.7 [4.6–6.8] vs 8.7 [5.8–11.6] °) and higher knee flexion-extension GVS (10.4 [8.1–12.6] vs 7.3 [5.4–9.3] °). They also tended to be older with higher BMI.

Conclusion: Maintaining high levels of motor function and gait capacity of children with CP during the transitional period towards adulthood may be essential to ensure high levels of AP and participation in community.

#### Poster presentation 93

### Application of gene therapy in patients with spinal muscular atrophy – Own experience

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Introduction: Spinal muscular atrophy (SMA) is a neuromuscular disease characterized by the degeneration of motor neurons. Patients experience progressive muscle wasting and weakness. All patients with SMA lack the SMN1 gene, but at least 1 copy of the SMN2 gene is present. However, the amount of SMN protein (produced by the SMN2 gene) is insufficient for the survival of motor neurons, leading to progressive muscle weakness and wasting. Zolgensma (Onasemnogene abeparvovec) - gene therapy based on the AAV9 viral vector. The AAV capsid is the protein envelope that surrounds and protects the viral genetic material. The production of the SMN protein begins several dozen hours after intravenous administration of the drug.

Patients and Methods: Zolgensma was used in 6 children with SMA I, 3 with SMA II. Five boys and four girls. The drug was administered intravenously as a 60-min infusion. Before and 4 weeks after administration, children were assessed in the CHOP and HFSME scales. In addition, liver enzyme levels were monitored for 3 months after drug administration.

*Results*: A significant improvement in the CHOP and HFSME physiotherapeutic scores was observed in 8 patients as early as 4 weeks after the administration of Zolgensma. In all patients, a transient increase in liver enzymes was observed, which subsided after the administration of steroid therapy.

*Conclusion*: The use of Zolgensma has very promising therapeutic effects in patients with SMA. The drug should be especially used in infants and presymptomatic patients.

Gene therapy should present new challenges and opportunities in neurological diseases.

A systematic review and meta-analysis of nonsurgical interventions for improving upper extremity function in children with cerebral palsy

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Introduction: The objective was to systematically review literature for interventions that are effective for upper extremity function in children 0-21 with cerebral palsy.

Patients and Methods: Cochrane, PubMed, CINAHL, and Web of Science were queried and articles were screened using PRISMA guidelines to include full-text, cerebral palsy, upper extremity, treatment, and pediatric. T-tests, ANOVA, and regression analysis were performed using SAS statistical software.

Results: After removing duplicates, 3855 studies were screened to reach a final total of ten studies (n=65) with nine interventions and individual patient data meeting the inclusion criteria. Five outcome measures were analyzed: QUEST (n=33), range of motion (n=26), Melbourne Assessment of Unilateral Upper Limb Function (MUUL) (n=27), Modified Ashworth Scale (MAS) (n=12), and Assisting Hand Assessment (AHA) (n=40). QUEST scores were significantly higher in the BoNT-A/splinting group (F = 13.51; 95% CI = 1.67–25.355; p < 0.05) when compared to virtual reality therapy. AHA scores were significantly higher in the CIMT group (F = 5.05; 95% CI = 2.12-7.97; p < 0.05) when compared to splinting. AHA scores were significantly higher in the transcranial direct current stimulation group (F = 3.26; 95% CI = 0.48–6.04; p < 0.05) when compared to splinting. There was no difference in mean change in the other outcome measures studied between any other interventions.

Conclusion: There is a large selection of interventions along with a varied set of outcomes for upper extremity cerebral palsy, but no study comparing all treatments and outcome measures. We recommend further research aimed specifically at evaluating intervention selection based on age and desired functional outcomes.

#### Poster presentation 95 Did the COVID-19 pandemic affect orthopedic surgical care for children in New Jersey with neuromuscular disorders?

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Introduction: The purpose of this study was to determine the impact of the COVID-19 pandemic on elective surgeries for children with neuromuscular disorders in the United States (New Jersey). We compared surgical cases performed during the COVID-19 pandemic between March and December 2020 with the same time period in 2019.

Patients and Methods: This study was a retrospective, IRB approved chart review of surgical cases of three pediatric orthopedic surgeons operating at four hospitals. The hospitals studied included two dedicated children's hospitals, a level-2 pediatric academic trauma center, and a community hospital. There were 998 total surgical cases identified, including 56 involving patients with neuromuscular disorders.

Results: There were a total of 612 cases performed between March and December 2019 compared to 386 cases during the same time period in 2020. In 2019, there were a total of 196 elective surgeries versus 97 in 2020. Of these, there were 30 electively scheduled surgeries for children with a neuromuscular disorder in 2019, versus 26 during 2020. When divided by procedure type, comparing 2019 to 2020, there were 11 versus 8 lower extremity contracture releases; 1 versus 1 upper extremity contracture release; 8 versus 7 hip reconstructions; 6 versus 5 scoliosis corrections; and 4 versus 5 removals of hardware.

Conclusion: The number of orthopedic elective cases performed for extremity contracture, hip dysplasia, and spinal deformity in patients with neuromuscular disorders remained relatively constant. Further analysis is needed in order to determine how to preserve care pathways for children with disabilities even under adverse conditions.

#### Poster presentation 96

#### A 3D printed dynamic upper extremity orthosis (DUEO) for children with cerebral palsy: A pilot

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Introduction: New technology has evolved into using 3D printing to fabricate orthotics, prosthetics, assistive devices, and adaptive equipment. The purpose of this pilot study was to design and examine the effect of a low cost, functional, dynamic 3D printed upper extremity orthosis (DUEO) on upper extremity functioning in children with upper extremity CP.

Patients and Methods: Pediatric patients were enrolled if they met the following inclusion criteria (a) hemiplegic or triplegic CP (b) MACS levels III to V (c) active elbow arc of motion of at least 75 degrees and (d) ability to follow one step directions. Informed consent/assent was obtained for this Institutional Review Board approved study.

Results: The participants included four males and one female, aged 13-17 years. Three had right hemiplegia, one had left hemiplegia, and one had triplegia with left upper extremity involvement. MACS levels were III for one participant and IV for the other four. Four participants showed a clinically significant improvement in their AHA logit-score. For the Melbourne Assessment-2, higher post-treatment raw scores were found for four participants for range of motion, three for accuracy, three for dexterity, and two for fluency. In the PMAL, four participants had increases; for the PedsQL, three respondents reported improvements in several domains.

Conclusion: A multidisciplinary team designed a low cost, functional, dynamic 3D printed upper extremity orthosis, the DUEO, for this pilot study. When paired with goal-directed OT, a small group of pediatric patients with CP with unilateral upper extremity involvement showed gains in their upper extremity function.

#### Augmented feedback for treatment of upper extremity function in children with cerebral palsy: A systematic review

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Introduction: For children with cerebral palsy and upper extremity dysfunction, augmented feedback can include methods such as mirror therapy, video games, virtual reality, robotics, and biofeedback frequencies. The purpose of this study was to evaluate the outcomes and quality of current literature on augmented feedback.

Patients and Methods: A comprehensive search of PubMed, Cochrane, Web of Science, and CINAHL databases was performed from inception to July 2020 and screened using PRISMA guidelines. The search was conducted with the following terms and other iterative variations: 'cerebral palsy', 'upper extremity/ hand', 'pediatric', and 'treatment'. After removing duplicates, 3855 studies were screened to reach a final total of 80 full text papers. The papers were reviewed for the following criteria: outcomes, quality, sample size, followup, therapy used, and itemized/

Results: There were 47 outcome measures collected, of which the most common were Quality of Upper Extremities Skills Test (QUEST, 17 studies), Melbourne Assessment (MA-2, 17 studies), and the ABILHAND test, 13 studies. There were 36 randomized control studies. The average sample size was 21 patients, with a follow up of 6 weeks. The most common therapy used was visual or sensory feedback (22 studies), followed by video games (21), electrical stimulation (16), robotic therapy (12), and virtual reality (9). Twenty-six papers had itemized data.

Conclusion: Augmented feedback is an emerging therapeutic field for children with upper extremity dysfunction and cerebral palsy. Further analysis of the current literature using a meta-analysis will be able to determine which therapy is optimal for the desire outcome.

#### Poster presentation 98

#### The impact of SARS-CoV-2 on the accessibility of multidisciplinary diagnostics of neurodevelopmental disorders in Flanders, Belgium

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Introduction: Early detection and smooth trajectories of diagnostics, rehabilitation and support affect the development and opportunities of the child with a neurodevelopmental disorder (NDD). While accessibility to multidisciplinary diagnostics in Flanders (Belgium) is problematic in regular times, the measures taken in response to the SARS-CoV-2 pandemic could amplify this problem. This contribution explores the impact of lockdown policy measures on the accessibility of multidisciplinary diagnostics of NDD.

Patients and Methods: This 'rapid response' study was commissioned by the Flemish authorities, as a follow up of a study on accessibility of multidisciplinary diagnostics. A questionnaire with open-ended questions was sent out to respondents of three key types of facilities: the Centers for Ambulatory Rehabilitation, Autism Reference Centers and Centers for Developmental Disorders. Qualitative data were thematically analyzed in an iterative process by researcher triangulation.

Results: Measures taken in response to the SARS-CoV-2 pandemic negatively impacted on waiting periods. Guidelines to minimize the risk of virus contamination impact on planning, time management and the quality of the diagnostic assessments. Respondents reported their implementation as being time consuming, uncomfortable, increasing workload and reducing the number of daily diagnostic activities.

Conclusion: The existing problematic accessibility to multidisciplinary diagnostics of NDD in Flanders is reinforced by the SARS-CoV-2 pandemic. More interorganisational collaboration to enhance efficient and effective diagnostic trajectories adapted to the needs of the children, is needed on a longer term. To tackle the increasing waiting times 'bridging care' during waiting periods in the child's trajectory would increase accessibility and quality of care.

#### Poster presentation 99

#### Quality of life of primary caregivers of children with cerebral palsy

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Introduction: Cerebral palsy (CP) is the most common cause of childhood disability. Patients with CP are often dependant, requiring long-term care by family members and health systems. Caregivers (mostly parents) will frequently be in charge of decision-making, support and execution of daily activities, meaning high stress levels. Burden is a psychological state influenced by physical, emotional and socioeconomic implications of taking care of disabled persons. The main objective of this study was to assess risk factors and characteristics of both caregivers and patients, using the Zarit Interview, Gross Motor Function Classification System, Barthel Index and semi-structured interviews.

Patients and Methods: Quantitative, descriptive, correlational, transversal, non-probabilistic discretional sampling. Sample: Primary caregivers of children with CP (n=36). Direct interview by the investigators; written consent. Data analysis using Statistical Package for the Social Sciences, correlating variables, with central tendency, frequency tables and general tables.

Results: Most of the caregivers were female, patients' mother. No significant statistical difference was found related to the caregivers' age, educational level, marital status, nor economical level. There was a directly proportional relationship between dependency degree, motor function and caregivers' burden level, as well as the daily hours dedicated to caregiving.

Conclusion: The Zarit Interview is a useful tool to assess burden in primary caregivers of children with CP. Burden level is directly associated with worse motor function and greater dependency levels. Female caregivers are the most susceptible population.

Interventions and strategies to prevent caregivers' physical and psychological health issues should be considered.

#### Poster presentation 100 Health needs of individuals with neurodevelopmental disorders in transition to adult

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Introduction: Transition to adulthood is critical for youths with disabilities. In developing countries such as Brazil, transition programs are not well established; health care needs of these individuals are unknown. Here we describe the access to health services and concerns/priorities of adolescents with physical disabilities and their families.

Patients and Methods: Medical records of 15 (mean age at entry: 15 years SD 2.37; 6 females) youths with physical disabilities followed at an outpatient follow-up service from 2015 to 2020 were analyzed. Functional mobility scale classifications were: 1,1,1 (n=6); 3,1,1 (n=2); 5,5,5 (n=5); 6,6,6 (n=1). Health needs and priorities were collected from several tools, including the About My Child and the Canadian Occupational Performance Measure.

Results: Participants were served by public (73.3%) and private (26.7%) health systems. None were receiving regular rehabilitation services other than annual physical therapy consultation. Twelve patients presented health needs, which were met along the years in eight cases, while four remained unsolved. The main needs were psychological support (n=6), due to aspects such as bullying and vocational coaching, and orthopedic surgery (n=4). Productivity (33.3%), self-care (26.7%) and leisure (20%) were the most frequently reported priorities/concerns.

Conclusion: Findings show a variety of health needs and priorities that need to be addressed. The relevance of establishing a continuous multidisciplinary transition care program is emphasized.

#### Poster presentation 101

#### Families' perceptions and preferences regarding physical therapy services received during the Covid-19 pandemic in Brazil

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Introduction: Social distance measures needed to face the COVID-19 pandemic had a significant impact on the rehabilitation services provided to children and adolescents with disabilities and their families. In this study, we explored the lived experiences of families towards physical therapy interventions received during

Patients and Methods: After signing informed consent, mothers of 18 children (7.33  $\pm$  4.6 years; 12 males; 77.8% with diagnosis of cerebral palsy; 55.6% non-ambulant) that attended physical therapy services before the pandemic responded to an online questionnaire on the impact of social distancing in the services provided and parent perception about the physical therapy

received during this period. Thematic analysis analyzed the most relevant topics raised by families.

Results: During the pandemic, most families received regular instructions for offline in-home activities (38.9%), followed by inperson (22.2%) and remote (16.7%) physical therapy. All participants reported to miss in-person physical therapy sessions, although telerehabilitation was well received in many cases. Environmental changes and regular check ins were often suggested to support home stimulation.

Conclusion: Families need support in order to feel empowered and able to provide adequate stimulation when social distancing is mandatory. Despite the positive aspects of telerehabilitation, there was consensus that in-person rehabilitation is desirable. Factors such as lack of in-home environmental support and structure, and social interactions enabled by attending in-person therapy sessions may account for this finding.

#### Poster presentation 102

#### Sensory function influences unimanual and bimanual dexterity in unilateral cerebral palsy

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Introduction: The recently developed Tyneside Pegboard Test (TPT) assesses both unimanual and bimanual dexterity in children with unilateral cerebral palsy (uCP). Our aim was to explore the TPT psychometric properties and the impact of sensorimotor impairments on unimanual and bimanual dexterity.

Patients and Methods: Forty-nine children with uCP (mean age 9 years 8 months, SD 1 year 11 months, 30 males, 23 right-sided uCP) performed the unimanual and bimanual TPT providing task duration. For the psychometric properties, known-group validity was evaluated using ANCOVA (between MACS levels) and concurrent and construct validity with Spearman's correlations (r) with known and valid tests (Jebsen-Taylor Hand Function test (JTHFT), Assisting Hand Assessment (AHA), ABILHAND-Kids and Children's Hand Use Experience Questionnaire (CHEQ). The impact of sensorimotor impairments (spasticity, grip force, stereognosis and mirror movements) was investigated using multiple linear regression ( $\alpha < 0.05$ , R2).

Results: Unimanual and bimanual dexterity differed between MACS levels (known-group validity) (p< 0.001). The TPT tasks correlated to the JTHFT (concurrent validity, r = 0.86-0.88), the AHA, ABIL-HAND-Kids and CHEQ (construct validity, r = -0.38-[-0.78]). Stereognosis was the main factor influencing all tasks (p < 0.001,  $R^2 = 37-50\%$ ). Unimanual dexterity was further explained by grip strength (p< 0.05, R2 = 8–9%) and mirror movements in the moreimpaired hand (p< 0.05, R2 = 4-8%), while bimanual dexterity was additionally explained by mirror movements in the more-impaired hand (p < 0.01, R2 = 10–16%) and spasticity (p = 0.04, R2 = 5%).

Conclusion: The TPT is a valid assessment to measure unimanual and bimanual dexterity. This study further highlights that stereognosis is the main determinant for unimanual and bimanual dexterity in children with uCP.

#### Poster presentation 103

#### New insights into the muscle weakness of both upper extremities in children with unilateral spastic cerebral palsy

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Introduction: It has been shown that in children (7-12 years) with unilateral spastic cerebral palsy (USCP) muscle weakness exists in both upper extremities (UE). Whether muscle weakness exists in a larger age range and if functional muscle weakness also exists is unknown. In addition, it is also unknown whether (functional) muscle weakness is linked to specific Manual Ability Classification System (MACS) levels.

Patients and Methods: In a cross-sectional study design, isometric arm (wrist flexion, wrist extension with flexed and extended fingers, elbow flexion/extension), grip/pinch and functional muscle strength was assessed in 175 children (7-18 years, mean age = 12.3 [SD = 3.1] years) with USCP, MACS levels I to III and in 280 children with typical development (TD) (7-18 years, mean age = 12.7 [SD = 3.2] years). Arm strength was measured with a hand-held dynamometer, and grip/pinch strength was measured with a calibrated, modified (digitized) grip dynamometer and a pinch meter. Functional strength was measured with the bimanual Box-task and the unimanual Cup-task.

Results: In all measurements except for elbow extension of the 'non-affected' UE, children with USCP were significantly weaker than children with TD. In the 'non-affected' UE, 7% to 33% less (functional) muscle strength was found, compared to children with TD. In the affected UE the muscle weakness was between 31% and 83%. There was no clear indication that muscle weakness is more common in a certain MACS level.

Conclusion: In children with USCP, (functional) muscle weakness occur in both UEs, in a large age-range and in all MACS-levels.

#### Poster presentation 104 Glycopyrronium bromide oral solution in the treatment of sialorrhea in a paediatric patient with Goldenhar syndrome

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Introduction: Sialorrhoea (chronic pathological drooling) can occur in patients with neurodegenerative disorders, like Goldenhar syndrome (oculo-auricular-vertebral syndrome). One complication is posterior drooling which can lead to respiratory morbidity with recurrent infections of the respiratory tract, a major problem in the rehabilitation unit. This case study examines the efficacy and tolerability of glycopyrronium bromide oral solution (320 µg/ml Sialanar®, Proveca Pharma Ltd) for sialorrhea, resulting from Goldenhar syndrome.

Patients and Methods: A 6-year-old child with Goldenhar syndrome had severe maxillofacial dysmorphism, a tracheostomy, PEG. Sialorrhoea, accentuated by exclusive PEG feeding, led to recurrent respiratory tract infections. Following the failure of botulinum toxin and scopolamine therapy, the patient commenced glycopyrronium treatment, 320 µg/ml oral solution, for improved administration and dosage management, at a starting dose of 0.480 mg (1.5 ml) bd (0.960 mg/day), November 2018. The Drooling Impact Scale (DIS) and the modified Teachers' Drooling Scale (mTDS), used to calculate severity and rate of drooling, were assessed before initiating therapy and at 12 months. At this point, the dose was increased to 0.960 mg (3.0 ml) tds (2.88 mg/day). Results: The scores at baseline and 12 months respectively were: 79 and 29 for DIS, 8 and 2 for mTDS. These results have been maintained to date (August 2020) without clinically relevant side effects and with a positive psychosocial impact on the quality of

Conclusion: Reduction of drooling scores in both scales assessed, leads to the conclusion that glycopyrronium oral solution is an effective and well-tolerated therapeutic approach to treat sialorrhea in pediatric patients with Goldenhar syndrome.

#### Poster presentation 105

#### Can tele-practice be used to effectively deliver training to families of children with intellectual disabilities and sensory processing disorders?

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Introduction: Use of tele practice is rapidly increasing due to the COVID-19 pandemic. Seashell Trust provides specialist education and residential care for children and young people with complex intellectual disabilities and sensory impairments. During the first UK lockdown, Occupational Therapy services at Seashell Trust moved to an online service working with parents providing training to enable them to support their children more effectively at home. Patients and Methods: The purpose of this small scale service evaluation was to understand the lived experiences of parents who participated in Occupational Therapy intervention via tele practice. A qualitative design was adopted using semi-structured interviews. Thematic analysis was carried out independently by two Occupational Therapy students on practice placement which were then compared to increase reliability of findings.

Results: Five key themes were identified, including emotional responses, positive experiences, opportunity to enhance collaborative working, impact of telehealth on facilitating engagement.

Conclusion: This service evaluation suggests that using tele-practice to deliver Occupational Therapy intervention was a positive experience for parents resulting in improved understanding of how to understand and support their child's unique needs and implement strategies to support engagement. Further study is needed to determine the effectiveness of tele-practice as an alternative form of service delivery.

#### Case series to show COVID-19 impact measured using neurodevelopmental assessment tools

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Introduction: The COVID-19 outbreak could result in increased levels of psychological distress in all individuals, specifically among young individuals suffering from neurodevelopmental conditions like developmental delay, attention-deficit/hyperactivity disorder (ADHD) and autism spectrum disorder (ASD). Such children are at a risk of worsening of prognosis due to the sudden, unpredictable changes that might be perceived as more complex to them. This case series focuses on the impact of COVID-19 pandemic on five such individuals measured using standardized neurodevelopmental assessment tools.

Patients and Methods: We present five cases of children diagnosed with different neurodevelopmental disorders such as ASD, ADHD and global developmental delay. The neurodevelopmental assessment tools administered were of two kinds: Developmental tests (Griffiths Mental Development Assessment tool and Weschler Intelligence Scale for Children - V) and Behavioural test (The Conners 3rd Edition - Parent).

Results: A comparative study of the tests' findings demonstrates the impact of restricted access to multidisciplinary therapies enforced by the lockdown during COVID-19. A significant impact of COVID-19 on the worsening of the prognosis in the cases was observed. The IQ of the children suffered and declined by 5-10 points while scores in inattention and hyperactivity spiked post-lockdown. After the restart of therapies post withdrawal of lockdown, the children have started improving with the help of the multidisciplinary management.

Conclusion: The measurement of neurodevelopmental tools clearly indicate the benefits of optimal management. These unique cases equally and clearly show the impact of interruption in the treatment so commonly caused by COVID-19.

#### Poster presentation 107 A study on factors affecting sleep in late adolescents during COVID- 19 pandemic

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Introduction: Insomnia and sleep disturbances have both been a major concern for public health. Many researches have shown that insomnia is prevalent among adolescents and young adults. The coronavirus pandemic has negatively impacted the lives of all individuals in various ways. Emerging research studies have shown

evidence that the COVID-19 pandemic has led to disrupted sleep and poorer health functioning in individuals overall. The aim of this study was to see the effect of personal factors on sleep disturbance in late adolescents during pandemic.

Patients and Methods: A total number of 160 participants from the Indian population participated via a voluntary web-based survey after agreeing to an electronic informed consent requested for each participant. The age range of the participants selected randomly was 17-21 years. The tools used for the online survey were the Insomnia severity Index (ISI), the Self Report Questionnaire (SRQ), Intolerance to uncertainty (IUS) and Brief Resilience Scale (BRS).

Results: The results indicate that, on average, there is a subthreshold level of insomnia. A significant positive correlation indicated that presence of psychiatric morbidity was related to Insomnia. Interestingly, resilience scores showed a high positive correlation with psychiatric morbidity in both males and females, although it was found to be unrelated with insomnia.

Conclusion: It may be concluded that the real stressor in this coronavirus situation is the pandemic itself that is leading to various sleep problems and psychiatric problems in people.

#### Poster presentation 108

#### Effects of an intensive therapy (HABIT-ILE) on the precision grip control while walking down a step in pediatric unilateral cerebral palsy

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Introduction: This study aimed to assess the effect of Hand-Arm Bimanual Intensive Therapy Including Lower Extremities (HABIT-ILE) on the precision grip force and load force of children with unilateral cerebral palsy (UCP) while performing an intersegmental task of walking down a step with a handheld object.

Patients and Methods: Thirty children with UCP (age range: 5-17 years) received 90 h of conventional therapy followed by 90 h of HABIT-ILE. Children were asked to walk down a step while holding a grip-lift manipulandum to assess the forces coordination before and after each intervention as well as at 3 months of follow-up. Each hand was tested separately. Various dynamic and temporal variables were analysed. The maximum voluntary contraction (MVC) generated during static position and the percentage of MVC used for the grip force were also assessed.

Results: No significant changes were observed after 90 h of conventional treatment. Children presented on their more-affected hand, a smaller temporal course from forces onset to maximum load increase and, on their less-affected hand, a decrease in load force scaling just after HABIT-ILE but not at follow-up. The children's MVC on both hands also increased both after HABIT-ILE and at follow-up, inducing lower percentages of MVC used during the whole task (only significant on the more-affected hand).

Conclusion: HABIT-ILE is able to induce a transient modification in the anticipatory control (timing) and the load force scaling. The intervention also induces a more prolonged increase in MVC. This may explain, partially, the functional improvements observed after HABIT-ILE in other studies.

### Using Rasch analysis to develop a school-based screening tool of fundamental movement skills

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Introduction: Many children are not able to perform age-appropriate fundamental movement skills (FMS). It is important, therefore, to assess FMS for efficient identification of children needing additional support. Universal screening of FMS in schools has great potential, but research has established that current assessment tools are not optimal for this purpose. This research aimed to develop a free, feasible measure of FMS for primary schools. Patients and Methods: A screening tool (FUNMOVES) was developed based on: (1) a systematic review of current assessments; (2) a survey of teachers exploring barriers to school-based assessments; (3) expert opinion from psychology, public health, and physical activity professionals. Over three studies, 814 children (4-11 years) were assessed in school using FUNMOVES. Following each study, Rasch analysis was used to evaluate construct validity, and modifications were made to FUNMOVES based on the results and researcher implementation notes.

Results: Study 1 found a multi-dimensional measure that did not fit the Rasch model, with disordered thresholds, local dependency, and misfitting items. Study 2 showed a unidimensional measure, with acceptable internal consistency and no local dependency, but that did not fit the Rasch model, had a misfitting item and disordered thresholds. Study three revealed a unidimensional assessment tool that fit the Rasch model, with no further issues. Conclusion: FUNMOVES has good construct validity and allows teachers to assess the FMS of a whole class in under an hour, using resources available in schools. Future research will evaluate FUNMOVES' validity, reliability and acceptability.

#### Poster presentation 110

# Survey about epidemiological and emotional aspects related to COVID-19 among Italian adolescents with disability and their parents

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Introduction: As a consequence of the COVID-19 emergency, schools closed, and the rehabilitation of chronic conditions was mostly suspended. The isolation of disabled adolescents and the burden of daily management for parents were exacerbated. Many

families experienced serious economic difficulties. Professionals investigated the impact of rehabilitation activity reductions. Nonetheless, the perspectives of families with disabilities are lacking.

Patients and Methods: An anonymous online survey composed of multiple-choice questions was proposed to adolescents with disability and parents of disabled children, to describe their experience during lockdown and their concerns or expectations about rehabilitation. Fifty-three children and 239 parents completed the survey.

Results: Adolescents' ages were 13–18 years old (45.3% female). Parents were mostly between 35 and 55 years old (84.9% female). The increased time spent with family members was judged positively by 27.2% of parents and by 64.2% of adolescents. Concern for their child's disability was expressed by 47.3% of parents, while 73.6% of adolescents expressed concerns for the ban on meeting friends. Anxiety symptoms in both groups were correlated with fear of contracting COVID-19 and economic difficulties. The burden of daily management and concern for the future was significantly higher among parents of children with cognitive disability. Parents claimed increased remote support by school and health professionals, even though such measures were carried out for 60% to 70% of the participants. Adolescents' concerns were regarding social and recreational activities.

Conclusion: Socioeconomic measures, implemented assistive technology and telerehabilitation strategies appear crucial to support families and adolescents with disability.

#### Poster presentation 111

## What if 'Early' is too late? Supporting the theoretical perspective of 'On Time Mobility' in early childhood intervention

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Introduction: Throughout the world, early intervention is considered a hallmark of support and services for young children with disabilities. However, when considering 'early' use of augmented mobility, beliefs about disability and walking, practice priorities, design, and policy have resulted in dichotomous decision-making about the use of mobility devices, and consistent delays or barriers to access for children under 5 years old. The novel perspective of 'On Time Mobility' rejects this notion of 'early' and challenges professionals and caregivers to consider a multi-modal mobility approach at developmental ages and stages consistent with experiences of children without disabilities. 'On Time Mobility' calls for a critical examination of how mobility is defined, the timing of mobility support, the role of a multi-modal approach, and the importance of shifting both our language and actions to truly facilitate equitable participation, socialization, and exploration through mobility for children with disabilities.

Patients and Methods: This perspective focuses on developing and implementing effective and varied mobility solutions for children with mobility delays or disabilities in the first two years of life.

Results: 'On Time mobility' has the potential to drive the design and manufacturing of more high and low tech opportunities to

support mobility in the first two years of life, achieve wider access

to such technology, and support the emergence of agency, self-efficacy, and participation for children.

Conclusion: This novel perspective, based on current research evidence as well as decades of clinical mobility intervention experience, supports every child's right to self-initiated mobility along a developmentally appropriate continuum.

#### Poster presentation 112

#### Experience of using PEDI-CAT as an evaluation of functional changes in children with cerebral palsy following selective dorsal rhizotomy surgery

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Introduction: Selective dorsal rhizotomy (SDR) is a procedure for children with cerebral palsy (CP) which aims to permanently reduce spasticity in the lower limbs. The Paediatric Evaluation of Disability Inventory - Computer Adaptive Test (PEDI-CAT) is an assessment tool which measures functional performance in domains of Daily Activities, Mobility, Social and Cognitive skills. The aim is to share our experience of using the PEDI-CAT to measure functional changes in children with CP following SDR. Patients and Methods: The PEDI-CAT was administered with children with CP of Gross Motor Classification System (GMFCS) level II and III. The assessment was completed as a parent interview by the occupational therapist to yield additional subjective information. Scores of 28 children pre and 1 year post-surgery were reviewed using the Daily Activities and Mobility domains of the PEDI-CAT. The results were reviewed alongside parental report of functional changes and other clinical assessments.

Results: The PEDI-CAT is a quick and easy to use tool. It takes approximately 15 min to administer the content balanced options for daily activities and mobility domains. The initial findings suggest that assessment scores were not always consistent with subjective parental report of functional changes. For some children PEDI-CAT scores decreased although clinical assessment indicated functional improvements.

Conclusion: The PEDI-CAT is easy to administer and measures a degree of change in this population. However, some results do not consistently match the clinical and parent reported outcomes. The suitability of PEDI-CAT in this population needs to be explored further.

#### Poster presentation 113

#### Postural balance neurorehabilitation through hippotherapy in children with cerebral palsy: Kinetic and electromyographic evidence

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Introduction: we aimed to assess the short- and mid-term effect of hippotherapy on both dynamic postural balance and contractile properties of two key postural muscles during functional sitting in patients with moderate-to-severe sensorimotor impairment after cerebral palsy.

Patients and Methods: A first protocol was conducted to obtain a proof of principle of the short-term postural improvement. Five patients aged  $15.4 \pm 6.1$  years old were recruited. Ten minutes on a horse simulator followed by 20 min hippotherapy session were conducted weekly for 5 weeks. We analyzed the displacement of the Center of Pressure (COP) on the sitting surface of the simulator's saddle by means of a customized pressure pad. A second protocol was conducted to appraise the mid-term postural improvement. It consisted of 30-min hippotherapy sessions biweekly for 12 weeks. Eighteen patients aged  $18.1 \pm 5.7$  years old were recruited. Surface electromyography (EMG) was implemented bilaterally in rectus abdominis and adductor magnus. We quantitatively analyzed the EMG signals in the time domain and their spectral characteristics in the frequency domain.

Results: Analysis revealed: (1) at short-term, a significantly improved postural control both intra-session and from first to last session; (2) at mid-term, a more selective recruitment and contractile properties' shift of the examined muscles.

Conclusion: Hippotherapy allows a fast setting of postural rehabilitation with significant patterns' reshape and sustainable functional neuromotor changes at any stage of the pathology. The present study provides reliable quantitative data supporting the body of scientific evidence making hippotherapy the approach of choice for neurorehabilitation of cerebral palsy.

#### Poster presentation 114

#### Using interpretative phenomenological analysis (IPA) to understand the lived experiences of parents of children with neurodevelopmental conditions

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Introduction: Common manifestation in children with neurodevelopmental condition is emotional behavioural and communication difficulties which adversely affects the child's performance. Parents of such children face a lot of difficulties in their daily life in order to tackle these issues. Thus, parents go through a lot of negative streams related to the child, self, their society and childparent interaction throughout the intervention of their child. The present study unravels the lived experiences of parents as they continue engaging in an early intervention program (EIP). The focus here is to unfold the parents probable ongoing changes in the perspective of child behaviour, their own lifestyle and lastly there decision making process.

Patients and Methods: Mothers of four children who have been engaged for minimum of 6 months of intensive early intervention in the Child Development Centre for the neurodevelopmental condition of their children were interviewed. Semi-structured interviews were conducted by audio taping the sessions with consent from the parents. The sessions were transcribed, analyzed and interpreted by all the authors.

Results: Analyzing the interviews with interpretative phenomenological analysis (IPA), we saw that mothers reported significant positive changes in child's behaviour. They also stated that engagement in the program and working intensively with the child on a structured basis is enriching and satisfying psychologically. However, they reported a significant change from their

previous lifestyle to accommodate in the EIP. Also, the mothers reported reluctance to participate in social situation with their child due to their child's 'otherness'.

Conclusion: Results indicate the need to develop strategies to empower parents to be more self sufficient in handling children on their own.

#### Poster presentation 115

# Sensory integration program approach with animal assisted therapy dog with children diagnosed autism spectrum disorder

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Introduction: A significant number of children face challenges such as processing and integrating environmental stimuli. Difficulties in sensory processing and sensory integration are frequent differential diagnoses of various disorders and are among the diagnostic criteria for autism spectrum disorder (ASD). Positive outcomes of programs to encourage sensory integration in children with ASD in reducing self-stimulating behavior and enhancing functional behaviors, such as social interactions and play were found. In addition to standard scientifically based methods in dealing with persons with ASD, experts are opening up to other supportive interventions and animal-assisted intervention (AAT) is gaining importance.

Patients and Methods: To explore an AAT dog's support, a Sensory Integration Therapy Program in which an AAT dog was included was designed for children with ASD. Changes in behavior were monitored by showing the frequency of interaction in the presence of a dog, the frequency of purposeful activities, and the responses to tactile experiences in the children. The study included children diagnosed with ASD (N15), with an average age of 8 years, who were enrolled in a Program 1 to 2 times a week at the Silver Rehabilitation Center.

*Results*: Frequences of observed behaviors, under a given hypothesis in all the three measurements, and correlation to determine the dog's association with responses on tactile experiences in children with ASD were calculated.

Conclusion: Positive changes in the frequency of interactions with the dog; interactions with therapist and others; the initiation of purposeful activities; tactile responses interacting with dog and better score on the tactile processing scale were found.

#### Poster presentation 116

# Insights into the social, medical and legal aspects of management of domestic violence during the Covid-19 pandemic in Moldova

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Introduction: Violence against women and children is a violation of human rights and a major social and medical problem in public

health. The number of calls from victims of violence is registered by the police and NGOs.

Patients and Methods: The relevant (public and private) interagency support mechanisms for victims, before and during Covid-19, have been studied through a descriptive analysis of the available registrations from the police, NGOs, and the Hotline for Women and Girls. This research involved examining social, legal and medical aspects of victims.

Results: During the Covid-19 period, call volume increased by 30% (n=247 vs 162 in 2019: Hotline for Women and Girls), with 66 cases, where the police failed to provide assistance. The police reported that urban areas alone experienced a 35% increase in violence calls, and a 15% increase in emergency restraining orders (n=3650). Unenforced restriction orders increased by >49% (n=453) and repeated calls from victims were 51% in 2020 vs 28% in 2019. The NGO, La Strada Moldova reported a three-fold increase in children sexual abuse.

During the Covid-19 lockdown, hospitals restricted planned visits and suspended home-visits. Children with disabilities are at a high risk because they are limited in their ability to communicate about their experiences. The relevant authorities worked on a remote or part-time basis, which limited contact with victims. *Conclusion*: The public health emergency response has been insufficient in ensuring case management and alternative emergency care solutions during the Covid-19 pandemic, particularly affect-

#### Poster presentation 117

ing children with disabilities.

# Reliability of 3D kinematics and electromyography measurements of newly-acquired gait in toddlers with typical development and unilateral cerebral palsy

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Introduction: The aim was to determine the intersession and intertrial reliability and to assess three sources of variability (intersubject, intersession and intertrial) of lower limb kinematic and electromyographic (EMG) variables during gait in toddlers with typical development (TD) and unilateral cerebral palsy (UCP) (age <3 years, independent walking experience ≤6 months).

Material and Methods: Gait kinematics and surface EMG were recorded in 30 toddlers, 19 with TD and 11 with UCP, during two 3D motion capture sessions. The sources of variability were estimated (standard deviation) and the standard error of measurement (SEM) was calculated.

Results: Sixty-four percent of kinematic SEM-values were acceptable (2° to 5°). Measurements in the frontal plane were the most reliable. For toddlers with UCP, the EMG variables were most reliable for the distal muscles of their affected side. Intrinsic (intertrial and intersubject) variability was high, reflecting both motor immaturity and the high variability of toddler gait patterns;

and was amplified by the motor impairment and the delayed motor development in toddlers with UCP.

Conclusion: 3D gait analysis and surface EMG are partially reliable tools for use in clinical practice and research to study individual gait patterns in toddlers, although caution must be taken when interpreting some variables. Further research is needed in order to optimize the recording methods and limit measurement errors for toddlers: adapting the equipment to their anatomical particularities, developping a specific, validated kinematic model and protocols to overcome the normal behavioral limitations of assessing such very young children.

#### Poster presentation 118

#### Broadening the scope of healthcare for children and voung people with cerebral palsies over time: A prospective, longitudinal, population-based study K HORRIDGE, D GAVIN

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Introduction: Not so long ago, the focus of healthcare for children with cerebral palsies (CP) was on 'fixing' body structures, with regular 'birthday syndrome' orthopaedic surgery. As the definitions of disability and cerebral palsies have evolved, has the healthcare for these children kept up? This study aimed to describe variations in assessment, interventions and outcomes for children with cerebral palsies over time. Primary outcomes: subcategorised hospital admissions against the narrative of health care delivery model evolution, informed by consultation with families. Secondary outcome: number of complete hip dislocations identi-

Patients and Methods: Oct 2005 to March 2006 clinicians and families of children with CP reflected on the patient journey for children with CP, including in-depth family interviews. Data routinely collected since 1990 about the needs and hospital admissions of children with CP were interrogated.

Results: Based on qualitative patient journey work, the care pathway for children with CP was redesigned: all children with CP were offered multidisciplinary, 'one-stop-shop' clinics where all of their needs, child-and-family goals and possible interventions were considered.

From quantitative data, evidence of reduction in admissions for bony and soft tissue surgery over time, with increase in day-case admissions for botulinum toxin injections and MRI investigations. In the birth cohort 1987 to 2002, seven children had complete hip dislocations; this reduced to zero in the 2003 to 2016 cohort. Families reported preferring multidisciplinary clinics, evidenced by excellent attendance rates.

Conclusion: Collaboration with family service-users can lead to productive changes that improve experiences and outcomes for children with CP.

#### Poster presentation 119

#### Transition care pathways for young people built on population data evidencing complexity of needs

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Introduction: If health needs of disabled adults are to be adequately met, they must first be accurately identified and documented for children and young people (CYP), with clear arrangements as to how all needs are to be addressed, including who is responsible for leading clinical care.

Patients and Methods: Data capture is embedded at the point of care in Sunderland paediatric clinics. These underpin care pathway design, including on transition to adulthood. Identification of learning disability (LD) is prioritised. Joint paediatric-neurorehabilitation transition clinics have been held for 20 years. Collaboration with LD and adult palliative care teams has supported young people with the most complex needs through transition.

Data from birth years 1997 to 2003 were analysed. Complexity of needs was calculated using the Disability Complexity Scale.

Results: For 756 YP aged 17 years+, lead for adult healthcare was identified as: routine general practitioner (GP)-led care for 484; enhanced GP care, with annual LD health checks, for 183; epilepsy neurology clinic for 62; regional neurofibromatosis service for 5; neurorehabilitation service for 93; adult palliative + LD multidisciplinary team care for 9.

All young people on the palliative pathway had 11+ needs, with a higher burden of technology dependencies compared to other groups.

Conclusion: Population data evidencing increasing complexity of needs of disabled young people approaching transition to adulthood led to redesign of care pathways. Population data evidence equality of access to these care pathways for all young people with the same level of needs.

#### Poster presentation 120

#### Hip displacement in hypertonic versus hypotonic neuromuscular diagnoses: Comparison of cerebral palsy and spinal muscular atrophy

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Introduction: Hip displacement (HD) is common across neuromuscular disorders, but the impact of muscle tone on its development is controversial. The purpose of this study was to compare the changes in hip morphology for cerebral palsy (CP, hypertonic) and spinal muscular atrophy (SMA, hypotonic), to determine the influence of muscle tone on the development of HD.

Patients and Methods: Case-control study. Children with SMA (Types I,II) and CP (GMFCS IV-V) who developed HD (MP > 30%) were included. Outcomes included proximal femoral physeal tilt by head shaft angle (HSA), migration percentage (MP), acetabular index (AI), analyzed at ages: T1 (1-2.5 years), T2 (3-5 years), T3 (6-8 years).

Results: Sixty patients (CP, N = 41 [52 hips]; SMA, N = 19 [37 hips]) met the inclusion criteria. HSA remained high for both CP and SMA, but changes between T1, T2, T3 were not significant (NS). MP for T1, T2, T3 for CP and SMA was 23%, 36%, 45% (p < 0.01), and 37%, 57%, 61%, respectively (p = 0.02). Regression analysis showed significant increases in MP by age for CP (r = 0.41, p < 0.001), but not for SMA (r = 0.18, p = 0.09). AI increased linearly with MP for both diagnoses (CP: r = 0.41, p < 0.001; SMA: r = 0.48, p < 0.001), but not with HSA. HD occurred earlier in SMA (34 months) than CP (49 months)

Conclusion: Persistent lateral physeal tilt may represent a more unifying mechanism of HD, causing coxa valga and secondary acetabular dysplasia, with muscle weakness a possible cause of this abnormal physeal alignment. Strategies aimed at early modulation of physeal growth may be warranted to help prevent HD.

#### Poster presentation 121 Hip displacement in MECP2 disorders: Prevalence and risk factors

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Introduction: Hip displacement (HD) in MECP2 disorders including Rett syndrome (RS) and MECP2 Duplication Syndrome (MDS) - is thought to be common, but little has been reported. The purpose of this study was to report the prevalence and risk factors associated with the development of HD in MECP2 disorders.

Patients and Methods: Case-control study. Children with a genetically-confirmed diagnosis of MECP2 disorder were included. Outcome measures included the prevalence of HD (migration percentage (MP) >30%), age at HD onset, ambulatory status, scoliosis (>40° and/or surgery), genetic severity, presence of seizures, associated comorbidities. Analysis of proportions of categorical variables was performed using Chi-squared testing (p< 0.05).

Results: Fifty-six patients (RS: n = 54, MDS: n = 2) were included, with age at diagnosis 6.6 (SD: 4.7) years. Thirty-five (62%) patients were non-ambulatory and 21 (38%) were ambulatory, at a mean final follow-up of 4.5 (SD: 4.9) years. The prevalence of HD was 35.7%, with a mean age of onset of 7.7 (SD: 3.8) years. Significant risk factors for the development of HD were: non-ambulatory status (p=0.04), presence of clinically-relevant scoliosis (p=0.001), and the presence of seizures (p=0.04).

Conclusion: The prevalence of HD in MECP2-related disorders is comparable to cerebral palsy. Also similar, risk factors for HD in MECP2 disorders are associated with proxy measures of disease severity, most notably ambulatory status and clinically significant scoliosis. The results of this study can be used to inform the development of hip surveillance programs for the early detection of HD for children with MECP2 disorders, allowing for timely management.

#### Poster presentation 122

#### Translation and adaptation of the Gross Motor Function Measure-88 (GMFM-88) to the Croatian

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Introduction: The Gross Motor Function Measure-88 (GMFM-88) is a standardized observational instrument measuring gross motor function for children with cerebral palsy (CP) and Down syndrome (DS). Despite the growing interest of Croatian clinicians in using this measure, the GMFM-88 has not yet been translated and tested in Croatian. The aim of this research was to translate and adapt the GMFM-88 to the Croatian language.

Patients and Methods: We followed the first five steps of the Sousa & Rojjanasrirat (2010) guideline for the language translation and adaptation of the GMFM-88 to Croatian. Two authors independently translated the score sheet from English to Croatian (forward translation). The third author independently performed backward translation, which was checked and iteratively revised in consultation with the original measure's author. Once approved we recruited 7 clinicians to test the pre-final version of the translated measure through cognitive debriefing.

Results: Most suggestions were related to the word order or shortening of the translated item. Some participants identified unintentionally omitted words that were important for understanding. Participants pointed out the importance of the consistent use of terms throughout the measure. Seventy two of 88 items were changed.

Conclusion: With this research, we have initiated the adaptation of the GMFM-88 to Croatian. In order for the measure to be fully validated in the Croatian language, it is necessary to continue with the psychometric testing of the measure in children with CP and DS in Croatia.

#### Poster presentation 123

#### The effect of bimanual intensive functional training on sensory hand function in children with unilateral spastic cerebral palsy

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Introduction: While motor impairments are the hallmark of children with unilateral spastic cerebral palsy (USCP), they may also experience tactile impairments. The effects of intensive bimanual training on improvement of motor abilities have been abundantly shown, however, the effects on the sensory system are less known. This study investigates whether bimanual intensive functional therapy without using enriched sensory materials improves sensory hand function.

Patients and Methods: Twenty-five children with USCP (11-17 years) received 90 h intensive functional training aimed at improving individual bimanual treatment goals. Sensory hand function was measured prior to training (t1), directly after training (t2) and at 6 months follow-up (t3). Outcome measures consisted of: perception of thumb and wrist position; thumb localisation task; vibration sensation; monofilament task; and stereognosis.

Results: While improving on their individual treatment goals, the participants also showed significant improvements in vibration sensation, the monofilament task and stereognosis of the more affected hand after training. These improvements concerned the amount of vibrations as well as the intensity of vibration, a decrease in distance between pressure points and better object recognition. The improvements were retained at 6 months follow-up. Perception of thumb and wrist position and the thumb localisation task showed no improvement after training.

Conclusion: Intensive functional bimanual training without environmental tactile enrichment improved pressure and vibration sense and stereognosis of the more affected hand in children with USCP. Proprioception of the hand does not seem to be sensitive to change as a result of this training.

#### Poster presentation 124 Enable Ireland's YouTube channel

M JOHNSTON

Enable Ireland, Ireland

Introduction: Enable Ireland is one of Ireland's leading disability service providers. As a result of the Covid-19 pandemic and recurring lockdowns, face to face interventions were put on a hold.In an effort to bridge the gap between remote therapy and home practice while maintaining motivation of service users and families - an initiative to create home-made therapy and education videos was born.

Patients and Methods: Through the formation of a National Video Content group, therapists were educated on how to create standardised therapy and education video. Videos were created using phones, cameras and laptops for specific clients eg, therapy with specific handling techniques and also created to be suitable for a larger cohorts eg. active school aged children.

Results: Using YouTube as a platform, videos were shared via email and accessible to service users and the public. Families had previous experience of technology use for home schooling which allowed for easy access to the videos. Therapy and educational videos covered topics from physiotherapy, occupational therapy, social work, psychology and speech and language therapy. Family feedback from surveys informed that video was preferred and better adhered to when compared to written documents for home therapy programmes when provided remotely.

Conclusion: It is aimed that with the future creation of video by Enable Ireland staff and students, a comprehensive National Video Library will be available. Video creation has opened the doors for expanding the use of online learning and communication via Webinar and Tele Health as options beyond the pandemic.

#### Poster presentation 125

#### A cost effective innovative solution for sleep disorder in children with neurodevelopmental disability during Covid-19 pandemic — A longitudinal

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Introduction: During Covid-19, the effect of cost effective, innovative two-step sleep counseling sessions (called sKDM) conducted and reviewed online, in different time intervals with sleep disorder in children with neurodevelopmental disability is studied. sKDM means the Sleep Module of Kolkata Developmental Model (KDM).

Patients and Methods: Children with neurodevelopmental disability having sleep difficulties were picked up from developmental history since May 2019. Parents were given an online sleep counseling after completion of the parent training program called Program of Care (PoC) duringCoid19. Sleep reviews were done online at intervals of 2 weeks, 3 months and 6 months following KDM's standard sleep counseling to find out whether the child is able to maintain healthy sleep and wake up cycle.

Results: Results when compared with pre-Covid children's data shows major disturbances in sleep were dramatically reduced in the sleep initiation time and wake up phase at the end of 2 weeks and the positive effects were continued throughout the Covid period measured at 3 months, 6 months, and ongoing, even when there were obvious changes in child's lifestyle due to worldwide pandemic situation.

Conclusion: With the online mode and successive follow-ups, sKDM continues to be a smart and cost effective online intervention strategy for children with disability preventing further downward spiraling even when the world is changing at such a speedy pace. Since sleep disorders are comorbid conditions in neurodevelopmental disorder, our sKDM should be followed imparting a quick favorable clinical outcome of an otherwise difficult comorbid condition.

#### Poster presentation 126 Pain in adolescents with cerebral palsy; a longitudinal population-based study

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Introduction: Pain is a major challenge in care for the pediatric population with cerebral palsy (CP). Still, longitudinal studies on pain are lacking. The aim of this study was to investigate the prevalence and characteristics of pain in adolescents in a CP surveillance program and compare the results with findings five vears earlier.

Patients and Methods: Sixty-seven adolescents, (28 females; mean age 14 years 7 months; SD 1 year 5 months) with bilateral CP, GMFCS levels III to V were reassessed on pain. Primary caregivers marked recurrent pain sites on the body outline from the Brief Pain Inventory and responded to the two questions on pain interference with daily activities and sleep and to the questions on pain intensity and frequency from the Child Health Questionnaire (CHQ), transformed to a CHQ pain score (100 is no pain).

Results: Over a 5-year period the number of participants with recurrent pain increased from 45 to 62 (p< 0.001), and the mean number of pain sites increased from 1.9 to 3.4 (p< 0.001). The increase was statistically significant for pain in the neck (p=0.006) and the lower limbs (p< 0.001). Pain intensity and frequency increased (both p < 0.001), and mean CHQ pain score decreased from 65 (SD 29) to 44 (SD 27), (p< 0.001). Pain interference increased for daily activities (p=0.019), but not for sleep.

Conclusion: Pain prevalence, intensity, frequency and interference with daily activities all increased over five years in a pediatric population with CP despite follow-up in a CP surveillance program. An algorithm for pain management should be included in CP surveillance programs.

#### Poster presentation 127

#### Adaptation of the Walking Corsi Test (WalCT) for 2and 3-vear-old preterm and term-born toddlers

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Introduction: To determine whether adapted versions of the Walking Corsi Test (WalCT) to measure topographical memory can be used in 2- and 3-years old toddlers born at term (T) and preterm (PT).

Patients and Methods: The original WalCT was adapted to 20 T and 13 PT toddlers (27.74 months: SD = 5.13 months). Two versions were designed to simplify instructions and increase motivation: Adapted (AWalCT) and Treasure WalCT (TWalCT). During these tests, we mainly measured if toddlers could start the task (S) and the maximum sequence span they obtained (SS). Attention was evaluated by using the Teddy Bear Cancellation Test (TBCT).

Results: Binomial tests showed that not all toddlers could initiate AWalCT. While 2-year-old TD toddlers tried to perform the task in the 83% of the time (p=0.039 in the Binomial Test, Bayes Factor BF = 3.8), only 22% 2-year-old PT did it (p=0.006,BF = 15.05). PT showed less attentional level than their peers demonstrating an inverse moderate to strong correlation with the starting of the task at AWalCT (-0.714). On the other hand, both groups could start TWalCT but there were still significant differences in topographical memory variables (p=0.014, BF = 4.76). 3years-old TD group achieved a greater SS than the younger group (1.08 to 2.00; p = 0.001, BF > 100).

Conclusion: The ability to start AWalCT is related to the level of attention in 2-and 3-year-old toddlers, not been useful to study topographical memory in PT with lower attention. TWalCT, by increasing motivation, can be used to study topographical memory and detect differences between groups.

#### Poster presentation 128

#### Sleep disturbances experienced by children with cerebral palsy in Northern Ireland and their impact on the family

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Introduction: This study aimed to describe the sleep disturbances experienced by children with cerebral palsy (CP) in Northern Ireland (NI) and understand the impact on parents/caregivers and siblings.

Patients and Methods: A cross-sectional online survey was conducted. Questions pertained to the child's CP, family sleep and the Sleep Disturbance Scale for Children (SDSC), Caregivers of 112 children with CP aged 3-18 years participated. Data were analysed descriptively. Characteristics of the sample were compared to the NI CP register to ascertain representativeness.

Results: Significant sleep disturbance (SDSC score >70) was reported for 70% (78/111) of the sample. Disorders of initiating and maintaining sleep were most commonly reported (78%, 87/ 111). The sample was 63% (71/112) male; mean age 8.8 years (range 3-18), 62% (69/112) had spastic CP and 37% (42/112) were classified as GMFCS IV/V. No significant differences between the sample and individuals known to the NI CP register were identified, with the exception of age. Most caregivers (86%, 96/112) reported experiencing sleep disturbances such as sleeping <7 h per night (70%, 78/112) or providing night-time support to their child with CP (52%, 58/112). Sixty parents (54%) reported that sibling sleep was unaffected, although 7% of siblings provided night-time assistance to their sibling with CP (7/112).

Conclusion: Sleep disorders are common in children with CP, yet the very high prevalence of sleep disorders in this representative sample is concerning; as is the subsequent impact on parents. Further investigation and consideration of dedicated support services for this population are justified.

#### Poster presentation 129

#### Awareness of developmental coordination disorder: A cross-disciplinary and cross-national comparison EJ MEACHON, H MELCHING, GW ALPERS

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Introduction: Developmental coordination disorder (DCD) is a complex condition that often occurs but is not widely known. Substantial information gaps about DCD have even been reported for clinicians. This gap may be particularly wide outside of Anglo-Saxon countries. In addition, comparisons of symptomatic knowledge between DCD and similar neurodevelopmental disorders (e.g., ADHD) have not been described in detail. Therefore, the current study presents a comparison of general awareness, treatment experience, and specific features of DCD and ADHD across clinical professionals in German- and English-speaking countries.

Patients and Methods: A total of 346 clinicians (psychologists, occupational therapists, physical therapists, medical practitioners) practicing in German- (n=261) and English-speaking (n=85) countries participated in the online study.

Results: Overall, 95% were familiar with ADHD, but only 58% were aware of DCD. Furthermore, 68% had diagnosed or treated patients with ADHD while 42% had this experience with DCD

patients. While this did not differ between German- and Englishspeaking professionals, English-speaking professionals were more aware of specific DCD features (e.g., adulthood; social and physical relevance). In addition, the reported difficulty and frequency of treating patients with DCD significantly differed by occupation. For example, occupational therapists rated DCD as the hardest to treat but had the most expertise on this condition, while the opposite pattern existed for psychiatrists who were also less accurate about DCD features.

Conclusion: The results generally indicated that clinicians in the sample knew more about ADHD than DCD. The study highlights a concerning knowledge gap about specific features of DCD, especially between German- and English-speaking clinicians.

#### Poster presentation 130

#### Resting state waveforms in adolescents with developmental coordination disorder and attentiondeficit/hyperactivity disorder: An EEG study

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Introduction: Developmental coordination disorder (DCD) and attention-deficit/hyperactivity disorder (ADHD) co-occur in up to 50% of cases, but little is known about the differences in neural mechanisms of these conditions. There is especially limited evidence to indicate if neurophysiological differences are present between DCD and ADHD in rest-state activity. Therefore, we conducted a pilot EEG study to assess waveform differences at rest in groups of adolescents with DCD, ADHD, both conditions (DCD+ADHD) and no health conditions.

Patients and Methods: A total of 38 adolescent and young adult participants (age: M = 18.4; SD = 4.7; Range = 10-24) completed two 120 second rest phases (eyes open and eyes closed) while EEG was measured at 64 electrode sites. Global Field Power (GFP) analyses were conducted for frontal electrodes at various waveforms (alpha, beta, theta, gamma, mu).

Results: Analysis of variance for average GFP indicated that prefrontal activity for several waveforms (alpha, beta, theta) differed by group. More specifically, differences in alpha and beta waveforms were driven by the DCD versus ADHD groups such that alpha activity was higher for those with ADHD and beta activity increased for the DCD group.

Conclusion: Increased alpha activity is often associated with hyperactive states, a major symptom of ADHD relevant to this group in the present study. In addition, heightened beta activity in the DCD group might reflect increased focus to suppress motor functions. Overall, the results indicate there are symptom-relevant patterns for DCD versus ADHD observable at rest in adolescents.

#### Poster presentation 131

#### The associations between the functional profile of ambulatory children with cerebral palsy and their home and community participation

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Introduction: Children with cerebral palsy (CP) often have difficulties engaging in everyday activities. Participation and its optimization have been recognized as a relevant outcome in disability studies. This study aimed to investigate the association between the functional profile of ambulatory children with CP and their participation in home and community.

Patients and Methods: A convenience sample included sixty-five children with CP aged 7-18 years, GMFCS levels I-III (33 males; 22 diplegia; mean age: 12 years 10 months, SD: 3 years 3 months; GMFCS I: n = 14, II: n = 29, III: n = 22). To collect the data on home and community participation (diversity, frequency, involvement level), the Participation and Environment Measure for Children and Youth (PEM-CY) was used. The functional profile included data on the gross motor (GMFCS), fine manual (MACS) and bimanual abilities (BFMF), functional independence (Wee-FIM), the category of intellectual functioning, communication and social skills (both rated on a six-point ordinal scale). Partial correlation coefficients were calculated (environmental supportiveness and family income controlled).

Results: Except for the gross motor functioning, the functional profile was associated with the diversity of home participation and involvement level. Considering community participation, only fine manual and bimanual functioning, functional independence, communication and social skills correlated with the level of involvement. The highest correlations were noted between the functional independence and involvement in both home (r = 0.533,p < 0.001) and community settings (r = 0.438, p < 0.001).

Conclusion: It is necessary to reconsider the role of functional profile in order to further understand the possibilities of optimizing home and community participation of ambulatory children with CP.

#### Poster presentation 132

#### Promoting physical activity (PA) and healthy habits via telehealth in adolescents with a physical disability during COVID-19: A service review M MURPHY, A COOPER

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Introduction: Historically face-to-face group intervention provided through the CRC focused on increasing PA levels to enhance community participation. Due to COVID-19 face-to-face groupbased physiotherapist-led intervention (GBPLI) ceased and hence rapid adaptation to telehealth was undertaken in our service. Research has shown that adolescents with physical disabilities have reduced PA compared to peers and recent WHO PA guidelines (2020) included adolescents with a disability. Evidence for GBPLI and telehealth-based interventions is limited for adolescents with physical disabilities. This service review describes a group-based telehealth intervention and compares attendance to face-to-face group therapy.

Patients and Methods: GBPLI held via Microsoft Teams over 4 weeks using a combination of physical activity and health education. Eligibility criteria: diagnosis of a physical disability, independent ambulation, aged 11-17 years , (n=20). Participants completed an online survey following the group.

Results: Average attendance was 70% which compared to 61.25% attendance in previous face-to-face groups. Eleven completed the online survey. While 27% expressed a preference for virtual groups, all participants said they would consider attending another telehealth group. 31% of participants had their camera off during sessions, due to technology issues and concerns over privacy. 45% of participants felt encouraged to be more physically active following intervention.

Conclusion: GBPLI promoting PA via telehealth is a worthwhile intervention for adolescents with physical disabilities. Barriers including access to technology and privacy concerns need addressing. Qualitative parent feedback was overwhelmingly positive and continued service delivery via telehealth was encouraged. An objective measure of participants PA levels would provide further information on impact of the group on overall PA levels.

#### Poster presentation 133

### A pilot study of wearable motion sensors to guide physical therapy in children with cerebral palsy CJ NEWMAN, CN GERBER

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Introduction: Children with cerebral palsy (CP) rarely achieve the recommended level of daily physical activity. As an objective evaluation of motor performance in daily life, wearable motion sensors (WMS) detect patterns of activity and barriers and facilitators amenable to improvement. We investigated the clinical utility of WMS to guide therapy in children with CP.

Patients and Methods: Thirteen children with CP wore inertial sensors at baseline (week 0), at pre- (week 4) and post-intervention week 8) and follow-up (week 12). Their physiotherapists were supported to develop a training plan integrated in their patient's daily routine based on the sensors baseline physical activity outputs. Clinical utility of WMS was assessed by visual analogue scales (0–100) for children, caregivers and therapists, and by prepost- comparisons of activity measurements.

Results: Children were satisfied with the sensors (mean VAS 87.4) but experienced tiredness (VAS 53.4) during the training. Caregivers found the sensors useful (VAS 77.4) and 9/13 noticed an improvement in their child's physical performance. All therapists would consider implementing sensors in their practice (VAS 82.0) but scored their usefulness as average (VAS 66.0). Four children demonstrated significant and sustained improvements in daily time spent walking after training. Despite a better view of children's habitual physical activity with sensors (mean 70.0), physiotherapists had difficulty devising their training programme (VAS 49.0).

*Conclusion:* Several physiotherapists faced difficulties in adapting existing therapy according to sensor outcomes. The implementation of wearable sensors into clinics to guide therapy will require further adaptations to increase their relevance.

#### Poster presentation 134

Parents' and clinicians' perspectives on the 'Enabling VISions and Growing Expectations (ENVISAGE)' support program for parents of children with disabilities

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Introduction: ENVISAGE is a novel, 5-workshop program for parents of children with disabilities. It is designed to empower

parents to build self-efficacy, autonomy and sense of competence. It also provides opportunities to connect with other parents. The program was developed and tested in Canada and Australia; however, it was still unclear whether these ideas would be accepted in other cultures and languages. This pilot study aimed to explore parents' and clinicians' perspectives on the content and proposed mode of delivery of ENVISAGE: its comprehensibility, acceptability and usability for parents of children with disabilities living in Croatia. We also explored the feasibility of delivering the program in Croatia.

Patients and Methods: In this exploratory sequential mixed-method study, we recruited parents of children with disabilities (n=8) and professionals working with families of children with disabilities (n=7). They independently reviewed ENVISAGE materials, completed a series of surveys and participated in an optional individual interview. Quantitative data were analyzed using descriptive statistics and qualitative data were analyzed using qualitative content analysis.

Results: In this presentation, we will report the lessons we have learned throughout the cross-cultural intervention translation and adaptation process of ENVISAGE. We will also provide preliminary results on how parents and clinicians perceived the intervention. Our interim analysis showed that most participants thought that ENVISAGE is a comprehensive and acceptable intervention for families living in Croatia. With only minor revisions needed, this intervention can be further explored and implemented in Croatia.

#### Poster presentation 135

### Family centered care in children with cerebral palsy: A perspective from a developing country

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Introduction: The aim the study was to evaluate the care processes in terms of family centered care (FCC) in children with cerebral palsy (CP) from parental perspective in non-western developing country.

Patients and Methods: 215 children with CP age between 5 and 17 years (mean 9.63  $\pm$  3.24) and their parents were included to study. Children were classified according to the Gross Motor Function Classification System (GMFCS). Measurement of Process of Care-56 (MPOC-56) was used to evaluate FCC which has 5 subdomains: enabling-partnership (EP), providing-general-information (PGI), specific-information-about-child (SI), coordinatedcomprehensive-care (CCC), respectful-supportive-care (RSC) scored range between 1-7 and completed by parents of children. Data gathered from 3 main centers: public hospitals (PH), private medical centers (PMC) (covered by social insurance), special education-rehabilitation centers (SER). Data statistically given as mean  $\pm$  standard deviation, number, percentages. The different between groups were analyzed with the Mann-Whitney U test. Results: Distribution of number children with CP according to GMFCS levels; I: 30 (14%), II: 66 (30.7%), III: 46 (21.4%), IV: 54 (25.1%), V:19 (8.8%). Mean of MPOC-56 subdomains were, EP:  $5.34 \pm 1.17$ ; PGI:  $4.52 \pm 0.9$ ; SI:  $3.85 \pm 1.13$ ; CCC: 4.98; RSC:  $4.96 \pm 1.09$ . For all GMFCS levels the highest score was in EP subdomain (respectively to GMFCS levels:  $5.82 \pm 1.08$ ;  $5.19 \pm 1.08$ ;  $5.29 \pm 1.15$ ;  $5.30 \pm 0.95$ ;  $5.35 \pm 107$ ); the lowest score was in the SI subdomain (respectively to GMFCS levels: 4.46 + 1.26: 3.62 + 1.04: 3.85 + 1.17: 3.84 + 1.12:  $3.67 \pm 0.96$ ). When types of centers compared; SER was significantly higher than PC and PMC in all subdomains of MPOC-56

Conclusion: FCC from parental perspective not differs according to severity of children, on the other hand changed by service providers in terms of centers.

#### Poster presentation 136

Measure of processes of care (MPOC-56 and MPOC-20). Turkish adaptation, reliability and validity study D TURKER<sup>1</sup>, C ÖZAL<sup>2</sup>, S KARAHAN<sup>2</sup>, M KEREM GUNEL<sup>2</sup> <sup>1</sup>Health Sciences University, Istanbul, Turkey; <sup>2</sup>Hacettepe University, Hacettepe, Turkey

Introduction: The purpose of this study was to investigate the validity and reliability of the Turkish versions of the Measure of Processes of Care, MPOC-56 and MPOC-20, in children with disability aged 5-17 years.

Patients and Methods: A total of 290 parents of children with disability due to various disorders were evaluated with the MPOC-56 and MPOC-20. Internal consistency was determined with Cronbach's alpha, and test-retest reliability with the intraclass correlation coefficient (ICC). Confirmatory factor analysis was performed to investigate factor structure of the Turkish MPOC-56 and MPOC-20.

Results: Cronbach's alpha values for the MPOC-56 and MPOC-20 were 0.84 to 0.97 and 0.87 to 0.92, respectively. Test-retest ICC values were 0.96 to 0.99 for MPOC-56 and 0.94 to 0.98 for MPOC-20. The correlations of the subscale scores of MPOC-56 and MPOC-20 were shown to be at the very good to excellent reliability. Factor structure for MPOC-20 and MPOC-56 were found to be acceptable.

Conclusion: This study has shown that the Turkish versions of MPOC-56 and MPOC-20 are valid, reliable, and applicable for the evaluation of parents' experiences of the processes of care of children with disability aged 5-17 years.

#### Poster presentation 137

Functional and neuroplastic changes after a 2weeks motor-skill learning intervention in a child with neurodegenerative ataxia: A case study

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Introduction: Current scientific evidence support motor skill learning-based interventions as effective to improve motor function in children with cerebral palsy (CP), including those with ataxic CP. To our knowledge such intervention has not been performed in children with degenerative ataxia. We aimed to describe the functional and neuroplastic changes of a motor skill learning-based intervention; Hand-Arm Bimanual Intensive Therapy-Including Lower Extremities (HABIT-ILE) in a 4 years old child with degenerative ataxia.

Patients and Methods: Three testing sessions were performed: T0-T1 (baseline period-2 weeks of conventional treatment) vs T1-T2 (2 weeks HABIT-ILE camp). Outcomes were the Gross-Motor Functional Measure (GMFM-66), the Trunk Control Measurement Scale (TCMS), the Melbourne Assessment 2 (MA2), the Both Hand Assessments (BoHA) and the Canadian Occupational Performance Measure (COPM). The Minimal Clinical Important Difference (MCID) was used to indicate significant changes. Furthermore, diffusion tensor imaging was performed at T0 and T2 to quantify DTI metrics of the cortico-spinal tract (CST).

Results: During the baseline period no significant changes were observed for any functional tests. After HABIT-ILE (T1-T2), changes were above MCID for the GMFM-66, TCMS, BoHA, COPM and the MA2 for all subtests excepted fluency. In addition, DTI metrics of the CST improved after HABIT-ILE compared to before camp.

Conclusion: HABIT-ILE seems to be benefic to improve manual ability, trunk and gross motor function in other pediatrics neurological disorder than cerebral palsy, such as degenerative ataxic syndrome. In line with behavioral assessments, neuroplastic changes seem to have occurred after the intervention.

#### Poster presentation 138

#### Vision and motor development in typically developing children: A cross-sectional study

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Introduction: Many studies have established a relationship between visual function and motor development in toddlers. This is the first report to study two-year-olds via an assessment of their visual and motor skills. The purpose of this study is to describe the possible changes that can occur between visual and motor systems in typical developing toddlers.

Patients and Methods: A total of 116 toddlers were included in this observational, descriptive, and cross-sectional study. Their mean age was 29.57  $\pm$  3.45 months. Motor development variables studied were dominant hand/foot; stationary, locomotion, object manipulation, grasping, visual motor integration percentiles; gross motor, fine motor, and total motor percentiles; and gross motor, fine motor, and total motor quotients. Visual development variables were assessed including visual acuity, refractive error, ocular alignment, motor fusion and suppression, ocular motility, and stereopsis.

Results: Our findings demonstrated that typical developing toddlers with slow gross motor development had higher exophoria and further near point of convergence values compared to toddlers with fast gross motor development (p< 0.05). No statistically significant differences were found in visual acuity and stereopsis between slow and fast gross motor development toddlers.

Concluion: Neurotypical developing toddlers and without visual impairment with slow gross motor development had higher exophoria and further near point of convergence values compared with fast gross motor development toddlers.

### Online rehabilitation of children with developmental delay and cerebral palsy in COVID-19 world

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Introduction: Early intervention of children with developmental delay and continuity of rehabilitation of children with cerebral palsy were almost impossible during the COVID-19 spring lock-down and aggravated later when the pandemic was spreading. Intensive rehabilitation according to Stojcevic Polovina is based on training parents on performing specific rehabilitation task and in this situation, we switched to online sessions.

Patients and Methods: We present specialist's observations of online guidance of rehabilitation therapy, performed by parents of children with developmental delay or cerebral palsy.

Results: Online sessions of rehabilitation therapy were challenging for all included: therapists, parents and children. It needed specialists who were well-experienced in educating parents on how to perform therapeutic activities. It was extremely difficult in parents and children that were never seen in person and with whom the specialists were unfamiliar; easier with parents/children that were in therapy for longer time. It also required guiding of the person in charge of filming and guiding of the parent with child in the same time, which was very demanding.

Conclusion: Online guiding of the rehabilitation of children is a way to bridge gap in real-life therapy sessions. However, it comes with lot of limitations and it should be considered only when direct contact is impossible and performed by well-experienced specialists.

#### Poster presentation 140

#### Neurorehabilitation in children with cerebral palsy: Is therapeutic dosage the key? a systematic review G SAUSSEZ<sup>1,2</sup>, E SOGBOSSI<sup>2,3</sup>, Y BLEYENHEUFT<sup>2</sup>

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Introduction: Literature in motor function rehabilitation for children with cerebral palsy recommend the use of intensive interventions to promote larger motor function improvements and transfer in daily life activities. As the number of so-called 'intensive' interventions expands in research and clinical protocols, the aim of this study was to answer the following question: Whatever the rehabilitation content, is a high number of hours (dosage) enough to induce motor and functional improvements?

Patients and Methods: We conducted a systematic review based on Pubmed and Scopus databases, on February 2019, with no restriction of time. Search equation used terms such as: cerebral palsy, intensive therapy, intensive treatment, intensive training, intensive intervention, motor skill learning and constraint induced.

Results: From 1113 trials, we obtained a final number of 69 eligible randomized controlled trials. Participants had unilateral and bilateral cerebral palsy (7 months–30 years, MACS and GMFCS levels I–V) with a total therapeutic dosage from 0 (waitlist control) to 1008 h. The mean PEDRO score was 6 (from 4–8). Studies were classified in three subgroups: (1) different interventions

at different dosage; (2) similar interventions at different dosage; (3) different interventions at similar dosage. Among the tested interventions, we further documented the application of motor skill learning based therapeutic principles.

Conclusion: Although a minimal therapeutic dosage and frequency of sessions might play a role for improving motor outcomes in cerebral palsy, we found the therapeutic principles based on motor skill learning as major elements of such evidence based interventions.

#### Poster presentation 141

# Feasibility and acceptability of home based infant massage carried out by mothers in infants at high-risk for cerebral palsy

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Introduction: Infant massage (IM) could represent a potentially effective early intervention program, aimed to provide a form of environmental enrichment. It is hypothesized that tactile stimulation (parent-infant) can promote neurodevelopment, emotional regulation of behavioural states and parent-infant relationship. Although evidences of effectiveness of IM for promoting the neurodevelopment of preterm babies have been reported, studies on IM in infants with early brain damage are lacking. Based on this background, the main aim of the present study is to assess feasibility and acceptability of IM carried out by the mothers, after a home training, in infants at high-risk for cerebral palsy (CP) (Trial registration: NCT03211533 and NCT03234959).

Patients and Methods: Nineteen high-risk infants with perinatal brain injury, aged  $4.83 \pm 1.22$  months, carried out a 8-week daily IM at home with their mothers. The feasibility of training and study procedures was assessed through criteria derived from literature; acceptability and usability have been analyzed from an ad hoc questionnaire called Infant Massage Questionnaire Parent-Infant Experiences.

Results: The amount of IM was very high, with a daily dosage of  $27.79 \pm 7.88$  min and a total of  $21.04 \pm 8.49$  h in the 8 weeks. All feasibility criteria were achieved, mother compliance to the IM was very good, data collection was completed. The answers to the questionnaire had a total mean score of 82%, with the easy to do area of 77% and 84% in the mother's participation perception.

Conclusion: These preliminary data provide evidence of the feasibility of IM at home in infants at high-risk for CP.

#### Poster presentation 142 Quality of life of primary care givers of children with cerebral palsy-a critical review M SHARMA

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Introduction: Cerebral palsy (CP) is a disability that has complex care requirements and affects the caregivers and family in multiple ways. Efforts have been made by researchers to understand the social, economic and health impact of caring for a child with CP. This review intended to look at the impact of caring for CP on the quality of life (QOL) of the caregivers.

Patients and Methods: Using a predefined search strategy, we were able to identify 31 publications over the 10 year seach period that discussed the QOL of primary caregivers of CP children. A data extraction form was used and quality of each article was assessed using the GRADECERQual approach. Most studies had researched QOL using WHOQOL-BREF, SF-36 and NHP tools. Studies focussed on the mother or primary caregiver and one even interviewed the grandparent.

Results: Most studies reported poorer QOL with greater impact on psychological and physical domains. Severe the CP, poorer were the scores. There were reports of greater fatigue and physical pain amongst caregivers. Depression and anxiety were common mental ailments.

Some studies mention coping strategies and better QOL scores in parents who developed their coping strategies. A healthy marital life was associated with better coping and QOL scores. Most studies mention lack of appropriate social support in care of a CP child. A few studies also report on restricted social life of parents. Inspite of the difficulties, parents mention the enriching experience of caring for a child with CP. It helped parents develop meaningful relationships and develop as advocates for their children.

#### Poster presentation 143

#### Neurological monitoring is safe and effective for children with cerebral palsy undergoing spine fusion

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Introduction: Routine use of intraoperative spinal cord monitoring in children with cerebral palsy (CP) and scoliosis is both challenging and controversial. The purpose of this study was to determine if patients with CP can be appropriately and safely monitored during spine surgery with trans-cranial motor-evoked-potentials (TcMEP), and does this monitoring cause an increase in postoperative seizure activity.

Patients and Methods: This was a retrospective study of 304 patients with CP undergoing posterior spinal fusion (PSF) from 2011 to 2020 at a single children's hospital. Patients were followed postoperatively to determine any increase in seizure activity, and was compared to a control group of similar patients who did not have intraoperative monitoring (p< 0.05 for significance). Results: Of the 304 patients, monitoring was attempted in 231 (73 not monitored by surgeon preference and used as controls). 48 patients (20.7%) were unable to be monitored because they lacked baseline signals from the extremities, and 4 patients had some monitoring but poor baseline motor signals. One hundred seventy nine of the 231 patients (77.4%) were successfully monitored. There was no statistical significant in postoperative seizures between the group and controls (*p*=0.883).

Conclusion: This study demonstrates a high percentage of children (77%) with CP were successfully monitored with TcMEPs during PSF. This differs from what has previously been published and the common practice at many institutions. TcMEP can be successfully and safely used in the vast majority patients with CP undergoing PSF to improve intraoperative safety, and the presence of seizures is not a contraindication.

#### Poster presentation 144

#### A thousand hips over two decades: What we have learned about complications after hip surgery in children with cerebral palsy

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Introduction: Proximal femoral osteotomy (PFO) is a surgical procedure that treats hip dyplasia or internally rotated gait in children with cerebral palsy (CP). The purpose of this study was to define the risk factors related to surgical complications in patients with CP following PFO in a large series.

Patients and Methods: 1085 PFO procedures in 563 children with CP over 18 years were identified. Demographic characteristics, motor type, GMFCS level, medical comorbidities, additional surgical procedures (according to multi-level surgery [MLS] principles) and operative details were collected. A modified Clavian-Dado system was used to categorize complications, and risk factors were assessed with Fisher's exact test, along with multivariate analyses.

Results: The mean age was  $10.8 \pm 3.96$  years old, with a mean follow-up of  $5.84 \pm 3.85$  years. 208 patients (36.9%) were ambulatory (GMFCS Levels I, II, or III), and 355 (63.1%) were nonambulatory (GMFCS Levels IV or V). Surgical complications occurred in 143 (13.1%) of hips in 121 (21.4%) patients. 65 (6%) were cases of heterotopic ossification (HO), most of which were classified as mild, asymptomatic, and required no additional treatment. The rate of revision surgery was 13.1% (6.8% per hip). The presence of dystonia and epilepsy were the only independent risk factors identified for delayed/non-union in multivariate analyzes (p=0.001).

Conclusion: The overall surgical complication rate of hip surgery in children with CP was 13.1%. The most common complication was mild HO. Dystonia and the presence of epilepsy were the strongest predictors for the need for revision surgery after PFO.

#### Poster presentation 145

#### Education, employment, and independence: An assessment of adults with cerebral palsy after transition from a pediatric health care system

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Introduction: Lack of strong societal support is well documented and leads many young adults with cerebral palsy (CP) to struggle

with independence, higher education, and employment. The purpose of this project was to assess independence, employment, physical activity, access to health care, and daily physical function of an adult cohort of former patients from a pediatric CP spe-

Patients and Methods: Adults with CP self-reported quality of life outcomes (PROMIS) and wore a pedometer to monitor community walking activity. We collected educational level, degree of independent living, income level, use of supplemental disability income (SSDI), employment, access to health care, chronic health problems, and pain. We evaluated associations, stratified by GMFCS level, between walking activity and PROMIS physical function, educational level, employment, and level of independent

Results: 87 adults with CP, age  $29.7 \pm 4.3$  years, functioning at GMFCS levels: I (28%), II (46%), III, (24%) and IV (2%) participated. Educational levels were similar to the general population. Unemployment (33%) was higher than national levels, and 10% lived with a caregiver. Mean daily walking activity correlated with PROMIS physical function (r = 0.42, p < 0.001), employment level (r = 0.39,  $p \le 0.001$ ), and independent living status (r = -0.15, p = 0.01. This cohort reported outstanding access to primary care (98%), but 48% reported chronic pain.

Conclusion: This cohort of adults with CP had relatively high rates of unemployment, caretaker need, and SSDI utilization. Improvement in societal resources for adults with physical disabilities is urgently needed to allow more equitable access to employment and independent living opportunities.

#### Poster presentation 146 Participation after childhood stroke and its relation to hemiparesis severity

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Introduction: Childhood arterial ischemic stroke (AIS) is associated with considerable morbidity, whereby up to 50% of the children with AIS develop hemiparesis. Whilst it is assumed that hemiparesis may impair participation in activities with peers, it remains unknown what their participation patterns are and to what extent they relate to hemiparesis severity.

Patients and Methods: Thirteen children (range 5-15 years 6 months) with AIS (acquired between 6 months-6 years 8 months, 7 developed hemiparesis) and 21 controls (range 5 years 6 months-13 years 5 months) participated. We scored hemiparesis severity with hand strength asymmetry (pinch and grip strength), measured with a dynamometer. With questionnaires, we assessed manual ability (ABILHAND-Kids), socioeco-

nomic status (Family Affluence Scale) and participation (Participation and Environment Measure - Children and Youth). From structural MRI, we determined lesion size with the ABC/2 method normalized to brain volume. We investigated differences in participation and its relationship with hemiparesis severity using non-parametric partial correlations (controlling for lesion size, manual ability, and socioeconomic status), interpreted as no correlation (r < 0.25), weak (r = 0.25-0.50), moderate (r = 0.50-0.50) 0.75) or strong ( $r \ge 0.75$ ), using jamovi 1.6.3.

Results: Children with AIS (with and without hemiparesis) showed reduced participation frequency at school (p< 0.001), whilst participation at home and in the community resembles that of their peers. Severity of hemiparesis was moderately related to poor home participation frequency and involvement and to poor community involvement and high desire of change.

Conclusion: Participation at school after AIS is decreased, without being influenced by hemiparesis severity. Poor participation at home and in the community relates to hemiparesis severity, which may be improved with participation-focused intervention strategies.

#### Poster presentation 147

#### What we have done as pediatric rehabilitation professionals during the COVID-19 Pandemic in China

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Introduction: During the Covid-19 outbreak, everything was locked down early in February 2020 in China. The Chinese Association of Rehabilitation Medicine Pediatric Rehabilitation Committee (CARMPRC) quickly responded to the challenges and created a plan to provide rehabilitation services of afflicted children and support for the front line staff treating the infected .

Patients and Methods: (1) Working closely with front line medical staff in Wuhan and providing early intervention programs for children who had been infected with COVID-19. The Rehabilitation Department of Wuhan Children's Hospital is the only designated hospital for the treatment of children with COVID-19 in Wuhan. Our members formulated the rehabilitation project for early intervention of children who were infected with COVID-19. (2) The dissemination of virus prevention information in common languages, via every channel of media which helped inform children and families at home. (3) The set up of online therapy and conferences: more than 20 rehabilitation institutions held more than 40 free online consultation courses with over 48,000 partici-

Results: More than 2000 families with children with disabilities had 'home service' during the lock-down and more than 7700 people utilized the online services and lectures. The infection rate among these children and staff was zero.

Conclusion: The pandemic caused a dramatic change to the life and work of the people in China. CARMPRC managed the situation in a way that was suitable and feasible to meet the needs of these children and families. Through our professionals quick and effective response to the virus, these actions resulted in a successful campaign against COVID-19 in China.

#### Surgical options for treatment of spasticity in hereditary spastic paraplegia

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Introduction: To provide an overview of outcome and complications of selective dorsal rhizotomy (SDR) and intrathecal baclofen pump implantation (ITB) for spasticity treatment in children with hereditary spastic paraplegia (HSP), to improve walking pattern, prevent contractures or improve comfort and personal care.

Patients and Methods: retrospective study including participants with HSP, who had undergone SDR or ITB. For SDR, walking children had to meet strict selection criteria (strength, selectivity, no dystonia, motivation for a rehabilitation program, strong social support system). Gross motor function measure (GMFM-66) scores and level of spasticity (modified Tardieu scale) were assessed.

Results: Ten patients (5 males) were included (most had mutations in ATL1 [n = 3] or SPAST [n = 3] genes). Four patients walked without and two with walking aids. Four were non-walking children. Seven patients underwent SDR, two patients ITB and one patient both. Six of the SDR patients were walking patients. Mean age at surgery was  $7.8 \pm 5.1$  years, with a mean follow-up of  $3.4 \pm 1.6$  years. Postoperatively spasticity in the legs was reduced in all patients. The mean change in GMFM score was +8.0 (0-19.7 min-max). The three ITB patients treated (SPAST [n = 2] and PNPLA6 [n = 1] gene mutation) were non-walking children with a progressive disease course. No complications of surgery occurred. Conclusion: SDR is a feasible treatment option in carefully selected

children with HSP, especially in walking patients. The majority of patients benefit with respect to gross motor function, complication risk is low. ITB was used in children with severe and progressive disease.

#### Poster presentation 149

#### The patient beyond the genetic diagnosis: Identification, definition and treatment of intellectual disability syndromes

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Introduction: Intellectual disability (ID) affects approximately 1-2% of the general population. Until recently, the cause of ID remained unknown in 50-70% of the affected individuals. Knowing the genetic cause of ID in a relative can bring comfort to families and is of major importance in care and counselling. It provides insight in comorbidity, associated behavioral problems, prognosis and recurrence risk. The genetics of intellectual disability and autism is a highly dynamic area. Most notably, the next generation sequencing technologies have drastically impacted our diagnostic methods and created opportunities.

Patients and Methods: To illustrate the progress in syndrome definition, we give an example of an ID-syndrome that we have further characterized. Our research group previously discovered ADNP mutations as a frequent cause of a form of syndromic autism. We collected a large cohort of 78 patients with ADNP- Related Syndrome, and performed deep phenotyping. As an example of targeted therapy, we carried out a randomized, doubleblind, placebo-controlled, crossover trial of ganaxolone in fragile X syndrome, one of the most common inherited forms of ID.

Results: We demonstrate how deep phenotyping can be used to obtain a detailed characterization of an as yet ill-defined genetic syndrome, namely the ADNP-Related Syndrome. We show preliminary evidence of a genotype-phenotype correlation. In addition, we show that the fragile X syndrome is an example of how fundamental insights into pathophysiological mechanisms can be translated into clinical practice.

Conclusion: In this PhD-project, we illustrated the progress in the diagnostic landscape of ID/ASD syndromes, including the first steps into targeted therapy.

#### Poster presentation 150

#### The influence of spasticity on upper limb kinematics and movement velocity in children with dyskinetic cerebral palsy

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Introduction: Dyskinetic cerebral palsy (DCP) is the most disabling form of CP, with children with DCP often showing signs of spasticity. However, the impact of spasticity in children with DCP on their daily-life activities remains unclear. Therefore, this study aimed to compare upper limb kinematics and movement velocity in children with DCP with spasticity (DCP-Sp) and without spasticity (DCP-noSp).

Patients & Methods: 12 participants with DCP (mean age 17 years, range 8-25 years) were included. Five participants had both arms measured yielding information on 17 upper limbs using Vicon 3D Motion Capture. Participants performed 10 repetitions of three functional tasks (reach forward; RF, reach and grasp vertical; RGV, and reach sideways; RS) with reflective markers on the sternum, shoulder, arm, and hand. Presence of spasticity was assessed with the Modified Ashworth Scale and the Modified Tardieu Scale. Joint angles, trajectory deviation and maximal velocity were compared between DCP-Sp and DCP-noSp using independent t-tests.

Results: Participants with spasticity in the elbow flexors showed significantly lower elbow extension in comparison to DCP-noSp (RF: 43.22°-27.56°; RGV: 51.47°-27.27°; RS: 39.35°-29.28°; all p < 0.05). Spasticity in the elbow pronators resulted in lower supination values during RF (146.50°-140.70°; p = 0.039) and RGV (144.54°-31.82°; p = 0.024). No differences were found between DCP-Sp and DCP-noSp for the wrist joint or trajectory deviation (p> 0.05). Maximal velocity was lower in DCP-Sp during all functional tasks (RF: 0.90 m/s-1.09 m/s; RGV: 0.85 m/s-0.94 m/s; RS:1.20 m/s–1.42 m/s; all p < 0.05).

Conclusion: Presence of spasticity in children with DCP affects movement velocity and range of motion negatively during functional tasks. This may impact their execution of daily-life activities, and should be taken into consideration for rehabilitation treatment strategies.

### Quality of life of young adults with cerebral palsy: A longitudinal analysis of the SPARCLE study

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Introduction: While most of the individuals with cerebral palsy (CP) will have a similar life expectancy to the general population, international research has mainly focused on childhood and adolescence, and knowledge about the quality of life (QoL) of young adults with CP, its trajectories and predictors remains scarce. Patients and Methods: Individuals with CP were followed from childhood (8-12 years) to young adulthood (17-22 years) in five European regions. In total, 176 adults with CP who have previously participated in at least one of the two first waves of the SPARCLE cohort reported their OoL. Validated instruments (KIDSCREEN: 2 first waves, then WHO-OOL Bref) were used. We focused on the psychological and physical well-being as well as social relationships domains of QoL and used generalized linear mixed-effects models to assess changes in QoL from childhood to adulthood. To determine childhood factors associated with clusters of OoL's trajectories identified by KML shape method, we performed polytomous logistic regressions.

Results: Psychological well-being decreased with age until young adulthood (SE: -0.8129; p < 0.0001), whereas QoL in social relationships domain increased (SE: 1.1372; p < 0.0001), independently of impairment's severity. No significant variation in physical well-being was observed over time. Several shapes of QoL's trajectories have been identified for each QoL subdomains. Potential childhood predictors (impairments, pain, environment) associated with QoL' trajectories will be identified.

Conclusion: This study suggests that various QoL profiles from childhood to young adulthood exist. Further analyses will inform about potential facilitators to maintain or increase the QoL of individuals with CP over time.

#### Poster presentation 152 Validation of the Polish version of the CP QOL-Teen scale

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Introduction: Particular emphasis on patient subjectivity presented by WHO led to the creation of the concept of quality of life dependent on health (HRQOL). This made it possible to conduct research on the quality of life using standardized tools, including questionnaires with proven psychometric properties. The main aim of the study was to conduct the Polish cultural adaptation and assessment of validity and reliability of the CP QOL-Teen scale. Patients and Methods: 84 adolescents with CP aged 13–18 years and 81 parents were enrolled in the study. The group of teenagers consisted of 84 people, including 37 girls (44.05%) and 47 boys (55.95%). The process of translation and cultural adaptation of

the Polish version of CP QOL-Teen was carried out. In the next stage, psychometric properties of the Polish version of the CP QOL-Teen questionnaire were evaluated.

Results: As a result of the study, a Polish version of the CP QOL-Teen questionnaire was created. The Cronbach's alpha for individual subscales was from 0.858 to 0.953 in the analysis of teenagers' results and from 0.824 to 0.937 in the analysis of parents' results. The ICC used to assess temporal coherence was for individual subscales from 0.82 to 0.889 in the analysis of teenagers' results and from 0.702 to 0.798 in the analysis of parents' results. The validity of the questionnaire CP QOL-Teen:all CP QOL-Teen subscales correlated moderately between 0.5 and 0.6 with all KIDSCREEN-27 subscales.

Conclusion: The Polish adaptation of the CP QOL-Teen questionnaire is a valid and reliable research tool for the assessment of the quality of life in teenagers with CP.

#### Poster presentation 153

### Assessment of the quality of life in the adolescents aged 13–18 years with cerebral palsy

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Introduction: Assessment of quality of life dependent on health has a huge importance in the daily life of persons with disability. We can measure the subjective perception of quality of life of children with cerebral palsy in different areas of life. General and specific well-being can be checked after e.g. medical intervention.

Patients and Methods: 84 adolescents with CP aged 13–18 and 81 parents were enrolled in the study. The group of teenagers consisted of 84 people, including 37 girls (44.05%) and 47 boys (55.95%). The group of parents consisted of 81 people, women dominated: 72 (88.89%) and 9 men (11.11%). The assessment of the quality of life by teenagers and the assessment of the teenagers' quality of life in the parents' opinion were examined by means of Polish version of CPQOL-Teen questionnaire.

Results: The best quality of life for adolescents was in the domains of 'social well-being': 79.48 and 'feelings about functioning': 73.58, and the weakest in the domains 'general well-being and participation': 68.99 and 'school wellbeing': 69.5. The best results of the assessment of the teenagers' quality of life in the parents' opinion were obtained in the domains of 'social well-being': 78.83, and 'communication and physical health': 67.36, and the worst in the domains 'family health' 64.24 and 'access to services' 56.81.

Conclusion: Teenagers with CP aged 13–18 years assessed their quality of life at a good level which was in line with their parents' assessment. However, one should think about how to improve it, taking into account the results in individual subscales

Using principal components and confirmatory factor analysis to improve measurement of children's sensorimotor control in large-scale communitybased studies

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Introduction: Kinematic assessments measure how movements are performed, providing a wealth of information regarding the subtleties of children's sensorimotor control. More accurate, detailed information is captured in kinematic assessment compared to traditional, observation methods, making it more practical for use in large-scale settings. However, kinematic data are often complex, with empirically driven methods in deciding how they are summarised rarely employed. Consequently, interpretation can be challenging. A large proportion of systematic variance captured by kinematic devices often does not get analysed. Data reduction

techniques offer a solution to ensure that the largest proportion of systematic variance explaining sensorimotor control possible is accounted for, whilst reducing unnecessary noise.

Patients and Methods: The present study used a principal components analysis (PCA) and confirmatory factor analysis (CFA) to determine the theoretical constructs that best underpin sensorimotor control. This was based on three tasks from the Clinical-Kinematic Assessment Tool (CKAT) using data from 23,996 4 to 11-year-old typically developing children.

Results: Findings suggest that complex kinematic data can be reduced to a smaller number of dimensions related to sensorimotor control whilst reducing noise and redundancy. Three sensorimotor tasks could be reduced to three dimensions for Steering and Aiming, and eight dimensions for Tracking.

Conclusion: We suggest that analysis and interpretation of kinematic data should reflect its multifaceted nature and that metric selection should be based upon theoretical and empirical evidence in combination. We argue that this technique for selecting metrics would be of beneficial to employ in all kinematic assessments.