



**Cerebral Palsy**  
ALLIANCE



**CELEBRATING  
20 YEARS  
of the CPA Research Institute**

## Turning vision into global impact

For more than 80 years, Cerebral Palsy Alliance (CPA) has been a leader in innovation, advocacy and support for people with cerebral palsy (CP). Since establishing our dedicated Research Foundation and Research Institute two decades ago, we've transformed what's possible.

The CPA Research Foundation was founded with the ambitious goal of improving outcomes for people with cerebral palsy, and is underpinned by a philosophy of collaboration with people with lived experience. Twenty years later, the Research Foundation is now the world's largest private funder of cerebral palsy research. This funding enables CPA Research Institute to conduct life-changing research and analysis – from contributing to a 40% decline in the rate and severity of cerebral palsy in Australia, to shaping clinical practice globally through investigation, data and innovation.

The CPA Research Foundation also supports grants that fund tailored research in countries outside Australia, helping address local needs and drive meaningful change for communities around the world.



**PROFESSOR  
NADIA BADAWI AM**  
Chair of Cerebral Palsy  
at Cerebral Palsy Alliance  
Research Institute.

## Welcome from the Chair

Twenty years ago, a bold vision took shape: to uncover the causes of cerebral palsy, develop new treatments, and improve the lives of people with cerebral palsy around the world. What began as a hope has become a movement, and today we celebrate the power of that commitment.

We have seen remarkable change: a 40% drop in the rate and severity of cerebral palsy in Australia, the implementation of life-changing interventions, and the emergence of globally recognised research leaders. But at the heart of our work has always been people – individuals with CP, their families, and the clinicians, researchers and philanthropists around the world who stand with us every day.

Thank you for being part of this journey. Together, we're reimagining what's possible.

## A legacy built on vision

CPA was founded in 1945 by a determined group of parents. Over the ensuing decades, it became clear to CPA's leadership that research was crucial to changing the lives of people with cerebral palsy. As a result, in 2005 the Research Institute was established by the newly created Research Foundation.

This was only possible thanks to a generous and pivotal gift in Will from the co-founder of Marshall Batteries, Elsie Thompson, and a donation from the Australian Government. That legacy has created a powerhouse of innovation and collaboration, which continues today under the able leadership of CEO Rob White, Chair of Cerebral Palsy Professor Nadia Badawi AM, and their team.



In 1958, the Country Children's Hostel was officially opened by the Governor of New South Wales, later becoming the site of Cerebral Palsy Alliance Head Office.



A baby in the Grace Centre for Newborn Intensive Care, Westmead

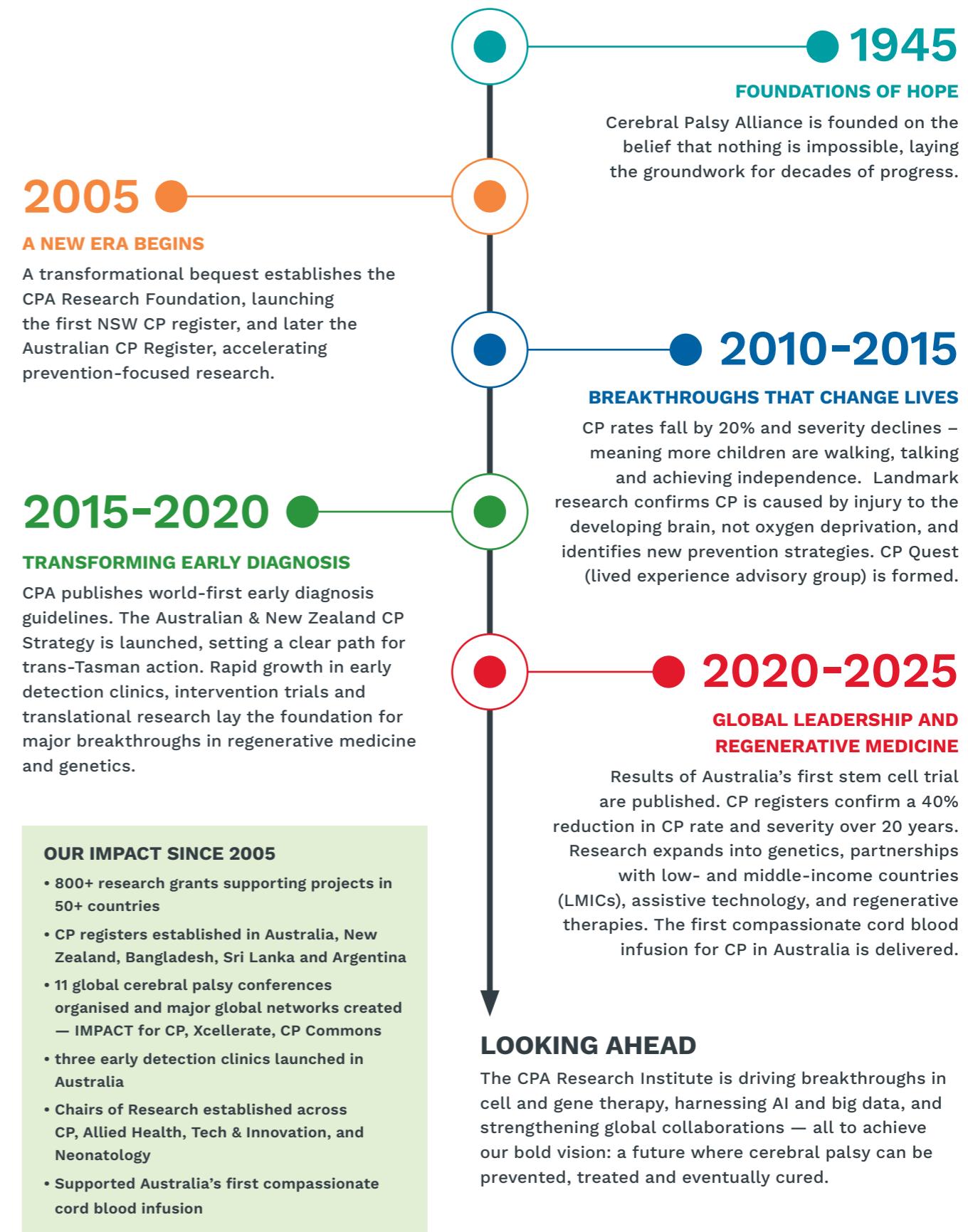
## A vision to change the future

The CPA Research Institute was founded with one clear goal: to improve outcomes for people with cerebral palsy through world-leading, evidence-based research.

In the two decades since its founding, the Research Institute has grown from a small, passionate team into a global research powerhouse, with more than 40 dedicated staff, a team of postgraduate researchers and hundreds of collaborative partners worldwide.

Its staff support research shaped by lived experience and are dedicated to understanding cerebral palsy – from early detection and intervention to regenerative medicine, genomics, and the creation of global CP registries and assistive technologies.

## 20 years of impact: Our research journey at a glance



# Strategic leadership and focus

At the CPA Research Institute, we:

- focus only on cerebral palsy, the most common childhood physical disability
- invest in people and partnerships
- prioritise impact over competition
- collaborate globally, aiming for equitable access to services, early detection and intervention where it is most limited.

This focus allows us to attract leading researchers, contribute to groundbreaking findings and drive significant shifts and improvements in CP research.



Young members of our Advocacy team, CPActive

## CP QUEST: POWERED BY PEOPLE

At the heart of our work are people with lived experience. Launched in 2015, CP Quest is a world-leading collaboration between the Cerebral Palsy Alliance research team and people with cerebral palsy, their families, carers and advocates. Through CP Quest, we ensure that research is guided by the voices of those it's designed to benefit.

Since 2015, more than 165 people with lived experience of CP have:

- informed research priorities
- co-designed studies and tools
- presented at global forums
- contributed to academic publications.

## LEADING EXPERTS AND TEAMS

Our impact is powered by people. We back and support the best minds – because great minds think differently.

**Our Chairs advocate, influence and educate:**



**PROFESSOR**  
**NADIA BADAWI AM –**  
**Chair of Cerebral Palsy**

Professor Badawi is a global neonatal expert. Her work has improved neurodevelopmental outcomes for at risk babies, improved neonatal intensive care survival rates to >96%, and supported a decrease in rate of CP by 40%.



**Professor**  
**Iona Novak AM –**  
**Chair of Allied Health**

Professor Novak is a knowledge translation expert who focuses on building global capacity and clinical trial innovation.



**PROFESSOR**  
**SARAH MCINTYRE –**  
**Epidemiology**

Professor McIntyre is an expert in the incidence, distribution and causes of CP.



**ASSOCIATE PROFESSOR**  
**CATHY MORGAN –**  
**Early Diagnosis and Early Intervention**

Professor Morgan is a pioneer of early diagnosis and intervention.



**DR PETRA KARLSSON –**  
**Technology**

Dr Karlsson is an award-winning leader in communication and access solutions for people with CP.



**DR MEGAN FINCH-EDMONDSON –**  
**Regeneration**

Dr Finch-Edmondson is an expert in cord blood and other cell therapies for CP.



**PROFESSOR**  
**ROD HUNT –**  
**Chair of Victoria**

Professor Hunt is a neonatologist, neuroimaging expert and governance advocate, leading clinical trials and investigating novel treatment options.



**PROFESSOR**  
**ALISTAIR MCEWAN –**  
**Chair of Technology and Innovation**

Professor McEwan is a medical device expert and advocate for device development, whose work bridges academia and industry.

## Our impact

CPA IS NOT JUST A MISSION, IT'S A MOVEMENT.

Since CPA's inception, we have:



helped drive a **40% drop** in the rate and severity of CP in Australia



reduced the **average age** of CP diagnosis from 19 months to as young as **3 months** of age



raised over **A\$100 million** for global cerebral palsy research



founded the world's **three leading early diagnosis clinics**, assessing more than **680 infants**



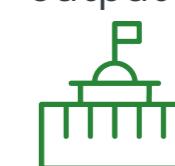
influenced clinical care with **world-first early diagnosis guidelines** adopted in more than **36 countries**



supported the establishment of **14 cerebral palsy registers** in low-and middle-income countries



established the largest national CP register **in the world**



become recognised as the **top research institute globally** for CP research output (Expertscape).

**And we're just getting started....**



## PRE-BIRTH AND BIRTH RESEARCH



Dr Hugh Stump with his wife Hanako and their two beautiful daughters

### Dr Hugh Stump's story

In 2020, general practitioner Dr Hugh Stump and his wife Hanako received difficult news during a pregnancy check-up. Their unborn daughter showed signs of congenital CMV, a common but often overlooked virus that can cause lifelong disability.

Despite his medical background, Hugh hadn't known how serious CMV could be, or how preventable it is.

Today, his daughter is thriving. She lives with profound deafness.

"She's a beautiful kid," Hugh says. "But we just wish we were told about CMV."

### Groundbreaking milestones – the Australian Cerebral Palsy Register

Established in 2008, the Australian Cerebral Palsy Register (ACPR) is the largest single-country CP registry in the world, with information on more than 11,000 people with CP. Funded at the Australian level by CPA, it is a collaboration with locally managed registers in every state and territory. As a confidential research database of clinical information about people with cerebral palsy, it enables researchers, clinicians and policymakers to:

- report prevalence and trends of CP
- provide data to support public health policy
- identify major CP risk factors (like cytomegalovirus (CMV) infection)
- measure prevention strategies in real-world settings.

The CPA Research Institute's epidemiology team conducts research focused on pregnancy, birth and the newborn period. Using the ACPR and other methods, they develop and analyse large datasets to track and understand the causes, trends and severity of cerebral palsy in Australia and globally.

Today, we partner with more than 14 countries to build national CP registers by sharing tools, training and insights to report on key issues and accelerate progress, especially in low- and middle-income countries.

### Pregnancy

• **CMV** – pregnant people newly infected with cytomegalovirus (CMV) are often asymptomatic, but there is a risk their unborn baby will also become infected. Some babies may be born with a disability and/or CP as a result of a CMV infection. CPA has been raising awareness about lowering the risk of CMV in pregnancy through campaigns since 2018, reaching more than 17 million Australians each year.

• **MgSO4** – in the case of very and extremely preterm births (born under 32 weeks' gestation), magnesium sulphate (MgSO4) can be given to the pregnant person just before delivery to protect the baby's brain and blood flow. This has been shown to substantially reduce the risk of CP by 30%. CPA researchers have contributed to research that is helping eligible people receive MgSO4 for neuroprotection of their preterm babies.

• **Identify Causal Pathways** – to ensure that prevention measures are focused on the main causes of CP.

• **Data Linkage** – link the ACPR with health datasets to improve equitable access to services.

### CP in Aboriginal and Torres Strait Islander populations

Led by Aboriginal researchers, the epidemiology team used data from the ACPR to show that the rate and severity of CP in Aboriginal and Torres Strait Islander children is declining in line with non-Indigenous Australians.

### Genetic contribution to CP

**Genomics** – the epidemiology team investigates genetic variation that contributes to CP and other neurodevelopmental disorders, including in families with siblings with different conditions.

The CPA Research Institute is a founding member of the International Cerebral Palsy Genomics Consortium (ICPGC) and lead the CP Commons, a global database of genetic data.



### OUR FUTURE PRIORITIES

- Ensure the ACPR is fully funded to continue monitoring trends, improving service access, and informing strategies to reduce severity for babies born with CP.
- Continue to foster collaborations with international CP registries, focusing on improving outcomes for children in low- and middle-income countries.
- Drive public health initiatives and partnerships to prevent CMV and establish a national CMV registry and network.
- Map the causal paths of CP into an interactive diagram that is continually updated as new evidence comes to light.
- Learn more about the neurobiology of CP, particularly genetic contributions.
- Collaborate with leading researchers and clinicians to develop personalised CP treatments through advanced genomic research.

# RESEARCH IN EARLY CHILDHOOD

## Early Diagnosis and Early Intervention

Our three Early Diagnosis Clinics link families to support and therapy both before and after diagnosis.

CPA has supported more than 680 infants since 2018, linking them into life-changing interventions at a crucial stage. Early intervention at CPA clinics offers access to:

- neuroplasticity studies
- clinical trials, including early intervention for babies at risk of CP (the Goals, Activity, Motor Enrichment (GAME) study)
- a multidisciplinary team to assist each family.

## General Movements Assessment and potential medicines for brain damage

Our researchers contribute studies, data and expertise towards the General Movements Assessment, a non-invasive and cost-effective way to identify neurological issues from birth to 20 weeks of age for infants at risk of cerebral palsy.

Our PhD students are uncovering how different medicines can assist with reducing causes of brain damage and creating protective treatments for the brain.

## Supporting early days

- Early Natural History of CP study – our researchers are conducting the first-ever global study of the early developmental trajectories in infants with CP in the first two years of life.
- Early Communication Intervention study – our researchers are conducting the first-ever clinical trial of communications therapy for infants at risk of cerebral palsy to determine if it's ever 'too early' to provide communications intervention for young children.

## Post-birth support

Research over the last 20 years has repeatedly confirmed that the first two years of life are the most vital for a child's development, when neuroplasticity – the brain's ability to repair itself

We've pioneered early detection and intervention by:

- championing General Movements Assessment (GMA) and Hammersmith Infant Neurological Examination (HINE) training for healthcare professionals to improve early detection of CP
- establishing the world's first early diagnosis clinics
- leading international clinical guidelines for diagnosis and early intervention
- sharing early intervention strategies globally.

Together, these innovations are changing the trajectory for babies with CP: diagnosing them earlier, treating them sooner, and improving outcomes.

and adapt to injury – is at its peak. Unfortunately, many children with cerebral palsy aren't diagnosed until their second year of life.

Our Early Detection and Early Intervention team is dedicated to changing this. Over the last two decades, their expertise and research have helped reduce the age of access to a diagnosis and evidence-based early intervention.



## OUR FUTURE PRIORITIES

**Our ambitious research goal in the next 20 years is standardised early detection assessment, diagnosis and intervention for every Australian child at high risk of CP, as a model for global application.**

We are working towards this through a range of initiatives, including:

- a growing network of clinicians skilled in early diagnosis of CP (GMA network)
- increased number of CPA's Early Diagnosis Clinics
- ongoing clinician training
- advocacy for national universal screening for CP in Australia.

Internationally, we are working to identify feasible early diagnosis solutions in low- and middle-income countries.

## Kylie and Anika's story

*Kylie's journey began nine years ago with the birth of her daughter, Anika, who in the first few weeks of her life had seizures and was subsequently diagnosed as a stroke.*

*At just six weeks of age, Anika was given a life-changing referral to CPA. At a CPA Early Diagnosis Clinic, she was diagnosed with CP by a healthcare professional trained in General Movements Assessment. This early intervention not only allowed Anika to thrive but also gave her access to treatments for babies who have suffered strokes.*

*Anika's clinical information is also listed on the NSW and Australian CP Registers, contributing to data on the incidence and severity of CP.*

*Children like Anika can take part in studies that aim to empower them and their parents. Recent studies undertaken by CPA researchers include the Early Communication Intervention study, the Early Natural History of CP study, and the Early Diagnosis and Early Intervention program. A new study, the Very Early Intervention Project, has been recently launched with the aim of empowering parents to support their children during early intervention.*



# LIVED EXPERIENCE AND RESEARCH

## CP Genomics Reference Group

As research into the genomics and genetics of CP continues to gain momentum, the Cerebral Palsy Alliance Research Institute has started a community reference group for CP genomics. This group helps ensure the voices of people with lived experience of CP are heard.

## Stem Cell Reference Group

The purpose of this group is to provide the perspective of people with CP and their families to shape decisions about research priorities, specific research questions and the design of new stem cell research projects.

All are welcome: people living with CP, carers, new parents and family members, and researchers from around the world.

## Mindfulness-Based Stress Reduction study

A modified Mindfulness-Based Stress Reduction (MBSR) study was shown to support improvements in depression, stress, and emotion regulation for people with CP throughout their life.

## cpThrive

cpThrive is a mobile app for people with CP and their families. It gives up-to-date, easy-to-understand information about different treatments. The app was jointly developed by researchers and people who have lived experience of CP.



Aaryan speaking at CPA's  
80 Years Celebration Gala

### Aaryan's story

*Aaryan works with the research team to share and influence research projects through his experience of living with CP.*

*With degrees in media and communications and psychology, Aaryan is a radio presenter and public speaker, and has represented Australia as a professional boccia player.*

*A client of CPA since he was 12 years old, Aaryan stars in our 'What is CP?' videos. He has also been a Steptember ambassador and has achieved many of his physical and mental goals. Along the way he has been instrumental in advising the research team on key projects including exoskeletons and mentoring engineers during product development.*

*Aaryan says the happiest moments of his life include getting piggybacked up to the top of Machu Picchu, swimming in the Amazon River, going to Africa and visiting Venice.*

CP Quest is a world-leading collaboration between the Cerebral Palsy Alliance research team and people with cerebral palsy, their families, carers and advocates.

The group was launched in 2015 to better integrate the lived experience of people with cerebral palsy into our research programs. As a complex and varied condition, everyone's experience of cerebral palsy is different – and it is these unique perspectives that researchers must deeply understand when conducting research into treatment and prevention of CP.

Involving the CP community in CP research:

- improves the quality of research
- ensures that research is meaningful for families
- reduces the time it takes to move research into practice
- results in better outcomes for people living with CP and their families.

We do this by training researchers, people with CP and their families and providing opportunities for meaningful contribution and engagement.

In addition, CPA's involvement in chairing and contributing to the Australian and New Zealand Cerebral Palsy Strategy has resulted in the Lived Experience Engagement Fund. This was established through the CPA Research Foundation to support early-stage projects involving people with lived experience across Australia and New Zealand.



### OUR FUTURE PRIORITIES

CP Quest partners – people with CP, families, carers and advocates – will continue to work with researchers to ensure relevance and impact.

Priorities include:

- gathering insights and lived experience in relevant areas of study, including early detection and intervention, investigating causal pathways (including genomics), and preventative strategies
- conducting research into technology, assistive devices and communication
- influencing studies towards improving daily living, pain management, employment, ageing and community participation.

CP Quest creates community engagement, supports knowledge translation, reduces stigma, encourages inclusive dissemination of findings, and makes research accessible and equitable.



### **Gulam's story – Transforming cerebral palsy care in low - and middle-income countries (LMICs)**

CPA is working with Professor Gulam Khandaker and the Global LMIC Cerebral Palsy Register ([www.glmcp.org](http://www.glmcp.org)) to scale up the Sustainable Model of early intervention and Tele-rehabilitation (SMART CP Model), an innovative, data driven approach reshaping cerebral palsy care in Bangladesh and across LMICs.

In Bangladesh, where half of children with CP have never accessed rehabilitation and specialist shortages are severe, SMART CP has pioneered a network of tele-rehabilitation, community informants, and parent support groups. This model reduces travel burdens, lowers costs, improves timely diagnosis, and expands access to assistive devices.

The impact has been recognised in *JAMA Pediatrics* and is now guiding similar initiatives in other LMICs through CPA's collaboration with the Global LMIC Cerebral Palsy Register. By building capacity, sharing data, and supporting locally driven solutions, CPA and its partners are helping to close the gap in CP early diagnosis and intervention services, creating sustainable pathways to better health outcomes worldwide.

Nadine Griffiths, Foundation Grant recipient,  
Grace Centre for Newborn Intensive Care,  
The Children's Hospital at Westmead

### **Global Clinical Trials Network**

CPA's leading researchers have spearheaded a global initiative set to revolutionise and transform the landscape of cerebral palsy research.

Driving this conceptual shift in CP research on a global level is by sharing information and results, and accelerating the pace of clinical trials to quickly find and develop new treatments for CP.

### **Global CP registers**

Alongside supporting multiple international CP initiatives, CPA co-funds the Global LMIC CP Register (GLM CPR), the first and largest international CP register dedicated to low- and middle-income countries. The GLM

## **GLOBAL REACH AND EQUITY**

Through the CPA Research Foundation and our partnerships, we've:

- funded over 800 projects in 51 countries
- supported more than 40 research scholarships in LMICs
- advised the World Health Organization (WHO) and global coalitions.

Our support has helped establish national CP registers in 14 countries and has laid the foundations for change on a global scale.

### **Global commitment**

CP360 is a first-of-its kind global initiative to engage governments, organisations, clinicians, researchers and people with lived experience of CP to transform outcomes for people with CP. CPA is excited to be part of this coalition of global partners and plays a leading role in its formation.

In 2025, CP360 partners convened landmark gatherings in Geneva with WHO member states and at the UN in New York, uniting global leaders and calling for a World Health Assembly resolution on cerebral palsy.

We believe in achieving equity through collaboration — not competition.

CPR strengthens the prevention and management of CP through research, capacity building, service delivery, and advocacy.

Since commencing in 2017, the GLM CPR has expanded to 24 countries across Asia, Africa, Latin America and the Pacific, and has now registered more than 11,000 children with cerebral palsy through hospital, community and population-based surveillance. The program has produced 80+ peer-reviewed publications, delivered over 60 international conference presentations, developed multiple clinical and research manuals, and supported over 20 PhD, postdoctoral and early-career researchers across several LMICs.

### **Grants**

As the world's largest private funder of ground-breaking cerebral palsy research projects, we have committed almost \$100 million and funded 423 researchers from 193 institutions across 51 countries since being established.

Research Foundation projects and grants are informed by frequent consultations with consumers who bring lived experience to the table.

Our vision is to enable the world's best cerebral palsy experts to find ways to prevent and treat cerebral palsy.



### **OUR FUTURE PRIORITIES**

Cerebral palsy research is advancing rapidly worldwide, yet children in LMICs often face major barriers to diagnosis, treatment and support. The growth of international CP registers — including the Australian Cerebral Palsy Register, the Surveillance of Cerebral Palsy in Europe and the Global LMIC CP Register — is helping close this gap.

Led by Professor Gulam Khandaker and collaborators across the Asia-Pacific, new national registers in countries such as Bangladesh, Nepal, Sri Lanka, Indonesia and Vietnam are transforming our understanding of CP. In the past 20 years, CPA has helped reduce the rate and severity of CP in Australia by 40%. By sharing this knowledge and tracking global incidence, there is enormous potential to improve outcomes and change lives for people with CP around the world.

# ASSISTIVE TECHNOLOGY

CPA's work with assistive technology research spans cognitive assessment, facilitates communication and supports mobility, through workshops and innovative devices.

## Technology for inclusion and independence

We believe in inclusive innovation. Our Technology Program explores innovations to support inclusion for people with disability across mobility, communication and cognition. We aim to:

- inform priorities for assistive technology research
- support innovations that enhance communication access and speed
- advance personalised technologies to meet individual needs
- enable the commercialisation of emerging solutions.

This work supports lifelong independence and participation for people living with CP.

## Switch Adapted Toy workshops

CPA's adapted toy workshops teach caregivers and therapists the skills and confidence to safely transform off-the-shelf battery-operated toys into switch-accessible ones, right in their own home or clinic.

## CogTest

Accurate cognitive assessment is vital for supporting communication, education, and participation for people with CP. Standard tests often exclude those with severe physical disability. This CPA study compares eye gaze and brain-computer interfaces for vocabulary testing, evaluating which best supports children and adults with CP and to gauge cognitive ability.



## My Voice Library

My Voice Library is a database that engineers will use to create innovative communication technology for children with CP and dysarthria. It is being developed by our multidisciplinary research team, including people with lived experience of CP, clinicians, engineers and researchers.

## Switch App

In collaboration with the Holland Bloorview Research Institute in Canada, CPA is developing software for recognising users' sound or facial movements. These movements and sounds can then be used as commands for controlling a computer or communication board. Switch App is an AI-based program that can learn a person's specific movement and keywords, so that it can be used easily in a home environment.



## New frontiers

Technologies supporting people with CP in mobility, communication and cognition will continue to be an enabler for access and equity.

We are focused on the development of technologies in using AI in early detection, providing developmentally appropriate toys for children's physical and cognitive development, supporting mobility throughout a person's lifespan, and improving communication.

## Rachel's story

*Rachel has been part of the CPA community for most of her life and has built an amazing community through the people she's met.*

*She's accessed a range of therapies and technologies through CPA, including physiotherapy, hydrotherapy, occupational therapy and speech therapy. She also accessed respite care when she was younger.*

*Learning to use eye gaze assistive technology has transformed her ability to communicate with family and friends, improved her confidence and opened up opportunities socially as well as for work and hobbies.*



## OUR FUTURE PRIORITIES

Communication is a human right. Our team is working to break down barriers to communication by accurately assessing the learning and use ability of children and adults with severe, complex communication needs. Through our collaborative work, we are looking at how we can assist movement using bionics, robotics and artificial intelligence to help people with CP stay better connected to their communities. We have ambitious technology goals to enable transformative discoveries in prevention, treatment and cures for CP and to enable inclusion and improve quality of life with a focus on cognition, communication and mobility.

# REGENERATIVE MEDICINE – OUR NEXT FRONTIER

Regenerative medicine aims to harness the body's own healing capabilities to fight disease or repair injuries. It is at the cutting edge of medical research and holds huge possibilities for people living with CP. Our goal is to see safe, effective and accessible cell therapies and other treatments developed for people with CP in Australia. We are:

- investigating the benefits of cell therapies and other treatments that can positively impact the brain
- supporting leading clinical trials in cell therapies
- supporting and advocating for people with CP in Australia to have access to cord blood.

## International collaboration

Our researchers were proud to contribute to PREMSTEM, a five-year international research project funded by the European Union's Horizon 2020 program, exploring the use of umbilical cord stem cells to treat brain injury in premature babies. Through collaboration with researchers, clinicians, parent advocates and industry partners, the team has taken important steps toward a potential new therapy to protect preterm infants from cerebral palsy and related disabilities.

## Future possibilities: neuroprotection and neuroregeneration

Research into neuroprotective and preventative treatments is advancing rapidly, with promising work underway at Monash University under the guidance of Professor Rod Hunt and through Associate Professor Atul Malhotra's cord blood trials for preterm babies.

These studies aim to protect the developing brain from injury and improve outcomes for vulnerable newborns. Looking ahead, novel neuroprotective and neuroregenerative therapies hold real potential to change the future of care – offering hope that one day we may prevent, or even repair, the early brain injuries that cause cerebral palsy.

## New frontiers

Our Regenerative Medicine team is playing a leading role in stem cell research, working to demonstrate the safety and efficacy of cell therapies as future treatments for cerebral palsy. Over the last decade, they have:

- collaborated to deliver the first compassionate access to cord blood treatment for a child with cerebral palsy in Australia
- published the largest global analysis of cord blood treatment for people with cerebral palsy
- established the CPA Stem Cell Reference Group, which now includes more than 60 members of the CP community.



## Zara's story

*The first child with CP treated compassionately with their own cord blood in Australia.*

*In a national first, six-year-old Zara received a compassionate infusion of her own umbilical cord blood to treat cerebral palsy (CP), supported by Cerebral Palsy Alliance, Cell Care, and the Hudson Institute. Compassionate access is a pathway that allows patients access to treatments that they would not usually have access to.*

*The treatment, administered in April 2025 at Monash Children's Hospital under the Therapeutic Goods Administration's Special Access Scheme, aims to improve movement and communication by encouraging brain repair. It's a promising step toward a future where cell therapy treatment is part of early care for people with CP.*

*Zara's infusion marks a significant milestone, with her family hoping for positive cognitive and physical changes. The procedure was safely delivered and her progress is being monitored.*

*CPA is working to ensure more Australian children can access this evidence-backed treatment locally rather than travelling overseas.*

## OUR FUTURE PRIORITIES



### Enable access to umbilical cord blood treatment in Australia

We aim to identify barriers and develop solutions to enable autologous and sibling umbilical cord blood treatments for children with CP in Australia, aligning access with programs in the US and Europe. Our long-term vision is to establish a Centre for Regenerative Medicine – a clinical research and treatment hub where advances in cell and brain-targeted therapies can be translated into real treatments for children with cerebral palsy and babies at risk of brain injury.

### Engage and empower the CP community in stem cell research

We will strengthen our network to support education, engagement, research and implementation by partnering with people with lived experience, families, clinicians, researchers, government, industry and health networks. Through evidence-based and accessible content, we aim to empower the CP community to take an active role in shaping the future of stem cell research and treatment.



## Looking ahead – 2045 and beyond

We're not done yet. Over the next 20 years, we will push even further toward prevention, personalised treatments, and global equity.

### OUR GOALS ARE TO:

- establish a national early screening program
- enable access to cell and other brain-targeted therapies for people with CP across Australia
- drive research growth in areas of unmet need through innovative methodologies and targeted collaborations
- increase equitable access for families worldwide to information tools such as cpThrive
- support data infrastructure, advocacy, and prevention strategies in low - and middle-income countries
- develop the next generation of CP experts through CPAdvance – our global training pipeline
- improve quality of life for children, teens, adults and families with CP across their lifespan.

Our future is powered by your support, passion and belief that a better world is possible for people with CP.

Our impact is made possible by you, our CP community: donors, funders, people with lived experience, health professionals, and researchers.

### THANK YOU

Whether you're a philanthropist, clinician, policymaker, health professional or person with lived experience – thank you for standing with us. Your support has made the impossible, possible.





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