December 2018



CREATE CHANGE

Bi-annual Research Update







Director's Message

Dear Families and Collaborators,

2018 has been a fast-paced year for the Queensland Cerebral Palsy and Rehabilitation Research Centre, where our focus has been on implementing the second year of two major research programs – the Advance Queensland Innovation Partnership (AQIP) Program and the Australasian Cerebral Palsy Clinical Trials Network Centre for Research Excellence (AusCP-CTN CRE). Funded by the Queensland Government, and National Health and Medical Research Council respectively, 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. The most exciting news from the AusCP-CTN is the latest report from the Australian Cerebral Palsy Register that highlights a reduction in the rate of CP by 30% from 1 in 500 infants to 1 in 700 infants.

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 keep our eye on the ball and notch up some impressive achievements since our last newsletter. In early November, we partnered with the Cerebral Palsy Alliance to bring together parents, researchers and clinicians at our annual Education week, made possible under the AusCP-CTN umbrella.

Our training achievements have also been enormous throughout 2018, thanks to AQIP and AusCP-CTN funding. The Network delivered basic General Movements Training in Auckland, Perth, Sydney and Melbourne, to 116 clinicians throughout Australia and New Zealand and put a further 25 clinicians through the Advanced course. The national HINE trainers delivered Hammersmith Infant Neurological Examination (HINE) training to more than 630 clinicians throughout Australia and New Zealand. The HINE is another early detection tool for CP that is used to assess infants at risk of CP from 2-24 months of age. This national implementation of 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.

Through the AusCP-CTN CRE, we also helped support the research skills of clinicians and researchers through our systematic review and intensive grant writing courses. Training was conducted in Brisbane and across 3 continents to help attendees to develop skills in research design, critical analysis of literature, publishing papers in peer reviewed journals, and knowledge in the science and theories underpinning health care and clinical practices. We were honoured to have the CEO of the NHMRC Anne Kelso visit our intensive grant writing course conducted at Curtin University in Perth in July.

Finally, I was very proud to be awarded the Mentorship award at the American Academy for Cerebral Palsy and Developmental Medicine in Cincinnati, Ohio in October this year. The award recognised that I have spent my career mentoring tens of Honours, Masters and PhD students to begin their research careers.

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

With Warm Regards,

Prof. Ros Boyd Scientific Director Queensland Cerebral Palsy & Rehabilitation Research Centre



Feature Stories

AusCP-CTN Education Week 2018 in Sydney

From 1st to 6th November 2018, the Australasian Cerebral Palsy Clinical Trials Network (AusCP-CTN) welcomed over 150 researchers, families, medical clinicians and health professionals from all over Australia and internationally, at the annual AusCP-CTN Education Week, hosted by the Cerebral Palsy Alliance, New South Wales. The multi-event program featured:

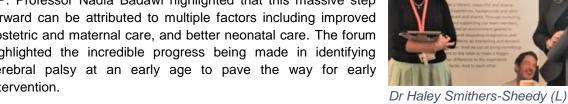
- A 'Consumer Engagement Workshop for Researchers', hosted by renowned consumer advocate Anne McKenzie AM, aimed at helping researchers to engage consumers in the research process,
- A 'Train-the-Trainer Workshop' also hosted by Anne, to help researchers understand the issues faced by parents and how to best partner with them through the research process, and
- The Hot Topics in CP Research Forum, which brought together international and local experts in CP to share the latest research outputs with a packed audience of more than 100 medical clinicians, allied health professionals, researchers, and families from all over Australia and overseas.

The research forum featured presentations from leading researchers and clinicians in the field of neurology and disability in children, showcasing the work being done to improve early diagnosis and intervention for children with, or at risk of, cerebral palsy.

Professor Steven Miller (Head of Neurology, The Hospital for Sick Children, Toronto) was featured as the keynote speaker for the forum. Prof. Miller highlighted the power of using advanced imaging technology to examine brain development that occurs in babies born preterm throughout their medical care in a NICU, where preterm birth remains a leading cause of childhood and lifelong disability.

The program was very well received by our audiences, in particular presentation from Hiam Sakakini (Board Member, Cerebral Palsy Alliance). As a parent with a child with CP, Hiam shared her personal experiences and views on the importance of early detection and 'evidence-based' trials. She highlighted the importance of advocating for transparent communication and collaboration across the board (clinical, research, community) for better patient care.

A major highlight of the forum was an update from the Australian Cerebral Palsy Register by Drs Sarah McIntyre and Hayley Smithers-Sheedy. The ACPR report¹ that was launched in December, 2018 has reported a 30% reduction in the rate of Cerebral Palsy from 1 in 500 children to 1 in 700 children born with CP. Professor Nadia Badawi highlighted that this massive step forward can be attributed to multiple factors including improved obstetric and maternal care, and better neonatal care. The forum highlighted the incredible progress being made in identifying cerebral palsy at an early age to pave the way for early intervention.



For more information: 2018 AusCP-CTN Education Week².

Dr Haley Smithers-Sheedy (L) and Prof. Iona Novak, Cerebral Palsy Alliance.

CELEBRATING OUR

DIFFERENCES

QEDIN: The Queensland Early Detection and Early Intervention Network

The Advancing CP in Queensland program has implemented the new Queensland Early Detection and Intervention Network³ (QEDIN) across Queensland. Ethics approval has been achieved for recruitment of clinicians and referral of infants for screening at risk of Cerebral Palsy status from 9 out of 17 Hospital and Health Services across Queensland by our research co-ordinator for Infant Studies Dr Tracey Evans. The network has already trained > 200 clinicians in standardised assessments for the early detection of CP by conducting 4-hour practical courses on the Hammersmith Infant Neurological Assessment (HINE), and further

¹ ACPR Report Full Version: https://qcprrc.centre.uq.edu.au/article/2018/12/qcprrc-bi-annual-research-update-december

² 2018 AusCP-CTN Education Week: https://cre-auscpctn.centre.uq.edu.au/event/720/2018-auscp-ctn-education-week-2018-1st-6thnovember-allambie-heights-sydney-hosted-cerebral-palsy-alliance

³ QEDIN: https://qcprrc.centre.uq.edu.au/article/2018/08/qedin-cp-queensland-early-detection-and-early-intervention-network



General Movements Training will be 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 12 HINE courses for >200 clinicians 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).

Hot Topics in Muscle Research Symposium

As part of the educational program for the Australasian Cerebral Palsy Clinical Trials Network (AusCP-CTN), a one-day symposium on muscle and biomechanical research in cerebral palsy was held on the 30th Friday November 2018, at the Centre for Children's Health Research in Brisbane.

Our featured international keynote is a world renowned leader in biomechanics and orthopaedic surgery research, Prof. Rick Lieber from the Shirley Ryan Ability Laboratory, Northwestern University in Chicago. Prof. Lieber's seminar focused on his current research effort in developing state-of-the-art approaches to understanding muscle contractures that result from cerebral palsy, stroke and spinal cord injury. National invited speakers for the symposium included Prof. David Lloyd and Dr Christopher Carty (Griffith University), A/Prof. Glen Lichtwark and Prof. Andy Cresswell



Invited speakers for the AusCP-CTN Hot Topics in Muscle Research Forum, 30th November 2018.

(The University of Queensland), Dr Lee Barber (Central Queensland University), A/Prof Jane Valentine (UWA) and Prof. Susan Stott (The University of Auckland).

For more information: Hot Topics in Muscle Research Symposium⁴.

Studies currently recruiting

Early Detection & Early Intervention Studies:

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

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 Australia. Thirty-two Infants with a diagnosis of CP or diagnosis of 'high risk of



VISIBLE Trainers, Federica D'Acunto, Adina Bancale, A/Prof. Andrea Guzzetta (L-R).

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

 $^{^{4} \ \}text{Hot Topics in Muscle Research Forum:} \ \underline{\text{https://qcprrc.centre.uq.edu.au/event/356/hot-topics-cerebral-palsy-muscle-research-forum} \\$



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.

VISIBLE therapists from across Australia undertook the intervention training in Brisbane in October delivered by A/Prof. Andrea Guzzetta and his team from the SMILE lab in Pisa. The study has ethics approval and will commence recruitment in south east Queensland, Townsville and Cairns in early 2019.

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.

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 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 three centres, the Royal Brisbane and Women's Hospital (RBWH), Mater Mothers' Hospital (MMH) and the Queensland Children's Hospital (QCH). Recruitment is ready to commence at the RBWH now with the MMH and QCH to start early in 2019.

Contact Details: Dr Tracey Evans, NEBO Clinical Research Coordinator, (07) 3069 7365, QCPRRC@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.

Wearable Sensors: Study of Infant General Movements

A new study is using new wearable sensor technology developed by CSIRO 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 my help augment existing clinical assessments and facilitate earlier diagnosis of CP.

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.



<u>GAME</u>⁵: Harnessing Neuroplasticity to Improve Motor Performance in Infants with Cerebral Palsy: A Pragmatic Randomised Controlled Trial

This multicentre, study is recruiting infants (aged 3-6 months corrected age) from across New South Wales, Queensland, Victoria and Western Australia, and randomly assigning them 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 98 families already taking part in the study.

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 Guzetta, Dr K Prelog, Prof W Tarnow-Mordi, Prof S Rose, Ms C Galea, Ms S Clough, A/Prof R Morton, Dr A Tran.

REACH⁶: 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 coordination 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. REACH is continuing recruitment in QLD, NSW, VIC and WA with 59 families already taking part in the study. Three new teams in the USA in Minnesota, Ohio and Riverside County in the US have been trained on the REACH protocol and certified in the Hand Assessment of Infants ready to commence recruitment to expand the study internationally. Families are recruited between 3 to 9 months C.A. and continue in the study until they complete the follow-up assessments at 24 months corrected age. Forty-two of the study children have already completed their 12 months assessments, with 18 of these having also completed assessments at 24 months corrected age.

Contact Details: Dr Tracey Evans, REACH Clinical Research Coordinator, (07) 3069 7365, QCPRRC@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.

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

Child Studies:

Participate-CP⁷, 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

⁵ GAME study: https://cre-auscpctn.centre.uq.edu.au/project/game

⁶ REACH study: https://qcprrc.centre.uq.edu.au/reach

⁷ Participate-CP study: https://qcprrc.centre.uq.edu.au/participate-cp



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.

In late August we hosted therapists from Sydney, Cairns and Perth for the first ever training session in Participate-CP. The program was kicked off by a day of introductory training in Motivational Interviewing (MI) by renowned and engaging Psychologist and accredited MI trainer, Dr Stan Steindl. Therapists are now ready to start recruiting children with CP aged 8-12 to participate in the study. Participate-CP is a large, multi-site study led by QCPRRC Senior Research Fellow Dr Leanne Sakzewski. The therapy was developed by Dr Sarah Reedman, Postdoctoral Research Fellow at QCPRRC and the results have now been published in Archives of Physical Medicine and Rehabilitation. We are excited to be able to bring Participate-CP to more children across Australia, including in regional settings.

Sites: Brisbane, Cairns, Sydney, NSW Regional, and Perth (+150km radius from each site).

Contact Details: Mika Shimada, Study Coordinator, (07) 3069 7356, participqte.qcprrc@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.

HABIT-ILE⁸: Randomised controlled trial of Hand Arm Bimanual Intensive Training Including Lower Extremity Training for children with bimanual cerebral palsy

First HABIT-ILE camp a success in September!

In the September school holidays, seven excited children with cerebral palsy (CP) took part in the very first HABIT-ILE research therapy camp in Australia. Days were filled with endless games, arts and crafts, dancing, running, and memorable moments of the viral song 'Baby Shark'. Participating children worked extremely hard on their chosen functional goals, supported by almost 20 qualified therapists and over 10 student volunteers across the two week school holiday program.

We are still actively recruiting children 6-16 years of age with bilateral CP (where both sides of the body are impacted, usually called 'diplegia', 'triplegia' or 'quadriplegia') for the Brisbane site. Further camps will be held during school holiday periods in April and 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 with you.

The Hand Arm Bimanual Intensive Training including Lower Extremity Training (HABIT-ILE) study is a large, multi-site study funded by the National Health and Medical Research Council of Australia and led by Chief Investigator and QCPRRC Senior Research Fellow Dr Leanne Sakzewski. 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 Neurorehabilitation, Institute of Neuroscience at UCLouvain in Belgium.



The HABIT-ILE therapy team.



Children attending the HABIT-ILE camp, parttaking in group activities.

⁸ HABIT-ILE study: https://qcprrc.centre.uq.edu.au/article/2018/08/habit-ile-randomised-controlled-trial-hand-arm-bimanual-intensive-training-including



Contact Details: For recruitment and general enquiries, contact the team at habitile.qcprrc@uq.edu.au. For scientific & media enquiries: Dr Leanne Sakzewski at I.sakzewski1@uq.edu.au; 07 3069 7345.

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.

<u>PREDICT CP</u>⁹: 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 2006-2009), are invited to take part in the PREDICT CP study at the Centre for Children's Health Research (CCHR), South Brisbane.

We have now had 70 families from all over Queensland and northern New South Wales attend the one-off comprehensive assessment. A big **THANK YOU** to all of these families for your time and support of this study. Bookings are filling up for January 2019! We look forward to making contact in the New Year with all the families who have expressed interest in being involved.



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

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.

Imagine CP: Genome and Connectome Study

The Queensland Cerebral Palsy and Rehabilitation Research Centre, in collaboration with the Queensland Brain Institute, has introduced a genetic component (Imagine CP) to the Predict CP study. The aim of Imagine CP is to identify genetic risk factors that contribute to CP, and to 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 sample from children in the Predict CP study, as well as their parents. 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 identity 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 led to personalised treatment for children with CP.

Contact Details: Dr Shaneen Leishman, Clinical 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.

⁹ PREDICT study: https://qcprrc.centre.uq.edu.au/predict-cp-0



SMART¹⁰: Strengthening Mental Abilities Through Relational Training

Nearly half of all children with Cerebral Palsy (CP) experience cognitive difficulties that can impact everyday functioning and educational 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. Recruitment has recently begun at QCPRRC for a randomised controlled trial that aims to test the effectiveness of a novel online cognitive training program for children between 8 and 12 years old with mild to moderate CP. The program, Strengthening Mental Abilities Through Relational Training (SMART) is founded upon relational frame theory. This theory 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.



All participants in the SMART study will gain access to the web-based SMART *Child using SMART* training program that can be completed from home, over lapton, PC or tablet either *program*.

training program that can be completed from home, over laptop, PC or tablet either *program*. 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, 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. Recruitment is now under way and will continue over the next 12 months. Recruitment for the SMART study commenced in July, with 10 participants for either intervention or waitlist

Who can participate?

control.

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.

Contact Details: Jane Wotherspoon, PhD student, (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.

PACT¹¹ & Early PACT¹²: 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 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 for this study. 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.

¹⁰ SMART study: https://qcprrc.centre.uq.edu.au/smart-strengthening-mental-abilities-through-relational-training

¹¹ PACT study: https://qcprrc.centre.uq.edu.au/pact-0

¹² Early PACT study: https://qcprrc.centre.uq.edu.au/early-pact-early-parenting-acceptance-and-commitment-therapy



Early PACT: adaptation of PACT for Parents of infants under 2 years old. We are excited to announce that recruitment has opened for our Early PACT study. This novel study will launch in Jan 2019. 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.

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.

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.

Studies concluded

We have concluded our FAST-CP, MIYOGA and Participate-1 studies with several new publications. Please see Publications section, or <u>past studies</u>¹³, for further details.

Our Output & Achievements

Grant & Funding Successes

PREBO-6: Prediction of childhood Brain Outcomes in infants born preterm using neonatal MRI and concurrent clinical biomarkers

This project has been funded by an NHMRC New Investigator Project Grant (\$830k).

Chief Investigators: Dr Joanne George, Dr Alex Pagnozzi, A/Prof Sam Bora

Associate Investigators: Prof Roslyn N Boyd, Prof Paul Colditz, Prof Stephen Rose, Prof Rob Ware, Dr Kerstin Pannek, Dr Jane Bursle.

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. Early identification of those at risk of adverse long-term outcomes enables initiation of targeted interventions and provision of family psychological and financial supports. The team have established an innovative, internationally 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. We were amongst the first to show that brain MRI earlier than the current clinical standard of term equivalent age, is predictive of neurodevelopmental outcomes at 1-2 years

¹³ Studies concluded: https://qcprrc.centre.uq.edu.au/past-studies



corrected age (CA). We now propose to compare 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 significance of this project is that (i) parents and caregivers will have earlier, accurate prognostic information; (ii) clinical researchers will have comprehensive tools to assist the rational development and testing of neuroprotection, neurorestoration 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.

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

NHMRC PhD Scholarship Successes:

Lynda McNamara, BSc Physiotherapy (Hons1), Senior Physiotherapist (Advanced) at the Cairns Base Hospital was awarded a prestigious NHMRC PhD scholarship to undertake her doctoral program entitled: Implementation of the early diagnosis of cerebral palsy guidelines in the Australian context: exploring the impact of online educational interventions on physician behaviour and patient outcomes. Supervisors: Prof. Iona Novak, Prof. Karen Scott, Prof. Roslyn Boyd.

Rose Gilmore, BOccThy (Hons1), BA (Music Theatre Performance), Senior Occupational Therapist at the Queensland Paediatric Rehabilitation Service at the Queensland Children's Hospital was awarded a prestigious NHMRC PhD scholarship to undertake her doctoral program entitled: Social skills training for teenagers with brain injuries: Randomised controlled trial investigating a parent assisted social skills group program. Supervisors: Dr Leanne Sakzewski (QCPRRC UQ), Prof. Jenny Ziviani (UQ).

Awards & Recognitions

American Academy of Cerebral Palsy - Mentorship Award 2018 - Prof. Roslyn Boyd

Professor Roslyn Boyd was awarded the AACPDM mentorship award for her mentorship of research in the field of Cerebral Palsy. Dr Leanne Sakzewski and Prof. Catherine Elliott nominated her for the award, which was presented at the Annual meeting in Cincinatti. Prof. Boyd has mentored over 27 PhD students with 23 completed, 2 MPhil, 2 Clinical Doctorates in Psychology, 12 Physiotherapy honours (all 1A), and 13 MBBS honours (11 as 1A, 2 as 2A Honors). Ros has had a long-standing involvement with the American AACPDM since 1997 and has served on number of committees. Members of Ros's team have been awarded the Gayle Arnold Award for best paper at the AACPDM on three occasions. Ros has also been involved in the International Cerebral Palsy



Dr Leanne Sakzewski (L) and Prof. Roslyn Boyd (R) at the AACPDM.

Conferences and has served on a number of the boards and scientific committees including the International Academies of Childhood Disability. Ros is most proud of the development of the Australasian CP Clinical Trials Network, which involves 5 sites around Australia which as really moved cerebral palsy research forward in Australasia. This network has created a framework for mentoring students and early career researchers conducting research along the pipeline from bench to bedside and then translation. One of the very exciting developments is the work in India with Dr Kath Benfer, training over 200 clinicians on early detection and implementation of a clinical trial called "Leap CP: learning through everyday activities and play" which has led to the screening of over 900 infants for risk of CP and enrolling 147 families in this novel clinical trial.

For more information: AACPDM 2018 and full presentation of the award14.

¹⁴ AACPDM Mentorship Award 2018: https://bit.ly/2PJxlrz



Two Promising Career Awards for Dr Joanne George

The Australasian Academy of Cerebral Palsy and Developmental Medicine and the American Academy of Cerebral Palsy and Developmental Medicine have both honoured Dr Joanne George 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. Working as a Senior Research Physiotherapist at QCPRRC, Jo 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.



Dr Joanne George was awarded the Promising Career Award at AusACPDM 2018.

UQ Faculty of Medicine Child Health Research Centre, Student Paper of 2018

Dr Sarah Reedman's most recent publication was awarded the UQ Children's Health Research Centre 2018 Student Paper of the Year. Sarah's research paper focuses on the efficacy of a participation-focused therapy (ParticiPAte CP) on leisure-time physical activity goal performance and satisfaction and habitual physical activity (HPA) in children with cerebral palsy (CP).

Reedman SE, Boyd RN, Trost SG, Elliott C, Sakzewski L. <u>Efficacy of participation-focused therapy on performance of physical activity participation goals and habitual physical activity in children with cerebral palsy: a randomized controlled <u>trial.</u> ¹⁵ Arch Phys Med Rehabil. 2018;accepted.</u>

Conferences & Presentations

American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) Conference 2018, Cincinnati USA

The 72nd Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM) took place 9th – 13th October 2018, at the Duke Energy Convention Center in Cincinnati, Ohio, USA. With 'Transformative Journeys' as the theme for the conference, the AACPDM aims 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. Videos of the general sessions are now available to view online¹⁶.



AACPDM Student Scholarship Recipients: Andrea Burgess and Sarah Reedman

Presentations from the team include:

Dr Sarah Reedman: What's in your toolbox? Participation-focused therapy for children with CP.

Update on evidence for interventions to improve participation in physical activities and habitual physical activity level in children with CP.

Andrea Burgess: Stability of the manual ability classification system in a longitudinal study of children with CP. **Ellen Armstrong**: The efficacy of cycling interventions to improve body functions and activities in children with CP: a systematic review and meta-analysis

Dr Katherine Benfer: Community-based early detection of infants at high risk of CP in a low-middle income country. **Dr Joanne George**: Combination of early neonatal MRI scores and clinical assessment findings determine motor outcome at 12 months corrected age in infants born very preterm.

¹⁵ Reedman *et.al*: Efficacy of participation-focused therapy on performance of physical activity participation goals and habitual physical activity in children with cerebral palsy: a randomized controlled trial.

¹⁶ AACPDM: http://www.aacpdm.org/resources/multimedia#AM-highlights



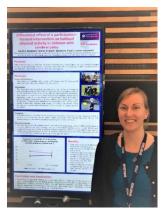
Occupational Therapy Australia – NT-QLD Regional Conference 2018 – Challenges and Choices

PhD candidate Nataya Branjerdporn was the invited Keynote Speaker for the NT-QLD Regional Conference - Challenges and Choices. Nataya's presentation 'Square Peg in a Round Hole: New approaches to old problems' highlighted her PhD experience in Kolkata, India and how she can apply her learning about harnessing the power of community members, innovating everyday resources and integrating technological developments into clinical practice here in Australia. The Conference attracted over 200 participants and the presentation received positive feedback.

More information about Nataya's presentation at <u>OT Australia – NT-QLD Regional</u> Conference 2018¹⁷.



Nataya at the OT Australia NT-Qld Regional Conference 2018.



'Movement to Move' Conference

Dr Sarah Reedman, a postdoctoral research fellow at QCPRRC, travelled to Adelaide in November 2018 to present at the Inaugural 'Movement To Move' conference. This conference was an opportunity to release the Children's Physical Activity Global Matrix 3.0 - the third generation of physical activity report cards on children's physical activity levels and sedentary behaviour. Alarmingly, only about 20% of Australian children are getting as much physical activity as they should. For this effort, Australia was graded a D- on overall physical activity levels. Sarah's research focuses on promoting participation in physical activities in children with cerebral palsy as a way to boost their levels of daily movement. Find out more about 'Movement to Move' 18.

Dr Sarah Reedman presenting at the Movement to Move conference.

Congratulations to five new PhD's conferred at QCPRRC

Congratulations to our most recent scholars, who have their PhD theses accepted and degree conferred over the last few months:

Dr Jarred Gillett in the School of Human Movement and Nutrition Sciences at The University of Queensland

Title: FAST CP: The effect of Functional Anaerobic and Strength Training on muscle properties, functional capacity, and gait in adolescents and young adults with Cerebral Palsy.

Supervisors: Dr Lee Barber, A/Prof. Glen Litchwark, Prof. Roslyn Boyd

Publications:

- 1. Gillett JG, Lichtwark GA, Boyd RN, Barber LA. Functional anaerobic and strength training in young adults with cerebral palsy. Med Sci Sports Exerc 2018;50(8):1549-57.
- 2. Gillett JG, Lichtwark GA, Boyd RN, Barber LA. Functional capacity in adults with cerebral palsy: Lower limb muscle strength matters. Arch Phys Med Rehabil 2018;99(5):900-6.

¹⁷ OT Australia NT-Qld Regional Conference 2018: http://www.otausevents.com.au/events/nt-qld-regional-conference-2018/custom-20-460edd4ac7cc4e14b59427edbc69353d.aspx

¹⁸ Movement to Move: http://www.movementtomove.com.au/



- 3. Gillett JG, Boyd RN, Carty CP, Barber LA. The impact of strength training on skeletal muscle morphology and architecture in individuals with spastic cerebral palsy: A systematic review. Res Dev Disabil 2016;56:183-96.
- 4. Gillett JG, Lichtwark GA, Boyd RN, Barber LA. FAST CP: protocol of a randomised controlled trial of the efficacy of a 12-week combined Functional Anaerobic and Strength Training programme on muscle properties and mechanical gait deficiencies in adolescents and young adults with spastic-type cerebral palsy. BMJ Open 2015;5:e008059.

Dr Sarah Reedman, Bachelor of Physiotherapy (Honours) graduated her PhD from the Faculty of Medicine at The University of Queensland on the 20th December, 2018.

Title: ParticiPAte CP: A randomised, waitlist-controlled trial of a physiotherapy and behaviour change intervention to increase physical activity through participation for children with cerebral palsy and their caregiver

Supervisors: Dr Leanne Sakzewski, Prof. Roslyn N Boyd.

Publications:

- Reedman S, Boyd RN, Sakzewski L. The efficacy of interventions to increase physical activity participation of children with cerebral palsy: a systematic review and meta-analysis. Developmental Medicine & Child Neurology. 2017;59: 1011-8.
- 2. Reedman SE, Boyd RN, Elliott C, Sakzewski L. ParticiPAte CP: a protocol of a randomised waitlist controlled trial of a motivational and behaviour change therapy intervention to increase physical activity through meaningful participation in children with cerebral palsy. BMJ Open. 2017;7.
- 3. Reedman SE, Boyd RN, Trost SG, Elliott C, Sakzewski L, Efficacy of participation-focused therapy on performance of physical activity participation goals and habitual physical activity in children with cerebral palsy: a randomized controlled trial, *Archives of Physical Medicine and Rehabilitation (2019)* doi: https://doi.org/10.1016/j.apmr.2018.11.012.

Dr Catherine Ka-Bik Mak BSc Psychology (Hons) graduated from the School of Psychology at The University of Queensland.

Thesis: MIYOGA: A randomised, waitlist-controlled trial of an embodied mindfulness program based on hatha yoga principles for children with cerebral palsy and their parents

Supervisors: Dr Koa Whittingham, Prof. Roslyn Boyd, A/Prof. Ross Cunnington.

Publications:

- 1. Mak, C., Whittingham, K., Cunnington, R., & Boyd, R. N. (2017a). Efficacy of mindfulness-based interventions for attention and executive function in children and adolescents a systematic review. Mindfulness, 9(1), 59-78.
- 2. Mak, C., Whittingham, K., Cunnington, R., & Boyd, R. N. (2017b). MiYoga: a randomised controlled trial of a mindfulness movement programme based on hatha yoga principles for children with cerebral palsy: a study protocol. BMJ Open, 7(7), e015191. 3
- 3. Mak, C., Whittingham, K., Cunnington, R., & Boyd, R. N. (2018). Effect of mindfulness yoga programme MiYoga on attention, behavioural and physical outcomes in cerebral palsy: a randomized controlled trial. Developmental Medicine and Child Neurology. Vol. 60, Issue 9:p922-932.
- 4. Mak, C., Whittingham, K., & Boyd, R. N. (2018). Experiences of children and parents in MiYoga, a mindfulness yoga program for children with cerebral palsy: A qualitative study. Complementary Therapies in Clinical Practice (accepted Dec 12th, 2018).



CREATE CHANGE

Dr Annice Kong BSc (Hons) was conferred for her PhD thesis in the Faculty of Medicine at The University of Queensland.

Thesis: Brain structure assessed using diffusion MRI and function assessed using quantitative EEG in very preterm infants and the ability to predict neurodevelopmental outcomes

Supervisors: Prof. Paul Colditz, Dr Simon Finnigan, Prof. Roslyn Boyd and Prof. Stephen Rose.



Publications:

- 1. Kong AHT, Lai MM, Finnigan S, Ware RS, Boyd RN, Colditz PB. Background EEG features and prediction of cognitive outcomes in very preterm infants: A systematic review. Early Human Development 2018; 127: 74. incorporated into Chapter 1.
- 2. George JM, Boyd RN, Colditz PB, Rose SE, Pannek K, Fripp J, Lingwood BE, Lai MM, Kong AH, Ware RS, Coulthard A, Finn CM, Bandaranayake SE. PPREMO: a prospective cohort study of preterm infant brain structure and function to predict neurodevelopmental outcome. BMC Pediatr 2015; 15:123. incorporated into Chapter 2
- 3. Kong AHT, Finnigan S, Pannek K, Fripp J, Ware RS, George JM, Rose SE, Boyd RN, Colditz PB. Brain connectivity and cognitive outcome in very preterm infants. Submitted to Clinical Neurophysiology. incorporated into Chapter 5.

Dr Olga LaPorta Hoyos graduated her PhD in the Doctoral Program in Medical Research and Translational Medicine at the University of Barcelona.

Thesis: Neuroimaging and Executive Function in Dyskinetic Cerebral Palsy.

Publications:

 Laporta-Hoyos, O., Ballester-Plané, J., Póo, P., Macaya, A., Meléndez-Plumed, M., Vázquez, E., Delgado, I., Zubiaurre-Elorza, L., Botellero, V.L., Narberhaus, A., Toro-Tamargo, E., Segarra, D., Pueyo, R. (2017). Proxy-reported quality of life in adolescents and adults with dyskinetic cerebral palsy is associated with



Dr Olga LaPorta Hoyos, second from left with her supervisor Prof Rosa Pueyo and her readers at her thesis defence.

executive functions and cortical thickness. Quality of Life Research, 26, 1209-1222.

- 2. Laporta-Hoyos, O., Ballester-Plané, J., Leiva, D., Ribas, T., Miralbell, J., Torroja-Nualart, C., Russi, M.E., Toro-Tamargo, E., Meléndez-Plumed, M., Gimeno, F., Macaya, A., Pueyo, R. Executive function and intellectual functioning in dyskinetic cerebral palsy: comparison with spastic cerebral palsy and typically developing controls. Working paper (under review in Research in Developmental Disabilities).
- 3. Laporta-Hoyos, O., Pannek, K., Ballester-Plané, J., Reid, L.B., Vázquez, E., Delgado, I., Zubiaurre-Elorza, L., Macaya, A., Póo, P., Meléndez-Plumed, M., Junqué, C., Boyd, R., Pueyo, R. (2017). White matter integrity in dyskinetic cerebral palsy: Relationship with intelligence quotient and executive function. *Neurolmage: Clinical*, *15*, 789-800.
- 4. Laporta-Hoyos, O., Fiori, S., Pannek, K., Ballester-Plané, J., Leiva, D., Reid, R.B., Pagnozzi, A.M., Vázquez, E., Delgado, I., Macaya, A., Pueyo, R., Boyd, R. (2018). Brain lesion scores obtained using a simple semi-quantitative scale from MR imaging are associated with motor function, communication and cognition in dyskinetic cerebral palsy. *NeuroImage: Clinical*, 19, 892-900.



Congratulations to Mr Julien Savina, our Research Assistant at QCPRRC who graduated in a Master of Physiotherapy and Exercise Science at the Griffith University in December 2018. Julien has been working with the QCPRRC team since 2012 on MRI scans and clinical assessments across a number of studies. In 2019 Julien will begin to practice as a Physiotherapist at a clinic on the south side of Brisbane. Julien has also recently awarded first place in the Australian Windsurf Foil Championships in Sydney for 2018.



New Key Publications from QCPRRC

Development of hand function during the first year of life in children with unilateral cerebral palsy

Leanne Sakzewski, Elisa Sicola, Cornelia H Verhage, Giuseppina Sgandurra, Ann-christin Eliasson. Developmental Medicine and Child Neurology. 2018. https://doi.org/10.1111/dmcn.14091

<u>AIM:</u> To identify developmental trajectories of hand function in infants aged 3 months to 12 months with unilateral cerebral palsy (CP).

<u>METHOD</u>: Infants at high risk of unilateral CP were recruited from 3 months of age from follow-up programmes and clinics in Sweden, the Netherlands, Italy, and Australia. Measurements on the Hand Assessment for Infants (HAI) were completed until 12 months of age. Group-based trajectory modelling was used to identify subgroups of infants with similar trajectories of development. Multinomial logistic regression determined associations between demographic variables and trajectory membership.

<u>RESULTS:</u> Ninety-seven infants (52 males, 45 females; median gestational age 38wks [interquartile range 30–40wks]) were included. Infants were assessed between two and seven times (mean 4, SD 1.2) with a total of 387 observations. A three-group trajectory model identified a 'low-functioning group' (n=45: 46%), 'moderate-functioning group' (n=30: 31%), and 'high-functioning group' (n=22: 23%). Mean posterior probabilities (0.91–0.96) and odds of correct classification (26.3–33.2) indicated good model fit. Type of brain lesion, sex, side of hemiplegia, country, gestational age, and access to intensive intervention were not associated with group membership.

Functional Anaerobic and Strength Training in Young Adults with Cerebral Palsy

Gillet, J. G., G. A. Lichtwark, R. N. Boyd, and L. A. Barber. Medicine and Science in Sports Exercise, Vol. 50, No. 8, pp. 1549–1557, 2018. https://doi.org/10.1249/MSS.0000000000001614

<u>AIM:</u> This study aimed to investigate the efficacy of a12 wk combined functional anaerobic and strength training program on neuromuscular properties and functional capacity in young adults with spastic-type cerebral palsy. <u>METHOD:</u> A total of 17 young adults (21 T 4 yr, 9 males, Gross Motor Function Classification System I = 11 and II = 6) were randomized to 12 wk, 3 sessions per week, of high-intensity functional anaerobic and progressive resistance training of the lower limbs (n = 8), or a waitlist control group (n = 9). Pre- and post-training plantarflexor and tibialis anterior muscle volumes and composition, passive and active plantarflexor muscle properties, and functional capacity outcomes were assessed.

<u>RESULTS:</u> The training group had higher values compared with the control group (adjusted mean difference) at 12 wk for the following: more- and less-impaired total plantarflexor and tibialis anterior muscle volumes, maximum isometric plantarflexion strength, muscle power sprint test peak power, agility shuttle time, composite functional strength score, and 6-min walk test distance. The change in total plantarflexor muscle volume was associated with the change in plantar flexor muscle strength. There were relationships between the change in plantarflexor muscle strength and the change in functional capacity outcomes (functional strength; 6-min walk test).



Efficacy of participation-focused therapy on performance of physical activity participation goals and habitual physical activity in children with cerebral palsy: a randomized controlled trial

Reedman SE, Boyd RN, Trost SG, Elliott C, Sakzewski L, Archives of Physical Medicine and Rehabilitation (2019), doi: https://doi.org/10.1016/j.apmr.2018.11.012

<u>AIM:</u> To determine the efficacy of a participation-focused therapy (ParticiPAte CP) on leisure-time physical activity goal performance and satisfaction and habitual physical activity (HPA) in children with CP.

METHOD: Randomized waitlist-controlled trial. Setting: Home and community. Participants: Thirty-seven children Gross Motor Function Classification System (GMFCS) I-III were recruited (18 males, mean age 10y 0mo [SD 1y 5mo]) from a population-based register. Interventions: Participants were randomized to ParticiPAte CP (an 8-week goal-directed, individualized, participation-focused therapy delivered by a physical therapist) or waitlist usual care. Main Outcome Measures: The primary outcome was Canadian Occupational Performance Measure (COPM). Accelerometers were worn for objective measurement of HPA (min-day-1 moderate to vigorous physical activity, MVPA, and sedentary time). Barriers to participation, community participation, and quality of life outcomes were also collected. Data were analysed by intention-to-treat using generalized estimating equations.

RESULTS: ParticiPAte CP led to significant improvements in goal performance (MD=3.58, 95% CI=2.19 to 4.97, p<0.001), satisfaction (MD=1.87, 95% CI=0.37 to 3.36, p=0.014), and barriers to participation (MD=26.39, 95% CI=6.13 to 46.67, p=0.011) compared with usual care at eight weeks. There were no between group differences on min-day-1 MVPA at eight weeks (MD=1.17, 95% CI=-13.27 to 15.61, p=0.874). There was a significant difference in response to intervention between participants who were versus were not meeting HPA guidelines at baseline (MD=15.85, 95% CI=3.80 to 27.89, p<0.0061). Following ParticiPAte CP, low active participants had increased average MVPA by 5.98 (SD=12.16) min-day-1.

Success from our Collaborators

RaceRunning Taking Off in Queensland

On Saturday 24 November, the sport of RaceRunning19 was brought to Queensland for the very first time! Sarah Reedman, Postdoctoral Research Fellow from QCPRRC and Emma Beckman, Senior Lecturer from the School of Human Movement and Nutrition Science welcomed over 50 people including people with disabilities, families and caregivers, and health professionals at the UQ Athletics Track. The event was sponsored by Dejay Medical (who are the sole suppliers of RaceRunning bikes in Australia) and was supported by Disability Sports Australia.

RaceRunning is a new sport for people with CP and similar disabilities. It involves an athlete racing a running bike on an athletics track against other athletes. Running bikes are similar to a tricycle without pedals. RaceRunners allow athletes to experience significant running speed, which can otherwise be impossible. RaceRunning and running bikes were invented by Connie Hansen, a para-athlete and Occupational Therapist from Denmark. Connie recognised the benefits that upright, weight-bearing exercise could have for people with moderate-to-severe mobility impairments. These benefits include increased physical activity, reduced pain, increased sensory and perceptual development and increased wellbeing. RaceRunning is most suitable to people with cerebral palsy at GMFCS levels II, III and IV. Some athletes at GMFCS V may be able to participate if they can maintain some head control in a prone position when their body is supported.

If you are interested in getting involved in RaceRunning, please contact Dr Sarah Reedman, s.reedman@uq.edu.au, (07) 3069 7336.



Participant enjoying a day out at RaceRunning.

¹⁹ RaceRunning: http://www.racerunning.org/FrontPage/?id=15



Opening of the KidStim Lab at Child Health Research Centre, The University of Queensland

The KidStim Lab, as part of the <u>Acquired Brain Injury in Children (ABiC)</u>²⁰ at The University of Queensland's Child Health Research Centre, is Australia's first laboratory dedicated to improving outcomes for children with brain injuries. Non-invasive brain stimulation uses magnets or tiny electrical currents can change specific regions of brain activity.

Associate Professor Karen Barlow (Dr Paul Hopkins Chair of Paediatric Rehabilitation in Acquired Brain Injury) said "children's brains responded differently to injury than adult brains. Non-invasive brain stimulation can help recovery by improving communication between brain regions that have been altered as a result of the brain injury. KidStim will extend the range of non-invasive treatment options for children with brain injuries".

KidStim Laboratory has been awarded a prestigious NHMRC Equipment grant, as well as receiving funding from The University of Queensland, the Children's Health Foundation, and the Ian Potter Foundation.

To learn more about upcoming studies in the KidStim lab or if you are interested in conducting research in the KidStim laboratory, please contact <u>uq_abic@uq.edu.au</u>.

For more information about KidStim Lab Opening²¹.



A/Prof. Karen Barlow, research lead of the ABiC (L), and Prof. Roslyn Boyd.



Dr Kartik Iyer (L) and A/Prof. Karen Barlow at the KidStim Lab.

New Team Members

The AusCP-CTN was also pleased to welcome five new PhD students in 2018, who are conducting studies in:

- Nataya Branjerdporn (The University of Queensland): Process evaluation of a community-based parent-delivered early intervention program for infants at high risk of cerebral palsy in lowresource contexts.
- Rose Gilmore (The University of Queensland): Social skills training for teenagers with acquired or congenital brain injuries. A randomised controlled trial of PEERS® social skills program.
- Lynda McNamara (The University of Sydney): Early diagnosis of cerebral palsy guideline implementation: exploring the impact of online educational interventions on physician behaviour and patient outcomes.
- Bithi Roy (The University of Sydney): Stroke in Australian Children under 2-years of age.
- Miles Seidel (The University of Queensland): The relationship between neonatal MRI measures
 of the thalamus, hippocampus, and associated white matter and neurodevelopmental outcomes
 in preterm neonates.

 $^{^{20}\,}ABiC:\,\underline{https://child-health-research.centre.uq.edu.au/acquired-brain-injury-children-abic}$

²¹ KidStim Opening – UQ News: https://child-health-research.centre.uq.edu.au/article/2018/11/australian-first-lab-improve-treatment-brain-injured-children



Upcoming events

General Movements Training Qld – Cairns & Brisbane – Registrations OPEN!22

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. The 1-day **GMs Refresher Course** will provide a 1-day additional intensive training in correct judgement. This training will deal with the details of the assessment, the proper terminology and technique as well as with the application of individual developmental trajectories. Participants should bring one case study. These courses fulfill the standards specified by the GM-Trust²³.

<u>Cairns:</u> Friday 1st March, 2019, <u>1-day GMs Refresher Course</u>

Instructor: A/Prof. Andrea Guzzetta, MD PhD

Cost: \$550 interstate/international or \$275 for Queensland clinicians*

To attend the 1-day Refresher Course, participants must have attended and passed the

Basic or Advanced GMs course.

Saturday 2nd - Tuesday 5th March (3.5 days), 2019, Basic GM's Course

Instructor: A/Prof. Andrea Guzzetta, MD PhD

Cost: \$1,650 interstate/international or \$825 for Queensland clinicians**

Brisbane: Sunday 10th – Wednesday 13th March (3.5 Days), 2019; <u>Basic and Advanced GM's Courses</u>

Instructors: A/Prof. Andrea Guzzetta, MD PhD (Advanced); A/Prof. Alicia Spittle, PhD (Basic)

Cost: \$1,650 interstate/international or \$825 for Queensland clinicians**

Hand Assessment for Infants Training – Registrations OPEN!²⁵

Monday 4th and Tuesday 5th March, 2019 at the Child Health Research Centre

The Aus-CP-CTN network is supporting training in the HAI, 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 registration fee is \$770 and will be conducted by Dr Sue Greaves and Danni Cemterone. For more information about HAI 2019.

5th Biennial Rehab for Kids Conference - Registration OPEN!²⁶

Wednesday 6th – Friday 8th March 2019

Hosted by the Queensland Paediatric Rehabilitation Service (QPRS), Queensland Children's Hospital, Brisbane; Including an Australasian-CP-Clinical Trials Network **Hot Topic's in Cerebral Palsy Symposium** on Friday 8th March, 2019 – <u>preliminary conference program</u>.

Hammersmith Infant Neurological Examination (HINE) Training

2019 Dates TBC

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 Trainings²⁷.

^{*}Supported by the Advancing CP in Queensland project (AQIP), cost for Queensland-based clinicians to undertake General Movements Trainings has been discounted as a 'Reduced-fee Scholarship'²⁴. Please contact <u>qcprrc@uq.edu.au</u> for application.

²² GMs Courses 2019 Queensland – Cairns and Brisbane – Registrations: https://qcprrc.centre.uq.edu.au/article/2018/10/general-movements-2019

²³ GM-Trust: <u>www.general-movements-trust.info</u>.

²⁴ GMs 'Reduced-fee Scholarship' Application: https://qcprrc.centre.uq.edu.au/advancing-cerebral-palsy-queensland

²⁵ HAI Training 2019: https://cre-auscpctn.centre.uq.edu.au/event/session/764

²⁶ QPRS Conference 2019 Registration: https://www.childrens.health.qld.gov.au/conference-2019-rehab-for-kids/

²⁷ HINE 2019: https://cre-auscpctn.centre.uq.edu.au/education/HINE%20Training



CREATE CHANGE

Research projects at the QCPRRC are proudly supported by:













Merchant Charitable Foundation

AusCP-CTN CRE partners:





Contact details

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CRICOS Provider Number 00025B