# Newsletter

September 2015

### Message from the Scientific Director, Professor Roslyn Boyd

#### Dear Families and Collaborators,

The QCPRRC has moved to our exciting new location in the Centre for Children's Health Research (CCHR), next door to the new Lady Cilento Children's Hospital, the largest Paediatric facility in Australia at Southbank. Our move maintains our strong links with UQ and enables closer collaborations with our clinical researchers at Children's Health Queensland and QUT. There is a state of the art motion analysis laboratory and naturalistic observation rooms providing better facilities, with parking under the building for our families to participate in our new comprehensive surveillance project "PREDICT" where we will be inviting children back from our birth years of 2006 and 2007. Recently we welcomed two of our overseas collaborators Prof Ann Christian Eliasson and A/Prof Lena Krumlinde-Sundholm from the Karolinska Institute, Sweden to conduct international training for the commencement of our exciting new NHMRC funded multisite REACH project on early infant upper limb rehabilitation. The QCPRRC have achieved an important milestone with five of our next generation of clinical researchers completing their PhDs and progressing to new careers in Academia (Dr Laura Miller), with the Qld Chief Scientist (Dr Louise Mitchell) and to conduct work with in Africa (Dr Kath Benfer). Our NHMRC Early Career Researcher Dr Lee Barber was invited as a speaker to present his innovative work on muscle mechanics in Cerebral Palsy at the European Academy of Childhood Disability. The QCPRRC also presented our early findings on the early biomarkers for detecting CP from the PREMMO study and results of our PREMM massage study for preterm babies. I was invited to present a keynote lecture at the East European Academy of Cerebral Palsy with a public lecture to the city of Poznan, in Poland, where I highlighted the opportunities for children with CP in Australia to be active members of society, participating in CP Football, surfing, paddle-boarding and skiing. In this issue we introduce an exciting new study Participate CP which focuses on helping families of children with CP to enable their children to be more active members of society. The QCPRRC has achieved another important milestone with recommitment of our philanthropic Merchant Foundation and UQ funding for our 4<sup>th</sup> program of research, based on our successful track record of outputs, competitive national and international grants with a >3.1 return on investment. We look forward to your collaboration in new projects highlighted in this issue. With very best wishes, Ros Boyd.

## **QCPRRC** has moved!

As of August 2015, we have moved into the brand new Centre for Children's Health Research (CCHR) building, next to the Lady Cilento Children's Hospital (LCCH).

#### Our new address is:

Queensland Cerebral Palsy and Rehabilitation Research Centre (QCPRRC) Level 6 Centre for Children's Health Research 62 Graham Street South Brisbane Q 4101

Due to the move, all of our phone numbers have changed. Therefore if you are trying to get in contact with one of our team, please email



#### Congratulations to Dr Louise Mitchell and Dr Laura Miller on their PHD graduations in Dec 2014.





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## Queensland cerebral palsy & rehabilitation research centre Recent Publications

#### **Connect and Shape: A parenting meta-strategy**

Whittingham K. Journal of Contextual Behavioural Science. 2015;4(2):103-6. *Abstract online*: <u>http://www.sciencedirect.com/science/article/pii/S2212144715000162</u>

The existing parenting literature is dominated by two worldviews: the behavioral worldview and the relational/emotional worldview. Points of tension between these two worldviews result in parental confusion and professional disagreements. For example, parents may wonder how they should respond when their child is both misbehaving and distressed. In this paper, I outline a new parenting meta-strategy 'connect and shape' that combines behavioral and the relational/emotional strategies into a single parent-child interaction. The elements of connect and shape are not new. What is new is that parental responsiveness/emotion coaching and behavioral parenting strategies have been combined into a single, clearly elucidated parenting strategy.

#### Randomized comparison trial of density and context of upper limb intensive group versus individualized occupational therapy for children with unilateral cerebral palsy



Sakzewski L, Miller L, Ziviani J, Abbott DF, Rose S, Macdonell RA & Boyd RN. Developmental Medicine & Child Neurology. 2015;57(6):539-47. Abstract online: <u>http://www.ncbi.nlm.nih.gov/pubmed/25627092</u>

This paper reports the primary outcomes of our COMBiT study. This randomised controlled trial compared: (1) intensive group therapy combining constraint induced movement therapy and bimanual training delivered over 2 weeks; AND (2) weekly individual occupational therapy sessions for 6 weeks with a home program carried out over 12 weeks. Both the group and individual therapy aimed to provide 45 hours of intervention. Our key findings were: 1. Few differences in children's outcomes with the two models of therapy 2. Children who received individual therapy made greater changes 6 months following intervention than children receiving intensive group therapy in how they used their two hands together in bimanual activities. More children receiving individual therapy maintained their improvements 6 months later. 3. Children in both models of therapy improved the speed and dexterity of their impaired arm/hand and occupational performance goals. 4. About 30-40% of children made clinically meaningful changes in how they use their two hands together in bimanual activities which is less than other studies which had higher training doses of therapy. 5. 45 hours of therapy was likely not enough to lead to meaningful changes in their upper limb motor outcomes. A commentary by Ann-Christin Eliasson from Karolinska Institute suggested that children learn something when practicing hand function intensively for a short period. She suggested that children must "overlearn" (by higher-dosage training) in order to transfer the effect to their everyday lives or training must be performed in a distributed way that allows time to practice in daily life between sessions. Intensive group models of therapy may not be available for children with unilateral CP, and individual occupational therapy augmented with a goal directed home program is an equally effective alternative to achieve functional goals and improve hand function.

#### Sedentary and active time in toddlers with and without cerebral palsy

Oftedal S, Bell KL, Davies PSW, Ware RS & Boyd RN. Medicine & Science in Sports & Exercise. 2015;47(10):2076-83. *Abstract Online:* <u>http://www.ncbi.nlm.nih.gov/pubmed/26378944</u>



This paper looks at the differences in time spent sedentary and levels of habitual physical activity between children with cerebral palsy (CP) of different gross motor function capacity (GMFCS I-V) compared to children with typical development aged 18 months to three years. We compared sedentary time and habitual physical activity levels to the Australian Physical Activity guidelines which recommend children aged 1-5 years spend at least three hours in active play every day and not be sedentary for more than one hour at a time. Children who walk without aids (GMFCS I-II) and children with typical development spend on average 50% of their waking hours being sedentary, while children who walk with aids (GMFCS III) and those who are in wheelchairs (GMFCS IV-V) spend on average 60% and 70% of their waking hours sedentary respectively. Children with CP classified as GMFCS I-II children with typical development were more likely to meet the three hour play recommendation than the GMFCS III and IV-V groups. All children classified as I, II and III and those with typical development kept their sedentary periods shorter than one hour. The fact that we did not find a difference in sedentary time and habitual physical activity between children with CP more sedentary than their peers without CP. We need to identify why children with CP start spending more time sedentary as they grow older in order to help prevent this, and we also need to identify strategies to aid children classified as GMFCS III, IV and V in decreasing their sedentary time as physical activity is important for development of muscle mass and healthy bones among other health benefits.

## Achievements

# The QCPRRC team has 6 scientific posters, 8 free papers, 1 demonstration poster and 2 instructional courses accepted for the American Academy for Cerebral Palsy and Developmental Medicine meeting in Dallas, Texas in October 2015.

The program is available at: http://www.aacpdm.org/UserFiles/file/AM15-Prelim.pdf

#### Abstracts at AACPDM: Free papers

- Very early brain structure and neurological function detects brain injury in preterm infants at 30 weeks and 40 weeks postmenstrual age George J, Fripp J, Pannek K, Fiori S, Guzzetta A, Ware R, Rose S, Colditz P, Boyd RN
- Relationship between oropharyngeal dysphagia, gross motor function and day to day variation in energy intakes of preschool aged children with cerebral palsy Davenport C, Lofthouse M, Zhang J, Davies P, Weir K, Stevenson R, Boyd RN, Bell K
- Relationship between habitual physical activity and quality of life in children with cerebral palsy at aged 5 years Keawutan P, Bell K, Stevenson R, Davies P, Boyd RN
- A longitudinal study of the development of fat mass and lean mass in preschool children with cerebral palsy across the spectrum of functional capacity Oftedal S, Bell K, Boyd RN, Stevenson R, Davies P
- Longitudinal study of the tracking of physical activity level in preschool children with cerebral palsy across the spectrum of functional capacity Oftedal S, Keawutan P, Bell K, Davies P, Stevenson R, Boyd RN
- Stability of the gross motor function classification system: comparison between high and low-resource countries Benfer K, Jordan R, Bandaranayake S, Finn C, Ware R, Boyd RN
- Randomised controlled trial of a web-based multimodal training program on activity capacity and performance for children with an acquired brain injury Baque E, Barber L, Sakzewski L, Boyd RN
- Best responders following web-based therapy for children with unilateral cerebral palsy James S, Sakzewski L, Ziviani J, Boyd RN

## In addition, the team has received two nominations for best paper (Gayle G. Arnold Award) at the AACPDM international meeting.

## Very early brain structure and neurological function detects brain injury in preterm infants at 30 weeks and 40 weeks postmenstural age

#### George J, Fripp J, Pannek K, Fiori S, Guzzetta A, Ware R, Rose S, Colditz P & Boyd RN.

This paper examines the relationships between very early MRI and clinical measures of neuromotor, neurological and neurobehavioural performance at 30 and 40 weeks postmenstrual age (PMA), and then the ability of measures at 30 weeks PMA to predict outcomes at 40 weeks PMA. Modest associations were found between MRI brain structure, neurological and neurobehavioral function in preterm born infants at 30 and 40 weeks PMA. Early MRI and clinical measures at 30 weeks PMA predicted outcomes at 40 weeks PMA.



### Randomised Controlled Trial of a Web-based Multimodal Training Program on Activity Capacity and Performance for Children with an Acquired Brain Injury

#### Baque E, Barber L, Sakzewski L & Boyd RN.

Interactive computer play technologies have emerged as a new and potentially cost-effective approach for delivering intensive therapy to individuals with reduced physical capacity. Emmah's randomised controlled trial investigated the efficacy of the home-based "Move it to improve it" (Mitii<sup>™</sup>) program on gross motor capacity and performance in ambulant children aged 8-16 years with an Acquired Brain Injury (ABI). It showed that Mitii<sup>™</sup> is an effective intervention to improve overall functional strength in children with an ABI.





## **Achievements**

The QCPRRC team presented 5 abstracts at the European Academy of Childhood Disabilities (EACD) conference in Copenhagen in May 2015. Dr Lee Barber represented the QCPRRC as an invited speaker and he reports on this event:



"New ways, new moves". In the beautiful medieval city of Copenhagen the EACD 2015 Scientific Committee chose four main topics for the meeting: neuroplasticity, nutrition and exercise, cognition and technology. The jam-packed four-day scientific program delivered upto-date information to parents and paediatric specialists alike. Site visits to interdisciplinary institutions Helene Elsass Center and Troldemosen & Børneterapien demonstrated the Danish way of family centred therapy for children with disabilities and spectacular "Food for Brains" meals based on the recipes book (<u>http://foodforbrains.dk/en/</u>) were on offer. Our research featured highly in the program and was embraced with great enthusiasm by the audience. Review the program and details at <u>http://eacd2015.org/</u>.



Helene Elsass Center

#### Abstracts presented were:

- Relationship between early brain structure on MRI, white matter integrity (diffusion MRI) and neurological function at 30 weeks post menstrual age in infants born very preterm Boyd RN, George J, Fripp J, Pannek K, Chan A, Fiori S, Guzzetta A, Ware R, Rose S, Colditz P.
- Randomised controlled trial of multi-modal web based training: neuroplasticity outcomes Boyd RN, Reid L, James S, Mitchell L, Rose S.
- Randomised controlled trial of PREMM: preterm early massage therapy Lai M, D'Acunto G, Guzzetta A, Fripp J, Rose S, Ngenda N, Whittingham K, Colditz P, Boyd RN.
- Very early brain structure and neurological function detects brain injury in preterm infants at 30 weeks and 40 weeks postmenstrual age Boyd RN, George J, Fripp J, Pannek K, Fiori S, Guzzetta A, Ware R, Rose S, Colditz P.
- UPBEAT: Randomised Controlled trial of Action-Observation training for infants with asymmetric brain injury Guzzetta A, Tealdi G, Burziz V, Perez M, Findlay L, Shannon B, Ziviani J, Boyd RN.

#### **Congratulations to our recent Cerebral Palsy Alliance Grant recipients**

Parenting Acceptance and Commitment Therapy (PACT): innovative, web-based support for families of children with CP. Chief Investigators: Whittingham K, Boyd RN, Sheffield J

#### Funding \$219,000

The aim of this project is to develop and trial an accessible parenting support package grounded in Acceptance and Commitment Therapy (ACT) for families of children with cerebral palsy. We are developing the parenting support package using the edx platform, the same platform used to for Massive Open Online Courses (MOOCs); it has an e-course feel. We want honest feedback from parents in order to develop a truly useful approach that can be offered to parents across the world.

Testing novel measures of community function and participation in adults with CP. Chief Investigators: Thorpe D, Chan D, (uni of North Carolina), Boyd RN (QCPRRC), Trost S (QUT), Lichtwark G, Barber L (UQ), Bagatell N, Faldowski R. Funding \$213,000

The aims of this project are to; (1) Utilise Global Positioning system (GPS) tracking and Geographic Information System (GIS) mapping technology to measure how adults with CP are integrated into their communities by describing the locations they frequent, activities in which they participate and resources they utilise. (2) Examine the relationship between each adult's degree of community integration and individual factors of current function related to impairments and mobility, health, service provision, and employment status.



## Dr Katherine Benfer has been awarded her PhD!



Oropharyngeal dysphagia in preschool children with cerebral palsy: relationship to gross motor function, dietary intake, and nutritional status Supervisors: Professor Roslyn Boyd, Dr Kelly Weir, Professor Peter Davies

Kath's doctoral research explored the prevalence and patterns of oropharyngeal dysphagia (impaired feeding, OPD) in preschool children with cerebral palsy, according to gross motor functional severity and the relationship to dietary intake and nutritional status. Four substudies were explored: (1) the tests we use to measure oropharyngeal dysphagia; (2) the prevalence and patterns of oropharyngeal dysphagia in different subgroups; (3) changes in oropharyngeal dysphagia during a position of transitional feeding skills, and association between early OPD and later health outcomes; (4) differences in the prevalence and patterns of OPD in a low-resource country (Bangladesh). This thesis supports the proposition that OPD is present in the majority (approximately 60%) of children with CP, and across all levels of gross motor function. A greater awareness of OPD is needed, particularly in children with ambulatory CP, as it may be frequently overlooked by both parents and clinicians. This thesis has provided useful information as a basis for earlier identification of children with CP who are at risk of growth or respiratory consequences associated with OPD, as well as in planning optimal oropharyngeal sensorimotor therapies and nutritional interventions. Over the duration of her study, Kath has shared these findings in 10 published articles (2 under review) and at numerous international conferences.

## Dr Sarah James has been awarded her PhD!

# Efficacy of web-based therapy program on occupational performance in children and adolescents with unilateral cerebral palsy

Supervisors: Professor Roslyn Boyd, Professor Jenny Ziviani



Sarah completed her PhD studies within the large randomized controlled trial of "Move it to improve it" (Mitii™) under the supervision of Professor Roslyn Boyd and Professor Jenny Ziviani. Mitii™ is a web-based therapy program that involves upper limb, physical activity and cognitive activities. The study involved 102 children aged 8-16 years with cerebral palsy impacting one side of their body (unilateral cerebral palsy) from Queensland and New South Wales. Sarah's PhD focused on occupational therapy outcomes from this study. Overall, she found that children improved their activities of daily living skills, individual goals, visual perception (the way your brain makes sense of what you see), and speed of movements in their dominant hand after doing Mitii™ compared to children doing their usual care. Sarah was fortunate to present her work at a number of national and international conferences. A highlight of her candidature was obtaining a University of Queensland Graduate School International Travel Award to undertake a research visit to Holland Bloorview Kids Rehabilitation Hospital and the University of Toronto in Ontario, Canada. Sarah received the prestigious international Gayle Arnold award for her work. Sarah submitted her PhD in March 2015 and commenced work within Queensland Paediatric Rehabilitation Service at the Lady Cilento Children's Hospital in Brisbane.



## Michael Herd has submitted his PhD!

A randomised controlled trial to determine the efficacy of Baby Triple P with parents of very preterm infants on regulatory difficulties, child behaviour and parenting style

Supervisors: Dr Koa Whittingham, Prof Roslyn Boyd, Professor Matthew Sanders & Professor Paul Colditz



Michael's PhD consisted of three components – a systematic review and meta-analysis of preterm parenting interventions on later child behaviour outcomes, the development of a measure of parenting style for parents of children 12 months of age (PS-12M) and a Randomised Controlled Trial (RCT) of the Baby Triple P Program with parents of infants born <32 weeks gestation. The systematic review and meta-analysis revealed a small but significant effect for preterm parenting interventions on child behaviour and the measure of parenting style, the PS-12M, was found to have good test-retest reliability and convergent validity. The Baby Triple P intervention used in the RCT consisted of 8 sessions, 4 conducted while the parents and infants were still in the Neonatal Intensive Care Unit (NICU) and 4 follow-up telephone consultation when the parents returned home. At 6 weeks corrected-age post intervention there were less reports of regulatory difficulties by parents who completed the intervention compared to those who did not, but no difference between groups for how often regulatory difficulties occurred or parental confidence dealing with these difficulties. At 12 months corrected-age post intervention there were no differences between groups for reports of regulatory difficulties, how often they occurred or parental confidence, child behaviour or parenting style.

## Tracey Evans has submitted her PhD!

Preventing Relationship Difficulties between a mother and her very preterm infant: Implementation and evaluation of Baby Triple P for parents of a very preterm infant

Supervisors: Dr Koa Whittingham, Prof Roslyn Boyd, Professor Paul Colditz & Professor Matthew Sanders

Tracey graduated from The University of Queensland with a Bachelors Degree in Arts with Honours, and has just submitted her PhD thesis. Her research investigated the effects of Baby Triple P for parents of a very preterm infant on maternal bonding and responsiveness, and on the relationship between the mother and her very preterm infant. Tracey's research also investigated the effects of maternal self-efficacy, trauma symptoms and depression, as predictors of maternal bonding and responsiveness.



## Meet our new team members...

### Ms Kym Morris: Research Physiotherapist

Kym joined the team at QCPRRC in February 2015 and has over 30 years' experience working as a physiotherapist in developmental paediatrics within hospital and community settings. She spent 10 years working in the special care nurseries of Mater Mother's Hospital, Brisbane during which time she completed her Master of physiotherapy (by research). Kym has joined the PPREMO and PREBO studies looking at the relationship between brain structure and function of very preterm infants in predicting neurodevelopmental outcomes.





#### Ms Alana Muir: Occupational Therapist, Masters Student

Alana is an Occupational Therapist currently working part-time in the Child Development Service at the Lady Cilento Children's Hospital. She has enrolled in a Master of Philosophy through The University of Queensland. Her project examines therapist and parent/carer intervention fidelity (within the REACH study). She is supervised by Dr Leanne Sakzewski, Dr Jenny Ziviani and Prof. Ros Boyd.

## Mrs Andrea Burgess: Occupational Therapist, Masters Student

Andrea is an occupational therapist who has worked with children and their families, across a variety of different services, including community, hospital and private practice. Andrea has joined the PREDICT CP team to examine the development of self-care abilities of children with CP across all MACS levels, and to examine the relationship between bimanual upper limb performance and selfcare performance and cognition. Andrea will carry out a clinimetric review on upper limb activity measures for children with bilateral CP classified as MACS levels I to III. Andrea has enrolled in a Master of Philosophy through the University of Queensland and is supervised by Dr Leanne



### Ms Sarah Reedman: PhD Student, Physiotherapist

Sarah Reedman is a Physiotherapist who began her PhD studies with QCPRRC in January on an APA returning to the centre after a year working in rural and remote Queensland schools (Sarah completed her honours project here in December 2013). Sarah's current research is centred on the factors affecting participation and habitual physical activity in children with cerebral palsy (CP). She aims to develop and trial an intervention that can increase engagement in active sports and recreation in children with CP using a participation-focused approach. Sarah is supervised by Dr Leanne Sakzewski and Prof Ros Boyd.



#### Ms Debra Khan: Occupational Therapist, REACH Project

Debra is an Occupational Therapist who has joined us from the Queensland Paediatric Rehabilitation Service where she has worked with children with cerebral palsy for almost 5 years. She has 12 years experience working in paediatrics across a range of settings and will be joining the REACH team as a clinician who will provide intervention to children at risk of developing cerebral palsy and their caregivers.

#### Ms Felicity Read: PhD Student, Physiotherapist

Felicity's PhD will focus on clinical measures of muscle structure and function in children with Cerebral Palsy, including gait measures performed in the Queensland Children's Gait Laboratory. Felicity has been awarded an APA scholarship to undertake her PHD under the supervision of Dr Lee Barber and Prof Ros Boyd.



## Infant Study Updates

### **PPREMO: Prediction of PREterm Motor Outcomes & PREBO**

**Chief Investigators:** Ms Joanne George, Prof Roslyn Boyd, Prof Paul Colditz, A/Prof Stephen Rose, Dr Kerstin Pannek, Dr Jurgen Fripp.



PPREMO is examining the relationship between brain structure (MRI) and function (General Movements, Dubowitz, NNNS etc) of very preterm infants (born <31weeks) to predict neurodevelopmental outcomes.

• The PPREMO study has achieved our recruitment target with 120 preterm and 21 term infants recruited and enrolled in the study. Initial 30 week postmenstrual age MRI and clinical assessments have been completed, 40 week MRI and clinical assessments will be completed within the next month, 3 month follow up assessments are due to be completed by the end of September 2015, with half of the 1 year follow up assessments completed and the remainder will be completed over the next 12 months.

• As a result of PPREMO demonstrating feasibility and promising early findings, a broader research team have been successful in achieving funding to expand the current study to a multisite study (RBWH and Monash in Melbourne – the only 2 sites in Australia with an MRI compatible incubator), recruiting a further 200 preterm infants and 40 term born infants, and expanding follow up to 2 years of age. This new NHMRC funded study: PREBO – Preterm Brain Outcomes has received ethical approval and is due to start in the October.

• The PPREMO research team have recently presented early findings at the European Academy of Childhood Disability conference in Copenhagen, have had abstracts accepted at the American Academy of Cerebral Palsy and Developmental Medicine conference in October 2015, and were nominated for consideration of the Gayle Arnold Award for best paper.

• We would like to thank all of the families who have participated in this study so far, and look forward to starting the expanded study, and performing our data analysis so we can start to understand and publish our study findings.





Ms Joanne George <u>j.george2@uq.edu.au</u> Trial ID: ACTRN12613000280707



## Infant Study Updates

### **Prem Baby Triple P: Supporting Parents of Preterm Infants**

**Chief Investigators:** Prof Paul Colditz, Prof Matthew Sanders, Prof Roslyn Boyd, Dr Margo Pritchard, A/Prof Peter Gray, A/Prof Michael O'Callaghan, Prof Virginia Slaughter, Dr Koa Whittingham. (NHMRC 1024345) **PhD students:** Michael Herd, Tracey Evans, Jessica Ahern

Thanks to the generosity of the 322 families participating in the study (RBWH N = 156, Mater N = 166) we have now reached our recruitment target. With recruitment finalised the focus now shifts entirely to continuing follow-up data collection at 6 weeks, 12 months and 24 months corrected age. So far across both sites 80 families have returned for their child's 24 month neurodevelopmental assessment and completed their participation. It is a delight to have our families returning at 24 months. The growth and development from NICU to toddler is a joy to see. Follow up will continue until approximately July 2016.

A huge thank you goes to our two recruitment nurses, Karen Taylor, RBWH, and Judy Macey, Mater Mothers for their hard work over the past two plus years. We would also like to congratulate Tracey Evans, Michael Herd and their advisor, Dr Koa Whittingham on the respective submissions of their PhDs earlier this year.

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

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





### PREMM Study: PREMature infants Massage therapy

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

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

infant attachment at 12 and 24 months corrected age. The study recruitment target of 60 VPT infants was reached in February this year with TEA assessments completed in April. Preliminary data was presented at the EACD in Copenhagen, in May and AACPDMin Texas, USA in October.

For more information about the PREMM study, please contact Dr Melissa Lai E: melissa.lai@uq.edu.au





## **Child Studies Concluding**

#### **CP Child: Gross Motor and Brain Development**

**Chief Investigators:** Prof Roslyn Boyd, Dr Lynne McKinlay, Ms Megan Kentish, Ms Meredith Wynter, Ms Christine Finn, Ms Rachel Jordan (NHMRC 465128)

#### Growth, Nutrition and Physical Activity

Chief Investigators: Prof Peter Davies, Prof Roslyn Boyd, Dr Kristie Bell, Prof Richard Stevenson Ms Camilla Davenport, Ms Stina Oftedal, Ms Kelly Weir, Ms Kath Benfer, Ms Piyapa Keawutan (NHMRC 569605)

The Queensland Cerebral Palsy Child Studies are now both complete. Our sincere thanks goes to the 245 families from all over QLD who participated in these studies which ran over the last 6 years. Without your hard work and effort these studies would not have been possible!! Thanks to your help we now know a lot more about brain structure, motor development, nutrition, physical activity and growth in children with CP across the full range of abilities. These families will now be invited to return for the PREDICT study (below) at 8-9 years.

For more information, please contact Camilla Davenport, Study Co-ordinator. Ph: (07) 3069 7355 or E: <u>camilla.davenport@uq.edu.au.</u>



## **Child Study Commencing**

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

#### NHMRC Partnership Grant 1077257 - \$1,593,519

**Chief Investigators:** Prof Roslyn Boyd, Prof Peter Davies, Prof Jenny Ziviani, Prof Stewart Trost, Dr Lee Barber, Dr Robert Ware, A/Prof Stephen Rose, Dr Koa Whittingham, A/Prof Jennifer Whitty, Dr Kristie Bell **Associate Investigators:** Prof Paul Scuffham, Dr Chris Carty, A/Prof John Walsh, Ms Megan Kentish, Dr Priya Edwards, Dr Lisa Copeland, Ms Kelly Weir, Dr Leanne Sakzewski, Dr Andrea Guzzetta, Dr Denise Brookes, Prof Alan Coulthard, Dr Rebecca Pelekanos, Mr Owen Lloyd, Dr Adina Piovesana

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

In this study we are aiming to investigate the relationship between brain development and physical capacity, growth, physical activity, communication, cognition, participation and educational outcomes of children who have cerebral palsy.

In one study visit at 8-9 years of age this project will provide a comprehensive assessment of outcomes to inform the development of timely and effective interventions and predict future outcomes for children with cerebral palsy. Families from the 2009 birth year who participated in the CP child studies will be shortly invited to participate in the PREDICT study in a one-off visit over 1.5 days.

For more information, please contact the Study Coordinator. Ph: (07) 3069 7355 or E: <u>QCPRRC@uq.edu.au</u>.



## **Child Study Commencing**

### <u>REACH</u>: Randomised trial of <u>Rehabilitation very EArly in Congenital</u> <u>Hemiplegia</u>

#### NHMRC 1078877 - \$939,038

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

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

Children with congenital asymmetric brain lesions frequently develop hemiplegia with major limitations in use of their impaired hand which results in poor bimanual coordination and impacts on the performance of daily activities in home, school and community life. By 8 months corrected age (c.a.) over 70% of infants with asymmetric brain lesions already perform bimanual tasks in a maladaptive fashion, however these children are frequently not referred to or receive therapy until 12 months c.a. Currently, two very different intensive therapy approaches are used each with some evidence of improving outcomes for school-aged children. Traditional therapy adopts a bimanual approach (BIM) in which equal use of both hands is trained in bimanual tasks. More recently constraint induced movement therapy (CIMT) employs a unimanual approach whereby the unimpaired arm is constrained in a glove with intensive unimanual training of the hemiplegic arm. This randomised trial will directly compare an intensive infant friendly **ONE handed approach using modified Constraint Induced Movement Therapy (mCIMT)** to an equally intensive **TWO handed approach Bimanual Therapy (BIM)** in very young infants with asymmetric brain lesions. This is a multisite study involving Queensland, New South Wales, Victoria and Western Australia.



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

There are a variety of PhD opportunities for candidates in occupational therapy and physiotherapy linked to this research. Please contact the research team if interested.



QLD: r.boyd@uq.edu.auNSW: INovak@cerebralpalsy.org.auVIC: sue.greaves@rch.org.auWA: Catherine.Elliott@health.wa.gov.au

## **Child Study Updates**

#### MiYoga: Mindfulness Yoga for Children with Cerebral Palsy and their Caregivers

#### Ms Catherine Mak, Dr Koa Whittingham, Prof Roslyn Boyd and A/Prof Ross Cunnington

The trial of MiYoga for children with cerebral palsy is continuing into 2015. Parents and children who have participated in MiYoga so far have reported enjoying the opportunity to take part, meet other families and learn some mindfulness and yoga techniques that can be incorporated into everyday life.

Participants will be able to receive a brief neuropsychological report that outlines the child's cognitive functioning. This written report will highlight their strengths and difficulties. Along with the report there will be some general recommendations and tips on how parents can help their child develop and strengthen different cognitive abilities.

We are currently recruiting for families in the Brisbane area for the start of **our last MiYoga group starting soon in Brisbane**. If you have a child with diplegia or hemiplegia between 6 - 16 years of age and would like to be involved in this novel study, or if you would like to find out more about this project, please contact our registered psychologist, yoga teacher and study coordinator: **Catherine Mak** 

#### Ph: (07) 3069 7356

E: <u>c.mak@uq.edu.au</u> or visit our website <u>https://exp.psy.uq.edu.au/miyoga/</u>



Come and join us on our MiYoga*have been* adventures! We *busy exploring through yoga.* We have travelled into Space, visited Santa at the North Pole and we even got to meet Superman! I wonder where MiYoga will take you?



## **Child Study Updates**

### **Cerebral Palsy Muscle Research**

Dr Lee Barber, Dr Chris Carty, Dr Glen Lichtwark, Mr Jarred Gillet, Mr Steve Obst, Prof Roslyn Boyd

Individuals with cerebral palsy have muscles that have adapted and function in different ways than typically developing muscles. Our Cerebral Palsy Muscle Research group is working hard to understand how best to keep the muscles working.

We welcome Ms Felicity Read back to our group as a PhD student. She was awarded a prestigious UQ APA Scholarship to continue her studies investigating the longitudinal effects of Botulinum toxin type A on walking ability in children with CP. Felicity will be busy both in the Queensland Children's Gait Laboratory and the Lady Cilento Children's Hospital.

Mr Jarred Gillett, PhD scholar is very busy with an important study investigating the impact of combined weight training and skills training on contracture and walking function in young adults with CP. If you are a young adult with CP and would like 12 weeks of one-on-one exercise training to improve your strength and fitness please contact us.



Dr Glen Lichtwark and Ms Shari O'Brien, from the School of Human Movement Studies, The University of Queensland are continuing to recruit adults with CP for our study investigating physical activity capacity and how muscle change across the lifespan.

Dr Lee Barber was invited to the 27th annual meeting of the European Academy of Childhood Disability (EACD) in Copenhagen, Denmark to present research investigating Muscle Growth in Children with CP. Lee also spent a week at the Helene Elsass Center, Charlottenlund, Denmark, one of the leading CP research and therapy facilities internationally.





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

Dr Lee Barber. Ph: (07) 3069 7334 E: <u>l.barber@uq.edu.au</u>. Web <u>https://www.facebook.com/CPMuscleResearch</u>



### **Congratulations!**

### Dr Felicity Brown – Dean's Award

Felicity's PhD research focussed on developing an understanding of the unique parenting experiences, challenges and coping strategies of parents of children with an Acquired Brain injury (ABI). Felicity has recently been awarded an Australian Government Endeavour Queen Elizabeth II Diamond Jubilee Scholarship for 2015 to undertake postdoctoral research at Harvard University into refugee mental health in the

Research Program on Children and Global Adversity. She will explore interventions For resettled refugee youth and families and will gain experience in refugee Mental health, cross cultural psychology, and community-based research.



### Dr Henry Tsao – Dean's Commendation

Henry's research examined the integrity of white matter projections of the sensorimotor system in children with congenital hemiparesis. The work

showed that reduced integrity of these projections were associated with deficits in sensorimotor function. Henry currently work as a medical doctor at the Royal Brisbane & Women's Hospital.



#### A New Motivational Physiotherapy Program to Facilitate <u>Participation</u> in <u>Physical Activities for Kids with Cerebral Palsy</u> This new research study is coming soon

We want to know if a new, integrative approach to Physiotherapy is effective at helping kids with CP to become <u>more physically active</u>. We also want to know if this approach works because it encourages the caregiver to support their child's *autonomy*, or if it changes how children are *motivated* to engage in healthy behaviours. This research study will soon be looking for volunteers:

- Children with cerebral palsy (all motor types) born 2004-2008 who will still be enrolled in primary school in 2016
- Living within 200km of South Brisbane, Queensland; and
- The child's primary caregiver (one person who has a major 'parenting' role)

This study is *not* limited to children who can walk with or without a walker or sticks; children who *self-propel* wheelchairs will also be able to participate.



Unlike 'regular' Physiotherapy, this program will focus on many of the less visible barriers to full participation, rather than on the child's visible limitations. The Physiotherapist will work in partnership with the caregiver and their child to **set and achieve goals related to being physically active**.

If you would like more information about this upcoming study please contact Sarah Reedman (Study Physiotherapist).

Ph: (07) 3069 7336 or E: <a href="mailto:sarah.reedman@uqconnect.edu.au">sarah.reedman@uqconnect.edu.au</a>

Welcome to Isla Belle born to proud parents Adina Piovesana and Darren on 9<sup>th</sup> March weighing 3.48 kg.



### **Baby news!**

Welcome to Charlotte Eloise born to proud parents Bernadette Shannon and Philip on 3<sup>rd</sup> June, weighing 3.14 kg.



Welcome to Evelyn Rose born to proud parents Jo George and Nicholas on 7<sup>th</sup> August, weighing 3.4 kg.



## How does exercise affect your muscles?

## Help us understand how different forms of exercise impact how your muscles work.

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

If you (or someone you know) have cerebral palsy, are between the ages of **15-30 years**, and can walk independently, you could really help us. We will be conducting the study during 2014 and 2015 and the findings may help tailor future exercise programs for people with cerebral palsy. If this has sparked your interest and you would like to volunteer, or if you have further questions, please contact us and we can send you an information pack.

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

Dr Lee Barber, Queensland Cerebral Palsy and Rehabilitation Research Centre, School of Medicine, University of Queensland. Ph: (07) 3069 7334 or E: <a href="mailto:lee.barber@uq.edu.au">lee.barber@uq.edu.au</a>

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

Prof Roslyn Boyd, Queensland Cerebral Palsy and Rehabilitation Research Centre, School of Medicine, University of Queensland. Ph: (07) 3069 7372 or E: <a href="mailto:r.boyd@uq.edu.au">r.boyd@uq.edu.au</a>





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

We are investigating the factors which contribute to declines in function across the lifespan in people with Cerebral Palsy. This project aims to look at muscle degradation throughout life and its relationship to changes in physical activity levels. We will be using a questionnaire, ultrasound, functional measures, an activity monitor and strength testing equipment to look at how your muscles function and changes in your physical activity involvement.



If you have Cerebral Palsy, are between the ages of 18-65 years, and can walk (with or without a walking aid) you could really help us. We will be conducting the study during 2014 and 2015 and the findings may help your function and activity levels. If this has sparked your interest and you would like to volunteer, or if you have further questions, please contact us.

Dr Glen Lichtwark, School of Human Movement Studies, University of Queensland. Ph: (07) 3365 3401 or E: <u>g.lichtwark@uq.edu.au</u> Dr Lee Barber, Queensland Cerebral Palsy and Rehabilitation Research Centre, School of Medicine,

University of Queensland. Ph: (07) 3069 7334 or E: lee.barber@uq.edu.au

## New study commencing

### **REACH: Randomised trial of <u>R</u>ehabilitation very** <u>EA</u>rly in <u>Congenital Hemiplegia</u>.

What is this study about? This project is about children with asymmetrical brain injury where only one side of the brain is impaired or one side is significantly more impaired Than the other. These infants can have problems with the development of hand skills of the arm opposite to the side of the injury (or the more impaired side of the brain). Early treatments are recommended to improve hand and arm development.



The first one is called **infant-friendly modified Constraint-Induced Movement Therapy (mCIMT)**. A sock or fabric glove is placed on the infant's more able hand, so the child can practice movement and skills with the impaired hand and arm. mCIMT consists of daily sessions in which one of the parents plays with the infant to encourage him/her to use their impaired hand/arm to interact with toys and the parent. The second intervention is called **infant-friendly Bimanual Therapy (BIM)**. BIM also consists of daily sessions in which one of the parents plays with their infant to encourage equal use of both hands and arms.

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

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

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

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

#### **Benefits:**

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

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

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

Debra Khan (QLD REACH Occupational Therapist) Ph: 07 3069 7357 or E: <u>debra.khan@health.qld.gov.au</u> Tuesday, Wednesday, Friday Dr Leanne Sakzewski (Senior Occupational Therapist) Ph: 07 3069 7345 or E: <u>l.sakzewski1@uq.edu.au</u> Monday – Thursday





