

INNOVATION AND INSPIRATION:

Cerebral Palsy Alliance Research Institute Report 2023





Artwork by Leah Cummins, a proud Mayi woman from North-Western Queensland

ACKNOWLEDGEMENT OF COUNTRY

We acknowledge the Traditional Custodians of Country throughout Australia and recognise their continuing connection to land, waters and community. We pay our respects to Aboriginal and Torres Strait Islander cultures; and to Elders past, present and emerging.

Cerebral Palsy Alliance is a ground-breaking, global centre of expertise for cerebral palsy research, advocacy, intervention and assistive technology innovation. For over 75 years, we have been guided by our founders' mission that 'nothing is impossible'.

Cerebral Palsy Alliance Research Foundation is the world's largest private funder of CP research. The Cerebral Palsy Alliance Research Institute, funded by the Foundation, has research priorities shaped by consultation with individuals living with CP and their families. Our diverse, multidisciplinary research team includes medical specialists, allied health professionals, engineers and researchers together with people with CP and their families. With a focus on Epidemiology, Regeneration, Technology and Early Detection and Early Intervention, our research is at the heart of our organisation, driving interventions, shaping our initiatives, and uniting communities worldwide for positive change.

Cerebral Palsy Alliance Research Institute

Established in 2005 through a generous Gift in Will, Cerebral Palsy Alliance Research Institute embarked on a mission to prevent CP and address the challenges faced by children and adults with CP across Australia and around the world. At that time in Australia, approximately 1 in 400 babies each year were diagnosed with CP. Today, that number has decreased significantly to approximately 1 in 700 babies – a remarkable, 40% reduction.

Our groundbreaking research is made possible by the generosity of our 150,000 supporters. From individual and corporate contributions to the resounding success of events such as the annual Grace Gala, The Retreat, The Escape, Might and Power, and virtual challenge STEPtember. The efforts of our Governors and board members in New South Wales and Victoria, who volunteer to enhance philanthropic and corporate support, complement our fundraising initiatives.

We extend our heartfelt gratitude to our valuable fundraising and philanthropic partners, whose unwavering support enables our research to inform policy changes and advocate for equity, inclusivity, and diversity in health, education, and employment. Together, we turn these aspirations into reality, working towards a future where individuals with CP and similar disabilities live in a world full of opportunities.

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Nadia Badawi leads research strategy and direction, and extends her clinical and research expertise on a day-to-day basis, supporting parents of newborns and supervising the care of critically ill babies in the Grace Centre Newborn Intensive Care unit.

Welcome from the Chair

PROFESSOR NADIA BADAWI AM, CHAIR OF CEREBRAL PALSY

As we head towards 20 years of the Cerebral Palsy Alliance Research Institute, I am delighted to reflect not only on the achievements of 2023, but where our journey has taken us over this time.

Today, Australia has one of the lowest perinatal mortality rates and one of the lowest rates of CP in the world (1 in 700). This has been achieved by the incredible collaboration between doctors, nurses, allied health professionals, engineers, scientists, and of course, with people with CP and their families.

Nearly 50% of children diagnosed with CP will have spent time in a Neonatal Intensive Care Unit (NICU) or Special Care Nursery (SCN). This focused care can have a big impact on the life trajectory of a baby and their family. My clinical role as a Newborn Intensive Care Specialist at the Grace Centre at the Children's Hospital at Westmead enhances and works seamlessly with my research role as Professorial Chair of the Cerebral Palsy Alliance Research Institute at the University of Sydney.

In 2023, we continued to push boundaries in the pursuit of prevention, better interventions and possible cures for people with CP. Our research work is grouped into four themes: Epidemiology, Early Diagnosis and Early Intervention, Technology, and Regeneration.

This year, the Epidemiology team published the sixth Australian CP Register Report. It provided evidence of a 40% drop-in the rate of CP to 1 in 700 live births. It also found that one third of

children with CP live in regional, rural, or remote Australia, highlighting the need for high quality, accessible, and culturally safe services.

Our Early Diagnosis and Early Intervention team have completed and are currently analysing the results of the largest early intervention study in CP ever conducted, the GAME (Goals Activity Motor Enrichment) trial. Following the success of two Early Diagnosis Clinics at Randwick and Prairiewood, we opened a third Early Diagnosis Clinic in the Hunter region. These clinics are crucial in offering families in NSW access to early detection for children as young as 3 months, and thus, enabling access to early intervention. More than 400 infants and families have been supported by CPA Early Diagnosis Clinics in the past five years.

Our Technology team has been working on applying technology and offering opportunities for people with CP to participate, such as SwitchApp for control, and the world's first voice library for children with CP.

One of the highest priorities for people with CP and their families is stem cell therapies. The Regeneration team is leading several collaborative studies investigating cell therapies and other advanced therapeutics for the prevention and treatment of CP. They have also been focused on information-sharing and progressing access to cell therapies in Australia.

This report delves deeper into some of these achievements in 2022-2023, and the foundations we are laying for the future.

Updates from our leadership team

Pushing the boundaries of technology and innovation



Professor Alistair McEwan, Chair of Technology and Innovation

Technological innovations to improve communication, cognition, and mobility are the lifeblood of the team's work and we continue to

push the boundaries of what can be done to improve the lives of people with disability.

In partnership with the Cerebral Palsy Alliance Research Foundation (CPARF) in the US and Remarkable™, Cerebral Palsy Alliance's global disability start-up accelerator, we have established annual international summits on assistive technology innovations, bringing together disability industry innovators from Google, Apple, Meta, and world-leading researchers to brainstorm ideas and create solutions.

An exciting area is our development of Brain Computer Interface (BCI). BCI allows the user to choose words on a screen, create sentences, and have them read out by the computer, simply by the user thinking of the words on the screen. This device can restore and enable communication for people who cannot verbally communicate with others and do not have the manual or visual ability to control a computer.

This technology was user-tested by people with lived experience when designing the device. This project has progressed using the Microsoft HoloLens device and will be suitable for 18% of Australians affected by mobility, communication and learning disabilities.

Lived experience is a core tenet of our work, and I bring this with me to my role as Chair of Technology and Innovation at the University of Sydney. A team of 10 people with lived experience regularly present lectures and attend tutorials to co-design new and innovative technologies with students from my Rehabilitation Engineering course. This has enriched the cultural environment within Cerebral Palsy Alliance and University of Sydney, and is valued by the students as evidenced by the class growing from 20 students in 2020 to more than 60 in 2023.

Two of my PhD students founded start-ups in disability tech. The first aims to aid resuscitation of newborns, which is now being trialled in three Australian hospitals. And the second, an electrical muscle function sensor developed by PhD student Jett van der Wallen, is currently being commercialised by Aussie Biosense.

The talent, energy, and commitment of the next generation of innovators is exciting to see. Australia continues to be a leading light in the development of assistive technology, and mentoring these young trailblazers continues to be a vital part of my role.

Research in Victoria going from strength to strength



Professor Rod Hunt, Director of CP Research, Victoria

In Victoria, our small but dedicated team is tirelessly working to raise awareness for CP. We support the Victorian CP Register, a

vital resource in our research activities.
Our strong research ties with Murdoch
Children's Research Institute (MCRI) and
Monash University have a focus on neurology
and stem cell therapies for CP.

In 2020, Professor Rod Hunt was appointed as CPA Director of Research for Victoria along with a Victorian council of governors who assist growth in the region and amplify our impact in advancing CP research.

Victorian researchers have continued to play to their strengths, with world-leading science in neuroprotection and neuro-repair translated into clinical space. We continue to invite our Discovery Scientist colleagues into the Neonatal Intensive Care Unit (NICU) to help define areas of need. We are doing this so that the right questions are asked of our pre-clinical models before translation into the clinical space.

Dr Elly Green has finished recruitment for the ANAKINRA Phase 1 clinical trial, which will evaluate the feasibility and safety of a drug that helps reduce inflammation (IL-1 Receptor antagonist). This is a promising antiinflammatory therapy for preterm

infants. Planning for the Phase 3 randomised controlled trial is underway.

Dr. Simone Huntingford, our first Neonatal Neurology Fellow, started her PhD to better understand hypoxic-ischemic encephalopathy (decrease in blood flow and oxygen to the brain, leading to brain damage) in preterm infants.

In the lab, Drs. Rob Galinsky and Courtney McDonald are working on new therapies, such as expanding research on neural stem cells and creating new protective treatments for the brain. Professors Rod Hunt and Suzie Miller, along with Dr Tamara Yawno, are finalising safety tests for a new anticonvulsant drug called Ganaxolone. This drug will soon be tested in the NICU and compared against a drug that helps reduce the occurrence of seizures (phenobarbital) in a clinical trial.

The Victorian CP Register continues to be one of the world's leading registers, following children through to adulthood. They contribute important data to the Australian CP Register which means we can continue to report trends of CP.



From left to right – Rod Hunt, Elly Green, Rebeca Atkinson (trial co-ordinator), Claudia Nold, Rob Galinsky, Marcel Nold

\$2.5m funding awarded to establish a CP Centre of Research Excellence

Professor Iona Novak, Chair of Allied Health, Head of Research Translation

Cerebral Palsy Alliance and the University of Sydney are leading a Centre for Research Excellence supported by \$2.5 million in funding awarded by the National Health and Medical Research Council. The Centre of Research Excellence is called 'Directing Research Into Very Early Cerebral Palsy' (DRIVE CP) and is a five-year research program aimed at making CP less severe, diagnosing babies earlier, and making sure that help quickly follows.

As Chief Investigator for the project, I am excited and inspired to be collaborating with a team of CP experts who are among the best in the world. Together we are holistically researching the questions of importance to people with CP – from early diagnosis, clinical trials, genetics, machine learning and artificial intelligence to knowledge translation and implementation.

This project is being made possible through the collaborative efforts of families and partners at The University of Sydney, The University of Queensland, Monash University, CSIRO, Deakin University, and the University of Melbourne.

Cerebral Palsy Global Clinical Trials Network

The Elsass Foundation, based in Denmark, has generously awarded more than \$3.7 million to establish the CP Global Clinical Trials Network. The mission of the CP Global Clinical Trials Network is to enhance the well-being and outcomes of individuals living with CP by expediting the pace of clinical trials and swiftly integrating novel treatments into standard care protocols.

The Network's overarching objectives include:

- Accelerating Discovery: expediting the identification and development of new treatments for CP.
- Facilitating Translation: accelerating the process of integrating these new treatments into routine care practices for individuals with CP.

Through the Network's commitment to innovation, strategic partnerships, and the implementation of adaptive trial designs, we are revolutionising global CP research. Adaptive trial designs allow us to modify and refine clinical trials in real-time, ensuring efficient resource allocation, accelerating treatment development, reducing costs, and maximising the potential for ground-breaking discoveries.





Award Winner!

Iona Novak

- recognised in the

2023 King's Birthday

Honours for advances
in CP research

Our Research Impact



CPA researchers in the **top 1%** of CP experts globally

Established World
CP Day as a global
community event

140 people with lived experience connected to research through **CP Quest**

Organised 10 global summits on topics such as stem cells, neonatal stroke and assistive technology

CPA therapists

contributing to and implementing breakthroughs in research

Supporting improved healthcare outcomes for **First Nations** people

40% decline

in rate and decreased severity of CP in Australia

Average age of CP diagnosis now 19 months to as young as **3 months**

Australia has one of the lowest rates of CP in the world



\$93m+ invested in research and disability technology development:

\$89m+ invested in global research

incl. **\$4m** invested in low to middle income countries

\$4m invested in disability tech startups

•2016

CPA Research Foundation established in New York

2015

Remarkable™ Disability Tech Start-up Accelerator established

780+ research grants across 48 countries 183 institutions and 408 researchers supported in a global research community

Areas of Research Focus >> Pioneering World Firsts in Cerebral Palsy

EARLY DETECTION AND EARLY INTERVENTION



400+ babies supported in 3 early diagnosis clinics

Championed implementation of **General Movements Assessment** in all Australian NICUs

TECHNOLOGY



World first clinical guidelines for eye-gaze tech for CP

Establishing My Voice Library - capturing words through gamification

EPIDEMIOLOGY



Assisting in establishing
14 CP registers globally

Pioneering CMV research and prevention campaigns

REGENERATION



Supported first cord blood stem cell trial for CP in Australia

Stem cell community group established

Progress in our areas of research focus

Our research priorities are informed by people with CP and their families, and CP Quest leads our research partnership with people with lived experience. This has helped shape the four priority areas: Early Detection and Early Intervention, Epidemiology, Technology, and Regeneration. These areas while distinct, work together closely to create better understanding into the causes, prevention, and possible cures of CP.

CP Quest – integrating lived experience

CP Quest was launched in 2015 to integrate and involve people with lived experience of CP, their families, and advocates into all aspects of research.

We believe that partnering with people with lived experience of CP throughout the research cycle greatly enriches projects and improves CP research. CP Quest has a strong and passionate leadership team, and has recently appointed a new CP Quest Coordinator, Sophie Marmont. For nearly 30 years Sophie has worked as a youth coach at CPA and is a qualified assistive technology mentor. As a research partner, Sophie applies her own experience living with CP to support CP Quest members and encourages new members to join.

In 2023, CP Quest widened its network by working with researchers from other institutions including the University of Queensland and University of Western Sydney.

To date, we have more than 140 members with lived experience in CP Quest who have volunteered to be involved in research projects. Our research partners have collaborated on at least 13 new projects over the last year, and many more projects that are continuing.



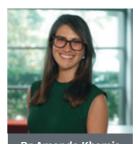
Sophie Marmont, CP Quest Coordinator



Early Detection & Early Intervention



Dr Cathy Morgan Senior Research Fellow and Program Lead, Early Detection & Intervention



Dr Amanda Khamis Research Fellow



Research Fellow



Dr Michelle Jackman Research Fellow



Research Fellow



Monica Toohey Senior Research Therapist







Research Therapist



CP is often detected too late to make the most out of the critical early time when the brain can adapt and change easily, with many infants missing out on getting help early enough.

The Early Detection and Early Intervention team is led by Dr Cathy Morgan. What excites Cathy the most about her work is the momentum for early diagnosis and early intervention on a global scale, to improve opportunities and outcomes for kids born with CP, no matter where they live.

Cathy is one of only two Australian tutors for the General Movements Assessments (GMA), a unique and sensitive assessment that classifies the spontaneous movements of infants. The GMA is now consistently used to assess high risk infants between 12-14 weeks of age to screen for CP. Typically, CP is diagnosed after 12 months of age, so use of the GMA at 12-14 weeks allows earlier detection of CP, and, importantly, earlier referral for early intervention that leads to improved outcomes for these babies.

Three Early Diagnosis Clinics established

To offer more families in NSW greater access to early detection and intervention, our network of early intervention clinics has been expanded to the Hunter region. All three clinics are funded through generous donors, and the team is grateful for their ongoing support. Our data shows that the average age of diagnosis for infants attending the clinic is eight months, significantly lower than the national average of 19 months.

"We are moving the dial down from diagnosis at an average age of 19 months to well below 12 months and as young as 3 months. We have really championed the movement away from a 'wait and see' attitude to let's get this child and family all the support they need as early as possible,"

Dr Cathy Morgan Program Lead and Senior Research Fellow

Advancing cerebral palsy research through GAME: a case study

The team's work in early detection facilitates recruitment to critical early intervention studies that cross several areas of development including motor, eating and communication skills. Cathy and her team have recruited 302 babies across four states in the largest early intervention study ever conducted, the GAME (Goals, Activity, Motor Enrichment) trial.

GAME takes an important, but different approach to intervention by delivering therapy in the home. This approach empowers parents to feel confident in supporting their children at home, where the majority of a baby's development happens. Parents interviewed about how the GAME approach helped them during a vulnerable period were positive about their experience. Their views were published early in 2023, and we are looking forward to publishing the full GAME study results in 2024.

"Isolde's therapy team have given me confidence and strategies that I can use in our home environment for her ongoing therapy practise, which is so valuable and practical."

Kate. Isolde's mother



Meet Isolde, a little fighter born too soon, weighing only as much as a small bag of sugar. Her early days were tough, facing multiple brain bleeds and uncertainty about her survival. Thanks to the GAME trial called Goals Activity Motor Enrichment (GAME) that investigated early and sustained motor and cognitive stimulation, Isolde's story took a brighter turn.

Now at two years old, Isolde is defying the odds. Her mum says she is a very strong-willed little girl who loves pretending to feed her doll and delights in building things with craft and in the sandpit.

"If we hadn't been selected for the GAME clinical trial, I honestly don't know how we would have done those therapies. We couldn't have afforded it, and we had no way of knowing what to do ourselves," said Isolde's mother.

"It's a huge weight off to be guided by experts who can say, 'Research tells us this, so this is the best thing to do right now'," she added.

Traditional trials like GAME take a long time – years and years – before new discoveries can help kids like Isolde. The CP Global Clinical Trials Network offers a promising alternative. Adaptive clinical trials are a new way of doing trials – they are faster, more effective, and less expensive than standard trials.

Importantly for people with CP in Australia, adaptive trials don't require large numbers of participants in one country. Australians could be part of the same trial as people in Denmark for example, and researchers could continually adapt the trial according to live data to create more accurate, more effective and faster results.

Isolde's story shows us why research matters. Every day counts for kids like her, treatments that could change their lives. By supporting research like GAME and the CP Global Clinical Trials Network, we can give kids like her, these treatments could change their lives.

Amanda Khamis - 3 Minute Thesis award winner for I-EAT

A PhD thesis is a mammoth body of work. It's often more than 80,000 words and can take years to complete. The Three Minute Thesis (3MT) is a competition that challenges PhD students to develop an engaging 3-minute "elevator pitch" to summarise the aims and outcomes of their research project. The competition aims to cultivate academic, presentation and research communication skills and is now conducted in over 900 universities across more than 85 countries in the Asia Pacific region.

In 2022, Amanda Khamis, was delighted to present her work titled "I-EAT, you eat, but can we all eat? Feeding therapy for babies with CP and dysphagia." Her research showed that the novel Baby Intensive Early Active Treatment program successfully used approaches shown to build new brain pathways and safely challenge these babies' feeding skills. This program holds promise for improving the eating and drinking skills of the 85% of infants with CP who have dysphagia.

Not only did Amanda win first place in both the Faculty of Medicine and Health, and the University of Sydney 3MT competition, she then went on to achieve second place out of 57 semi-finalists in the 3MT grand final across the Asia Pacific region.

You can watch a recording of the winning entry here: https://vimeo.com/763224887





Amanda Khamis presenting

Improving accuracy of cognition assessment - Low Motor Bayley

Children with CP are more likely to experience cognitive impairment than typically developing children. These difficulties can significantly impact learning, socialising and independence.

Clinical experience backed by research data shows that early intervention improves aspects of cognition. However, a barrier to customising early intervention is accurately assessing cognition at an early age. For children under 3.5 years of age, one commonly used assessment is the Bayley Scales of Infant and Toddler Development.

Children are challenged to perform various tasks through play to determine their motor, cognitive, and language abilities. However, for children with special needs, this assessment can be inaccurate due to the test's requirements for verbal responses, fine motor control, and restrictive time limits. Dutch researchers have developed a version of the Bayley-III for children with motor, vision and/or verbal impairment (Bayley-III LM/LVi). This version requires less accurate fine motor manipulation, removes time limits, and allows nonverbal responses, appropriate for children living with CP.

CPA has translated this version of the Bayley-III to English and has been trying to understand whether the assessment still tests cognition in the same way and has not become easier or harder due to the changes, and if there is a sub-group of children with CP that it is most useful for.

This research is expected to result in more accurate assessment of cognition in children with CP. This will enable us to better identify which children experience cognitive impairment early, to ensure that they have the greatest opportunity to receive intervention and support.

Cathy's team was awarded a grant from the Cerebral Palsy Alliance Research Foundation to support this work and are currently mid-way through recruitment, with about 75 children already participating in the study.

Early communications study - 'It Takes Two to Talk'

Dr Ashleigh Hines and lead speech pathologist Naomi Hodder are leading a study to determine if early parent/ child interaction training leads to better communication outcomes at two years of age using the well-known Hanen program "It Takes Two to Talk" (ITTT).

The study, titled "Early Communication Intervention for Infants with or at Risk of Cerebral Palsy," aims to address a critical gap in early intervention strategies for children with CP. It empowers parents to facilitate communication and interaction with their infants at home and in day-to-day settings.

This is the largest randomised study of a communication intervention ever conducted in Australia with over 170 children with mild to moderate CP participating.

Infants are randomly assigned to either an early intervention group, receiving the ITTT program before their first birthday, or a later intervention group, receiving the program after turning two years old. Through this randomised control trial, researchers aim to evaluate the effectiveness of the ITTT program for infants with CP.



Epidemiology



Award Winner! **Dr Sarah McIntyre**– 2022 Mentorship

Award AusACPDM



Dr Sarah McIntyre Senior Research Fellow and Program Lead, Epidemiology



Emma Waight
Senior Research
Assistant



Georgina Henry Research Assistant



The Epidemiology team manages the Australian and

congenital infections and congenital anomalies.

NSW/ACT Cerebral Palsy Registers and conducts work

on understanding trends of CP and the complex causal

pathways to CP, including the contributions of genomics,

Dr Hayley Smithers-Sheedy Principal Research Fellow



Kath Swinburn
Research Officer and
Governance Manager



Research Assistant



Dr Shona Goldsmith Sophie M Senior Research Fellow CP Quest C



Sophie Marmont Dr Tas

CP Quest Coordinator Rese



Dr Tasneen Karim Research Fellow



Research Officer

The 2023 Australian Cerebral Palsy Register Report showed that the 40% drop-in the rate of CP from 1 in 400 live births to 1 in 700 had been sustained, along with a decrease in severity. This has been driven by research investment and implementation in public health, maternal health and newborn intensive care.

Driving collaborations across Australia and internationally, the Epidemiology team leads awareness and prevention efforts for known risk factors such as congenital infections, which are infections that exist at birth, such as cytomegalovirus. The team's other recent projects have explored the role of risk factors including congenital anomalies, multiple births and the causes of postneonatal CP. Importantly, this work informs the identification of opportunities to implement preventive strategies. The CPA Research Foundation funded the establishment of the International Genomics Consortium in 2017, and the Epidemiology team supports the consortium through sustained administration and leadership. Research from the consortium indicates that between 10% and 30% of CP has a genetic basis.

"The fact that people with CP are living better lives than any time in history is a milestone to be celebrated – without the ACPR, we would not be able to track and report these important trends and show so effectively the impact of new clinical interventions and improvements."

The Honourable Bill Shorten MP, Minister for the NDIS and Government Services, in the foreword for the 2023 ACPR report.



Rifat (child, middle) with his family in Shahjadpur, Bangladesh

Collaboration on global CP registers

Over the last decade, the number of new CP registers and surveillance programs internationally has rapidly increased. Major CP registers and surveillance networks include our Australian Cerebral Palsy Register, the Surveillance of Cerebral Palsy in Europe, and the Global Low-and Middle-Income (LMIC) Country Cerebral Palsy Register. Our Epidemiology team collaborates widely with registers across the globe to conduct new research, improve access to services, and support new and developing registers. Professor Gulam Khandaker and his team have worked closely with us over many years to spearhead this work.

The ACPR Group has been privileged to work with researchers across the Asia-Pacific region to support the establishment and development of new CP registers including in New Zealand, Singapore, Bangladesh, China, Indonesia, Nepal, Sri Lanka, and Vietnam.

Importantly, the establishment of the Global Low-and Middle-Income Country Cerebral Palsy Register has brought together CP data from across LMICs to report on key issues.

Our close collaboration with the Surveillance of Cerebral Palsy Europe (SCPE), a network of over 20 CP registers in Europe, continued in 2022-2023. Our recent shared projects have included an update on global prevalence, exploration of risk and outcomes of CP in higher order multiples (triplets and quadruplets), and exploring congenital anomalies in children with CP.



Access here

Global prevalence of Cerebral Palsy: A systematic analysis

First comprehensive Aboriginal and Torres Strait Islander study completed

In this landmark study, funded by an Early Career Grant sponsored by the Cerebral Palsy Alliance Research Foundation, a multidisciplinary team of researchers from every state and territory analysed data from 514 children with CP born between 1995 and 2014. It is the most comprehensive epidemiological study of Aboriginal and Torres Strait Islander people with CP to date.

Two in five Aboriginal and Torres Strait Islander children and young adults with CP were born in, or lived in, socioeconomically disadvantaged areas, with 28% of children living in remote and very remote areas. "This research will give health and disability service providers, policymakers and other stakeholders valuable new information to advocate for culturally appropriate services for Aboriginal children with disabilities," said Sarah McIntyre.

The ACPR sought guidance from the Community, Aboriginal and Torres Strait Islander Reference Group during the development and interpretation of the findings of this research and received ethical support from Aboriginal Health and Medical Research Committees across Australia.

Along with the Epidemiology team, Ms Tan Martin, a proud Ngemba woman and researcher at the University of Sydney's School of Nursing and Midwifery, has published the largest study on CP among Aboriginal and Torres Strait Islanders, showing a reduction in CP from 4.8 children per 1000 live births to 1.9 per 1000 live births over the last twenty years.



From left to right: Emma Waight, Tan Martin, Dr Hayley Smithers-Sheedy, Dr Sarah McIntyre

Out-of-pocket costs for people with CP

In 2018, researchers and economists estimated some of the financial costs related to CP in Australia. However, this did not include the out-of-pocket costs for families. While the National Disability Insurance Scheme (NDIS) helps cover some disability-related costs, many families and individuals need to spend their own money each year to manage CP.

Research Assistant Georgina Henry, with a team of researchers and members of CP Quest, completed a project to estimate out-of-pocket costs related to health, assistive technology, personal care, housing, occupation, transport, leisure, respite and holidays. Nintey-four per cent of the 271 survey respondents reported out-of-pocket costs, with a median of \$4,460 per year, and some up to more than \$20,000 per year.

Georgina's work provides practical estimates for the costs of CP, empowering individuals and families with knowledge to assist with financial planning and budgeting. These findings have been used to support advocacy for equitable access to necessary funding and support, and are used to inform government policy, funding, and clinical decisions to best support people with CP and their families.

New research study Out-of-pocket costs of cerebral palsy People with CP and their families are being faced with significant financial burdens due to disability-related costs, according to a new study from Cerebral Palsy Alliance researchers. people with CP, their of those surveyed had families & carers were out-of-pocket (OOP) costs. surveyed about the despite 85% receiving financial impact of CP. disability funding. reported annual expenses of more than \$20,000 per-year. are experiencing high to overwhelming Severity of CP is directly linked to financial impact, with OOP costs more than twice as high for those requiring mobility assistance. \$10,990 \$2,660 The most common areas for OOP spending were: Health: \$1,190 Transport: \$1,050 Home modifications: \$1,000

This research has been co-designed by people with lived

experience of cerebral palsy. Families have told us they

are extremely grateful for the NDIS - it has

been a game-changer. Yet, there is still

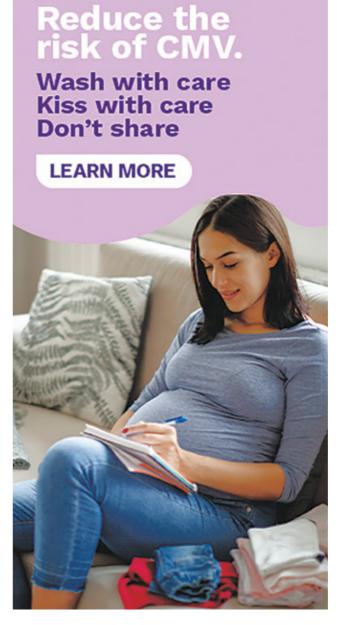
scope to improve how we best support people to have equal opportunity.

Georgina Henry
CPA Research Institute

Cerebral Palsy

Raising awareness and improving education on CMV

Cytomegalovirus (CMV) is a common herpes virus, spread through close person-to-person contact with infected bodily fluids like saliva and urine. CMV is harmless to most people, however, if a pregnant woman is infected with CMV, there is a risk that the virus will be passed to her unborn baby, causing injury to the baby's developing brain. Every year in Australia, close to 2000 babies are born with CMV. Of these, about 400 will go on to have life-long disabilities, including deafness and CP.



"Easy Ways to Care" CMV campaign 2023

National maternity guidelines recommend all pregnant women be informed about measures to reduce their risk of CMV infection. However, less than 20% of pregnant women are aware of CMV and just 10% of maternity health professionals report that they routinely discuss CMV with pregnant women and families in their care. Led by Dr Hayley Smithers-Sheedy, Cerebral Palsy Alliance has embarked on a new campaign to change this.

To mark CMV Awareness Month in June, Cerebral Palsy Alliance and CMV Australia joined forces with researchers from the University of Sydney, University of New South Wales and University of Melbourne, clinicians, virologists and families with lived experience of CMV. Together we launched the 'Easy Ways to Care' campaign to educate and inform pregnant women and their families, medical professionals, and the wider public about the risks of CMV – and importantly, how it can be prevented.

This campaign included a publishing partnership with Kiindred, a parenting and education platform with a 5.1 million monthly impressions across digital platforms; digital channels such as Google Ads; content seeding; and a digital and social media campaign. The campaign resulted in a 141% increase in visits to the CPA CMV webpage, with a reach of 101,000 unique page views among our target audience and a click volume increase of 3.75 times, compared to the 2022 campaign, demonstrating the interest and increasing impact of the campaign.

To improve knowledge of CMV, a free e-Learning course for midwives was developed by a team from Cerebral Palsy Alliance led by Hayley and Kath Swinburn, The University of Sydney, CMV Australia and the Australian College of Midwives (ACM). Launched in 2020, over 1500 midwives from across Australia have now enrolled in the course, with 500 midwives enrolling in 2023. Buoyed by this success, a similar module was launched for General Practitioners in March 2023. Interim evaluation results show that after completion of the module, 96% of general practitioners (GPs) intended to routinely provide CMV counselling to patients in their care.

'I found out the hard way': Why this GP is talking about CMV

The full article was originally published in The Royal Australian College of General Practitioners (RACGP) on 2 June 2023.

Dr Hugh Stump has a very personal reason for trying to bridge some surprisingly wide gaps in knowledge. In late 2020, Hugh was in his car when he took a call that will stay with him forever. Already a father to a young daughter, the GP and his wife, Hanako, were expecting their second child and needed to travel away from their home in Orange, NSW, for further tests.

Up to that point the pregnancy had mostly seemed routine. However, during a 28-week ultrasound, Hugh recalls a sonographer spotting a suspected small pericardial effusion around their baby daughter's heart. Around the 30-week mark, they made the journey back to Nepean Hospital for a full foetal MRI.

'I will never forget ... as we were driving back to Orange, we got a call from the foetal medicine specialist saying that there were some pretty complex brain changes that would be consistent with congenital CMV [cytomegalovirus],' Hugh said. 'I think the words they used were "a high chance of severe disability",' he said.

While his training meant Hugh knew about congenital CMV, he was not aware of the risk it could pose during pregnancy when it mattered most. And that fact that it can be preventable.

'There's so many health professionals who have never even heard of congenital CMV," said Hugh.

Hugh and his family want to help others to avoid a similar situation, and believe GPs are ideally placed to flag the risks and what can be done to mitigate them. Fortunately, Hugh's youngest daughter, now two and a half, is thriving compared to that bleak original prognosis. While she has profound bilateral deafness and uses cochlear implants, she is free of the neurodevelopmental disabilities such as epilepsy and CP that can occur.

'[Our daughter] didn't get away with it scot-free, but she's a beautiful kid,' Hugh said. 'She's got a really vibrant personality, and we wouldn't change anything.

'But you also wouldn't wish it on any parent. We just wish we were told about the risks of CMV.'

Hugh, Hanako and their two beautiful daughters

Technology

The Technology team is a diverse group of engineers, clinicians, and researchers. Their goals are to advance cutting-edge projects focused on inclusive design, further unlock the future of assistive technology, enable accessible cognitive assessments, and to enhance current communication and mobility solutions for people with CP.

Dr Petra Karlsson and her team collaborate widely across the University of Sydney and leading global research groups and technology companies.



Dr Petra Karlsson Program Lead for Technology, Adjunct Senior Lecturer



Professor Alistair
McEwan
Chair of Technology
& Innovation



Dr Ingrid Honan ant Senior Research Fellow Cognition, CP Strategy



The My Voice Library team at the launch at CPA Head Office at Allambie, Sydney and streamed online.

My Voice Library: a world-first database

Petra is the proud recipient of a prestigious \$1.1 million grant from the Australian National Health and Medical Research Council to establish "My Voice Library," a world first voice archive for children with CP. This groundbreaking project will collect dysarthric voices of people living with CP, creating a unique voice data resource for engineers and researchers who need big data sets to test their novel speech innovations.

Speech is difficult or impossible for 50% of children with CP, posing a significant barrier to participation in everyday life. The My Voice Library project will provide a comprehensive database that leverages recent advances in artificial intelligence, virtual and augmented reality, and Brain-Computer Interface technology. These technological advancements, combined with new analysis techniques, offer the potential to develop effective solutions for speech difficulties.







Darryl Chiu, and researchers from the University of Sydney, visiting the Chinese University in Hong Kong

Trying out some fun new accessible toys.

TechToys supporting play for the sake of play

Play is vital for the development of many skills in a child. However, infants and toddlers with physical disabilities often experience a less independent form of play, resulting in overall reduced playtime. Toys and games that are commercially available are often not adapted for children with motor impairments.

The TechToys project is a multi-stakeholder research team consisting of parents, clinicians, engineers, and researchers. The goal is to design toys that children with severe CP can play with to support physical, cognitive, language and social-emotional developmental outcomes.

A core part of the team are bio-medical engineering students at The University of Sydney, who drive the design and build of these toys. "Come and Try" days were held at four CPA sites with 11 children with CP aged between six months and three years coming along to help with the toy testing. Three toys have currently been designed, and trialled with 10 families and pending funding will be commercialised.

Developing soft exoskeletons to make moving easier

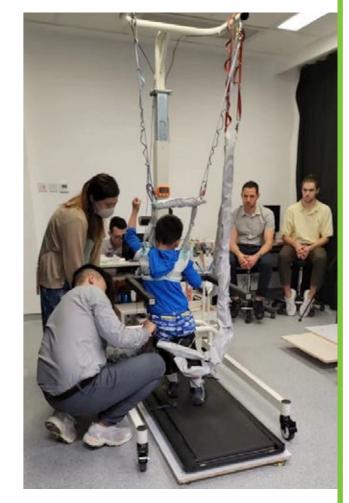
Children with severe CP may have difficulty with movement and control of their legs. This can greatly reduce interactions with their environment in terms of mobility and their ability to explore and learn. Traditional interventions to improve mobility in children may consist of physiotherapy, strength training and aquatic therapy.

In the last few years, numerous sensorless and sensor-based exoskeletons have been developed for rehabilitation to enhance and support motor function, however, options for children have been very limited.

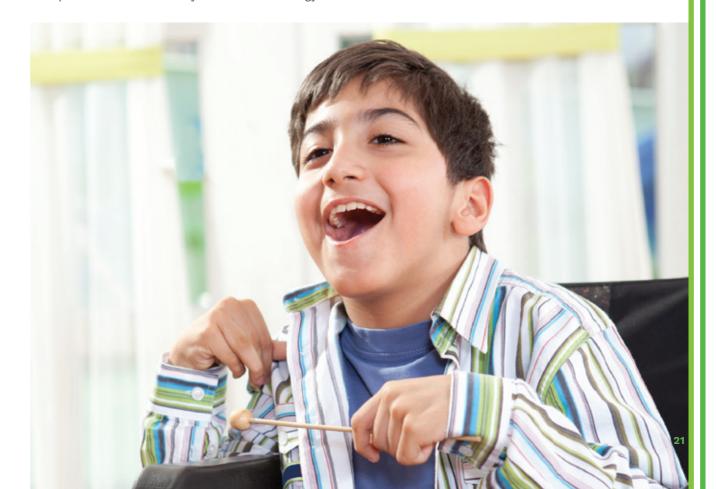
In collaboration with the Chinese University of Hong Kong, Alistair McEwan, Darryl Chiu and Petra Karlsson, together with researchers at the University of Sydney, have been working on a project using pneumatic actuators as a 'soft exoskeleton' to assist with different movements such as walking or sit to stand, for children with CP.

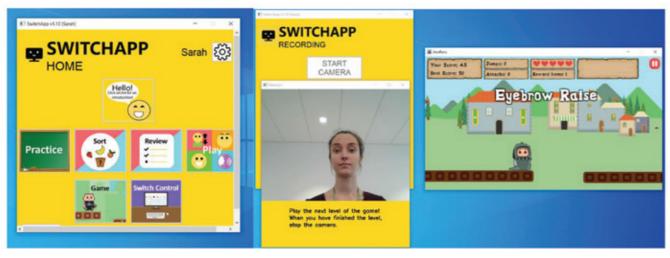
Pneumatic actuators (which convert energy in the form of compressed air into motion) are wrapped in a soft material around the child's knees, with pressure pumped into the actuators to inflate the cuff at the back of the knees.

Controlling the inflation and deflation of the cuff to the child's ability will assist the child with various movements. Early studies show that after 20 sessions children had a much-improved walking pattern, and hold promise for a novel early intervention strategy.



A child with CP using the soft exoskeleton to walk on a treadmill, Hong Kong.





SwitchApp can recognise sound and facial movements (such as raising your eyebrows) to then use those movements as controls for a video game or communication device.

SwitchApp – control through sound and facial movement

Our researchers, Darryl Chiu and Petra are collaborating with Professor Tom Chau, A/Professor Silvia Orlandi, Fanney Hotze and the team at the PRISM lab from the Holland Bloorview Institute in Toronto, Canada, on a project called SwitchApp – software for recognising sound and facial movements from a user to then control a program.

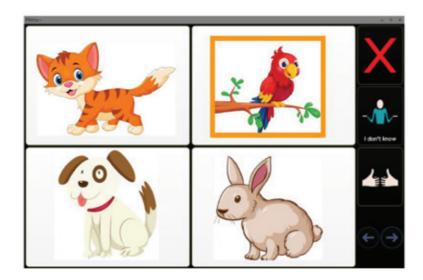
SwitchApp can recognise facial movements (such as smiling or raising an eyebrow) and sounds/key phrases (such as a simple yes or no) through a camera and microphone. These movements and sounds can then be used as commands for controlling a computer or communication board.

To test the usability and performance of the SwitchApp, the software is currently being tested by children with CP to see if they are able to play a custom video game using facial movements and/or keywords as the controls.

Cognitive assessments modified for use with assistive technologies

It is often difficult to assess a child's cognitive ability if they have movement or speech impairments. Researchers Petra Karlsson and Ingrid Honan have started have started a study called CogTEST-Children, a project to examine the psychometric properties of standardised cognitive assessment tools when modified for use with assistive technologies such as switch and eye-gaze control technology.

This project holds the potential to, for the first time, enable equal access to accurate cognitive assessments. This is essential in recognising a child's strengths in the classroom and to enable them to reach their full potential.



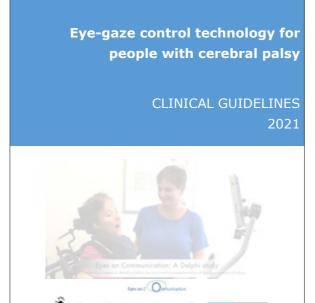
Here is an example of a test question. The child is asked to 'find bird' and the computer scans through the different pictures and when the orange box is around the bird, the child makes their selection with the switch.

Developing Clinical Guidelines for eye-gaze technology

Eye-gaze control technology is an access method. Instead of using hands to control a mouse, keyboard, or touch screen, a person can use their eyes to access a computer or device. Eye-gaze technology set up can be complicated, usually involving different trials across a variety of environments including the clinic, home, and at times school/preschool.

Parents, clinicians and researchers identified that there was a need for research on how to best decide which device to choose and how it is best mounted and set up for the eye-gaze user. To address this need Petra established and led a research team and global advisory panel - The Eyes on Communication Research Group and Advisory Panel.

Members of Eyes on Communication are researchers, clinicians, suppliers, parents and people currently using eye-gaze technology. This resulted in the development of Clinical Guidelines that set out guidelines for the assessment, trial, implementation, support and review of eye-gaze technology and discusses recommendations for when eye-gaze technology is not currently an appropriate access method. Building on this, two honours projects were conducted through interviewing clinicians, and people with lived experience. These projects identified barriers and facilitators for implementation of these guidelines, and supported the creation of resources such as case studies and evaluations as supports.







Award Winner! **Dr Petra Karlsson**- 2023 Good Design Awards:
My Voice Library awarded two
coveted Good Design trophies,
in the 'social impact' and 'digital
- apps and software' categories.

Access the Clinical Guidelines here



Regeneration



Dr Megan Finch -Edmondson Senior Research Fellow and Program Lead,



Research Fellow



Research Fellow

Remy Blatch Research Assistant

Stem cells are special cells that can make copies of themselves, create different cell types, reduce inflammation, influence other cells, and can indirectly and directly repair and rebuild tissues.

Members of the CPA Regeneration team are researching how stem cells could be useful for treating or even preventing CP through their ability to protect vulnerable brain cells and preserve their function, help to repair injury, or even support replacement and regeneration of damaged cells.

Current projects are focused on progressing:

- the use of umbilical cord blood cells for CP
- investigating mesenchymal (bone marrow, cord cells) stem cells for babies at risk of CP
- · working with the CP community to inform, raise awareness and answer questions people with CP and their families may have about stem cell treatments.

Regeneration theme researchers are also investigating several non-stem cell therapies coined "advanced therapeutics". Dr Alex Griffin is leading this area of research and is currently working on a trial of non-invasive brain stimulation known as 'transcranial direct current stimulation' (tDCS) for children with CP. This is a collaboration with world leaders in paediatric brain stimulation from the University of Wisconsin-Madison.





"Stem cell research is a really exciting area to be working in. In the last 15 years we have seen great progress in this field, with potential for many new CP discoveries. Importantly, we know that stem cell research is a high priority for the CP community, and we are working hard, together with a network of collaborators, to drive research in this space."

Dr Megan Finch-Edmondson

tDCS is a safe form of non-invasive brain stimulation that can improve motor skills in children with CP when combined with motor training. The amount of energy introduced into the brain during tDCS is smaller than the amount of energy that brain cells produce on their own. However, the effects are noteworthy. tDCS works by providing a boost to the brain during the practice of motor skills, which is believed to improve the brain's ability to learn and adapt.

To date, tDCS has only been used for children with CP in the clinic. Because the effects of tDCS are cumulative, in other words, the effects increase over time with repeated stimulation, multiple, consecutive days of treatment provide the best results. Travelling to and from the clinic can be burdensome for families, and providing this treatment face-to-face also limits accessibility for families in rural and remote regions of Australia.

We are preparing to open a trial of remotely delivered tDCS where we will be working with families across the country to establish safety and feasibility of this technology in the home environment. This is the first trial of its kind in the world and we hope it will pave the way for a future tDCS clinical program in Australia.

Australian-first study of umbilical cord blood for **CP** published

A big milestone in 2022 was the publication of the results of Australia's first trial of umbilical cord blood stem cells as a treatment for CP, called the SCUBI-CP trial. This phase I clinical trial included 12 participants aged 1-16 years from across Australia. Over 12 months, children were closely monitored for any adverse effects after receiving their sibling's cord blood cells.

This trial found that collecting and storing cells from a baby's umbilical cord and later giving them to a sibling with CP is safe. However, researchers emphasised that treatment should take place in tertiary hospitals that are equipped to handle any rare adverse reactions.

In terms of effects on development and symptoms, results showed that most participants demonstrated typical developmental progress over the monitored year, although three children showed remarkable improvements in gross motor function just three months after treatment.

Although these changes were less pronounced after a year, it was highlighted that younger children showed the most significant improvements, suggesting that early intervention may give the best results.

The findings are an important step forward in confirming the safety and feasibility of using umbilical cord blood in managing CP in Australia. CPA researchers are looking at next steps for umbilical cord blood research in Australia, in line with the progression of international research in this area.



Emily was one of the first children with CP to be treated using umbilical cord blood stem cells in Australian research. Her mother, Claire, says "I wish the floodgates would open so we could do as much research as possible."

Claire and Emily Sayers participated in the SCUBI-CP trial

Big wins for parent involvement in stem cell research for babies with stroke

Neonatal stroke is a leading cause of CP. There are no available effective treatment options for babies who have had a stroke that can be applied early to prevent brain injury. Stem cell research is now at a breakthrough stage where we can begin to move findings from the lab and into the early phases of clinical research. Regeneration team member Dr Madison Paton has been working closely with parents, specifically Mrs Kylie Facer, OAM, to advance clinical trials in Australia and bring new research innovations into neonatal intensive care.

Our latest research aims to bring a cutting-edge stem cell treatment into the clinic for babies with stroke. To make this possible, Madison and the team (including Principal Investigator, Dr Himanshu Popat pictured) have spent the last year raising awareness for this research, priming neonatal intensive care units and working towards establishing this important study across

Australian hospitals. This research represents a huge collaboration between science and the CP community and has involved extensive consultation with the Cerebral Palsy Alliance Stem Cell Reference Group and the Monash Newborn Consumer Advisory Group.

Efforts to involve parents in clinical research design for stem cell therapies have been recognised with a 2021/2022 Power of One Grant from the White Coats Foundation, awarded to Madison. This award will support ongoing involvement of parent investigators and other people with lived experience to attend necessary team meetings, conferences and workshops to design this world-leading research for babies with stroke. The team was also recently recognised in national competitive research grants. We look forward to progressing this clinical trial and bringing stem cell research innovations into neonatal intensive care.



Dr Himanshu Popat, Mrs Kylie Facer OAM and Dr Madison Paton who are working together to develop stem cell research for babies who have had a stroke.

"It is critically important to respect the lived experience of the people with CP receiving this potential treatment and the views of their support network. By involving consumer stakeholders early in the research process, the treatment can both be better understood by the community and targeted to the groups that are willing to use the treatment,"

Natasha Garrity said.

PhD student Madeleine Smith surveys the CP community

CPA researchers Megan and Madison collaborated with PhD student Dr Madeline Smith and Dr Courtney McDonald from the Hudson Institute of Medical Research, and the CP community, to explore the boundaries of stem cell therapy. Advancing stem cell research is a priority for the CP community and neural stem cells offer potential as a future regenerative treatment. However, neural stem cells are often thought to be a complex potential treatment, with ethical and moral considerations.

To better understand the acceptability of neural stem cell treatment within the CP community, the team collaborated on a survey that received responses from 232 Australians with CP, their parents and/or carers.

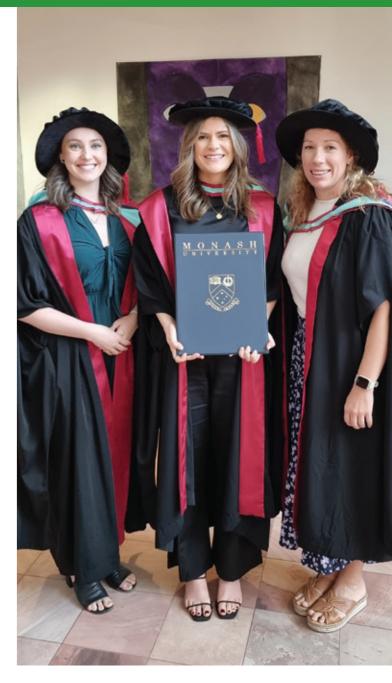
Natasha Garrity, Research Assistant at Cerebral Palsy Alliance Research Institute and Co-Chair of the CPA Stem Cell Reference Group welcomed this research as an important opportunity for people living with CP and their families to provide their perspectives.

CPA Stem Cell Reference Group celebrates five years of connection and shared learning

May 2023 saw the 10th meeting of the Cerebral Palsy Alliance Stem Cell Reference Group, founded by Dr Megan Finch-Edmondson in 2018. The group aims to empower members of the CP community by increasing their knowledge and engagement in stem cell research. Now comprising more than 50 members, the group meets twice a year to hear updates on the field of stem cell research and learn about opportunities to get involved in research projects.

Reflecting on five years of the group Megan said, "This group has been invaluable to our team and collaborators, providing insights and priorities from the CP community."

"Through this network we have been able to involve people with lived experience in the process of designing new projects, on applications for project funding, and members have spent time reviewing and providing feedback on documents for several studies. This really improves the quality of our research, and we are so grateful for their involvement," she said.



Dr Madeleine Smith (centre) who led this work as a PhD student with two of her supervisors, Dr Madison Paton (left) and Dr Courtney McDonald (right).



Alex Griffin awarded Thrasher Research Fund Early Career Award & Brain Australia Research Grant

Our team is incredibly excited to have received funding for our trial of remotely delivered transcranial direct current stimulation (tDCS). The Thrasher Research Fund Early Career Research Award and the Brain Australia Medical Research grant is supporting our team, including lived experience research partners and expert clinical and research staff, to deliver this technology remotely to families across the country.

We look forward to opening this trial and promoting equitable access to innovative technologies for children with CP.



Award winner! Sarah Reedman
CPA Implementation Fellow, Therapy
Services – awarded 2023 Sydney
Health Partners Implementation
Science Academy Fellow

Australia and New Zealand Cerebral Palsy Strategy

In 2020, a collaboration of Australian and New Zealand CP organisations, researchers, health professionals and people with lived experience released the Australian and New Zealand Cerebral Palsy Strategy. The Strategy guides key decision makers to deliver support, promote excellence in research, leverage funding avenues and enhance community knowledge.

In 2023, an Impact Report for the Strategy was released. The four priorities of focus in the Impact Report were:

- Reducing the age of CP diagnosis to enable early intervention
- 2. Improving outcomes through partnership with the National Disability Insurance Agency
- 3. Improved health and wellbeing for people with CP across their life-span
- 4. Improved community understanding of CP including complex communication

In rating progress, priorities 1 and 3 require further funding for sustainability and priority 2 requires further government commitment. Pleasing progress was made for priority 4, with many initiatives being led by CPA, including our flagship fundraising drive, STEPtember, World CP Day, CPActive community work, CMV Awareness Month and the building of the My Voice Library.



PhD Research

PhD students are crucial to the progress of research studies. There is a wide breadth and depth of studies conducted by PhD students who work with CPA. The following is an update on some of the amazing work by some of our PhD students, who are accelerating breakthroughs in prevention, interventions and cures for CP.

HAIFENG ZHAO – Wearable Augmentative and Alternative Communication (AAC)

Haifeng Zhao is a PhD student at the University of Sydney, with a background in biomedical engineering. He recently submitted his PhD, under the supervision of our Chair, Professor Alistair McEwan; Program Lead, Dr Petra Karlsson; and from the University of Sydney, Associate Professor Omid Kavehei.

Currently, available assistive communication devices often lack privacy, convenience, portability, and social acceptability. To overcome these issues, Haifeng is inventing a novel wearable device that combines three innovative technologies:

- Mixed Reality (MR), a type of virtual reality presented with the real environment on regular glasses and eyetracking technology using cameras mounted on the glasses;
- 2. Brain-Computer Interfaces (BCI) that pick up the electrical activity of the brain from a head-worn sensor; and
- Real-time item recognition based on machine learning and image processing to help to interpret users' intentions and provide contextual information to make communication faster and more natural with increased usability and inclusion.

He hopes that these technologies will assist people with different communication needs, and his findings are due to be published.



Haifeng using an AAC



EMMA WAIGHT Aetiological (causative) risk factors
and opportunities for prevention of
postneonatally acquired cerebral palsy

Emma is a Senior Research Assistant at the Cerebral Palsy Alliance Research Institute.

Children with acquired CP, after one month of life and before two years of age, account for roughly 5% of CP in Australia. The causal pathways of post-neonatally acquired CP are generally known, with certain causes considered preventable. Due to small numbers, there is limited research on this group, and little is known about the impact of preventive health interventions on post-neonatally acquired CP prevalence and trends.

Emma's research will explore what post-neonatally acquired CP looks like in Australia, identify risk factors, and investigate current and historic preventive health interventions.

YANA WILSON -

Phenotype-genotype studies in multiplex families of cerebral palsy and other neurodevelopmental disorders

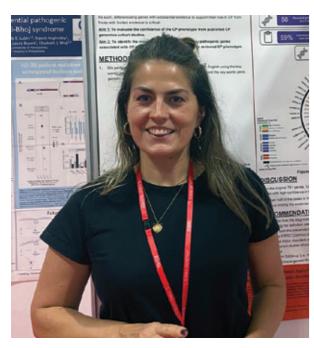
Yana is a Research Officer at the Cerebral Palsy Alliance Research Institute and in her fifth year of a part-time PhD.

Yana recently presented a study entitled, 'Evaluating clinically relevant genes identified in CP cohorts following a review of the CP description and phenotype' at the European Society of Human Genetics.

This study evaluated the quality of the CP description and diagnosis in studies looking for genetic variants that contribute to CP.

Currently, genetic variants can be identified in 5-40% of people with a CP diagnosis, depending upon the sequencing method used and the inclusion criteria for participants. We found that there were inconsistent approaches to how CP was described and diagnosed among many of these studies, impacting the interpretation of these genetic findings to CP aetiology. Our findings underscore the importance of accurately describing and reporting the clinical traits of individuals in future genetic studies of CP, as well as the ongoing follow up of individuals with genetic findings to better understand their long-term outcomes.

Yana is currently recruiting families to a new study that examines genetic causes to understand why some siblings of people with CP may be more at risk of developing another neurodevelopmental disorder, such as autism, epilepsy or intellectual disability. This is the first study of its kind, and Yana hopes that this study will provide evidence for future research into this currently little understood and resourced space.





DR AMANDA KHAMIS – Baby Intensive Early Active Treatment (babiEAT)

Dr Amanda Khamis is a Speech Pathologist and Postdoctoral Research Fellow at Cerebral Palsy Alliance Research Institute and was awarded her PhD in June 2023.

Amanda undertook her PhD research due to the scarcity of high-quality studies on therapies for infants with feeding and swallowing difficulties related to CP.

After surveying more than 230 speech pathologists globally, specialising in this clinical area, it was found that speech pathology services do not align with the available evidence. Amanda created a new and innovative feeding program called Baby Intensive Early Active Treatment (babiEAT).

This program challenges babies' eating and drinking skills using principles recently proven to help teach children with CP to walk. Amanda led a study testing babiEAT against usual care and found that those babies who received babiEAT were feeding more efficiently, were more independent with drinking, consumed more advanced food textures, and had shorter mealtimes without negatively impacting their intake, health, or weight.

We are excited to see a larger study to strengthen these outcomes in the future.

Closing remarks from the Chair

As we reflect on the notable achievements of 2023 and the journey that has brought us to almost two decades of the Cerebral Palsy Alliance Research Institute, we are profoundly grateful for the collaborative efforts that have reshaped outcomes for individuals with CP and their families.

Today, Cerebral Palsy Alliance Research Institute stands as a global leader in neo/perinatal care, boasting one of the lowest rates of CP worldwide at 1 in 700 births. This success demonstrates the collective dedication of doctors, nurses, allied health professionals and the invaluable insights shared by individuals with CP and their families.

In 2023, our Research Institute continued to lead breakthroughs in prevention, interventions, and potential cures for CP across four key research themes: Epidemiology, Early Diagnosis and Early Intervention, Technology, and Regeneration. Our researchers are amongst the top leaders in the field of worldwide, and our work has been referenced by policies from the World Health Organisation.



Looking forward, we continue to work on many of these studies such as the Australian Cerebral Palsy Register, which provides valuable data for researchers and clinicians; work on early detection and intervention strategies to support babies and parents; developing assistive technologies to help people living with CP to have fuller lives; and we are invested in paving the way for stem cell therapies.

We are also forging new frontiers through genetic research, understanding natural history of CP, refining use of cord blood as a treatment for CP, and communication innovation.

This report reviews the foundation we have laid in 2022-2023 and sets the stage for transformative advancements in the years to come.

With heartfelt appreciation to our supporters, partners, and the broader community, we continue our pursuit of a future where individuals with CP thrive in a world full of opportunities.

Thank you for your continued support.

Professor Nadia Badawi AM, Chair of Cerebral Palsy

Academic publications

The research team, alongside their collaborators, published 70 papers in 2023, making a significant contribution to the body of work about CP and potential treatments. Thirty-seven per cent of these publications are international collaborations, and have been cited in 46 different countries, indicating our global standing.

In FY2023 alone, the work of the CPA Research Institute has collectively received more than 30 news mentions, 552 on X (previously known as Twitter), and significantly, one mention from a WHO (World Health Organisation) policy paper. In this short time, twelve of these publications are now amongst the top 10% of the most cited publications worldwide, demonstrating the scientific importance of the work we do, and also the impact of this research.

In order of chronology, papers published or accepted for publication between July 1, 2022 and June 30, 2023.

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- 5. Bekteshi S, Konings M, Karlsson P, Criekinge TV, Dan B, Monbaliu E. Teleintervention for users of augmentative and alternative communication devices: A systematic review. Dev Med Child Neurol. 2023;65(2):171-84.
- 6. Popat H, Angiti R, Jyoti J, Webb A, Barnes E, Halliday R, Badawi N, de Lima J, Spence K, Thomas G, Shun A. Continuous local anaesthetic wound infusion of bupivacaine for postoperative analgesia in neonates: a randomised control trial (CANWIN Study). BMJ Paediatr Open. 2022;6(1).

- 7. Jahan I, Al Imam MH, Muhit M, Chhetri AB, Badawi N, Khandaker G. Epidemiology of cerebral palsy among children in the remote Gorkha district of Nepal: findings from the Nepal cerebral palsy register. Disability and Rehabilitation. 2023;45(17):2808-17.
- 8. Finch-Edmondson M, Paton MCB, Honan I, Galea C, Webb A, Novak I, Badawi N, Trivedi A. Proportion of Infant Neurodevelopment Trials Reporting a Null Finding: A Systematic Review. Pediatrics. 2023;151(2).
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- 11. Jahan I, Ruiz Brunner MLM, Muhit M, Hossain I, Cuestas E, Cieri ME, Condinanzi AL, Escobar Zuluaga LJ, Badawi N, Khandaker G. Novel weight estimation equation for children with cerebral palsy in low-resource settings: Validation in a population-based cohort. Dev Med Child Neurol. 2023;65(4):517-25.
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- 13. Caserta A, Reedman S, Morgan P, Williams CM. Physical activity and quality of life in children with idiopathic toe walking: a cross sectional study. BMC Pediatrics. 2022;22(1):544.
- 14. Huggins JE, Karlsson P, Warschausky SA. Challenges of brain-computer interface facilitated cognitive assessment for children with cerebral palsy. Frontiers in Human Neuroscience. 2022;16.
- 15. Miller SL, Bennet L, Sutherland AE, Pham Y, McDonald C, Castillo-Melendez M, Allison BJ, Mihelakis J, Nitsos I, Boyd BJ, Hirst JJ, Walker DW, Hunt RW, Jenkin G, Wong F, Malhotra A, Fahey MC, Yawno T. Ganaxolone versus Phenobarbital for Neonatal Seizure Management. Annals of Neurology. 2022;92(6):1066-79.

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- 19. Burne L, Sitaula C, Priyadarshi A, Tracy M, Kavehei O, Hinder M, Withana A, McEwan A, Marzbanrad F. Ensemble Approach on Deep and Handcrafted Features for Neonatal Bowel Sound Detection.

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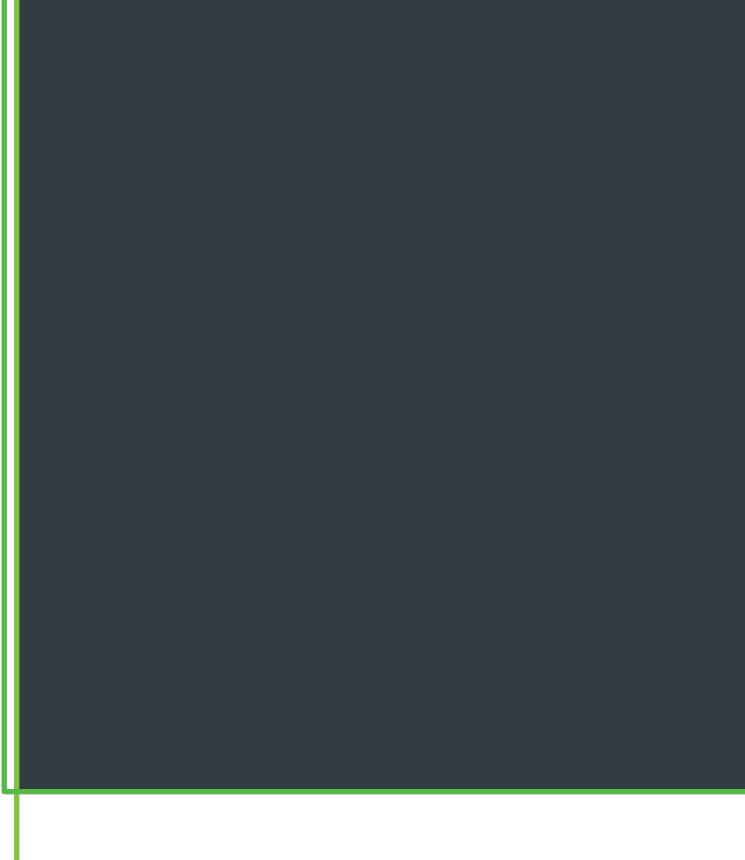
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