

Australasian Cerebral Palsy Clinical Trials Network (AusCP-CTN) Centre for Research Excellence

Hot Topics in Cerebral Palsy Research Forum

Date: Thursday 9th and Friday 10th November

PROGRAM BIOGRAPHY'S AND ABSTRACTS

Professor Roslyn Boyd PhD

Chief Investigator on the Australian-Cerebral Palsy-Clinical Trials network CRE;
Scientific Director of the Queensland Cerebral Palsy and Rehabilitation Research Centre.

Presentation Title: Vision for Cerebral Palsy: “In 5 years time”

The Australasian CP Clinical Trials Network has a work plan to uplift earlier detection of CP, fast track children to multisite randomised clinical trials of new neuroprotectants and to develop and test new rehabilitation. Knowledge translation studies will ensure effective transfer to enhanced clinical practice. The CRE will overcome known barriers to implementation, developing international clinical practice guidelines guided by a consumer network. The changes in outcomes of children with CP due to the new clinical trials will be tested in Australian Cerebral Palsy Register (ACPR).



International Invited Speakers:

Professor Leena Haataja, MD, PhD.

Professor of Child Neurology,
University of Helsinki, Chief Physician,
Helsinki University Hospital, Finland.

Biography: Professor Haataja’s research focuses on the study of fetal and neonatal risk factors with >150 publications (e.g. prematurity, brain injuries, inflammation) and potential protective factors (e.g. genetic mechanisms, early parent-infant interaction) and their possible long-term neurodevelopmental effects. Another focus is to standardize clinically applicable developmental assessment methods (e.g. HINE) and compose treatment guidelines which harmonize clinical treatment processes at a national level in Finland. Prof Haataja has been a senior author along with Prof Frances Cowan on publications using the Hammersmith Infant Neurological Assessment (HINE) in both research and clinical implementation. She has also had a lead role in the PIPARI Study Group following the long term outcomes of very low birth weight children.



Abstract 1: Integration of evidence-based assessment methods of early detection of CP in clinical practice

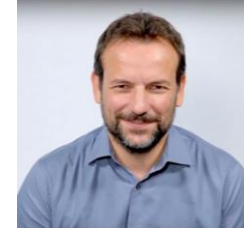
Systematic review evidence shows that the most predictive tools for detecting high risk of cerebral palsy before 5 months’ corrected age are term-age brain MRI, assessment of General Movements and the Hammersmith Infant Neurological Examination (HINE). Despite evidence there is a wide diversity in assessment methods and follow-up protocols applied in clinical practice of at risk infants (preterm, birth asphyxia, perinatal infarction) in the five University Hospitals in Finland. Lack of consensus on national at-risk infant follow-up practice make benchmarking or intervention studies impossible between tertiary care hospitals. The obstacles and challenges in an attempt to harmonize clinical practice taking a recent multi professional project of establishing a core set of outcome measures for children with cerebral palsy as an example will be reviewed. The present state and practical solutions in order to establish evidence-based predictive tools for early detection of children with high-risk of CP will be described and discussed.

Abstract 2: “The PIPARI preterm follow-up study: lessons to be learned”

The PIPARI study (The Development and Functioning of Very Low Birth Weight Infants from Infancy to School Age) (www.utu.fi/pipari) aims to evaluate the functional outcome, assess the risks and protective factors for development and early signs of abnormal development of very preterm infants. The ongoing regional follow-up study covering a population of 5000 births per year started in 2001. The highlights of the findings and their clinical relevance as well as the numerous and diverse demands for running a multidisciplinary long-term follow-up project will be summarized. The importance of establishing evidence-based follow-up programs in order to focus the follow-up and interventions in a cost-effective way will also be discussed.

Associate Professor Andrea Guzzetta, MD, PhD, Child Neurology and Psychiatry, Head of Stella Maris Infant Lab for Early-intervention (SMILE) and A/Professor at the University of Pisa, Department of Clinical and Experimental Medicine, Italy.

Biography: A/Professor Guzzetta has >150 publications in child neurology focusing on the effects of early brain damage on the development of different functions (motor, visual) and the underlying neuroplastic mechanisms with an overall aim of improving early intervention paradigms. He will provide an update on use of the General Movements assessment in the early diagnosis of neurodisability. He will present a keynote lecture on new directions of early intervention for infants with early brain injury. With his colleagues he will present a workshop on the assessment and early intervention for infants and children with Cerebral Visual impairment (VISIBLE: Vision intervention for severely impaired babies: learning & enrichment). He is an accredited Trainer at the GM-Trust (www.general-movements-trust.info).



Abstract: New opportunities for Early intervention in infants with early brain injury

Extensive studies in humans and non-human models suggest that early intersubjectivity is the foundation of emotional and cognitive development, in both typical and atypical development. Both mother's and infant's wellbeing are necessary for the healthy development of early interactions and consequently, for the subsequent infant outcomes.

It is unquestionable that early development of intersubjectivity in babies with congenital brain damage is at a very high risk. The ability to generate (transmit) and to recognize (receive) social stimuli is potentially disrupted in both components of the dyadic relationship, due to the physical wound in the baby and the psychological one in the parent. One of the main sensory channels, vision, which is active in newborns from the first hours and critical to the connection with the environment, is generally affected, preventing the infant from receiving critical social cues. Profound pain and sense of discomfort during spontaneous, and therefore unavoidable, behaviours are further barriers to the accessibility of the baby to early interaction. Therefore, congenital brain damage should be considered as a paradigmatic model of disruption of early interaction, and opportunities for focused intervention should be investigated.

Within this framework, the presentation will include the review of recent scientific findings on brain mechanisms supporting the interactive, motor and social processes of infant development. By focusing on the effects of specific sensorimotor and social experiences, we will evaluate the limits and potentials of intervention strategies centred on the promotion of early intersubjectivity to overcome the adverse effects of neonatal brain lesions.

Abstract 2: Early assessment and Intervention for infants with Cerebral Visual Impairment

More than two thirds of the human brain are devoted, directly or indirectly, to vision. It is therefore not surprising that cerebral visual impairment is common in children with cerebral palsy. As for other brain functions, early brain damage induces specific mechanisms of neuroplastic reorganization in the visual system and non-invasive tools to explore them are now available, such as advanced neuroimaging and electrophysiology. Simple clinical tools can be used from birth onwards to thoroughly assess and characterize visual disorders in infants at risk for cerebral palsy, which give reliable insights on long term visual outcome. Starting from the understanding of early neuroplasticity of the visual system, the best tools for early detection of cerebral visual impairment and the therapeutic strategies to optimize visual outcome will be presented.

Professor Ann-Christian Eliasson, PhD, OT

Department of Neuropaediatrics, Karolinska Institute, Stockholm, Sweden.

Professor Anki Eliasson's main interest is the development of hand function in children with CP. Her challenge is whether the children's abilities can be improved by intervention and understanding the factors influencing the development after early brain lesion. Her research focuses on the impact of rehabilitation, different perspective of development and new assessment tools. She will provide an update on the early prediction of hand function in infants following Neonatal Stroke reporting her longitudinal data and early trajectories of hand function. She will also give an **"Update on her new early interventions for children with bilateral CP and internet training for Constraint Induced Movement Therapy"**.



Associate Professor Lena Krumlinde-Sundholm PhD, OT.

Department of Neuropaediatrics, Department of Woman's and Children's Health, Neuropediatric unit, Karolinska Institute, Stockholm, Sweden.

A/Professor Lena Krumlinde-Sundholm has a clinical and research interest in hand function, functional performance and participation in everyday tasks in children and adolescents with disabilities. She is the primary author of the Assisting Hand Assessment (AHA), is one of the developers of the Manual Ability Classification System (MACS) and the Children's Hand-use Questionnaire (CHEQ). She is engaged in the National Quality Register for persons with cerebral palsy, CPUP in Sweden. Current research projects involve further instrument development (the HAI, BOHA) and evaluation of interventions for children with disabilities, from infancy to adulthood. Lena will present an **"Update on the new Hand Assessment for Infants (HAI): validation, reliability and normative data and information about the "AHA family" of assessments and introduce the new BoHA, the Both Hands Assessment"**.



Richard Ellenson, CEO Cerebral Palsy Foundation New York.

Richard Ellenson has brought enormous vision and energy to the Cerebral Palsy Foundation, spearheading major new initiatives as well as building robust partnerships with groups as diverse as ABC Television, Microsoft, and the NYC Department of Education. Prior to this, he was founder of two companies, Blink Twice and Panther, which helped reimagine the field of assistive technology. In his earlier career, he was an advertising executive, penning the classic line, "It's Not TV. It's HBO." He has been the recipient of two NIH Grants as well as numerous awards. Mr. Ellenson is the father of a 20-year-old son, Thomas, who has cerebral palsy. He has worked tirelessly to create awareness about people with disabilities, and to share stories about their vibrant lives. He and his son have been featured as ABC World News People of the Year, in an ESPN segment and in a New York Times Sunday Magazine cover story. Richard lives in NYC with his wife Lora, an NIH-funded researcher who runs Gynaecological Pathology at NY Hospital, as well as with his two very special children, Thomas and Taite.



National Invited Speakers:

Associate Prof Mark Mackay, MBBS PhD, Child Neurologist, Royal Children's Hospital, Melbourne

Biography: A/Professor Mackay is Director of the Children's Stroke Program, Murdoch Children's Research Institute, Melbourne and an Honorary Research Fellow the Florey Institute of Neurosciences and Mental Health. Dr Mackay has established a dedicated paediatric stroke program at the Royal Childrens Hospital, Melbourne-and he is a major contributor to the International Pediatric Stroke Study. He is lead author on the Australian Paediatric Stroke Guidelines. Recently he was recognised for his work as the 2016 Stroke Care Champion for his outstanding dedication and commitment to Australia's youngest stroke patients by the National Stroke Foundation.

Topic: The Australian Paediatric Stroke Guidelines



Australasian Cerebral Palsy Clinical Trials network speakers

Dr Kerstin Pannek, PhD

Physicist at the
Australian e-health Research Centre,
CSIRO.

Kerstin Pannek (PhD) is a Research Scientist at the CSIRO Australian E-Health Research Centre. She has more than 10 years of experience in neuroimaging analysis including structural and diffusion magnetic resonance imaging (MRI) across all age groups. Her research interest is improving the image quality of MRIs in difficult patient populations. Kerstin's current work focuses on prediction of outcomes from early MRI in preterm-born infants, and neuroplasticity in response to intervention in children and infants with or at high risk of developing cerebral palsy.

Topic: Fetal and Neonatal brain MRI update:

**Dr Jurgen Fripp, PhD**

Senior Research Scientist
Group Leading the medical image
analysis team at the CSIRO Australian
E-Health Research Centre, CSIRO.

Jurgen Fripp (PhD) is a Senior Research Scientist, leading the medical image analysis team at the CSIRO Australian E-Health Research Centre. He has been conducting research for over 10 years into algorithms (segmentation, registration, shape and appearance modelling) for applications in Positron Emission Tomography (PET), Magnetic Resonance Imaging (MRI), Computed Tomography (CT). The developed workflows have been standardised and deployed either on HPC or cloud environment applied to support various large clinical studies, including into neurodegeneration, neurodevelopment, osteoarthritis and radiotherapy planning. Jurgen's current research focus is developing algorithms for ultra high field MRI, and to more accurately and reliably extract quantitative biomarkers related to development and disease progression in challenging populations. These are being evaluated for use in the quantification of MRI in infant cohorts.

Topic: Fetal and Neonatal brain MRI update:



Joanne George (PhD) is a senior
research physiotherapist with the
Queensland Cerebral Palsy and
Rehabilitation Research Centre in Brisbane.

Jo George has undertaken early brain imaging studies in very preterm infants at the Royal Brisbane and Women's Hospital, seeking to identify earlier imaging and clinical biomarkers to identify infants at risk of adverse outcomes for her PhD in the PPREMO study. She is involved in implementation of the Queensland Early Detection and Intervention network (QEDIN-CP) which aims to improve earlier detection of infants at risk of CP, and fast track them to targeted early interventions aimed at improving outcomes.

Topic: Early MRI and clinical biomarkers of preterm outcomes



Associate Professor Michael Fahey

PhD, Child Neurologist and Geneticist is Head of Paediatric Neurology at Monash Medical Centre, and a Chief Investigator on the Aus-CP-CTN CRE and member in two themes – the Pre-clinical and Neuroprotection theme and the Early Detection and Neuroimaging Theme.

Professor Jenny Ziviani, PhD is the inaugural Professor of Children's Allied Health Research with Children's Health Queensland, And Professor in Occupational Therapy at the School of Health and Rehabilitation Sciences, The University of Queensland. She is a Chief Investigator on the CRE and Chair of the Engagement and Health Policy theme.

Professor Paul Colditz,

MBBS, MBIomed Eng, DPhil (Oxford), FRACP, FRCPCH, Director of the Perinatal Research Centre, UQCCR. Practicing neonatologist at the Royal Brisbane and Womens Hospital. Chief Investigator on the CRE and member of the Pre-Clinical & Neuroprotection theme. He has senior roles in the Division of Paediatrics and Child Health within the Royal Australasian College of Physicians (President-elect).

Topic: Update on Genetics in Cerebral Palsy

Michael's research focuses on using neurogenetics to understand the causes of movement disorders and diseases of the muscle and nerve including Cerebral Palsy. Michael collaborates on research into treatments for Cerebral Palsy with researchers at the Ritchie Centre, part of the Monash Institute of Medical Research. The work focuses on melatonin, a hormone produced in the brain, and Michael is confident the research will soon move to human trials. In addition he collaborates on gene discovery research with Genetic Health Services Victoria and experts at the Alfred Hospital. He is involved in the treatment of rare neuro-metabolic diseases with partners at the Royal Melbourne Hospital. Outside of the lab, Michael maintains a heavy workload as a physician in Paediatric Neurology and in Neurogenetics clinics. He still finds the time to act as neurologist at the Paediatric Rehabilitation Clinic and has co-founded a mitochondrial clinic.

Topic: Engaging families & children with CP in intervention clinical trials

Professor Ziviani's background is in occupational therapy as a clinician, academic and researcher. Her recent focus has been to understand the ingredients which enhance children's motivation in therapy and how families can be engaged to optimize therapy outcomes. With her colleagues in Canada and the United States Jenny has been developing a suite of measures of engagement in rehabilitation. These measures focus on self-report from the perspectives of parents, children and therapists as well as observational. The Paediatric Rehabilitation Measure of Engagement General Research Version is currently being trialled in early intervention studies.

Abstract: Engagement is a term often used to describe a critical feature of the therapy process. Active involvement of both children and families is essential in family-centred practice, where joint collaboration between service providers and clients in terms of goal setting and intervention planning are critical to the success of the therapy process. Engagement in the therapeutic intervention underlies this active process, but there are many questions remaining about the nature and function of engagement. For instance: What is engagement? How does a client, family member, or practitioner know when engagement is at an optimal state to influence the therapeutic outcome? How can engagement be enhanced in the delivery of interventions to children and families? This presentation will explore the concept of engagement, the impact of engagement on therapeutic outcomes, proposed methods for assessing and measuring engagement, and future research and practice directions to deepen our understanding and development of engagement.

Topics: Hot Topics in Neuroprotection for CP

His research focuses on clinically important perinatal health problems and translation to clinical practice. It includes investigations relating to seizure identification and prevention, brain injury and neuroprotection, neural plasticity, stem cell therapies, structure/function relationships in brain development using brain MRI and EEG, body composition, stillbirth, congenital malformations and pathways to improving neurodevelopmental outcomes. He has a large multidisciplinary national and international network of collaborations, including an ongoing successful collaboration with the University of Qatar, resulting in grants >\$9M in the last 5 years for perinatal biomedical engineering research. Professor Colditz was the lead investigator on competitive grants for the acquisition of the southern hemisphere's first neonatal MRI compatible incubator.



Dr Hayley Smithers-Sheedy, PhD, MPH, BAppSc (Sp Path)
NHMRC ECF Research Fellow, Cerebral Palsy Alliance, The University of Sydney.

Topic: Update Epidemiology of CP from the Australasian CP Register

Dr Hayley Smithers-Sheedy's key roles is to generate and support the conduct of the research from the Australian CP Register. Hayley also works with researchers internationally to support the establishment of new CP Registers in the region. Hayley's recent research has focussed on congenital cytomegalovirus as a potentially preventable contributing cause of CP.

Abstract: Cerebral Palsy Registers that include nearly all individuals with cerebral palsy (CP) within a specified geographic region are the optimal source of data for studying temporal trends in overall birth prevalence and by gestational age, birthweight and severity. Analysis of birth prevalence of CP within these specific subgroups using population data provides an opportunity to explore risk factors and the real world impact of advances in maternal and neonatal care. Here we will provide an update from the Australian Cerebral Palsy Register (ACPR) and report recent findings from research completed by Claire Galea and the ACPR Group, regarding trends in birth prevalence of CP, gestational age, motor type, spastic topography and severity using ACPR data.

Topic: Update Epidemiology of CP from the Australasian CP Register

Dr Sarah McIntyre has expertise in epidemiology, aetiology and translation research. She plays a key role in the policy group of the Australian CP Register and leads the NSW/ACT Register. With her colleagues, she is developing the first international CP research network, IMPACT for CP, and will facilitate links with the CRE.

Dr Sarah McIntyre, PhD MPS
BAppSc (OT) Hons
Senior Research Fellow & NHMRC Early Career Fellow, Cerebral Palsy Alliance, The University of Sydney.
Associate Investigator on the CRE and Member of Pre-clinical and Neuroprotection, Engagement & Health Policy themes.

Professor Iona Novak, PhD, MSc (Hons), BSc (OT), Head of Research, Cerebral Palsy Alliance Research Institute, School of Medicine, The University of Sydney, Australia.
Professor Novak is a Chief Investigator on the CRE, NSW Co-Lead, Chair of the Knowledge Translation and Implementation theme, member of the Pre-Clinical and Neuroprotection and Clinical Trials themes and Chair of the Australian CP Register.

Topic: Practical Tips for Developing a GRADE and AGREE II Compliant Clinical Practice Guideline: Functional Therapy for Cerebral Palsy Exemplar.

Professor Iona Novak is the Head of Research at Cerebral Palsy Alliance, University of Sydney, Australia. Iona is a Fulbright Scholar establishing "Xcellerate" - an American-Australian Cerebral Palsy Stem Cell Research Consortium that pools collective efforts to find a cure. Driven by an internal belief that research and healthcare has the potential to change lives, Iona has pursued projects and roles with the greatest possible impact on children and families, including, leadership of the Australian Cerebral Palsy Register. Along with Dr Morgan she has recently lead a publication of the international Clinical Practice Guideline on the Early Detection of Children with Cerebral Palsy in JAMA Pediatrics.

Abstract:

1. Gain an understanding of the key methodological requirements for writing high-quality trustworthy Clinical Practice Guidelines, following recommendations from the: (a) World Health Organisation; (b) the Grading of Recommendations Assessment, Development and Evaluation (GRADE) framework; and (c) the Appraisal of Guidelines, Research and Evaluation (AGREE II) quality rating tool.
2. Practice applying the GRADE framework to a body of evidence to assess quality.
3. Practice applying the GRADE framework to formulate recommendations as part of a multidisciplinary panel.
4. Gain practical tips about how to meet the AGREE II instrument recommendations for improving guideline rigour.

Summary: This workshop session will outline the processes involved in developing a GRADE and AGREE II compliant Clinical Practice Guideline, using Functional Therapy for children with cerebral palsy as an exemplar. The presenters



have all published summaries of best-available evidence for functional therapy in cerebral palsy and will lead the participants in: (i) grading the quality of best-available evidence; and (ii) forming recommendations. All children with cerebral palsy have a physical disability and therefore almost always have used or have had “Functional Therapy” recommended as part of their intervention plan. A systematic review of the efficacy of interventions for children with cerebral palsy, identified that “Functional Therapy” (also known as Goal Directed Therapy) using an intensive motor learning approach, improves motor task performance and independence in self-care in children with cerebral palsy, and is supported by high-quality evidence. Based on this best-available evidence we are developing an International Clinical Practice Guideline to inform clinicians about the: (i) mode and fidelity; (ii) dose; (iii) provider attributes; (iv) attributes of responders; and (v) outcome measurement.

Interactive Element: Delegates attending this workshop will actively contribute to authoring this Guideline through participation in multidisciplinary panel discussions. This workshop will be structured using the GRADE methodology for developing clinical recommendations from best-available evidence. Delegates will form an expert multidisciplinary panel and carryout the following tasks: (i) weigh up the balance between the desirable and undesirable consequences of the alternative management strategies; (ii) weigh up the magnitude of the benefits and harms of an intervention; (iii) weigh up the variability in, values and preferences of parents, children and clinicians. Parent and child preferences will be sought prior to the conference, via a Delphi methodology with a consumer reference group, and tabled for delegates to consider; and (iv) consideration of cost.

Dr Leanne Sakzewski, PhD, OT Senior Research Fellow and NHMRC ECF at the QLD Cerebral palsy and Rehabilitation Research Centre, The University of QLD. Dr Leanne Sakzewski is an Associate Investigator on the CRE and a member of three themes: Clinical Trials, Knowledge Translation and Implementation, and Engagement and Health Policy.

Dr Leanne Sakzewski is a lead fellow in the Knowledge Translation and Implementation theme of the CRE. Her research focuses on developing implementation strategies and programs to facilitate the timely and effective uptake of research evidence into practice. She has expertise in randomised clinical trials in upper limb rehabilitation in children with cerebral palsy and systematic reviews and meta-analyses (2), and clinimetric reviews of outcome measures (3). She has recently published results of her translational research, investigating barriers and enablers to evidence uptake and piloting an implementation strategy to increase the uptake of evidence in upper limb therapies into clinical practice.



Michelle Jackman, BAppSc^{4,5}, is a Doctoral Research fellow at: The University of Sydney, Sydney, Australia, and John Hunter Hospital, Newcastle, Australia.

Ms Michelle Jackman, PhD Scholar, University of Sydney Senior Occupational Therapist, John Hunter Children’s Hospital
Michelle Jackman is currently undertaking her PhD investigating the benefits of cognitive-based task specific upper limb training and functional hand splinting for children with cerebral palsy or brain injury. Michelle is passionate about evidence-based healthcare with a focus how interventions can change the day-to-day lives of children and their families.



Dr Cathy Morgan, PhD, PT is a Research Fellow at the Cerebral Palsy Alliance Research Institute.

Dr Cathy Morgan is a recognised expert on early detection of cerebral palsy and evidence based early intervention for infants and toddlers with cerebral palsy and her expertise is sought after to support research in high risk infants. She is a member and network coordinator of the International Steering Group of IMPACT for CP and coordinates a network of clinicians and researchers focused on improving the early detection of cerebral palsy in high risk infants in NSW, Australia. Along with Professor Novak she has recently lead a publication of the international Clinical Practice Guideline on the Early Detection of Children with Cerebral Palsy in JAMA Pediatrics.



Dr Roslyn Ward, PhD, BSc (Sp Path)

Senior Research Fellow, Curtin University, School of Occupational Therapy and Social Work/Department of Paediatric Rehabilitation, Princess Margaret Hospital.

Lead Post-Doctoral Fellow for WA, NHMRC Aus CP-CTN.

Adjunct Research Fellow, Curtin University, School of Physiotherapy.

Sessional Academic, Curtin University, School of Psychology and Speech.

Dr Ward is actively engaged in clinically driven research with a focus on knowledge generation and translation. She is recognised for her specialist skills in the assessment and management of motor speech disorders. As a PROMPT (motor-speech intervention) Instructor, she teaches 3-day workshops in the Asia Pacific region. She leads communities of practice for motor-speech disorders within WA; and continues to mentor speech pathologists working with children with neurodevelopmental disabilities. She is a collaborator within the *West Australian Health Translation Network (WAHTN)*; and has an active collaboration with the Oral Dynamics Laboratory at the University of Toronto.

Abstract: The longitudinal development of babbling in infants identified as “at risk” of cerebral palsy.

Background: Early vocal behaviours (babbling) of infants are considered cornerstone to the development of early language, with the literature identifying delayed onset of babbling as a strong predictor of speech and language difficulties. Whilst it is well established that children with cerebral palsy (CP) are at risk of speech/language and communication difficulties, little is known about the development of babbling.

Aim: To report on a prospective longitudinal study aimed at describing the longitudinal development of babbling in infants identified as “at risk” of CP. Outcome measures include the Infant Monitor of Vocal Production (IMP) and Infraphonological Analysis Profile (IFAP).

Method: Infants were included if they were identified at risk of bilateral spastic CP by a medical practitioner, recruited < 6mos corrected age and medically stable. The IMP was utilised to obtain typical “stage for age” and percentage ranking of frequency and variety of vocal production. The IFAP was obtained from a 15 minute audio sample collected using the Language Environment Analysis (LENA).

Results: Data has been collected on four infants (3 male, 1 female), to a maximum of 4 timepoints (6, 9, 12, 15mo). IMP data show delayed babbling in all infants, with a percentage rank score that ranged from 50% to 60% at 6 months, 50% to 68% at 9 months and 50% to 77% at 12 months of age. The trajectory of change for 3 of the 4 participants was negative.

Conclusion: The participants of this study show delayed onset of canonical babbling, and suggests potential prognostic value.



Ms Cathryn Crowle, PhD scholar, MSpEd (Sensory Disability), BAppSc (OccTh) Hons. Senior Occupational Therapist at the Children’s Hospital at Westmead, Grace Centre for Newborn Intensive Care

Cathryn is currently completing her PhD investigating the use of the General Movements assessment with infants following major surgery in the neonatal period. She is the Senior Occupational Therapist in the NICU at the Children’s Hospital Westmead, and has extensive clinical experience with infants and children with cerebral palsy and vision/hearing impairment. Cathryn is a member of the NSW GMs Rater Network and collaborates with researchers at the CP Alliance to improve early detection of CP.

Abstract: Utility of the GMs assessment for early detection of CP in the neonatal surgical population

Background: Infants who undergo major surgery in the neonatal period are known to be at risk of poor neurodevelopmental outcomes, including CP, however there is a paucity of information on the use of the GMs assessment to predict outcomes in this population.

Method: This was a prospective cohort study of 278 infants who had undergone either cardiac surgery (n=149), non-cardiac surgery (n=123) or both types of surgery (n=6). Infants were assessed using the GMs at term and at three months of age and videos were independently rated by three advanced trained assessors, two blinded to infant details. Infants were re-assessed at 12 mths of age.



Results: At three months the majority of infants had normal fidgety movements (n=248, 89%), twenty five (9%) had absent fidgety, and five had abnormal fidgety. At 12 months, there was a significant difference in the developmental outcomes of infants with absent fidgety movements compared to those with normal fidgety movements, on all subtests of the BSID-III ($p < 0.05$). Of the 248 infants with normal fidgety, none had a diagnosis of CP at 12 months of age, however as expected in the surgical population, a large proportion (n=118, 48%) demonstrated delayed development. Of the twenty-five infants with absent fidgety, fifteen demonstrated clinical signs of CP at 12 months of age, and another six had developmental delay.

Conclusion: The GMs is a valid complementary assessment tool to enhance prediction of outcomes following early neonatal surgery.

Professor Susan Ngaire Stott,

PhD, FRACS, MB ChB
Professor of Paediatric Orthopaedic Surgery
University of Auckland, NZ.
Clinical Director, Department of Paediatric Orthopaedics, Starship Children's Hospital NZ.
Professor Stott is a Chief Investigator on the CRE, New Zealand lead, a member of the Clinical Trials Theme and Chair of the New Zealand CP Register.

Topic: Hot Topics on Muscle in CP Symposium

Professor Susan Stott is an academic paediatric orthopaedic surgeon, who has an interest in the consequences of chronic physical disability in childhood. The major focus of my research is the impact of acquired musculoskeletal disability on musculo-skeletal function and walking ability in childhood. I have been the principal investigator in a number of clinically based research projects which have sought to objectively assess functional outcomes after different orthopaedic interventions. Funding has been achieved for these projects through the multiple sources including HRC, AMRF, Neurological Foundation and Wishbone Trust. I am currently the clinical lead on the NZ Cerebral Palsy Register and am a CI on the NHMRC funded Centre of Research Excellence in Cerebral Palsy Research (UQ).



Abstract: "What do clinicians and researchers need to know about early musculoskeletal development in CP?"

Muscle volume in adults can be predicted exceptionally well with knowledge of gender, weight and body dimensions. However, the same prediction in the typically developing infant is more challenging. Infants exhibit larger muscle volume relative to their skeletal size and undergo extraordinarily rapid musculoskeletal growth over the first 2-3 years of life. This growth is exquisitely timed to match the developmental needs; for example, upper limb muscle growth is ahead of lower limb development, to facilitate early handling of objects and crawling.

Lack of normal developmental movement has significant effects on muscle growth, both longitudinal and volume in the small child. Children with hemiplegic CP demonstrate this when their affected and less loaded leg reaches muscle maturity well behind their contralateral leg. Fifty percent of growth will be complete by the age of 3 years; thus targeting early muscle development is key to ensuring better long-term outcomes for children with CP."

A/Professor Jane Valentine is a Paediatric Rehabilitation consultant and Head of Department of Kids Rehabilitation (a clinically integrated research unit) at the Perth Children Hospital (PCH). Kids Rehab has recently established Irehab – an intensive activity based Rehabilitation program with a strong focus on locomotor training incorporating robotics. The unit also have an established research program stream in the long term outcomes of Botulinum toxin in children with CP.



Associate Professor Jane

Valentine, FAFRM, FRACP
(Paediatrics) MRCP, MBBS
Head of Department Paediatric Rehabilitation, Princess Margaret Hospital for Children, WA.
Associate Professor, School of Paediatrics & Child Health, University of Western Australia.
Child Health Research Fellow,
Australasian Faculty of Rehabilitation Medicine

Topic: Hot Topics on Muscle in CP Symposium

Abstract: It is well recognised that both ambulatory and non-ambulatory children with CP have smaller, weaker muscles and increased sedentary behaviour compared to their typically developing peers. Of those children with CP who can walk, one in three are at risk of losing their ability to walk by early adulthood. Physical inactivity and sedentary behaviours are now recognised general national health issues known to contribute to obesity, diabetes and heart disease. There is evolving evidence that adults with CP have higher rates of these chronic diseases. This update will discuss early interventions and new ways of looking at current interventions to maintain

A/Professor Jane Valentine is a member of the Clinician network and is a member of two CRE themes: Clinical Trials; Knowledge Translation and Implementation.

Dr Lee Barber, PhD, M Phty, BAppSci (Hon), NHMRC ECF Postdoctoral Research Fellow, Queensland Cerebral Palsy and Rehabilitation Research Centre, Child Health Research Centre. Dr Lee Barber is an Associate Investigator on the CRE and a member of the Clinical Trials theme.

Mr Jarred Gillett, BExSc (Hons 1) PhD Scholar
Queensland Cerebral Palsy and Rehabilitation Research Centre, and School of Human Movement Science, The University of Queensland

musculoskeletal and cardiovascular health and reduce sedentary behaviour in the young child with a view to maintaining long term strength and improved activity and participation. Topics covered will also include activity based rehabilitation and robotics.

Topic: Hot Topics on Muscle in CP Symposium

Dr Barber is a post-doctoral fellow at QCPRRC in muscle mechanics, gait analysis and functional capacity and has more than 10 years clinical experience as a physiotherapist. His expertise is in muscle and tendon morphology and mechanics in children/adults with CP, including 3D freehand ultrasound, 3D motion capture, surface EMG and dynamometry to measure in-vivo muscle and tendon structure and function during gait. This data has been incorporated into patient specific musculoskeletal biomechanical models which allow orthopaedic surgeons to perform virtual surgery. Dr Barber also develops clinical tools to measure muscle mechanics and investigate how treatments for spastic type CP impacts muscle growth, structure and function and an individual's capacity to perform activities of daily living.

Topic: Hot Topics on Muscle in CP Symposium

Mr Gillett is a PhD Candidate within QCPRRC investigating structural and mechanical properties of muscle in individuals with CP, and how these can be influenced by physical interventions. He previously worked as a biomechanist at the Queensland Children's Motion Analysis Service. Mr Gillett is currently leading a randomised controlled trial to examine the impact of a combined functional anaerobic and strength training intervention on lower limb muscle structure and function in individuals with CP. This study is utilising musculoskeletal biomechanical techniques including ultrasound, 3D motion analysis, dynamometry, electromyography, and functional capacity assessments. Mr Gillett believes there may be long term benefits of this type of training in slowing the deterioration of muscle problems in people with CP and improve functional capacity.

Abstract: FAST CP: An RCT of a Functional Anaerobic and Strength Training Program

Progressive resistance training leads to increases in muscle size and strength. In individuals with CP, the evidence for neuromuscular adaption following progressive resistance training is limited, with no previous robust randomised controlled trials, varied training methods used, and a lack of objective outcome measures following training. Young adults with CP undertook a 12-week combined functional anaerobic and resistance training programme. Participants trained three sessions per week and included lower limb progressive resistance training (3-4 sets per exercise, progressive overload 12 to 6 RM) and functional anaerobic exercises (2-3 exercises, 20-30s all-out efforts). In the training group compared to a control group, there were increases in triceps surae and tibialis anterior muscle volume; maximum isometric strength; and functional capacity (sprint power, functional strength, walking distance) after training. Muscle hypertrophy enhances skeletal muscle metabolic capacity which may benefit overall cardiovascular health. The addition of anaerobic training to progressive resistance training may assist in the transfer of neuromuscular improvements to functional capacity in individuals with CP.



Dr Leanne Sakzewski, PhD, OT
Senior Research Fellow and NHMRC
ECF at the QLD Cerebral palsy and
Rehabilitation Research Centre, The
University of QLD. Dr Leanne
Sakzewski is an Associate Investigator
on the CRE and a member of three
themes: Clinical Trials, Knowledge
Translation and Implementation, and
Engagement and Health Policy

Professor Catherine Elliott, PhD
PhD, BSc (OT)
Chair of Allied Health, Child and
Adolescent Health Service, Princess
Margaret Hospital.
Professor, Faculty of Health Sciences,
School of Occupational Therapy and
Social Work, Curtin University.
Professor Elliott is a Chief Investigator
on the CRE, WA lead, and a member of
the Clinical Trials theme, Knowledge
Translation and Implementation
theme and the Clinician network.

Dr Claire Willis, PhD, BExSci (Hons)
Postdoctoral Research Fellow, FitSkills
NHMRC Partnership Project
La Trobe University, Melbourne

Topic: Participation for children with CP: What's hot and what's not?

Abstract: Traditional interventions targeting activity limitations have had little impact on reducing participation restrictions in children with cerebral palsy. Current evidence for and theoretical frameworks underpinning participation-focused therapies will be presented. Results from two studies using different models of participation focused interventions will be highlighted.

(i) Participate CP is an individually-tailored, goal-directed intervention, utilising a toolbox of strategies (e.g. goal-setting, barrier identification, strategy creation, and motivational interviewing) aimed at increasing participation in active physical leisure goals of choice. Results from a randomised waitlist controlled trial of Participate CP demonstrated that Participate CP led to significantly greater performance of attendance and/or involvement in active physical leisure participation goals, and fewer barriers to participation. Children who did not meet national guidelines for physical activity prior to Participate CP demonstrated on average an increase in daily moderate to vigorous physical activity of 13 minutes.

(ii) The Local Environment Model at Beitostolen Healthsports Centre in Norway is a group-based, intensive intervention seeking to enhance lifelong physical activity participation for children with disabilities. Evaluation of the intervention demonstrated significant improvements in performance and satisfaction of physical activity participation goals in 92 children and youth. Perspectives of children, parents, staff, and community service providers define the program mechanisms and contexts that promote meaningful outcomes, to inform translation and implementation in Australia. An overview of consumer and stakeholder engagement in the development and implementation of this participation-focused intervention will be described.

Topic: Participation for children with CP: What's hot and what's not?

Prof Elliott's clinical research position as the Chair of Allied Health (Curtin University and Child and Adolescent Health Services) supports the translation and implementation of clinical outcomes directly into clinical practice to improve the outcomes of, children and youth. . Professor Elliott advocates for and facilitates strong consumer engagement in research and has established a steering group to guide clinical research at Princess Margaret Hospital. . . Professor Elliott is also an adjunct professor at Telethon Kids and the University of Western Australia. She is as an inaugural elected member of the National Occupational Therapy Research Foundation.

Abstract: As above

Topic: Participation for CP: what's Hot and what's not?

Dr Claire Willis is an Accredited Exercise Physiologist and Postdoctoral Research Fellow within the FitSkills NHMRC Partnership Project in Melbourne, investigating the feasibility and health economics of a community-based physical activity participation intervention for youth with disabilities. Claire completed her PhD at the University of Western Australia in collaboration with Princess Margaret Hospital, and coordinated the Exercise and Health Promotion Service in the Department of Paediatric Rehabilitation. Claire is a passionate advocate for involving consumers and the community in child health research and service delivery, implementing and evaluating a model that has been utilised across these contexts. Claire is also part of an international collaborative team developing research guidelines and assessment tools for children with disabilities in low and middle-income countries.



Topic: Participation for CP: what's Hot and what's not?

Ms Sarah Reedman, BPhty (Hons)
PhD Student, ParticiPAte CP

Queensland Cerebral Palsy and
Rehabilitation Research Centre, The
University of Queensland

Sarah Reedman is a Physiotherapist and PhD student leading the ParticiPAte CP randomized clinical trial, investigating the efficacy of a novel participation-focused therapy intervention to facilitate participation in active leisure activities in children with cerebral palsy. Sarah has worked in the area of childhood disability since graduating from The University of Queensland in 2013, including a year working in a rural setting in south-west Queensland. Sarah has a strong interest in and passion for the access and participation of people with a disability in all areas of daily life, especially sports and recreation. Sarah is also involved in a project to restructure the service delivery model of the QLD Department of Education and Training Occupational Therapy and Physiotherapy Services, in order to align with contemporary evidence for participation-focused therapy. In her spare time, Sarah volunteers as a coach for the Brisbane Paralympic Football program.



Topic: Participation for CP: what's Hot and what's not?

Registration at: <https://cre-auscptn.centre.uq.edu.au/event/453/cp-research-forum>;

Registrations close on Monday 30th October.

- General Public 1 session ONLY \$25
- General Public 1 day ONLY \$50
- General Public 2 days \$100
- Student \$100
- External researcher/clinician 1 day \$150
- External researcher/clinician 2 days \$300

Location:

The venue has changed from originally advertised due to unforeseen circumstances. The new venue is:
Room 212, Sir Llew Edwards Building (Building 14)
St Lucia Campus, The University of Queensland.