

Bi-annual Research Update



Director's Message

Dear Families and Collaborators,

The beginning of 2019 has been a productive year for the Queensland Cerebral Palsy and Rehabilitation Research Centre (QCPRRC), and for the Advance Queensland in Cerebral Palsy and the Australasian Cerebral Palsy Clinical Trials Network (AusCP-CTN) NHMRC Centre of Research Excellence programs. These programs both complement and leverage-off one another to improve early detection for infants with cerebral palsy (CP) and fast-track them to early interventions to improve their long-term health outcomes.

Thanks to the hard work and dedication of our team – coupled with the enthusiasm and generosity of our families and collaborators – we have been able to notch up some impressive achievements since our last newsletter. In early November 2018, we partnered with the AusACPDM at the Queensland Paediatric Rehabilitation Services conference to report on current research.

We have continued to undertake training throughout 2019, thanks to Advance Queensland and AusCP-CTN funding. We have delivered a series of General Movements Training in Brisbane (2 basic and 1 advanced), Cairns (1 basic and a 1-day refresher), and Hobart (1 basic), to ~150 clinicians from throughout Australia, New Zealand and overseas (2 from Singapore). The national HINE trainers have delivered Hammersmith Infant Neurological Examination (HINE) training to more than 500 clinicians so far throughout Australia and New Zealand. This national implementation of HINE training is a huge achievement that will see a quick translation of early identification techniques into the clinical community across Australasia. This is great news for families of infants at high risk of CP, allowing them to be identified early, and fast-tracked to early interventions.

In the coming months the AusCP-CTN CRE will be supporting the development of research skills of clinicians and researchers through our annual Systematic Review Workshop (18th July – 5th September, Brisbane) and intensive Grant Writing Course which will be conducted 10th – 11th October at the Monash University in the Department of Paediatrics.

Our team had a significant presence with invited keynote presentations, free papers and workshops at the European Academy of Childhood Disability in Paris in May. We reported on our findings which were recently published in the Journal of Paediatrics from the Prem Baby Triple P trial at the Perinatal Society of Australia & New Zealand (PSANZ) conference at the Gold Coast in March. Our research studies have been very busy with intensive therapy camps for the HABIT-ILE study in Brisbane, Perth and Sydney. Our NHMRC funded REACH intervention trial for infants with asymmetric brain lesions is in its final year of recruitment and we have extended the study to the USA, partnering with teams at Ohio, Minnesota and Riverside, California. Members of the team have undertaken some important translation work supporting the Great Brisbane Bike Ride (Ellen Armstrong), and a strong media coverage for our HABIT-ILE camps (Dr Leanne Sakzewski and Dr Sarah Reedman).

We hope you enjoy reading more about our latest research updates and look forward to your involvement in our research centre and our national programs.

With warm regards,

Ros Boyd

Professor of Cerebral Palsy Research,
Faculty of Medicine, The University of Queensland.
Scientific Director
Queensland Cerebral Palsy & Rehabilitation Research Centre
Email: r.boyd@uq.edu.au

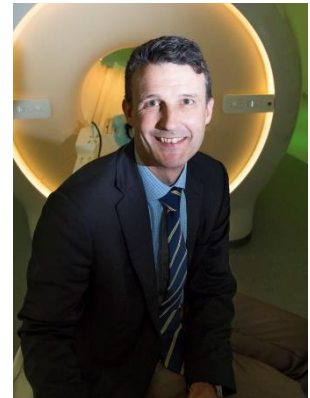


Feature

Fulbright Senior Scholar – A/Prof. Michael Fahey

Personalised treatment for cerebral palsy¹

Associate Professor Michael Fahey has been awarded a [Fulbright Scholarship](#) in 2019-2020 which will allow him to draw together two distinct research arms into genomics and brain imaging primarily located in Australia and the United States. The research will include extending an existing Database of Clinical, and Genomic Data to include world-leading Neuroimaging data in individuals with cerebral palsy (CP). Using contemporary genomic techniques, he will help to identify and characterise new genetic changes that lead to cerebral palsy. A particular strength of the program is that it is integrated with and nested within a larger program of collaborative research into CP, and so will both be enriched by the broader program and, in turn, inform and enrich the broader aims. Specific aims for this scholarship include: 1) To strengthen collaborations on CP genomics between Australia and the United States 2) To develop Neuroimaging analysis and incorporate this data within the CP Commons Database 3) To incorporate new Australian Genomic Data within the Database 4) To use Brain Imaging data as a new phenotypic marker to undertake trait specific analysis, and 5) To increase the recognition of the Genomic contribution to CP through education.



A/Prof. Michael Fahey, Head of Child Neurology, Monash Children's Hospital.

Associate Professor Michael Fahey is a Chief Investigator on the AusCP-CTN CRE, Victoria Lead and member in two themes – Pre-clinical and Neuroprotection and the Early Detection and Neuroimaging. This work is also part of the Australian portion of the broader International Cerebral Palsy Genomics Consortium.

Contact A/Prof. Michael Fahey for more information and collaborative opportunities: michael.fahey@monash.edu.

HABIT-ILE: Randomised controlled trial of Hand Arm Bimanual Intensive Training Including Lower Extremity Training for children with bimanual cerebral palsy

HABIT-ILE in the media²

During our April Brisbane HABIT-ILE camp we were lucky to be visited by 10 News First Queensland. The crew filmed our participants and therapists having a blast, and Dr Leanne Sakzewski and Dr Sarah Reedman were interviewed about the therapy and trial process. The segment is available on the 10 News Queensland Facebook page: <https://www.facebook.com/10NewsQLD/videos/1205603096268506>



HABIT-ILE trooper Felix is working on his abilities to stand and taking small objects to train and control for his hand grasp strength.

We are still actively recruiting children 6-16 years of age with bilateral CP (where both sides of the body are affected, usually called 'diplegia', 'triplegia' or 'quadriplegia') for the Brisbane site. Further camps will be held during school holiday periods in September 2019, and April and September 2020. Please get in touch with the research team to find out more about [HABIT-ILE](#); recruitment is subject to some further eligibility criteria which will be discussed on the phone. HABIT-ILE is based on state-of-the-art science in neuroplasticity and motor learning for children with bilateral CP. The therapy was developed by Professor Yannick Bleyenheuft, Chair of Neurophysiological Evidence in Intensive

¹ Fulbright Scholar – A/Prof. Michael Fahey: <https://qcprc.centre.uq.edu.au/article/2019/07/personalised-treatment-cerebral-palsy>

² HABIT-ILE in media: <https://qcprc.centre.uq.edu.au/article/2019/07/habit-ile-media>



Kane is playing a game with supervising Occupational Therapist to improve his hand strength and bimanual skills.

Neurorehabilitation, Institute of Neuroscience at UC Louvain in Belgium.

Contact Details: For recruitment and general enquiries, contact the team at habtile.qcprc@uq.edu.au.

This project is funded by NHMRC 1144846.

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

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

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

Great Brisbane Bike Ride 2019³

Congratulations to 30 of our ACTIVATE-CP study participants, families, and volunteers who braved the early morning start to complete the community ride as part of the Great Brisbane Bike Ride in May. Participation by either running and/or bike riding, there were big smiles and high-fives all round as riders completed the 6km course, with many time and distance goals exceeded. It was fantastic to see participants ride on a variety of adapted bikes, including tricycles, recumbent and tandem cycles. A big thank you to Bicycle Queensland for facilitating the event and to the families, friends, volunteers and staff who supported us across the finish line!

ACTIVATE-CP is investigating the effects of an 8-week training program of functional electrical stimulation (FES) powered cycling, recreational cycling and sit-to-stand transfer training in children with CP who are classified as level II, III or IV on the Gross Motor Function Classification Scale. The study was developed to address the paucity of evidence-based interventions to help children with CP to improve their sit-to-stand transfers and participation in recreational cycling. Functional electrical stimulation powered cycling has been used among people with spinal cord injuries, CP and other neurological conditions to reduce or prevent muscle atrophy, improve circulation and increase joint range of motion. The addition of FES-powered cycling in the training program will assist children in achieving higher intensities of exercise and will supplement a home cycling program using adapted tricycles. Participant's goals for the project so far have ranged from learning to pedal, to participating in cycling events in the community. Thanks to the support of the Queensland Paediatric Rehabilitation Service, our local bike shops and input from our families, our bike library has expanded to include recumbent-style bikes that are suited to children who have difficulty transferring onto traditional upright trikes. Recruitment for this study is currently closed and as we're working through last few sessions with participants and data analysis.

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

For more photos of our other amazing riders: <https://raceatlas.com/photos/great-brisbane-bike-ride>

Contact Details: For recruitment and general enquiries, contact Ellen Armstrong ellen.armstrong@griffithuni.edu.au.

This project is funded by the Griffith University Postgraduate Research Scholarship.

Chief Investigators: Ms Ellen Armstrong, Dr Chris Carty, Prof Roslyn Boyd, Dr Sean Horan, and Ms Megan Kentish.



ACTIVATE-CP Participant Harmony and family proudly at the finish line of GBBR 2019.

³ Activate-CP Grate Brisbane Bike Ride 2019: <https://qcprc.centre.uq.edu.au/article/2019/07/great-brisbane-bike-ride-2019>

Program Update

AusCP-CTN Education Theme⁴ – General Movements – Brisbane, Cairns, Hobart

The Australasian Cerebral Palsy Clinical Trials Network (AusCP-CTN CRE) aims to foster and develop current and future leaders in cerebral palsy research and clinical practice. Our vision for the future workforce for children with cerebral palsy is to build national capacity comprising individuals with expertise in more than one key area of research and/or training (basic science/ neuroscience, epidemiology, clinical/health services initiatives, and translation/ implementation).

As part of AusCP-CTN's Educational Theme, we hold and facilitate a range of trainings and workshops to upskill researchers and allied health professionals who are working in the field of paediatrics and neuroscience. Partnering with instructors from the General Movements Trust in Italy, and colleagues across the eastern coast of Australia, we've held 5 sessions of General Movement trainings, across Brisbane, Cairns, and Hobart in early 2019.

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 an important supplement to the traditional kind of neurological examination. The training is provided to The GMs training attracted ~150 attendees (Medical specialists, Neonatologists, Occupational Therapists, Physiotherapists, Registered Nurses, other Allied Health professionals in the field of infant neurology) across the three cities.



Thirty clinicians from Cairns, Townsville and Far North Queensland (including doctors, therapists and indigenous community workers) attended the Basic General Movements Course in Cairns in February conducted by Prof. Andrea Guzzetta from the University of Pisa.

Over the next few months AusCP-CTN will be holding a range of interactive trainings: Systematic Review Workshop, GRADE Analysis, HINE trainings, with more GMs training in Sydney and Melbourne. Please see Upcoming Events section for further information.

In particular, we will be hosting our **3rd Annual AusCP-CTN Hot Topics in Cerebral Palsy Research Forum⁵**, 21st – 22nd October 2019 in Melbourne. In partnership with colleagues at the Monash University, the Forum will be held at the Monash Health Translation Precinct, featuring international invited keynote speakers including:

- Prof. Bernard Dan (Université libre de Bruxelles), *Neuroprotection and Neuroplasticity in CP*;
- Prof. Alistair Jan Gunn (The University of Auckland), *Progress in Neonatal Neuroprotection*;
- Prof. Laura Bennet (The University of Auckland), *Biomarkers for detecting the evolution of fetal and neonatal brain injury*; and
- Prof. Yannick Bleyenheuft (Université catholique de Louvain), *Intensive motor interventions for children with cerebral palsy*.

The 2-day Hot Topics in CP Research Forum will feature presentations from leading researchers and clinicians in the field of neurology and disability in children, to share the latest research outputs on neuroprotection in clinical and pre-clinical trials, harmonisation and automated analysis of neuroimaging, automated assessments of General Movements, and evidence-based rehabilitation.

For more information about [2019 AusCP-CTN Hot Topics in CP Research Forum](https://cre-auscpcn.centre.uq.edu.au/2019-AusCPCTN-HotTopics).

⁴ AusCP-CTN Education Theme: <https://cre-auscpcn.centre.uq.edu.au/education>

⁵ AusCP-CTN Hot Topics in CP Research Forum: <https://cre-auscpcn.centre.uq.edu.au/2019-AusCPCTN-HotTopics>

QEDIN: The Queensland Early Detection and Early Intervention Network

The Advancing CP in Queensland program has implemented the new [Queensland Early Detection and Intervention Network](https://qcprcc.centre.uq.edu.au/qedin-cp)⁶ (QEDIN) across Queensland. Ethics approval for recruitment of clinicians and referral of infants for screening at risk of Cerebral Palsy status from all 16 Hospital and Health Services across Queensland and the Mater Health Services has been achieved by our research co-ordinator for Infant Studies Dr Tracey Evans. The network has already trained >300 clinicians in standardised assessments for the early detection of CP by conducting 4-hour practical courses on the Hammersmith Infant Neurological Assessment (HINE). Further General Movements Training was conducted in March 2019 in Cairns and Brisbane. The QEDIN team has been actively assisting local teams to screen for infants at high risk of CP using the Baby Moves App to retrieve videos of infant between 12-16 weeks for screening on the General Movements Assessment. Dr Joanne George together with other Queensland HINE trainers have conducted 18 HINE courses across Queensland. This has enabled infants at high risk of Cerebral Palsy with Absent Fidgety Movements and/or low scores on the HINE to be referred to clinical trials that the infant is eligible for. Current studies that infants can be recruited to include REACH, GAME, and PREBO, and new studies that have commenced are (Early-PACT, NEBO, Wearable Sensors, and VISIBLE).

Studies currently recruiting

Early Detection & Early Intervention Studies:

GAME⁷: Harnessing Neuroplasticity to Improve Motor Performance in Infants with Cerebral Palsy: A Pragmatic Randomised Controlled Trial

GAME is a multi-site (New South Wales, Queensland, Victoria, and Western Australia) study which infants aged 3-6 months corrected age are enrolled and randomly assigned to either a traditional passive early intervention, or a weekly intervention involving active motor training, parent education and environmental enrichment. Infants at risk of Cerebral Palsy (as screened by the General Movements Assessment, MRI and/or Cranial Ultrasound (CUS) by 3 months and/or the Hammersmith Infant Neurological Assessment (HINE) by 6 months corrected age may be eligible for this study. There are 130 families already taking part in the study, with 25 of these from Queensland.

At the conclusion of the study when children are aged two, their gross and fine motor skills will be measured and scored to determine the most effective intervention to improve children's motor skills. Ultimately, the study will advance the evidence for early intervention, determine critical periods for intervening, and increase knowledge of early development of infants with brain injuries.

Contact Details: Dr Tracey Evans, GAME Clinical Research Coordinator, (07) 3069 7365, QCPRRC@uq.edu.au.

This project is funded by NHMRC Project Grant 1120031.

Chief Investigators: Prof. Iona Novak, Dr Cathy Morgan, Prof. Nadia Badawi, Prof. Roslyn Boyd, A/Prof. Alicia Spittle, Prof. R Dale, Ms A Kirby, A/Prof R Hunt, Dr K Whittingham, Dr K Pannek. A/Prof M Fahey.

Associate Investigators: A/Prof K Walker, A/Prof A Guzzetta, Dr K Prelog, Prof W Tarnow-Mordi, Prof S Rose, Ms C Galea, Ms S Clough, A/Prof R Morton, Dr A Tran.

NEBO: Neonatal Encephalopathy Brain Outcomes: Prospective study of Clinical and MRI Biomarkers in term born infants to improve accurate early prediction of Cerebral Palsy

The Neonatal Encephalopathy Brain Outcomes (NEBO) study is a prospective, observational trial of 80 term born infants with Hypoxic Ischemic Encephalopathy (HIE) and a healthy term reference group (20). Research has indicated that induced hypothermia reduces the combined rate of death or major neurodevelopmental disability for term born infants with HIE, however 23% of these infants will still be diagnosed with cerebral palsy (CP). The diagnosis is often not confirmed until >2 years of age, well after the period of greatest brain development when interventions to improve the prognosis may be most effective. The aim of the NEBO study is to determine the ability of clinical assessments and neuroimaging to predict neurodevelopmental outcomes

⁶ QEDIN: <https://qcprcc.centre.uq.edu.au/qedin-cp>

⁷ GAME study: <https://qcprcc.centre.uq.edu.au/article/2019/07/game>

including motor, cognitive, neurological outcomes and a diagnosis of high risk of CP. Identifying which term born babies with HIE may have problems later in life means that those babies and their families can be provided with the help they need as early as possible. The study is being conducted in Brisbane QLD across two centres, the Royal Brisbane and Women's Hospital (RBWH) and the Mater Mothers' Hospital (MMH). Recruitment has just commenced at the RBWH and the MMH is due to commence recruitment next month.

Contact Details: Dr Tracey Evans, NEBO Research Coordinator, (07) 3069 7365, QCPRRRC@uq.edu.au.

This project is funded by the Advance Queensland Innovation Partnerships Program Grant 16-103.

Chief Investigators: Prof. Roslyn N Boyd, Prof. Paul Colditz, Dr Pieter Koorts, Prof. Alan Coulthard, Dr Jane Bursle, Prof. Helen Liley, Prof. Stephen Rose, Dr Kerstin Pannek, Dr Jurgen Fripp, Dr Joanne George, Dr Nicola Previtera, Dr Steve Mehrkanoon, Prof. Boualem Boashash, Prof. Rob Ware, A/Prof. Josh Byrne, Prof. Paul Scuffham, Dr Simona Fiori, A/Prof. Andrea Guzzetta.

Associate Investigators: Dr Tracey Evans, Ms Kym Morris, Mrs Christine Finn.

REACH⁸: Rehabilitation Early for children at risk of Congenital Hemiplegia

The REACH study is determining if modified Constraint Induced Movement Therapy (mCIMT) is more effective than Bimanual Therapy (BIM) in improving the symmetrical development of reach, grasp and bimanual co-ordination for infants who are at risk of unilateral CP (UCP). Infants can be screened on the GMs, HINE for risk of CP and then assessed on the Hand Assessment of Infants for their asymmetry of early reach and grasp behaviours, to enter the REACH study before 9 months corrected age (C.A.). The specially trained REACH therapists will provide one home-visit and one virtual Skype visit each month with each family to support their child's daily therapy administered by the child's parents. Families are recruited between 3 to 9 months corrected age (C.A.) and continue in the study until they complete the follow-up assessments at 24 months C.A. Seventy-one families have been recruited from QLD, NSW, VIC, WA and the newly approved recruitment site of Ohio in the US. Two further US sites, Minnesota and Riverside County, are ready to begin recruitment soon. Forty-nine of the study children have already completed their 12 month assessments, with 34 of these having also completed assessments at 24 months C.A.

Contact Details: Dr Tracey Evans, REACH Clinical Research Coordinator, (07) 3069 7365, QCPRRRC@uq.edu.au.

This project is funded by NHMRC Project Grant 1078877.

Chief Investigators: Prof. Roslyn Boyd, Prof. Jeny Ziviani, Dr Leanne Sakzewski, Prof. Iona Novak, Prof. Nadia Badawi, Dr Kerstin Pannek, Prof. Catherine Elliott, Dr Sue Greaves, A/Prof. Andrea Guzzetta, Dr Koa Whittingham, Dr Nataie Maitre, Dr Jill Heathcock, Dr Bernadette Gillick, Dr Kym.

Associate Investigators: A/Prof. Jane Valentine, Prof. Paul Colditz, Prof. Robert Ware, Dr Cathy Morgan, Prof. Stephen Rose.

VISIBLE⁹: Vision Intervention for Seeing Impaired Babies: Learning through Enrichment

The University of Pisa hosted the World Vision Conference on Children with Cerebral Visual Impairment, in May 2019. Prof. Boyd presented Dr Swetha Phillip's Systematic Review of the relationship between brain structure and CVI in children with CP.

Visual impairment in children with cerebral palsy (CP) is very common with a prevalence of 40 to 50%. The majority of children with CP have visual problems due to a neurological impairment not caused by ocular lesions, and in about 1 in 10 cases the condition is severe. The role of vision difficulties is often overlooked so there is an urgent need for the development of evidence-based vision interventions for infants with cerebral vision impairments.

The VISIBLE study is a pilot randomised controlled trial to address a gap in rehabilitative interventions for infants with brain damage and severe vision impairments. Infants will be identified from neonatal follow-up programs and early detection networks in Pisa (Italy), Queensland, New South Wales, Victoria and Western



L – R: VISIBLE Trainer Ms Adina Bancale (Developmental Therapist) with Dr Lea Hyvarinen (developer of Hiding Heidi assessment) at the World Vision Conference for children with Cerebral Visual Impairment.

⁸ REACH study: <https://qcprrc.centre.uq.edu.au/reach>

⁹ VISILE: <https://qcprrc.centre.uq.edu.au/article/2019/07/visible-vision-intervention-seeing-impaired-babies-learning-through-enrichment>

Australia. Thirty-two Infants with a diagnosis of CP or diagnosis of 'high risk of CP' with a severe visual impairment will be recruited between 3-6 months corrected age. The infants will be randomised into the VISIBLE program or the Standard of Care (SoC) group. VISIBLE is an early intervention program based on the core principles of optimising the infant's visual experience during the first phases of development. The general principles are activity-dependent learning and environmental enrichment. In Queensland, the study has approval to commence recruitment at the Royal Brisbane and Women's Hospital (RBWH) and the Queensland Children's Hospital (QCH), with Townsville Hospital and Cairns Hospital due to commence recruitment soon.

Contact Details: Dr Tracey Evans, VISIBLE Clinical Research Coordinator, (07) 3069 7365, QCPRRC@uq.edu.au.

This project is funded by Cerebral Palsy Alliance.

Chief Investigators: Prof Roslyn Boyd, Prof. Andrea Guzzetta, Prof Iona Novak, Dr Cathy Morgan, Dr Alison Salt, Prof. Catherine Elliott, Prof Glen Gole, Dr Swetha Philip, Prof Nadia Badawi, Prof Stephen Rose, Dr Jurgen Fripp, Dr Kerstin Pannek.

Wearable Sensors: Study of Infant General Movements

A new study using new wearable sensor technology developed by CSIRO is designed to measure patterns of movement in young infants around 3 months (12-16 weeks C.A.) which may give insight into how their brain is developing. Measuring those patterns may help identify infants who are developing more slowly and may require help earlier than they would otherwise. This study seeks healthy babies born at term (between 38-41 weeks gestation) who did not have any complications prior, during, or directly following delivery. Participation in the study involves visiting the Child Health Research Centre (CHRC) for four (4) different visits. We will place small sensors and reflective markers on your baby's hands, feet, chest, and forehead to measure how they move over a short period of time. We will also take video of the baby's movements to compare to the data that we collect using the sensors.



A wearable motion sensor used to measure infant movements that may help augment existing clinical assessments and facilitate earlier diagnosis of CP.

The research governance of the study has been completed and recruitment for participants is well underway from Queensland Children's Hospital, Royal Brisbane & Women's Hospital, in collaborations with researchers from The University of Queensland and CSIRO.

Contact Details: Dr Christian Redd, Principal Investigator, (07 3253 3612 / 0419 232 637, christian.redd@csiro.au; Dr Tracey Evans, Clinical Trials Coordinator, (07) 3069 7365, t.evans3@uq.edu.au.

This project is funded by the Advance Queensland Innovation Partnerships Program Grant 16-103.

Child Studies:

Participate-CP¹⁰, a response to low physical activity in children with cerebral palsy

Most Australian children do not get enough physical activity each day for growth and healthy development. In the recent 2018 Active Healthy Kids Australia Physical Activity Report Card, Australia scored a D- for overall physical activity level, placing us in a tie for 32nd place out of 49 participating countries. Children with cerebral palsy (CP) are particularly at risk for low levels of physical activity and low rates of participation in community sports and physical recreation. Effective ways to promote physical activity in children with CP are desperately needed. Participate-CP, a model of participation-focused therapy to promote participation in physical activities has been developed to respond to this emerging problem. Participate-CP recognizes the role of environmental factors in restricting participation for youth with disabilities. Therapists assist families to set meaningful goals around their child's participation and employ strategies to overcome barriers.

¹⁰ Participate-CP study: <https://qcprrc.centre.uq.edu.au/participate-cp>

Seven participants have now been recruited to the Participate-CP study across sites in Perth and Sydney. Children have been working on achieving physical activity participation goals including riding a bike to and from school, and running at the park. Three Brisbane therapists, Sian Spencer, Deb Khan and Nicola Blum, will begin seeing participants locally from the second week of August. Participate CP is all about tackling tricky barriers that families face when their child with CP wants to participate in sports and physical activities. If you think Participate CP could benefit your child, you live within 150km of Brisbane, your child is between the ages of 8-14 years, they have a confirmed diagnosis of cerebral palsy, and are classified at GMFCS levels I, II, III or IV, then please get in touch! The therapist travels to you in your home and community, so there is no need to worry about transport to our research centre. **Sites:** Brisbane, Cairns, Sydney, NSW Regional, and Perth (+150km radius from each site).

Contact Details: Dr Natalie Dos, Study Coordinator, (07) 3069 7356, participqte.qcprc@uq.edu.au.

This project is funded by NHMRC 1140756.

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

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

LEAP-CP (India): Learning through Everyday Activities with Parents

The Learning through Everyday Activities with Parents (LEAP-CP) intervention is a community-based, parent delivered early detection and intervention program for babies at high risk of cerebral palsy. In low and middle income contexts, geographical distance and the high cost of health care are barriers for families to access intervention. LEAP-CP is an innovative peer to peer approach that provides support in the home to help caregivers be their baby's best teacher.

Led by Dr Katherine Benfer (Queensland Cerebral Palsy & Rehabilitation Research Centre, The University of Queensland), a team of dedicated researchers, local site coordinators, and community disability workers from our partner organisations (Asha Bavan Centre, Dr. BC Roy Postgraduate Institute of Paediatric Science, Child in Need Institute, Indian Institute of Cerebral Palsy, and Apollo Gleneagles Hospital), have collaboratively worked to implement the intervention with local communities.



Infant with CP in Kolkatta practicing Active motor and learning games with his mother and community worker.

The LEAP-CP project has now finished recruitment in Kolkata India, with 749 babies with birth risk factors screened with the General Movements and HINE, and 142 babies at high risk of CP (12-40 weeks) recruited.

Contact Details: Dr Katherine Benfer, k.benfer@uq.edu.au.

This project is funded by Cerebral Palsy Alliance and Endeavour QEII Diamond Jubilee Fellowship.

Chief Investigators: Dr Katherine Benfer, Prof. Roslyn Boyd, Prof. Iona Novak, Prof. Naila Khan, Dr Anjan Bhattacharya, Dr Cathy Morgan, Dr Koa Whittingham, Dr Kristie Bell, Prof. Robert Ware, and Dr Sasaka Bandaranyake.

PREBO-6¹¹: Prediction of childhood Brain Outcomes in infants born preterm using neonatal MRI and concurrent clinical biomarkers

Infants born preterm are at risk of adverse long-term neurodevelopmental outcomes, including cognitive (30-60%), behavioural (45%) and motor deficits (including cerebral palsy, CP, 5-10%). These adverse outcomes can significantly impair social and educational functioning and quality of life. The team has established a unique cohort (n=178) of infants born very preterm (<31 weeks postmenstrual age, PMA) with early neonatal advanced MRI (30-32 weeks PMA) and concurrent clinical biomarkers. The team are now comparing these early trajectories to motor, cognitive, executive function, behaviour, educational achievement, screening for autism and brain structure (sMRI, dMRI, fMRI, EEG) at early school age (6 years CA). This is important as intellectual, learning and behavioural outcomes are only able to be fully evaluated later in childhood. Additionally, a diagnosis of CP may not be confirmed until after 2 years CA. The new PREBO-6 project will enable: (i) parents and caregivers to have earlier, accurate prognostic information; (ii) clinical researchers will have comprehensive tools to assist the rational development and testing of neuroprotection, neurorestoration

¹¹ PREBO-6: <https://qcprc.centre.uq.edu.au/article/2019/07/prebo6>

and neurorehabilitation interventions. (iii) Infants at risk of neurodevelopmental delay, CP and autism will be detected earlier, leading to (iii) earlier implementation of targeted interventions aimed at improving neurodevelopmental outcomes; and (iv) a reduction in neurodevelopmental disability and its high financial costs to individuals, families and society.



FLASH Thomas our first PREBO-6 participant just after completing his MRI.

As a follow-up study to the PREBO (involving infants up to 24 months) project, PREBO-6 will involve children at 6 years of age. Recruitment for the study has commenced in June 2019 and support for travel and accommodation will be offered to families travelling from regional and rural Queensland, interstate, or New Zealand. Each child will receive a comprehensive assessment of their development and parents will be provided with a report. This report can also be made available to your child's Pediatrician/GP.

There are three parts to this study which will be offered over 2 days:

1. Movement, learning and language assessments (including parent questionnaires) (preterm born children only)
2. EEG (recording brain activity)
3. MRI (brain scan)

Contact Details: Dr Joanne George, Team Leader PREBO6, (07) 3069 7371, j.george2@uq.edu.au.

This project is by NHMRC New Investigator Grant 1161998.

Chief Investigators: Dr J George, Dr A Pagnozzi, A/Prof S Bora

Associate Investigators: Prof R Boyd, Prof P Colditz, Prof S Rose, Prof R Ware, Dr K Pannek, Dr J Bursle, A/Prof Karen Barlow, Dr Kartik Iyer

PREDICT CP¹²: Implementation of comprehensive surveillance to Predict outcomes for children with Cerebral Palsy

The PREDICT CP study, which is a continuation of the CP Child Study and the Growth, Nutrition and Physical Activity Study (GNPA), aims to explore the relationship between brain development and physical capacity, growth, physical activity, communication, cognition, participation, and educational outcomes of children who have CP. This important information will enable us to build prediction models that will allow us to develop timely and effective interventions and predict future outcomes for children with CP. Families with children born in Queensland, aged between 8-12 years (born in the birth years 2006-2011), are invited to take part in the PREDICT CP study at the Centre for Children's Health Research (CCHR), South Brisbane.

Information from the study will help children with cerebral palsy and their families in the future. Summary information on your child will be reported back to you after this one-off assessment, which will be conducted over 1-1.5 days. Support for travel and accommodation will be provided for families travelling from regional and rural Queensland or interstate.

We have now had 81 families from all over Queensland and northern New South Wales attend the one-off comprehensive assessment. 'Thank you' to all of these families for your time and support of this study. Bookings are filling up! Please contact Dr Shaneen Leishman for more information.

Contact Details: Dr Shaneen Leishman, Clinical Research Coordinator, (07) 3069 7354, QCPRRC@uq.edu.au.

This project is funded by NHMRC Partnership Grant 077257.

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, 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 K Benfer, Mr O Lloyd, A/Prof J Byrnes, Dr J Fripp, Dr K Pannek.



Jacob (8 y.o.) - one of our incredible research champions!

¹² PREDICT study: <https://qcprrc.centre.uq.edu.au/predict-cp>

SMART¹³: Strengthening Mental Abilities Through Relational Training

Cerebral palsy (CP) is typically associated with motor impairments, but nearly half of all children with CP also experience cognitive impairment, potentially impacting educational and vocational achievement. While there is growing awareness of these challenges, interventions for CP have typically focused on improving physical activity, limb function, and participation in daily living activities. Having identified the gap in the range of interventions for CP, research teams at UQ's Faculty of Medicine and Faculty of Health and Behavioural Sciences have co-developed a randomised controlled trial: Strengthening Mental Abilities Through Relational Training (SMART), which aims to test the effectiveness of a novel online cognitive program for children with mild to moderate CP. SMART is founded upon relational frame theory, which suggests that language and complex thinking are underpinned by our ability to understand relationships between objects, known as relational framing. If efficacious, an online program designed to train relational framing ability and potentially improve complex reasoning would be a cost-effective intervention, accessible from home for children with CP.



Child using SMART program at home.

All participants in the SMART study will gain access to the web-based SMART training program that can be completed from home, over laptop, PC or tablet either immediately or after 6 months. Participants will receive training in relational framing through an online, user-friendly platform. Children answer problems and receive immediate feedback during 30-minute online training sessions, three times a week for approximately 12 weeks. Participants will be randomly assigned to an intervention group or waitlist control, so that all participants will receive access to the program by the end of the study. A comprehensive psychological assessment will be completed before beginning the study, at 20 weeks after beginning, and again at 40 weeks.

Jane Wotherspoon, Clinical Psychologist is undertaking this for her PhD research. She has published the study protocol in BMJ Open in June 2019¹⁴. Recruitment for this clinical trial is well underway through QCPRRC and we aim to complete recruitment by December 2019, with data collection finalised by June 2020.

This study is open to children living in Queensland who meet the following criteria:

- Children aged from 8 to 12 years of age, with mild to moderate Cerebral Palsy (GMFCS I-IV, who are able to access an online program and perform tasks on iPad, tablet, Mac or PC, and able to attend three assessment sessions at the Centre for Children's Health Research in Brisbane.
- Children with unstable epilepsy or brain injury; children currently undergoing active medical treatment (chemotherapy, radiotherapy or neurosurgical treatment) are excluded.

For more info about SMART and contact details: Jane Wotherspoon, (07) 3069 7367, j.wotherspoon@uq.edu.au.

This project is funded by the Australian Postgraduate Award (APA) Scholarship.

Chief Investigators: Jane Wotherspoon, Dr Koa Whittingham, Dr Jeanie Sheffield, and Prof. Roslyn Boyd.

Imagine CP: Genome and Connectome Study

QCPRC collaboration with the Queensland Brain Institute, has obtained funding to identify genetic risk factors that contribute to CP. The Imagine CP study will examine relationships between genetic factors, brain structure and functional outcomes in children with the condition. A genetic basis of CP is suspected in up to 30% of CP cases. As has been shown with other neurodevelopmental disorders (e.g. Autism, Epilepsy, Intellectual disability), genetic insights have the potential to provide a framework for understanding the neurobiological pathways that lead to CP. Imagine CP is obtaining a blood or buccal swab sample from children and adults with CP (aged 30 years and under), as well as their parents. Recruitment is well underway and we have collected samples from 48 families to date. Once all samples have been collected, DNA will be extracted and analysed in search of genes of possible importance to CP. We will search for changes that occur in children with CP but not in their parents. This can help to identify new mutations, or changes, in genes that may be linked with CP. This will provide new insights into our understanding of CP, and in the era of personalised medicine, may lead to personalised treatment for children with CP.

Contact Details: Dr Shaneen Leishman, Research Coordinator, (07) 3069 7354, QCPRRC@uq.edu.au.

This project is funded by Cerebral Palsy Alliance Project Grant PG5115.

Chief Investigators: A/Prof M Wright, Prof R Boyd (QCPRRC), Prof S Rose, A/Prof Michael Fahey.

¹³ SMART study: <https://qcprc.centre.uq.edu.au/project/smart-strengthening-mental-abilities-through-relational-training>

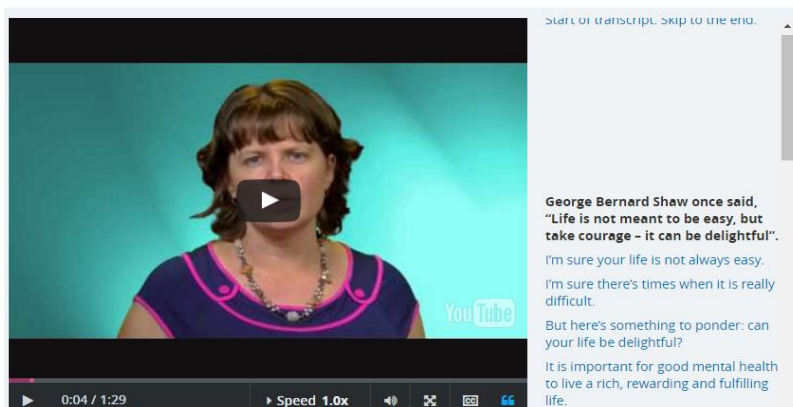
¹⁴ SMART Protocol Publication: <https://bmjopen.bmj.com/content/9/6/e028505.full>

PACT & Early PACT¹⁵: Parenting Acceptance and Commitment Therapy

The PACT study is an RCT of an online intervention with families of children (2-10) with CP. We developed PACT into an online course called PARENT101 Parenting with Purpose using the EdX Edge platform. Grounded in the Acceptance and Commitment Therapy (ACT) model, PARENT101 supports parents to become psychologically flexible, with full awareness of the present moment, in accordance with their personal values. The content of the course includes short videos, text, online activities, moments of reflection, guided mindfulness, acceptance and compassion exercises and a moderated discussion board.

A total of 74 parents participated in the PACT study and so far the majority of the parents provided positive feedback and that the online nature of the course was easily accessible. Recruitment has closed and data collection is complete. We are preparing the data for analysis. We sincerely thank all the parents who participated in this study and we will let you know the results when they become available.

Meaningful Life



Early PACT: adaptation of PACT for Parents of infants under 2 years old.

This novel study has launched in January 2019 and we are excited to announce that recruitment has opened for Early PACT study. Early PACT is an adaptation of the PACT parenting support package previously designed for families of young children (2-10 years of age) with CP (Whittingham, Sheffield, & Boyd, 2016). The process of adapting PACT for earlier dissemination to families following earlier diagnosis for their infant has involved reviewing the core aspects of PACT with these families. Our research team conducted qualitative explorations with families who received an early diagnosis of CP risk regarding the feasibility of the PACT program (Dickinson, Sheffield, Boyd, & Whittingham). These families guided the development of Early PACT content and the elements of PACT most applicable for delivery at this earlier time.

EdX Edge Parenting 101 developed by Dr Koa Whittingham.

Early Parenting Acceptance and Commitment Therapy (Early PACT) was developed for families of infants identified as high risk of cerebral palsy (CP) at less than 24 months corrected age, and will be tested in a randomised controlled trial (RCT). We predict that Early PACT will have benefits to both parents and the infant and enhance family functioning by leveraging the understanding, skills and the day to day interactions within the family system. Early PACT is consistent with the philosophy of family-centred care and, if effective, could be used to empower parents of infants identified at high risk of CP worldwide.

We are excited to have received a great interest in the project and quite a few numbers of participants have already enrolled in the program.

Who can participate?

This study is open to parents (including adoptive, step parent or legal guardian) of an infant under 2 years of age, who has been diagnosed with or is at high risk of CP. This study is testing an online course so you need to have: reliable internet access, a mobile phone (text messages are part of the course), and basic computer and internet literacy.

Contact Details: Dr Catherine Mak, Post-doctoral Research Officer, earlypact@uq.edu.au.

This project is funded by the Cerebral Palsy Alliance.

Chief Investigators: Dr Koa Whittingham, Dr Jeanie Sheffield, Prof. Roslyn Boyd, and Dr Catherine Mak.

¹⁵ Early PACT study: <https://qccprc.centre.uq.edu.au/project/earlypact>

Studies concluded

We have concluded our FAST-CP, MIYOGA and Particpate-1 studies with several new publications. Please see Publications section, or [past studies](#)¹⁶, for further details.

Our Output & Achievements

Grant & Funding Successes

Mary McConnel Career Boost Program for Women in Paediatric Research¹⁷

Dr Katherine Benfer has been successful in receiving \$50,000 Mary McConnel Career Boost Program for Women in Paediatric Research, through the Children's Research Foundation (CHF). Dr Benfer is a Post-Doctoral Research Fellow focusing on community-based early detection and intervention for infants at high risk of cerebral palsy in low-resource countries (Bangladesh and India). Kath has led the 'LEAP-CP (India): Learning through Everyday Activities with Parents' project and has worked with a team of dedicated researchers, local site coordinators, and community disability workers from our partner organisations (Asha Bavan Centre, Dr BC Roy Postgraduate Institute of Paediatric Science, Child in Need Institute, Indian Institute of Cerebral Palsy, and Apollo Gleneagles Hospital), have collaboratively worked to implement the intervention with local communities. The LEAP-CP project has now finished recruitment in Kolkata India, with 749 babies with birth risk factors screened with the General Movements and HINE, and 142 babies at high risk of CP (12-40 weeks) recruited. Funding received from the CHF will further support Dr Benfer in carrying out her project in rural regions of Queensland and working with indigenous communities.



Contact Details: Dr Katherine Benfer, E: k.benfer@uq.edu.au Dr Kath Benfer, Prof. Ros Boyd and the Kolkata LEAP-CP coordinators.

Child Health Research Centre Travel Grant

Two of our Early Career Research Fellows, Dr Catherine Mak and Dr Sarah Reedman, were successful in receiving Travel Grants from the Child Health Research Centre, Faculty of Medicine, The University of Queensland. Dr Mak will be using the funding support to attend the American Academy for Cerebral Palsy and Developmental Medicine (AAPDM)¹⁸ Conference 2019, Anaheim USA. As a joint presentation with Prof. Roslyn Boyd at AAPDM, Dr Mak will be presenting 'Supporting parents of infants identified as at risk of cerebral palsy through Parenting and Mindfulness-based Approaches'.

Dr Sarah Reedman will be using the funds to attend the 2020 Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM), in Perth.

¹⁶ Studies concluded: <https://qcprc.centre.uq.edu.au/past-studies>

¹⁷ Mary McConnel Career Boost Dr Kath Benfer: <https://qcprc.centre.uq.edu.au/article/2019/07/mary-mcconnel-career-boost-benfer>

¹⁸ AAPDM 2019 Program: <http://www.aacpdm.org/meetings/2019/program>

Achievements & Recognitions

Book publication by Dr Koa Whittingham

QCPRRC's Senior Research Fellow and resident clinical psychologist Dr Koa Whittingham is now a proud co-author of '[Acceptance and Commitment Therapy – The Clinician's Guide for Supporting Parents](#)'¹⁹. Published on the 18th June 2019, the book is aimed at mental health clinicians and practitioners (psychologists, psychiatrists, social workers etc.) and school counsellors working with parents. The book constitutes a principles-based guide for clinicians to support parents across various stages of child and adolescent development. It uses Acceptance and Commitment Therapy (ACT) as an axis to integrate evolution science, behaviour analysis, attachment theory, emotion-focused and compassion-focused therapies into a cohesive framework; from this integrated framework, the authors explore practice through presenting specific techniques, experiential exercises, and clinical case studies.

Contact Dr Koa Whittingham for more information and collaborative opportunities: koawhittingham@uq.edu.au

PSANZ 2019²⁰

In March 2019, Dr Joanne George from QCPRRC claimed two prestige awards from the Perinatal Society of Australia & New Zealand ([PSANZ](#)) Conference 2019:

- New Investigator Award – Allied Health/Other Specialties or Disciplines (Oral),
- PSANZ President's Award – New Investigator (Oral)

Working as a clinical paediatric physiotherapist (Queensland Paediatric Rehabilitation Services) and research fellow (The University of Queensland), Dr George was recognised for her work on PPremo project, which uses the ability of very early MRI and early clinical measures of motor, neurological and neurobehavioural function to identify infants at high risk of adverse motor outcomes following very premature birth. Jo also focuses on developing and implementing the state-wide [Qld Early Detection and Intervention Network \(QEDIN\)](#), for children at risk of Cerebral Palsy. The ultimate vision of QEDIN-CP is to improve the health and wellbeing of children with CP and their families through early detection and provision of early intervention.

Contact: Dr Jo George for collaborative and PhD project opportunities: j.george@uq.edu.au.

2019 Pursuit Award²¹ in Childhood Disability Research

Hosted by the Holland Bloorview Kids Rehabilitation Hospital and Research Institute, QCPRRC's Dr Catherine Mak took home Second Prize of the annual International Pursuit Award, for her work on '*MiYoga: An embodied, mindful-movement program for children with cerebral palsy and their parents - a randomised controlled trial*'. MiYoga is a novel family-centred lifestyle intervention based on mindfulness and hatha yoga principles, which aims to enhance child and parent outcomes for children with CP. The award ceremony was held in Toronto, Canada, on the 15th May 2019, and was supported by the Holland Bloorview Foundation donors, the Ward Family, and the Bloorview Research Institute.

Dr Mak is a registered psychologist and Post-Doctoral Research Officer at the QCPRRC. Her current research focuses on Early PACT²²). **Contact Dr Catherine Mak** for more information about MiYoga and Early PACT, and collaborative opportunities: c.mak@uq.edu.au



L – R: Pursuit Award Finalists Dr Emma Grace (Flinders University), Dr Alicia Hilderley (University of Calgary), and Dr Catherine Mak (The University of Queensland), with Holland Bloorview Foundation donors (Ward Family), and President of Holland Bloorview Kids Rehabilitation hospital.

¹⁹ Acceptance and Commitment Therapy: https://www.elsevier.com/books/acceptance-and-commitment-therapy/whittingham/978-0-12-814669-9?ccid=EAlalQobChMli-enn7al4wIVyBwrCh2dSA9iEAQYAIABEqJYRPD_BwE

²⁰ PSANZ2019: <https://qcprrc.centre.uq.edu.au/article/2019/07/psanz-2019-george>

²¹ 2019 Pursuit Award: <https://qcprrc.centre.uq.edu.au/article/2019/07/2019-pursuit-award-mak>

²² Early PACT: <https://qcprrc.centre.uq.edu.au/project/early-pact-early-parenting-acceptance-and-commitment-therapy>

Conferences & Presentations

European Academy of Childhood Disability (EACD) 2019

The 31st Conference of the European Academy of Childhood Disability took place 23rd – 25th May 2019, at the conference centre of la Cité des Sciences et de l'Industrie (City of Sciences and Industry) of La Villette, Paris, France.

With “Innovation for Participation” as the theme of the conference, the EACD 2019 aimed to provide a professional platform, where expertise around the world can get together and showcase information and findings on new developments in applied and translational sciences, prevention, diagnosis, treatment, and technology for individuals with CP and other childhood onset disabilities.



QCPRRC Research Team and collaborators at the Eiffel Tower for EACD Conference Dinner, Paris May, 2019.

From QCPRRC, Dr Leanne Sakzewski and Prof. Ros Boyd presented a joint keynote lecture on the ‘Active ingredients of activity-based rehabilitation and unpacking the black box of participation-focused interventions’. Dr Joanne George presented a free paper on ‘The relationship between very early brain microstructure at 32 and 40 weeks postmenstrual age and 12-month motor outcome in very preterm born infants: a diffusion MRI study’, and Dr Sarah Reedman conducted a workshop on “A toolbox for participation-focused therapy – practical guide for therapists to enable participation in physical activities for youth with physical disabilities”. Colleagues from the Cerebral Palsy Alliance provided an update on the development of a new clinical practice guideline on the evidence for functional therapies for children with cerebral palsy.

More information about the [conference](#) and the program are now available to view online²³.

2019 Rehab for Kids Conference²⁴ – Queensland Paediatric Rehabilitation Service

The Rehab for Kids conference is a national conference organised by the Queensland Paediatric Rehabilitation Service (QPRS), Queensland Children’s Hospital, to provide the latest information and research relevant to paediatric rehabilitation. The conference program included a variety of presentation types, including key note addresses, short workshops and research papers, which provided opportunities for attendees to update knowledge and network with colleagues involved in the rehabilitation of children with brain injuries, cerebral palsy, spinal cord injury, limb difference, spina bifida and other low incidence conditions. Many of QCPRRC researchers and collaborators were involved in the conference.



L – R: AusCP-CTN AI Dr Sian Williams (Muscle development in children with CP and the effect of interventions), and QCPRRC Researchers Drs Catherine Mak (MiYoga: RCT of Mindfulness and Yoga for children with CP) and Sarah Reedman (RCT of participation focused intervention for children with CP).



Chief Investigators Prof. Andrea Guzzetta (Child Neurologist) and Dr Swetha Phillip (Ophthalmologist and PhD Scholar at UQ) presented on “Cerebral Visual Impairment” at the Queensland Paediatric Rehabilitation Services conference.

²³ EACD 2019: <http://eacd2019.org/home/>

²⁴ 2019 Rehab for Kids QPRS: <https://www.childrens.health.qld.gov.au/conference-2019-rehab-for-kids/>

2019 College of Education and Developmental Psychologists Conference - Hobart

PhD candidate Jane Wotherspoon attended the College of Education and Developmental Psychologists (CEDP) conference in Hobart in March 2019. Jane presented her work on a systematic review titled “Can computerised cognitive training improve performance on tests of fluid intelligence in children with neurodevelopmental disorders?”, highlighting the efficacy of computerised cognitive interventions for children with neurodevelopmental and neurological disorders in studies that included performance on tests of fluid intelligence as an outcome. The conference attracted over 225 participants and the presentation received positive feedback.

More information about Jane's presentation at [CEDP 2019²⁵](https://apsevents.eventsair.com/QuickEventWebsitePortal/cedp19/confprogram/Agenda).

*QCPRRC PhD Candidate
 Jane Wotherspoon at CEDP.*



New Publications from QCPRRC

A Randomized Trial of Baby Triple P for Preterm Infants: Child Outcomes at 2 Years.

Paul B. Colditz, Roslyn N. Boyd, Leanne Winter, Margo Pritchard, Peter H. Gray, Koa Whittingham, Michael O'Callaghan, Luke Jardine, Peter O'Rourke, Louise Marquart, PhD⁸, Kylee Forrest, Carmen Spry and Matthew R. Sanders, The Journal of Pediatrics. <https://doi.org/10.1016/j.jpeds.2019.01.024>

AIM: To determine the efficacy of a hospital-based intervention that transitions into existing community support, in enhancing developmental outcomes at 2 years of corrected age in infants born at less than 32 weeks.

RESULTS: Mean gestational age of infants was 28.5 weeks (SD = 2.1), and mothers' mean age was 30.6 years (SD = 5.8). A total of 162 families (n = 196 infants) were allocated to intervention and 161 families (n = 188 infants) received care-as-usual. There was no significant adjusted difference between treatment groups on dysregulation (0.2; 95% CI -2.5 to 3.0, P = .9) externalizing (0.3; 95% CI -1.6 to 2.2, P = .8), internalizing (-1.5; 95% CI -4.3 to 1.3, P = .3), observed aversive (0.00; -0.04 to 0.04, P = .9), or nonaversive behavior (-0.01; 95% CI -0.05 to 0.03, P = .7). Intervention children scored significantly higher on cognition (3.5; 95% CI 0.2-6.8, P = .04) and motor skill (5.5; 95% CI 2.5-8.4, P < .001), and approached significance on language (3.8; 95% CI -0.3 to 7.9, P = .07).

Stability of the Manual Ability Classification System in young children with CP

Andrea Burgess, Roslyn Boyd, Jenny Ziviani, Mark D Chatfield, Robert S Ware and Leanne Sakzewski. Developmental Medicine & Child Neurology. <https://doi.org/10.1111/dmcn.14143>

AIM: To examine the stability over time of the Manual Ability Classification System (MACS) levels in children with cerebral palsy (CP) aged 18 to 60 months.

RESULTS: There were 1030 unique observations, with each of the 252 participants seen between two and six occasions (median=4). Average specific positive agreement over the study period was 76% for MACS level I, 67% for level II, 50% for level III, 51% for level IV, and 83% for level V. MACS levels I and V have the highest degree of stability, while levels III and IV have the lowest. We show how this may be explained by the proportion of children in each MACS level.

²⁵ CEDP 2019: <https://apsevents.eventsair.com/QuickEventWebsitePortal/cedp19/confprogram/Agenda>

Development and validation of a screening tool for feeding/swallowing difficulties and undernutrition in children with cerebral palsy

Kristie L Bell, Katherine A Benfer, Robert S Ware, Tania A Patrao, Josephine J Garvey, Joan C Arvedson, Roslyn N Boyd, Peter SW Davies and Kelly A Weir, Developmental Medicine & Child Neurology.
<https://doi.org/10.1111/dmcn.14220>

AIM: To develop and validate a screening tool for feeding/swallowing difficulties and/or undernutrition in children with cerebral palsy (CP).

RESULTS: Feeding difficulties impacted on swallow safety in 26 children (29%) and 26 children (29%) were moderately or severely undernourished. The 4-item final tool had high sensitivity and specificity for identifying children with feeding/swallowing difficulties (81% and 79% respectively) and undernutrition (72% and 75% respectively). The tool successfully identified 100 per cent of children with severe undernutrition and 100 per cent of those classified as EDACS level IV or V.

Validity and reliability of a freehand 3D ultrasound system for the determination of triceps surae muscle volume in children with cerebral palsy

L. Barber, C. Alexander, P. Shipman, R. Boyd, S. Reid and C. Elliott, Journal of Anatomy.
<https://doi.org/10.1111/joa.12927>

ABSTRACT: This study assessed the validity, intra-rater and inter-rater reliability of segmentation of in vivo medial gastrocnemius (MG), lateral gastrocnemius (LG) and soleus (SOL) muscle volume measurement using a single sweep freehand 3D ultrasound (3DUS) in children with cerebral palsy (CP). The MG, LG and SOL of both limbs of 18 children with CP (age 8 years 4 months – 1 year 10 months, 11 males, unilateral CP = 9, bilateral CP = 9, Gross Motor Functional Classification System I = 11, II = 7) were scanned using freehand 3DUS and magnetic resonance imaging (MRI). All freehand 3DUS and MRI images were segmented and volumes rendered by two raters. Validity was assessed using limits of agreement method. Intra-rater and inter-rater reliability was assessed using intra-class correlation (ICC), coefficient of variance (CV) and minimal detectable change (MDC). Freehand 3DUS overestimated muscle volume of the MG and LG by < 0.3 mL (1%) and underestimated SOL by < 1.3 mL (1.5%) compared with MRI. ICCs for intra-rater reliability of the segmentation process for the freehand 3DUS system and MRI for muscle volume were > 0.98 and 0.99, respectively, for all muscles. ICCs for inter-rater reliability of the segmentation process for freehand 3DUS and MRI volumes were > 0.96 and 0.98, respectively, for all muscles. MDCs for single rater freehand 3DUS and MRI were < 4.0 mL (14%) and 3.2 mL (11%), respectively, in all muscles. Freehand 3DUS is a valid and reliable method for the measurement of lower leg muscle volume that can be measured with a single sweep in children with CP in vivo. It can be used as an alternative to MRI for the detection of clinically relevant changes in calf muscle volume as the result of growth and interventions.

Actigraph assessment for measuring upper limb activity in unilateral cerebral palsy

Elena Beani, Martina Maselli, Elisa Sicola, Silvia Perazza, Francesca Cecchi, Paolo Dario, Irene Braitto, Roslyn Boyd, Giovanni Cioni and Giuseppina Sgandurra, Journal of NeuroEngineering and Rehabilitation.
<https://doi.org/10.1186/s12984-019-0499-7>

AIM: Detecting differences in upper limb use in children with unilateral cerebral palsy (UCP) is challenging and highly dependent on examiner experience. The recent introduction of technologies in the clinical environment, and in particular the use of wearable sensors, can provide quantitative measurement to overcome this issue. This study aims to evaluate ActiGraph GT3X+ as a tool for measuring asymmetry in the use of the two upper limbs (ULs) during the assessment with a standardized clinical tool, the Assisting Hand Assessment (AHA) in UCP patients aged 3–25 years compared to age-matched typically developing (TD) subjects.

RESULTS: The MANDH was significantly lower in UCP compared to TD, while the AI was significantly higher in UCP compared to TD. Moreover, in UCP group there were significant differences related to MACS levels, both for MANDH and AI.

Efficacy of cycling interventions to improve function in children and adolescents with cerebral palsy: a systematic review and meta-analysis

Ellen L Armstrong, Sian Spencer, Megan J Kentish, Sean A Horan, Christopher P Carty and Roslyn N Boyd, Clinical Rehabilitation Journal. <https://doi.org/10.1177/0269215519837582>

AIM: The aim of this study was to determine the efficacy of cycling to improve function and reduce activity limitations in children with cerebral palsy; the optimal training parameters for improved function; and whether improvements in function can be retained.

METHOD: Six databases were searched (until February 2019) and articles were screened in duplicate. Randomized or quasi-randomized controlled trials and pre–post studies were included. Methodological quality was assessed using the Downs and Black scale. Outcomes were reported under the International Classification of Functioning, Disability and Health domains of body functions and activity limitations. Quantitative analyses were completed using RevMan V5.3.

RESULTS: A total of 533 articles were identified and 9 studies containing data on 282 participants met full inclusion criteria. Methodological quality ranged from low (14 of 32) to high (28 of 32). Significant improvements were reported for hamstring strength (effect size = 0.77–0.93), cardiorespiratory fitness (effect size = 1.13–1.77), balance (effect size = 1.03–1.29), 3-minute walk test distance (effect size = 1.14) and gross motor function (effect size = 0.91). Meta-analysis suggested that cycling can improve gross motor function (standardized mean difference = 0.35; 95% confidence interval = (–0.01, 0.70); $P = 0.05$); however, the effect was insignificant when a poor-quality study was omitted.

New Team Members

The QCPRRC is pleased to welcome new members in 2019:



Dr Natalie Dos Santos – Clinical Trials Coordinator

Natalie holds a PhD in Psychology from the Queensland University of Technology. With experience and expertise both as an academic and research manager in working with clinical trials projects, Natalie has a broad range of knowledge in research governance, developing research practices and protocols, and liaising with a range of stakeholders across the research and healthcare sectors. Prior to joining the QCPRRC team, Natalie was a Research Project Manager at Australian Catholic University, working on a longitudinal study of early literacy and numeracy development in young children.



Janine Cezar – QCPRRC Administration Officer

Janine holds a Bachelor's degree in Business (Event Management). She has experience working in project and event management, stakeholder engagement, and course coordination in the tertiary sector. Her previous roles include providing welfare support to international students, managing campus wide events, coordinating development courses as well as providing administration support.



Lakshmi Jayan – UQ Winter Scholar Student

Lakshmi Jayan is currently studying a Bachelor of Health Sciences with a Nutrition Major. Lakshmi has an interest in public health interventions, health literacy, digital interventions and indigenous health. For her winter project, Lakshmi completed an analysis of intervention content from Dr Sarah Reedman's PhD project ParticiPate CP. This analysis will shed light on the clinical reasoning process, and will help in the translation of the research outcomes into clinical practice.

Upcoming events

Systematic Review Workshop²⁶

Thursdays over 8-weeks; 18th July – 5th September 2019

8-week interactive workshop which aims to enable the attendees to gain a comprehensive knowledge and practical experience in conducting a systematic review and meta-analysis of efficacy of treatment, a clinimetric review of measures, and/or a review of diagnostic criteria for a clinical area. Fully day Meta-analysis and GRADE methods will be included in the training for a transparent approach to rating the certainty of evidence and developing healthcare recommendations. **– For more details.**

1-Day GRADE Analysis Workshop²⁷

Thursday 1st August 2019

As part of the Systematic Review Workshop, we have invited Dr Sue Brennan from Melbourne GRADE Centre, to conduct a one-day interactive session on GRADE analysis. GRADE (Grading of Recommendations, Assessment, Development and Evaluations) is a transparent framework for developing and presenting summaries of evidence and provides a systematic approach for making clinical practice recommendations. Workshop topics include: Overview (GRADE in systematic review, guideline process), Interpreting effect estimates, How to GRADE the evidence, Using the GRADE criteria, Making recommendations. **– For more details.**

Grant Writing Workshop²⁸ – Monash Health Translation Precinct

Thursday 10th – Friday 11th October 2019

Co-lead with Hudson Institute of Medical Research, the workshop aims to provide guidance in grant/fellowship writing, grantsmanship, clinical trial design, biostatistics, budgeting, bibliometrics and career development through mentorship, lectures and group discussions. The workshop is designed so that attendees (early/mid-career researchers, clinical researchers) will be assigned an experienced primary and secondary mentor and will receive individual feedback on their application. **– For more details.**

3rd AusCP-CTN Hot Topics in Cerebral Palsy Research Forum²⁹ – Registration OPEN!

Monday 21st – Tuesday 22nd October 2019

Held at the Monash Health Translation Precinct, Clayton, Melbourne, AusCP-CTN invites you to join us at the "Hot Topics in Cerebral Palsy Research Forum" to hear some of the work being done to improve early diagnosis and intervention for children with, or at risk of, cerebral palsy. Our invited international keynote speakers include Prof. Bernard Dan (Université libre de Bruxelles), Prof. Alistair Jan Gunn (University of Auckland), Professor Laura Bennet (The University of Auckland), and Prof. Yannick Bleyenheuft (Université catholique de Louvain).

The two-day Forum focuses on themes including neuroprotection, early detection of cerebral palsy, epidemiology, evidence-based interventions for cerebral palsy, and also a PhD Student 3-Minute Thesis session. **– Preliminary Program Available.**

²⁶ 2019 Systematic Review Workshop: <https://cre-auscpcntrn.centre.uq.edu.au/event/777/systematic-review-workshop-2019>

²⁷ 1-Day GRADE Analysis Workshop: <https://bit.ly/30q7cJg>

²⁸ Grant Writing Workshop: <https://cre-auscpcntrn.centre.uq.edu.au/event/811/grantwritingworkshop>

²⁹ 2019 AusCP-CTN Hot Topics in CP: <https://cre-auscpcntrn.centre.uq.edu.au/2019-AusCPCTN-HotTopics>

Hand Assessment for Infants Training – Melbourne – Registrations OPEN!³⁰

Monday 28th - Tuesday 29th October 2019

HAI is a research analysed and score-able early upper limb assessment for infants 3-15 months whom are at risk of hemiplegia or unilateral CP. The two-day course will be held at The Larwill Studio (48 Flemington Road, Parkville, Melbourne); Registration fee is \$800 and will be conducted by Dr Sue Greaves and Danni Cemterone. - [For more information](#).

General Movements Training – Melbourne & Sydney – Registrations OPEN!

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 **Basic GMs Course** provides an introduction to Prechtl'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. The **Advanced GMs Course** will provide additional intensive training in correct judgement. This training will deal with the details of the assessment, the proper terminology and techniques, as well as with the application of individual developmental trajectories. 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. Participants should bring one case study. These courses fulfill the standards specified by the GM-Trust³¹.

Melbourne³²: *Wednesday 23rd – Saturday 26th October 2019 – Basic and Advanced Courses*
Instructors: Prof. Arie Bos, MD PhD (Advanced); A/Prof. Alicia Spittle, PhD (Basic)
Cost: \$1,500 + GST - [For more information](#).

Sydney³³: *Wednesday 30th October – Saturday 2nd November 2019 -*
Instructors: Prof. Arie Bos, MD PhD (Advanced); A/Prof. Alicia Spittle, PhD (Basic)
Cost: \$1,650 - [For more information](#).

Hammersmith Infant Neurological Examination (HINE) Training

The Aus-CP-CTN network is supporting training in the HINE, a standardised and scoreable clinical neurological examination that can be used to assess infants from 2-24 months of age which is 80% accurate to detect infants at high risk of Cerebral Palsy. For more information about upcoming [HINE Trainings](#)³⁴.

³⁰ HAI Training 2019: <https://cre-auscpcntrn.centre.uq.edu.au/event/787/hand-assessment-infants-hai-training-melbourne>

³¹ GM-Trust: www.general-movements-trust.info.

³² 2019 GM – Melbourne: <https://www.trybooking.com/book/event?eid=490045>

³³ 2019 GM – Sydney: <https://www.eventbrite.com.au/e/basic-prechtl-s-method-of-the-qualitative-assessment-of-general-movements-tickets-59871295657>

³⁴ HINE 2019: <https://cre-auscpcntrn.centre.uq.edu.au/education/HINE%20Training>

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