NEWSLETTER | December 2017

Queensland cerebral palsy & rehabilitation research centre

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Message from the Scientific Director, Professor Roslyn Boyd

Dear Families and Collaborators,

The Queensland Cerebral Palsy and Rehabilitation Research Centre has had a very successful 12 months with the launch of our two new programs. The Advance QLD Innovation Partnership (AQIP) program undertook training of 77 Researchers and clinicians from across QLD, Australia and overseas on the internationally accredited General Movements course (p5). Our NHMRC CRE the Australasian Cerebral Palsy Clinical Trials Network hosted a week of training and research translation with a multiple events including a two day Hot Topics in Cerebral Palsy program and commenced consumer training with parents conducted by Anne McKenzie (Telethon Institute). The Aus-CP-CTN events included four courses including training 25 trainers on the Hammersmith Infant Neurological Assessment with 70 clinicians from across Australia with a key international expert Prof Leena Haataja from Helsinki. For the first time we conducted an intensive, 3 day residential national grant and fellowship writing course attended by 15 early and mid career researchers. In October we welcomed our new team member MAIC Paul Hopkins Professor Karen Barlow from Calgary to lead a program in Pediatric Brain Injury (p2). Our senior lecturer Dr Leanne Sakzewski achieved outstanding success at NHMRC with two new project grants as CIA (p3). Our early career researcher Dr Katherine Benfer was awarded an NHMRC Early Career Fellowship to undertake a novel clinical trial of"Early detection and early intervention to improve outcomes for families of children with Cerebral Palsy in Indigenous Australians" (p3). In December, Dr Joanne George was awarded her PhD for her study of Preterm infants in the PREMO prospective cohort study (p11) and our Medical Honours student Dr Noah Betar was awarded 1st class honours. For the 5th Year in succession the QCPRRC team were awarded the a large number of free papers and workshops at both the forthcoming AusACPDM in Auckland in March 2018, and at the recent American AACPDM in Montreal in September 2017 (p10). We hope you enjoy reading our latest news and look forward to your involvement in our research centre.

With Warm Regards, Ros Boyd

In December 2017, Prof Ros Boyd was the winner of the Leader of the Year award for the Faculty of Medicine at The University of Queensland

Our Chief Investigators from NHMRC CRE Australasian Cerebral Palsy Clinical Trials network hosted a week of Training and Research translation

Research supported by

Children's Hospital Foundation

Children's Health Queensland Hospital and Health Service

The University Of Queensland AUSTRALIA

Welcome to Professor Karen Barlow

Our new MAIC Paul Hopkins Chair of Paediatric Rehabilitation

A joint new Professorial Chair in Paediatric Rehabilitation at The University of Queensland (UQ) and Children's Health Queensland (CHQ) has been funded by Queensland Government, the Motor Accident Commission, CHQ, UQ, with support from the Children's Health Foundation (CHF).

Over the past decade more than 2750 children have received serious injuries as a result of road traffic crashes in Queensland. Children who sustain significant brain and spinal cord injuries can receive specialist rehabilitation through the **Queensland Paediatric Rehabilitation Service (QPRS),** which was established with funding from the Motor Accident Insurance Commission (MAIC), the regulator of the Qld CTP scheme. The QPRS is a state-wide service based at the Lady Cilento Children's Hospital, and providing regional outreach services. Research conducted at the QPRS has been integral to achieving successful outcomes for injured children. To foster leadership and drive expansion of paediatric rehabilitation research at the QPRS, MAIC and three funding partners have established an inaugural **Professorial Chair in Paediatric Rehabilitation, the 'Dr Paul Hopkins Chair'**.

The Queensland Government, through CHQ and MAIC, has contributed over $2.1 million over five years, in partnership with CHF and UQ who will together contribute over $500,000. The Chair is named after Dr Paul Hopkins, who pioneered rehabilitation services as the first Director of Rehabilitation for the State of Queensland from 1981 until his retirement in 1998.

Prof Karen Barlow received her medical degree from the University of Edinburgh where she stayed to complete her pediatric and pediatric neurology training as well as a research fellowship studying infantile traumatic brain injury (shaken baby syndrome). Karen completed a fellowship in pediatric neurology in Vancouver at the University of British Columbia. Her most recent position was the Associate Professor of Pediatric Neurology at the University of Calgary and Director of the Complex Concussion and Traumatic Brain Injury Research Program at the Alberta Children's Hospital (ACH). She has completed formal training in clinical trials through the University of London (London School of Hygiene and Tropical Medicine).

The main aim of Karen's program is to combine her skill sets and knowledge as a Paediatric Neurologist and Clinical Trialist to improve the care and outcome of Traumatic Brain Injury (TBI) in children and adolescence. To do this, we need to understand the biological "drivers" of symptom persistence and more objective evidence about the best management and treatment practices. Factors influencing outcome of mTBI have important implications for clinical practice. Karen's publications significantly contribute to this area including: the natural history of recovery from mTBI in children (Barlow, 2010, 2015); assessment of mTBI in the emergency department using computerized technology (Brooks, 2015, 2016); the role of serotonin receptor alleles and environmental stressors in development of Post Concussion Syndrome (Smyth, 2014); perceptions of recovery in mTBI (highest-rated manuscript published in the Journal of Clinical Neuropsychology, Brooks 2013); reduced interhemispheric cortical communication in PCS detected by near infrared spectroscopy, (Urban, J Neurotrauma 2015); and Cerebral Perfusion changes in PCS (Barlow 2016, J Neurotrauma).

Currently there are few evidence-based treatments for post-concussion syndrome (PCS) (Barlow, J Child Neurology, 2014). Karen's research is exploring various aspects of management and treatment. Contrary to earlier literature, children with PCS often respond to medical therapies. Prof Barlow is the team lead on an ongoing CIHR-funded randomized controlled trial of Melatonin in the treatment of PCS (www. PlayGametrial.ca), with a protocol published in Trials 2014. Other treatments she is investigating include Insomnia-Cognitive behavioural therapy for sleep disorders following TBI (RCT), rTMS for intractable PCS (open-label) and occipital nerve blockade for severe acute post-traumatic headaches (open label). Karen joined us recently from Calgary and brings her husband Brad Denis (a stockbroker and fellow keen sailor) and Chester (their Golden Retriever). We warmly welcome Karen and her family to QCPRRC and value her enormous experience in interventional treatments for TBI and her extensive international network of collaborators.

For further information and collaborative opportunities contact: Dr Karen Barlow , E: K.Barlow@uq.edu.au.

NHMRC Awards

TWO new NHMRC Project grants for Dr Leanne Sakzewski!!!

HABIT-ILE: A randomised trial of Hand Arm Bimanual Intensive Training Including Lower Extremity training for children with bilateral cerebral palsy

NHMRC 1144846 - $1,100,902

Chief Investigators: Dr Leanne Sakzewski, Prof Roslyn Boyd, Professor Yannick Bleyenheuft, Prof Iona Novak, Prof Catherine Elliott, Dr Nicholas Dowson, Dr Cath Morgan, Dr Kerstin Pannek.

Associate Investigators: Dr David Rowell , Prue Gollard, Prof Robert Ware.

In Australia, 35,000 people are living with cerebral palsy (CP) and 600 children are newly diagnosed each year. The largest group of children with CP (60-79%) have bilateral impairments impacting movement on both sides of the body. This can have a profound impact on their ability to use their arms effectively, to walk and become independent in daily life tasks. People with CP have poorer health outcomes (<1.9 standard deviations) compared to age matched peers. Increased severity of physical disability is associated with reduced general health, greater pain and discomfort, reduced independence in daily life skills and poorer vocational outcomes. Interventions that reduce the impact of the physical disability and promote independence in daily life skills, inclusion and community participation is a major priority area of the National Disability Strategy. There has been a paucity of evidence for effective interventions to improve motor outcomes for children with bilateral CP. We have a new motor learning approach that integrates an intensive model of bilateral upper limb and lower extremity training (Hand Arm Bimanual Training + Intensive Lower Extremity: HABIT-ILE) which has been pilot tested with strong effects to improve manual ability and gross motor function. We now propose a randomised controlled trial of HABIT-ILE for 126 children, 6-16 years of age with bilateral CP to increase manual ability, gross motor function and independence in daily life tasks. This RCT addresses a major gap in the evidence for the largest and most disabled group of children with CP and results will have a major influence on global practice and nationally on implementation of effective rehabilitation through the National Insurance Disability Scheme.

PARTICIPATE-CP: Optimising participation in physically active leisure for children with cerebral palsy: A randomised controlled trial

NHMRC 1140756 - $1,014,871

Chief Investigators: Dr Leanne Sakzewski, Prof Catherine Elliott, Prof Roslyn Boyd, Prof Jenny Ziviani, Prof Iona Novak, Prof Steward Trost, Prof Annette Majnemer.

Associate Investigators: Dr David Rowell, Dr Keiko Shikako-Thomas, Prof Robert Ware.

People with CP have poorer health outcomes, are more sedentary and have a 1.2 to 1.6 greater risk of chronic health conditions such as diabetes, hypertension and stroke compared with age matched peers. From early years, children with CP participate less in physically active leisure activities compared to typically developing peers and participation reduces over time. The Australian Government National Disability Strategy lists personal/community support to promote inclusion and community participation as a major priority area. Our recent systematic review established that traditional interventions aimed at remediating impairments and activity limitations are ineffective in increasing participation in physically active leisure activities and overall levels of physical activity for children with CP. We have developed and pilot tested a novel multi-faceted intervention, Participate-CP, with strong effects to increase attendance and involvement in active physical leisure activities of choice for primary school children with CP. We now propose a randomised controlled trial of Participate-CP for 8-12 year old children with CP to increase physical activity levels through participation in physically active leisure activities of choice. Establishing healthy patterns of physical activity in early childhood aims to mitigate the known decline in physical activity in adolescence.

For further Information contact: Dr Leanne Sakzewski at E: l.sakzewski1@uq.edu.au.

NHMRC Early Career Fellowship Award

LEAP-CP: Early detection and early intervention to improve outcomes for families of children with Cerebral Palsy in Indigenous Australians

Chief Investigators: Dr Katherine Benfer (UQ)

Associate Investigators: Prof Roslyn Boyd, Dr Koa Whittingham (UQ), Dr Alan Rubens (Cape York); Prof. Iona Novak, Dr Cath Morgan (CP Alliance)

Consistent with the prevailing trend for poorer health outcomes for Indigenous Australians, cerebral palsy (CP) prevalence is significantly greater than that for non-Indigenous Australians, with CP arising after birth five times more likely. LEAP-CP (Learning through Everyday Activities with Parents) explores the effectiveness a peer-delivered culturally adapted early intervention for infants at risk of cerebral palsy from Indigenous Australia. Seventy infants aged between 3 months and 2 years will be randomly assigned to one of two intervention groups; community-based parent-delivered intervention (goal directed learning, enriched environments and nutritional support), or standard care (health advice). Infants receiving the intervention are expected to have better performance on motor/ cognitive outcomes at 3 years, and caregivers to have improved mental health, which have the potential to reduce the burden of disability in Indigenous communities.

For more information, please contact Dr Katherine Benfer. E: k.benfer@uq.edu.au.

CRE Update

UPDATE from Hot Topics

Australasian Cerebral Palsy Clinical Trials Network (AusCP-CTN)

NHMRC Centre for Research Excellence (CRE) APP116442

Chief Investigators: Prof Roslyn Boyd (UQ), Prof Iona Novak (CPA, USyd), Prof Euan Wallace (Monash), Prof Nadia Badawi (CPA, USyd), Prof Paul Colditz (UQ), Prof Stephen Rose (CSIRO), A/Prof Michael Fahey (Monash), Prof Jenny Ziviani (UQ, CHQ) Prof Catherine Elliott (Curtin Uni.), Prof Sue Stott (Uni. Auckland).
Associate Investigators: A/Prof Andrea Guzzetta (Uni Pisa), Dr Sarah McIntyre (CPA), Dr Koa Whittingham (UQ), Dr Leanne Sakzewski (UQ), Dr Lee Barber (UQ), Prof Robert Ware (Griffith), Prof Peter Davies (UQ), A/Prof Anthony Smith (UQ), A/Prof Ray Russo (SA).
Associate Investigators: A/Prof Jane Valentine (WA), Dr Priya Edwards, Ms Megan Kentish (QLD).
CRE Manager: Dr Susan Sullivan, Dr Annie Chen (Senior Research Partnerships and Program Manager).

The CRE held a very successful week of training (3 Basic and 1 Advanced General Movements Course for 66 participants; the Hand Assessment of Infants Course (20 Participants); Intensive Grant and Fellowship writing course (15 Participants); HINE: Hammersmith Infant Neurological Assessment for Training the trainers (21 participants) and a two day Hot Topics Symposium (15 speakers, 109 participants) and two Consumer training workshops (21 participants). We welcomed three international GMs trainers (A/Prof Guzzetta, Dr Vittorio Belmonte, Dr Natascia Bertoncelli) and A/Prof Alicia Spittle from UniMelb; an international expert on the HINE Prof Leena Haataja from Helsinki, Mr Richard Ellenson, and Rachel Bryne from the International CP Foundation in New York and National Speaker A/Prof Mark Mackay head of the Childhood Stroke network at MCRI Melbourne.

Organiser, Professor Roslyn Boyd, said the forum was an initiative of the Australasian Cerebral Palsy Clinical Trials Network Centre for Research Excellence (AusCP- CTN CRE), a research group dedicated to improving outcomes for children with cerebral palsy.

Over 100 participants from Australia and New Zealand attended the two day Hot Topics Symposium in November 2017 at The University of Queensland.

One highlight in the varied program was a non-research perspective from guest speaker, Mr Richard Ellenson, father of a 20 year old youth with cerebral palsy and CEO of the Cerebral Palsy Foundation in New York. Mr Ellenson is a passionate advocate for children with disabilities and was behind the development of a range of assistive technologies and a purpose-built cerebral palsy channel aimed at families that features videos from disability advocates and world experts on cerebral palsy.

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

AusCP-CTN CRE Partners: **W:** www.cre-auscpctn.centre.uq.edu.au **E:** auscpnetwork@uq.edu.au

The University Of Queensland AUSTRALIA · The University of Sydney · Curtin University · The University of Auckland · Griffith University · Cerebral Palsy Alliance Research Foundation · CSIRO · Monash University · Università di Pisa · Australian Government National Health and Medical Research Council

https://cre-auscpctn.centre.uq.edu.au/

UPDATE from the Advance QLD Partnership Program

Advancing Cerebral Palsy: Early Detection & Early Intervention in QLD
QLD State Government Advance QLD Innovation Partnership (AQIP #16-103)

ADVANCE QUEENSLAND

Chief Investigators: Prof Ros Boyd (QCPRRC), Dr Koa Whittingham (QCPRRC), Prof Paul Colditz (UQCCR), Prof Stephen Rose (CSIRO), Dr Mohan Karunanithi (CSIRO), A/Prof Anthony Smith (UQ COH), Prof Paul Scuffham (Griffith University), Dr Priya Edwards (CHQ), Prof Iona Novak (CPA, USyd), Prof Nadia Badawi (CPA, USyd), Dr Catherine Morgan (CP Alliance).

Partners: The University of Queensland (QCPRRC, Perinatal Research Centre at UQCCR, Centre for Online Health), Australian eHealth Research Centre (CSIRO), Griffith University (Menzies Institute), Children's Health Queensland, Cerebral Palsy Alliance, Merchant Charitable Foundation through Children's Health Foundation.

The AQIP program is a partnership between The University of Queensland, the Australian e-Health Research Centre (AeHRC), Griffith University, Cerebral Palsy Alliance and Children's Health Queensland. Advance CP will develop, test and implement new "toolboxes" of biological and clinical markers, for very early detection of CP in preterm and term-born infants. These innovative toolboxes will be translated into clinical products/technologies (e.g. smartphone APPs, Telemedicine).

GMs Training:

The AQIP program delivered three Basic and one Advanced internationally accredited training in the General Movements Assessment (GMs) in November 2017. This assessment assesses video of a baby's spontaneous movement and is highly predictive of a later outcome of CP. Seventy-seven clinicians were trained, of which 61 were clinicians practising in Queensland. The AQIP program has employed Dr Christian Redd, a postdoctoral fellow, to investigate the ability of wearable sensors to perform automated assessment of GMs.

HINE Training:

Professor Leena Haataja, one of the original authors of the Hammersmith Infant Neurological Examination (HINE), visited in November 2017. The HINE is a standardised and scoreable clinical neurological examination that can be used to assess infants from 2-24 months of age. The International Clinical Practice Guideline for the Early Accurate Diagnosis of CP recommends the use of the HINE, particularly in situations where the most predictive tools (GMs and MRI) are not able to be used. Professor Haataja trained a group of 21 senior clinicians from throughout Australia and New Zealand as trainers in the HINE assessment. Each of these clinicians have now been tasked with delivering HINE training locally in their respective states. A further 3 training courses were delivered in Brisbane for 49 clinicians (Medical and Allied Health).

For further information contact: Prof Roslyn Boyd Ph: (07) 3069 7372, E: r.boyd@uq.edu.au,
W: https://qcprrc.centre.uq.edu.au/advancing-cerebral-palsy-queensland

NEW Infant Studies

QEDIN-CP: Queensland Early Detection & Intervention Network: Cerebral Palsy

ADVANCE QUEENSLAND

QEDIN-CP is a clinical network which aims to assist in earlier identification of babies at high risk of a later diagnosis of CP by providing support to clinicians involved in identification of babies who may have CP. It will also provide education and training on early detection and early interventions for babies at risk of CP, and the ongoing maintenance of clinical skills for early detection.
QEDIN-CP has ethics approval and we are currently in the process of seeking research governance approvals in each of the Hospital and Health Service districts in Queensland. Any clinicians who wish to register their interest in the network and join our mailing list in the interim, please visit our webpage https://qcprrc.centre.uq.edu.au/qedin-cp and use the link to register. We will use this mailing list to send out updates on progress of the network, provide online GMs calibration sessions, and advise of training in GMs and the HINE assessment.

For more information, please contact Dr Joanne George (Senior Research Physiotherapist and QEDIN-CP Coordinator): qedincp@uq.edu.au.
Prof Roslyn Boyd (Principal Investigator) 07 3069 7372, r.boyd@uq.edu.au.

REACH: Randomised trial of Rehabilitation very EArly in Congenital Hemiplegia

Australian Government National Health and Medical Research Council NHMRC

NHMRC Project Grant 1078877

Chief Investigators: Prof R Boyd, Prof J Ziviani, Dr L Sakzewski, Prof I Novak, Prof N Badawi, Dr K Pannek, Prof C Elliott, Dr S Greaves, A/Prof A Guzzetta, Dr K Whittingham.
Associate Investigators: A/Prof J Valentine, Prof P Colditz, Dr R Ware, Dr C Morgan, Dr M Wallen, A/Prof K Walker, Dr R Dale, Prof S Rose, Dr R Ward, Dr M Sharp, Dr N French, Ms L Findlay, Dr P Edwards, Dr R Hunt. Dr M Mackay, Ms M Thorley, Mrs R Caesar, Dr L Weber, A/Prof M Fahey.

The aim of the REACH study is to determine whether modified Constraint Induced Movement Therapy (mCIMT) is more effective than Bimanual Therapy (BIM) in improving the symmetrical development of reach and grasp and bimanual co-ordination at 12-15 months corrected age for infants with asymmetric brain lesions. mCIMT involves constraint of the unimpaired hand using a material mitten and intensive activity based training of the impaired hand, compared to BIM where there is no constraint and equal training of both hands. Parents complete daily therapy with their child, supported by monthly home visits and Skype sessions by a REACH therapist.

Infants must be 3 to 9 months corrected age at the time of recruitment. Thirty-five infants have already entered the study across QLD, NSW, VIC and WA, with the first of these infants now completing their 24 months assessments. One mother who completed the sessions with her infant (pictured) described the study as "a wonderful experience for us and I am so glad that we can help the team learn more about Cerebral Palsy and the best therapy options. If we had the chance, I would definitely do it again!".

For more information, please contact Dr Tracey Evans, the Clinical Research Coordinator Ph: (07) 3069 7365 or E: QCPRRC@uq.edu.au or W: https://qcprrc.centre.uq.edu.au/reach.

NEW Infant Studies

GAME: Harnessing neuroplasticity to improve motor performance in infants with cerebral palsy - a pragmatic randomized controlled trial

Australian Government National Health and Medical Research Council NHMRC

NHMRC Project Grant 1120031

Chief Investigators: Prof I Novak, Dr C Morgan, Prof N Badawi, Prof R Boyd, A/Prof A Spittle, Prof R Dale, Ms A Kirby, A/Prof R Hunt, Dr K Whittingham, Dr K Pannek. A/Prof M Fahey.
Associate Investigators: A/Prof K Walker, A/Prof A Guzetta, Dr K Prelog, Prof W Tarnow-Mordi, Prof S Rose, Ms C Galea, Ms S Clough, A/Prof R Morton, Dr A Tran.

The GAME study will recruit 300 infants aged between 3 to 6 months corrected age with a diagnosis of cerebral palsy or diagnosis of "high risk of cerebral palsy" across 26 sites in QLD, NSW and VIC. Infants will be randomised into the GAME group, an early training intervention based on the key neuroscience principles of activity dependent plasticity and enriched environments, or the Traditional Early Intervention group, using passive experiences of normal movement and symmetry applied by a therapist to correct movement. The study will evaluate the effects of GAME versus Traditional Intervention at 2-years-of-age on gross and fine motor skills and also on neuroplasticity, motor capacity, cognitive skills, independence in daily living and quality of life. Thirty infants have been recruited and commenced therapy in New South Wales and Victoria. Recruitment has just commenced in QLD at the Lady Cilento Children's Hospital, Gold Coast University Hospital and Royal Brisbane and Women's Hospital, with approval at The Mater Mothers' Hospital and the Sunshine Coast University Hospital coming soon in 2018.

For more information, please contact Dr Tracey Evans, the Clinical Research Coordinator Ph: (07) 3069 7365 or E: QCPRRC@uq.edu.au or W: https://cre-auscpctn.centre.uq.edu.au/project/game.

PACT: Parenting Acceptance and Commitment Therapy Innovative, web-based support for families of children with Cerebral Palsy - fully recruited!

Cerebral Palsy Alliance

Cerebral Palsy Alliance Grant PG0214

Chief Investigators: Dr Koa Whittingham, Prof Roslyn Boyd, Dr Jeanie Sheffield, Catherine Mak, Dr Ashleigh Wright.
The PACT study is a trial of an innovative online parenting support course, called PARENT101, developed specifically for families of children (2-10 years) with cerebral palsy. PARENT101 is grounded in a psychological therapy called Acceptance and Commitment Therapy (ACT). The online course involves exploring what matters most to you as a parent and as a person, investigating ways to build a stronger relationship with your child and develop strategies for coping with challenges along the way. We recruited 71 parents with 40 parents have already completed the course. We would like to thank all families who have taken part in this study. With their help, we hope to make a difference in the lives of families of children with cerebral palsy.

Early-PACT: Parenting acceptance and Commitment Therapy to improve psychological outcomes for families with an early diagnosis 'at risk' of CP

Chief Investigators: Dr Koa Whittinghan, Prof Roslyn Boyd, Dr Corrine Dickinson, Dr Jeanie Sheffield
The Early PACT study aims to explore the psychological impact for families at point of detection of cerebral palsy risk. We have conducted a systematic review of all literature available on interventions for parents in the infancy period and we will present the results at the upcoming 2018 AusACPDM Conference. We have commenced a qualitative study and Dr Corrine Dickinson has been conducting interviews with health professionals and parents to explore experiences of early CP risk diagnosis. The results of the qualitative study will help to form an adapted version of the PACT online support program for families with infants. We would like to thank the parents and health professionals who have already participated and shared their personal experiences.

For more information, please contact Senior Research Psychologist Dr Corrine Dickinson on 07 3069 7346 or c.dickinson@uq.edu.au.

UPDATE Child Study

LEAP-CP: Early detection and early intervention to improve outcomes for families of children with Cerebral Palsy in LMIC (Kolkatta, India)

Chief Investigator: Dr Katherine Benfer (UQ).
Associate Investigators: Prof Ros Boyd, Dr Koa Whittingham (UQ), Prof. Iona Novak, Dr Cath Morgan (CPA).

Trying out his chair for the first time to assist with upper limb training.

612 Beautiful Bengali Babies have now been referred to the LEAP-CP study. Our highly committed and hard working team from five partnering organisations here in West Bengal (as well as the team in Oz!) are working tirelessly to stay on top of eligibility assessments (GMs and HINE) so that we can get the right babies started in home-based parent-delivered intervention at the right time. We have had huge success with the program thus far, having screened almost 300 babies, and 49 now enrolled in the program. The light is emerging from the end of the tunnel, with recruitment due to wrap up in 3 short months.

Cerebral Palsy ALLIANCE

For more information, contact Dr Katherine Benfer. E: k.benfer@uq.edu.au.

PREDICT CP: Implementation of comprehensive surveillance to predict outcomes for children with cerebral palsy

NHMRC Partnership Grant 1077257114484 6 - $1,593,519

Australian Government National Health and Medical Research Council NHMRC

Chief Investigators: Prof Roslyn Boyd, Prof Peter Davies, Prof Jenny Ziviani, Prof Stewart Trost, Dr Lee Barber, Dr Robert Ware, A/Prof Stephen Rose, Dr Koa Whittingham, A/Prof Jennifer Whitty, Dr Kristie Bell.
Associate Investigators: Prof Paul Scuffham, Dr Chris Carty, A/Prof John Walsh, Ms Megan Kentish, Dr Priya Edwards, Dr Lisa Copeland, Ms Kelly Weir, Dr Leanne Sakzewski, Dr Andrea Guzzetta, Dr Denise Brookes, Prof Alan Coulthard, Dr Rebecca Pelekanos, Mr Owen Lloyd, Dr Adina Piovesana.

We are delighted to welcome Dr Shaneen Leishman to the PREDICT CP team as our new Study Co-ordinator. The PREDICT CP study, which is a continuation of the CP Child Study and the Growth, Nutrition and Physical Activity Study (GNPA), aims to explore the relationship between severity of cerebral palsy and brain structure using diffusion MRI. We have now commenced MRI scans at the Herston Imaging and Research Facility (HIRF) for eligible participants, which will provide important information for building prediction models for the planning of effective interventions for children with CP. Over 40 families have participated to date in the comprehensive clinical assessment which includes assessments of motor function, neuropsychology, communication, nutrition, bone health and a blood test. We would like to say THANK YOU to all of these families for your time and support of this study.

In November, our first regional family flew down to Brisbane from Cairns to participate in the study, with three more traveling down in December. Bookings are filling up fast for January 2018! We look forward to making contact in the New Year with all the families who have expressed interest in being involved.
For more information, please contact Dr Shaneen Obrien, the Clinical Research Coordinator for PREDICT. Ph: (07) 3069 7354 or E: QCPRRC@uq.edu.au.

NEW Publications

Parent-reported indicators for detecting feeding and swallowing difficulties and undernutrition in preschool-aged children with cerebral palsy

Katherine A Benfer, Kelly A Weir, Robert S Ware, Peter S.W. Davies, Joan Arvedson, Roslyn N Boyd, Kristie L Bell.

Developmental Medicine and Child Neurology. 2017. DOI: 10.1111/dmcn.13498 1181.

AIM: To determine the most accurate parent-reported indicators for detecting (1) feeding/swallowing difficulties and (2) undernutrition in preschool-aged children with cerebral palsy (CP).
METHOD: This was a longitudinal, population-based study, involving 179 children with CP, aged 18 to 60 months [Gross Motor Function Classification System level I, 84; II, 23; III, 28; IV, 18; V, 26]). Feeding/swallowing difficulties were determined by the Dysphagia Disorders Survey and 16 signs suggestive of pharyngeal phase impairment.
RESULTS Primary parent-reported indicators associated with feeding and swallowing were 'moderate–severe parent stress' (odds ratio [OR]=3.2 [95% confidence interval {CI} 1.3–7.8]; p<0.01), 'moderate–severe concern regarding growth' (OR=4.5 [95% CI 1.7–11.9]; p<0.01), and 'any respiratory condition' (OR=1.8 [95% CI 1.4–5.8]; p<0.01). The indicator associated with undernutrition was 'moderate–severe concern regarding growth' (height–weight OR=13.5 [95% CI 3.0–61.3]; p<0.01; skinfold OR=19.1 [95% CI 3.7–98.9]; p<0.01). 'Significant difficulty eating and drinking' was most sensitive/specific for feeding outcome (sensitivity=58.6%, specificity=100.0%), and 'parent concern regarding growth' for undernutrition (sensitivity=77.8%, specificity=77.0%).
INTERPRETATION Parent-reported indicators are feasible for detecting feeding and swallowing difficulties and undernutrition in children with CP, but need formal validation.

Early, Accurate Diagnosis & Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment

Iona Novak *et. al.*, JAMA Pediatrics 2017. doi:10.1001/jamapediatrics.2017.1689

IMPORTANCE Cerebral palsy describes the most common physical disability in childhood and occurs in 1 in 500 live births. Historically, the diagnosis has been made between age 12 and 24 months but now can be made before 6 months' corrected age.
OBJECTIVES To systematically review best available evidence for early, accurate diagnosis of cerebral palsy and to summarize best available evidence about cerebral palsy–specific early intervention that should follow early diagnosis to optimize neuroplasticity and function.
FINDINGS Six systematic reviews and 2 evidence-based clinical guidelines met inclusion criteria. All included articles had high methodological Quality Assessment of Diagnostic Accuracy Studies (QUADAS) ratings. In infants, clinical signs and symptoms of cerebral palsy emerge and evolve before age 2 years; therefore, a combination of standardized tools should be used to predict risk in conjunction with clinical history. Before 5 months' corrected age, the most predictive tools for detecting risk are term-age magnetic resonance imaging (86%-89% sensitivity), the Prechtl Qualitative Assessment of General Movements (98%sensitivity), and the Hammersmith Infant Neurological Examination (90% sensitivity). After 5 months' corrected age, the most predictive tools for detecting risk are magnetic resonance imaging (86%-89% sensitivity) (where safe and feasible), the Hammersmith Infant Neurological Examination (90% sensitivity), and the Developmental Assessment of Young Children (83% C index). Topography and severity of cerebral palsy are more difficult to ascertain in infancy, and magnetic resonance imaging and the Hammersmith Infant Neurological Examination may be helpful in assisting clinical decisions. In high-income countries, 2 in 3 individuals with cerebral palsy will walk, 3 in 4 will talk, and 1 in 2 will have normal intelligence.
CONCLUSIONS AND RELEVANCE Early diagnosis begins with a medical history and involves using neuroimaging, standardized neurological, and standardized motor assessments that indicate congruent abnormal findings indicative of cerebral palsy. Clinicians should understand the importance of prompt referral to diagnostic-specific early intervention to optimize infant motor and cognitive plasticity, prevent secondary complications, and enhance caregiver well-being.

Achievements

The QLD Paediatric Rehabilitation Team were awarded the Child Health QLD research team Excellence award (QPRS)

Dr Kristy Bell (winner of Individual researcher of the year award) Meredith Winter, Megan Kentish and Prof. Ros Boyd received the Research Team award on behalf of the QLD Paediatric Rehabilitation Service team from Fionnagh Dougan Health Service Chief Executive of Child Health QLD.

Dr Alex Pagnozzi received the Best Poster award at the Australasian Academy of Cerebral Palsy & Developmental Medicine (AACPDM)

In September 2017, Dr Alex Pagnozzi was awarded the award for his best Scientific Poster at the American Academy of Cerebral Palsy and Developmental Medicine in Montreal entitled: "Measuring Neuroplasticity Associated with Cerebral Palsy Rehabilitation"
L to R: Catherine Mak, Joanne George, Prof Ros Boyd, Dr Alex Pagnozzi (with award), Megan Kentish, Meredith Wynter and Sarah Reedman attended AACPDM (Dr Leanne Sakzewski is not in the photo).

Henley Masters Regatta 2017

Dr Tracey Evans (on left) our Clinical Trials Co-ordinator won the women's pair in the >50 categaory and the women's eight >55 years at the Henley on Thames Masters Rowing Regatta in July 2017.

UQ Three Minute Thesis - People's Choice Award

Congratulations to our PhD scholar Shari Obrien enrolled at School of Human Movement Sciences and QCPRRC with A/Prof Geln Litchwark and Dr Lee Barber. Shari received the People's Choice award for the 3Minute thesis final in the Faculty of Medicine, UQ.

Three Minute Thesis (3MT®) celebrates the exciting research conducted by PhD students around the world. Developed by The University of Queensland (UQ), the competition cultivates students' academic, presentation, and research communication skills. Presenting in a 3MT competition increases their capacity to effectively explain their research in three minutes, in a language appropriate to a non-specialist audience. Competitors are allowed one PowerPoint slide, but no other resources or props.

Shari's thesis is entitled: *"Enhancing lower limb muscle function through targeted motor learning in cerebral palsy."*

Graduation

Congratulations Dr Joanne George!!

Title of thesis: The relationship between brain structure and function of very preterm infants, and the ability to predict neurodevelopmental outcomes

Supervisors: Prof Roslyn Boyd, Prof Paul Colditz, Prof Stephen Rose

Jo's doctoral research examined the ability of very early MRI and clinical assessments performed early in the neonatal period, to detect adverse outcomes or cerebral palsy in babies born very preterm. Jo designed, developed and implemented the PPREMO study, where 119 babies born preterm underwent MRI and clinical assessment between 30-32 weeks postmenstrual age, and were then followed up until they reached 12 months corrected age. A group of healthy, term born babies were also recruited as a reference group to compare the MRI and clinical assessment findings.

She developed and validated a scoring system for very early structural MRI obtained shortly after birth and again at term equivalent age. This scoring system was able to detect later adverse motor and cognitive outcomes at 12 months corrected age. Relationships with clinical measures of motor, neurological and neurobehavioural function, obtained concurrently with MRI, were determined. These very early brain imaging and clinical biomarkers provide an improved ability to identify, at an earlier time point, which preterm babies may have adverse motor outcomes which enables earlier referral for targeted interventions to improve outcomes. Jo published 3 first author publications and another paper is currently under review. Jo's thesis is freely available online at the following link: https://espace.library.uq.edu.au/view/UQ:686088 or by clicking here. Jo is now working at QCPRRC, implementing the state-wide Queensland Early Detection and Early Intervention Network (QEDIN-CP), which aims to improve early detection of infants at risk of CP and fast-track them to very early interventions and early family supports.

For further information contact Dr Joanne George: j.george2@uq.edu.au.

Conferences 2018

Australasian Academy of Cerebral Palsy & Developmental Medicine (AusACPDM)

Empowerment and Partnership
9th Biennial AuAACPDM conference
21-24th March, 2018 The Langham, Auckland NZ

AusACPDM Australasian Academy of Cerebral Palsy and Developmental Medicine

Conference program is available at: https://www.ausacpdm.org.au/conference-program-now-available/

PZANZ: Perinatal Society of Australia and New Zealand Annual Scientific Congress

* provide an opportunity for members to broaden their perspectives of perinatology;
* stimulate research activities aimed at improving perinatal care
* present scientifically rigorous and valid new information
* debate new information and ideas of relevance to perinatology

Perinatal Society of Australia & New Zealand
Annual Scientific Congress
25 - 28 March 2018
ANZ Viaduct Events Centre, Auckland, New Zealand
Whenua ki Whānau
Nurturing the people of our land

25-28th March, 2018 Viaduct Centre, Auckland NZ
Conference program is available at: http://psanz2018.com.au

Meet our new team members

Dr Mark Bowles: *Research and Operations Manager*

Mark began his career in the research and, having risen to senior positions moved laterally into the general management of the School of Medicine, University of Queensland with 450 staff and more than 20 sites including Brunei and New Orleans. Prior to joining QCPRRC as Research and Operations Manager, Mark was the Chief Operating Officer for the Mater Research which manages all research undertaken by Mater Health staff across multiple sites. Mark brings significant experience in senior executive roles for a range of areas including finance, IT, strategic alliances, HR and risk management.

Dr Annie Chen: *Senior Research Partnerships and Program Manager*

From The University of Queensland, Annie obtained her PhD in Bioengineering, and also Graduate Certificate in Research Commercialisation. Annie has accumulated a variety of professional experience from academia, large-scale research alliances and industry, both as a research scientist and strategic development manager. As the Senior Research Partnerships and Program Manager, Annie will support the QCPRRC to promote the strategic growth of the NHMRC Centre of Research Excellence and the Advance Queensland Innovation Partnerships Programs, and to generate strong and beneficial partnerships between key internal and external stakeholders for the broader cerebral palsy network.

Dr Shaneen Leishman: *Clinical Research Coordinator*

Shaneen joined the QCPRRC team as a Clinical Research Coordinator for the PREDICT study in December 2017. She completed a BSc (Hons) degree at UQ and was awarded her PhD (dentistry) in 2013. Her areas of expertise include molecular biology, immunology, and microbiology. Shaneen was previously based at the UQ School of Dentistry where she was involved in a number of NHMRC and industry funded projects looking at preventive strategies for early childhood tooth decay. She has a personal interest in Cerebral Palsy and has been a competitive coxswain for women's rowing for many years.

Mika Shimada: *Clinical Research Co-ordinator*

Mika will join the QCPRRC in January 2018, focussing on co-ordinating the new Habitile and Particpate 2 clinical trials. Mika moved to Brisbane from Japan to attend university in 2008.
She studied Biomedical Science then Master of Health Management.
She has worked at Wesley Medical Research for 4 years and very excited to join Queensland Cerebral Palsy research team.

Dr Christian Redd: *Research Scientist*

Christian joined CSIRO and the QCPRRC team as part of the AQIP research program in September 2017. He received a B.S. and M.S. from the University of Utah in mechanical engineering with an emphasis in bioinstrumentation. He received his Ph.D. in Bioengineering from the University of Washington in 2017. During his time at the University of Washington he developed and explored wearable sensors for extraclinical monitoring of limb health and prosthesis use for persons with amputations. His areas of expertise include wearable sensors, rehabilitation medicine, and medical diagnostics. He lived aboard a 10 meter sailboat for the duration of his graduate studies and enjoyed taking his home out to race on a regular basis.

Associate Professor Mark Chatfield: *Senior Biostatistician*

Mark has worked as an applied biostatistician in academic health research since 2002 in Cambridge, Sydney, Darwin and Brisbane, analysing and presenting data for publications, and assisting with study design. He is a chief investigator on several NHMRC-funded randomised controlled trials. He has a strong maths background with a Master's degree in Maths from Oxford, and a Master's degree in Statistics from Southampton. He will join the QCPRRC team in January 2018. He is also a cricket tragic and is going for "the other team" in the Ashes!