Message from the Scientific Director, Professor Roslyn Boyd

Dear Families and Collaborators,

The Queensland Cerebral Palsy and Rehabilitation Research Centre has had a very successful 6 months since moving to our new location in the new Children's Health Research Centre at South Brisbane. Our young rising stars have had some outstanding success, a testament to the stability and strength of the QCPRRC research team. Our early career researcher Dr Katherine Benfer won the prestigious Queen Elizabeth II Jubilee Endeavour Award (only 1 awarded per year) to undertake a novel clinical trial of “parents training parents of children with Cerebral Palsy in a low resource country”. If successful the program has the potential to impact thousands of children with CP and will be easily translatable to other low resource countries (Page 3). Dr Benfer was also awarded a prestigious PHD platform presentation at the upcoming national Australasian Academy of Cerebral Palsy and Developmental Medicine (P7). In December Dr Tracey Evans and Dr Michael Herd were both awarded their PhDs for their studies on the Prem Baby Triple P clinical Trial (P9) and all six of our Medical Honours students were awarded 1st class honours (P6). In December 2015, with our collaborators, we were awarded two new project grants from the CP Alliance Foundation: (i) the Imagine CP study on Genetics and Neuroimaging ($200k over 2 years), and (ii) “Participate Now” an RCT to enhance community participation in Leisure for children with CP ($50k for 2016) (P4). In December, the order was placed for a new MRI compatible incubator funded by an NHMRC equipment grant which will enable the safe neuroimaging of small infants from the Mater Mothers Hospital and the Lady Cilento Children’s Hospital. This MRI incubator, the third in Australasia, enables the safe neuroimaging of infants at risk of CP both north and south of the river. In December we were delighted to give Minister Enoch a final report and demonstration of our Ebrain program that her department had funded (P3). Recently, two new clinical trials have recruited their first subjects in the PREDICT (P11-12) and REACH studies (P10). We are very grateful to the families who have agreed to return for a one off visit in the PREDICT study around their child’s 8-10th birthday. For the 4th Year in succession the QCPRRC team were awarded the most free papers at both the forthcoming AusACPDM in Adelaide in March 2016 (P6-7), and the American AACPDM in Austin in September 2015. In July 2015 I undertook my first of two visits to Curtin University as the Haydyn Williams visiting Professor to build collaborations with our colleagues in WA (P5), and was honored to be awarded an NHMRC Research Fellowship in November (P5). We hope you enjoy reading our latest news and look forward to your involvement in our research centre. With warm regards Ros Boyd

In December 2015, the Queensland Minister for Innovation, Science and the Digital Economy and Small Business, Leanne Enoch, visited QCPRRC

Congratulations to Dr Katherine Benfer who received the Endeavour QEII Jubilee Award from the Prime Minister in Canberra
Interpreting Intervention Induced Neuroplasticity with fMRI: The Case for Multimodal Imaging Strategies
Published online: http://dx.doi.org/10.1155/2016/2643491.

Direct measurement of recovery from brain injury is an important goal in neurorehabilitation, and requires reliable, objective, and interpretable measures of changes in brain function, referred to generally as “neuroplasticity.” One popular imaging modality for measuring neuroplasticity is task-based functional magnetic resonance imaging (t-fMRI). In the field of neurorehabilitation, however, assessing neuroplasticity using t-fMRI presents a significant challenge. This commentary reviews t-fMRI changes commonly reported in patients with cerebral palsy or acquired brain injuries, with a focus on studies of motor rehabilitation, and discusses complexities surrounding their interpretations. Specifically, we discuss the difficulties in interpreting t-fMRI changes in terms of their underlying causes, that is, differentiating whether they reflect genuine reorganisation, neurological restoration, compensation, use of pre-existing redundancies, changes in strategy, or maladaptive processes. Furthermore, we discuss the impact of heterogeneous disease states and essential t-fMRI processing steps on the interpretability of activation patterns. To better understand therapy-induced neuroplastic changes, we suggest that researchers utilising t-fMRI consider concurrently acquiring information from an additional modality, to quantify, for example, haemodynamic differences or microstructural changes. We outline a variety of such supplementary measures for investigating brain reorganisation and discuss situations in which they may prove beneficial to the interpretation of t-fMRI data.

Rehabilitation and neuroplasticity in children with unilateral CP
Lee B Reid, Roslyn N Boyd, Stephen Rose.
Published online 16 June 2015: http://dx.doi.org/10.1038/nrneurol.2015.97

Cerebral palsy is a childhood-onset, lifelong neurological disorder that primarily impairs motor function. Unilateral cerebral palsy (UCP), which impairs use of one hand and perturbs bimanual co-ordination, is the most common form of the condition. The main contemporary upper limb rehabilitation strategies for UCP are constraint-induced movement therapy and bimanual intensive therapy. In this review, we outline the factors that are crucial to the success of motor rehabilitation in children with UCP, including the dose of training, the relevance of training to daily life, the suitability of training to the age and goals of the child, and the ability of the child to maintain close attention to the tasks. Emerging evidence suggests that the first 2 years of life are a critical period during which interventions for UCP could be more effective than in later life. Abnormal brain organization in UCP, and the effects of development on rehabilitation, must also be understood to develop new effective interventions. Therefore, we also consider neuroimaging methods that can provide insight into the neurobiology of UCP and how the condition responds to existing therapies. We discuss how these methods could shape future rehabilitative strategies based on the neurobiology of UCP and the therapy-induced changes seen in the brain.

Safety of Botulinum Toxin Type A for Children with nonambulatory CP
Priya Edwards, Leanne Sakzewski, L Copeland, Laura Gascoigne-Pees, K McLennan, M Thorley, Megan Kentish, Roz Ware, Roslyn N Boyd.
Pediatrics. 2015, 136(S): 895-904. Published online 19 October 2015: http://dx.doi.org/10.1542/peds.2015-0749.

OBJECTIVE: To determine safety of intramuscular botulinum toxin A (BoNT-A) injections to reduce abstract spasticity and improve care and comfort of nonambulatory children with cerebral palsy (CP).

METHODS: Nonambulatory children with CP were randomly allocated to receive either BoNT-A (n = 23) or sham procedure (n = 18) in Cycle 1. In Cycle 2, the BoNT-A group received a second episode of BoNT-A (n = 20) and sham group received their first episode of BoNT-A (n = 17). A pediatric rehabilitation specialist masked to group allocation graded each adverse event (AE) according to system, severity (mild, moderate, serious, sentinel) and causality (unlikely/unrelated; possible; probable/definite).

RESULTS: There was no difference for all moderate/serious AEs between the BoNT-A and sham/ control groups in either Cycle 1 (incident rate ratio = 1.30, 95% confidence interval = 0.43–4.00; P = .64) or Cycle 2 (incident rate ratio = 0.72, 95% confidence interval = 0.30–1.75; P = .47). In Cycle 2, 1 serious, 3 moderate (single-episode group), and 24 mild (single-episode group n = 10; 2 episode group n = 14) AEs were probably/definitely related to BoNT-A.

CONCLUSIONS: Children receiving BoNT-A were at no greater risk of moderate/serious AEs compared with a sham control procedure. There was no increased risk of moderate/serious AEs between one and two episodes of BoNT-A.
Winner of the 2016 Endeavour Queen Elizabeth II Diamond Jubilee Award: Dr Katherine Benfer

Project: Early intervention to improve outcomes for families of children with Cerebral Palsy in Bangladesh (Parents training Parents)
Chief Investigator: Dr Katherine Benfer (UQ),
Co-investigators: Prof Roslyn Boyd (UQ), Professor Iona Novak (CP Alliance); Dr Nyla Khan (Shishu Hospital and the Centre for Rehabilitation of the Paralysed (Bangladesh))

Congratulations to Dr Katherine Benfer who was awarded the highly prestigious Endeavour QEII Jubilee Award at a special ceremony with the Prime Minister at Government House in Canberra on 24th November, 2015. The Endeavour QE II Diamond Jubilee scholarship is awarded to “an exceptional candidate in any field of study to undertake an international research programme that will contribute to the advancement of women’s leadership in Australia”.

Cerebral palsy (CP) is the most common cause of childhood disability, with 80% of the estimated global burden in low-resource countries. The current state of evidence allows us to reliably predict children at risk of CP from 13 weeks, however children in both high and low resource settings are not receiving a diagnosis or intervention until after 19 months. This means we are missing a significant window of opportunity for treatment when infants’ neuroplasticity is optimal.

This Endeavour Fellowship will enable Dr Katherine Benfer to conduct a randomised controlled trial of early community-based parent-delivered interventions for infants at high risk of CP in Bangladesh. The fellowship will allow her to develop and test a parent-delivered community-based early detection and intervention program for children at high risk of cerebral palsy (CP).

To our knowledge, no studies have evaluated early interventions in infants identified as high risk of CP in a low-resource country. Children in Bangladesh may have later diagnosis and face numerous barriers to receiving treatment, particularly economic and physical factors. A community-based intervention of enriched environments and nutritional support, delivered parent-to-parent in the home presents a viable and sustainable solution in the low resource setting of Bangladesh. 212 infants will be randomised into a community-based parent-delivered intervention (15 fortnights of enriched environment; goal-directed motor training; and parent education, including nutrition, parenting and health) versus standard care (based on the Integrated Management of Childhood Illness). The intervention will be conducted through a train-the-trainer model to ensure long-term sustainability and the potential to be upscaled in other low-resource settings, including Indigenous Australia.

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

Visit by the Queensland Science Minister Enoch to QCPRRC

The QCPRRC team were delighted to report the successful outcomes of our Ebrain Program on December 16th, 2015 to the Minister. Three of our young participants, Christian, Natasha and Abbey demonstrated the Mitti: Move It to Improve It program and reported on their experiences.

The program undertook and published two randomised clinical trials, developing and testing a novel web based multimodal rehabilitation program for children with CP and ABI from across Queensland including remote and isolated families. Ebrain was a successful collaboration between the Qld Department of Innovation, UQ (QCPRRC), CSIRO (Australian eHealth Research Centre), Griffith University (Health Economics unit) and the Merchant Charitable Foundation, an excellent example of collaboration to advance Queensland.

Further reports on the ABC can be seen at: http://www.abc.net.au/news/2015-12-16/e-health-trial-improving-outcomes-for-kids-with-cerebral-palsy/7031180?section=qld
Imagine Cerebral Palsy: Genome and Connectome study

**Chief Investigators:** Margaret Wright (QBI), Roslyn Boyd (QCPRRC), Stephen Rose (UQ, CSIRO), Gai McMichael (WIHI), Michael Fahey (Monash University). (awarded $200k for 2016-2017)

The “Imagine CP” study examines the relationship between genetics and brain structure and function in children with CP to identify aetiological pathways. This study will be the first internationally to use whole exome sequencing (WES) to conduct an unbiased analysis of rare de novo and inherited variants in CP and relate brain structure to genetics using advanced neuroimaging.

**This novel study explores the genetic risk factors for CP and the association of these risk factors on the brain connectome in children with Cerebral Palsy (CP).**

1. Blood samples will be collected from a cohort of 400 children with CP (240 already funded for phenotyping and advanced MRI in NHMRC 1077257) and their parents for whole exome sequencing (WES).
2. Sequence the exome of 400 children with CP and their parents (400 trios), to identify rare de novo mutations and inherited variants.
3. Identify whether brain lesion pattern and severity, or specific neural networks (brain connectivity) are associated with the risk variants, and whether environmental factors act in concert with genetic risk and severity of CP.

Deep phenotyping will help establish whether a particular genetic variant is causal, and provide biological insight into the disease mechanisms of CP. The combination of genomics, connectomics, and clinical, cognitive and behavioral phenotyping will allow an unprecedented evaluation of genetic vulnerability to CP, and a valuable resource for future national and international collaborative studies into the aetiology of CP. Our proposal expands on prior work by combining WES and MRI to identify rare/unique potentially highly penetrant, genetic variants in child-parent trios.

**For further information contact:** CIB Roslyn Boyd, E: r.boyd@uq.edu.au

Participate NOW:
Optimizing participation for children with CP & their families

**Chief Investigators:** Catherine Elliott (Curtin Uni); Leanne Sakzewski (QCPRRC); Sonia Girdler (Curtin Uni); Roslyn Boyd, Sarah Reedman (QCPRRC, UQ), Claire Willis (Curtin Uni).

Awarded $50k from the CP Alliance for 2016.

Participate Now is an intervention aimed at increasing active leisure and sports participation for children with CP, guided by individual child and family participation goals. Barriers to participation are carefully investigated and targeted on an individualized basis through one of two site-specific interventions. Families will access a 12-week motivational physiotherapy intervention, in either a child-parent dyad with a therapist in Queensland or in groups of 3-4 children in Western Australia.

**Aim 1:** The primary aim will be to test efficacy of a goal-oriented, family-centred, ecological and participation based intervention in a wait-list control design.

**Aim 2:** The secondary aim will develop a model of service provision which harnesses resources readily available in local communities, to ensure translation of trial outcomes with enhanced active community participation of children with CP and their families.

**For further information contact:** Sarah Reedman, E: sarah.reedman@uqconnect.edu.au
Achievements

NHMRC Fellowship and Visiting Professor

NHMRC Research Fellowship

NEURO-RESTORATIVE REHABILITATION FOR INFANTS AND CHILDREN WITH CEREBRAL PALSY

Chief Investigator: Roslyn Boyd (QCPRRC), (awarded for 2016-2020).

A major focus of this Research Fellowship is developing and testing novel therapies and neurorestorative rehabilitation to improve functional outcomes and to reduce parent stress providing an optimal environment for early brain development, to enable better school readiness and improved quality of life for families of children with cerebral Palsy (CP). My two previous Career Development Awards at QCPRRC have focused on building strong collaborative teams, the attraction and developing high quality PhDs, competitively funded postdocs, building population-based cohorts, a network of clinicians trained in the early detection of CP and a pipeline of advanced brain imaging analysis. I have published the results of numerous randomised clinical trials (RCTs, 14), systematic reviews (34) and meta-analyses (3). This has led to an increasing trajectory of publications (total 190, >85% senior author). In the last 5 years this has resulted in (>110 publications), >$10M funding, and securing funding for 3 NHMRC postdocs and clinician scientists, ready to translate results of new RCTs of interventions into Clinical Practice Guidelines.

AIMS:
The aims of the proposed Neuro-restorative Rehabilitation program (2016-2020) comprise:
(1) To improve accurate earlier detection of CP by understanding the nature of early brain structure via structural MRI (sMRI) and diffusion MRI, (dMRI) and clinical markers of neurodevelopmental function in infants born <30 weeks gestation at 30 and 40 weeks post menstrual age PMA;
(2) To develop and test the efficacy novel neuro-rehabilitation interventions to improve outcomes of infants at high risk of CP and children and youth with CP. (e.g. REACH: RCT of Rehabilitation EArly for Congenital Hemiplegia; PREM Triple P: RCT of early parenting intervention: PACT a web based Parenting, Acceptance and Commitment Therapy study; and GAME: RCT of goal directed motor enrichment). To examine the relationship between brain structure and function (motor, cognitive, communication) in a longitudinal cohort to improve prediction of outcomes of children with CP (e.g. NHMRC Partnership, the PREDICT study).

For further information contact: Roslyn Boyd, E: r.boyd@uq.edu.au

Haydyn Williams Visiting Professorship to Curtin University

On 29th July 2015, Prof Boyd presented the 2015 Haydn Williams Fellowship Lecture at Curtin University entitled: “Rehabilitation to optimise neuroplasticity and improve outcomes for children with cerebral palsy and their families”. Prof Boyd undertook the first of two visits to Perth as a visiting professor with the Department of Rehabilitation at the Princess Margaret Hospital, the Schools of Occupational Therapy and Physiotherapy at Curtin University and Telethon Kids. Prof Boyd was nominated by Prof Catherine Elliott and A/Prof Jane Valentine for the fellowship which will lead to the development of collaboration on multisite trials and national grant applications. Already the visit has led to successful collaborations on the NHMRC funded REACH trial; a multisite RCT of the effect of intramuscular Botulinum toxin A on muscle mechanics in young CP and a new CP Alliance grant on a clinical trial to enhance participation in children with CP as well as collaborative supervision of post graduate students. The WA team have international expertise in clinical trials to enhance participation and novel work on measurement of the effects of BoNTA on muscle with structural MRI. Future visits will extend this work and build collaborations towards a Australasian Clinical Trials network.
Australasian Academy of Cerebral Palsy and Developmental Medicine

The QCPRRC team has been awarded 26 paper presentations, 3 scientific posters and 4 workshops at the 8th Biennial Scientific Conference for the Australian Academy for Cerebral Palsy and Developmental Medicine meeting in Adelaide in 30th March to 2nd April 2016. The program is available at: http://www.dcconferences.com.au/ausacpdm2016/pdf/AusACPDM_2016_Program_Overview.pdf

Free Paper Presentations: (title and authors)

- Randomised controlled trial of web-based multimodal therapy for children with acquired brain injury to improve gross motor capacity and performance: Baque E, Barber L, Sakzewski L, Boyd RN
- Validation of the actigraph accelerometer to measure physical activity in children with an acquired brain injury: Baque E, Barber L, Sakzewski L, Boyd RN
- Calf muscle growth in ambulant children with hemiplegia and diplegia cerebral palsy age 2-9 years: Barber LA, Read FA, Lichtwark GA, Boyd RN
- Calf muscle passive stiffness and function during gait in children with cerebral palsy: Barber LA, Carty CP, Walsh HPJ, Lichtwark GA, Boyd RN
- Stability of the Gross Motor Function Classification System: Comparison between High and Low-Resource Countries: Benfer K, Jordan R, Bandaranayake S, Finn C, Ware R, Boyd RN
- Relationship between white matter integrity at 3T MRI and neurological function in preterm infants at 30 weeks postmenstrual age: George J, Fripp J, Shen K, Pannek K, Chan A, Ware R, Rose S, Colditz P, Boyd RN
- Muscle function in young adults with cerebral palsy walking uphill and downhill: Gillett JG, Lichtwark GA, Boyd RN, Barber LA
- Relationship between clinical assessment of mirror movements and microstructural integrity of corticospinal and thalamocortical tracts in children with congenital hemiparesis: Houston E, Boyd RN
- Relationship between habitual physical activity and quality of life in children with cerebral palsy at age 5 years: Keawutan P, Bell K, Davies PSW, Boyd RN
- Relationship between habitual physical activity, motor capacity and performance in children with cerebral palsy aged 4-5 years: Keawutan P, Bell K, Davies PSW, Boyd RN
- MiYoga, an embodied movement program for children with cerebral palsy: Experiences of children and parents: Mak C, Whittingham K, Boyd RN, Cunningham R
- A longitudinal study of growth status and growth velocity in a population based cohort of children with CP between the ages of 18 months and 5 years across the spectrum of functional abilities: Oftedal S, Bell K, Ware R, Boyd RN, Davies P
- Assessment of reach to grasp to determine delayed fine motor development in infants with asymmetric brain injury: Perez M, Ziviani J, Guzzetta A, Ware RS, Tealdi G, Burzi V, Boyd RN
- Longitudinal assessment of gait quality in children with diplegia following serial lower limb intramuscular Botulinum Toxin-A injections: Read FA, Boyd RN, Barber LA
Australasian Academy of Cerebral Palsy and Developmental Medicine

The QCPRRC team has 26 paper presentations, 3 scientific posters and 4 workshops accepted for the 8th Biennial Scientific Conference for the Australian Academy for Cerebral Palsy and Developmental Medicine meeting in Adelaide in 30th March to 2nd April 2016. The program is available at:

Paper Presentations Cont’d:

- Efficacy of Therapy and Behaviour Change Interventions to Increase Participation in Physical Activities for Children with Cerebral Palsy: A Systematic Review and Meta-Analysis: Reedman S, Sakzewski L, Boyd RN
- Poor description of upper limb therapies for children with unilateral cerebral palsy: do we really know what they were testing? Sakzewski L, Hoffman T
- Understanding practice change following an implementation study: The how and why of evidence adoption by occupational therapists working with children with cerebral palsy: Sakzewski L, Ziviani J
- Does early communication explain the relationship between motor ability and social function in children with cerebral palsy? Lipscombe B, Boyd RN, Coleman A, Fahey M, Rawicki B, Whittingham K

Scientific Posters include:

- Systematic Review of Physiotherapy Interventions to improve Gross Motor Capacity and Performance in Children and Adolescents with an Acquired Brain Injury Baue E, Barber L, Sakzewski L, Boyd RN
- Impact of laterality on intelligence and executive functioning (EF) in youth with unilateral cerebral palsy (UCP) Piovesana AM, Ross S, Whittingham K, Lloyd O, & Boyd, RN
- Randomised controlled trial of web-based multimodal therapy program to improve executive functioning in youth with acquired brain injury (ABI) Piovesana AM, Ross S, Lloyd, O Whittingham K, Ware R, & Boyd, RN

Invited Workshops include:

- Application of MiYoga, a Mindfulness Movement Program, for Children with Cerebral Palsy: Mak C, Whittingham K, Boyd RN, Cunningham R
- Supporting parents of children with disabilities well: simple strategies: Whittingham K

PhD Platform Presentation:

- Dr Katherine Benfer, Orthopharyngeal Dysplasia (OPD) in preschool aged Children with Cerebral Palsy: Supervisors: Boyd RN, Weir K, Davies P.

The Australasian Academy of Cerebral Palsy and Developmental Medicine themed as “Innovation to Participation” will be held at the Adelaide Convention Centre.
Achievements
Graduations

Six 1st Class honors in MBBS

Congratulations to our six graduating MBBS honors students who all received 1st class honors (left to right) Dr Aminda Nanayakkara, Dr Sean McKeague, Dr Jane Poon, Dr Ella Houston (and Dr Muqtasid Hussaini, Dr Jinwen He).

The students undertook the following projects: Dr Aminda Nanayakkara: Reproducibility of the General Movements Assessment; Dr Sean McKeage: Reproducibility of the Hammersmith Neurological Assessment; Dr Jane Poon: Relationship between brain structure and manual ability in preschool CP; Dr Ella Houston: Relationship between clinical assessment of mirror movements and microstructural integrity of corticospinal and thalamocortical tracts in children with unilateral cerebral palsy, Dr Jinwen He: Relationship between brain lesion severity of school readiness in preschool age children with CP and Dr Muqtasid Hussaini: Relationship between brain lesion severity and hip displacement in pre school aged children with CP. This is an outstanding achievement by the students and will fast track them towards their chosen pathways in their medical careers.

PhD awards

Congratulations to Dr Sarah James and Dr Kelly Weir, who have successfully completed their PhDs and graduated in July 2015.
Meet our new team members…

**Dr Susan Sullivan: Research and Operations Manager**

Susan’s background is in biomedical research. Her research has investigated cellular neuroscience during development and in diseases related to hypoxic-ischemic brain injury. Susan will be filling in as the Research and Operations Manager at QCPRRC while Anna MacDonald is on maternity leave. Susan will use her significant experience in the research and tertiary sector to provide staff and students at QCPRRC with high-level research and operational management.

**Ms Kate O’Brien: Clinical Research Coordinator**

Kate joined the QCPRRC team in October 2015 as Clinical Research Coordinator for the PREDICT study. Kate completed her Bachelor of Speech Pathology at the University of Queensland in 2000. Over the past 15 years, she has worked as a Senior Speech Pathologist in hospital and community based positions in Australia, Ireland and the United Kingdom, and was most recently employed in the Language Neuroscience Laboratory at the UQ Centre for Clinical Research as a clinical research assistant.

**Mr Steven Obst: Research Physiotherapist**

Steven Obst is musculoskeletal physiotherapist with over 10 years clinical experience. He recently completed his Doctoral thesis at Griffith University investigating the effects of acute exercise on the strength and function of the human Achilles tendon. He is now employed part-time as a Postdoctoral Research Fellow within the Queensland Cerebral Palsy and Rehabilitation Research Centre and will be responsible for 3D gait and muscle-tendon assessments for the PREDICT study.

**Ms Irene Braito: Medical RHD Student**

Irene is a final year medical student, visiting from the Medical School at the University of Pisa (Italy). Irene is particularly interested in Child Neuropsychiatry, and is completing her thesis project at the “Stella Maris” Research Centre in Pisa. Irene was awarded a Scholarship to complete her dissertation, which gave her the opportunity to join QCPRRC for three months, providing trainee support on the PREDICT project.

**New Collaborators**

**A/Prof Margaret Wright** is Chief Investigator A on the new “Imagine CP study”. A Principal Research Fellow and Group leader, Imaging Genomics, The Queensland Brain Institute and Centre for Advanced Imaging, University of Queensland. Her research focuses on the neurobiological causes and modifiers of normal cognitive function and, especially brain disorders, using neuroimaging, neuropsychological tests, and behavioural and molecular genetic approaches. She pioneered the collection of multi-modal imaging from large population samples (e.g. The ENIGMA consortium). A/Prof Wright directs the Queensland Twin Imaging (QTIM) Study, which began in 2007 and includes multi-modal imaging on >1200 healthy young adult twins.

**Ms Gai McMichael** is a Research Fellow in Genetics at the Australian Genome Research Facility and The University of Adelaide. She has undertaken her PhD in genetics in cerebral palsy, which was submitted in January 2016. She holds a Master of Philosophy (Medical Science) in genetics in cerebral palsy for which she received a letter of commendation from the Pro Vice-Chancellor and Dean of Graduate Studies, The University of Adelaide. She was awarded the inaugural Robert F Seamark Scholarship to the most outstanding PhD student, The University of Adelaide. Gai is collaborating with QCPRRC as an Investigator on the new Imagine CP study funded by the CP Alliance.
PPREMO: Prediction of PREterm Motor Outcomes

Chief Investigators: Ms Joanne George (PhD scholar), Prof Roslyn Boyd, Prof Paul Colditz, A/Prof Stephen Rose, Dr Kerstin Pannek, Dr Jurgen Fripp.
Study Personnel: Kellie McGory (research nurse); Chris Finn (PT), Kym Morris (PT)

The PPREMO study is examining the relationship between brain structure (MRI) and function of very preterm infants (born <31 weeks) to predict neurodevelopmental outcomes. So far 119 of the 120 infants required have been recruited.
• 30 week and 40 week MRI and clinical assessments have been completed.
• 3 month corrected age follow up assessments have been completed.
• Two thirds of the 1 year corrected age follow up assessments have been completed with the remainder expected to be complete by February 2017.
• Data analysis is in progress and two publications have been submitted.
• 2 year corrected age follow up of PPREMO participants has commenced.

A full study protocol has been published:

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

Trial ID: ACTRN12613000280707
The infant born very preterm (23-31 weeks gestation) is at high risk of an adverse neurodevelopmental outcome (10% cerebral palsy, 50% learning and behavioural difficulties at school age). In the several months after very preterm birth, the brain is at its maximal capacity for neuroplasticity and repair. This study aims to predict adverse neurodevelopment earlier and more accurately than currently possible.

To do this we will use (i) advanced brain imaging (MRI) to determine the structural wiring diagram of the brain (‘brain connectome’), (ii) dense array electroencephalogram (EEG) to establish the functional activity or electrical ‘traffic’ being carried on the main branches of the connectome, and (iii) structured clinical neurodevelopmental assessments to provide a cutting-edge view of the state of brain development. This research will represent a major advance towards better neurodevelopmental outcomes for preterm babies through the very early detection of those likely to have adverse neurodevelopment outcome, the creation of a platform for the development of rationally based very early interventions, and the rapid testing of the efficacy of these interventions.

The team assembled to undertake this research brings together Australia’s only sites with an MRI-compatible incubator into an exceptional multidisciplinary research team of international standard.

- 200 preterm infants and 40 term born infants will be recruited with follow up to 2 years corrected age.
- 2 year corrected age follow up of PPREM0 participants has commenced as part of this new study.
- Term born recruitment has commenced.

There are a variety of PhD opportunities including physiotherapy, occupational therapy, psychology and medicine around early detection of cerebral palsy, parenting acceptance and commitment therapy and neuro-imaging etc. Please contact the research team if interested. Roslyn Boyd r.boyd@uq.edu.au, Paul Colditz p.colditz@uq.edu.au or Michael Fahey Michael.Fahey@monash.edu.au
Prem Baby Triple P: Supporting Parents of Preterm Infants

Chief Investigators: Prof Paul Colditz, Prof Matthew Sanders, Prof Roslyn Boyd, Dr Margo Pritchard, A/Prof Peter Gray, A/Prof Michael O’Callaghan, Prof Virginia Slaughter, Dr Koa Whittingham. (NHMRC 1024345)

PhD students: Michael Herd, Tracey Evans, Jessica Ahern

With recruitment now finalised, the study is continuing on track with the follow-up assessments. To date, 74 RBWH families and 65 Mater Mothers’ families have returned for their twenty-four month corrected age neurodevelopmental assessments. With a total of 322 families participating in the study across both sites, our last baby is due to be assessed in August 2017.

Huge congratulations goes to Dr Tracey Evans and Dr Michael Herd, who were both awarded their PhD’s in December 2015, after making a significant contribution to the success of this project. We wish them every success in their future careers.

If you would like to find out more about this project please visit our website http://exp.psy.uq.edu.au/prembaby.

Contact us: Dr Leanne Winter (Project Coordinator) Ph: (07) 3646 2349 E: prembabytriplep@psy.uq.edu.au

PREMM Study: PREMature infants Massage therapy

Chief Investigators: Dr Melissa Lai, Dr M Giulia D’Acunto, Dr Andrea Guzzetta, Prof Roslyn Boyd, Prof Paul Colditz, Ms Naoni Ngenda, Ms Penny Love, Ms Bernadette Shannon, Ms Sonia Sam, Dr Kerstin Pannek

The PREMM study is investigating the neurobiological effects of an early intervention programme to enrich the postnatal environment of the very preterm (VPT) infant. Mothers with infants who were born very preterm were recruited and randomised into a massage group or a care as usual group. Mothers in the intervention group were taught to massage their babies from enrolment until term equivalent age (TEA). Outcomes were assessed with brain imaging (MRI), electroencephalography (EEG), body composition, neurodevelopmental assessments at TEA and infant observations and questionnaires to assess maternal-infant attachment at 12 and 24 months corrected age. Preliminary data was presented at the EACD and AACPDM conferences in 2015 with the paper entitled:


Recruitment has been completed with 60 preterm infants randomised to an intervention group, who received infant massage by their mothers from enrolment until term equivalent age (TEA), or a control group. TEA follow up has been completed, while 12 month and 24 month follow up assessments continue to be collected.

For more information about the PREMM study, please contact Dr Melissa Lai
e: melissa.lai@uq.edu.au
REACH: Randomised trial of Rehabilitation very EARly in Congenital Hemiplegia

NHMRC 1078877 - $939,038

Chief Investigators: Prof Roslyn Boyd, Prof Jenny Ziviani, Dr Leanne Sakzewski, Prof Iona Novak, Prof Nadia Badawi, Dr Kerstin Pannek, A/Prof Catherine Elliott, Dr Susan Greaves, Dr Andrea Guzzetta, Dr Koa Whittingham

Associate Investigators: A/Prof Jane Valentine, Prof Paul Colditz, Dr Robert Ware, Ms Cathy Morgan, Dr Margaret Wallen, Dr Karen Walker, Dr Russell Dale, A/Prof Stephen Rose, Dr Roslyn Ward, Ms Brittany Choy, Dr Mary Sharp, Dr Noel French, Ms Lisa Findlay, Dr Priya Edwards.

This randomised trial will directly compare an intensive infant friendly ONE handed approach using modified Constraint Induced Movement Therapy (mCIMT) to an equally intensive TWO handed approach Bimanual Therapy (BIM) in very young infants with asymmetric brain lesions. This is a multisite study involving Queensland, New South Wales, Victoria and Western Australia. The REACH team have been joined by clinical occupational therapists in each state who will visit babies and their caregiver’s at home to support them in providing infant friendly modified Constraint Induced Movement Therapy (mCIMT) or infant friendly Bimanual Therapy (BIM). In September 2015, the clinical occupational therapists and investigators met in Brisbane with Associate Professor Lena Krumlinde-Sundholm from the Karolinska Institutet in Stockholm. The therapists were trained in the use of the Hand Assessment for Infants which will be used to guide treatment and measure outcomes in the study. The clinical occupational therapists also received training in the two intervention protocols. The sessions were very practical with videos and case studies provided by the investigators from Australia and overseas. Recruitment of infants with asymmetrical brain injury in all states is due to start in early 2016.

The REACH team with our international visitor Prof. Ann-Christian Elliasson from the Karolinska Institute, Stockholm

If you would like to find out more, please contact:
Debra Khan (QLD REACH Occupational Therapist)
Ph: (07) 3069 7370 or E: debra.khan@health.qld.gov.au

Tuesday, Wednesday, Friday

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Child Study

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

NHMRC Partnership Grant 1077257 - $1,593,519

Chief Investigators: Prof Roslyn Boyd, Prof Peter Davies, Prof Jenny Ziviani, Prof Stewart Trost, Dr Lee Barber, Dr Robert Ware, A/Prof Stephen Rose, Dr Koa Whittingham, A/Prof Jennifer Whitty, Dr Kristie Bell

Associate Investigators: Prof Paul Scuffham, Dr Chris Carty, A/Prof John Walsh, Ms Megan Kentish, Dr Priya Edwards, Dr Lisa Copeland, Ms Kelly Weir, Dr Leanne Sakewski, Dr Andrea Guzzetta, Dr Denise Brookes, Prof Alan Coulthard, Dr Rebecca Pelekanos, Mr Owen Lloyd, Dr Adina Piovesana

The Qld Cerebral Palsy and Rehabilitation Research Centre (QCPRRC) in collaboration with the Children’s Nutrition Research Centre, University of Qld, QUT and Qld Health, has secured NHMRC funding to follow up all the children from both CP Child studies at 8-9 years of age, in a new project, Predict CP: A Comprehensive Surveillance to Predict Outcomes for Children with Cerebral Palsy.

In this study we are aiming to investigate the relationship between brain development and physical capacity, growth, physical activity, communication, cognition, participation and educational outcomes of children who have cerebral palsy. In one study visit at 8-9 years of age this project will comprehensively assess outcomes to inform the development of timely and effective interventions and predict future outcomes for children with cerebral palsy. Currently, families from the 2006 and 2007 birth years who participated in the CP child studies are being invited to participate in the PREDICT study in a one-off visit over 1.5 days.

For more information, please contact Kate O’Brien the Clinical Research Coordinator for PREDICT. Ph: (07) 3069 7354 or E: QCPRRC@uq.edu.au.

Our first participant, Billy, walking in the Motor Analysis laboratory with surface placed 2D ultrasound providing a model of how he walks.
Spotlight on PREDICT participants!

**Spotlight on PREDICT participant!**

How old are you Will? 9 years

How many research studies have you participated in with the QCPRRC? 3 studies so far (INCITE, Circus Motivate, CP Child and now PREDICT).

What did you think of the new building? Good. Loved the Level 9 view.

What did you enjoy most about your day with the PREDICT team? The needle, I loved looking at my blood.

Feedback from Will’s mum: Today was great and Will has enjoyed his day. I don’t think that he was aware of having all of the assessments because he was having so much fun. Beautiful building with very helpful and amazing staff that made Will and myself feel very at ease with everything.

Will shows us his passport after a successful visit!

All children and families participating in PREDICT will be offered a range of comprehensive assessments tailored to their child's individual needs which may include:

**Motor Skills and Physical Activity:**
- Gross Motor Function Classification System
- Motor type and distribution
- Gross Motor Function Measure (GMFM-66)
- Range of motion
- 10 metre fast walk
- 6 minute walk test
- Shuttle run
- Dyskinesia Impairment Scale
- Assisting Hand Assessment/ Bilateral Hand Assessment
- 7 day physical activity monitoring (Actigraph)

**Imaging:**
- Magnetic Resonance Imaging (brain structure)
- Hip and spine x-ray, Bone-age

**Feeding, Growth and Nutrition:**
- Dietary intake (3-day weighed food record)
  - Energy intake
  - Micronutrient analysis (vitamins & minerals)

**Anthropometry**
- Height, weight, BMI
- Lean mass (kg)
- Fat mass (kg)
- Body fat (%)

**Bone health**
- DXA

**Oropharyngeal dysphagia (feeding)**
- Dysphagia Disorders Survey
- Schedule for Oral Motor Assessment
- Clinical signs suggestive of pharyngeal phase impairment
- Thomas-Stonell & Greenberg Saliva Scale
- Eating and Drinking Ability Classification System

**Communication and Cognition:**
- Clinical Evaluation of Language Fundamentals (CELF-4):
  - Screen and core language subtests
  - Expressive Vocabulary Test (EVT)
  - Peabody Picture Vocabulary Test (PPVT)
  - Assessment of Intelligibility of Dysarthric Speech (ASSIDS)
- Communication Competency Checklist (Triple C)
- Communication Function Classification System and Functional Communication Classification System
- Viking Speech Scale
- WIAT-II
- BRIEF
- CONNERS 3
- Benton Controlled Oral Word Association Test

**Participation and Quality of Life:**
- Paediatric Evaluation of Disability Inventory
- Paediatric Pain Questionnaire
- Carer Experience Scale
- Depression, Anxiety and Stress Scale
- Participation and Environment Measure for Children and Youth

**ETHICS HREC/14/QRCH/329**
MiYoga: Mindfulness Yoga for Children with Cerebral Palsy and their Caregivers
Ms Catherine Mak, Dr Koa Whittingham, Prof Roslyn Boyd and A/Prof Ross Cunnington

The MiYoga project has now completed recruitment and we are in the final stages of data collection and preparing for data analysis. A total of 45 families took part in the study, from Brisbane, the Sunshine Coast, and the Gold Coast. The majority of the participants, both children and parents, have reported positive experiences with the MiYoga program. Child participants reported that MiYoga was fun and relaxing while the parent participants reported that they enjoyed the mindfulness aspects of the program and noticed increased awareness in their everyday life. Some parent participants reported that they would have liked additional help in integrating the skills from MiYoga sessions into their everyday life while some parents were unsure whether their children fully understood the concept of mindfulness. We will be presenting a workshop on Mindfulness Yoga at the upcoming AusACPDM in Adelaide in April.

If you would like any further information on this study, please contact:
Catherine Mak
Ph: (07) 3069 7356
E: c.mak@uq.edu.au
or visit our website https://exp.psy.uq.edu.au/miyoga/
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 working.

We welcome two Summer Scholarship Students from the School of Medicine: Ms Molly Hubert and Ms Ritika Johal. Molly will be assisting Ms Felicity Read to collect and analyse freehand 3D ultrasound measurements of the calf muscles as part of a study investigating the longitudinal effects of Botulinum toxin type A on muscle function and walking ability in children with CP. Ritika will be working with Ms Shari O’Brien and Professor Stewart Trost (QUT) on our Adult CP study to investigate physical activity performance in adults with CP.

We congratulate Ms Shari O’Brien, from the School of Human Movement and Nutrition Sciences, The University of Queensland who has received a prestigious NHMRC PhD Student Scholarship, project title “Training to enhance lower limb motor control in individuals with CP”. To this time Shari has been working with Dr Lee Barber and Dr Glen Lichtwark on our Adult CP study investigating the relationship between muscle quality, functional capacity and functional performance through the adult lifespan in CP.

Dr Lee Barber, Mr Jarred Gillett and Ms Felicity Read have been invited to present their research at the Australasian Academy of Cerebral Palsy and Developmental Medicine Conference, Adelaide (March 2016). Lee will discuss muscle growth in children with unilateral and bilateral CP and the relationship of muscle stiffness and walking. Jarred will present his findings from investigation of muscle function in young adults with CP walking uphill and downhill. Felicity will present her findings of a study investigating the longitudinal assessment of gait quality in children with diplegic CP receiving intramuscular Botulinum Toxin-A injections. Lee and Felicity have also been invited to present their research at the International Conference on Cerebral Palsy and other Childhood-onset Disabilities, Stockholm (June 2016). We wish them luck with their presentations.

Thank you very much to those that have already been involved in our projects and we look forward to meeting new interested participants. If you would like to be involved please contact us and don’t forget to keep up with information at our Facebook page https://www.facebook.com/CPMuscleResearch.

Dr Lee Barber. Ph: (07) 3069 7334 E: l.barber@uq.edu.au. Web https://www.facebook.com/CPMuscleResearch
NEW Child Intervention Study

A New Motivational Physiotherapy Program to Facilitate Participation in Physical Activities for Kids with Cerebral Palsy
Ms Sarah Reedman, Dr Leanne Sakzewski, Prof Roslyn Boyd

The PARTICIPATE NOW study will examine if a new, integrative approach to Physiotherapy is effective at helping kids with CP to become more physically active. We also want to know if this approach works because it encourages the caregiver to support their child’s autonomy, or if it changes how children are motivated to engage in healthy behaviours.

This study is recruiting volunteers now:
• Children with cerebral palsy (all motor types) born 2004-2008 who will still be enrolled in primary school in 2016
• Children who can walk with or without aids/orthoses and/or self-propel a manual wheelchair, for medium distances in the community
• Children who can communicate with a familiar listener about their likes, dislikes, thoughts about themselves and their family, and thoughts about the future
• Children who live within 200km of South Brisbane, Queensland
• The child’s primary caregiver is also a participant (one person who has a major ‘parenting’ role)

This study involves an eight week intervention with weekly face-to-face sessions of family-centred, holistic, Physiotherapy delivered with a guiding communication style called Motivational Interviewing. The Physiotherapist travels to participants on most occasions at a time that is suitable to them. All participants will receive the intervention at no cost. Families can expect a different type of Physiotherapy than they are used to. This program is focused on less-visible or rarely addressed barriers to participation in physical activities. Children can expect to explore physical activities that are of interest to them and families can expect to learn new ways and gain new tools to facilitate participation.

Amy at the Brisbane Paralympic Football Program
Physical activity mentors Declan and Jarrod
Sarah Reedman (Physiotherapist)

If you would like more information about this study please contact:
Sarah Reedman (Study Physiotherapist).
Ph: (07) 3069 7336 Mob: 0437 332 606 E: sarah.reedman@uqconnect.edu.au
How does exercise affect your muscles?

Help us understand how exercise impacts how your muscles work.

**Recruiting:** Young adults with CP aged 15-30 years, who walk independently!!

We are comparing different types of exercise and training on how the leg muscles and tendons work in young adult with cerebral palsy. We will be using ultrasound, strength testing equipment, and exercise tests to look at how you and your muscles function before and after exercise training.

If you (or someone you know) has cerebral palsy, are between the ages of 15-30 years, and can walk independently, you could really help us. We will be conducting the study during 2015 and 2016. The findings may help tailor future exercise programs for people with cerebral palsy. If this has sparked your interest and you would like to volunteer, or if you have further questions, please contact us and we can send you an information pack.

Mr Jarred Gillett, Queensland Cerebral Palsy and Rehabilitation Research Centre, School of Medicine, University of Queensland. Ph: (07) 3069 7188 or E: jarred.gillett@uqconnect.edu.au

Dr Lee Barber, Queensland Cerebral Palsy and Rehabilitation Research Centre, School of Medicine, University of Queensland. Ph: (07) 3069 7334 or E: lee.barber@uq.edu.au

Dr Glen Lichtwark, School of Human Movement Studies, University of Queensland. Ph: (07) 3365 3401 or E: g.lichtwark@uq.edu.au

Prof Roslyn Boyd, Queensland Cerebral Palsy and Rehabilitation Research Centre, School of Medicine, University of Queensland. Ph: (07) 3069 7372 or E: r.boyd@uq.edu.au

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Muscle Function and Physical Activity over the Lifespan in People with Cerebral Palsy

**Recruiting:** Adults with CP aged 18-65 years, who walk independently!!

We are investigating the factors which contribute to declines in function across the lifespan in people with Cerebral Palsy. 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, an activity monitor and strength testing equipment to look at how your muscles function and changes in your physical activity involvement.

If you have 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 will be conducting the study during 2014 and 2015 and the findings may help your function and activity levels. If this has sparked your interest and you would like to volunteer, or if you have further questions, please contact us.

Dr Glen Lichtwark, School of Human Movement Studies, University of Queensland. Ph: (07) 3365 3401 or E: g.lichtwark@uq.edu.au

Dr Lee Barber, Queensland Cerebral Palsy and Rehabilitation Research Centre, School of Medicine, University of Queensland. Ph: (07) 3069 7334 or E: lee.barber@uq.edu.au
PhD, MPhil and Honours Opportunities at QCPRRC in 2016-17

All research training opportunities involve supervision from a supportive team of experts in the field and the opportunity to be part of a multidisciplinary research team. Honours, MPhil and PhD students select topics embedded in current clinical trials and population based cohort studies. They are closely supported by senior staff and postdoctoral fellows, and have the opportunity for practical clinical data collection, clinical experience linked to the relevant studies, or a program embedded within clinical teams in our state-wide service from the Department of Paediatric Rehabilitation. All postgraduate students have the opportunity to be involved in our annual training course on systematic reviews and meta-analysis (8 sessions), which will assist them in developing skills for their literature search and systematic review of the literature or the psychometric properties of measures that they will use.

For details of available projects please visit our website http://www.som.uq.edu.au/cerebralpalsy/RHD-opportunities-2016-2017 or for general enquiries contact us at QCPRRC@uq.edu.au.

International Conference on Cerebral Palsy and other Childhood-onset Disabilities
Stockholm 1–4 June 2016 www.eacd2016.org

5th International Conference of Cerebral Palsy (ICPC)
28th Annual Meeting of the European Academy of Childhood Disability (EACD)
1st Biennial Meeting of the International Alliance of Academies of Childhood Disability (IAACD)

Baby news!

Welcome to Molly Nieve MacDonald born to proud parents Anna MacDonald and David on 23rd October, weighing 2.743kg.

**REACH: Randomised trial of Rehabilitation very EARly in Congenital Hemiplegia.**

**What is this study about?** This project is about children with asymmetrical brain injury where only one side of the brain is impaired or one side is significantly more impaired than the other. These infants can have problems with the development of hand skills of the arm opposite to the side of the injury (or the more impaired side of the brain). Early treatments are recommended to improve hand and arm development. This study compares two types of intervention to improve hand and arm skills and general motor development. The interventions will start between 3 and 6 months corrected age and 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 infant’s more able hand, so the child can practice movement and skills with the impaired hand and arm. mCIMT consists of daily sessions in which 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 and arms.

**How can you help?** This study seeks 150 babies with asymmetric brain lesions from 4 states across Australia. Babies in the study will be randomly assigned to one of the two types of training.

**Inclusion criteria:** Infants 6 months (corrected age) or younger with:

- Asymmetric brain lesion identified on MRI or cranial ultrasound; AND/OR
- Absent Fidgety Movements on General Movements assessment at 12 weeks corrected age; AND/OR
- Reduced upper limb function with asymmetric reach and grasp

**What do you need to do?** You will be taught techniques to train your baby’s hand skills, for reaching, grasp and manipulation of toys in play activities as part of your daily routine. The therapist will visit you monthly and maintain contact between visits with skype or phone calls. We will ask you to video some of the training sessions. In addition to this daily training, we will need to assess your infant. Assessments at study entry and 6 months of age consist of a short video (30 minutes) of your infant and some questionnaires for you to complete, which we can do in your home. The final 2 assessments at 12 and 24 months take a little more time and will need to be done at the Lady Cilento Children’s Hospital. This will include an MRI at 24 months.

**Benefits:**

- The training may enhance your child’s reaching and grasping skill
- You will receive a summary report of your child’s assessment result
- You will be assisting us to gather information that may influence treatment for children with brain injury and provide better outcomes for their future

If you would like to find out more or know someone who might be interested, please contact:

**Professor Roslyn Boyd (Principal Investigator)**
Ph: 07 3069 7372  Mob: 0434 608 443
E: r.boyd@uq.edu.au  Monday – Friday

**Dr Leanne Sakzewski (Senior Occupational Therapist)**
Ph: 07 3069 7345 or E: l.sakzewski1@uq.edu.au
Monday – Thursday

**Debra Khan (QLD REACH Occupational Therapist)**
Ph: 07 3069 7357 or E: debra.khan@health.qld.gov.au
Tuesday, Wednesday, Friday
New study commencing

PACT
Parenting Acceptance and Commitment Therapy

Would you like to help us by test-driving an innovative online parenting support package?

What is this research program?
We have developed an innovative online approach that we hope will provide parenting support for families of children with cerebral palsy – ‘PARENT101’. But, we need your help to ensure that PARENT101 hits the mark! The purpose of this research is to test whether PARENT101 is acceptable and useful for those who matter most – families of children with cerebral palsy.

With your help, we hope to develop PARENT101 into an effective and useful online parenting support package with the longer-term aim to make PARENT101 accessible to parents of children with cerebral palsy across the world.

What is PARENT101?
PARENT101 is grounded in a psychological therapy called Acceptance and Commitment Therapy (ACT); described as Parenting Acceptance and Commitment Therapy. PARENT101 is NOT yet another ‘how to’ parenting guide. Instead, it 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, building a rich, rewarding life, and coping with difficulties and challenges along the way. The format of PARENT101 is based on online educational courses. In fact, PARENT101 uses the global educational platform edX, the same platform used by universities across the world in developing and running massive open online courses or MOOCs. PARENT101 is a six-week course with a booster session. All participants in this project will receive PARENT101.

Can I participate?
You can participate in this study if you are the parent (including adoptive, step parent or legal guardian) of a child aged from two to six years with cerebral palsy. You also need to have reliable internet access and a mobile phone in order to complete PARENT101.

Your active participation and feedback is valued! Please help us to review and develop further this innovative resource.

If you would like to find out more or know someone who might be interested, please contact:
Ashleigh Wright (Research Manager)
Ph: 0423125993 E: ashleigh.wright@uqconnect.edu.au.