

Update on CP Quest - 'Community and Researchers together'

CP Quest is now two years old, and we would like to thank you all for your time and expertise. This short report outlines the activities that have been completed through CP Quest.

CP Quest partners have been involved in CP Research through the following mechanisms:

Priority setting partnerships which are designed to seek information from community members about their priorities for future research.

The CP Quest Research Priorities have been developed as follows:

- A survey regarding research priorities for our CP Quest group, was developed and analysed with CP Quest partner, Natasha Garrity. These research priorities are now being advertised as priorities for our Research Foundation Grants. Thank you to the 30 people who responded. <https://research.cerebralpalsy.org.au/funding/how-to-apply/>
- Through open discussions between CP Quest partners and researchers new ideas were identified. One particular question from our chair Shannon Clough "why did one of my children have CP and the other one have autism?" developed into a PhD study for one of our researchers, Yana Wilson. Yana is now working on genetic studies in siblings with cerebral palsy and other neurodevelopmental disorders.

We encourage more discussions such as these. If you have specific research questions, please contact us.

Research Buddies have discussions with researchers about their research, provide links between a researcher and other community members, organisations or the research funder and help disseminate the results of research back to the community. Buddies meet with their researcher once or twice a year.

- Our first research buddy Rozzy Dickson is now working with Shona Goldsmith from the Research Institute for her research program on causal pathways to CP via Assistive Reproductive Technology and congenital anomalies.

We will be calling for new research buddies soon.

Reference groups bring together community members to provide advice to a specific project or program of research.

- A stem cells reference group, coordinated by Dr Megan Finch-Edmondson is now working with researchers to shape decisions about CP stem cell research priorities, specific research questions and to help design new research projects. There are currently 26 members of the group, and the first meeting was held in June this year with 7 families attending and 10 people calling in. Fiona and Natasha Garrity volunteered to be co-chairs of the reference group going forward.

This reference group needs more with CP who are interested in stem cell research for CP. If you are interested, please contact Megan: mfinch-edmondson@cerebralpalsy.org.au

Advisory groups provide advice and a community perspective at a strategic level on research programs.

- 3 CP Quest partners are part of the NSW/ACT CP Register advisory group. This group comes together twice a year to provide expert advice and expertise.
- CP Quest partners are involved in the Community and Aboriginal and Torres Strait Islander Reference Group (CARG). The CARG provides expert guidance to the ACPR Research and Policy Group. One key role of the CARG is to increase community involvement in the use and reporting of ACPR data and research. One of the members of the CARG attended the annual Australian Cerebral Palsy Register meeting to provide important family perspectives. This perspective was appreciated by all at the meeting.

Community researchers are co-investigators with researchers and help shape the research from the beginning of a project.

- Partners of CP Quest helped develop a project around people with CP and families' perceptions about genomics research in CP, bio-banking samples and international data sharing. Three CP Quest partners are investigators on this project. This study is completed and is in the write up phase now. Partners of CP Quest will be acknowledged as authors on the paper.
- A CP Quest partner is co-investigator in the Eye-Gaze study. If this paper is accepted at the European Academy of Childhood Disability (EACD), this partner has been invited to co-present the findings in a mini-symposium. Another CP Quest partner helped develop the study and gave input from an eye-gaze technology user or a parent of a user's perspective. A family assisted with creating a recruitment video.
- Three partners of CP Quest assisted with the development of a study around prevention and early detection of cerebral palsy in different sociodemographic profiles, those partners also assisted with the analysis and interpretation in writing up. They are also listed as authors on the newly published paper: Impact of social disadvantage on cerebral palsy severity. *Developmental Medicine & Child Neurology* July 2018.

"The CP Quest volunteers were invaluable in all aspects of the project; they are also listed as co-investigators on the paper we published. They were fantastic and gave me invaluable advice. They worked with me all year and I would have asked their advice, edits of article via email about once a month."

- 3 CP Quest partners are co-investigators on an Australian Catholic University project with an occupational therapy research student to find out what adolescents and parents think are the best ways of working together in CP research. We look forward to learning about these findings with partners of CP Quest.
- CP and Epilepsy Research – two CP Quest partners helped us with the proposal for a new program of research, told us what was important to focus on, and helped us refine our protocol. We are currently seeking funding for this project.
- Two members of the Stem cell reference group are Associate Investigators on grant applications for stem cell studies.

Community members on research teams help develop questionnaires, give feedback on forms and forward research on through networks.

- Feedback was given on the draft Proposal for the Consumer Network and Consumer Council for the NHMRC Centre of Research Excellence: Australasian Cerebral Palsy Clinical Trials Network (AusCP-CTN) and on the content for families on the AusCP-CTN website <https://cre-auscpctn.centre.uq.edu.au/>.
- A survey to develop and test a new way to assess visual abilities of children with CP was completed by partners and passed on through networks.
- An invitation was sent to partners asking for their help with research questions around improving physical and mental health in young people with cerebral palsy.
- Feedback was given on the Neura website <https://www.neura.edu.au>. Neuroscience Research Australia (NeuRA) is an independent, not-for-profit research institute based in Sydney. Their goal is to prevent, treat and cure brain and nervous system diseases, disorders and injuries through medical research.
- Feedback was given on articles for the CP Register Newsletter; a plain language summary
- 3 members of Stem cell reference group have provided feedback on documents for Phase 2 of the stem cell trial ethics submission.
- Partners of CP Quest have provided feedback on the Opportunities for prevention and early detection of cerebral palsy in Australian Aboriginal and Torres Strait Islander children through the examination of sociodemographic and clinical profiles study.
- Partners also gave input on the Research Foundation website's content and made suggestions to make it more family friendly and identified missed opportunities to better inform the community.

Community representatives

- Our CP Quest Chair Shannon Clough has represented the CP Community at major fundraising events for CP Research with Prof Nadia Badawi.
- Shannon is also a member of the Steering Committee shaping the Australia and New Zealand CP Strategy Consultation and Strategy. CP Quest Partners have provided feedback during community consultation and we are looking forward to sharing the strategy with everyone when it is launched.

Participation in research

- An invitation was sent to partners to participate in 2 studies around partnering with researchers and asking their opinion.
- A survey was completed by partners about how to best support parents to feed their child with CP as part of a study from the School of Nursing and Midwifery, Western Sydney University.
- An invitation was sent to partners to participate in, and a request to pass on information on 'The Friends Project' PEERS Randomised Controlled Trial. This project will finish in December.
- A survey was completed by partners on family perceptions about genomics research in CP, bio-banking and international data sharing.
- CP Quest partner completed a short survey about what areas associated with cerebral palsy in adulthood would be beneficial to include on the Research Foundation website

Inform - newsletters

- [September 2017](#)
- [February 2017](#)

Training for researchers and community members

In October last year our CP Quest group had the pleasure of inviting Anne McKenzie AM from *involving people in research* to facilitate an Introduction to Research training. A number of parents and people living with CP participated in a training session to better understand how to be involved in research and how their lived experience can improve the quality of research. Researchers from the Research Institute also spent a day with Anne to learn how to best incorporate peoples lived experience into research. Both days were extremely worthwhile and gave us a lot of food for thought for CP Quest. We have made some changes to the structure of CP Quest as a result.

We offered the same training again on Thursday 1st November 2018 at Cerebral Palsy Alliance in Allambie Heights through [AusCP CTN](#) and our invitation was very well received. Our CP Quest Partners, medical practitioners and researchers from the broader CP Community across Sydney and from interstate attended the course. We plan to run this training once a year. In addition, Anne McKenzie also spent a day training some researchers to run the course. CP Quest partner Marelle Thornton, attended this valuable 'Train the Trainer' workshop and as a result, our own CP Quest team will be able to offer training to our CP Quest partners later in 2019.

New Terms of Reference (TOR) At the end of the research training last year in October we held our last CP Quest Committee meeting and agreed that we should dissolve the committee, keep CP Quest as one big group i.e. CP Quest Partners with one chair (Mrs Shannon Clough) and one research lead (Dr Sarah McIntyre). We had to change our Terms of Reference to reflect this. We thank Anne McKenzie and former committee members for their input and suggestions, which have been incorporated into this new version. Please click on the link to open the [new TOR](#) document available on our webpage.

We would like to thank everyone involved in CP Quest and we hope to continue working together to advance and improve the quality of CP Research.

Special thanks to: Shannon Clough, Marelle Thornton, Rozzy Dickson, Natasha Garrity, Fiona Garrity, Saskia Van Otterloo, Clare Masolin, BJ Dee Price, Leanne Diviney, Sophie Marmont, Marita Morgan, Anne Masi, Gurleen Anand, Frances Pellegrini and Rene Pereksles.

We are always looking for more Research Partners. People who are interested to join this group can let us know through an Expression of Interest (small survey) - https://www.surveymonkey.com/r/CP_QUEST_Partners.

Please have a look at our updated [CP Quest page](#) on the Cerebral Palsy Alliance [Research Foundation website](#).

To give feedback on CP Quest, the CP Quest page OR the CP Research Foundation website, email us at cpquest@cerebralpalsy.org.au
