



AusCP-CTN

**Australasian Cerebral Palsy
Clinical Trials Network**

CENTRE FOR RESEARCH EXCELLENCE

International Hot Topics in Cerebral Palsy Research Forum

5 March 2021

Australian Eastern Standard Time

WELCOME

FRIDAY 5 MARCH 2021

THE AUSTRALASIAN CEREBRAL PALSY CLINICAL TRIALS NETWORK (AUSCP-CTN) IS PROUD TO PRESENT THE 2021 INTERNATIONAL HOT TOPICS IN CEREBRAL PALSY RESEARCH FORUM, DELIVERED ONLINE VIA ZOOM

The event will unite key opinion leaders and colleagues in the field from Finland, Norway, Italy, USA, and of course our very own local experts across Australasia. The one-day international forum will showcase latest achievements and advancement in early diagnosis and intervention to improve outcomes for children with CP around the world. We would also like to take the opportunity to officially launch the free Jooay in Australia app - connecting children with disabilities to leisure activities in their local communities!

For more info:
[cre-auscpctn.centre.uq.edu.au/
2021-AusCPCTN-HotTopics](https://cre-auscpctn.centre.uq.edu.au/2021-AusCPCTN-HotTopics)



INVITED KEYNOTE SPEAKERS



A/Prof. Guro Andersen

Vesfold Hospital Trust, Tønsberg,
Norway



Prof. Iona Novak

Cerebral Palsy Alliance
Research Institute



Prof. Nadia Badawi AM

Cerebral Palsy Alliance
Research Institute



Dr Sandra Julsen Hollung

Oslo University Hospital; Vestfold
Hospital Trust, Tønsberg, Norway



A/Prof. Andrea Guzzetta

The University of Pisa, Italy



Olena Chorna

The University of Pisa, Italy



Prof. Rod Hunt

Monash Health



Prof. Sampsa Vanhatalo

Helsinki University Hospital



Mahesha Gentry

Cerebral Palsy Alliance Research
Institute



Dr Shona Goldsmith

Cerebral Palsy Alliance Research
Institute



Prof. Yannick Bleyenheuft

Professor, Institute of Neuroscience,
Université catholique de Louvain,
Bruxelles



A/Prof. Michael Fahey

Monash Children's Hospital



Dr Sarah McIntyre

Cerebral Palsy Alliance Research
Institute

PROGRAM

FRIDAY 5 MARCH 2021

Time (EST; UTC/GMT -5)	Time (CET; UTC/GMT +1)	Time (EET; UTC/GMT +2)	Time (AEDT; UTC/GMT+11)	Time (AEST; UTC/GMT+10)	Speaker	Topic
Forum Opening & Introduction – Prof. Roslyn Boyd						
1700-0705 Thu 4 Mar	2300-2305 Thu 4 Mar	0000-0005	0900-0905	0800-0805	Prof. Ros Boyd	Welcome & Introduction
1705-1715 Thu 4 Mar	2305-2315 Thu 4 Mar	0005-0015	0905-0915	0805-0815	Prof. Ros Boyd	AusCP-CTN CRE: Annual Report Card
Plenary Keynotes – Chair: Prof. Nadia Badawi						
1715-1745 Thu 4 Mar	2315-2345 Thu 4 Mar	0015-0045	0915-0945	0815-0845	A/Prof. Guro Andersen Dr Sandra Hollung	Update from the Norwegian Quality and Surveillance Registry for Cerebral Palsy (NorCP)
1745-1815 Thu 4 Mar	2345-0015 Thu 4 Mar	0045-0115	0945-1015	0845-0915	Dr Shona Goldsmith Dr Sarah McIntyre	Update from Australian CP register
1815-1845 Thu 4 Mar	0015-0045 Fri 5 Mar	0115-0145	1015-1045	0915-0945	Prof. Nadia Badawi	Prevention of CP: What else can we do?
1845-1850 Thu 4 Mar	0045-0050 Fri 5 Mar	0145-0150	1045-1050	0945-0950	Natasha Garrity	Official Launch - Jooay in Australia App
1850-1715	0050-0115	0150-0215	1050-1115	0950-1015		Break
1715-1945 Thu 4 Mar	0115-0145	0215-0245	1115-1145	1015-1045	A/Prof. Michael Fahey	Update on Genomics of CP
1945-2000 Thu 4 Mar	0145-0200	0245-0300	1145-1200	1045-1100	Yana Wilson	ICPGC Updates: The CP Commons and Common Data Elements
2000-2015 Thu 4 Mar	0200-0215	0300-0315	1200-1215	1100-1115	Prof. Iona Novak	Stem Cells for Cerebral Palsy: Current State of the Science
2015-2030 Thu 4 Mar	0215-0230	0315-0330	1215-1230	1115-1130	Prof. Rod Hunt	Neuroprotection for the Extremely Preterm Infant: A potential role for stem cells
2030-2045	0230-245	0330-0345	1230-1245	1130-1145		Break

PROGRAM

FRIDAY 5 MARCH 2021

Early Detection & Neonatal Clinical Trials – Chair: Prof. Roslyn Boyd

2045-2100 Thu 4 Mar	0245-0300	0345-1400	1245-1300	1145-1200	Anne te Velde	Understanding the Early Natural History of Cerebral Palsy Study Update
2100-2115 Thu 4 Mar	0300-0315	0400-0415	1300-1315	1200-1215	Rachel Byrne	Implementation of Early Detection of CP in the USA
2115-2130 Thu 4 Mar	0315-0330	0415-0430	1315-1330	1215-1230	Dr Sian Williams	The Cerebral Palsy Diagnosis Experience and Ensuing Clinical Pathways: using a co-design approach to improve the healthcare journey
2120-2145 Thu 4 Mar	0330-0345	0430-0445	1330-1345	1230-1245	Prof. Jane Valentine	Implementation of Early Detection and Early Intervention for Babies at risk of Cerebral Palsy at Perth Children's Hospital in Western Australia: a service evaluation
2145-2200 Thu 4 Mar	0345-0400	0445-0500	1345-1400	1245-1300	Dr Eliza Maloney Clare Wiltshire	Humble Beginnings: The quest for an equitable, evidence-based, state-wide pathway for 'at risk' Tasmanian neonates
2200-2215 Thu 4 Mar	0400-0415	0500-0515	1400-1415	1300-1315	Carly Luke Prof. Ros Boyd	Aboriginal and Torres Strait Islander Infants at risk of Adverse Neurodevelopmental Outcomes: a prospective cohort study
2215-2245	0415-0445	0515-0545	1415-1445	1315-1345	Break	

Child & Adolescent CP Clinical Trials – Chair: A/Prof. Leanne Sakzewski

2245-2300 Thu 4 Mar	0445-0500	0545-0600	1445-1500	1345-1400	Dr Sarah Reedman	An Update on the Participate CP RCT of Participation-focused Physical Activity Intervention in Children with CP
2300-2315 Thu 4 Mar	0500-0515	0600-0615	1500-1515	1400-1415	A/Prof. Leanne Sakzewski	Hand Arm Bimanual Intensive Training Including Lower Extremity: HABIT-ILE Australia Update
2315-2330 Thu 4 Mar	0530-0530	0615-0630	1515-1530	1415-1430	Dr Dayna Pool	Locomotor Training in Children with Cerebral Palsy, GMFCS levels IV and V
2330-0045	0530-0545	0630-0645	1530-1545	1430-1445	Break	

PROGRAM

FRIDAY 5 MARCH 2021

Neuroimaging in Neonates & CP – Chair: Dr Jurgen Fripp

2345-0000 Thurs 4 Mar	0545-0600	0645-0700	1545-1600	1445-1500	Dr Kerstin Pannek	Brain MRI of Preterm Newborns
0000-0015 Fri 5 Mar	0600-0615	0700-0715	1600-1615	1500-1515	Dr Alex Pagnozzi	Using Cloud-based Tools to Deliver Advanced MRI Analyses to the Clinic
0015-0030	0615-0630	0715-0730	1615-1630	1515-1530	Prof. Sampsa Vanhatalo	Wearable Technology for Early Neurological Diagnosis: challenges and promises
0030-0045	0630-0645	0730-0745	1630-1645	1530-1545		Break

Infant & Preschool CP Clinical Trials – Chair: Prof. Roslyn Boyd

0045-0100	0645-0700	0745-0800	1645-1700	1545-1600	Dr Sarah Reedman	Active Start Active Future: swapping sedentary time for active time in pre-school children with CP using the science of behaviour change
0100-0130	0700-0730	0800-0830	1700-1730	1600-1630	Prof. Yannick Bleyenheuft	Recent Advances for Early HABIT-ILE in Children with Cerebral Palsy
0130-0200	0730-0800	0830-0900	1730-1800	1630-1700	A/Prof. Andrea Guzzetta	Update on the VISIBLE study for Seeing Impaired Infants
0200-0230	0800-0830	0900-0930	1800-1830	1700-1730	A/Prof. Andrea Guzzetta Olena Chorna	BornTogether: Implementation of Early Detection and Early Intervention Service Delivery in Infants at Risk for Cerebral Palsy to Promote Infants' Psychomotor Development and Maternal Health
0230-0245	0830-0845	0930-0945	1830-1845	1730-1745	Dr Kath Benfer	Update on the LEAP-CP Programs - RCT of Peer delivered early intervention for children with CP: Indian and Aboriginal & Torres Strait Islander Trials
0245-0255	0845-0855	0945-0955	1845-1855	1745-1755	Prof. Ros Boyd	Closing Remarks

WELCOME & OPENING

AUSTRALASIAN CEREBRAL PALSY CLINICAL TRIALS NETWORK (AUSCP-CTN): 4 YEAR REPORT CARD

The Australasian Cerebral Palsy Clinical Trials Network (AusCP-CTN, NHMRC Centre for Research Excellence) is a multi-national team of experts in paediatric neurology, neonatology, epidemiology, rehabilitation and knowledge translation – coming together with one vision – reduction of CP and improved outcomes in children. Since establishment of the network in 2017, the team has been working tirelessly towards our vision, through developing and implementing three international clinical practice guidelines across clinical settings (early diagnosis, early intervention, and functional therapy); upskilling 1,000+ clinicians on gold standard tools for detection of infants at risk of CP; testing efficacy of novel interventions (13 national multisite trials) for children with cerebral palsy and their families, and working with 50+ consumers and families to develop inclusive user-friendly apps for the community. The Australasian CP Clinical Trials Network has progressed on our work-plan to uplift earlier detection of CP, fast tracked children to multisite randomised clinical trials of new neuroprotectants, and to develop and test new

rehabilitation. Outputs from the Network have contributed towards the Australian Cerebral Palsy Register, which the latest report showed the rate of CP has fallen from 1 in 400, to 1 in 700 live births, due multifactorial and concerted team effort across Australia of families, clinicians and researchers in the areas of public health, obstetrics and midwifery, neonatology, paediatrics and of course epidemiology.

Through generous funding support from the NHMRC-EU Horizon 2020 grant, the AusCP-CTN is also the Australian arm of the international BORNTOGETTHERE Consortium (led by AI A/Prof. Andrea Guzzetta, The University of Pisa). Going forward, the AusCP-CTN will partner with Consortium members to exploit current evidence on early detection, characterisation and intervention for infants at high risk of CP by implementing the first International Clinical Practice Guideline in multiple sites in Europe (Italy, Denmark, Netherlands), in low and middle-income countries (Georgia, Sri Lanka) and hard to reach populations (Queensland and remote Australia).

Prof. Roslyn Boyd

Chief Investigator and Director of the AusCP-CTN CRE
Scientific Director of the Queensland Cerebral Palsy Rehabilitation & Research Centre, Faculty of Medicine, The University of Queensland

Professor Boyd leads an internationally recognised team of researchers conducting clinical trials of novel interventions geared to optimising neuroplasticity, early detection of cerebral palsy, longitudinal comprehensive outcomes linked to brain structure and function. Her team has conducted 17 RCTs in CP and infants born preterm. She has received >\$40M in grants including 13 NHMRC, 1 ARC, 1 NIH and has published >305 publications. She has had continuous NHMRC people support, being a Research Fellow (2016-2021) and previous QLD Smart State Fellow. She and her research team have been awarded the most prestigious international prize for CP Research, the Gayle Arnold Award, in 2010, 2011 and 2014. Recently she received the Mentorship Award from The American Academy for Cerebral Palsy and Developmental Medicine and the Faculty of Medicine at The University of Queensland.



KEYNOTE SESSION

UPDATE FROM THE NORWEGIAN QUALITY AND SURVEILLANCE REGISTRY FOR CEREBRAL PALSY (NORCP)

The aim of the Norwegian Quality and Surveillance Registry for Cerebral Palsy (NorCP) is to promote knowledge-based and equal treatment for people with cerebral palsy. NorCP is the result of many years of close cooperation between the Cerebral Palsy Registry of Norway and the Cerebral Palsy Follow-up Program, which in 2020 was merged into one registry. Participation in NorCP means that children with cerebral palsy from the time of early diagnosis and up to age 18 years are systematically

assessed by a multi-disciplinary team of professionals according to standardized protocols, and that data from the assessments are registered in the national registry. Our main aims are to monitor prevalence of CP, specifically causes and risk factors, and to ensure that every child receives “the right treatment at the right time” using evidence-based measures.

We will report on the latest NorCP research and quality improvement projects.

A/Prof. Guro L. Andersen

Pediatrics Specialist, Habilitation Center, Vestfold Hospital Trust, Tønsberg, Norway

Dr. Guro L. Andersen, MD is an authorized Pediatrics Specialist working as a neuropaediatrician at the Habilitation Center, Vestfold Hospital Trust, Tønsberg, Norway. She is one of the founders and current Leader of the Norwegian Quality and Surveillance Registry for Cerebral Palsy (NorCP) (formerly: Cerebral Palsy Registry of Norway).

She holds a part time position as Associate Professor at the Department of Clinical and Molecular Medicine, Faculty of Medicine and Health Sciences, Norwegian University of Science and Technology in Trondheim, Norway.

Her PhD is in Public Health and her research experience is mainly in the field of cerebral palsy (risk factors, motor function and associated impairments). She is Principal Investigator/Project Leader for many national and international research projects including: CP-NORTH: Living Life with Cerebral Palsy in the Nordic Countries, The WE Study: Does botulinum toxin A make walking easier in children with cerebral palsy, and the CPPain programme.



Dr Sandra Julsen Hollung

Health Informatics Specialist and Researcher, Vestfold Hospital Trust, Tønsberg, Norway and Oslo University Hospital, Oslo, Norway.

Dr Sandra Julsen Hollung is a Health Informatics Specialist and Researcher for the Norwegian Quality and Surveillance Registry for Cerebral Palsy (NorCP) at the Vestfold Hospital Trust, Tønsberg, Norway and Oslo University Hospital, Oslo, Norway.

Her PhD is in Medicine and Health Sciences and her research experience is in the field of cerebral palsy (prevalence and comorbidities). She is a research team member in many national and international research projects including: CP-NORTH: Living Life with Cerebral Palsy in the Nordic Countries, CPPain programme and Global trends and prevalence of cerebral palsy: a systematic analysis study. Her expertise is also in the validation/quality of registry data and linking national registries.

Since 2012, she has been an Elected Member of the European Union Joint Research Centre/Surveillance of Cerebral Palsy in Europe Management Committee. She has been a member of the American Academy for Cerebral Palsy & Developmental Medicine International Committee since 2020.



KEYNOTE SESSION

UPDATE FROM THE AUSTRALIAN CP REGISTER (ACPR)

The Australian CP Register (ACPR) exists as a result of a collaboration between state/territory cerebral palsy (CP) registers across Australia and includes records for >9000 children with CP. The CP registers are important resources for both epidemiological and clinical research. Historically, one challenge in epidemiological CP research has been the limited number of cases available after stratification when studying small subgroups of CP. In this presentation, we will illustrate the utility of a collaboration between the ACPR and the Surveillance of Cerebral Palsy

in Europe. This collaboration has provided sufficient numbers of records to conduct research aimed at better understanding the clinical profile and specific aetiological risk factors in small but important CP subgroups (eg. higher order multiples and post-neonatally acquired CP). In the second half of this presentation, we will provide an overview of current research and quality assurance activities being conducted by state/territory CP registers from across Australia.



Dr Shona Goldsmith

Research Fellow, Cerebral Palsy Alliance Research Institute, The University of Sydney

Shona is a Research Fellow in Epidemiology at the Cerebral Palsy Alliance Research Institute, The University of Sydney. Shona runs the ACT CP Register and is a Policy Group member of the Australian Cerebral Palsy Register. Her research focuses on aetiology and prevention, with recent studies on congenital anomalies, assisted reproductive and multiple births. Shona is motivated by the power of national and international collaborations to build epidemiological research capacity.



Dr Sarah McIntyre

Senior Research Fellow, Cerebral Palsy Alliance Research Institute, The University of Sydney

Sarah is a Senior Research Fellow at Cerebral Palsy Alliance Research Institute, The University of Sydney. She is responsible for running the NSW CP Register and is the current Chair of the Australian Cerebral Palsy Register Group. She is a perinatal and paediatric epidemiologist and her work focuses on the aetiology and prevention of cerebral palsy and other developmental disabilities. Sarah strongly believes in community involvement in research and she is the research lead for CP Quest – community and researchers together.

KEYNOTE SESSION

PREVENTION OF CP: WHAT ELSE CAN WE DO?

Two years ago, the Australian Cerebral Palsy Register Report showed a remarkable 30% drop in the rate of cerebral palsy with Australia now having one of the lowest recorded rates in the world. This decrease was sustained in the latest report in 2020. Falls of a lesser magnitude are also being reported in other regions including Europe. These promising results are encouraging health professionals, families, researchers and others to search for other ways to protect the brain of the developing fetus, the high risk newborn in intensive care and those infants thought to be at high risk of cerebral palsy.

Around 50% of people who are diagnosed with CP spent time in a newborn intensive care unit or special care unit suggesting this may be an optimal time to study and institute preventative strategies. Already there is considerable energy being expended to decrease the potentially neurotoxic effects of newborn intensive care through skin to skin care, support of breastfeeding and neurodevelopmental care.

Prematurity remains a major risk factor for cerebral palsy. Promising strategies are emerging including the Western Australian Preterm Birth

Prevention and the “Birthing on Country” initiatives. We are also witnessing a decrease in intracranial haemorrhage in preterm infants in Australia and New Zealand. New evidence has also been published around the role of therapies such as caffeine, erythropoietin and delayed cord clamping as well as confirming the protective effect of antenatal magnesium sulphate.

For term babies there is acceleration of breakthroughs in the areas of genomics, cytomegalovirus infection prevention, antenatal diagnosis of birth defects and the search for adjuvant therapies to therapeutic hypothermia. There is increasing interest in the role of engineering, technology and artificial intelligence to predict and prevent adverse events. Further improvements will require data sharing facilitating accelerated large multicentre trials with multidisciplinary teams.

Research in the area of cerebral palsy prevention and mitigation has become a vibrant and rapidly progressing area of clinical and academic endeavour that is creating real and meaningful progress.



Prof. Nadia Badawi AM

Macquarie Group Foundation Professor; Chair of Cerebral Palsy, Cerebral Palsy Alliance Research Institute

Professor Nadia Badawi AM is the Macquarie Group Foundation Professor and Chair of Cerebral Palsy at the Cerebral Palsy Alliance Research Institute, The University of Sydney. She is the Medical Director and co-Head of the Grace Centre for Newborn Care and a member of the NICUS Managers Group. She is a member of the Australian CP Register; and has been a Co-Chair of 8 International Cerebral Palsy Prevention and Cure Summits. She has been a leader in changing developmental follow-up procedures for all children who have surgery and was involved in the establishment of an Australian and NZ Neonatal surgery network. Nadia was a member of the committee for the Australian Cerebral Palsy Strategy Development. She was awarded an AM in the Queen's Birthday Honours List: for significant service to paediatrics, neo-natal intensive care and research into cerebral palsy in 2014 and was selected as one of the 100 Australian Women of Influence (Australian Financial Review & Westpac): global category for leadership in the search for prevention and cure of cerebral palsy, and providing educational opportunities for children in developing countries.

KEYNOTE SESSION

OFFICIAL LAUNCH: JOOAY IN AUSTRALIA - CONNECTING CHILDREN AND YOUTH WITH DISABILITIES TO LEISURE

Background: Children with disabilities experience restrictions participating in the community. Increased participation in leisure and recreation enables social connectedness and physical activity, enhancing health and quality of life. The challenge is finding the appropriate community leisure opportunities which are accessible and inclusive for individuals with disabilities and health conditions. There is currently no centralized resource to help families find such leisure opportunities in their local communities. A Canadian application 'Jooay' (<https://jooay.com/>) provides a platform which could address this need.

Jooay in Australia: Jooay is a free app that helps families locate leisure opportunities that are accessible, suit their needs and abilities, match their preferences, and enhance their ability to participate in their local communities. While the current focus of the app is Canadian activities, we are partnering with colleagues in Western Australia and New South Wales to build a community of inventory of community leisure/recreation activities.

What are community leisure activities?

Community leisure activities include organised sports, camps, arts or miscellaneous activities (scouts, clubs and societies etc.) that are genuinely recreational in nature. Community



leisure does not include respite care or activities in which the primary aim is therapeutic.

How does it work? Jooay can be downloaded and installed on phones running iOS 10.3 or later, or Android 4.4 and up. It is a GPS-based repository of information about leisure and recreation opportunities. Users can see activities on a map or in a list (with the distance to their current location). Users can also search for activities and apply filters to return results that are likely to meet their needs.

We have been able to complete this project with thanks to Prof Catherine Elliott and the team at Curtin University and Dr Keiko Shikako-Thomas and Dr Annette Majnemer and the Canadian Jooay Team. More info on: <https://cre-auscpcn.centre.uq.edu.au/article/2021/18/JOOAY>



Natasha Garrity

Research Assistant (Jooay), Cerebral Palsy Alliance Research Institute

Natasha graduated from high-school in 2018, volunteered as a research assistant at the Cerebral Palsy Alliance Research Institute and is now enrolled at Macquarie University. She is also an ambassador for the Cerebral Palsy Research Foundation and an active member of CP Quest, and a member of the NSW/ACT CP Register Advisory board. Natasha is interested in becoming a health researcher with a focus on cerebral palsy prevention and treatment.

Natasha is currently working as a casual research assistant to develop the content and implement the ACT/NSW arm of the JOOAY App in Australia. This application aims to promote community-based recreation activities for children and adults living with a disability to improve their health and wellbeing.

KEYNOTE SESSION

UPDATES ON GENOMICS OF CP

The International Cerebral Palsy Genomics

Consortium (ICPGC) is a global consortium that was established in 2017, with the major goal of creating an open forum for collaboration among clinicians and researchers dedicated to unravelling the genomic basis of cerebral palsy. In support of this effort, the ICPGC is developing the CP Commons, a unified data repository that enables data sharing. This talk will give you a brief update on the consortium, our current projects and what we are aiming to achieve.



A/Prof. Michael Fahey

Department of Paediatrics, Monash University; Head of Child Neurology, Director of Neurogenetics, Monash Children's Hospital

Associate Professor Michael Fahey is 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. Michael's research focuses on using neurogenetics to understand the pathways that lead to 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. Among the work is research into melatonin, a hormone produced in the brain, with good efficacy in preclinical trials. Excitingly, this work is now moving to human trials.

Michael maintains a workload as a physician in Paediatric Neurology and in Neurogenetics clinics as well as neurologist at the Paediatric Rehabilitation Clinic. Associate Professor Michael Fahey has also been awarded a Fulbright Scholarship in 2019-2020 which will allow him to draw together two distinct research arms into genomics and brain imaging primarily located in Australia and the United States.

KEYNOTE SESSION

ICPGC UPDATES: THE CP COMMONS AND COMMON DATA ELEMENTS

The International Cerebral Palsy Genomics Consortium (ICPGC) was formed as a collaborative international network of clinicians, researchers, and advocates to maximise their collective impact on evaluating the genomic contribution to cerebral palsy (CP). To achieve this goal, we have created the CP Commons, an online resource that aggregates genomic and clinical data collected from people with CP. This presentation will demonstrate the CP Commons and give an update on the Common Data Elements for clinical data in CP genomics studies.



Yana Wilson

Research officer, CP Genomics, Cerebral Palsy Alliance Research Institute, The University of Sydney

Yana Wilson is a Research Officer at the Cerebral Palsy Alliance Research Institute. Her main research interests are investigating genetic variation that contribute to cerebral palsy and other neurodevelopmental disorders, and the harmonisation, standardisation and management of big data assets. Yana is a founding member and Governance Council member of the International Cerebral Palsy Genomics Consortium (ICPGC), and leads the development of the CP Commons, a data platform that will allow researchers and clinicians to share de-identified data to accelerate cerebral palsy genomics.

KEYNOTE SESSION

STEM CELLS FOR CEREBRAL PALSY: CURRENT STATE OF THE SCIENCE

Stem cells are a new frontier in medicine. Many parents of children with cerebral palsy feel compelled to buy cell therapies overseas, given the lack of available treatments in Australia. COVID-19 has interrupted many family's stem cell tourism travel plans. This talk will provide an overview of the latest safety and efficacy research of stem cell therapies for cerebral palsy, including numbers treated and clinical trial results. We will also examine the changing attitudes to stem cell therapies. The talk will conclude by critically evaluating next steps for the field, the barriers and facilitators to accelerating the research pipeline.



Prof. Iona Novak

Head of Research, Cerebral Palsy Alliance Research Institute, The University of Sydney

Professor Iona Novak is Head of Research at Cerebral Palsy Alliance Research Institute, Sydney.

Professor Novak oversees the research activities of Institute and supports the Australian Cerebral Palsy Register. Professor Novak is a Fulbright Scholar and her background is in occupational therapy with research interests in evidence-based practice; home programs; and neuroprotection.

KEYNOTE SESSION

NEUROPROTECTION FOR THE HIGH-RISK NEWBORN INFANT

In this presentation Professor Hunt will review current and future therapies for which trials are being developed to protect the newborn brain. High-risk newborns, whether born prematurely or at term, are vulnerable to cerebral injury, with white matter injury being most prevalent. Therapies targeting protection of the immature white matter, if beneficial, should bring further reductions to the rate of cerebral palsy.

Prof. Rod Hunt

Professor of Neonatal Medicine, Monash University; Co-Director of Neonatal Research at Murdoch Children's Research Institute; Director of Research in Victoria, Cerebral Palsy Alliance

Rod Hunt is the Professor of Neonatal Medicine at Monash University, Co-director of Neonatal Research at MCRI, and Director of Research in Victoria for the Cerebral Palsy Alliance. His research has included MR imaging of the newborn brain, as well as utilisation of neuromonitoring tools such as aEEG and NIRS. He has had a strong focus on neurodevelopmental outcomes for high-risk newborns, and he is interested in neuroprotection for the preterm and term born infant.



EARLY DETECTION & NEONATAL CLINICAL TRIALS

IMPLEMENTATION OF EARLY DETECTION OF CP IN THE USA

The Cerebral Palsy Foundation (CPF) is a charitable organisation, based in New York City, USA. The CPF defines and leads research, innovation and collaboration that changes lives for people with cerebral palsy. CPF's collaborative Networks bring together many of the world's most prestigious medical institutions, as well as innovative thinkers and key opinion leaders in diverse areas such as technology and media, in order to accelerate not only the development of critical advances, but also their delivery.

While CPF's work includes important strides being made towards the eventual prevention of cerebral palsy and developmental disabilities, CPF's focus is on the translational research, clinical application and knowledge transfer that can dramatically change lives today.

Rachel Byrne

Executive Director, Cerebral Palsy Foundation, USA

Rachel Byrne is the Executive Director at the Cerebral Palsy Foundation. She has been working in the field of pediatric rehabilitation and cerebral palsy research for the past 14 years. Rachel has a background in physical therapy, with a particular interest in neuroplasticity and motor learning. Her early career as a clinician delivering physical therapy services in schools, hospitals and private practice is underpinned by her research interests focused on knowledge translation and the impact on a person's ability to participate in the community across the lifespan.

At the Foundation, she has continued her research interest in evidence-based practice, knowledge translation, early detection and interventions across the lifespan and population studies for cerebral palsy. Rachel was instrumental in developing the Just Say Hi inclusion curriculum which is now being taught nationally. In the last 12 years she has given multiple presentations at international conferences and managed large multisite research projects.



EARLY DETECTION & NEONATAL CLINICAL TRIALS

THE CEREBRAL PALSY DIAGNOSIS EXPERIENCE AND ENSUING CLINICAL PATHWAYS: USING A CO-DESIGN APPROACH TO IMPROVE THE HEALTHCARE JOURNEY

The receipt of the diagnosis of cerebral palsy (CP) presents a family with one of the first significant moments in the management of the condition and is believed to play a central part in shaping the parental role for years to come. The diagnosis experience, early care pathway and the patient/family journey can be a complex and varied process, but with growing access to and awareness of evidence-based assessment tools and early management, there continues to exist opportunities for improvement in health service delivery. Co-design is a participatory approach to prioritising solutions and strategies for change in healthcare that recognises value in collaboration between patients, support people, and healthcare staff. Our aim was to co-create prioritised solutions and strategies for change, with a goal to support improvements in early health service delivery around early diagnosis and management in CP. Two Co-design workshops, facilitated by an external Health Design team were held in Auckland, New Zealand. The 'Discovery' workshop focused on around sharing experiences, opinions, and ideas on the topic, whilst the second workshop 'Prototyping' centred on ideas around 'solutions'. Six mothers (of children ranging GMFCS I-IV, diagnosis

between 12-24mo of age) and 9 clinicians (Paediatric Neurologist, Paediatrician, Developmental Paediatrician (n=2), Paediatric physiotherapist, Developmental Occupational Therapist, Neuropsychologist, Doctor) participated in the co-design process. Three of the 9 clinicians attending both workshops, and all but one mother attended both workshops. Two more workshops are planned for Māori families and clinicians, which will be co-led by a Māori Health Service worker and will follow culturally appropriate practices.

The Discovery workshop revealed powerful stories about early experiences (what works well, what does not), the needs within clinician-family communication, and the needs within service provision. The Prototyping workshop revealed that it was felt that digital information on CP can be overwhelming, often country-specific, and not always trustworthy, and recommendations were co-created around what should be prioritised within a resource. The development of an educational resources targeted for families, but packaged also as guidance for clinicians, is currently underway by the Design for Health team, with further input planned from Maori families and clinicians planned.

Dr Sian Williams

Research Fellow, Curtin University and The University of Auckland, NZ

Dr Sian Williams is a Senior Lecturer at the School of Allied Health, Curtin University, and post-doctoral fellow with the Australasian Cerebral Palsy Clinical Trials Network, based in Auckland New Zealand. The key focus of Sian's work in New Zealand has centred on the early detection of cerebral palsy (CP), supporting the training and implementation of key diagnostic tools for earlier detection, and the generation of new knowledge around current practice- with a large emphasis on involving the family perspective and identifying potential inequities in service access. Further to this, Sian is also working to understand impaired muscle growth in infants born prematurely and at risk of neurological injury, seeking to understand the relationship between delayed/impaired musculoskeletal growth, motor development, and neurological injury.



EARLY DETECTION & NEONATAL CLINICAL TRIALS

IMPLEMENTATION OF EARLY DETECTION AND EARLY INTERVENTION FOR BABIES AT RISK OF CEREBRAL PALSY AT PERTH CHILDREN'S HOSPITAL IN WESTERN AUSTRALIA: A SERVICE EVALUATION

Background: The Kids Rehab WA Early Intervention Service (EIC) is a tertiary program that provides specialist, multidisciplinary assessment, diagnosis and intervention for babies and children up to 4 yo with complex neurodevelopmental needs.

Between July 2015 and December 2019 EIC expanded to implement the published recommendations for early detection and early intervention for babies at risk of cerebral palsy. This expansion was done in three phases;

1. a pilot to introduce early detection protocols and training
2. an expansion phase to increase clinical services and research
3. an evaluation phase

The implementation has been fully supported by the active Kids Rehab Consumer Group, which confirmed that early intervention is a priority and has guided implementation and evaluation. The EIC research integrated into the EIC clinical service was supported by the NHMRC funded Australian Cerebral Palsy Clinical Trials Network (AusCP-CTN). In alignment with evidence-based family-centred practice in early intervention, the tertiary PCH service works closely with health and disability service providers who deliver community and home-based support for babies and families.

Objectives: To describe the implementation of the recommendations for early detection and early intervention for babies at risk of cerebral palsy in the Kids Rehab WA EIC at PCH and the outcomes.

Design: The Knowledge to Action Framework¹ was used to guide implementation of the recommendations for early detection and early intervention for babies at risk of cerebral palsy. An observational quantitative cohort study design with prospective and retrospective data collection was used to measure change following the implementation and to identify factors that determined service access.

Methods: Implementation measures included number of babies and age of referral, number of assessments (GMAs, HINE and MRI) delivered at time points aligned with the early detection algorithm², number of clinicians trained in early detection assessments, clinical resources and activity used for service provision, number of children enrolled in clinical research trials, data collection compliance and quality and parent satisfaction.

All babies referred to EIC between 1/7/2015 and 31/12/2019 were included and allocated to a cohort aligned with the three implementation phases. Change in outcome variables (age of cerebral palsy diagnosis and number of children diagnosed with cerebral palsy) between the three phases were compared to the pre-implementation cohort referred for diagnosis of cerebral palsy between 1/7/2014 and 30/6/2015.

Descriptive statistics; mean, median, standard deviations and proportions, were reported for all continuous variables, and frequencies and percentages for categorical variables. Sociodemographic variables (Australian Bureau of Statistics SEIFA scores and Adverse Childhood Experience scores) were used as covariates to assess for significant association with other variables in a logistic regression model. This study has ethical approval from the West Australian (WA) Child and Adolescent Health

EARLY DETECTION & NEONATAL CLINICAL TRIALS

Service (RGS0000004288) and reciprocal approval from Curtin University, WA.

Results: Data for 640 babies and children was analysed for the period 1/7/2014 to 31/12/2019; Results will be presented.

Conclusions: The recommendations for early detection and early intervention for children at risk of cerebral palsy have been successfully implemented at PCH in the Kids Rehab WA EIC and improved outcomes for babies referred to the service. This preparation for implementation of a state-wide network aims to improve outcomes for all babies in Western Australia at risk of CP and their families by improving access to gold standard, evidence based early detection and early intervention. Furthermore, planned research will build on this to provide a framework for development of clinical networks for other neurodevelopmental disabilities.



Prof. Jane Valentine

Paediatrician, Perth Children's Hospital

Prof. Jane Valentine is a Paediatrician in the Kids Rehab Department at the Perth Children's Hospital WA and Head of Research for Kids Rehab WA. Prof. Valentine is also a Clinical Professor at The University of Western Australia, Medical School.

EARLY DETECTION & NEONATAL CLINICAL TRIALS

HUMBLE BEGINNINGS: THE QUEST FOR AN EQUITABLE, EVIDENCE-BASED, STATE-WIDE PATHWAY FOR 'AT RISK' TASMANIAN NEONATES

The SPARK Project is an 18-month project currently operational in Tasmania. SPARK is an acronym for **S**tate-wide **P**athway for **A**t **R**isk **K**ids, but moreover refers to the SPARK of neuroplasticity that early intervention can elicit in the developing brain*. The SPARK Project's primary aim is to develop a state-wide clinical pathway for 'at risk' Tasmanian infants incorporating international guidelines for early detection of cerebral palsy (CP).

Whilst many individual Tasmanian clinicians were aware of the benefits of early detection and the existence of the international guidelines (Novak et al, 2017), there was previously no state-wide approach regarding implementation of these principles. A handful of GM-trained clinicians were raising awareness in their individual work areas, but a coordinated, state-wide approach was lacking. Clinicians working in 'at risk' infant follow-up clinics across the three Tasmanian regions were eager for a coordinated approach and welcomed the SPARK Project to support their hard work in this area.

Our Project followed a co-design approach, incorporating consumers on our state-wide steering committee and undertaking in-depth interviews with a selection of families. We also learnt an enormous amount from clinicians at leading hospitals on the mainland who were extremely generous with their time. After the

initial research and scoping phase, the Project began to work through its main priorities:

Developing a state-wide clinical guideline outlining eligibility, assessments, and specific review ages for children in follow-up clinics across Tasmania

Developing resources for families

Delivering training to clinicians working in 'at risk' infant follow-up clinics.

Clinical redesign efforts to support implementation including development of new forms, guidelines, advocacy with eHealth regarding GM IT infrastructure, funding of equipment, re-naming clinics, etc.

Tasmania is a small island with a population of around 500,000 people. We are in the unique position of having just one health service. The SPARK Project was strengthened by the formation of state-wide steering committee and working groups, in which passionate clinicians worked together to create a pathway for Tasmania's 'at risk' infants over time. From humble beginnings, we now have a state-wide vision to guide our work in this area and hopefully *spark* many neurons for years to come.

*funding was provided by the Australian Government through the National Partnership Agreement on Improving Health Services in Tasmania.

Dr Eliza Maloney

State-wide Paediatric Rehabilitation Consultant, FRACP, AFRM

Dr Eliza Maloney is a state-wide Paediatric Rehabilitation Consultant and a General Paediatrician based in Hobart, Tasmania. She holds a Senior Lecturer Position at University of Tasmania.



Clare Wiltshire

Physiotherapist and SPARK Project Officer

Clare is a physiotherapist and project officer working alongside Dr Eliza Maloney on the SPARK (State-wide Pathway for At Risk Kids) Project. Alongside a clinical interest in neurology, Clare is studying a Grad. Cert. in Clinical Redesign and is passionate about ensuring that health systems deliver equitable, evidence-based care with the client at the heart of the picture.



EARLY DETECTION & NEONATAL CLINICAL TRIALS

ABORIGINAL AND TORRES STRAIT ISLANDER INFANTS AT RISK OF ADVERSE NEURODEVELOPMENTAL OUTCOMES: A PROSPECTIVE COHORT STUDY

Many Australian First Nations infants experience a range of birth, post neonatal, socioeconomic and environmental factors in the first 12 months of life, increasing their risk of developmental vulnerability. This prospective cohort study will investigate the early identification of adverse neurodevelopmental outcomes (NDO) in Aboriginal and Torres Strait Islander infants living in Queensland (birth years 2020-2022). Accuracy and feasibility of early screening tools for identifying infants 'at risk' of a later diagnosis of specific neurodevelopmental disorder (NDD) (i) Cerebral Palsy (CP), (ii) Autism Spectrum Disorder (ASD) (iii) Fetal Alcohol Spectrum Disorder (FASD) and/or adverse NDO (significant delay) will be determined at 12 months corrected age (CA).

The LEAP-CP early detection study will examine the relationship between risk factors, screening results and developmental and diagnostic outcomes at 12 months CA, to enable culturally appropriate prediction of infants 'at risk' of adverse NDOs.

Carly Luke

Senior Physiotherapist, Queensland Paediatric Rehabilitation Service, Queensland Children's Hospital; PhD candidate, The University of Queensland

Ms Carly Luke (MAPaedPhysPrac, BPT) is a Senior Physiotherapist with the Queensland Paediatric Rehabilitation Service at the Queensland Children's Hospital in Brisbane and a PhD candidate with The University of Queensland. Throughout her career she has worked extensively across tertiary, acute and community paediatrics, specialising in complex rehabilitation, developmental and neurological caseloads. Carly has completed her Masters of Advanced Paediatric Physiotherapy and has worked as a research physiotherapist with the Queensland Cerebral Palsy and Rehabilitation Research Centre, screening and providing early intervention to infants at 'high risk' of cerebral palsy and adverse neurodevelopmental outcomes.



EARLY DETECTION & NEONATAL CLINICAL TRIALS

UNDERSTANDING THE EARLY NATURAL HISTORY OF CEREBRAL PALSY STUDY UPDATE

The diagnosis of cerebral palsy (CP) is between 12 and 24 months in high income countries, but as late as 5 years in low and middle income countries. A consequence of late diagnosis historically being the norm, very little is known about the early development of infants with CP under two years of age. Implementation of the 2017 Early Accurate Diagnosis of CP international clinical guidelines means infants are starting to have a CP diagnosis as young as 3 months of age. Subsequently parents are asking for specific prognostic information for their babies earlier than ever before. Understanding the Early

Natural History of CP is a prospective longitudinal cohort study which will map a range of developmental domains of infants with, or at high risk of CP over the first two years. Recruitment is ongoing in Australia, Sweden and Italy. In this session we will provide an update on study objectives, eligibility, local and international recruitment. The Cerebral Palsy Alliance/ New South Wales (NSW) Health Early Diagnosis Clinic for CP will be presented as a case study showcasing how the study is operating in NSW.



Anna te Velde

PhD candidate, The University of Sydney; Research Physiotherapist, Cerebral Palsy Alliance Research Institute

Anna te Velde is a PhD candidate at The University of Sydney and a Research Physiotherapist with Cerebral Palsy Alliance Research Institute, Australia. Anna has over 10 years' experience as a paediatric physiotherapist, working primarily with children and infants with cerebral palsy.

Anna works as a physiotherapist in the Cerebral Palsy Alliance Early Diagnosis Clinic, Australia's first multidisciplinary early diagnosis clinic for CP. Anna's work in early diagnosis and classification of cerebral palsy, particularly classification under two years of age. She is working on the Early Natural History of Cerebral Palsy study, an international collaboration tracking infants with cerebral palsy and high risk of cerebral palsy over the first two years of life. Anna is a co-investigator on a collaboration with CSF Global Bangladesh evaluating early diagnosis and Early Natural History of Cerebral Palsy in Bangladesh. Anna's research interests also include evaluating implementation of the Early, Accurate Diagnosis in Cerebral Palsy international clinical guideline.

CHILD & ADOLESCENT CP CLINICAL TRIALS

AN UPDATE ON THE PARTICIPATE CP RCT OF PARTICIPATION-FOCUSED PHYSICAL ACTIVITY INTERVENTION IN CHILDREN WITH CP

Children with cerebral palsy (CP) participate less often in physical activities compared to peers without CP. Participate CP is a multi-modal, participation-focused physical activity intervention designed to address barriers to participation. Dr Sarah Reedman will present an update on the Participate CP intervention including an analysis of the intervention contents, behavioural mechanisms and progress of the large, multi-site NHMRC-funded definitive trial.



Dr Sarah Reedman

Postdoctoral Research Fellow, The University of Queensland;

Dr Sarah Reedman is a postdoctoral research fellow at the Queensland Cerebral Palsy and Rehabilitation Research Centre at The University of Queensland. Dr Reedman is a physiotherapist clinician-researcher, and focuses on promotion of physical activity in children with cerebral palsy (CP). Dr Reedman developed the first randomized controlled trial of a participation-focused therapy intervention, and is currently co-leading the development and implementation of international guidelines to support decision-making for effective physical activity interventions in children with CP.

CHILD & ADOLESCENT CP CLINICAL TRIALS

HAND ARM BIMANUAL INTENSIVE TRAINING INCLUDING LOWER EXTREMITY: HABIT-ILE AUSTRALIA UPDATE

Background: HABIT-ILE is an intensive goal directed intervention using a motor learning approach that simultaneously addresses coordination of the upper and lower limbs. This presentation will provide an update on this multi-site NHMRC project which commenced in 2018.

Design: Single blind randomised controlled trial will compare HABIT-ILE to usual care for school aged children with bilateral CP.

Study participants: Children aged 6-16 years with bilateral CP, GMFCS II-IV.

Progress to date: A total of 92 children have been recruited and randomised across three sites (QLD=42; WA=21; NSW=29). 11 HABIT-ILE camps have been completed and 2 final waitlist camps will be conducted in July/August 2021. A modified version of HABIT-ILE has been adapted for preschool children aged 2 to 5 years and will be tested in a new trial. The protocol for the Preschool HABIT-ILE study will be discussed.

A/Prof. Leanne Sakzewski

NHMRC Career Development Fellow, The University of Queensland

Dr Sakzewski is a senior research fellow with the internationally recognised Queensland Cerebral Palsy and Rehabilitation Research Centre at the University of Queensland. Dr Sakzewski is leading nationally funded (NHMRC) multi-centre clinical trials testing the efficacy of intensive models of motor training, social skills programs and participation-focused therapy to enhance the functioning and quality of life of children with cerebral palsy. She has received >Aus\$10M in funding with 60+ publications. Dr Sakzewski graduated as an occupational therapist (BoccThy) from The University of Queensland and completed her PhD at the University of Queensland in 2010. She has held continuous fellowships since completion of her PhD including training in implementation science through a NHMRC Translating Research into Practice Fellowship.



CHILD & ADOLESCENT CP CLINICAL TRIALS

LOCOMOTOR TRAINING IN CHILDREN WITH CEREBRAL PALSY, GMFCS LEVELS IV AND V

Locomotor training is an activity-based intervention that has largely been adopted and implemented in spinal cord injury rehabilitation. It represented a significant paradigm shift in the area, recognising the role of activity dependent plasticity for both motor and health and well-being outcomes. In our recent study iStride, locomotor training was adopted and implemented in children with cerebral palsy classified with GMFCS levels IV and V. In this randomised controlled trial (n=40) children attended hourly sessions, three times a week for six weeks. The intervention was well tolerated with perceived improvements in functional mobility, active recreation as well as personal care goals. This study suggests that locomotor training can be safely implemented in children classified with GMFCS levels IV and V. It provides

a useful starting point for developing much needed interventions in this group of children that aim to improve not only motor capacity but also health and well-being outcomes.



Dr Dayna Pool

Physiotherapist; Research Fellow, Curtin University

Dr Dayna Pool is a physiotherapist and early career researcher at Curtin University. Her clinical research interests include the development and implementation of activity-based interventions in a community setting, involving consumers and knowledge translation. Dr Pool has founded two not-for-profit charitable organisations, both of which aim to translate evidence-based interventions into clinical practice both in Australia and abroad in developing countries.

NEUROIMAGING IN NEONATES AND CP

BRAIN MRI OF PRETERM NEWBORNS

Infants born very preterm are at an increased risk of adverse neurodevelopmental outcomes, including Cerebral Palsy. Earlier identification of at-risk infants enables earlier access to targeted intervention. Brain MRI can provide valuable information about brain growth, development, and abnormalities, which are related to later neurodevelopmental outcomes. In this talk, I will present our recent findings using MRI of very preterm infants to investigate associations between brain microstructure and morphology, and neurodevelopmental outcomes at 2 years.



Dr Kerstin Pannek

Senior Research Scientist, Australian E-Health Research Centre, CSIRO

Kerstin is a Research Scientist at the Australian E-Health Research Centre, CSIRO. She is an internationally recognised expert in Brain MRI, specifically in Diffusion MRI and its application in the newborn and paediatric brain to study normal and abnormal brain development for early diagnosis and prognosis of adverse neurodevelopmental outcomes. She has more than 10 years' experience in brain diffusion MRI and tractography analysis across all age groups including neonatal and paediatric populations, as well as using in vivo piglet and lamb brain MRI and ex vivo mouse/rat brain MRI.

NEUROIMAGING IN NEONATES AND CP

USING CLOUD-BASED TOOLS TO DELIVER ADVANCED MRI ANALYSES TO THE CLINIC

Neuroimaging is routinely performed for infants born preterm, and for children with neurodevelopmental disorders like Cerebral Palsy (CP), in order to understand the type and severity of brain injury. However these images are currently only used qualitatively in clinical assessment, missing out on a great deal of information from the image. Our group is developing several cloud-based tools to quantify

brain structure and microstructure, allowing subtle differences from typically developing cohorts to be identified, as well as the potential estimation of clinical outcomes. In this presentation, I will provide an outline of these tools for the early detection of CP in neonates at risk of CP, and for the brain structural characterisation of children with CP.



Dr Alex Pagnozzi

Medical engineer and Advance Queensland fellow, Australian E-Health Research Centre, CSIRO

Dr Alex Pagnozzi is a medical engineer and Advance Queensland fellow at the Australian e-Health Research Centre, a joint venture between CSIRO and the Queensland Government. During his PhD he utilised machine learning and statistics to extract clinical useful information from medical images that could be used to predict patient function. Now as a postdoctoral researcher, he is developing web-based tools to make these methods available to researchers and clinicians, accelerating brain research and improving outcomes for children with neurological injuries.

NEUROIMAGING IN NEONATES AND CP

WEARABLE TECHNOLOGY FOR EARLY NEUROLOGICAL DIAGNOSIS: CHALLENGES AND PROMISES

This talk will present an overview of the rationale how to build infant wearables for neurological diagnostics. While the sensor technology has evolved dramatically over the past few years, there are major challenges en route to making them functional for the medical user case; and moreover to making the results intuitive and transparent for the clinicians, for the ultimate benefit of a patient. Development of such products is a highly multidisciplinary exercise, recruiting medical and health care personnel from different medical subfields, as well as engineers with expertise in sensor hardware, different software components, as well as artificial intelligence.

This all used to be a primarily technical challenge, but it has rapidly evolved to become a challenge for clinical researchers: they are now requested to think, and re-think, the concepts; to define the actual and reachable aims in an iterative dialogue between different disciplines. The novel infant wearables are

solutions that won't emulate existing practices and/or clinicians. They are offering complementary insights, such as quantitative and objective assessment of infant motility in out-of-hospital settings.



Prof. Sampsa Vanhatalo

Professor; Senior Consultant in clinical neurophysiology, Helsinki University Hospital, Finland

Prof Sampsa Vanhatalo has EU qualification (board exam) as a clinical neurophysiologist, and he is the professor and senior consultant in clinical neurophysiology in Helsinki University Hospital. He obtained his MD and PhD degrees in 1998 from the University of Helsinki, Finland, and he also has clinical experience in general practice, pediatrics, pediatric neurology, epileptology, neurology, and emergency medicine.

Dr. Vanhatalo is leading the BABA center in Helsinki Children's Hospital, dedicated to studies on baby brain activity (www.babacenter.fi). For the past fifteen years, he has focused on developing methodology for neonatal neurophysiology ranging from the development of EEG hardware to other devices (eg. EEG caps and stimulators), mathematical signal analyses, as well as neurobiological models underlying early EEG activity. Most recently, Vanhatalo's group has initiated projects to develop medical wearables for the mobile assessment of infant sleep and mobility. All these activities have a heavy translational emphasis whereby the targets of research have been set to result in medical applications, and hence ultimately benefit clinical work and ill babies.

INFANT-PRESCHOOL CP CLINICAL TRIALS

ACTIVE START ACTIVE FUTURE: SWAPPING SEDENTARY TIME FOR ACTIVE TIME IN PRE-SCHOOL CHILDREN WITH CP USING THE SCIENCE OF BEHAVIOUR CHANGE

By 5 years of age, some children with cerebral palsy (CP) are already spending up to 90% of their day in sedentary postures. Sedentary time also peaks around this age in ambulant children with CP, but current interventions are designed for children over the age of 8. Active Start Active Future is a new intervention grounded in the science of behaviour change that works with adult family and caregivers around the child to help swap sedentary for active time in children with CP, including children with severe CP and intellectual disability.

Dr Sarah Reedman

Postdoctoral Research Fellow, The University of Queensland

Dr Sarah Reedman is a postdoctoral research fellow at the Queensland Cerebral Palsy and Rehabilitation Research Centre at The University of Queensland. Dr Reedman is a physiotherapist clinician-researcher, and focuses on promotion of physical activity in children with cerebral palsy (CP). Dr Reedman developed the first randomized controlled trial of a participation-focused therapy intervention, and is currently co-leading the development and implementation of international guidelines to support decision-making for effective physical activity interventions in children with CP.



INFANT-PRESCHOOL CP CLINICAL TRIALS

RECENT ADVANCES FOR EARLY HABIT-ILE IN CHILDREN WITH CEREBRAL PALSY

Hand and Arm Bimanual Intensive Therapy Including Lower Extremities has gained a growing interest since its development in 2011. This motor-skill learning based intervention uses functional goals defined by the children and their parents to promote autonomy and participation. Its effectiveness has been demonstrated in school-aged children with both unilateral and with bilateral CP. This keynote will focus on the application of the key principles of HABIT-ILE in pre-school children, the improvements obtained in pilot studies for early HABIT-ILE, the first motor and non-motor results as well as the barriers witnessed in the large randomized trials running for children 1 to 4 years old.



Prof. Yannick Bleyenheuff

Professor, Institute of Neuroscience,
Université catholique de Louvain, Bruxelles

Prof. Yannick Bleyenheuff PT PhD, is a Professor at the Institute of Neuroscience, Université catholique de Louvain, Brussels, Belgium and honorary attached to the Center for Cerebral Palsy Research of the Teachers College, Columbia University, NY, USA. Yannick Bleyenheuff has training in physiotherapy and rehabilitation, with a complementary degree in neuroscience and a PhD in movement sciences dedicated to the motor control of children with cerebral palsy (CP). She is currently holder of the first Chair fully dedicated to intensive neurorehabilitation in children with CP and has developed HABIT-ILE, an intensive intervention combining bimanual coordination with a constant lower extremity and/or postural stimulation, which has been successfully applied both in children with unilateral and with bilateral CP.

INFANT-PRESCHOOL CP CLINICAL TRIALS

UPDATE ON THE VISIBLE STUDY FOR SEEING IMPAIRED INFANTS

Vision difficulties in the context of rehabilitation are often under-recognised, under-treated and under-researched, pointing to an urgent need for the development of evidence-based vision interventions for infants and toddlers with cerebral vision impairments (CVI).

VISIBLE is a multisite pragmatic pilot randomized controlled feasibility and acceptability study of a 6-to-9 month early vision-awareness & parent-directed environmental enrichment program for infants with severe cerebral vision impairment (CVI) and at high risk of cerebral palsy (CP). This intervention protocol is built on previous evidence of the importance of parent involvement, multidisciplinary team support, goal orientation, utilization of the vision channel, and environmental enrichment.

A two group Randomised Controlled Trial (RCT) (n = 32) is being conducted. Infants age 3-6 months old at entry, with a severe visual impairment and at high risk of CP, are enrolled and randomised to receive the VISIBLE

intervention plus standard community-based care (SoC), compared to SoC alone. A physiotherapist and occupational therapist, or neurodevelopmental therapist (TNPEE – in Italy) visit the family in their home (or through teleconference) once every two weeks. Between visits, intervention is provided by parents in their home including environmental enrichment and vision-aware goal directed developmental activities.

In this presentation we will review the study progress, challenges and opportunities presented by limited possibilities for in-person visits, and important elements in carrying out a research protocol with severely-affected young infants and their families.

We will also review the structure of training and continued communication framework established between the sites for maintaining fidelity of assessment and treatment, and for individualised intervention strategies sharing.

A/Prof. Andrea Guzzetta

Head of Stella Maris Infant Lab for Early-intervention (SMILE), the University of Pisa, Italy

Associate Professor Andrea Guzzetta is an Associate Investigator on the CRE and a member of the Early Detection and Neuroimaging theme.

Dr Guzzetta is Head of Stella Maris Infant Lab for Early-intervention (SMILE), A/Professor at the University of Pisa, Medical School, and an accredited international trainer with the General Movements Trust. He will provide expertise in both clinical and neuroimaging data as a Member of the Early Detection and Neurosciences theme in the CRE.

Dr Guzzetta's main research has focused on the effects of early brain damage on the development of different functions and the underlying neuroplastic mechanisms, with the final aim to improve early intervention paradigms and outcomes. In his still relatively short research career, he has provided significant contribution to a number of research questions in the area, thanks to his compound training experiences in some of the most productive European centres in the field, including the Hammersmith Hospital and the Visual Development Unit in London (Great Britain) and the Department of Child Neurology in Tuebingen (Germany).



INFANT-PRESCHOOL CP CLINICAL TRIALS

BORNTOGETHER: IMPLEMENTATION OF EARLY DETECTION AND EARLY INTERVENTION SERVICE DELIVERY IN INFANTS AT RISK FOR CEREBRAL PALSY TO PROMOTE INFANTS' PSYCHOMOTOR DEVELOPMENT AND MATERNAL HEALTH

Despite advances in the medical management of high-risk pregnancies and deliveries, cerebral palsy (CP) remains the most common physical disability in childhood in high and low-to-middle income (LMIC). In addition, caregivers of children with CP are at higher risk of needing psychiatric support services, which further increases health and socio-economic burden to the families. Declining birth prevalence and lower severity have been reported in Australia. International evidence-based clinical practice guidelines for the early detection of cerebral palsy were published in 2017. Medical systems support and trainings are needed for system-wide implementation into clinical service delivery in Europe and LMIC.

The overarching aim of the BORNTOGETHERE project is to exploit current evidence on early detection and efficacy of EI for infants at high risk of CP by implementing the International Clinical Practice Guideline. Within this framework, the presentation will review this multi-national project, funded by European Commission and the Australian National Health and Medical Research Council, involving the Tuscan region of Italy, Denmark, the Netherlands, Georgia, Sri-Lanka and parts of remote regions in Australia.

By focusing on the multifaceted knowledge translation planned for the project we will review also the limitations and opportunities presented by the shift of in person trainings to online learning platforms.

A/Prof. Andrea Guzzetta

Head of Stella Maris Infant Lab for Early-intervention (SMILE), the University of Pisa, Italy

Associate Professor Andrea Guzzetta is an Associate Investigator on the CRE and a member of the Early Detection and Neuroimaging theme.

Dr Guzzetta is Head of Stella Maris Infant Lab for Early-intervention (SMILE), A/Professor at the University of Pisa, Medical School, and an accredited international trainer with the General Movements Trust. He will provide expertise in both clinical and neuroimaging data as a Member of the Early Detection and Neurosciences theme in the CRE.

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Olena Chorna

Research Coordinator, Stella Maris Infant Lab for Early-intervention (SMILE), the University of Pisa, Italy

Olena Chorna currently works at the Department of Developmental Neuroscience, IRCCS Fondazione Stella Maris. She is a PhD candidate in Neuroscience at the University of Florence. Olena does research in Pediatrics, Neurology and Clinical Trials.

INFANT-PRESCHOOL CP CLINICAL TRIALS

UPDATE ON THE LEAP-CP PROGRAMS - RCT OF PEER DELIVERED EARLY INTERVENTION FOR CHILDREN WITH CP: INDIAN AND ABORIGINAL & TORRES STRAIT ISLANDER TRIALS

Background/Objectives: To determine whether a peer delivered early intervention program (LEAP-CP: Learning through Everyday Activities with Parents) is more effective than a WHO health advice program (CAU). An update of the trial results from India (i) will be presented, along with progress on the Australian Aboriginal and Torres Strait Islander adaptation (ii).

Study Design: Single blind controlled trial.

Study Participants and Setting: Infants aged 12 weeks corrected age (CA) to 12 months CA identified as at high-risk of CP (absent fidgety on General Movements and scores below published cut-offs on Hammersmith Infant Neurological Examination, HINE) are eligible for the LEAP-CP trials. Families are randomized using central concealed random allocation to receive either the LEAP-CP (plus CAU) or health advice (plus CAU).

Material/Methods: LEAP-CP and Health advice are provided from age of identification (12-52 weeks) for 30 weeks of home visits by a peer trainer (community member/ health worker from local community). LEAP-CP components included: (i) goal-directed training (parent-identified goals, including motor, feeding, communication, vision); (ii) LEAP-CP Learning Games (based on the Learning Games curriculum modified for CP); (iii) parent education (including active learning strategies, responsive parenting, caregiver mental health, feeding, nutrition and general health). LEAP-CP is based on a parent coaching model which promotes caregiver problem solving and self-determination.

- (i) Primary infant outcome (India): mobility domain of the Paediatric Evaluation of Disability Inventory-Computer Assisted Testing (pre-, post-intervention, and final outcome at 18 months corrected age). Secondary child outcomes included the Peabody Developmental Motor Scales-2,

the Bayley Scales of Infant Development-3, Canadian Occupational Performance Measure, and growth anthropometry (length and weight z scores). The primary caregiver outcome was the Depression Anxiety and Stress Scale (DASS).

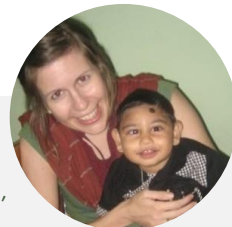
- (ii) Primary infant outcome (Australia): composite of Peabody and Bayley (cognition and communication). Primary caregiver outcome: DASS

Results:

- (i) Final data in India were available for 117 of the 151 infants randomised to the study (reasons for withdrawal: eleven prior to commencing the program, eight deceased, five moved region, four due to family pressure/ problems, one due to illness, four did not wish to continue); 84 males, mean age 25.6 ± 11.7 weeks CA, 36.8% of HINE scores <40 [non-ambulant CP]. Final analysis will be presented.
- (ii) Recruitment has not yet commenced for the Australian study, but an update on study progress will be provided.

Dr Katherine Benfer

NHMRC Early Career Research Fellow,
The University of Queensland



Dr Benfer leads the LEAP-CP program (Indian and Australian trials). She has had an outstanding research trajectory since completing her PhD in 2015, having received approximately \$1 million in research funding as a CI, including two NHMRC personal support grants (Early Career Fellowship – Health Professional and Medical and Dental Postgraduate Scholarship), the prestigious Endeavour QEII Diamond Jubilee Post-Doctoral Research Fellowship (Commonwealth Government, top female researcher); 18 peer review publications and over 40 national and international conference presentations.

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AusCP-CTN CRE Associate Investigators:

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