Welcome to our NSW/ACT CP Register Newsletter, August 2020 edition.

We hope you have been well, are keeping safe and adjusting to this new world.

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 via email: cpregister@cerebralpalsy.org.au

Best wishes!

Sarah, Hayley, Shona, Katarina, Emma and Isabelle

I. Latest News

**AusACPDM** - March 2020 Conference, Perth

The Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) aims to provide scientific education and promote excellence in research and best practice clinical care for children and adults with cerebral palsy and other developmental conditions. A week before lock-down in early March, researchers from the Cerebral Palsy Alliance attended and presented at the biennial AusACPDM conference in Perth.
We would like to thank everyone that participated in these research projects, including the CP Register participants. Your participation helps advance knowledge and improve practice!

Here are some of the key findings that the team and their collaborators from around the world presented.

The Australian Cerebral Palsy Register (birth years 1995-2012) reported:

- Rates of CP for singleton born children declined amongst those born extremely preterm (less than 28 weeks gestation) and at term (37+ weeks gestation), with more children having milder disability. These declines were seen in non-Indigenous children, but not for Indigenous children. Further research in this area is now a high priority.
- Post-neonatally (after one month of age) acquired CP (PNN-CP) accounted for 6% of CP in Australia, with the most common causes being cerebral vascular accidents, infection and non-accidental injury. Rates of PNN-CP were higher in children born to teenage mothers, and for these children, infection was the most common cause. Socio-economic disadvantage was not associated with PNN-CP.
- Triplets and quadruplets in Europe and Australia are at higher risk of CP than twins (probably because many are born very preterm), but their clinical outcomes are similar.
- Using a large dataset from Australia and Europe, we found that nearly one-in-four children with CP have a congenital anomaly, with brain and heart anomalies most common.

Other findings presented at AusACPDM:

- Multifaceted strategies are currently being used to: promote the uptake of guidelines for prevention and treatment of congenital cytomegalovirus (cCMV) and to improve parental and health care worker knowledge about preventive strategies for cCMV.
- The combined accuracy of three tests (General Movements, HINE and MRI) to detect CP in infants who are admitted to a neonatal intensive care is 98%. These are now the Gold Standard tests for an early diagnosis of CP.
- In a new early diagnosis clinic based in South Western Sydney 88 infants had been seen up to March 2020 with 58% of these infants receiving a diagnosis. The average age at which a diagnosis was made is 7 months. Early detection research is continuing to enable access to best practice early interventions.
- Consensus-based clinical guidelines to support implementation of eye-gaze control technology have been developed. Using a Delphi (multiple surveys) method, statements were agreed upon and categorized into clinically relevant sections including features which defined eye-gaze control technology as a unique access method; requirements of an assessment prior to a trial of eye-gaze control technology; issues guiding conduct of trials; factors supporting implementation of eye-gaze control technology measurement and outcomes; guidance for follow-up and review; considerations for funding applications, and preparation for future use.
• Preliminary results exploring non-pharmacological alternatives (distraction therapy vs. BrightHearts relaxation training app) for procedural pain management during botulinum toxin injections show high acceptability and satisfaction reported by children, parents and clinicians.

• Attending a 14-week program of PEERS® has shown to improve social skills knowledge and increase gettogethers for teenagers with CP and ABI who struggle to make and maintain friends.

For more information on any of these projects contact the research team – researchinstitute@cerebralpalsy.org.au

Lived Experience Photo Exhibition

AusACPDM and CP-Achieve have launched the inaugural Lived Experience Photo Exhibition and is inviting the community to submit original photos of people with cerebral palsy and other childhood-onset disabilities doing things they love – think family, friends, art, craft, music, magic, drama, work, leisure or a special moment. Photos may depict ways we have adapted to living during COVID-19.

Photos will be showcased on the AusACPDM website where the community will be able to vote for their favourite photo.

The four photos with the highest number of votes will win $100 each. The images may also be used to complement future online and published work by AusACPDM and CP-Achieve.

For more information or to submit your photos please go to https://www.ausacpdm.org.au/about/ausacpdm-photo-exhibition/
Entries close midnight October 8th 2020.
Don’t forget to check back to vote once the voting opens on October 12th 2020.

Click here to see the flyer
CP Strategy

The Australian and New Zealand Cerebral Palsy Strategy was launched at the AusACPDM conference this year in Perth.

Cerebral palsy is the most common physical disability in childhood but remains under-recognised in the public and political arena. A united voice is needed to improve the quality of life for people with cerebral palsy and increase awareness in the broader community.

The Australian and New Zealand Cerebral Palsy Strategy was developed by people with cerebral palsy, their families, professionals and researchers across Australia and New Zealand.

The strategy has 4 key goal areas:

- Inclusion and Engagement
- Health and Well-being
- Intervention and Disability
- Support Prevention and Cures

For more information, to access a range of resources developed about The Strategy, or to get involved, please visit https://cerebralpalsystrategy.com.au/
Meet our team


Natasha Garrity - Junior Research Assistant

Hi, I’m Natasha Garrity and I am currently working for the CPA Research Institute as a casual research assistant whilst I study for a bachelor degree at Macquarie Uni. My current roles include: maintaining the NSW activity base on the Jooay app (read more later in this newsletter) and helping researchers write “lay summaries” of their research papers. I also sit on the CP Register Advisory Committee and have been a CPA Research Ambassador since I was 8 or 9, and I am volunteering as a CP Quest Research Partner on the stem cell advisory group.

I mostly credit my parents for encouraging my interest in research from an early age. Since I was first diagnosed with CP at 12 months and throughout my childhood my mother was constantly on the lookout for the best treatments available to help my development. This often led to the “cutting edge” research and technologies of the time. She was also stunned at the lack of research in the early 2000s and has been an advocate ever since. She was also not afraid to question and the doctors and at times challenge their treatment ideas due to her background in nursing. My father works in the IT industry and was not afraid to explain difficult concepts and ideas on a range of topics from finance to science if I or my brother asked. This early exposure to research and encouragement of my curiosity fed and nurtured my passion for CP research and I was honoured to get a job on the team last year.
1. Cost of CP survey

Researchers from the Cerebral Palsy Alliance, The University of Sydney and Research Partners from CP Quest are conducting an online research survey to understand the out of pocket costs and measure financial stress for families and people living with cerebral palsy in Australia. This research study will involve completing an online anonymous survey. We know that the impact of CP varies from person to person, and the support they require will vary too. We want to find out, from your perspective, the out of pocket costs associated with living with CP.

To contribute to this research click here if you are a person with CP.

If you are a carer or parent click here.

Results from this study will be written in a report that we will share with you and the broader CP Community. We envisage the report created from this research will promote policy changes, as well as provide families and organisations with a tool to advocate for more funding.

For more information contact Claire Galea, cgalea@cerebralpalsy.org.au, or Isabelle Balde ibalde@cerebralpalsy.org.au (02) 9975 8928.

contact Claire
2. Genetic NDD Twin Study

Do you know or are you part of an identical twin pair who are differently affected by cerebral palsy, epilepsy, autism spectrum disorder or an intellectual impairment?

Researchers at The University of Adelaide are investigating the causes of differences in developmental outcomes in identical twins.

If you are interested in being involved in this research, please contact (08) 8313 1404 or twinstudy@adelaide.edu.au.

Contact Researchers

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3. Coroner investigation

This is an invitation to take part in a research project about the experience of family members who have been involved in an investigation by the coroner because of the death of a relative with disability. This project is being conducted by researchers from the University of Sydney.

Understanding the experience and impact on families will help inform professionals how to better support family members who may participate in a coronial investigation in the future.

Participation in this research involves the completion of a short questionnaire and a face-to-face interview that will take no more than 2 hours.

If you would like further information about this research please contact the researcher, Ms Susan Kaszonyi by phone on 0412 989 138 or by email at skas8102@sydney.edu.au.

Contact Susan
4. PROPOSE

Professional Referral to Physical Activity, Sport and Exercise.

The Institute for Musculoskeletal Health is interested in talking to young people about their experiences with sport and physical recreation to help health professionals support young people to increase their participation.

Are you aged 13 or over with a physical disability? And do you play any sports or other physical activities?

Please help us with our research study and book an interview. Interviews will be held via phone or video call.

If you are interested in finding out more, please contact PROPOSEstudy@sydney.edu.au, call (02) 8627 6248 or visit www.PROPOSEstudy.org.au.
5. ParticiPate

Helping kids with cerebral palsy to be more physically active through doing sports and leisure.

Children (8-14 yo) with CP (GMFCS I-IV)

Kids with cerebral palsy participate in sports and physical activities less frequently than their peers without cerebral palsy. We’ve designed a different type of program delivered by a physiotherapist (PT), occupational therapist (OT) or exercise physiologist (EP) that aims to get kids with cerebral palsy to do sports and physical activities that they think are meaningful.

The new program respects barriers (things that get in the way) to your child’s participation, but also their strengths and individuality. **The program is designed to suit your family circumstances and unique situation.**

What are the details?

- 1 hour per week face-to-face therapy for 12 weeks
- Delivered by a PT, OT or EP
- Partnering with you and your child to achieve goals about participating in sports and physical activities
- Guiding you to create solutions to problems you face when trying to help your child be more physically active
- Linking you up with the tools and information you need
- Delivered in your home and places where sports happen in your local community

For more information contact Emma Stanton

estanton@cerebralpalsy.org.au - (02) 4736 8722.

Contact Emma
6. HABIT-ILE
Helping kids with CP to improve their movement and independence in daily life

Children (6-16 yo) with bilateral CP (GMFCS II-IV)
Kids with cerebral palsy can find it difficult to use their two hands together to do everyday activities. They can also have trouble with their gross motor skills and how they move around. **We are testing an intensive type of therapy called Hand Arm Bimanual Intensive training Including Lower Extremity Training (HABIT-ILE)** delivered by physiotherapists, occupational therapists and therapy students that helps kids to improve their motor skills and independence in daily life activities.

*The Sydney HABIT-ILE research camps will run in January 2021 and July 2021 at Cerebral Palsy Alliance in Prairiewood, NSW.*

**What are the details?**
- 6.5 hours/day for 10 weekdays during 2 weeks of school holidays
- Groups will include 10-12 kids
- Delivered by a PT, OT and therapy students
  - 1-on-1 therapy with a dedicated therapist
- Using play, craft, cooking, everyday living skills and gaming technologies
- Personalised to your child’s goals, priorities and interests

*For more information contact Ashleigh Hines ahines@cerebralpalsy.org.au - (02) 8777 1777.*
Jooay Australia

Participation in community activities is an important goal of children and adults with disabilities as well as their families. Our Canadian colleagues have created a website and app called Jooay (Jouer - to play) to connect children, youth and adults with disabilities to leisure activities adapted to them, in their community.

A team of researchers from WA, QLD and NSW are working on putting Australian activities on the Jooay app and we anticipate to launch Jooay Australia by the end of the year.

This free app is already available to download. If you know of any leisure or sports activities in your area that cater for people with a disability please let us know how we can get in touch.

Join us on the Jooay Australia Facebook page so we can stay in touch! We will also post activities you can do online during the Covid-19 pandemic.

For more information please contact - jooay@cerebralpalsy.org.au
IV. CP Quest - Community and Researchers together

CP Achieve

We are seeking involvement from young people with lived experience of CP and their families, to inform what we research and how we undertake research. Please register here if you would like more information or want to become involved.

We are excited to share that a new Centre for Research Excellence (CRE) in Cerebral Palsy has been awarded in Melbourne, with some of the planned work to occur in NSW. This Centre is called CP Achieve which stands for the Australian Centre for Health, Independence, Economic Participation and Value Enhanced care for adolescents and young adults with cerebral palsy. It has been funded for five years by the National Health and Medical Research Council (NHMRC).

CP Achieve is focussed on adolescents and young adults (aged 10 – 30 years) with cerebral palsy. It aims to understand and address the health care and service needs of this group. Currently there is very little research in this area. CP Achieve’s vision is to ensure that adolescents and young adults receive the best health care throughout this critical period of development, to enable them to contribute to, and participate in, all aspects of life.

CP Achieve aims to deliver a program of research in partnership with people who have cerebral palsy, their families, clinicians and other interested people.

CP Achieve plans to improve physical and mental health and promote participation by:

- Understanding how common physical and mental health problems are for adolescents and young adults;
- Learning about how those health problems impact participation in the community;
- Understanding the long-term outcomes of some childhood treatments - like surgery;
- Delivering therapy that supports participation in healthy lifestyles and recreation;
- Understanding and promoting good quality transition from childhood to adult health care.

An overall plan to work on these issues has been prepared, but we need your help and input. CP Achieve are committed to involving people with cerebral palsy, their families, clinicians, service-providers and other interested people, so they can contribute to and influence this research.

If you think you want to be involved, or want to be kept up-to-date on our activities, please leave your details [here](#).
Lily Collison (parent) in conjunction with senior medical staff at Gillette Children's Specialty Healthcare (Minnesota) have recently written a book about Spastic Diplegia–Bilateral Cerebral Palsy.

The book addresses how spastic diplegia/bilateral CP develops over the lifespan and explains the evidence-based, best-practice treatments. It aims to empower parents of young children, as well as adolescents and adults with CP, to become better advocates and co-decision makers in the medical process.

The book is available to order on Amazon or through bookstores (ISBN 978-1952181009). All proceeds are going to CP Research.

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 web-page:


CP Research Newsletter

Stay up to date with the latest CP Research. 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