NEWSLETTER | July 2017 Queensland cerebral palsy & rehabilitation research centre

Message from Prof Ros Boyd, Scientific Director

The QCPRRC team have had a very busy first half of 2017 launching our two new programs (i) Advance QLD Innovation Partnership (AQIP) program and our (ii) NHMRC Clinical Centre for Research Excellence (CRE) to lead an Australasian Cerebral Palsy Clinical Trials Network.

The AQIP program has recruited new team members and set up a state-wide QLD Early Detection and Early Intervention **Network** (p5) for (QEDIN) Medical and Allied Health clinicians to screen infants to determine if they are at high risk of cerebral palsy (CP) and to fast track them to new clinical trials of early interventions including REACH (p6) and GAME (p6). With use of the "Baby Moves app" the network will help with training in early detection on the General Movements (GMs) and the Hammersmith Infant Neurological Examination (HINE) (p12).

The Australasian Cerebral Palsy Clinical Trials Network has launched its website (p4) and recruited post-doctoral fellows in each site to progress the work of the CRE Themes of (i) Preclinical trials; (ii) Early detection and Neuroscience; (iii) Clinical Trials; (iv) Knowledge Translation and



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In May, I was invited to provide an update on the Early Detection of CP at the Japanese Child Neurology Meeting.

In July the QCPRRC team has four graduating PhD students (p3) and we wish them well with their chosen career paths.



Dr Piyapa Keawutan and one of her proud supervisors, Prof Ros Boyd.

Several team members made a major contribution to the European Academy of Childhood Disability (EACD) in Amsterdam in May (see report p10) and Dr Kath Benfer our rising star was awarded the best paper from a competitive field. We hope that you (our collaborators, fellow clinicians and families) will be able to join us for our Education week and Hot topics in CP update in Brisbane on November 5th-11th (p12).

With Warm Regards, Ros Boyd

EACD Annual Conference in Amsterdam in May (L-R): Olga Laporta Hoyos, Jo George, Kelly Weir, Kath Benfer, Ros Boyd, Cath Mak, Simona Fiori and Andrea Guzzetta.



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CONTACT

QCPRRC UQ Child Health Research Centre **Adress:** Centre for Children's Health Research Level 6 62 Graham Street South Brisbane QLD 4101 **Phone:** +61 7 3069 7370 **Email:** qcprrc@uq.edu.au **Website:** www.qcprrc.centre.uq.edu.au





Joanne George: Senior Research Physiotherapist

Joanne George is a Paediatric Physiotherapist completing her PhD at the University of Queensland. Her research project, PPREMO, investigated the ability of very early MRI and early clinical measures of motor, neurological and neurobehavioural function to identify infants at high risk of adverse motor outcomes following very premature birth. Jo will be joining us as a Senior Research Physiotherapist for the AQIP program. Her role is to implement the state-wide Qld Early Detection and Intervention Network (QEDIN), progress early MRI studies in preterm and term infants, and as a therapist in the NHMRC-funded GAME study.

Ellen Armstrong: PhD Student

Ellen has a Masters in Physiotherapy from Griffith University and a Masters in Adapted Physical Activity from the University of Leuven in Belgium. She is currently completing her PhD studies with Dr Chris Carty, Ms Megan Kentish, Dr Sean Horan and Professor Roslyn Boyd. Her research will investigate the effects of Functional Electrical Stimulation (FES) cycling, recreational cycling and goal-directed transfer training on functional outcomes for children with cerebral palsy.

Bernadette Shannon: Research Occupational Therapist

Bernadette re-joined the team at QCPRRC in January 2017 after returning from maternity leave. She has previously worked as part of the UPBEAT team looking at Upper Limb Baby Early Action Observation Training and the PREMM massage study. Prior to this Bernadette worked in neonatal nurseries in Melbourne and London, specialising in the assessment and treatment of infants and supporting their families. She returns to QCPRRC to work as part of the AQIP program, "Advancing Cerebral Palsy in Queensland". AQIP will develop, test and implement new "toolboxes" of biological and clinical markers in order to assist in the very early detection of cerebral palsy in preterm and term-born infants and aims to fast-track infants identified to early interventions.

Carly Dickinson: Senior Research Physiotherapist

Carly is a physiotherapist with the Queensland Paediatric Rehabilitation Service and has 9 years experience working with children with complex developmental and neurological conditions across a variety of settings. She recently completed her Masters of Advanced Health Care Practice specialising in paediatric physiotherapy and will be joining the GAME study as a clinician who will provide intervention to infants at high risk of developing cerebral palsy.

Congratulations to Dr Koa Whittingham!

Koa and Wade have welcomed their baby girl, Keeva Amabel Oakley on 20th April. Big sister Louvie was delighted to meet her new sibling. Koa and Keeva are both doing well and are already settling in at home.

New to QCPRRC

Dr Corrine Dickinson: Senior Research Psychologist

Corrine is a registered Clinical Psychologist with experience working with children and families within community settings and Neonatal and Paediatric Intensive Care Units in Townsville. Corrine's clinical areas of practice include developmental assessment of high risk infants, perinatal mental health, trauma and anxiety, and cochlear implant candidacy assessment. Corrine is also experienced in research areas of health behaviour change and psychological symptoms of parents with infants in NICU. Corrine joined the QCPRRC team in March to conduct research in supporting families psychologically, following initial diagnosis of cerebral palsy with the Early PACT study.











PhD Graduations

Congratulations Dr Piyapa Keawutan!

Supervisors: Prof Roslyn Boyd, Dr Kristie Bell, Prof Peter Davies Title of Thesis: Relationship between habitual physical activity, gross motor function, community mobility and

quality of life in 4-5 year old children with cerebral palsy Piyapa's doctoral research was part of two large cohort studies funded by NHMRC, CP Child: Brain Structure and Motor Function (465128) and CP Child: Growth, Nutrition and Physical Activity (569605). Her studies found that children with CP aged 4-5 years spent more than half of their day in sedentary time. Habitual physical activity of young children with CP was associated with gross motor function and community mobility while it was not associated with parent-reported quality of life.

The study suggests that children with CP should be encouraged to be physically active and have breaks in sedentary time from the age of 4 years. Piyapa has published four journal articles from her PhD studies. She was funded by the Thai government. Since graduating, Piyapa is working as a lecturer at the Department of Physical Therapy, Thammasat University, Thailand.

Congratulations Dr Emmah Bague!

Supervisors: Prof Roslyn Boyd, Dr Lee Barber, Dr Leanne Sakzewski

Title of Thesis: Efficacy of an online multimodal therapy program on gross motor outcomes in children and adolescents with an acquired brain injury

In an adequately powered randomised controlled trial, Mitii[™] "Move it to Improve it" offers a homebased multimodal training program that may increase functional strength in children with an acquired brain injury (ABI). Our intervention incorporated specific functional strength training modules, supporting the concept of specificity of training. These measured improvements in functional strength were not

significant enough to be clinically meaningful, in part due to inconsistency in dosage. Future studies should consider alternative structures of Mitii[™] delivery to enhance treatment adherence as well as to compare the efficacy of Mitii[™] against off-the-shelf games. Regardless of geographical location, Mitii™ offers an opportunity for all children with an ABI and their families to access a therapist monitored, training program to enhance activity outcomes.

Congratulations Dr Alex Pagnozzi!

Supervisors: Prof Stephen Rose, Dr Nicholas Dowson, Prof Andrew Bradley

Title of Thesis: Automated injury segmentation to assist in the treatment of children with cerebral palsy Alex's doctoral research investigated the use of automated image quantification techniques for analysing the Magnetic Resonance Images (MRIs) of children with cerebral palsy (CP). His research involved developing new methods for quantifying anatomy that unlike existing approaches, could accommodate potentially severe brain injury. These methods revealed associations between brain structure and patient outcomes, which were shown to accurately predict patients' motor, cognitive, visual and communication function. For clinical assessment, such estimates of patient outcome could be used to tailor treatment

strategies for children with CP, improving long-term function. Alex is looking to develop these automated methods into a decision support tool to assist clinicians tasked at analysing the MRI of children with CP. During his PhD studies, Alex has published eight journal articles (including five first-author publications).

Congratulations Dr Lee Reid!

Supervisors: Prof Stephen Rose, Prof Roslyn Boyd, Prof Ross Cunnington

Title of Thesis: Measuring motor-training induced neuroplasticity using diffusion and functional MRI:A Sensitive, Pathology-Robust Approach

Lee's doctoral research focussed on developing new methods to measure brain changes using a combination of diffusion and functional MRI. Specifically, he developed advanced methods capable of measuring minute changes in white matter, including changes driven by motor training. These methods were particularly special in that they overcame existing issues associated with analysing brains with pathology. This means that future rehabilitative studies are able to include children with severe brain

injury, whose pathology may have previously impeded analysis. For children with unilateral CP in the Mitii™trial, it was demonstrated that five clinical measurements of motor capability correlated well with the diffusion MRI measures of the motor-tract white-matter. During his candidature, Lee was author on eight publications (five first-author), working with The Queensland Brain Institute, QCPRRC and CSIRO.







Australasian Cerebral Palsy **Clinical Trials Network** (AusCP-CTN)



Australasian Cerebral Palsy **Clinical Trials Network**

AusCP-CTN

Centre for Research Excellence

NHMRC Centre for Research Excellence (CRE) APPIII6442

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).



Australian Government National Health and

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 Medical Research Council Davies (UQ), A/Prof Anthony Smith (UQ), A/Prof Ray Russo (SA).

Clinical Leaders: A/Prof Jane Valentine (WA), Dr Priya Edwards, Ms Megan Kentish (QLD). **CRE Manager:** Dr Susan Sullivan (QCPRRC Senior Research Partnerships and Program Manager).

Our CRE website has been launched! Find us at https://cre-auscpctn.centre.ug.edu.au/

The Australasian Cerebral Palsy Clinical Trials Network (AusCP-CTN) is a Centre for Research Excellence (CRE) funded by NHMRC (\$2.49m over 5 years). The AusCP-CTN will conduct world standard, multisite, clinical trials to improve early detection and determine the best interventions and treatments for children with CP. We have a work plan to uplift earlier detection of cerebral palsy, fast track children to multi-site randomised clinical trials of new neuroprotectants and to develop and test new rehabilitation. Our future vision is one of a continuing decline in the rate of CP and an improvement in health outcomes as children with CP become more contributing members of society.

The AusCP-CTN CRE will function via three main networks: Researchers, Clinicians and Consumers (people with CP and their families).

The AusCP-CTN CRE includes an array of research across five themes (image, right):

SAVE THE DATES!! 5th to 11th November 2017

The AusCP-CTN CRE is hosting our annual meeting and education/ training sessions in Brisbane in November. See p12 for further details on our events.



including General Movements Training, NIH-Style Grant Writing Workshop, HAI training, HINE workshop, Annual Meeting, Hot Topics Research Forum and Parents/Consumers day.

> There will be a variety of Postdoctoral and PhD opportunities for candidates linked to this research. Contact: CRE Manager: <u>auscpnetwork@uq.edu.au</u> OR: QLD: r.boyd@uq.edu.au NSW: INovak@cerebralpalsy.org.au VIC: m.fahey@monash.edu.au SA: Ray.Russo@sa.gov.au WA: Catherine.Elliott@health.wa.gov.au NZ: s.stott@auckland.ac.nz



Advancing Cerebral Palsy: Early Detection and Early Intervention in Queensland

QLD State Government Advance QLD Innovation Partnership (AQIP #16-103)

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: 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 termborn infants. These innovative toolboxes will be translated into clinical products/technologies (e.g. smartphone APPs, Telemedicine).

Staff recruitment has been a key focus of the first six months, including a research physiotherapist, research occupational therapist and neuroimaging postdoctoral research fellow. The AQIP program will continue to train clinicians in the General Movements (GMs) Assessment, for the early detection of CP See page 12 for our next GMs training in Brisbane (5-8th November 2017), at which QLD clinicians will receive discounted registration fees.

QEDIN-CP: Queensland Early Detection and Intervention Network – Cerebral Palsy

QEDIN-CP is part of the Advancing Cerebral Palsy in Queensland partnership. QEDIN-CP will unite interested parties and health professionals across Queensland to support the implementation and maintenance of best practice for the early identification and management of CP.

Infants can be referred to the network via their treating clinicians. If an infant is between 12-16 weeks corrected-age (CA), the General Movements Assessment may be undertaken which involves a simple video of the infant's spontaneous movements when they are awake. If an infant is older than 16 weeks CA, the Hammersmith Infant Neurological Examination (HINE) may be undertaken which is a standardised non-invasive clinical assessment that assesses things like nerve function, posture, reflexes and reactions.

QEDIN-CP aims to provide support for clinicians involved in the identification of infants who may have CP. It will also provide education and training on early detection and early interventions for infants at risk of CP, and the ongoing maintenance of clinical skills for early detection.

QEDIN-CP is a clinical network which may assist in earlier identification of all infants at high risk of a later diagnosis of CP who are currently living in Queensland. Earlier detection will ensure appropriate services are engaged to support children and families at an earlier stage and enable children to receive targeted interventions earlier in order to optimise this critical period of brain development. This may lead to improved outcomes for the child, reduced family burden and improved family well-being.

QEDIN-CP has recently gained ethical approval and should be ready to commence throughout Queensland in the near future.

- If you would like to find out more, please contact:
- Prof Ros Boyd (Principal Investigator) 07 3069 7372, <u>r.boyd@uq.edu.au</u>
 Joanne George (Senior Research Physiotherapist and QEDIN-CP
 - Coordinator): <u>gedincp@ug.edu.au</u>



Advance Queensland Fellowships

Dr Lee Barber (right) of QCPRRC was successful in his application for a 3 year Advance QLD Early Career Fellowship for his study entitled "CP muscle-movement toolbox: expand early detection of cerebral palsy". Dr Barber's Fellowship will investigate novel muscle ultrasound and wearable sensor movement technology to enhance early diagnosis of CP and qualify distribution, severity, and functional outcomes. Early diagnosis of CP, at three months utilising new techniques, will enable referral to early intervention and surveillance programs for musculoskeletal comorbidities at a time of maximum brain and muscle remodelling capability, to lower physical disability.

Other QCPRRC-related Fellowship recipients are:

- Dr Chris Carty (Griffith University; Honourary QCPRRC Fellow): "The Personalised Digital Patient: helping children with lower limb deformities.'
- Dr Lee Reid, (CSIRO, former QCPRRC student): "CONSULT: A connectivity-based surgical planning tool, incorporating advanced functional neuroimaging."
- Dr Alex Pagnozzi, (CSIRO, former QCPRRC-associated student): "Innovative web-based clinical decision support tool for paediatric brain injury."
- Dr Steve Mehrkanoon (UQ, QCPRRC collaborator): "The early diagnosis of neurodevelopmental disabilities using integrated bioengineering technology."

REACH: Randomised trial of Rehabilitation very EArly in **Congenital Hemiplegia** (NHMRC Project Grant 1078877)

Chief Investigators: Prof R Boyd, Prof | 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, Dr K Walker, Dr R Dale, Prof S Rose, Dr R Ward, Dr M Sharp, Dr N French, Ms L Findlay, Dr P Edwards

The REACH study will recruit 150 infants aged between 3 and 6 months corrected age who present with asymmetrical development of their hand/arm function, often after an asymmetrical brain injury, from Queensland, New South Wales, Victoria and Western Australia. In Queensland, the Gold Coast University Hospital and Sunshine Coast University Hospital have now been added to the Lady Cilento Children's Hospital, Mater Mothers' Hospital and Royal Brisbane and Women's Hospital as recruitment sites. Twenty-five infants and their families are already participating in the REACH Study, with each infant receiving either infant-friendly modified Constraint-Induced Movement Therapy (mCIMT) or infant-

friendly Bimanual Therapy (BIM). REACH therapists have been visiting the infants' home each month, following up with a videoconference appointment between visits and supporting the infants' caregivers in delivering the daily therapy sessions. Fourteen of the infants have already completed their therapy sessions and reached their 12-month assessment time-point. Thank you to our REACH families for their involvement in the study.

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

(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. Associate Investigators: A/Prof A Guzetta, Ms C Galea, A/Prof Karen Walker, Dr K Prelog, A/Prof M Fahey, Ms S Clough, Prof S Rose, Prof W Tarnow-Mordi

The purpose of this research is to investigate whether a new brain training intervention for infants, called "GAME", is better than traditional standard intervention for improving movement and capability, neuroplasticity, intelligence, independence in daily activities and quality of life. The main differences between GAME and traditional standard care are that the GAME intervention is individualised to your goals, your home and to your child's favourite toys, brain injury and potential. This multicentre randomised controlled trial will recruit 300 infants with a diagnosis of cerebral palsy OR diagnosis of "high risk of cerebral palsy" across 11 collaborating centres and 26 sites, in the three east-coast states of Australia. The study has already commenced recruitment in New South Wales and will soon begin recruitment in Queensland and Victoria.

For more information on the REACH and GAME studies, contact: Prof Ros Boyd (Investigator) 07 3069 7372, <u>r.boyd@uq.edu.au</u> Dr Tracey Évans (QLD Coordinator) 07 3069 7365, reach.qcprrc@uq.edu.au

Websites: https://qcprrc.centre.uq.edu.au/reach https://cre-auscpctn.centre.uq.edu.au/project/game











Parenting Acceptance and Commitment Therapy (PACT): Innovative, web-based support for families of children with Cerebral Palsy (Cerebral Palsy Alliance Grant PG0214)



Research Team: Dr Koa Whittingham, Prof Roslyn Boyd, Dr Jeanie Sheffield, Ashleigh Wright.

The PACT study is a trial of an innovative online parenting support course, called PARENTIOI, that we have developed specifically for families of children with cerebral palsy. PARENTIOI 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 that you can build a stronger relationship with your child and develop strategies for coping with difficulties and challenges along the way. We are recruiting any parent (including adoptive, step parent or legal guardian) of a child aged from 2-10 years with cerebral palsy. We understand family life is busy, so the program is designed to be flexible and time commitment varies between **3-8 hours.** You just need to have reliable internet access and a mobile phone. So far, we have recruited 41 parents to the study, and feedback from parents who have completed the course has been very positive! We are in the final stages of recruitment, so please contact us if you are interested in finding out more.

With your help, we hope to perfect PARENTIOI and make it accessible to parents of children with cerebral palsy across the world.

For more information, please contact the study coordinator Ashleigh Wright on 07 3069 7360 or <u>a.wright@uq.edu.au</u> or see https://qcprrc.centre.uq.edu.au/pact-0

Parenting Acceptance and Commitment Therapy to improve psychological outcomes for families of infants with an early diagnosis 'at risk' of CP (Early-PACT)

Research Team: Dr Koa Whittingham, Dr Jeanie Sheffield, Prof Roslyn Boyd, Dr Corrine Dickinson.

With advances in the early detection of Cerebral Palsy risk, this study aims to provide therapeutic support and empowerment to families sooner. This study aims to explore the psychological impact for families at point of detection of cerebral palsy risk and to trial the efficacy of an online parenting course grounded in Acceptance and Commitment Therapy. The study will aim to support the parent-infant relationship during a highly vulnerable period, which may encompass feelings of grief and loss, trauma and perinatal mental health risk. The study is currently in the early stages of development and will commence Qualitative Interviews with families and clinicians very soon.



For more information, please contact Dr Corrine Dickinson c.dickinson@uq.edu.au

Learning through Everyday Activities with Parents (LEAP-CP)

An early detection and intervention delivered in the home, parent-to-parent in a lowmiddle income country (Cerebral Palsy Alliance Grant PG6916) Investigators: Dr K Benfer (UQ; QEII Endeavour Fellow), Prof R Boyd (UQ), Prof I Novak, Dr C Morgan Cerebral Palsy



(CP Alliance), Dr N Khan (Bangladesh), Dr A Bhattacharya (Apollo Gleneagles Hospital, Kolkata). To begin is half the work... let half still remain (Marcus Aurelius).

Like a fine wine, it has taken some time to be ready, but after only one month of active recruitment, we have already had 90 babies with risk factors for CP referred. Our local partners, Apollo Gleneagles Hospital (referral hospital and fellowship host), Asha Bhavan Centre (a nongovernment disability organisation in Howrah District), Child In Need Institute (a non-government maternal child health organisation working in slum communities in Kolkata urban), and Dr BC Roy Hospital (in conjunction with Dr Sandip Samanta's private chambers in North 24 Parganas District) have incredible strengths in their staff commitment, hard work and community networks; which have been critical to the success of our first steps.



For more information, please contact Dr Kath Benfer, k.benfer@uq.edu.au or see https://qcprrc.centre.uq.edu.au/leap-cp

PREDICT CP: Implementation of comprehensive surveillance to Predict outcomes for children with Cerebral Palsy (NHMRC Partnership Grant 1077257)

Chief Investigators: Prof R Boyd, Prof P Davies, Prof J Ziviani, Prof S Trost, Dr L Barber, Dr R Ware, Prof S Rose, Dr K Whittingham, A/Prof J Whitty, Dr K Bell.

Associate Investigators: Prof P Scuffham, Dr C Carty, A/Prof J Walsh, Ms M Kentish, Dr P Edwards, Dr L Copeland, Dr K Weir, Dr L Sakzewski, Dr A Guzzetta, Dr D Brookes, Prof A Coulthard, Mr O Lloyd.

Families of children, who participated in the CP Child Studies, are being invited to take part in PREDICT CP, which includes a one-off clinical assessment day and a brain MRI scan.

Background: The PREDICT CP study is a continuation of the valuable work undertaken in the CP Child studies, which include the Motor & Brain Development Study and the Growth, Nutrition & Physical Activity Study (GNPA). In addition to comprehensive reports on health outcomes, the PREDICT CP study aims to explore the relationship between severity and brain structure using diffusion MRI. This important information will enable us to build prediction models that will allow us to predict outcomes and develop timely and effective interventions for children with CP.

Study progress: Recruitment to PREDICT CP is well underway, with 30 children having already completed their clinical assessments. We are now ready to start supporting families from regional parts of QLD to attend the assessment in Brisbane, which includes travel and accommodation.

Study involvement: Child: Comprehensive clinical assessment, completed during a one-off visit and includes motor capacity (gross and fine motor function), neuropsychology, communication, nutrition, bone health (DXA Scan), pathology (blood test). Brain MRI scan (if eligible), conducted at the new Herston Imaging Research Facility (HIRF), which takes approximately 30min. Parents and carers: **Ouestionnaires and home activities**

A comprehensive report will summarise key findings from the visit for the family and their child's designated, treating clinicians.

Thank you! We would like to extend our thanks to all families that have taken part in this study for their time and valuable support.

For more information, please contact Enna Salama: 07 3069 7354 or predict.gcprrc@ug.edu.au or see https://qcprrc.centre.uq.edu.au/predict-cp-0

The Friends Project (PEERS): Optimising social competencey in youth with acquired brain injury and cerebral palsy

Chief Investigators: Dr Leanne Sakzewski, Ms Nicola Hilton, Ms Rosemary Gilmore, Dr Sarah McIntyre, Dr Hayley Smithers-Sheedy, Dr Tracey Williams, Ms Anne-Maree Sarandea, Dr Elizabeth Laugeson, Dr Elise Davis. New project grant funded by Motor Accident Insurance Commission Queensland.

A person's ability to make friends and relate socially with others contributes to the development of meaningful relationships, long-term psychological well-being, academic and career achievement, community participation and avoidance of criminal activity and substance abuse, therefore profoundly impacting quality of life. Social difficulties are reported as one of the most significant problems for youth with acquired brain injuries (ABI) that can persist long term into adulthood. For youth with cerebral palsy (CP), making friends and maintaining social networks can be a major challenge. One evidence-based parent assisted social skills training program (Program for the Education and Enrichment of Relational Skills: PEERS) has demonstrated effectiveness to improve social functioning of youth with Autistic Spectrum Disorder and Attention Deficit and Hyperactivity Disorder.

Aim I: This study for teenagers with ABI and CP aims to pilot test PEERS to see if it improves their social skills and friendships.

Aim 2: To determine whether the PEERS program is acceptable and feasible for youth and their caregivers.

We are conducting this study in both Queensland and New South Wales and will be recruiting a total of 40 youth with ABI and CP (20 in each state). Our highly experienced clinician researchers have completed training to deliver PEERS in this study.

For further information contact Dr Leanne Sakzewski Lsakzewski1@uq.edu.au







Joe (10 years) - one of our incredible research champions!





ParticiPAte is fully recruited! (CP Alliance PG 3915) Investigators: Ms S Reedman, Prof C Elliott, Dr L Sakzewski, A/Prof S Girdler, Ms C Willis, Prof R Boyd.

The ParticiPAte CP study is fully recruited! Since April 2016, children with CP between eight and 12 years old have set goals about how they would like to become more physically active, and have been busy working on (and achieving!)

those goals. We have collected data about children's level of habitual physical activity using ActiGraph[™] accelerometer devices, as well as information about how parents and children are motivated to engage in physical activity.

Highlights since the last update include:

- Nick (11 years; top right) received a referral to an Athletics Australia classification panel as part of the study, being allocated a T/F38 classification. In May, Nick competed at his District Cross Country Carnival for the first time. He placed second in his classification, and as a result has been selected for the Met North Regional Carnival. Good luck Nick!
- Hayden (8 years; bottom right and with his soccer team on PII) joined his local football team and has been playing regularly since he participated in the study. Hayden enjoys running and wants to be classified for athletics and football when he is old enough. Reach for the stars Hayden!

Sarah Reedman (PhD student and physiotherapist) has been accepted to present interim results of the study at the 7 I st Annual Meeting of the American Academy of Cerebral Palsy and Developmental Medicine in Montreal, Canada, September 2017. Sarah received a prestigious student scholarship from AACPDM and will also be leading a workshop together with the research team on the delivery of participation-focused interventions, with the insights gained from ParticiPAte.

For information about the study, please contact Sarah Reedman on (07) 3069 7336 or sarah.reedman@ugconnect.edu.au or see https://gcprrc.centre.ug.edu.au/participate-cp

Activate-CP: A randomised controlled trial of functional electrical stimulation powered cycling, recreational cycling and sit-to-stand transfer training for children with moderate cerebral palsy

Chief Investigators: Ms E Armstrong, Dr C Carty, Ms M Kentish, Dr S Horan, Prof R Boyd

Activate-CP is a new study investigating the effects of an 8-week training program of functional electrical stimulation (FES) powered cycling, recreational cycling and sit-to-stand transfer training in children with CP who are classified as Gross Motor Function Classification Scale level III or IV. The study has been developed to address the paucity of evidence based interventions to help children with moderate CP to improve their sit-to-stand transfers and participation

in recreational cycling. Functional electrical stimulation powered cycling has been used among people with spinal cord injuries, CP and other neurological conditions to reduce or prevent muscle atrophy, improve circulation and increase joint range of motion. The purpose of incorporating FES-powered cycling in the Activate-CP training program is to help children with CP to achieve higher intensities of exercise and to supplement a home cycling program using adapted tricycles. It is anticipated that 40 participants will be recruited across 5 cohorts and will engage in Activate-CP training at one of two sites: the Queensland Paediatric Rehabilitation Service or Griffith University at the Gold Coast.

Potentially eligible participants will be children with CP who:

- are aged 8-18 years old
- are classified as Gross Motor Functional Classification Scale level III or IV
- have the goal to improve their sit-to-stand transfer ability and/or cycling ability

The study has been registered at http://www.ANZCTR.org.au/ACTRN12617000644369p.aspx

We are currently sourcing adapted tricycles for participants to borrow throughout the study. If you would like more information about the proposed study, please contact Ellen Armstrong (ellen.armstrong@griffithuni.edu.au)







MUSCLE RESEARCH UPDATE

Investigators: Dr Lee Barber, Dr Steven Obst, Dr Chris Carty, Dr Glen Lichtwark, Prof Roslyn Boyd, Mr Jarred Gillett, Ms Felicity Read, Ms Shari O'Brien.

Individuals with cerebral palsy have muscles that have adapted and function in different ways than typically developing muscles. Our Cerebral Palsy Muscle Research group is working hard to understand how best to keep the muscles functioning.

The CP muscle research group had a strong presence at the 29th European Academy of Childhood Disability Conference, Amsterdam, The Netherlands (http://www.eacd2017.org/), with six presentations. Jarred Gillett showcased findings from his recent FAST CP training study in young adults with CP, with improvements in muscle strength and size and functional abilities after 12 weeks of training. Studies in the areas of: muscle function during walking up and down hills in adults with CP (Jarred Gillett); muscle size and walking ability in children with CP (Felicity Read); muscle function following surgery in children with CP (Dr Lee Barber); muscle size measurement in children with CP (Dr Lee Barber); and musculoskeletal modelling during walking in children with CP (Dr Chris Carty) were also presented. Dr Lee Barber was invited to be involved in the half-day Pre-Conference Symposium: Muscle Function in CP, and a Workshop



focused on exercise and musculoskeletal health in CP - Mechanisms to Prescription.

Ms Shari O'Brien will be beginning her Targeted Active Movement Training study for young adults with CP very shortly. Can the brain adapt to improve movement skills in cerebral palsy? If you would like 6 weeks of one-on-one movement control training to improve your strength, fitness and walking ability, please contact Shari (s.obrien12@uq.edu.au). We would like to thank all of the participants and their families who have been involved with our studies so far. If you would like to be involved please contact Dr Lee Barber on (07) 3069 7334 or I.barber@uq.edu.au and don't forget to keep up with information at our Facebook page: www.facebook.com/CPMuscleResearch

European Academy of Childhood Disability (EACD) Annual Meeting 17 - 20 May 2017, Amsterdam, The Netherlands

At the 29th Annual meeting of the European Academy of Childhood Disabilities (EACD) in Amsterdam, the Netherlands in May 2017, the QCPRRC team delivered a total of 10 oral presentations, 4 poster presentations, 3 symposiums and an instructional course.

A major feature of the team's presentations was on the latest evidence and clinical applications of brain imaging in children with CP and of early brain imaging in infants born preterm. Information presented included:

- The Fiori semi-quantitative scale of brain lesion severity (which has strong predictive value of gross motor ability, manual ability, communication, oropharyngeal dysphagia, school readiness and hip development) and the full automation of the brain-image scoring system which will use the latest cloud computing technology.
- PPREMO toolbox. The use of a multi-modal approach (using a mix of • brain imaging and clinical assessments) has enabled the development of a toolbox of biomarkers that clinicians can use to assist in predicting outcomes for preterm infants.

Dr Katherine Benfer was awarded Best Oral Presentation for her research on Risk factors for identifying feeding difficulties and undernutrition in children with CP. Her co-authors were Kelly Weir, Peter Davies, Roslyn Boyd, Joan Arvedson and Kristie Bell. Feeding difficulties are prevalent in 60% of children with CP, and impacts negatively on nutritional status. Dr Benfer's research aimed to



Some of the team at EACD (L-R): Jo George, Kerstin Pannek, Andrea Guzzetta, Ros Boyd and Simona Fiori

determine the relationship between risk factors or "red flags" and feeding difficulties and undernutrition. A longitudinal, population-based study design was used. Red flags that were associated with feeding difficulties included 'parent stress', 'concern regarding growth' and 'respiratory difficulties'. Undernutrition was associated with 'concern regarding growth' and 'parent stress'. These red flags appear to be feasible screening questions for parents of children with CP, although such a screening tool needs to be properly validated.



Recent Publications

The efficacy of interventions to increase physical activity participation of children with cerebral palsy: A systematic review and meta-analysis

Authors: Sarah Reedman, Roslyn Boyd and Leanne Sakzewski.

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Journal: Developmental Medicine and Child Neurology (Published online ahead of print, March 2017) <u>doi:10.1111/dmcn.13413</u>

Children with CP face a number of different barriers to accessing and participating in leisure-time physical activities. On average, they also have lower levels of habitual physical activity (that is, physical activity performed during the usual activities of daily living).Traditionally, clinicians have set therapy goals with respect to impairments in body structures and functions and/or activity limitations. Recently, there has been a move to setting treatment goals that are directly related to the participation restrictions experienced by the child and their family.

The aim of this work was to determine whether there is evidence to suggest that therapy and behaviour change interventions increase the level of participation in leisure-time physical activities and habitual physical activity in children and young people with CP.

The authors conducted a systematic review and meta-analysis. A systematic review appraises and summarises existing research studies using a rigorous and clearly documented methodology. Data about the studies'

treatment effects are pooled together through a process called meta-analyses.



The authors concluded that the few studies that have been conducted were capacity-focused and not designed to be sensitive enough to detect change. However, therapy and behaviour change interventions have the potential to increase participation of children and young people with CP in leisure-time physical activities. There is a need to depart from impairment-focused approaches. Inappropriate selection of outcomes and inadequate reporting of complex interventions are barriers to progress in this field.

Validation of an MRI Brain Injury and Growth Scoring System in Very Preterm Infants Scanned at 29- to 35-Week Postmenstrual Age.

Authors: Joanne George, Simona Fiori, Jurgen Fripp, Kerstin Pannek, Jane Bursle, Randal Moldrich, Andrea Guzzetta, Alan Coulthard, Robert Ware, Stephen Rose, Paul Colditz and Roslyn Boyd.

Journal: American Journal of Neuroradiology (Published online ahead of print, May 2017) <u>doi:10.3174/ajnr.A5191</u>

Preterm infants are at risk of brain injury and impaired brain growth. Consequently, they are at risk of poorer outcomes in infancy and childhood.

Quantifying or scoring structural brain images to classify injury and growth has been validated for preterm infants when they reach term-equivalent age. With safe earlier imaging now possible with imaging-compatible incubators, there is a need to validate such scoring methods in infants before they reach term-equivalent age. Therefore, the aim of this study was to validate a brain-imaging scoring system in a group of infants born < 30 weeks gestational age with their brain imaging occurring between 29 and 35 weeks' postmenstrual age. The study also aimed to establish the ability to use the scoring system to predict motor and cognitive outcomes at 12 months corrected age.

Infants underwent early brain imaging between 29 and 35 weeks' postmenstrual age and then had another brain scan at term-equivalent age. At 12 months corrected age, they also underwent neurodevelopmental assessment (to look at for



example, motor and cognitive development, and neurological and sensory motor function).

The result of the study indicated that the imaging scoring system is valid for use at 29 to 35 weeks postmenstrual age in infants born very preterm. The scoring system has good reproducibility and showed significant associations with motor and cognitive outcomes at 12 months corrected age. Therefore, it enables identification of infants at risk of adverse outcomes before the current standard of term-equivalent age.

Upcoming Events:

General Movements training from the GMs Trust

(3.5 days, 2x basic and 1x advanced courses)

Herston Brisbane, 5th-8th November.

https://cre-auscpctn.centre.uq.edu.au/event/428/gms-training

The Basic Course provides an introduction into Prechtl's Method on the Qualitative Assessment of General Movements in young infants. The Advanced Course will provide an additional intensive training in correct judgement.

TRAINERS: A/Prof Andrea Guzzetta, A/Prof Alicia Spittle, Dr Vittorio Belmonti

NIH-Style grant writing workshop for early to mid-career researchers South Brisbane, 5-7th November

https://cre-auscpctn.centre.uq.edu.au/event/437/grant-workshop

This NIH-style grant writing workshop will assist Early and Mid-Career Researchers with grantsmanship and offers mentorship and individual feedback from successul researchers. Attendees should bring along a grant application that can be workshoped during the course.

Hand Assessment for Infants (HAI) training

South Brisbane, 6-7th November

https://cre-auscpctn.centre.uq.edu.au/event/444/hai-training

A new assessment of hand function, the Hand Assessment for Infants (HAI), has recently been developed for infants at risk of developing cerebral palsy (CP) in the age range of 3-12 months. The HAI intends to Hand Assessment the degree and quality of goal directed actions performed with each hand separately as well as

with both hands together.

TRAINERS: Dr Sue Greaves, Danni Centorame

Hammersmith Infant Neurological Examination (HINE) workshop Brisbane, 8th November

https://cre-auscpctn.centre.uq.edu.au/event/479/hine

The Hammersmith Infant Neurological Examination (HINE) has been proposed as one of the early neurological examination tools for the diagnosis of cerebral palsy. This workshop will present the theory and demonstrate the practical application of the HINE, a standardised and scorable clinical neurological examination for infants between 2 and 24 months of age.

Hot Topics in Cerebral Palsy Research Forum

Edwin M.Tooth Lecture Theatre, RBWH Education Centre, Herston QLD, 9th-10th November https://cre-auscpctn.centre.uq.edu.au/event/453/cp-research-forum

This 2-day research forum will feature presentations from leading researchers and clinicians in the field of cerebral palsy. A face to face meeting of the Australasian Cerebral Palsy Clnical Trials Network (AusCP-CTN) Centre for Research Excellence (CRE) will be held on Wedneday 8th November at South Brisbane. All chief investigators, associate investigators and key personnel will meet to discuss progress of the CRE and review key performance indicators.

Parents and Consumer Day

Lady Cilento Children's Hospital, South Brisbane, 11th November https://cre-auscpctn.centre.uq.edu.au/event/session/485

Do you have cerebral palsy or have a family member with (or at high risk of) cerebral palsy? Members of the public are invited to attend the parents and consumers day on Saturday 11th November at the Lady Cilento Children's Hospital Auditorium. The AusCP-CTN CRE will present topics of interest from leading researchers and clinicians in the area of cerebral palsy.

Further details including formal registration for these events will be updated on the above web links, accessed via <u>https://cre-auscpctn.centre.uq.edu.au/events</u>

For Further information on these events please contact the CRE manager,

Dr Susan Sullivan on auscpnetwork@uq.edu.au



