

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

## HOT TOPICS IN CEREBRAL PALSY RESEARCH FORUM

5 NOVEMBER 2018

Hosted by the Cerebral Palsy Alliance, Sydney

### RESEARCH TEAM

#### AusCP-CTN CRE Chief Investigators

Prof. Roslyn Boyd, Prof. Iona Novak, Prof. Euan Wallace, Prof. Nadia Badawi, A/Prof. Michael Fahey, Prof. Stephen Rose, Prof. Paul Colditz, Prof. Jenny Ziviani, Prof. Catherine Elliott, Prof. Susan Stott.

#### AusCP-CTN CRE Associate Investigators

Dr Lee Barber, Prof. Peter Davies, A/Prof. Andrea Guzzetta, Dr Sarah McIntyre, Dr Leanne Sakzewski, A/Prof. Anthony Smith, Prof. Robert Ware, Dr Koa Whittingham, A/Prof. Ray Russo.

### CONTACT

E: [auscpnetwork@uq.edu.au](mailto:auscpnetwork@uq.edu.au)

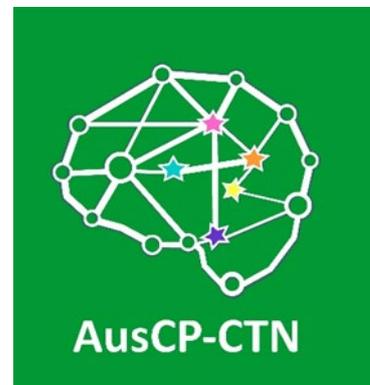
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# Hot Topics in Cerebral Palsy

Monday 5 November 2018

Cerebral Palsy Alliance, Allambie Heights, NSW

## Featured Speakers



Prof. Nadia Badawi



Prof. Roslyn Boyd



Prof. Catherine Elliott



Hiam Sakakini



Dr Jurgen Fripp



Prof. Steven Miller



Prof. Rod Hunt



Dr Alex Pagnozzi



Dr Kerstin Pannek



Dr Cathy Morgan



A/Prof. Andrea Guzzetta



Dr Koa Whittingham

## Morning Session

Time	Topic
0900-0905	Introduction, <b>Prof. Nadia Badawi</b>
0905-0910	Annual Report Card of the CRE, <b>Prof. Ros Boyd</b>
<b>Engagement and Health Policy: Chair - Theme Leader, Prof. Catherine Elliott</b>	
0910-0920	Importance of consumer and community engagement in research and the CRE, <b>Prof. Catherine Elliott</b>
0920-0930	Parent view on early detection, <b>Hiam Sakakini</b>
<b>Early Detection and Neuroimaging: Chair - Theme Leader, Dr Jurgen Fripp</b>	
0930-1030	Promoting Brain Health of the Preterm Newborn, <b>Prof. Steven Miller</b>
1030-1045	Q and A time with <b>Prof. Steven Miller</b>
1045-1100	Prediction of CP: CUS v MRI and when to use what, <b>Prof. Rod Hunt</b>
<b>1100-1120</b>	<b>MORNING TEA</b>
1120-1135	Automated reading of MRI's for Cerebral Palsy, <b>Dr Alex Pagnozzi</b>
1135-1150	Automated reading of early MRIs, <b>Dr Kerstin Pannek</b>
<b>Clinical Trials: Chair - Theme Leader, Prof. Ros Boyd</b>	
1150-1220	Clinical trials currently recruiting through the AusCP-CTN Study Updates from: <b>GAME (Dr Cathy Morgan)</b> , <b>REACH (Prof. Roslyn Boyd)</b> , <b>VISIBLE (Prof. Andrea Guzzetta)</b>
1220-1230	Parenting Interventions PACT, <b>Dr Koa Whittingham</b>
1230-1240	AMNION: Stem cell clinical trial, <b>Prof. Rod Hunt</b>
1240-1250	Q and A time with Theme Presenters
1250-1340	<b>LUNCH</b>

# Hot Topics in Cerebral Palsy

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## Featured Speakers



A/Prof. Michael Fahey



Prof. Russell Dale



Dr Kavitha Kothur



Dr Shekeeb Mohammad



Yana Wilson



Dr Stacey Ellery



Dr Esther Tantsis



Dr Sarah McIntyre



Dr Sue Woolfenden



Dr Hayley Smithers-Sheedy

## Afternoon Session

Time	Topic
<b>Pre-clinical and Neuroprotection: Chair - Theme Leader, Prof. Nadia Badawi</b>	
1340-1350	Implications of Genomics in Cerebral Palsy: towards the era of Personalised Medicine, <b>A/Prof. Michael Fahey</b>
1350-1400	CP phenotyping for multiple aetiologies and mechanisms. Preparing for the future of individualised therapies, <b>Prof. Russell Dale</b>
1400-1410	Epilepsy in cerebral palsy: defining prevalence and risk factors, quality of life, and subgroups of genetic and surgically remediable epilepsy, <b>Dr Kavitha Kothur</b>
1410-1420	Genomics of dystonia and candidacy for DBS, <b>Dr Shekeeb Mohammad</b>
1420-1430	Genomics – ICPGC, <b>Yana Wilson</b>
1430-1440	IUGR Melatonin, <b>A/Prof. Michael Fahey</b>
1440-1450	Creatine: A nutritional supplement to improve cellular energetics in babies at risk of cerebral palsy, <b>Dr Stacey Ellery</b>
1450-1510	Q and A time with Theme Presenters
<b>1510-1530</b>	<b>AFTERNOON TEA</b>
<b>Knowledge Translation and Implementation: Chair - Theme Leader, Prof. Iona Novak</b>	
1530-1540	The Early Diagnosis Clinic – cohort review and future directions, <b>Dr Esther Tantsis</b>
1540-1550	ACPR Rates and Mortality, <b>Dr Sarah McIntyre</b>
1550-1600	The impact of social disadvantage on indicators of cerebral palsy (CP) severity - an examination of the Australian CP Register, <b>Dr Sue Woolfenden</b>
1600-1610	Congenital cytomegalovirus - using social media and search engine optimisation for prevention messaging, <b>Dr Hayley Smithers-Sheedy</b>
1610-1625	Q and A time with Theme Presenters
1625-1630	Closing address, <b>Prof. Ros Boyd</b>

### More Information:

[www.cre-auscpcn.centre.uq.edu.au/event/session/717](http://www.cre-auscpcn.centre.uq.edu.au/event/session/717)

## HOT TOPICS OPENING ADDRESS

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**Professor Nadia Badawi AM**  
**Macquarie Group Foundation Professor and Chair of Cerebral Palsy,**  
**The University of Sydney.**

### **BIOGRAPHY**

Professor Nadia Badawi AM is the Macquarie Group Foundation Professor and Chair of Cerebral Palsy at the Cerebral Palsy Alliance Research Institute, dedicated to the prevention and cure of cerebral palsy through a research program of neuro-protective and neuro-regenerative clinical trials. She is the Medical Director and Co-Head of the Grace Centre for Newborn Intensive Care. Nadia is a leader in her field and was made a Member of the Order of Australia and named as one of the “100 most influential women in Australia” for her contribution to international cerebral palsy (CP) research and the improvement of clinical care in low and middle-income countries.

## AusCP-CTNE CRE VISION

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**Professor Roslyn Boyd**  
**Chief Investigator and Director of the CRE, QLD Lead, Chair of the Clinical**  
**Trials theme and a member of the Early Detection and Neuroimaging theme;**  
**Scientific Director of the Queensland Cerebral Palsy Rehabilitation &**  
**Research Centre, Faculty of Medicine, The University of Queensland.**  
**NHMRC Research Fellow.**

### **BIOGRAPHY**

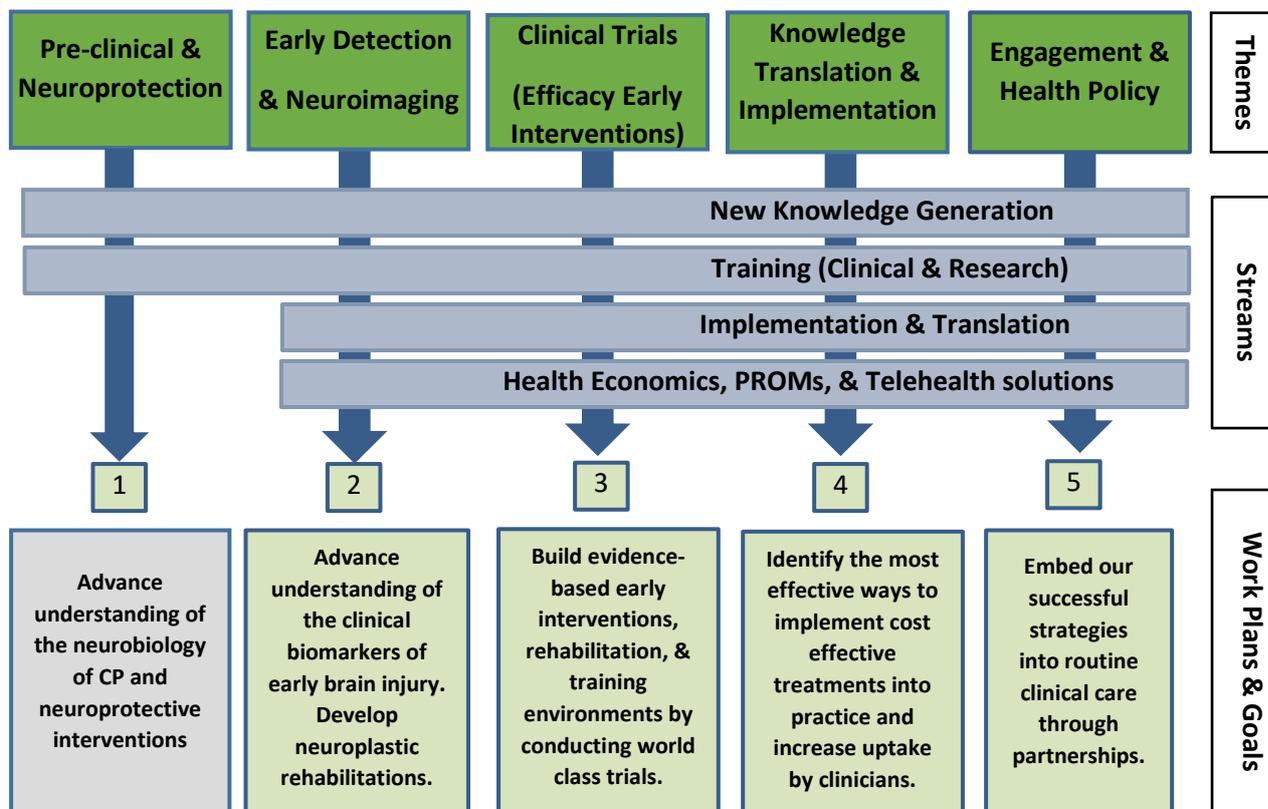
Professor Boyd leads an internationally recognised team of researchers conducting clinical trials of novel interventions geared to optimising neuroplasticity, early detection of cerebral palsy, longitudinal comprehensive outcomes linked to brain structure and function. Her team has conducted 17 RCTs in CP and infants born preterm. She has received >\$36M in grants including 13 NHMRC, 1ARC, 1 NIH and has published >275 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.

### **OPENING SPEECH**

#### **Annual Report card for the Australasian Cerebral Palsy Clinical Trials Network**

The Australasian CP Clinical Trials Network has progressed on its 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. Some Knowledge Translation studies have commenced to ensure effective transfer to enhanced clinical practice. The CRE has commenced a new International clinical practice guideline on Functional Therapy and is setting up a national consumer network aided by Anne McKenzie, AM. The changes in outcomes of children with CP will be tested in the Australian Cerebral Palsy Register.

**CRE framework for generating new knowledge across the five themes**



**ABSTRACT**

**REACH Study Update**

The REACH study is determining if modified Constraint Induced Movement Therapy (mCIMT) is more effective than Bimanual Therapy (BIM) in improving the symmetrical development of reach, grasp and bimanual co-ordination for infants who have an asymmetric brain lesion. The specially trained REACH therapists provide one home-visit and one virtual Skype visit each month with each family to support their child’s daily therapy administered by the child’s parents.

REACH is continuing recruitment in QLD, NSW, VIC and WA with 53 families already taking part in the study. Three new teams in Minnesota, Ohio and Riverside County in the US have been trained on the REACH protocol and certified in the Hand Assessment of Infants ready to commence recruitment to expand the study internationally.

Families are recruited between 3 to 9 months corrected age and continue in the study until they complete the follow-up assessments at 24 months corrected age. Forty-two of the study children have already completed their 12 months assessments, with 18 of these having also completed assessments at 24 months corrected age.

## INTERNATIONAL INVITED SPEAKERS

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**Professor Steven Miller**

**Head of Neurology (The Hospital for Sick Children), Professor in Paediatrics, University of Toronto.**

### BIOGRAPHY

Professor Miller is Head of the Division of Neurology and of the Centre for Brain & Mental Health at The Hospital for Sick Children. He is a Professor in the Department of Paediatrics at the University of Toronto and holds the Bloorview Children's Hospital Foundation Chair in Paediatric Neuroscience.

Collaborating with a multidisciplinary team, Dr. Miller's research program focuses on better understanding brain injury and development in the newborn. He and his team use advanced brain imaging and detailed long-term follow-up to help children who were born early or with conditions that put them at risk of neurological and developmental deficits. He has contributed to our understanding of how preterm birth, perinatal asphyxia, and congenital heart disease impact the brain and child development.

### ABSTRACT

#### **Promoting Brain Health of the Preterm Newborn**

Preterm birth is a major public health issue affecting an estimated 13 million babies worldwide. In recent decades, improved neonatal intensive care unit (NICU) therapies have reduced the mortality and increased the survival of preterm newborns. As such, it is an urgent priority to improve the health and developmental trajectories of these children.

Despite advances in NICU care, preterm birth remains a leading cause of childhood and lifelong disability in North America and elsewhere. Despite efforts to improve the brain health of babies born preterm, there remains wide variation in abilities later in life, even when comparing children born at the same gestational age. Today, there are many children born preterm who thrive, despite their earlier start in life.

In this lecture we will explore the dramatic period of brain development that occurs in babies born preterm through their medical care in a NICU. With new insights from brain imaging, we will examine how our understanding of brain injury in the baby is evolving towards a greater appreciation of how these injuries impact early brain development. We will also explore how the "everyday" experience of the baby born preterm, including pain, can favorably or negatively influence this incredible process of brain development, and how these changes ultimately impact a child's development.



**A/Professor Andrea Guzzetta**  
**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.**

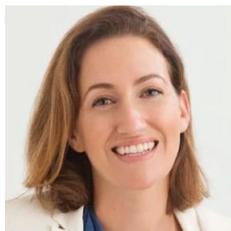
### **BIOGRAPHY**

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 is an accredited trainer at the GM-Trust ([www.general-movements-trust.info](http://www.general-movements-trust.info)).

### **ABSTRACT**

#### **VISIBLE STUDY UPDATE: Early assessment and intervention for infants with Cerebral Visual Impairment**

More than two thirds of the human brain is 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 reorganisation 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 characterise 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 optimise visual outcome will be presented.



**Ms Hiam Sakakini**  
CEO and Co-Founder, ThinkChangeGrow.

### **BIOGRAPHY**

Hiam Sakakini is an expert navigator of change who built stellar leadership teams during her 14+ years of working for Fortune 500 companies and most recently, during her 10 years at Google. This is where she built internal business units and later, shifted into the heart of the People & Culture strategy team. Taking that experience, Hiam has co-founded a People & Culture consulting practice, ThinkChangeGrow and regularly speaks and writes on topics around Women in Business, How to Motivate Millennials and The Future of Work. Hiam is passionate about helping organisations to thrive through times of change and ambiguity.

### **ABSTRACT**

#### **Parent view on early detection**

As a parent with a child with CP, Hiam will share her personal experiences and views on the importance of early detection and 'evidence-based' trials. She will also discuss the importance of advocating for transparent communication and collaboration across the board (clinical, research, community) for better patient care.

## NATIONAL INVITED SPEAKERS

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**Professor Rod Hunt**  
**Director (Neonatal Medicine and Neonatal Research), The Royal Children's Hospital (Melbourne, Australia).**

### BIOGRAPHY

Professor Rod Hunt is Director of Neonatal Medicine and Neonatal Research at The Royal Children's Hospital in Melbourne. His research interrogates mechanisms of brain injury and repair in the vulnerable preterm and term newborn infant.

### ABSTRACT

#### **1. Prediction of CP: CUS v MRI and when to use what**

For some newborns with established cerebral injury, the prediction of cerebral palsy is straightforward, although with advances in early interventions, predicting severity is more challenging. For some infants who develop CP - there is little or no indication in the perinatal period, either clinically or from imaging, that this disorder is in evolution. There are now reasonably clear recommendations around neuroimaging for infants at risk that involve the use of both ultrasound and MRI - however there is little evidence for the predictive capacity of either modality in the context of CP. It is our intention to explore the predictive capability of both modalities through existing trials for infants at risk of CP.

#### **2. AMNION: Stem cell clinical trial**

For many years now, Australian scientists have been leading the way in trials of different types of stem cells as therapeutic agents for varying neuropathologies, at different gestational ages, in a number of different animal models. We believe that the evidence is now strong enough to translate this work into the first human trial of true neuroprotection, rather than neural rescue or repair, for very preterm infants at risk of white matter injury and the subsequent development of CP. We hope to start recruiting to this important trial of human amnion epithelial cells in early 2019, and look forward to sharing the details of this trial with our colleagues.



**Professor Russell Dale**  
**Head, Kids Neuroscience Centre at The Children’s Hospital at Westmead and**  
**The University of Sydney.**

### **BIOGRAPHY**

Professor Russell Dale is Head of the Kids Neuroscience Centre and a paediatric neurologist. He is also the group leader for Clinical Neuroimmunology and Movement disorders.

Russell is an expert in movement disorders and neuroimmune disorders in children, and his main priority is to improve the diagnosis and treatment of children with neurological disease.

He is a clinical academic at The Children’s Hospital at Westmead and The University of Sydney and has published over 210 peer-reviewed academic papers. Russell currently supervises five postgraduate PhD and Masters students.

### **ABSTRACT**

#### **CP phenotyping for multiple aetiologies and mechanisms. Preparing for the future of individualised therapies.**

Cerebral palsy is not one disease but instead a number of vulnerabilities resulting in injury to the developing brain. Different patients will require different treatments. This applies to the symptomatic treatment of CP which will differ according to the type of motor problem, but increasingly it will be important to understand causation. In some patients, the cause is manifest with a clear-cut severe brain injury around birth, but in many the cause is less clear. There are an increasing number of genetic mutations now associated with CP and the possibilities of gene therapy are an increasing reality, so defining the monogenic causes of CP will be essential. There will be other patients where there is some genetic vulnerability PLUS some environmental factors that result in the CP phenotype. We need to organise ourselves and have an aetiological framework to the approach to a patient with CP - this will increasingly involve complex data of clinical phenotyping, genomics, proteomics and immunology.



**Dr Alex Pagnozzi**

**Medical engineer and Advance Queensland fellow at the Australian e-Health Research Centre, CSIRO.**

### **BIOGRAPHY**

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 will be developing web-based tools to make these methods available to researchers and clinicians, accelerating brain research and improving outcomes for children with neurological injuries.

### **ABSTRACT**

#### **Automated reading of MRIs for Cerebral Palsy**

Quantitative radiological reporting of brain MRIs has the potential to assist the clinical assessment of children with Cerebral Palsy. We are developing automated tools for quantifying brain injury, and modelling the associations with brain structure and patient outcome. In this talk, I will present our currently available pipeline for brain MRI quantification, the proposed future developments and its potential impact on assisting the clinical assessment of CP.



**Dr Kavitha Kothur**  
Paediatric Neurologist, Children's Hospital at Westmead.

### BIOGRAPHY

Dr Kothur is a paediatric neurologist and a clinical researcher with a special interest in epilepsy genetics/surgery, neuroinflammation and brain injury. She underwent an epilepsy fellowship training programme where she was trained in the management of patients with complex epilepsy. She conducted research at Kids Neuroscience Centre, the Children's Hospital Westmead and was awarded a PhD on developing diagnostic biomarkers of inflammation in paediatric neurology using cerebrospinal fluid (CSF) cytokines and chemokines. She is involved in coordinating epilepsy genetic meetings and has published on genetic testing in children with refractory epilepsy. She also supervised projects on longitudinal seizure outcome, quality of life and psychosocial outcomes following epilepsy surgery.

Dr Kothur has an excellent track record for publications relative to opportunity with 19 publications to date. She presented her research as oral and poster presentations at local, national, and international conferences. She teaches at the Sydney Child Health Program run by the University of Sydney and The Sydney Children's Hospitals Network.

### ABSTRACT

#### **Epilepsy in Cerebral Palsy: Defining Prevalence and Risk Factors, Quality of Life, and Subgroups of Genetic and Surgically Remediable Epilepsy**

Epilepsy is a common problem in cerebral palsy (CP), and previous studies of children with CP reported a prevalence of epilepsy in up to 67% in selected samples and 28.8% across Australia in total populations (ACPR Report 2016). In Australia, 1799 children with cerebral palsy (CP) have epilepsy. Epilepsy poses a substantial economic burden and has been shown to affect cognition, behaviour, motor function, education and lower quality of life in children with CP. The population-based studies investigating the association between predictors of the occurrence of epilepsy and severity of epilepsy are sparse. There is a paucity of literature on genetic causes of combined CP and epilepsy and surgically treatable epilepsy in CP, which will require a different treatment approach. Through this study, we aim to describe the epilepsy characteristics, determine the clinical and radiological risk factors, quality of life for epilepsy in children with CP and investigate subgroups of genetic and surgical epilepsy. We hope that this study will improve understanding of this relatively under-explored area to highlight areas that need improvement to target healthcare services.



**Dr Shekeeb Mohammad**  
Paediatric Neurologist, Children’s Hospital at Westmead.

### **BIOGRAPHY**

Dr Shekeeb Mohammad is an Australian-based health professional. Shekeeb is trained as a Paediatric Neurologist and leads the movement disorder clinic, and movement disorder genetics and deep brain stimulation program at the Children’s Hospital at Westmead.

### **ABSTRACT**

#### **Genomics of dystonia and candidacy for DBS**

Shekeeb is leading a project supported by CPA - “Improvement of care delivery and determining best outcome measures in children with dystonia undergoing deep brain stimulation” and will introduce the project with illustrative video examples and a project plan. Selected children with dystonia can benefit from a neurosurgical procedure called deep brain stimulation (DBS), which involves permanent implantation of fine electrodes into parts of the brain called the basal ganglia. DBS is emerging as a standard of care for selected children with severe dystonia due to various underlying disorders and is provided via the Children’s Hospital at Westmead. We do not fully understand all patient and family related factors that can help decide which children will benefit most from DBS, what aspects of disability change the most, how to best monitor response, set goals, match patient expectations and measure outcomes. The underlying Genomic diagnosis can be a significant determinant of response to DBS, as will be introduced.



**Dr Stacey Ellery**

**NHMRC Peter Doherty Early Career Research Fellow, The Ritchie Centre, Hudson Institute of Medical Research.**

### **BIOGRAPHY**

Stacey is an NHMRC Peter Doherty Early Career Research Fellow at The Ritchie Centre, Hudson Institute of Medical Research. Her primary interest is in cellular energy homeostasis in the brain during events of perinatal compromise. Stacey leads an international program of work investigating the use of dietary creatine supplementation both during pregnancy and in the early postnatal period, to improve neonatal outcomes in babies at risk of developing cerebral palsy, including those affected by preterm birth, fetal growth restriction or perinatal asphyxia. This program of work is conducted by a multi-disciplinary team of basic scientists, nurses, midwives, obstetricians and neonatologists across Australia (Monash Health), New Zealand (Capital Coast DHB, Wellington) and the US (Oregon National Primate Research Facility). The team is engaged in both preclinical studies in relevant in vitro and animal models, and prospective studies in antenatal clinics and NICUs. The collective aim is to establish whether this simple nutritional supplement could improve outcomes for babies at risk of cerebral palsy.

### **ABSTRACT**

#### **Creatine: A Nutritional Supplement to Improve Cellular Energetics in Babies at Risk of Cerebral Palsy**

Creatine is a dietary metabolite essential for brain development and energy metabolism. Its primary role is in maintaining cellular energy (ATP) homeostasis. Creatine is readily obtained from a diet containing fish and meat, and is also synthesised endogenously by the body. Studies suggest that the developing fetus is reliant on a maternal supply of creatine until late in gestation. We hypothesise that premature birth and the premature removal of a maternal source of creatine will lead to cerebral creatine deficiency in preterm babies. This will jeopardise normal brain metabolism and development, predisposing the infant to neurological decline. We are now exploring this hypothesis with our Understanding Creatine for Neurological Health in Babies (UNICORN) observational study. The overall aim of this study is to establish circulating and cerebral creatine content, in association with brain morphology and neurological outcomes, for preterm infants. Results of this study may call for creatine supplementation as standard nutritional care of the preterm infant, in order to reduce neurological damage in this vulnerable population.

Dietary creatine supplementation can also be used to increase the intracellular pool of creatine available for regeneration of ATP, and can prolong cellular energy homeostasis, even in oxygen-depleted environments. We are thus studying the use of maternal dietary creatine supplementation during pregnancy as a prophylactic treatment for perinatal ischemic-reperfusion injuries. In our spiny mouse model of intrapartum asphyxia, we have clearly shown creatine supplementation to be neuroprotective. Before proceeding to clinical trials in pregnant women, we are now investigating the capacity of maternal dietary creatine supplementation to prevent brain injury in a non-human primate model of intrapartum asphyxia. This study includes using clinically applicable measures such as MRI/MRS, as well as comprehensive behaviour and motor coordination assessments using scales that directly correlate to developmental milestones in the newborn human infant. The findings of this project may provide the basis for recommending the use of maternal dietary creatine during pregnancy. As such, we are also conducting a series of feasibility and tolerability studies of dietary creatine supplementation in pregnant women. These ‘first in pregnant women’ will inform any future RCT of creatine supplementation during pregnancy.



**Dr Esther Tantsis**

**Paediatric Neurologist, Department of Neurology, Children's Hospital at Westmead.**

### **BIOGRAPHY**

Dr Tantsis graduated from the University of Sydney in 1998 with a Bachelor of Medical Science majoring in neuroscience and topographical anatomy. She then attended the University of Sydney medical school and completed an MBBS in 2002. Dr Tantsis worked as an intern at Westmead Hospital before completing paediatric training at the Children's Hospital Westmead for three years. She then trained for a further 6 years (whilst completing a PhD) and was admitted as a fellow of the Royal College of Physicians as a paediatric neurologist. Her paediatric neurology training was undertaken through fellowships in general neurology and neuroimmunology. She completed an additional year as the academic fellow at which time she broadened her experience in paediatric epilepsy and neurophysiology. Dr Tantsis is currently a staff specialist in the Department of Neurology at the Children's Hospital Westmead.

### **ABSTRACT**

#### **The Early diagnostic clinic – cohort review and future directions**

The CPA early diagnostic clinic is a dedicated multidisciplinary clinic for the assessment of infants at high risk of developing cerebral palsy. The clinic has been functioning for almost 6 months and has assessed almost 30 children by integrating clinical history, and neurological examination with the general movements assessment (GMA), the hammersmith infant neurological examination (HINE) and neuroimaging. I will present our cohort to date and discuss the diagnostic process including both the benefits and the limiting factors. I will also discuss future directions.



**Dr Sue Woolfenden**

**Clinical Lead, Integrated Care, Sydney Children's Hospital Network.**

### **BIOGRAPHY**

Sue Woolfenden is a senior staff specialist in the Department of Community Child Health and the clinical lead in Integrated Care at Sydney Children's Hospital Network. She is a Conjoint Associate Professor and Senior Research Fellow with the University of New South Wales School of Women's and Children's Health. In her clinical, service development and research roles she aims to address child health and health care inequities in Australia and globally particularly for children with neurodevelopmental problems. Sue has a total of 68 peer reviewed publications, over \$AUD 8 million worth of successful grant submissions. Sue is the co-chair a Royal Australasian College of Physicians working group for the Inequities in Child Health Position statement. She has been awarded an NMRC Career Development Fellowship for 2019-2022 to further undertake translational research in her field.

### **ABSTRACT**

#### **The impact of social disadvantage on indicators of cerebral palsy (CP) severity - an examination of the Australian CP Register**

**Aim:** Internationally, socioeconomic disadvantage has been associated with increased severity of cerebral palsy (CP) outcomes. We investigated the impact of disadvantage on motor and intellectual impairment and the presence of severe comorbidities in children with CP in Australia.

**Method:** Data from the Australian CP register were analysed. Socioeconomic disadvantage was assessed using maternal age, maternal country of birth and a measure of neighbourhood socioeconomic status (SES) at the time of the child's birth. Descriptive bivariate analysis, trend analysis, risk ratios (RRs) and mediation analysis was undertaken to examine the impact of these measures of disadvantage on CP severity outcomes.

**Results:** A socio-economic gradient for CP severity was seen with neighbourhood SES - with decreasing neighbourhood SES at birth there were increasing proportions of children who: were non-ambulant, had at least a moderate intellectual impairment; and/or a severe comorbidity in terms of functional blindness, deafness, epilepsy and/or non-verbal communication. Mothers younger than 20 years of age and/or who were of a minority ethnicity were more likely to have children with more severe CP outcomes, especially in term babies. Mediation analysis indicated that the impact of teen motherhood and maternal minority ethnicity on severity was not further modified by living in a low SES neighbourhood.

**Interpretation:** In Australia, socioeconomic disadvantage at birth impacts adversely on motor and intellectual impairment and the presence of severe comorbidities at age 5 years in children with CP. Interventions to reduce these inequities in CP severity are required at the family and neighbourhood level.



**Dr Hayley Smithers-Sheedy**  
 NHMRC Research Fellow, Cerebral Palsy Alliance Research Institute.

### **BIOGRAPHY**

Hayley is an NHMRC Post-doctoral Research Fellow at the Cerebral Palsy Alliance Research Institute, The University of Sydney and the Australasian Cerebral Palsy Clinical Trials Network.

In her role with the Cerebral Palsy Alliance Research Institute, Hayley coordinates and supports the establishment, maintenance, and execution of research from the Australian Cerebral Palsy Register. She also supports the organisation's strategic plan by building local and international research capacity focussed on understanding aetiological pathways to cerebral palsy and identifying opportunities for prevention. She is an investigator on the Bangladesh and Sri Lankan Cerebral Palsy Registers. Hayley's doctoral studies investigated congenital cytomegalovirus (cCMV) amongst children with cerebral palsy. In her post-doctoral research Hayley is investigating opportunities for prevention of cCMV and the early identification of neurodevelopmental disability associated with this common congenital infection.

### **ABSTRACT**

#### **Congenital cytomegalovirus - using social media and search engine optimisation for prevention messaging**

Congenital cytomegalovirus (cCMV) is a common virus and a known cause of sensorineural hearing loss and cerebral palsy. Less than 20% of women are aware of cCMV or the simple hygiene strategies than can reduce their risk of infection during pregnancy. Here we will (1) discuss the theoretical underpinnings for the use of social media and search engine optimisation in the context of public health messaging and (2) describe the development and results from a recent campaign which aimed to build awareness of cCMV prevention strategies in the general community. We will lastly discuss the next steps for the 2019 awareness campaign and outline a range of strategies being implemented to promote awareness of cCMV amongst maternity health professionals.



**Yana Wilson**  
Research Officer, CP Genomics, The University of Sydney.

### **BIOGRAPHY**

Yana joined the Cerebral Palsy Research Institute in March 2016 from the Garvan Institute of Medical Research to support the Chair of Cerebral Palsy in identifying research opportunities and partnerships in genomics.

Yana's chief interests are evaluating the variation of our DNA that contribute to nervous system function and dysfunction, and analysing the underlying biology and genetic pathways of cerebral palsy and other neurodevelopmental disorders. Yana also has an interest in the ethical and public policy challenges associated with the application of genomics in medicine and research.

In 2017, Yana became a Governance Committee member of the International Cerebral Palsy Genomics Consortium, and is working on the development of the ICPGC's data sharing platform, the CP Commons that will manage, store and share the de-identified clinical and genetic data from various teams around the world that are involved in the consortium.

### **ABSTRACT**

#### **Genomics – The International Cerebral Palsy Genomics Consortium ICPGC**

The International Cerebral Palsy Genomics Consortium (ICPGC) is a global consortium established in 2017, as a dedicated forum for collaboration among clinicians and researchers to unravel 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 introduction to who we are, and what we are trying to achieve.

## AusCP-CTN CRE INVITED SPEAKERS

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**Professor Catherine Elliott**  
 Chair of Kids Rehab, WA, Child and Adolescent Health Service, School of Occupational Therapy and Social Work, Curtin University.  
 Chief Investigator on the AusCP-CTN CRE.

### BIOGRAPHY

Professor Elliott's primary role as the Chair of Kids Rehab, WA is to generate, apply, and translate research findings into clinical settings in West Australia, with the aim of improving the health and wellbeing of children with cerebral palsy. Kids Rehab, WA (Perth Children's Hospital) provides tertiary clinical care for children with cerebral palsy and other rehabilitation needs across Western Australia. Professor Elliott is also the Chair of the Research Consultation Group of CoLAB Telethon Kids, on the committee of management of the WA Health Translation Network, as well as an inaugural elected member of the National Occupational Therapy Research Foundation.



**Professor Jenny Ziviani**  
 Professor of Occupational Therapy, School of Health and Rehabilitation Sciences, The University of Queensland.  
 Chief investigator on the Aus-CP-CTN CRE and Chair Engagement and Health Policy.

### BIOGRAPHY

Professor Ziviani holds a teaching and research appointment in the School of Health and Rehabilitation Sciences (UQ) with a primary role in the supervision of research higher degree students in the field of child health and disability. Professor Ziviani undertakes research into the effectiveness of intervention for children with cerebral palsy and developmental disabilities, with a specific interest in the active involvement of caregivers in the facilitation of children's participation in meaningful activities. She is an elected member of the American and Australian Research Academies in acknowledgement of her extensive contribution to children's health research.

### ABSTRACT

**Note: Professor Elliott is presenting on behalf of Professor Ziviani.**

#### **Importance of consumer and community engagement in research and the CRE**

Consumer and community involvement in research is about the active involvement of consumer, community members and researchers working together to make decisions about research priorities, policy and practice. This active partnership is helping us establish the priorities of the AusCP-CTN ensuring that the research is relevant to the needs of children and youth with cerebral palsy and their families. The AusCP-CTN has partnered with 'Involving people in research' to provide workshops to promote partnerships between consumers the community and researchers. This presentation will outline the process for consumer and community engagement in the Aus CP CTN as well as outlining a research project (promoting participation for children and youth with disabilities) that has been driven and co-designed by consumers of the AusCP-CTN.



**Associate Professor Michael Fahey**  
**Child Neurologist and Geneticist, Head of Paediatric Neurology at Monash Medical Centre.**  
**Chief Investigator on the AusCP-CTN CRE.**

## BIOGRAPHY

Associate Professor Michael Fahey is also 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.

## ABSTRACT

### 1. IUGR Melatonin

M Fahey, K Palmer, J Mockler, S Miller, E Wallace

Fetal growth restriction (FGR) is a significant health care issue, affecting 20,000 Australian pregnancies every year. FGR can cause significant impairments in short and long term health outcomes for the child. It is a major risk factor for preterm birth and is a recognised causal pathway to the neurodevelopmental injury underlying cognitive and behavioural impairment and cerebral palsy. Currently *no therapies exist* that can maximise fetal wellbeing in the setting of growth restriction and minimise the frequency of antenatally acquired brain injury due to in-utero hypoxia. Based on our preclinical and phase 1 data, we have commenced double-blind, randomised, parallel group, placebo-controlled trial to administer maternal melatonin or placebo supplementation antenatally in the setting of early-onset severe FGR to determine whether melatonin can PROTECT the fetal brain and lead to improved neurodevelopmental outcomes.

### 2. Implications of genomics in cerebral palsy: towards the era of personalised medicine

Recent studies indicate that about 30% of people with CP have a genetic contribution to their condition. This is surprising for many. For the people affected by CP, finding these answers is essential for counselling, surveillance, early detection and for developing therapeutic strategies. People affected by neurological disability are looking for a reason why this has happened and what to do about it. In the emerging era of precision medicine, where therapies are increasingly tailored to an individual genomic variation, the development of such data will eventually lead to personalised therapy. This may be with such diverse implications as using appropriate pharmaceutical or nutraceutical agents or by predicting that a syndrome may recur and counselling accordingly.



**Dr Kerstin Pannek**  
Research Scientist at the Australian e-health Research Centre, CSIRO.

### **BIOGRAPHY**

Kerstin Pannek is a Research Scientist at the CSIRO Australian E-Health Research Centre and the funded Neuroscience fellow on the Aus-CP-CTN CRE. She has more than 10 years of experience in neuroimaging analysis including structural and diffusion magnetic resonance imaging (MRI) across all age groups. 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.

### **ABSTRACT**

#### **Automated reading of early MRIs**

The assessment of brain structure and growth during the neonatal period shows great promise in the early prediction of neurodevelopmental outcomes. We are developing automated tools for quantitative radiological reporting of brain MRIs of children with cerebral palsy, and of newborns at risk of developing cerebral palsy. In this talk, I will present our currently available tools, and discuss their potential impact on early diagnosis and prognosis.



**Dr Sarah McIntyre**

**Senior Research Fellow and NHMRC Early Career Fellow, The University of Sydney**

### **BIOGRAPHY**

Sarah is the Senior Research Fellow at Cerebral Palsy Alliance Research Institute and is responsible for running the NSW/ACT CP Register. She is the part-funded Epidemiology fellow on the Aus-CP-CTN CRE. In 2016, Sarah began an NHMRC Early Career Fellowship at The University of Sydney (2016-2020). She is a perinatal and paediatric neuro-epidemiologist and her current work focuses on the aetiology and prevention of cerebral palsy and other developmental disabilities with a particular emphasis on congenital anomalies and neonatal encephalopathy. Sarah is also a policy member of the Australian Cerebral Palsy Register Group, and is the research lead for CP Quest – community and researchers together.

### **ABSTRACT**

#### **ACPR Rates and Mortality**

The Australian Cerebral Palsy Register (ACPR) is a source of data that supports research relating to the monitoring of rates of cerebral palsy in those born in Australia. This presentation will present data on birth years 1995-2009. The up-coming ACPR report which includes birth years 2010-2012 will be released in December 2018 and early results will be announced.

Western Australia was the first region to have a CP Register (Western Australian Register of Developmental Anomalies WARDA). As such it contains population data from the oldest people still living with CP in Australia. We have recently completed a survival and mortality analysis of WARDA after linkage to the National Death Index. The study includes 3185 people with CP born in WA (1956-2011) who had survived to at least one year of age. As of Dec 2014, 436 (13.7%) had died and this presentation will report causes of death and changing trends in age of death particularly for those with severe disabilities.



**Dr Cathy Morgan**  
Senior Research Fellow, Cerebral Palsy Alliance.

### **BIOGRAPHY**

Dr Cathy Morgan is a Senior Research Fellow at the Cerebral Palsy Alliance Research Institute, a centre dedicated to the prevention and cure of cerebral palsy (CP) through a research program of neuro-protective, neuro-regenerative and early intervention clinical trials. A paediatric physiotherapist with almost 30 years' experience, Cathy now conducts clinical research in the area of early detection and evidence based early intervention for infants and toddlers with cerebral palsy. She is the part-funded Research fellow for NSW on the Aus-CP-CTN CRE.

Cathy 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. She has conducted the first two RCTs of early intervention in cerebral palsy using GAME intervention and is currently coordinating a large multicentre RCT on the same intervention. Other research interests include developmental trajectories of infants with CP and translating evidence based early intervention strategies in low- and middle-income country settings.

### **ABSTRACT**

#### **GAME Study Update**

Cathy will provide a brief background to GAME intervention and an update on the current NHMRC funded GAME trial that is currently recruiting in four states of Australia.



**Dr Koa Whittingham**  
NHMRC Postdoctoral Research Fellow, Queensland Cerebral Palsy and Rehabilitation Research Centre, The University of Queensland.

### **BIOGRAPHY**

Dr Koa Whittingham is an Associate Investigator on the CRE and a member of two themes: Clinical Trials and Engagement & Health Policy themes.

Koa is a clinical and developmental psychologist and part-time research fellow with the QCPRRC at UQ. She has significant expertise in the application of evidence-based parenting interventions to neurodevelopmental disabilities and a leading researcher in the application of Acceptance and Commitment Therapy, to parenting. In 2010, she received the Early Career Research Award at the International Helping Families Change Conference. In 2014, she received the Award for Best Paper for Effective Intervention for People Living with CP at the AusAACPD. Dr Whittingham was a chief investigator on the first randomised controlled trial of a parenting intervention for families of children with cerebral palsy to test mindfulness-based therapeutic techniques. She is currently developing and testing a translatable by design online parenting support platform based on Acceptance and Commitment Therapy. She has written a self-help book for mothers grounded in ACT called *Becoming Mum* ([www.becomingmum.com.au](http://www.becomingmum.com.au)).

### **ABSTRACT**

#### **Parenting Interventions PACT**

The PACT study is assessing an online parenting course, grounded in Acceptance and Commitment Therapy and known as PARENT101. A pilot RCT with parents of children with cerebral palsy is drawing to a close and data will soon be analysed. An RCT of early PARENT101, adapted for parents of infants diagnosed as at risk of CP is also under development. If successful, we hope to develop PARENT101 into an effective and useful online parenting support package for parents of children with cerebral palsy across the world.

# Acknowledgements

**AusCP-CTN CRE Chief Investigators:** Prof. Roslyn Boyd, Prof. Iona Novak, Prof. Euan Wallace, Prof. Nadia Badawi, A/Prof. Michael Fahey, Prof. Stephen Rose, Prof. Paul Colditz, Prof. Jenny Ziviani, Prof. Catherine Elliott, Prof. Susan Stott.

**AusCP-CTN CRE Associate Investigators:** A/Prof. Andrea Guzzetta, Dr Sarah McIntyre, Dr Leanne Sakzewski, A/Prof. Anthony Smith, Prof. Robert Ware, Dr Koa Whittingham, A/Prof. Ray Russo, Dr Lee Barber, Prof. Peter Davies.

**Queensland Cerebral Palsy and Rehabilitation Research Centre team:** Prof. Roslyn Boyd, A/Prof. Karen Barlow, Dr Priya Edwards, Dr Susan Sullivan, Dr Anna MacDonald, Dr Annie Chen, Dr Mark Bowles, Dr Lee Barber, Dr Leanne Sakzewski, Dr Koa Whittingham, Dr Kath Benfer, Dr Joanne George, Dr Steve Obst, Dr Lisa Copeland, Dr Kristie Bell, Dr Chris Carty, Dr Tracey Evans, Dr Corrine Dickinson, Dr Ashleigh Wright, Ms Christine Finn, Ms Kym Morris, Ms Bernadette Shannon, Ms Camilla Davenport, Ms Debra Khan, Ms Carly Dickinson, Ms Sarah Goodman, Ms Rebecca Caesar, Mr Jarred Gillett, Mr Miles Seidel, Dr Catherine Mak, Ms Sarah Reedman, Ms Felicity Read, Ms Jane Wotherspoon, Ms Andrea Burgess, Ms Ellen Armstrong, Mr Noah Betar, Ms Denni Purcell, Mr Julien Savina, Ms Elyanna Fong.



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