

Biannual Research Update





Director's Message

Dear Families and Collaborators,

The Year of 2019 has been a productive for the Queensland Cerebral Palsy and Rehabilitation Research Centre (QCPRRC), and our major programs the Advance Queensland in Cerebral Palsy and the Australasian Cerebral Palsy Clinical Trials Network (AusCP-CTN). These programs have made significant steps towards early detection of infants at high risk of cerebral palsy (CP), to fast-track them to early interventions to improve their long-term outcomes.

I have just returned from Kolkata, India, where Dr Kath Benfer led the first 'LEAP-CP Symposium: Implementation of early detection and early intervention for children at risk of Cerebral Palsy in Low-Middle Income Countries' working with SAARC countries. With fantastic support from the Cerebral Palsy Alliance and The University of Queensland International Engagement teams, an 8-day training was conducted to 36



clinicians from India, Sri Lanka, Vietnam, Bhutan, Nepal and Bangladesh. Associate Professor Andrea Guzzetta led a basic General Movements course, which 30 out of 31 participants passed the international accreditation. At the SSKM Hospital, Kolkata, Carly Luke our new PhD Scholar supported by the Cerebral Palsy Alliance delivered a HINE training course to 70 clinicians and health workers from across the five SAARC countries. We were joined by Dr Linda Lawrence from US, an expert in the assessment and intervention of children with Cerebral Visual Impairment which is very much needed with reports of >50% CVI in come local cohorts. The teams from each country worked together on developing their in-country surveillance for the earlier detection of CP and preparation for the implementation of the LEAP-CP program in their own countries.

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 across Australia and New Zealand. The final discounted training on General Movements for QLD clinicians will occur in February and March 2020 in Townsville and Brisbane, supported by our Advance Queensland program.

The AusCP-CTN CRE had a very successful Hot Topics CP Research Forum in November at the Monash Health Translation Precinct. It was attended by 180+ researchers, clinicians and consumers, with a full day on basic science with keynote presentations on neuroprotection by Professors Nadia Badawi, Euan Wallace, Alastair Gunn and Laura Bennett. Our second clinical research day focused on Clinical Trials and commenced with keynotes on neuroplasticity with Prof. Bernard Dan, Active Ingredients of Rehabilitation by Prof. Ros Boyd, A/Prof Leanne Sakzewski and an update on the HABITILE studies by Prof. Yannick Bleyenheuft.

Our team had a significant presence with free papers and workshops at the 2nd Triannual IAACD / 73rd AACPDM conference, Anaheim USA, in September 2019, with our PhD scholar Ellen Armstrong receiving the Mac Keith Press Promising Career Award. Our NHMRC funded REACH intervention trial and PREBO cohort study conclude recruitment in December 2019. Team member Dr Sarah Reedman has supported the implementation of RaceRunning for Children with CP in Australia and A/Prof. Leanne Sakzewski was promoted and received the prestigious UQ Research Excellence Award and Ramaciotti Health Investments Grant.

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: <u>r.boyd@uq.edu.au</u>



Feature

LEAP-CP Symposium: Implementation of early detection and early intervention for children at risk of Cerebral Palsy in Low-Middle Income Countries

With support from the <u>Cerebral Palsy Alliance</u>¹ and The University of Queensland 'Global Strategy and Partnerships Seed Funding Scheme', UQ's Dr Katherine Benfer and Prof. Roslyn Boyd led an 8-day education program in Kolkata, India, 28th November to 6th December 2019.

As the first conference to implement training on the early detection of CP and early intervention using the LEAP-CP program "Learning through Everyday Activities with Parents" across the SAARC (South Asian Association for Regional Cooperation) countries, the event was held in central Kolkata at the SSKM Hospital. With local coordination by Mr Asis Ghosh at the Indian Institute of Cerebral Palsy, the event attracted over 70 attendees both in person and via teleconferencing. The symposium united six SAARC nations (India, Sri Lanka, Vietnam, Bhutan, Nepal and Bangladesh) in an evidence-based early detection and early intervention program which implements the first international CPG (Novak 2017).

The conference was opened by the Director of Medical Education, Department of Health, West Bengal Government, Dr Debasis Bhattacharya and Dr Suchandra Mukherjee, Head of Neonatology at the SSKM Hospital / Postgraduate Institute of Medical education and Research in Kolkata. Dr Mukherjee reported on their extensive experience in neonatal follow-up at the SSKM hospital. Involving experts from Australia (The University of Queensland



Dr Suchandra Mukerjee, Head of Neonatology at SSKM Hospital Kolkata.



Prof. Boyd & Dr Benfer launching the LEAP-CP training at SSKM Hospital Kolkata.

and Queensland Children's Hospital), India (Indian Institute of Cerebral Palsy, Asha Bhavan Centre, Dr BC Roy Postgraduate Institute of Paediatric Sciences, Indian Institute of Technology Kharagpur, Child In Need Institute), and Italy (General Movements Trust), the symposium began with a full 3.5-day General Movements Assessments training (conducted by A/Prof. Andrea Guzzetta, GMs Trust), a Hammersmith Infant Examination Assessment training (conducted by Carly Luke, Paediatric Physiotherapist, Queensland Children's Hospital, CP Alliance PhD Scholar), and an interactive workshop on delivering 'Learning through Everyday Activities with Parents of infants with Cerebral Palsy (LEAP-CP)' program (conducted by Dr Katherine Benfer and Prof. Roslyn Boyd).

Specifically, the symposium focused on:

- Early detection using two gold standard CP screening tools (General Movements and Hammersmith Infant Neurological Examination).
- Early intervention principles and techniques for infants at high risk of CP;
- LEAP-CP program content and service delivery model, and introduction to the UQX training platform.
- Practical implementation workshops for early detection and delivering LEAP-CP.



Participants from Sri Lanka, Bhutan, India, Nepal, Bangladesh, Vietnam with Prof. Andrea Guzzetta, Prof. Ros Boyd, Dr Kath Benfer, and Carly Luke at the GMs Training for the LEAP-CP Implementation Conference in Kolkata.

• Early assessment and early intervention for infants with Cerebral Visual Impairment and CP.

We were joined by an expert in the early assessment and intervention of children with Cerebral Visual Impairment, Dr Linda Lawrence from the University of Kansas, USA. Very early detection of CVI in infants at risk of CP is a much needed area of training with reports of >50% CVI in some local cohorts. The teams from

¹ Cerebral Palsy Alliance: <u>https://cerebralpalsy.org.au/</u>





Dr Linda Lawrence (on left), Clinical Professor of Ophthalmology, University of Kansas, Chair AAPOS Pediatric Low Vision Rehabilitation Committee, Member AAO Low Vision Committee and Consultant at Kansas State School for the Blind led the CVI workshop.

each country worked together on developing an early detection strategy to reduce the age of identification of infants at risk of CP, and preparation for implementation of the LEAP-CP program in their own countries.

The symposium aimed to enhance the visibility, research collaborations and organisational partnerships of The University of Queensland in the Indian Sub-Continent, particularly in the health sector. India accounts for a large number of university enrolments (second largest after China at UQ), and the health field is experiencing significant growth.

Sponsored by both the Cerebral Palsy Alliance and The University of Queensland, the symposium offered 26 travel scholarships to encourage attendance of strategic leaders and health professionals from the SAARC countries to attend, enhancing global connections and preparing for implementation of LEAP-CP Early Detection and Intervention Programs across six countries under the banner of UQ and the CP Alliance.

About LEAP-CP²: RCT of Learning through Everyday Activities with Parents of CP

Dr Benfer is an NHMRC Early Career Fellow focusing on community-based early detection and intervention for infants at high risk of cerebral palsy in low-resource countries. 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 Asha Bhavan Centre, Dr BC Roy Postgraduate Institute of Paediatric Science, Child in Need Institute, Indian Institute of Cerebral Palsy, to implement the intervention with local communities. The LEAP-CP project has now finished data collection 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 to an RCT of LEAP-CP. The project has received funding from Dr Katherine Benfer's NHMRC Early Career Fellowship, Queensland Children's Hospital Foundation and Cerebral Palsy Alliance, which will further assist Dr Benfer in carrying out her project in rural regions of Queensland and Western Australia working with indigenous communities.



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

Contact Details: Dr Katherine Benfer, NHMRC Early Career Fellow, k.benfer@uq.edu.au.

Dr Reedman helping RaceRunners get a rolling start

Dr Sarah Reedman was recently interviewed for the Australian Physiotherapy Association monthly magazine <u>inmotion³</u> for her efforts in helping to organise the new sport of RaceRunning in Queensland.

RaceRunning is a sport designed specifically for people who are not able to run due to severe motor and coordination disabilities. First invented in Denmark in 1991 to challenge the stereotypes of what people with cerebral palsy could or should do, the RaceRunning participants uses a custom-built three-wheeled trike – with a seat and chest pad for user's upper body and weight support but no foot pedals – so the racerunner is able to propel forward using their feet and steering with hands and arms. RaceRunning is adaptive to many activities – sport, general fitness, play, family time – it is also highly beneficial to people with neurological disabilities and cerebral



R – L: Dr Sarah Reedman (QCPRRC Researcher), Richard Keith (Chairperson for RaceRunning Australia), Malcolm Davidson (Dejay Medical), working with athlete Tarsha on RaceRunning.

² LEAP-CP: <u>https://qcprrc.centre.uq.edu.au/article/2019/02/leap-cp-learning-through-everyday-activities-parents</u>

³ Australian Physiotherapy Association magazine 'inmotion': <u>https://australian.physio/inmotion</u>



palsy in building muscle growth and bone density, leading to better posture, general strength endurance, and control of trunks and limbs.

Recognising the multiple benefits of RaceRunning, Dr Sarah Reedman (The University of Queensland) was determined to promote the sport in Australia and introducing it to the community. As part of the RaceRunning Australia working group, Sarah has been collaborating with like-minded researchers, allied health clinicians, and many potential athletes, to participate in come-and-try events across New South Wales, South Australia, Queensland, Victoria and the ACT. Teaming up with another researcher from UQ, Dr Emma Beckman (Exercise Physiologist), Sarah and Emma are establishing training facilities for athletes in conjunction with The University of Queensland Athletics Club, BLK Performance Centre and Disability Sports Australia. This initiative has already successfully received \$36k seed funding from the Brisbane City Council to purchase five RaceRunning bikes that will enable people with mobility impairment to participate in RaceRunning. The initiative is seeking further sponsorship from sporting manufacturers, philanthropists and research grants with the goal to give as many people as possible access to equipment and the sport. The approach will also help them gather much needed research evidence to support funding applications to the NDIS to purchase a racerunner.

To find out more details about RaceRunning: <u>https://australian.physio/inmotion/race-running-promote-good-health</u>. Contact Dr Sarah Reedman to get involved in the initiative: <u>s.reedman@uq.edu.au</u>.

Program Update

AusCP-CTN 3rd Annual Hot Topics in CP Research Forum

The Australasian Cerebral Palsy Clinical Trials Network (AusCP-CTN CRE) held its 3rd Annual Hot Topics in Cerebral Palsy Research Forum, 21st – 22nd October 2019, at the Monash Health Translation Precinct, Victoria.

AusCP-CTN 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 CP 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).

In collaboration with colleagues from the Monash University and Monash Children's Hospital, the two-day research forum was a great success, attracting 180+ attendees (70% clinicians, 24% researchers, and 6% students). The forum included 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 GMs, and evidence-based rehabilitation.



 $3^{\rm cd}$ AusCP-CTN Hot Topics in CP Research, Monash Health Translation Precinct.

In particular, the following international invited keynote speakers were featured:

• Prof. Bernard Dan (Université libtre 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 fetal and neonatal brain injury; and

• Prof. Yannick Bleyenheuft (Université catholique de Louvain), *Intensive motor interventions for children with cerebral palsy.*

For more information and program on the 2019 AusCP-CTN Hot Topics in CP Research Forum⁴.

⁴ 3rd Annual AusCP-CTN Hot Topics in Cerebral Palsy Research Forum full program: <u>https://cre-</u>

auscpctn.centre.uq.edu.au/files/2236/2019%20AusCP-CTN%20HT%20in%20CP%20-%20digital%20Program%20-%20v1_0.pdf

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AusCP-CTN Education Program

In 2019, AusCP-CTN has supported and facilitated a wide range of interactive trainings across Australia and New Zealand, including 35+ Hammersmith Infant Neurological Examination Courses, one Hand Assessment for Infants course, an 8-week Systematic Review workshop, GRADE Analysis training, and seven General Movements Assessment Courses. The trainings and workshops had benefited over 900+ clinicians/health professionals and researchers in developing their knowledge and skills in novel paediatric neurological interventions and diagnosis. In collaboration with mentors from Monash University (A/Prof. Suzie Miller), RMIT (Prof. David Walker and A/Prof. Mary Tolcos), Prof. Roslyn Boyd has led a 3-day intensive Grant Writing Workshop which aimed at refining grant writing skills for the next generation of scientific researchers.



3rd AusCP-CTN Intensive Grant Writing course at Monash Health Translation Precinct.

Early in 2020, the AusCP-CTN will continue to partner with accredited trainers from the GMs Trust to host GM trainings in Townsville, Brisbane, and Perth. Compelling evidence is now available that qualitative assessment of General Movements (GMs) at a very early age is the best predictor for cerebral palsy. For Further information see Upcoming Events.

<u>QEDIN</u>⁵: The Queensland Early Detection and Early Intervention Network

The Advancing CP in Queensland program has implemented the <u>Queensland Early Detection and Intervention</u> <u>Network</u> (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 were successfully completed earlier in 2019. The network now has 194 registered clinicians across Queensland, with 71 infants referred since 2018. QEDIN has already trained ~500 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 (3.5 days) 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 25 HINE courses across Queensland. This has enabled infants at high risk of CP 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:

Early PACT⁶: Parenting Acceptance and Commitment Therapy of Infants Under 2 Years.

Recruitment continues for our Early Parenting Acceptance and Commitment Therapy (Early PACT) study. So far we have recruited eight families to this novel study. Early PACT was developed for parents of infants (<24 months) identified as at high risk of CP. The development of Early PACT involved interviews and feedback from families who received an early diagnosis of CP risk regarding the feasibility of the supportive Parenting Acceptance Commitment Therapy (PACT) strategies at the time of early diagnosis (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. 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

⁵ QEDIN: <u>https://qcprrc.centre.uq.edu.au/qedin-cp</u>

⁶ Early PACT study: <u>https://qcprrc.centre.uq.edu.au/project/earlypact</u>



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.

The recently completed PACT study is an RCT of an online intervention with families of children (2-10 years) 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. Early PACT is now available 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, <u>earlypact@uq.edu.au</u>. **This project is funded by the Cerebral Palsy Alliance**.

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

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

The aim of the Neonatal Encephalopathy Brain Outcomes (NEBO) study is to learn which tests (clinical and MRI) can be used in the neonatal period, to accurately identify which babies born at term with Hypoxic Ischemic Encephalopathy (HIE) may have problems later in life. The study aims to recruit 80 term born infants with HIE from the Royal Brisbane and Women's Hospital (RBWH) and the Mater Mothers' Hospital (MMH). Recruitment has commenced with 3 infants already recruited from the RBWH and 7 infants recruited from the MMH. Infants complete an MRI at baseline (1-10 days after birth) and other assessments at baseline and at 3 months-of-age including neurological, visual and a GMs Assessment. At 24 months infants complete neurological, medical, motor and cognitive assessments

Contact Details: Dr Tracey Evans, NEBO Research Coordinator, (07) 3069 7365, <u>QCPRRC@uq.edu.au</u>.

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.

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

GAME is recruiting 300 infants with a diagnosis of cerebral palsy or at high risk of cerebral palsy in New South Wales, Queensland, Victoria and Western Australia to participate in the study. Infants are randomly assigned to either a traditional passive early intervention or a weekly intervention involving active motor training, parent education and environmental enrichment. Families in the motor training group are visited weekly in their home by specially trained GAME therapists. Across the four states, 181 infants have now been recruited, 32 of those from Queensland sites (Royal Brisbane and Women's Hospital, Queensland Children's Hospital, Mater Mothers' Hospital, Sunshine Coast University Hospital and Gold Coast University Hospital). Infants are enrolled between 3-6 months corrected age and complete their final assessments at 24 months C.A. The assessments at 24 months include neurological, motor, cognitive, level of independence, quality of life and behavioural assessments.



GAME baby working with mum on training her motor function skills.

Contact Details: Dr Tracey Evans, GAME Clinical Research Coordinator, (07) 3069 7365, <u>QCPRRC@uq.edu.au</u>. **This project is funded by NHMRC Project Grant 1120031**.

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



Chief Investigators: Prof. Iona Novak, Dr Cathy Morgan, Prof. Nadia Badawi, Prof. Roslyn Boyd, Prof. Alicia Spittle, Prof. R Dale, Ms A Kirby, 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.

REACH⁸: Rehabilitation Early for children at risk of Congenital Hemiplegia

The REACH study is a multisite randomised controlled trial which directly compares two types of therapy, an intensive infant friendly one handed approach using modified Constraint Induced Movement Therapy (mCIMT) to an equally intensive two handed approach using Bimanual Therapy (BIM) in very young infants with asymmetric brain lesions. The aim is to determine whether mCIMT is more effective than BIM in improving unimanual capacity and bimanual co-ordination at 12-15 months corrected age. Minnesota and Ohio in the US have joined Queensland, New South Wales, Victoria and Western Australia in recruiting participants to the study, with Riverside County in California ready to commence recruitment early in 2020. With the addition of the new sites the number of infants participating in the study has risen to 93. As recruitment nears its completion, infants who have been referred by the end of 2019 may still be eligible to participate in the study. Outcome data will continue to be collected up until each child reaches 24 months C.A. With recruitment nearly completed the study Investigators have commenced discussions regarding a plan for publishing the results.



REACH baby working with therapist on training his hand motor function skills.

Contact Details: Dr Tracey Evans, REACH Clinical Research Coordinator, (07) 3069 7365, <u>QCPRRC@uq.edu.au</u>. This project is funded by NHMRC Project Grant 1078877.

Chief Investigators: Prof. Roslyn Boyd, Prof. Jenny 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 Natalie Maitre, Dr Jill Heathcock, Dr Bernadette Gillick, Dr Young-min. Kim.

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

The VISIBLE study is a multisite pilot randomised controlled trial feasibility and acceptability study of a 6-month early vision-awareness and parent-directed environmental enrichment program for infants with severe cerebral visual impairment and high risk of CP. Thirty-two infants will be recruited between 3 to 6 months corrected age and will be randomised into either the VISIBLE program or the Standard Care group. VISIBLE trained developmental therapists will visit VISIBLE families on a fortnightly basis to contextualise the program to the infant's natural environment. Site specific applications have continued throughout the year and infants can now be recruited from the Royal Brisbane and Women's Hospital, Queensland Children's Hospital, Sunshine Coast University Hospital, Gold Coast University Hospital, Townsville Hospital and Cairns Hospital. In Queensland, 3 infants have already been recruited to the study through neonatal follow up clinics and early detection networks. Applications are being finalised so that soon infants will be recruited from New South Wales, Victoria, Western Australia and Pisa, Italy. Participants will complete a range of assessments at enrolment and 12 months corrected age, including visual, neurological, motor and cognitive assessments. If the intervention in this pilot study is feasible, it is planned that a larger trial will be conducted.

Contact Details: Dr Tracey Evans, VISIBLE Clinical Research Coordinator, (07) 3069 7365, <u>QCPRRC@uq.edu.au</u>. **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. Cath Elliott, Prof. Glen Gole, Dr Swetha Philip, Prof. Nadia Badawi, Prof. Stephen Rose, Dr Jurgen Fripp, Dr Kerstin Pannek.

RBCC study: <u>Relationship between Brain Structure and Cerebral Visual Impairment in</u> Children with <u>Cerebral Palsy</u> - a Prospective Cross sectional Study of an Australian Cohort.

Vision is an important aspect, required not only for seeing but also for communication, navigation, understanding the surrounding environment and giving an emotional value to what is seen/appreciated. RBCC study is a study aimed to understand the visual behaviour and needs of children with an early brain injury and diagnosis of cerebral palsy (CP)/ high risk of cerebral palsy. Available literature in the scientific domain

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



indicates that nearly 70% of children with early brain injury and CP have visual problems such as problems with recognition, orientation, crowding and attention.

RBCC study is recruiting children between 3 months corrected age and ≤ 14 years of age, with a diagnosis of cerebral palsy/ high risk of cerebral and an MRI scan already been done as part of the clinical diagnosis. This study is being conducted at the Queensland Paediatric Rehabilitation Centre, Queensland Children's Hospital, Brisbane, Queensland.

Contact Details: Dr Tracey Evans, VISIBLE Clinical Research Coordinator, (07) 3069 7365, QCPRRC@uq.edu.au. This project is funded by UQ Higher Degree Research Scholarship.

Chief Investigators: Dr Swetha Philip (PhD Candidate), Prof. Roslyn Boyd, Prof. Glen Gole, and Dr Priva Edwards.

Wearable Sensors: Study of Infant General Movements

Qualitative assessments of infant spontaneous general movements can be performed to measure neurodevelopmental status and provide early insight into the presence of any abnormalities. Clinical assessments of infant movements at 12 weeks post term age are up to 98% predictive of the eventual development of cerebral palsy, but their reach is often limited to infants already identified as high-risk within the traditional healthcare system.

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 my help augment existing clinical assessments and facilitate earlier diagnosis of CP.

Recruitment of 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:

HABIT-ILE⁹: Randomised controlled trial of Hand Arm Bimanual Intensive Training Including Lower Extremity Training for children with bimanual cerebral palsy

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 A/Prof 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

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 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

⁹ HABIT-ILE: <u>https://qcprrc.centre.uq.edu.au/project/habitile</u>



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 Neurorehabilitation, Institute of Neuroscience at UC Louvain in Belgium.

Contact Details: For recruitment and general enquiries, contact the team at habitile.qcprrc@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.

The Friends Project

The Friends Project is a multi-site (Sydney and Brisbane) study for adolescents with acquired brain injuries or cerebral palsy. It aims to determine if PEERS[®] (Program for the Education in Enrichment of Relational Skills) group based social skills program improves the social competency of adolescents with brain injury. Adolescents take part in a 90 min weekly session for 14 weeks, while their caregiver attends a separate parent group design to enhance social coaching. Adolescents and their caregivers work together to complete homework tasks each week to encourage the skills they have learnt in the group to be carried over to their home, school and community.

Thirty-six adolescents were enrolled in this study with 18 randomly assigned to the intervention group, with the other group accessing their usual care until receiving PEERS[®] 3 months after the intervention group completed the program. PEERS[®] was delivered in Sydney in 2018 and in Brisbane in 2018 and 2019, with the last group finishing in December this year. This finalises the delivery of the program. Analysis of the completed outcome measures has commenced and will contribute to the research evidence for how to improve social functioning in adolescents with brain injuries. This information can help guide current clinical practice.

We would like to thank all the teenagers and parents who participated in the study, our research partners at the Queensland Paediatric Rehabilitation Service, CP Alliance and Kids Rehab at The Sydney Children's Hospitals Network, and the Motor Accident Insurance Commission for generously funding this project. We expect the results to be published in 2020-2021.

Contact Details: A/Prof. Leanne Sakzewski, Chief Investigator <u>s.sakzewski@uq.edu.au</u>; Rose Gilmore PhD Candidate, <u>rose.gilmore@uq.edu.au</u>.

This project is funded by the Motor Accident Insurance Commission.

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.

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.qcprrc@uq.edu.au.

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



This project is funded by NHMRC 1140756.

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

<u>PREBO-6</u>¹¹: 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 an 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 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.



PREBO-6 Research Champion braving her first MRI scan at HIRF.

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 Joanne George, Dr Alex Pagnozzi, A/Prof. S Bora.

<u>PREDICT CP¹²</u>: 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.



One of our PREDICT Research Champions having a DXA bone density scan to assess bone health.

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

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



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 89 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. We look forward to making contact with families in the New Year with recruitment continuing until May 2020.

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

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.

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.

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, 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 an 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, <u>j.wotherspoon@uq.edu.au</u>. 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

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

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



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 54 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 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, Research Coordinator, (07) 3069 7354, <u>QCPRRC@uq.edu.au</u>. **This project is funded by Cerebral Palsy Alliance Project Grant PG5115**.

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

Studies concluded

We have concluded our FAST-CP, MIYOGA, ACTIVATE-CP and Particpate-1 randomised clinical trials with several new publications. Please see Publications section, or <u>past studies</u>¹⁵, for further details.

Our Output & Achievements

Grant & Funding Successes

A/Prof. Leanne Sakzewski received \$150k from Ramaciotti Foundation

Associate Professor Leanne Sakzewski has been successful in receiving \$150,000 (2020 – 2022) from The Clive and Vera Ramaciotti Foundation (Ramaciotti Health Investments Grant), to boost her work on the 'Intensive rehabilitation to improve motor skills of children, aged 2 to 5 years, with bilateral cerebral palsy'.

As one of the largest private contributors to biomedical research in Australia, The Ramaciotti Foundations has awarded over \$61M to date, supporting the importance of building capacity in the Australian biomedical and heath research sector.

For more information about the project and collaboration opportunities, please contact A/Prof. Leanne Sakzewski <u>l.sakzewski1@uq.edu.au</u>.

Cerebral Palsy Alliance supporting PhD candidate in implementing LEAP-CP program with indigenous community in far north Queensland

Ms Carly Luke, Paediatric Physiotherapist at the Queensland Children's Hospital was recently awarded a PhD scholarship from the <u>Cerebral Palsy Alliance</u>¹⁶ to undertake 'A Prospective cohort study of indigenous infants at high risk of Cerebral Palsy in Far North Queensland', as part of the LEAP-CP program based at the Townsville Base Hospital. Carly will be supervised by Prof. Ros Boyd and Dr Katherine Benfer at The University of Queensland. Carly recently conducted HINE training for 70 clinicians at the SAARC conference in Kolkata at the SSKM hospital.



Carly Luke leading the HINE

training at the 2019 LEAP-CP SAARC conference.

To find out more about Carly's PhD project: <u>carly.dickinson@uq.edu.au</u>.

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 used the funding support to attend the American Academy for Cerebral Palsy and

¹⁵ Studies concluded: <u>https://qcprrc.centre.uq.edu.au/past-studies</u>

¹⁶ Cerebral Palsy Alliance: <u>https://cerebralpalsy.org.au/</u>



Developmental Medicine (AACPDM) Conference 2019, Anaheim USA. As a joint presentation with Prof. Roslyn Boyd at AACPDM, Dr Mak presented a workshop on '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, March 2019.

Achievements & Recognitions

2019 UQ Foundation Research Excellence Awards¹⁷ – A/Prof. Leanne Sakzewski

QCPRRC's A/Prof. Leanne Sakzewski was awarded for her continuous commitment and outstanding track record in investigating effective therapies for infants and children with cerebral palsy. As one of the seven 2019 UQ Research Excellence Award winners, A/Prof. Sakzewski is currently leading a number of large research grants, including two NHMRC Project Grants – HABITILE Australia and Participate-CP.

Videos on 2019 UQ Research Awards: <u>https://vimeopro.com/uq/research-week-2019</u>

Mac Keith Promising Career Award 2019 – Ellen Armstrong

QCPRRC member Ellen Armstrong was the proud winner of the 2019 Mac Keith Press Promising Career Award, which was presented at the 2019 American Academy of Cerebral Palsy and Developmental Medicine. Working as a clinical paediatric physiotherapist and a PhD Scholar at Griffith University, Ellen is recognised for her continuous effort in leading the '<u>ACTIVATE-CP18</u>: A randomised controlled trial of functional electrical stimulation powered cycling, recreational cycling and sit-to-stand transfer training for children with moderate cerebral palsy'.

UQ Research Award winners 2019, Customs House.



Ellen Armstrong – proud awardee of the Mac Keith Promising Career Award 2019 from AACPDM.

The study has been registered at

http://www.ANZCTR.org.au/ACTRN12617000644369p.aspx.

Ellen's PhD co-supervisors are Dr Sean Horan, Dr Chris Carty, Ms Megan Kentish and Prof. Ros Boyd. Ellen is the third recipient under Prof. Boyd's mentorship in receiving this prestigious award. Previous winners from QCPRRC include Dr Joanne George (2018) and Dr Lee Barber (2014).

Contact Details: Ellen Armstrong, ellen.armstrong@griffithuni.edu.au.

Conferences & Presentations

Combined 2nd IAACD and 73rd AACPDM 2019 – Anaheim, CA USA

The combined 2nd Triannual International Alliances of Academies of Childhood Disability (IAACD) and 73rd Annual American Academy of Cerebral Palsy and Developmental Medicine (AACPDM) conference took place on the 18th – 21st September 2019, at the conference centre in Anaheim, California, USA. With *'Knowledge without the Borders'* as the theme of the conference, the conference 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,



Members of the AusCP-CTN team (L – R: A/Prof. Michael Fahey, A/Prof. Andrea Guzzetta, Dr Bernadette Gillick, Prof. Iona Novak, Lynda McNamara, Dr Cathy Morgan, and Anna te Velde) presented an 'Update on the Early Detection of CP' at the conference.

¹⁷ 2019 UQ Research Excellence Awards: <u>https://medicine.uq.edu.au/article/2019/09/uq%E2%80%99s-finest-researchers-awarded</u>

¹⁸ ACTIVATE-CP: <u>https://qcprrc.centre.uq.edu.au/article/2019/07/great-brisbane-bike-ride-2019</u>



diagnosis, treatment, and technology for individuals with CP and other childhood onset disabilities.

From QCPRRC, Prof. Ros Boyd presented several workshops with colleagues from the AusCP-CTN on 'Collaboration opportunities with the Australasian CP Clinical Trials network', 'Pearls and Pitfalls of Early Upper limb rehabilitation for Infants with hemiplegia', 'Early Intervention in Low Middle Income Countries' for the Dr Kath Benfer and the LEAP-CP team, 'Use of Automated structural Imaging analysis for children with CP in the International Genomics Consortium Conference with A/Prof. Michael Fahey and Dr Alex Pagnozzi, and co-ordinated a GRADE training for the Care Pathways Committee of the AACPDM. 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' and an



Members of the LEAP-CP team (Mr Sayak Chowdhury, Prof Ros Boyd, Mr Assis Gosh) who were awarded International Travel Scholarships to attend the 2nd IAACD / 73rd AACPDM conference in Anaheim.

'Update on Early Detection for Cerebral Palsy'. The LEAP-CP team were represented by two of our Indian scholars Mr Asis Gosh and Mr Sayak Chowdhury who received international Travel Scholarships to present their work on the LEAP-CP (Kolkata) study.

More information about the <u>conference</u> and the program are now available to view online¹⁹.

New Publications from QCPRRC

Self-care and manual ability in preschool children with cerebral palsy: a longitudinal study

Andrea Burgess, Roslyn N Boyd, Jenny Ziviani, Robert Ware, Leanne Sakzewski. Developmental Medicine & Child Neurology. (2019) 61 5, 570 – 578. (DOI: 10.1111/dmcn.14049).

<u>AIM:</u> To describe longitudinal development of self-care and its relationship to manual ability in children with cerebral palsy (CP) aged 18 months to 5 years across all functional abilities.

<u>RESULTS:</u> Self-care development achieved by 60 months was negatively associated with the severity of manual ability impairment. Distinct self-care developmental trajectories were found with estimated changes in PEDI self-care scaled scores per month: 0.61 for MACS level I, 0.46 for MACS levels II, 0.31 for MACS level III, 0.16 for MACS level IV, and 0.03 for MACS level V. Children classified in MACS level V had the lowest level of self-care skills at 18 months and showed no progress in self-care development.

SMART: Randomised controlled trial of a novel online cognitive rehabilitation programme for children with cerebral palsy: a study protocol.

Jane Wotherspoon, Koa Whittingham, Roslyn Boyd. Jeannie Sheffield. BMJ OPEN. (2019) 9 6,e028505. (DOI: 10.1136/bmjopen-2018-0285050).

<u>BACKGROUND/AIM</u>: 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. This paper reports the protocol for a randomised controlled trial of a computerised cognitive training intervention based on behavioural principles: Strengthening Mental Abilities through Relational Training (SMART). The study aims to investigate SMART's effect on fluid reasoning, executive function and academic achievement in children with CP.

<u>METHODS</u>: Sixty children with mild to moderate CP (Gross Motor Function Classification Scale I–IV) aged between 8 years and 12 years will be recruited. Participants will be randomly allocated to two groups: SMART cognitive training and waitlist control. Families will access the programme at home over a 4-month period. Assessments will be administered at baseline, 20 weeks and at 40 week follow-up for retention. The primary outcome will be fluid intelligence, while academic achievement, executive function and social and emotional well-being will be secondary outcomes.

¹⁹ 2nd IAACD / 73rd AACPDM 2019: <u>https://www.aacpdm.org/meetings/2019/</u>



Protocol for a multisite randomised trial of Hand – Arm Bimanual Intensive Training Including Lower Extremity training for children with bilateral CP: HABITILE Australia

Leanne Sakzewski, Yannick Bleyenheuft, Roslyn Boyd, Iona Novak, Cath Elliott, Sarah Reedman, Cathy Morgan, Kerstin Pannek, Jurgen Fripp, Prue Golland, David Rowell, Mark Chatfield, Rob Ware. BMJ OPEN. (2019) ;9:e032194. (DOI:10.1136/bmjopen-2019-032194).

<u>BACKGROUND/AIM</u>: Children with bilateral CP often experience difficulties with posture, gross motor function and manual ability, impacting independence in daily life activities, participation and quality of life (QOL). Hand– Arm Bimanual Intensive Training Including Lower Extremity (HABIT-ILE) is a novel intensive motor intervention integrating upper and lower extremity training. This study aimed to compare HABIT-ILE to usual care in a large RCT in terms of gross motor function, manual ability, goal attainment, walking endurance, mobility, self-care and QOL. A within-trial cost–utility analysis will be conducted to synthesise costs and benefits of HABIT-ILE compared with usual care.

<u>METHODS</u>: 126 children with bilateral CP aged 6–16 years will be recruited across three sites in Australia. Children will be stratified by site and Gross Motor Function Classification System and randomised using concealed allocation to either receiving HABIT-ILE immediately or being waitlisted for 26 weeks. HABIT-ILE will be delivered in groups of 8–12 children, for 6.5 hours per day for 10 days (total 65 hours, 2 weeks). Outcomes will be assessed at baseline, immediately following intervention, and then retention of effects will be tested at 26 weeks. Primary outcomes will be the Gross Motor Function Measure and ABILHAND-Kids. Secondary outcomes will be brain structural integrity, walking endurance, bimanual hand performance, selfcare, mobility, performance and satisfaction with individualised goals, and QOL.

Experiences of children and parents in MiYoga, an embodied mindfulness yoga program for cerebral palsy

Catherine K Mak, Koa Whittingham and Roslyn N Boyd, Complementary Therapies in Clinical Practice. (2019) 34, 208-216. 208-216. (DOI: 10.1016/j.ctcp.2018.12.006)

<u>AIM:</u> A mindfulness yoga program (MiYoga) was developed and trialled with children with CP and their parents. This mixed-method study explores the experiences of children and parents who participated in MiYoga, to assess its acceptability, feasibility and implementation. Results:

<u>METHOD</u>: Of the forty-two child-parent dyads who participated in the MiYoga randomised control trial, 19 children and 22 parents were interviewed individually in a semi-structured way about their experiences of MiYoga. Participants rated their mood on a 5-point scale before and after each session and completed short questionnaires at the end of each session.

<u>RESULTS:</u> Children and parents reported improved mood after each MiYoga session. Parents reported being more aware of their thoughts and feelings and possibly became more aware of their day-to-day mindlessness. <u>CONCLUSION:</u> MiYoga significantly improved children and parents' mood. Parents reported gains in awareness as well as challenges of adhering to the home practice.



Upcoming events

General Movements Training – Townsville, Brisbane, Perth – 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 techniques as well as with the application of individual developmental trajectories. Participants should bring one case study. These courses fulfil the standards specified by the GM-Trust²⁰.

- Townsville21:Tuesday 25th February 2020 One-day Refresher
Wednesday 26th Saturday 29th February Basic and Advanced Courses
Instructors: A/Prof. Andrea Guzzetta, MD PhD
Cost: \$1,650 exc. GST For more information.
- Brisbane²²: Sunday 1st Wednesday 4th March Basic and Advanced Courses
 Instructors: A/Prof. Andrea Guzzetta, MD PhD (Advanced); Prof. Alicia Spittle, PhD (Basic)
 Cost: \$1,650 exc. GST For more information.
- Perth²³:
 Saturday 7th Tuesday 10th March Basic and Advanced Courses

 Instructors:
 Prof. Giovanni Cioni, MD PhD, and A/Prof. Andrea Guzzetta, MD PhD

 Cost:
 \$1,650 inc GST For more information.

NOTE: These are the final 50% discounted courses for our Queensland Clinicians as supported by the Advance Queensland program.

Hammersmith Infant Neurological Examination (HINE) Training - Perth

The AusCP-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.

Prior to the AusACPDM conference, HINE training will be held on the Tuesday 10th March 2020, with course instructors including A/Prof. Domenico Romeo, MD, Dr Katherine Landon, Paediatric Rehabilitation Specialist, and Dr Joanne George, Physiotherapist. The 4-hour HINE training will include lecture, instruction using videos, live cases and small group discussion.

For more information about upcoming <u>HINE Training at Perth</u> please contact Dr Lynn Jensen for registration.

Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) Conference 2020 - Perth

The 10th Biennial AusACPDM Conference will be held at the Convention & Exhibition Centre, Perth, Westen Australia, from 10th – 14th March 2020. Themed as 'Visionaries', the AusACPDM aims to embolden participants to be Visionaries in their practice and research, leading to future-focused Visionary outcomes for the children and families they work with. It is intended that the Conference will provide new insights and ways of thinking, opportunities to learn new practice and research approaches, and build opportunity for community engagement.

For registration: https://www.ausacpdm.org.au/conference/

²⁰ GM-Trust: <u>www.general-movements-trust.info</u>.

²¹ 2020 GM – Townsville: <u>https://cre-auscpctn.centre.uq.edu.au/event/817/GM2020</u>

²² 2020 GM – Brisbane: <u>https://cre-auscpctn.centre.uq.edu.au/event/817/GM2020</u>

²³ 2020 HINE – Perth: https://cre-auscpctn.centre.uq.edu.au/files/2312/HINE_Course_Flyer_Perth_2020.pdf

Research projects at the QCPRRC are proudly supported by:













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AusCP-CTN CRE partners:



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CRICOS Provider Number 00025B