



NSW/ACT CP Register Newsletter

Welcome to our NSW/ACT CP Register Newsletter, November 2021 edition.

Our aim is to provide you with updates and news from the NSW/ACT CP Register, information on studies taking place and their findings when completed. If you have any suggestions for upcoming newsletters, please [contact us](#).

We wish you all the best for the holiday season ahead!

Sarah, Hayley, Shona, Emma, Georgie and Isabelle

I. Latest news - Hot off the press



Congratulations!

Dr. Petra Karlsson, together with colleagues from the Research Institute and an international team, have been awarded \$1.1 million to develop a world-first database of voices of children with cerebral palsy called the **MY Voice Library**. The data in MY Voice Library will help scientists and engineers create new real-time **communication solutions for children with cerebral palsy**.

Petra and her team are establishing an **Advisory panel** for the MY Voice Library Project. If you have experience of dysarthria (motor speech disorder), experience with assistive technology or databases and would like to support this work, please contact [Petra](#).



People with CP and their Family's Preferences about Genomics Research - Yana Wilson

This study captured the views of people with CP and their family, about genomics research, biobanking, and how genomic data is used and stored. Click [here](#) for a summary of these interesting results.



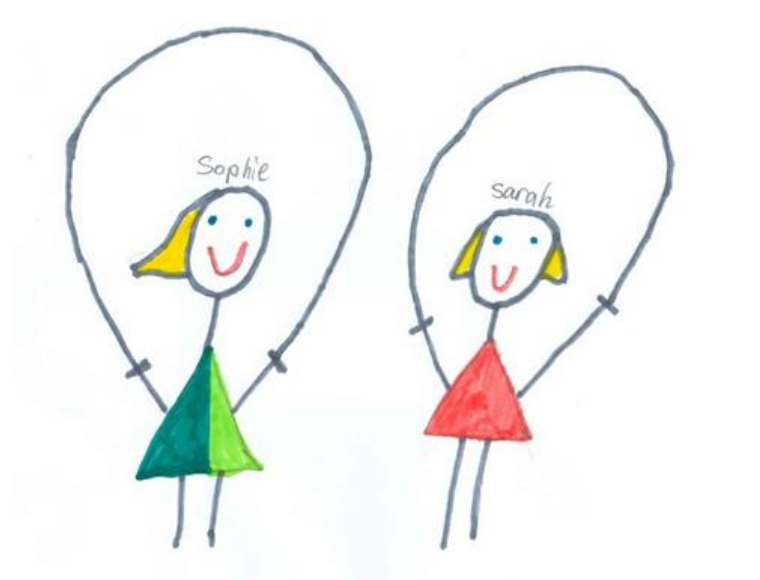
Wearable AAC technology: a novel way for communication for people with complex communication needs – Haifeng Zhao

This study showed that people hold positive attitudes to novel augmented reality based wearable communication devices. The survey results advanced the development of the next

generation of a wearable assistive communication device. A more user friendly prototype is now ready to be trialled. Contact [Haifeng](#)

II. Current Research seeking participants!

Click on the titles for more information



[ParticiPAte](#) - Do you want to try a new therapy to help your child be more physically active through sports and leisure? Contact [Emma](#)



[Selective Dorsal Rhizotomy \(SDR\)](#) - What information do you want to help you decide if a SDR surgery is right for your child? Please assist and take this online survey to develop new resources. [Survey link](#)



Neuro cCMV study - Did your child have CMV at birth? This study will identify if genetics played a role. Contact [Eloise](#) to be involved.



Mindfulness study for adults 20-40 years - Do you want to learn mindfulness-based strategies to reduce anxiety and help you feel more in control of your emotions? For more information about an online mindfulness program for adults please click [here](#).



Strength Training - Do you want to share your experiences about strength training? Please take this online survey examining the factors that help or hinder strength training for adults. [Survey link](#)



Person-first versus identity-first language - This an online survey assessing your preferences e.g. do you prefer 'a person with a disability' or 'a disabled person'? Take the [survey](#).

III. Future Projects and Events



AusACPDM/IAACD - Better together 2022 conference, 2-5 March 2022

Researchers and clinicians come together every two years to present and discuss new research, and best practice clinical care for children and adults with cerebral palsy and developmental conditions. Because of COVID the 'Better together 2022' conference will be fully virtual, and **open to everyone**. The content will be available for 3 months afterwards.

We have **20 passes available** (valued at \$165 each) for our CP Register families! The first 20 people to [email us](#) will receive a free pass.

Check out the [welcome video](#) and [program](#) overview for more information!

IV. CP Quest

Community Involvement



CP Quest connects people with CP or family members (Research Partners), and researchers so that they can work on projects together to improve cerebral palsy research.

We are committed to supporting families, community members and researchers to gain the confidence and knowledge to work together effectively. CP Quest has in previous years, facilitated **training** for researchers and community members on how to best work together to improve CP Research.

This year we are developing an **information booklet aiming to empower families and people living with CP** to be involved as a Research Partner. The brochure will be available on our [CP Quest](#) webpage in the coming weeks!



2022 Photo Exhibition Submission is open!

AusACPDM are seeking people of all ages with lived experience of childhood-onset disability to help celebrate diversity. Submit your original photographs within the themes of **Family, Fun, Fitness** or **Friends** by 21 December 2021 to have a chance to win!

Find more information [here](#).

[Download the flyer](#)

Join us!

Be involved and share your lived experience to improve cerebral palsy research. To learn more about CP Quest, how you can join, what is involved and how you can contribute please go to our [CP Quest web-page](#).

CP Research Newsletter

A weekly update on the latest prevention and intervention research on cerebral palsy, as indexed in the NCBI PubMed (Medline) and Entrez (GenBank) databases. [Subscribe here](#)

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