

Message from Prof Ros Boyd, Scientific Director

Dear Families and Collaborators

The QCPRRC team have had a very busy 6 months presenting the outcomes of our clinical trials and research at two major International conferences, the AusACPDM in Adelaide and the 6th International Cerebral Palsy Conference in Stockholm. Our team had the highest number of contributions to the AusACPDM with 26 paper presentations, 3 scientific posters and 4 workshops at the 8th Biennial Scientific Conference for the Australasian Academy for Cerebral Palsy and Developmental Medicine meeting in Adelaide (P3).

Members of the team were honoured to present our latest research findings and contribute to several State of the Science workshops at the largest ever International Cerebral Palsy conference (ICPC) in Stockholm with 1500 delegates in June. The ICPC was combined for the first time with the inaugural International Alliance of Academies of Childhood Disability (IAACD) which will be held every 3 years rotating around the continents with the next conference to be held in the US in 2019 with the American



Academy of Cerebral Palsy. As with the meeting in Stockholm, this will enable researchers and families of children with CP to participate in an international conference with the latest science from early development to adulthood. In Stockholm there were contributors from 66 countries enabling a focus both on the international rights of the child and delegates from low and middle income countries. A highlight of the conference was a preconference day with presentations from all current early intervention trials from around the world (P2).

In March we were delighted to install our new MRI compatible incubator at the Lady Cilento Children's Hospital enabling safe neuroimaging of tiny fragile infants safely from LCCH and the Mater Mothers' Hospital (P2). This coincided with an International Summit in February organized by the Cerebral Palsy Alliance on evaluation of new and emerging treatments for infants who sustain a Neonatal Stroke. There are many emerging interventions for children born with a diagnosis of CP which may continue to impact the incidence of CP which is declining (P5).



At ICPC, Stockholm the Conference Chair Prof Anki Eliasson and President Prof Hans Forsberg open the conference with children with CP on their Race runner bikes.

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New MRI compatible incubator funded by NHMRC



Torsten Loenneker-Lammers from LMT Medical Systems, Roslyn Boyd with Ben Cole from Imaging Solutions install the new MRI compatible incubator.

The MRI compatible neonatal incubator arrived in March 2016 and will provide safe clinical and research brain MR imaging for sick and premature babies weighing up to 4.5 kg from the Mater Mothers' Hospital and the Lady Cilento Children's Hospital. It is only the third such incubator in the Asia/Pacific region and will enhance the

earlier and accurate detection of brain injury for neuroprotection and early neurorehabilitation. By placing the baby



MRI compatible incubator tested by mother and baby.

inside the controlled environment of the MRI compatible incubator, we can now meet the needs of very preterm and

medically unstable infants for temperature control, monitoring, IV infusions and ventilation and obtain high quality brain images. The purchase of the incubator was supported by a 2015 UQ Major Equipment and Infrastructure (MEI) and NHMRC Equipment Grant and generous donations from the Children's Hospital Foundation and the Mater Foundation, The University of Queensland and CSIRO.



MRI compatible incubator tested by the LCCH and MMH teams.

Highlights from International Conference in Stockholm

(Reported by Leanne Sakzewski and Piyapa Keawutan)

The 5th International Conference on Cerebral Palsy (ICPC) and other Childhood-onset disabilities in Stockholm, Sweden (1st - 4th June 2016) was a major international meeting attended by 1500 delegates from over 60 countries. Research from the Queensland Cerebral Palsy and Rehabilitation Research Centre was showcased in 2 mini-symposiums, 1 instructional course, 8 free paper and 16 poster presentations.

Physical activity in children with cerebral palsy (CP) was a popular topic at ICPC in Stockholm. Recently, physical activity guidelines for people with cerebral palsy are available which recommend moderate to vigorous physical activity for 60 minutes, ≥ 5 days a week and sedentary time less than 2 hours a day or to break up sitting for 2 minutes every 30-60 minutes. As many children with CP are at high risk for deconditioning related to fitness, muscle strength and endurance (fatigue, reduce walking distance, reduce walking speed), changing physical behaviour (high physical activity and low sedentary behaviour) are recommended to start at young age. Increased awareness of physical activity

and break up sedentary behaviour (lying and sitting) are important for all children with CP.



QCPRRC team at ICPC, Stockholm: Prof Boyd, Dr Barber, Ms Keawutan, Dr Sakzewski, Ms Davenport (L to R)

A number of interesting therapy presentations are worth noting:

Bleyenheuft, Y., et al. (2016). Hand-Arm Bimanual Intensive Therapy including the Lower Extremities (HABIT-ILE) for children with bilateral cerebral palsy (GMFCS II to IV). Effectiveness of Hand-Arm Bimanual Intensive Therapy including the Lower Extremities (HABIT-ILE) has already been shown for children with unilateral

cerebral palsy. This latest paper extends this intervention to children with bilateral cerebral palsy (Gross Motor Function Classification II-IV). This very intensive model of 84 hours of therapy provided over 13 days showed children had marked improvements in gross motor function, balance, manual hand ability and individualised goals.

Jimeno, H., et al. (2016). Functional skills acquisition following cognitive-based intervention in childhood movement disorders.

A second small study of children with dyskinetic CP (n=9) who had undergone deep brain stimulation also received Cognitive Orientation to daily Occupational Performance (CO-OP) which is a cognitive based intervention used by occupational therapists. All children in the study improved in the performance of their 3 chosen goals and also improved in 2 other goal areas not specifically trained. This suggests that this approach helps children to find their own strategies to overcome motor problems outside of therapy.

AusACPDM Conference Wrap (Reported by Sarah Reedman)

A strong contingent of staff and students represented QCPRRC at the Australasian Academy of Cerebral Palsy and Developmental Medicine 8th Biennial Conference in Adelaide, 30 March – 2 April this year. The outstanding knowledge, talents, and research expertise of QCPRRC was on show for a national and international audience with over 26 paper presentations, 3 scientific posters, and 4 workshops.

Major academic highlights included inspiring keynote lectures delivered by Professor Tom Chau from the PRISM lab at the Holland Bloorview Kids Rehabilitation Hospital in Toronto, Canada. Professor Chau described new frontiers in brain-machine interfacing and access technologies, and how these can transform the ability of people with disabilities to communicate meaningfully with others. Dr Katherine Benfer, a recent doctoral graduate of QCPRRC, also spoke to a packed and enthralled crowd with her prestigious PhD platform presentation. World-class research was presented across streams of Activity and Participation, Vision and Upper Limb, Growth and Transition, Gait, Family and Carer issues, Medical and Surgical, and Rehabilitation. Popular sessions included a hilarious 'CO-OP' practical workshop where

participants attempted to teach each other complicated and novel skills including juggling and putting on a hairband with one hand, and Cathy Mak's MiYoga (Mindfulness Yoga) workshop where participants learned how to deliver and adjust yoga for kids with CP using mindfulness techniques.

Outside the conference hall, we experienced the shopping, food, and sights of the 'city of churches'. The official conference dinner was a huge hit, including a thoughtful address by Paralympic athlete and Physiotherapist Katrina Webb. Attendees each took turns to use a hammer and chisel to cut chunks from two GIANT block of Haigh's chocolate before dancing the night away.

QCPRRC would like to thank all of our research participants and their families. Without your involvement and partnership, we would not be able to complete the research that delivers new scientific advances and insights to be shared with researchers and clinicians at conferences like these. The next AusACPDM conference will be held in Auckland, New Zealand in 2018.



Olga Laporta, Irene Braitto, Micah Perez, Felicity Read, Alana Muir, Katherine Benfer, Camilla Davenport, Kym Morris, Sarah Reedman and Piyapa Keawutan experience the Adelaide roof-tops



Dr Kath Benfer
PhD Platform

Prof Ros Boyd and Dr Kath Benfer

Special Issue: Abstracts of the 8th Biennial Conference of the Australasian Academy of Cerebral Palsy and Developmental Medicine, 30 March – 2 April 2016, Adelaide, Australia. *Developmental Medicine & Child Neurology* 58: 6-58



Students Piyapa Keawutan, Alana Muir, Micah Perez, Irene Braitto, Sarah Reedman, Olga Laporta, and Felicity Read before the opening address



Prof Giovanni Cioni, Prof Ros Boyd and Dr Andrea Guzzetta from University of Pisa presented two workshops on the State of Science of brain imaging in CP & Preterm Infants



Olga Laporta, Ros Boyd, Irene Braitto, Felicity Read, Sarah Reedman at the conference dinner

Recent Publications from QCPRRC

Baque, E., et al. (2016). “Randomized controlled trial of web-based multimodal therapy for children with acquired brain injury to improve gross motor capacity and performance.” *Clinical Rehabilitation*.

Objective: To compare efficacy of a web-based multimodal training program, ‘Move it to improve it’ (Mitii™), to usual care on gross motor capacity and performance for children with an acquired brain injury. Design: Randomized waitlist controlled trial. Setting: Home environment. Participants: 60 independently ambulant children (30 in each group), whom were at least 12 months post-Acquired Brain Injury were randomly allocated to receive either 20 wks of Mitii™ training (30 minutes/day, six days/wk, total 60 hrs) immediately, or waitlisted (usual care control group) for 20 wks. 58 children completed baseline assessments (32 males; age 11 yrs 11 mths \pm 2 yrs 6 mths; Gross Motor Function Classification System equivalent I = 29, II = 29). Intervention: The Mitii™ program comprised of gross motor, upper limb and visual perception/cognitive activities. Main measures: The primary outcome was the 30-second, repetition maximum functional strength tests for the lower limb (sit-to-stand, step-ups, half-kneel to stand). Secondary outcomes were the 6-minute walk test, High-level Mobility Assessment Tool, Timed Up and Go Test and habitual physical activity as captured by four-day accelerometry. Results: Groups were equivalent at baseline. The Mitii™ group demonstrated significantly greater improvements on combined score of functional strength tests (mean difference 10.19 repetitions; 95% confidence interval, 3.26–17.11; $p = 0.006$) compared with the control group. There were no other between-group differences on secondary outcomes. Conclusion: Although the Mitii™ program demonstrated statistically significant improvements in the functional strength tests of the lower limb, results did not exceed the minimum detectable change, so cannot be considered clinically relevant for children with ABI.

Scheck, S. M., et al. (2015). “Structural connectivity of the anterior cingulate in children with unilateral cerebral palsy due to white matter lesions.” *NeuroImage: Clinical*, 9: 498-505.

In this work we investigate the structural connectivity of the anterior cingulate cortex (ACC) and its link with impaired executive function in children with unilateral cerebral palsy (UCP) due to periventricular white matter lesions. Fifty two children with UCP and 17 children with typical development underwent diffusion and structural MRI. Five brain regions were identified for their high connectivity with the ACC using diffusion MRI fibre tractography: the superior frontal gyrus, medial orbitofrontal cortex, rostral middle frontal gyrus, precuneus and isthmus cingulate. Structural connectivity was assessed in pathways connecting these regions to the ACC using three diffusion MRI derived measures: fractional anisotropy (FA), mean diffusivity (MD) and apparent fibre density (AFD), and compared between participant groups. Furthermore we investigated correlations of these measures with executive function as assessed by the Flanker task. The ACC–precuneus tract had significantly different MD ($p < 0.0001$) and AFD ($p = 0.0072$) between groups, with post-hoc analysis showing significantly increased MD in the right hemisphere of children with left hemiparesis compared with controls. The ACC–superior frontal gyrus tract had significantly different FA ($p = 0.0049$) and MD ($p = 0.0031$) between groups. AFD in this tract (contralateral to side of hemiparesis; right hemisphere in controls) showed a significant relationship with Flanker task performance ($p = 0.0045$, 0.5856), suggesting that reduced connectivity correlates with executive dysfunction. Reduced structural integrity of ACC tracts appears to be important in UCP, in particular the connection to the superior frontal gyrus. Although damage to this area is heterogeneous it may be important in early identification of children with impaired executive function.

Sakzewski, L., et al. (2016). “Impact of multi-modal web-based rehabilitation on occupational performance and upper limb outcomes: pilot randomized trial in children with acquired brain injuries.” *Developmental Medicine & Child Neurology*.

Aims: To determine whether the multi-modal web-based rehabilitation ‘Move it to improve it’ (Mitii) is more effective than wait list control (usual care) to improve occupational performance, upper limb function, and visual perception in children with Acquired Brain Injury (ABI). Methods: 58 randomly allocated children (53% males; mean age 11y 11mo, SD 2y 6mo; Manual Abilities Classification Scale I=32, II=24, III=2; mean Full-scale IQ 75.8, SD 16.2) received either 20 wks of Mitii ($n=29$) or usual care ($n=29$). Mitii comprised upper limb, cognitive, visual perception, and gross motor tasks, recommended for 30 mins per day, 6 days per wk, over 20 wks. Outcomes were the Assessment of Motor and Process Skills (AMPS), Melbourne Assessment of Unilateral Upper Limb Function, Jebsen–Taylor Test of Hand Function, Test of Visual Perceptual Skills, Assisting Hand Assessment (AHA), and Canadian Occupational Performance Measure. Primary comparison at 20 wks between groups was on the AMPS process and motor measures. Results: Groups were equivalent at baseline. Participants completed on average 17.6 hrs (range 0–46h) of Mitii. There were no differences between groups on the primary outcome (AMPS process: estimated mean difference -0.1, 95% CI -0.3 to 0.2, $p=0.589$; and AMPS motor: estimated mean difference 0.2, 95% CI -0.1 to 0.5, $p=0.192$). There were no differences between groups on overall visual perception, upper limb, and occupational performance outcomes. Interpretation: Mitii led to negligible changes on all primary and secondary outcomes compared with usual care. This likely reflects the small dose achieved and poses questions around the acceptability and feasibility of home-delivered Mitii in this population of children with ABI.

Did you know? - Hot Topics and Key Publications in the Field of Cerebral Palsy

Sellier, E., et al. (2016). "Decreasing prevalence in cerebral palsy: a multi-site European population-based study, 1980 to 2003." *Developmental Medicine & Child Neurology*, 58: 85–92.

Aim: To monitor the trends in prevalence of cerebral palsy (CP) by birthweight in Europe, 1980 to 2003. **Method:** Data were collated from 20 population-based registers contributing to the Surveillance of Cerebral Palsy in Europe database. Trend analyses were conducted in four birthweight groups: <1000g (extremely low birthweight [ELBW]); 1000 to 1499g (very low birthweight [VLBW]); 1500 to 2499g (moderately low birthweight [MLBW]); and >2499g (normal birthweight [NBW]). **Results:** The overall prevalence of CP decreased from 1.90 to 1.77 per 1000 live births, $p < 0.001$, with a mean annual fall of 0.7% (95% confidence interval [CI] -0.3% to -1.0%). Prevalence in NBW children showed a non-significant trend from 1.17 to 0.89 per 1000 live births ($p = 0.22$). Prevalence in MLBW children decreased from 8.5 to 6.2 per 1000 live births ($p < 0.001$), but not linearly. Prevalence in VLBW children also declined from 70.9 to 35.9 per 1000 live births ($p < 0.001$) with a mean annual fall of 3.4% (95% CI -2.4% to -4.3%). Prevalence in ELBW children remained stable, at a mean rate of 42.4 per 1000 live births. **Interpretation:** **The decline in prevalence of CP in children of VLBW continues, and confirms that previously reported. For the first time, there is also a significant decline among those of MLBW, resulting in a significant overall decrease in the prevalence of CP.**

Peterson, M.D., et al. (2015). "Chronic Conditions in Adults with Cerebral Palsy." *J American Medical Association (JAMA)*, 314(21):2303-2305.

Adults with cerebral palsy (CP) represent an increasing population whose health status and health care needs are poorly understood. Mortality records reveal that death due to ischemic heart disease and cancer is higher among adults with CP; however, there have been no national surveillance efforts to track disease risk in this population. We examined estimates of chronic conditions in a population-representative sample of adults with CP. We used the full-year consolidated and medical conditions files for 9 years (2002-2010) of the Medical Expenditure Panel Survey (US MEPS). Data are collected by interviews with a single respondent for the household; the survey has mean response rates of 60%. Of the 207 615 adults included, 1015 had CP. Age-adjusted prevalence rates of all chronic conditions were significantly greater among adults with CP vs without CP, including diabetes (9.2% vs 6.3%, respectively), asthma (20.7% vs 9.4%), hypertension (30.0% vs 22.1%), other heart conditions (15.1% vs 9.1%), stroke (4.6% vs 2.3%), emphysema (3.8% vs 1.4%), joint pain (43.6% vs 28.0%), and arthritis (31.4% vs 17.4%) ($P < .001$ for all comparisons; Table 1). The adjusted odds ratios were significantly different for all conditions except diabetes and ranged from 1.32 (95% CI, 1.04-1.67) for hypertension to 2.03 (95% CI, 1.39-2.97) for emphysema. In this population-based sample, **adults with CP had significantly higher odds of chronic diseases compared with adults without CP, raising important questions about preventable health complications in this population.** Accelerated functional losses are a concern in the aging CP population. A large percentage of individuals who were once mobile eventually stop ambulating due to fatigue, inefficiency of gait, and/or muscle and joint pain.

Dang, V.M., et al. (2015). "Predictors of participation of adolescents with cerebral palsy: A European multi-centre longitudinal study." *Research in Developmental Disabilities*, 36:551-564.

This large population based study investigated whether childhood factors that are amenable to intervention (parenting stress, child psychological problems and pain) predicted participation in daily activities and social roles of adolescents with cerebral palsy (CP). They randomly selected 1174 children aged 8-12 years from eight population-based registers of children with CP in six European countries; 743 (63%) agreed to participate. One further region recruited 75 children from multiple sources. We used the following measures: parent reported stress (Parenting Stress Index Short Form), their child's psychological difficulties (Strength and Difficulties Questionnaire) and frequency and severity of pain; either child or parent reported the child's participation (LIFE Habits questionnaire). **Pain in childhood predicted restricted adolescent participation in all domains except Mealtimes and Communication** (standardized total indirect effects beta -0.05 to -0.18, $0.01 < p < 0.05$ to $p < 0.001$, depending on domain). Psychological problems in childhood predicted restricted adolescent participation in all domains of social roles, and in Personal Care and Communication (beta -0.07 to -0.17, $0.001 < p < 0.01$ to $p < 0.001$). Parenting stress in childhood predicted restricted adolescent participation in Health Hygiene, Mobility and Relationships (beta -0.07 to -0.18, $0.001 < p < 0.01$ to $p < 0.001$). These childhood factors predicted adolescent participation largely via their effects on childhood participation; though in some domains early psychological problems and parenting stress in childhood predicted adolescent participation largely through their persistence into adolescence. We conclude that **participation of adolescents with CP was predicted by early modifiable factors related to the child and family.** Interventions for reduction of pain, psychological difficulties and parenting stress in childhood are justified not only for their intrinsic value, but also for probable benefits to childhood and adolescent participation.

New to QCPRRC

Ashleigh Wright - Study Coordinator

Ashleigh Wright is a provisionally registered psychologist who is currently undertaking the Doctor of Clinical Psychology program at the University of Queensland. She has an interest in paediatric clinical and health psychology.

Ashleigh is employed part-time within the Queensland Cerebral Palsy and Rehabilitation Research Centre as the study coordinator for the Parenting Acceptance and Commitment (PACT) study. Her role involves the day to day management of the research, as well as delivering the Skype-based psychological intervention component of the online course for parents of children with CP aged 2-10 years living anywhere in QLD.



Mirka Streckhardt - Administration Officer

Mirka has a Masters of Applied Media Research and joined QCPRRC in March 2016. Mirka brings 5 years administrative and HR experience from her previous roles within The University of Queensland.

She is the go-to person for QCPRRC, providing high level administrative support to the team.

Olga Laporta - Occupational Trainee

Olga Laporta is a psychologist who has been awarded an Endeavour research fellowship to work for 6 months at QCPRRC. Olga is experienced in the neuropsychological assessment of children and adults with dyskinetic CP and is undertaking her PhD at the University of Barcelona. Her current research is focused on the relationship between brain structure and cognitive functioning in people with dyskinetic CP. Olga is supervised by Prof. Roslyn Boyd from UQ and Dr Roser Pueyo from the University of Barcelona. She is collaborating with Dr Kerstin Pannek at CSIRO on brain imaging analysis during her visit.



Enna Salama - Clinical Research Coordinator

Enna's background and experience are in biomedical and neuroscience research. She has recently been appointed to undertake coordination and implementation of clinical research projects for QCPRRC and will primarily be focusing on the PREDICT-CP study. Over the last few years, Enna has worked on clinical research projects in acute stroke care that aimed to translate research findings and evidence based guidelines into medical practice.

Jane Wotherspoon - Research Psychologist

Jane is currently in her final year of a Masters of Psychology (Educational and Developmental), and completing a placement at Disability Services. She has recently been involved in a research project at the Lady Cilento Children's Hospital, investigating the long-term neurodevelopmental outcomes in adolescents with congenital heart disease who underwent surgery as infants. Through the QUT Psychology and Counselling Clinic, Jane has experience in psychological assessment and counselling of children and adults, and an interest in neurodevelopmental disability. Jane will be working on the PREDICT study, administering the psychology and communication assessments.



PPREMO: Prediction of Preterm Motor Outcomes

(CP Alliance IRG1413 & FMFC 2014-074)

Chief Investigators: Ms J. George (PhD scholar), Prof R. Boyd, Prof P. Colditz, Prof S. Rose, Dr K. Pannek, Dr J. Fripp
Study Personnel: Ms K. McGrory (Research Nurse), Ms C. Finn (PT), Ms K. Morris (PT)



Some babies that are born prematurely can have problems later in life with learning, movement or behaviour. Approximately 10% of very premature babies develop cerebral palsy. It is difficult to know which babies will have problems and which babies won't, delaying diagnosis and links to early intervention services such as the Better Start program.

In the PPREMO study we are investigating whether early brain scans (magnetic resonance imaging, MRI) combined with movement and neurobehavioural assessments can help accurately identify which babies are at risk of problems later in life, allowing those babies and their families to be provided with the help they need as early as possible. We have the opportunity to use an MRI compatible incubator which means we can safely scan preterm babies brains earlier than has been possible before.

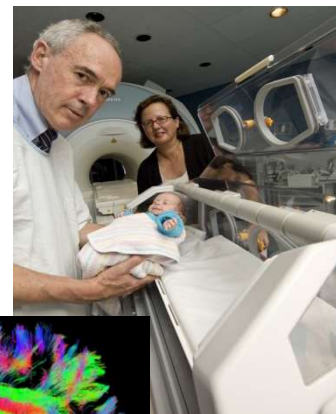


Clinical assessment of one of our term born babies

This study has been underway since February 2013. We have completed recruitment, with 146 preterm babies and 31 term babies participating in the study. All early MRI and clinical assessments have been completed and only a few last 3 and 12 month follow up assessments remain to be completed. Data analysis is underway with a number of manuscripts in preparation with our study findings.



Advanced analysis of our early brain scans showing how fibres connect in the brain



Professors Paul Colditz and Roslyn Boyd with the MRI incubator

As part of the expanded PREBO study, many of the PPREMO participants have joined for a follow up assessment at 2 years corrected age.

The full study protocol has been published and is available online via open access publication: George JM, Boyd R, Colditz PB, Rose SE, Pannek K, Fripp J, Lingwood BE, Lai MM, Kong AH, Ware RS, Coulthard A, Finn CM & Bandaranayake SE "PPREMO: a prospective cohort study of preterm infant brain structure and function to predict neurodevelopmental outcome" BMC Pediatrics (2015) 15:1123. (<http://bmcpediatr.biomedcentral.com/articles/10.1186/s12887-015-0439-z>)

We would like to thank all of the families who have participated in this study so far and those who have also joined the expanded study PREBO with a follow up assessment at 2 years corrected age. We look forward to completing data analysis and publishing our study findings.

For further information, please contact Ms Joanne George: j.george2@uq.edu.au
Website: <https://qcprrc.centre.uq.edu.au/ppremo>



A preterm participant returning for his 1 year follow up assessment

PREBO: Prediction of Preterm Brain Outcomes (NHMRC Grant 1084032)

Chief Investigators: Prof P. Colditz, Prof R. Boyd, Prof S. Rose, Prof B. Boashash, Dr K. Pannek, Dr R. Moldich
Associate Investigators: Prof A. Coulthard, Dr B. Lingwood, Ms J. George, Prof M. Breakspear, Dr R. Ware, Dr S. Finnigan, Dr S. Bjorkman
Study Personnel Qld: Ms K. McGrory (Research Nurse), Ms C. Finn (PT), Ms K. Morris (PT)



This new study is an extension of the PPREMO study, recruiting a larger number of babies across two sites and was later neurodevelopmental follow up at 2 years corrected age. The purpose of this research is to learn which tests (clinical assessments, MRI and EEG) can be used at 30 weeks and 40 weeks, to accurately identify which babies may have problems later in life, so that those babies and their families can be fast tracked to appropriate early interventions as early as possible.

We will merge two research teams using MR compatible incubators (RBWH and Monash Children's) to establish the role of cutting edge approaches in clinical assessment, MRI and EEG methods to improve neurodevelopmental outcomes for preterm infants.

Infants will undergo a brain MRI and EEG at 30 and 40 weeks GA to develop our understanding of the brain structure and maturation that occurs between these time points. A combination of neurological, neuromotor and neurobehavioural clinical assessments will be performed at 30 and 40 weeks GA to understand the relationship between brain structure and function. These data will be compared to clinical neurodevelopmental assessments at 3 months and 24 months corrected age.

NEW Baby Moves APP

At 3 months the General Movements (GMs) assessment (www.general-movements-trust.info) will be conducted via the "Baby Moves" App which will allow the parent to take a video of their baby at home and send it to a secure cloud so that the trained therapist can score it. One video is taken at 12 weeks and another at 14 weeks.

Preterm recruitment has commenced with 6 babies having had their 30 week MRI, EEG and clinical assessments. Two of these babies have also had their 40 week MRI, EEG and clinical assessments.

For more information, please contact Kym Morris: 07 3069 7338 or k.morris@uq.edu.au
Website: <https://qcprrc.centre.uq.edu.au/prebo>



REACH: Randomised trial of Rehabilitation very EARly in Congenital Hemiplegia (NHMRC Grant 1078877)

Chief Investigators: Prof R. Boyd, Prof J. Ziviani, Dr L. Sakzewski, Prof I. Novak, Prof N. Badawi, Dr K. Pannek, A/Prof C. Elliott,
Dr S. Greaves, Dr A. Guzzetta, Dr K. Whittingham

Associate Investigators: A/Prof J. Valentine, Prof P. Colditz, Dr R. Ware, Ms C. Morgan, Dr M. Wallen, Dr K. Walker, Dr R. Dale, Prof S. Rose, Dr R. Ward, Ms B. Choy,
Dr M. Sharp, Dr N. French, Ms L. Findlay, Dr P. Edwards, Dr R. Hunt, Dr M. Mackay, Ms M. Thorley, Ms A. Muir



One of our participants practising his reaching and grasping of toys.

The REACH study has commenced with babies recruited in Queensland, New South Wales, Victoria and Western Australia. This project compares two types of therapy to improve hand and arm skills and general motor development. The interventions are provided early to infants diagnosed with asymmetric brain injury, starting between 3 and 6 months corrected age. Each intervention will be provided by parents with the support of experienced occupational therapists and physiotherapists. The first one is called infant-friendly modified Constraint-Induced Movement Therapy (mCIMT). A sock or fabric glove is placed on the infants more able hand, so the child can practice movement and skills with the impaired hand and arm. mCIMT consists of play based activities carried out by parents at home, where one of the parents plays with the infant to encourage him/her to use their impaired hand/arm to interact with toys and the parent. The second intervention is called infant-friendly Bimanual Therapy (BIM). BIM also consists of daily sessions in which one of the parents plays with their infant to encourage equal use of both hands in play based activities.

Each state has employed experienced therapists who visit the homes of eligible babies monthly to support caregivers in providing the Baby CIMT or the Baby BIM intervention. The therapist and caregiver have a videoconference appointment between each home visit to help adapt the home program ideas to best suit the baby.

In Queensland the REACH study is recruiting from Lady Cilento Children's Hospital and Mater Mothers' Hospital, and we hope to be able to recruit from the Royal Brisbane and Women's Hospital in the coming weeks. Eligible babies are those who present with asymmetrical development of hand/arm function, often after an asymmetrical brain injury, who are between 3 and 6 months corrected age.

If you would like to find out more, please contact:

Professor Roslyn Boyd (Principal Investigator) 07 3069 7372 or r.boyd@uq.edu.au (Mo – Fri)

Dr Leanne Sakzewski (Senior Occupational Therapist) 07 3069 7345 or l.sakzewski1@uq.edu.au (Mo – Thu)

Debra Khan (QLD REACH Occupational Therapist) 07 3069 7357 or d.khan@uq.edu.au (Tue, Wed, Fri)

Website: <https://qcprrc.centre.uq.edu.au/reach>

PREDICT CP: Implementation of comprehensive surveillance to predict outcomes for children with cerebral palsy (NHMRC 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, Dr R. Pelekanos, Mr O. Lloyd.



Recruitment for the PREDICT-CP study is well under way for 2016. We have now had several families of children from the 2006 and 2007 birth years who participated in the CP child studies return to participate in the PREDICT study in a one-off visit over 1.5 days. The feedback we have received has been extremely valuable and has helped us plan and run this comprehensive surveillance program. We are now ready to start supporting families from regional parts of QLD to attend the assessment – this includes support for travel and accommodation. Our building is closely located to public transport hubs. We also offer on-site parking for those travelling by car. We are now ready to commence comprehensive MRI's as part of the assessment day – which will be conducted at the new Herston Imaging Research Facility (HIRF) at Herston.

For more information about the PREDICT-CP study, please contact

Enna Salama our Clinical Research Coordinator:

(07) 3069 7354 or predict.qcprc@uq.edu.au

Website: <https://qcprc.centre.uq.edu.au/predict-cp-0>



Nicholas, just after completing his DXA scan to learn about his bone health and body composition, holding the picture of his scan.



Savannah participating in walking and muscle studies in our new state of the art gait lab – one of her favourite sessions of the day. Photo collage kindly provided by Mum.

Spotlight on PREDICT participant Savannah!

How old are you Savannah?

Eight.

How many research studies have you participated in?

Two.

What do you think of our new building?

Good.

What did you enjoy most about your day with the PREDICT team?

Occupational therapy games and the gait lab.

Do you have any feedback or suggestions for the team?

Make it go for two days.

Feedback from Mum

How did you find the parking?

Fantastic! Very straight forward.

What do you think of our new facilities?

Beautiful, clean and well signed.

Feedback for the team?

All of the staff were wonderful throughout the day. Every need was met and Savannah was happy with each staff member.

STUDY DETAILS

The PREDICT project provides a comprehensive assessment of outcomes to inform the development of timely and effective interventions and predict future outcomes for children with cerebral palsy. Families with children aged between 8-10 years who participated in the original CP-child studies (born in the birth years of 2006, 2007, 2008, 2009 in Queensland) are invited back to participate in the PREDICT-CP study at our new location within the Centre for Children's Health Research (next to the Lady Cilento Children's Hospital).

Assessments will be completed across 1.5 days and include cognition and executive functioning (IQ and planning), communication, oropharyngeal dysphagia (eating and drinking), growth and nutrition, food diary and bloods (for Growth Hormone and Vitamin D), bone health – DXA scan, gross motor abilities and physical activity levels, 3D gait analysis and ultrasound of lower limb muscle properties, and parent and child questionnaires for quality of life, sleep, pain, stress and participation. A comprehensive report will summarise key findings from the visit for the family and their child's designated treating clinicians.

The first ParticiPate CP study cohort is underway! (CP Alliance PG 3915)

Chief Investigators: A/Prof C. Elliott, Dr L. Sakzewski, A/Prof S. Girdler, Prof R. Boyd, Ms S. Reedman, Ms C. Willis



ParticiPate CP is a study of motivational physiotherapy to facilitate participation in leisure time physical activities of choice, for kids with CP. Children and their caregivers in the intervention group are currently discussing their facilitators and barriers to participation with the physiotherapist (Sarah Reedman). Some of the children have started to practice important skills they will need to achieve their participation goals. Some families have recognised other barriers, such as limited time or negative community attitudes, and are beginning to discover ways to overcome these.

Families in both groups are excited to tackle goals that sometimes fall by the wayside, and are appreciative that the therapy sessions can be conducted in a place and at a time convenient to them (including after school and Saturdays).



Oliver (left) with his Dad Jamie and siblings Avé (middle) and Lachlan (right)

ParticiPate CP participant Oliver (left) with his Dad Jamie and siblings Avé and Lachlan pose in their AFL uniforms. Oliver achieved his goal of joining the same club as his dad and playing an AFL game once per week.

What was the goal you wanted to achieve? Did you achieve it?

Kick higher. Yes, because I am better at kicking from training and playing in the game.

What was the best part about being in the research study?

Playing AFL and learning to kick.

What do you like about AFL?

That I get to be part of a team and that I get to play AFL like my dad.

What do you want to be when you grow up?

I want to invent things.

A further 3 cohorts are planned (Oct 2016, Dec 2016, and Feb 2017) - Potentially eligible participants are children with cerebral palsy who:

- are 8 to 12 years of age (inclusive),
- can walk with or without aids in the community or can push a manual wheelchair by themselves,
- can communicate their wants, needs, desires for now and the future, and
- live within 200km of South Brisbane.

If you would like more information about this study please contact Sarah Reedman (Study Physiotherapist): (07) 3069 7336 or sarah.reedman@uqconnect.edu.au

How does Botulinum Toxin type-A (BoNT-A) treatment affect muscles? (CP Alliance IRG 2013)

Chief Investigators: Dr L. Barber

Associate Investigators: Dr C. Carty, Ms F. Read, Prof R. Boyd, Ms M. Kentish



Ms Felicity Read, PhD APA scholar presented her findings from the longitudinal walking and serial Botulinum Toxin type-A (BoNT-A) study at the AusACPDM conference in Adelaide this year with great reception from clinicians, orthopaedic specialists and other researchers.

This study showed an improvement in walking patterns on 2-dimensional videos after the first BoNT-A injections to calf muscles, followed by a maintenance of this gait pattern after the next two BoNT-A injections. The next step in Felicity's PhD is to determine if any relationship exists between the walking pattern and calf muscle size.

The CP muscle size and gait study has recruited 84 children to determine the relationship between calf muscle size and walking characteristics. This study is also assessing the change in calf muscle size and walking characteristics with two treatment cycles of BoNT-A. Participating children will be assessed each time they attend the Qld Paediatric Rehabilitation Service Gait lab for usual clinical follow ups associated with BoNT-A treatments. Currently, 31 children have begun their follow up appointments.

This study uses 3-dimensional ultrasound to capture images of the calf muscles. The 3D ultrasound has been very well tolerated by most children and is an innovative alternative to MRI measures of muscle size.



3D ultrasound set up in the QPRS gait lab at LCCH

For more information about this study, please contact Felicity Read: 07 3069 7341 or f.read@uq.edu.au

High intensity fitness program for lower limbs

(NHMRC Scholarship 1075642 and Australian Rotary Health funding partner scholarship)

Chief Investigators: Mr J. Gillett, Dr L. Barber, A/Prof G. Lichtwark, Prof R. Boyd



A FAST CP participant performing the Leg Press exercise.

The FAST CP trial for adolescents and young adults is continuing through 2016. Our training program is the first of its kind to combine strength training with anaerobic exercise in individuals with CP. It focusses on the type of fitness that is useful for short bursts of activity such as stair climbing. The exercise training program is both challenging and fun, with those who have participated so far getting fitter, stronger and faster.

All participants receive a full training report after completing the 12-week program (3 x 60 minute sessions per week) that outlines their functional capacity, strength and muscle size outcomes. We can also make some general recommendations following the training program on how to maintain the fitness gains and offer some tips on take-home exercises for those without ongoing access to a gym.

We would like to thank all of the participants and their families who have been involved with FAST CP so far.

Recruitment is ongoing for adolescents and young adults (15-30 years) with spastic CP who can walk independently in the South East Queensland area.

If you would like more information about this study please contact Jarred Gillett: j.gillett1@uq.edu.au or (07) 3069 7334
Website: <https://qcprc.centre.uq.edu.au/fast-cp>

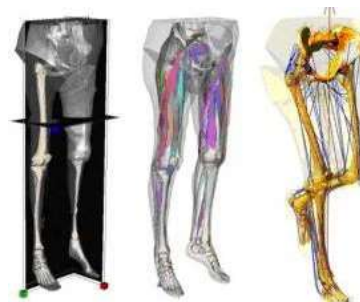
Habitual Physical Activity and Community Participation using GPS Testing novel measures of community function & participation in adults with CP. (CP Alliance PG3214)

Chief Investigators: A/Prof D. Thorpe, Prof S. Trost, A/Prof G. Lichtwark, Dr L. Barber, Prof R. Boyd



We have been funded by the Cerebral Palsy Alliance to investigate the factors which contribute to declines in function across the lifespan in people with Cerebral Palsy, to measure their community habitual physical activity and the relationship to community participation. This project aims to look at muscle degradation throughout life and its relationship to changes in physical activity levels. We will be using a questionnaire, ultrasound, functional measures, a physical activity monitor and strength testing equipment to look at how your muscles function and changes in your physical activity involvement.

As an additional part of this study aims to utilize Global Positioning System (GPS) and Geographic Information System (GIS) data linked with physical activity data to compare community integration in a cohort of adults with cerebral palsy across two continents with differing national healthcare systems. We will ask adults with CP to wear both a physical activity and GPS device in the community for 7 days. In this study we are collaborating with our colleagues at the University of North Carolina at Chapel Hill, who have used GPS to monitor how individuals participate in the community. If you are or know an adult with Cerebral Palsy, are between the ages of 18-65 years, and can walk (with or without a walking aid) you could really help us. We are continuing recruitment during 2016 and the findings may help understand your function and activity levels. If you would like to volunteer, or if you have further questions, please contact us.



Study contact: Ms Shari O'Brien, School of Human Movement Studies, University of Queensland

Ph: (07) 3365 3401 or E: s.obrien@uq.edu.au;

Professor Stewart Trost: Professor of Child Health, Leader – Children's Physical Activity Research Group

School of Exercise and Nutrition Sciences, Faculty of Health QUT Centre for Children's Health Research

Phone: + 61 7 3069 730 or E: s.trost@qut.edu.au

A/Prof. Glen Lichtwark, School of Human Movement Studies, UQ Ph: (07) 3365 3401 or E: g.lichtwark@uq.edu.au

Dr Lee Barber, Queensland Cerebral Palsy and Rehabilitation Research Centre, UQ Ph: (07) 3069 7334 or E: l.barber@uq.edu.au

Upcoming Events

American Academy for Cerebral Palsy and Developmental Medicine 2016

QCPRRC will be represented at the this years American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) in Hollywood, USA. The centres outstanding research will be shown to an international audience from 20th to 24th September 2016 in 3 free papers, 1 workshop and 4 scientific posters.

For details on the conference and the program please visit the website:

<https://www.aacpdm.org/meetings/2016>



Precht's Method of the Qualitative Assessment of General Movements

Basic and Advanced Training - Sunday 13th - Tuesday 15th November 2016 - Brisbane

The Basic Course provides an introduction into Precht's Method on the Qualitative Assessment of General Movements in young infants. This new assessment method has shown its merit for the prenatal and postnatal evaluation of the integrity of the nervous system. Compelling evidence is now available that qualitative assessment of General Movements (GMs) at a very early age is the best predictor for cerebral palsy. This method has become a potent supplement to the traditional kind of neurological examination.

The Advanced Course will provide an additional intensive training in correct judgement. This training will deal with the details of the assessment, the proper terminology and technique as well as with the application of individual developmental trajectories.

The course fulfils the standards specified by the GM-Trust.

Please see our Website for further details and online registration

<https://qcprrc.centre.uq.edu.au/event/321/gms-training>

QPRS Rehab Conference & Parent and Carer Day



Rehab for Kids
SHAPING FUTURES TOGETHER



The Lady Cilento Children's Hospital will soon play host to the 3rd Biennial Rehabilitation Conference of the Queensland Paediatric Rehabilitation Service (QPRS) – 'Rehab for Kids – Shaping Futures Together'.

The pre-conference workshops will run on **Wednesday 16th November, 2016.**

This will be followed by the conference on **Thursday 17th and Friday 18th November, 2016.**

We are also excited to announce the addition of a parent and carer day to this year's conference on **Saturday 19th November.** Our aim is to provide parents and carers with relevant information on the latest in clinical care and recent research in paediatric rehabilitation. This will also be an opportunity for accessing community supports and networking with other families and services.

The conference provides a forum for the sharing of ideas, presentation of research findings and discussion of professional issues relevant to children's rehabilitation. A number of dedicated streams with a variety of presentation types will provide delegates with opportunities to update their knowledge and understanding of a broad range of topics, network with colleagues from throughout Queensland and interstate, and learn from exhibitors.

Further details regarding the conference program, social function and registration will be available in the next few weeks.

If you have any questions or require further information please

email rehabconference@health.qld.gov.au or phone Timothy McGowan (07) 3068 2950.