Welcome to our NSW/ACT CP Register Newsletter, July 2019 edition.

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

Sarah, Hayley, Shona, Katarina, Emma and Isabelle

Email CP Register staff
Rates of Cerebral Palsy in Australia have declined!

by Hannah Diviney

Hi Guys! My name’s Hannah Diviney and I’m 19 years old, living with Cerebral Palsy. I was one of the first people who signed up for the Register back in the day and it’s because of my relationship with Sarah and the team that they wanted me to be the one to tell you all about the exciting news…

According to the Australian CP Register’s latest research and report, over a 10 to 15 year period, the rates of CP have decreased by a third! see the graph below

That includes a first-time reduction in the number of full-term babies born or diagnosed in early childhood with CP, the group that makes up the largest percentage of people with CP. It also includes a substantial reduction in CP for the smallest babies – those born under 28 weeks. This is really exciting landmark research and everyone involved is rightfully incredibly proud. I can tell you as someone living with CP, that those figures and the possibilities they suggest for the future bring a huge smile to my face, as they greatly reduce the possibility of young kids having to grow up and go through what I and so many others have.
These types of results while not being able to be linked to a distinct ‘why’ are the direct payoff of the work of unsung Australian heroes across our research and medical systems. They are the men and women on the frontlines making sure that clinical care is up to date with the latest research, to ensure that pregnancy, birth and those crucial years of early childhood (where most development occurs) are as healthy as possible.

This includes more nuanced approaches to treatment of high risk pregnancy, better understanding of how to care for the tiniest and sickest babies in intensive care, the discovery of ‘cooling’ as a technique to soothe swelling and inflammation in the brain, and a diverse range of public health campaigns promoting health pregnancies, child safety and health.

So, you might be asking after all of that, what’s next? Well, there is much to be hopeful about! Across Australia and New Zealand, studies are currently running to investigate the impact of cooling and this drug called EPO on babies considered at very high risk of developing CP. The possibilities of genome work are also being explored and see the next article about the preventing viruses in pregnancy.

Now, I wouldn’t be writing this if it weren’t for the ACPR group who work so tirelessly to give us these reports. All their work and this incredibly important, hopefully globally game-changing research could not be accomplished without the generosity of you guys as funders, donors or most importantly all the families throughout Australia who are willing to let the team use our important information.

Here is Sarah and me on Studio 10 - Dr Sarah McIntyre & Hannah Diviney video link

Here is Nadia on Sky news - Prof Nadia Badawi link

The Australian Cerebral Palsy Register (ACPR) is a research database that was established in 2008. It contains de-identified information about children and adults with cerebral palsy (CP), provided by each of the state and territory CP registers every three years.

Data from the ACPR can be used to tell us more about the number of children living with CP in Australia, and provide some information about the severity of CP and the causes or risk factors for CP.

The ACPR can be used to help researchers and service providers evaluate the outcome of new prevention strategies and plan services for Australian children and adults living with CP.

June was CMV awareness month

Cytomegalovirus (CMV) is a common virus. CMV infection usually doesn’t have any symptoms, but can cause problems in pregnancy if the virus passes from the mother to the developing baby.
Whilst most babies born with CMV will not have CMV disease, CMV can cause damage to the baby’s developing brain resulting in long term disabilities including hearing loss and cerebral palsy. Individuals caring for or working with small children are at increased risk of infection.

This month Prof Nadia Badawi and Dr Hayley Smithers-Sheedy from the Cerebral Palsy Alliance Research Institute, The University of Sydney have been working with some amazing families and CMV Australia to promote awareness of CMV and the simple hygiene precautions that reduce the risk of CMV infection in pregnancy.

If you would like more information or to request CMV Awareness posters/flyers please follow this link for more information.
Current Research

Seeking Participants!

1. Habit-ile

A randomised trial of Hand Arm Bimanual Intensive Training including Lower Extremity training for children with bilateral cerebral palsy.

A 10 day school holiday camp at Prairiewood NSW for children with bilateral cerebral palsy.

Who can be involved?

- Children aged 6 – 16 years
- who have bilateral cerebral palsy - GMFCS II, III and IV
- who can follow instructions

For more information contact Ashleigh - ahines@cerebralpalsy.org.au.

2. Emotions and Cerebral Palsy

Although cerebral palsy is a motor condition, it can impact other areas of everyday living. One important area of everyday living is how we experience emotions. So we are trying to find out more about how people with cerebral palsy experience emotions.
Who can be involved?

Adults with cerebral palsy aged 18 years or more, who don’t have a known moderate to severe intellectual disability.

What's involved?

You will be asked to complete a short, 15 minute survey asking questions about you, how you feel and how you experience emotions.

You can help us by completing the survey online [https://tinyurl.com/y6tnqqhz](https://tinyurl.com/y6tnqqhz)

For more information contact Hayley - hsmitherssheedy@cerebralpalsy.org.au.

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3. Livable bathrooms

Researchers are seeking participants to learn about the space requirements of public accessible washbasins for wheelchair users.

Who can be involved?

Adults with CP, aged 18 years or older; using a wheelchair for community access; able to independently use a washbasin and living with 25km of UNSW Sydney.

Eligible participants must be effective verbal communicators, with no more than a mild intellectual disability.

What's involved?
Attend a test session (approximately 3 hours in duration) at UNSW Sydney involving:

- A face-to-face interview about your washbasin experiences and opinions,
- Have a series of body measurements taken, and
- Perform simulated tasks at an adjustable washbasin set to varying heights and depths.

For more information contact Kim - LivableBathrooms@unsw.edu.au.

4. Pain in cerebral palsy

Researchers from the University of Sydney and Sydney Children's Hospital Network are trying to find out more about how pain impacts young people with cerebral palsy (CP). This study aims to gather an in-depth understanding of the lived experience of pain in youth, as reported by the child/young person with CP.

Who can be involved?

Any child aged between 9 and 17 years (inclusive), who has CP may be eligible to participate. The child must self-report experiencing pain; speak English; have no more than a mild intellectual delay, and be able to communicate verbally during a face-to-face interview.

What's involved?

A face-to-face interview between the researcher and the young person with CP, lasting between 30-60 minutes. The interview may be conducted at the Children’s Hospital at Westmead; Sydney Children’s Hospital Randwick or your home.

For more information contact Katarina - Katarina.ostojic@health.nsw.gov.au

5. Breaking the Limits

Researchers from Western Sydney University are investigating the obstacles to participation within society for young people with diverse physical abilities across New South Wales.

Who can be involved?
Young people (aged 15-24 years) with a physical disability that impacts their mobility.

**What's involved?**

You will be asked to participate in discussions about the issues you feel affect your ability to participate in society. These discussions can take place in individual interviews and focus groups, either face-to-face or online.

For more information contact Aaron - A.Millerand@westernsydney.edu.au

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**JOOAY is a FREE App for children, adults and families with disabilities to connect with sports & leisure activities in their community.**

Participation in community activities is an important goal of children and adults with disabilities as well as their families. Our Canadian colleagues have created an application in Canada called JOOAY to connect children, youth and adults with disabilities to leisure activities adapted to them. They are having great success with it. Feel free to have a look on their website to gain a better idea of what we are talking about [www.jooay.com](http://www.jooay.com). Our colleagues in WA have started this in Australia and other states are ready to get on board.

We would like to launch the NSW/ACT activities on the JOOAY App by the end of this year. But we need your help!

Do you know of such an organisation or leisure activity in your community? Let us know at [JOOAY@cerebralpalsy.org.au](mailto:JOOAY@cerebralpalsy.org.au) and we will get in touch!

Or forward this message to them: There are no costs for you to be listed on this new App and it allows potential participants to easily find your program. To start this
process simply click the link below to fill out a short survey to express your interest and leave a detailed description about your program. Please take five minutes to complete the JOOAY NSW Survey
https://survey.az1.qualtrics.com/jfe/form/SV_8IkRBPqQi9cW5dH

Thank you! Natasha & Isabelle

CP Quest
Community and Researchers together!

Contact JOOAY NSW/ACT

cpquest@cerebralpalsy.org.au

Congratulations to:

- **Ms Yana Wilson** - Using a sibling design approach to investigate genomics of CP and other neurodevelopmental disorders
- **Dr Courtney McDonald** - MRI guided-focused ultrasound: a novel delivery system for neural stem
cells to repair the injured neonatal brain
- Prof Alistair McEwan and Prof Raymond Tong - Soft robotics for improved standing and walking in infants with cerebral palsy

These researchers received a CPA Research Foundation grant. Their projects were ranked as high priority for our community and have therefore been chosen to be named "CP QUEST" Grant for 2019!

How Can You Be Involved in Cerebral Palsy Research?

How can I be involved?
As a parent or person with cerebral palsy you might be asked to be a research participant. But this is only one way that you can be involved. Parents and people living with cerebral palsy can also partner with researchers to plan and carry out research projects. You can help researchers decide what topics are important to study, how to run the study, and what questions to ask participants.

What are the benefits of partnering with researchers?
Everyone benefits when people with real life experience partner with researchers. Partnerships help make sure that research is relevant, meaningful, and addresses people's needs and concerns. Everyone can learn new skills (like writing or presenting at conferences) or use their existing skills in a new way to help other families who are on the same journey.

But what if I don't have any research training?
No Problem! Parents and people living with cerebral palsy bring something to the table researchers don't have: real life experience. Because of this parents, and people living with cerebral palsy, can advise researchers on things like what is important for them and/or how to best engage parents to participate in research.

What will I be asked to do as a research partner?
It depends on the project, your own interests and skills! You can join a reference group, review information forms, communicate results, co-author a publication, interview other members, review draft questionnaires, represent the views of the CP community, participate in focus groups, answer a survey... Be sure to discuss roles and expectations with the research team ahead of time. Some research projects have a small budget to cover expenses of partnering.

Where can I learn more?
CPQUEST@cerebralpalsy.org.au 02 9975 8928

*This resource was adapted with permission from Kings Placeuk & Pem Streetman 2019. How can parents be involved in cerebral palsy research? Kids Brain Network, McMaster University Canada.
Search for clinical trials currently registered in Australia and the rest of the world.

Search for clinical trials

Latest cerebral palsy research

CP Research

Cerebral Palsy ALLIANCE RESEARCH INSTITUTE

NEXT NEWSLETTER

Any CP research news that you want to know more about? Contact us if you have ideas for upcoming newsletters.
UPDATE YOUR DETAILS

Moved house? New email address? Up to date contact details on the register will ensure that you receive correspondence, including invitations to participate in research projects.

Cerebral Palsy Alliance
Research Institute

Your received this email because you or your child is on the CP Register