10 YEARS OF DISCOVERY
DEDICATED TO PREVENTION, TREATMENT AND CURE
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THE FUTURE WE DREAMED OF

By Rob White, CEO

This year marks the tenth anniversary of the Cerebral Palsy Alliance Research Foundation.

For over a decade we have been driving international research into the prevention, treatment and cure for cerebral palsy. We’ve dedicated millions of dollars to the study and implementation of preventions, and we’ve committed ourselves to the advancement of treatments for those who are living with cerebral palsy. But when it comes to the reason we’re here today - it’s because a cure is possible and we’re committed to finding it.

We don’t accept a future where 1 in 500 children are born with cerebral palsy. We don’t accept a future with all the physical and social challenges that are faced by people with cerebral palsy and their families.

I joined Cerebral Palsy Alliance as a psychologist 25 years ago. I expected to last 12 months, but the passion of the organisation, and the clear needs of the families I was working with demanded my complete commitment. They got it.

Providing support for those living with cerebral palsy, and other disabilities, was of course rewarding and vital, however there was something missing. Regular treatment and therapy can change lives, but the need for prevention was obvious; the day to day reality of those I was supporting sparked our dream for prevention and a cure.

Internationally, research was severely underfunded, with minimal communication between researchers. On my initial trips overseas to see what was happening around the world, I found pockets of excellence, but there was a lack of strategy and coordination.

We saw an opportunity - one that would secure the future and outcomes of cerebral palsy research. If cerebral palsy research had no home, we could give it one. If cerebral palsy research had no direction, we knew how to provide it.

The families struggling daily with cerebral palsy needed a vision for a better future. For the ones they loved, and for the next generation, we needed better outcomes.

With the establishment of the Research Foundation, we committed to designing a consolidated international roadmap for cerebral palsy research. We knew how, but we needed the funds to do it. Together we have built a foundation that has made great progress in prevention strategies and treatments, and put cerebral palsy on the map for the world’s research community.

Whilst 2005 doesn’t seem like a long time ago, in the world of cerebral palsy enormous strides have been taken.

Ten years ago there were few preventative treatments for premature, or at-risk babies. There was no understanding of the genetic causations of cerebral palsy. Social factors were overlooked. The incidence of cerebral palsy was 1 in 400 and severity was higher.

Simply put, the last decade has seen an exponential improvement in our understanding of cerebral palsy and our ability to treat it has followed suit. We can thank the commitment of researchers here at Cerebral Palsy Alliance Research Foundation, and the work of the best and brightest researchers around the world.

We’ve been blessed to have the support from our dedicated Council of Governors, major donors and passionate communities. Without them, we couldn’t have become the beacon of hope that we can proudly claim to be, for so many with cerebral palsy.

I’m incredibly proud of our leadership team - Professor Nadia Badawi and Professor Iona Novak, and their extraordinary commitment and dedication.

In the past three years they have led three international summits in San Francisco, Washington and Austria that united the best researchers in the world.

We’ve dedicated millions of dollars to prevention, and put cerebral palsy on the map for the world’s research community.

Research isn’t an end goal and it isn’t a motivation. Research is the journey between where we are and where we want to be. For the families we work with each and every day, research is the hope for a life lived to its complete potential.

Family is central to our life and our work. Cerebral Palsy Alliance was started 70 years ago, not by doctors or researchers, but by parents.

When their daughter Jennifer was diagnosed with cerebral palsy, Audrie and Neil McLeod were told that little could be done to help her. This family’s pioneering commitment to improve Jennifer’s quality of life led to the formation of The Spastic Centre, and then Cerebral Palsy Alliance. Neil McLeod famously said he believed that nothing was impossible. The legacy of this belief is infused in the fabric of Cerebral Palsy Alliance and drives our research efforts today.

Behind the facts and figures that populate this impact report is the power of the family and its ability to change lives.

The commitment and love that started our organisation is still in our DNA. Whether it’s developing pioneering genome research, continuing to improve early detection and intervention; developing new technologies to give a voice to those unable to speak.

To the generation of donors who empowered our efforts, from generations of children whose lives you will change, thank you.

Rob White
CEO Cerebral Palsy Alliance

“The commitment and love that started our organisation is still in our DNA.”
IN THE PAST

**BIRTH TRAUMA**

**CONSIDERED MAIN CAUSE OF CEREBRAL PALSY**

1/400 born with cerebral palsy

Cerebral palsy mostly considered **UNPREVENTABLE**

**CHILDREN RARELY DIAGNOSED PRIOR TO 24 MONTHS**

**LIMITED INTERNATIONAL COLLABORATION**

NO STUDIES INVESTIGATING CURE

FEW TARGETED EARLY INTERVENTIONS

NO CENTRAL DATABASE ABOUT CEREBRAL PALSY IN AUSTRALIA

**10 YEARS OF DISCOVERY**

**COLLABORATING WITH THE BEST RESEARCHERS IN THE WORLD**

**PREVENTION + CURE**

**BEING RESEARCHED AROUND THE WORLD**

**INTRODUCTION OF**

**MAGNESIUM SULPHATE, COOLING AND OTHER TREATMENTS AROUND THE TIME OF BIRTH**

to prevent or reduce the impact of cerebral palsy

**EARLY DETECTION FROM TWELVE WEEKS**

**BOTULINUM TOxin A**

**TREATMENT ROLLED OUT TO DECREASE MUSCLE STIFFNESS**

**MASSIVE INCREASE IN FUNDING FOR RESEARCH**

**GENETIC FACTORS REVEALED**

- Quality of life
- Interventions
- Treatments

**INTRODUCED CP CHECK-UP™**

Together researchers and clinicians have now **REDUCED THE RATE TO 1/500**
Ten years ago we decided to strategically analyse how we could contribute the most to cerebral palsy research. We wanted to attract the best researchers in the world and inspire them to focus their efforts on cerebral palsy. For that to happen, we needed more money available in the field.

The results have been amazing. In every aspect of our work, from detection through to genetics and detection, to brain scans and mapping; the field has made incredible breakthroughs.

The definition of cerebral palsy has always been ‘a condition with permanent, lifelong disability – and no cure’. Together, we can change that definition.

In the last decade we have witnessed fundamental improvements for children born with the risk of cerebral palsy, with the introduction of treatments that utilise new drugs and new technology to striking effect.

Those that can’t speak and don’t vote haven’t always had a voice. Through our research, our commitment and our care, we are giving them one.

The cure is in the details

The cerebral palsy registers (CP registers), first started in Western Australia by Professor Fiona Stanley, have become key research tools utilised by teams around the world. The Australian Cerebral Palsy Register is the largest data set of cerebral palsy information from one country in the world.

The data from CP registers have revolutionised research for cerebral palsy.

Research discoveries aren’t ‘eureka moments’ but the result of persistent and painstaking dedicated work. We are fortunate to be surrounded by incredibly passionate researchers, scientists and clinicians, committed to improving the lives of others.
Because of this group, we know that cerebral palsy often starts in the womb, or even before. We know that magnesium sulphate and body cooling can reduce brain injury during and directly after childbirth. And we are beginning to see the power that technology can have on the physical health, emotional wellbeing and mental resilience of children and families living with cerebral palsy.

Cerebral palsy has many faces, and many causes; research is going to uncover its cure.

“In every aspect of our work, from diagnosis, to genetics and detection, through to brain scans and mapping; the field has made incredible breakthroughs.”

How the CP Register is changing the world of CP

Cerebral palsy has had a fragmented research history. This is partly because people couldn’t see a need for it. The belief was that cerebral palsy was caused by complications during childbirth, so everyone was focussed on what could be done during labour – not before.

Things changed when Professor Fiona Stanley commenced the first CP Register in Australia in her home state of Western Australia. Her team were able to prove that the origin of most cerebral palsy occurred during pregnancy. That changed our whole way of thinking.

The field of medicine can be structured and conservative, so even when there’s a great breakthrough it can be very difficult to change people’s behaviour. But this was huge!

Affecting change requires something major - the CP registers are such a resource. We can’t stress the importance enough. The CP registers are the bedrock on which many of the breakthroughs in this report are based.

Those first pieces of research got the whole world looking and saying “Oh! So, what are the causes? What can we do about them?”

We knew that newborn brain damage was a precursor to cerebral palsy. Through our work with population scientists Professors Eve Blair, Carol Bower and Fiona Stanley, we confirmed that for the vast majority of children the problem originated before birth – and in some cases, started before conception.

It was a bold finding, but we had the data to back it up.

Epidemiology isn’t exciting in the classic sense; nobody takes photos of researchers poring over data - but in the last 10 years it’s revolutionised our research.

The exponential increase in computing power and the shift towards big-data analytics guarantees that the CP Register will continue to feed our life-changing work. Within its data are keys to the prevention and cure of cerebral palsy.

“The definition of cerebral palsy has always been ‘a condition with permanent, lifelong disability – and no cure.’ Together, we can change that definition.”
RESEARCH HIGHLIGHTS

Cerebral Palsy Alliance Research Foundation is dedicated to driving major advancements in the prevention, treatment and cure of cerebral palsy.

Our research priorities are informed by our clients and families. All grant applications need to match our research priorities, are assessed by external expert peer reviewers and approved by our Board. Together, these groups determine the projects we fund each year.

**FIVE PILLARS OF FOCUS FOR CEREBRAL PALSY RESEARCH**

1. Aetiology, causal pathways
2. Prevention
3. Early identification, early intervention
4. New treatments
5. Cure

**TOTAL FUNDING OVER 10 YEARS**

$21,897,455

**OVER THE LAST 10 YEARS WE HAVE**

194 RESEARCH GRANTS

105 RESEARCHERS

60 INSTITUTIONS

**OUR GLOBAL COLLABORATION, FUNDING AND REACH**

For grants listing see Page 40

**TOP INSTITUTIONS CEREBRAL PALSY ALLIANCE RESEARCH FOUNDATION HAVE PARTNERED WITH AND PROVIDED GRANT FUNDING TO:**

- Monash University
- Murdoch Children’s Research Institute
- University of Adelaide
- University of Queensland
- University of Sydney
- The Children’s Hospital at Westmead
Where does cerebral palsy begin? Is it in the delivery room, or the womb - or does it begin even earlier? The answer to this question contains the seeds of a cure for cerebral palsy. The more funding we receive, the better we can understand the causes; and the faster we can diagnose, the more effective we can be. Lives are being changed, futures are being re-written and this is all thanks to you, our loyal supporters.
I’ve been researching the causes of cerebral palsy for more than 30 years and this is the most exciting research I’ve done during my career. The ramifications are tremendous.

The field has been held back for many years with the non-evidence based belief that cerebral palsy is often due to trauma, loss of oxygen or inadequate blood supply to the brain during labour. This is only the case in a small percentage. Our recent research shows that many instances of cerebral palsy have a genetic cause and we are investigating how many cases are due to genetic susceptibility and whether there are environmental triggers during pregnancy.

In the last three years, thanks to remarkable advances in the genetic sequencing of the human genome we have been able to discover many different mutations (genetic variations) that are the likely cause of cerebral palsy. We are using both exome and soon whole genome sequencing. The exome is the 2-3% of the genome that makes proteins, and the protein messengers that tell the cell and the body what to do. We determined that if you have a mutation in the exome, you’re probably going to have dysfunction in the gene.

For the first time ever we found at least 14% of children with cerebral palsy have single point mutations and up to a further 32% may have copy number variations where large chunks of DNA may fail to be replicated or are replicated twice at cell division near conception.

These figures are significant and indicate that cerebral palsy is rarely the result of mismanagement during labour. The figures also call into question the wisdom of the high rates of caesarean section in Australia that have risen from 5% to 34% of all labours in the last 40 years.

Most significantly our ability to understand the true causes of cerebral palsy will lead to preventative strategies.
Connor is 20 years old, and the eldest of our three children. He was born a few months premature and it was pretty clear from early on that something was wrong. When we were told Connor had cerebral palsy we didn’t really know what that meant. Back then the doctors couldn’t tell us what this might mean for Connor in the future. Was he going to be able to walk, or not? Could he talk? Would he be deaf? What would cerebral palsy mean for him? We had no idea.

Connor has seen firsthand the shifting face of cerebral palsy over the last two decades. When he was born, there was so much uncertainty about the best way to identify and treat cerebral palsy. People didn’t know how to talk about it, they didn’t know what it was, they were unsure how to deal with it.

Back then there were dedicated staff who did what they could to help Connor, based on what they knew at the time. My husband and I set about finding out all that we could about cerebral palsy, and we know now that Connor certainly missed out in those early years.

We now know that the first months and years of life are critical in the treatment of cerebral palsy. Research has achieved so much and has provided us, and many other parents with far more information.

When Botulinum toxin A treatment became available we jumped at the opportunity to utilise this form of treatment which has helped Connor with his muscles through the years. But the thing that has helped him the most is his ability to communicate. His speech is clear and he has good hearing - that’s made a world of difference to him. Connor is certainly far more expressive and independent than we might have expected.

Connor is our regional Boccia champion – something we’re really proud of.

“...If research can help us understand cerebral palsy better, and help parents understand what to expect, then it’s vital.”
Diagnosing children with cerebral palsy is one of our great challenges.

Our work with Cerebral Palsy Alliance Research Foundation is focused specifically on developing techniques for early detection of babies who are likely to have cerebral palsy. The Research Foundation has provided key funding for the PREMO Project (Preterm Motor Outcomes Project). Together we’re helping revolutionise early diagnosis for premature babies through improved brain MRI scanning.

The task of the PREMO Project is to improve earlier detection of cerebral palsy and start earlier interventions programs to infants at the earliest opportunity. Using a special MRI compatible incubator (one of only two in the southern hemisphere), we are able to provide scanning of very small babies. This groundbreaking technology is changing the way we understand brain development. It’s safe and non-invasive – which is crucial when dealing with babies born less than 30 weeks gestation.

To be able to perform a brain scan on such premature infants (10 weeks before full-term) provides novel information. It’s this type of data that gives us a unique insight into the formation of the brain and therefore, the kinds of damage that may lead to cerebral palsy.

We can look at all the connections of a baby’s brain, including the white matter, and look at the integrity of those connections in the 10 week period before they would have been born. Considering that the majority of the brain’s relationship with muscle systems is finalised in the first six months, this development of brain connectivity in the pre-term period is critical for us to understand.

The other essential part of this work is linking this new knowledge on brain connections to the early assessment of motor behaviour and vision. Now, when we are analysing a pre-term child, we have several biomarkers that indicate the risk a child may face.

In the near future, we’ll be able to combine our brain scans with prediction modelling to determine where the risks lie and fast-track infants to the optimal early interventions accordingly.

My relationship with cerebral palsy started 24 years ago, with the birth of my daughter Monica who is a surviving triplet. She was born premature at 32 weeks and suffered a Grade 4 brain haemorrhage causing irreversible damage and was later diagnosed with having spastic quadriplegic cerebral palsy and receptive language difficulties.

The doctors did everything they knew and could at the time with the information they had at hand. Back then I was told by doctors and specialists to wait and see how Monica developed before treatments were recommended. I was frustrated and not willing to wait. I exhausted every medical avenue I could find to help Monica get the best start in life. The more I looked, the more I realised there just wasn’t enough being done in research to help those with cerebral palsy.

Since the formation of Cerebral Palsy Alliance Research Foundation, I have witnessed dramatic change. What they’ve achieved in the last 10 years is truly remarkable.

When we founded the Star Scientific Foundation, we wanted to support Cerebral Palsy Alliance’s initiatives. Without research, developments across new treatments, interventions and therapies would be nearly non existent. We know that research is the ultimate key to solving the complex puzzle of cerebral palsy and will lead us to the pathway of finding a cure.

We’re in a time of incredible breakthrough with new information coming to light, new research being revealed and unexpected results giving us new directions. Star Scientific Foundation, our parent company Star Scientific Limited, and the Horvath family are proud to be supporters of Cerebral Palsy Alliance Research Foundation. Your dedication and commitment to cerebral palsy research is outstanding - the future is indeed brighter for those living with cerebral palsy.
The last decade has seen a remarkable growth in new treatments and interventions introduced in the field of cerebral palsy. This is an era of breakthroughs, with new discoveries moving rapidly into clinical practice. Neonatal interventions have had a dramatic effect on the rate and severity of cerebral palsy in Australia, and new treatments and technologies are transforming lives daily. None of this would be possible if it wasn’t for the generous support we have received from you - our corporate partner, our foundation supporter, our community member and individual donor.
I’m a ‘she’ll be right’ kind of woman, but when Jessika was born I knew things weren’t right. I wasn’t even meant to be going into labour – I’d only been pregnant for 26 weeks.

When Jessika was born, she was the only baby in the humidicribs that was moving a lot. It turns out this wasn’t a good sign.

My mum was the first person to say there was something wrong. We were in hospital for six months and even when we were discharged, we’d be back in every three or four weeks with something. All the signs of cerebral palsy were there, but nobody said anything.

It was the week before Christmas and she’d gone in to have an MRI. I remember the paediatrician sitting on the bed in the hospital and asking if I’d heard about cerebral palsy? He said she’d probably never be an Olympic runner – that was an understatement.

There isn’t a more severe type of cerebral palsy than Jessika’s – she can’t speak, can’t hold her head up or move her body, she is immobile and they say she’s profoundly deaf.

All that said, Jessika doesn’t miss a trick. I was never someone who googled much, or cared to go looking for more information, but it’s been really obvious that things have changed in the last five years.

Jessika’s getting Botulinum toxin A treatment, which really helps with her arms, and communicating using the sip and puff machine means she’s not as frustrated as she used to be.

There are so many more interventions available to babies in the first few weeks of their lives thanks to early detection and early intervention research. Early detection using the General Movements assessment has allowed researchers to trial new therapies from as early as 12-weeks of age, when a baby’s brain is enormously flexible and has the power to ‘rewrite’ itself to overcome some of the damage.

Every now and then I can’t help but wonder how different things might have been for Jessika if she’d been born today!
I’m an Occupational Therapist specialising in research looking at the outcomes of active surveillance and the interventions for children and adults living with cerebral palsy.

Before moving to Australia in 2006, I was part of the Swedish active surveillance program for people with cerebral palsy called CPUP. In Sweden, CPUP has resulted in a dramatic reduction in severe contractures (down by 70%) and scoliosis (down by 60%), and almost a complete prevention of hip displacements or dislocations.

The success of the program led to its adoption by Cerebral Palsy Alliance, where it is known as CP Check-Up™.

The difference with CP Check-Up™ in Australia is the scope of the program. Cerebral Palsy Alliance is creating a comprehensive, holistic overview of a person’s life. Our aim is to determine what they need – from a medical, psychological and emotional point of view based on regular reviews of each person. In addition to looking at physical ability, mobility and hand function, CP Check-Up™ also monitors general health, pain and sleep, mealtime skills and nutrition, communication, learning and behaviour and wellbeing.

By identifying problems early, clinicians can work with families to develop and prioritise goals, and plan and provide timely interventions. The information on the CP Check-Up™ database is not only helping children who are currently participating in the program, but over time the data will contribute to information that will guide clinical practice. By systematically monitoring these children and recording the interventions they’ve used, it is possible over time to determine the best treatments and therapies.

Prospective surveillance programs such as CPUP in Sweden and CP Check-Up™ in Australia, provide a window of opportunity for better outcomes for individuals with cerebral palsy. It’s a bold new step to improving the quality of life of thousands of Australians living with cerebral palsy.

“IT'S A NEW STEP TO IMPROVING THE QUALITY OF LIFE OF THOUSANDS OF AUSTRALIANS LIVING WITH CEREBRAL PALSY.”
PREVENTION AND CURE

Nothing is impossible

Cerebral palsy has long been considered a life-long condition. There is no cure yet. When the Research Foundation was launched, we put a stake in the ground. We have already seen a decrease in the proportion of Australian children born with cerebral palsy and we’ve seen a marked decrease in severity due to new interventions. Now it’s time to go the next step, together.
Nobody knows cerebral palsy like the people living with it.

The voice of our clients and families has always been the focal point of our research vision. For some time, families had been asking for information about brain repair interventions that may improve the quality of life for their loved ones. Many families also talked about their dreams of prevention strategies for generations to come.

It's vital that we stay true to what these families want; that's where the really big ideas come from. Families are open to possibility, driven by their dream of a different future.

Stem cell research, early intervention, genetic causation – all of these complex components of the cerebral palsy puzzle are now under the spot light through the work of world-class researchers who have been inspired by the families living daily with cerebral palsy.

For us and for them, it's an exciting time in cerebral palsy research.

Building on important US research, we have focused our efforts on the critical first six months of life when we know that activating and using neural pathways from the brain to the muscle is so important for positive outcomes. When you activate and use neural pathways they go from being some sort of gravel road into a beautiful highway, allowing you to send elegant messages to your muscles.

That’s what early intervention really offers.

Stem cell interventions have enormous promise and, although the true picture is still unclear, it’s a focal area that is generating a lot of interest. It's an enormous field but there’s data coming out to suggest that stem cells do have a treatment effect for cerebral palsy. It’s mind boggling when you think how far we’ve come in just 10 years.

A decade ago the standard statement would be that cerebral palsy is not often preventable, nor curable and treatment and interventions were limited. All of this is changing and for the better.

We currently have at least 18 clinical trials underway looking at potential brain repair or cure ideas for cerebral palsy. All of these will continue to improve our understanding and will lead to new ideas and discoveries.

Cerebral palsy is a subject that ignites passions, for both families and researchers. The generous support from our donors has helped us galvanise the attention of the world’s best and brightest research minds. We have seen, here in Australia, how the likelihood of dying from childhood cancer have dropped three-fold from research identifying new treatments and cures, made possible thanks to extraordinary donations from the public, and the dedication and concerted effort of researchers.

New treatments and cures should therefore be researched for people with cerebral palsy in Australia and worldwide.

“A decade ago the standard statement would be that cerebral palsy is not often preventable, nor curable and treatment and interventions were limited. All of this is changing and for the better.”

The power of family and the passion of the research community fits with our history – and the story of Neil and Audrie McLeod who started the Cerebral Palsy Alliance some 70 years ago. They were told their daughter Jennifer had cerebral palsy and that very little could be done to help her. They didn’t want to accept a future without hope and promise for Jennifer and they adopted the motto “nothing is impossible.”

We must continue to pursue our vision for the very best interventions, prevention and ultimately the cure for cerebral palsy.
Our first son Ethan was born on Easter Sunday 2005. My husband and I were driving up to the Central Coast on holiday. Just before we turned onto the highway, I felt that something wasn’t right. I’d only been pregnant for 26 weeks, I didn’t expect to be going into labour.

Even though the signs were there, Ethan wasn’t diagnosed with cerebral palsy until he was 14 months old. We started therapy, but had no idea what we could hope for. Nobody did.

As Ethan grew up, we saw the difficulties increase. He couldn’t hold his head up, he couldn’t eat, he couldn’t walk, he couldn’t breathe properly, he couldn’t hear and he couldn’t speak.

If I had one wish, it would have been for Ethan to be able to hold his head up by himself, because just having that little bit more control over his own body would have changed his life completely.

Ethan required oxygen 24 hours a day. He needed a special moulded bed to hold him in place because he would spasm. He needed a sleep system so he wouldn’t roll around the bed. He needed change tables because he was in nappies his whole life and he needed a special walker just to stand up. To eat, he needed a special insert and special chair to sit in. He needed special spoons, special straws – everything.

Every part of his life he ‘needed’ – there wasn’t anything that he could do on his own, except smile.

He was a smart boy. We knew that the first time he encountered eye-gaze technology. He was the youngest person in Australia to test it and started using it immediately. He looked so happy. It was going to change his life. His system arrived on a Wednesday. He passed away in his sleep two days before.

“Ethan’s tragic loss has made me even more determined to support the research that we know holds the key to vastly improving – even saving – the lives of children like him.”
It meant working with big datasets of mother and baby pairs. We spent years analysing maternal infections, other pregnancy complications and genetic factors. It was humbling work because the more I looked at the questions of causation in cerebral palsy, the more complicated the answers became.

After those initial 10 years of my career, I realised that although I was publishing lots of papers, the studies were not leading to a change in care, or improving the quality of life. I wanted my research to have a more direct impact on the way cerebral palsy was treated.

I then became interested in treating newborn infants who are at very high risk of developing cerebral palsy with the aim of preventing it. This meant looking at babies who are born with specific signs of hypoxic-ischemic brain injury.

Together with support from Cerebral Palsy Alliance Research Foundation and the Thrasher Research Fund, that’s what I have been working on.

I believe that the hormone erythropoietin is going to have a tangible effect on the prevention of cerebral palsy for high-risk babies. Studies have shown that although I was publishing lots of papers, the studies were not leading to a change in care, or improving the quality of life. I wanted my research to have a more direct impact on the way cerebral palsy was treated.

Clinical trials have their own challenges, and obtaining funding when you have little preliminary data can be challenging. Cerebral Palsy Alliance Research Foundation believed in our work from the start, and has played a crucial role in progressing research in this area.

My first ten years as a researcher were spent trying to understand what the risk factors were for brain injury in the newborn period. This research led directly to my desire to understand cerebral palsy. I wanted to uncover the difference between children who had cerebral palsy and those who did not.
The last decade has seen an exponential increase in funding, public awareness and clinical outcomes for those living with cerebral palsy. What was once deemed impossible is now firmly on our agenda.

The growth in computing power has already had a marked effect on research outcomes, with many more to follow. In all areas of our work, new technology will define the next breakthrough in our understanding and treatment of cerebral palsy.

On a treatment level, new technology is already revolutionising the communication options for those without a voice. Improving access to communication through eye-gaze technology and new iPads and tablets will have positive outcomes on an emotional, physical and intellectual level.

The wheelchair has been the single greatest technological achievement for those living with cerebral palsy around the world. We believe that studies into robotics, and the exo-skeleton could have the same fundamental power – the power to transform lives.

In the coming year, the Research Foundation will see three significant changes:

1. The position of ‘Chair of Technology and Innovation’, will be introduced, creating a dedicated position to lead technological developments for cerebral palsy.

2. Our Research Institute is co-located at the Brain and Mind Centre, and the Discipline of Paediatrics and Child Health; both within the Sydney Medical School at The University of Sydney. This is one of the leading health and science faculties in the country. Access to their insights and sharing skills will continue to drive our achievements in this area.

3. And finally, Cerebral Palsy Alliance Research Foundation will open in New York. For our research capabilities, our support base, public awareness and most importantly our clients – this move will be the next step for cerebral palsy research globally.

“What was once fantasy is now reality; what was once impossible is now firmly on our agenda.”
Thank you
Without the support of these organisations and individuals, progress over the last ten years would not have been possible.

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Professor Iona Novak PhD MSc (Hons) BAAppSc, HEAD OF RESEARCH AT CEREBRAL PALSY ALLIANCE RESEARCH INSTITUTE
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Dr Cathy Morgan PhD BAAppSc (Physio), RESEARCH FELLOW
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Hayley Smithers Sheedly MPH BAAppSc (SpPath), RESEARCH FELLOW
Ingrid Horan MClInPyc, BPsc(Hons), RESEARCH OFFICER
Isabelle Balde DipAcc, RESEARCH ASSISTANT AND PROJECT COORDINATOR
Associate Professor Karen Walker PhD MClInNurs BAAppSc (Nurs) RN, SENIOR RESEARCH FELLOW, IMPACT FOR CP
Dr Margaret Wallen PhD MA BAAppSc (OT), RESEARCH FELLOW
Dr Petra Karlsson PhD MSc BAAppSc, RESEARCH FELLOW
Richard Barclay MClInPyc BSc (Hons) Psych, RESEARCH ASSISTANT
Dr Sarah McIntyre PhD MPS BAAppSc (OT) Hons, SENIOR RESEARCH FELLOW
Shona Goldsmith BPhysio (Hons), RESEARCH ASSOCIATE
Zoe Burrell CertBusAdmin, EXECUTIVE ADMINISTRATION, RESEARCH INSTITUTE

Thank you
Without the support of these organisations and individuals, progress over the last ten years would not have been possible.

Council of Governors
William (Bill) Bartlett CHAIRMAN
Anne Keating
Cathy O’Connor
Don Koch
Henry Tajer
James Hodgkinson OAM
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Joseph Fayyad
Monique Scattini
Naomi Simson
Neroli Best
Nick Moraitis AM
Phil Waugh
Roger Amos
Sally Loane

Research Staff
Professor Nadia Badawi AM PhD FRACP FRCPi MBCh (Hons I), MACQUARIE GROUP FOUNDATION CHAIR OF CEREBRAL PALSY
Professor Iona Novak PhD MSc (Hons) BAAppSc, HEAD OF RESEARCH AT CEREBRAL PALSY ALLIANCE RESEARCH INSTITUTE
Abigail Townsend MPubHealth BHealthSci, RESEARCH ASSISTANT
Dr Cathy Morgan PhD BAAppSc (Physio), RESEARCH FELLOW
Claire Galea GDipVET GDipAppStat BEdu, RESEARCH ASSOCIATE
Dr Danielle Herbert PhD MSc BSc, RESEARCH MANAGER
Hayley Smithers Sheedly MPH BAAppSc (SpPath), RESEARCH FELLOW
Ingrid Horan MClInPyc, BPsc(Hons), RESEARCH OFFICER
Isabelle Balde DipAcc, RESEARCH ASSISTANT AND PROJECT COORDINATOR
Associate Professor Karen Walker PhD MClInNurs BAAppSc (Nurs) RN, SENIOR RESEARCH FELLOW, IMPACT FOR CP
Dr Margaret Wallen PhD MA BAAppSc (OT), RESEARCH FELLOW
Dr Petra Karlsson PhD MSc BAAppSc, RESEARCH FELLOW
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Zoe Burrell CertBusAdmin, EXECUTIVE ADMINISTRATION, RESEARCH INSTITUTE
### RESEARCHER ACHIEVEMENTS: GRANTS LISTING

#### 2005 – Total Research Funding $513,406
- Research Institute: People Support & Infrastructure
  - Amount: $513,406

#### 2006 – Total Research Funding $870,969
- Eve Blair: Innovative Research Grant, Telethon Institute
  - Amount: $80,000
- Megan Thorley: Emerging Researcher Grant, Royal Children’s Hospital
  - Amount: $10,000
- Lex Doyle: Innovative Research Grant, Murdoch Children’s Research Institute
  - Amount: $40,000
- Adrienne Harvey: NHMRC Postgraduate Scholarship (Co-fund)
  - Amount: $27,563
- Christine Imms: NHMRC Postgraduate Scholarship (Co-fund)
  - Amount: $37,760
- Carol Maher: Doctoral Research Scholarship, University of SA
  - Amount: $10,000
- Catherine Gibson: Innovative Research Grant, Uni of Adelaide
  - Amount: $40,000
- Margaret Wallen: Doctoral Research Scholarship, Children’s Hospital Westmead
  - Amount: $100,000
- Student Grants: Undergraduate Student Scholarships
  - Various NSW Universities
  - Amount: $3,000
- Research Institute: People Support & Infrastructure
  - Amount: $522,646

#### 2007 – Total Research Funding $959,844
- CP Register: Innovative Research Grant, CPA Research Institute
  - Amount: $150,000
- Sarah Love: Innovative Research Grant, Princess Margaret Hospital
  - Amount: $25,000
- Enrico Cervera: Innovative Research Grant, Centre for Health Informatics
  - Amount: $120,000
- Liora Ballin: NHMRC Postgraduate Scholarship (Co-fund)
  - Amount: $40,500
- Abbey Eales: NHMRC Postgraduate Scholarship (Co-fund)
  - Amount: $40,500
- Alastair MacLennan: Innovative Research Grant, University of Adelaide
  - Amount: $115,000
- Student Grants: Undergraduate Student Scholarships
  - Various NSW Universities
  - Amount: $9,000
- Research Institute: People Support & Infrastructure
  - Amount: $459,844

#### 2008 – Total Research Funding $812,775
- Student Grants: Undergraduate Student Scholarships
  - Various NSW Universities
  - Amount: $9,000
- Grace Gala: Sponsorship, Grace Centre for Newborn Care
  - Amount: $1,200
- Dr SA Balandin: ARC Linkage Project, University of Sydney
  - Amount: $14,000
- George Mendz: Innovative Research Grant, University of Notre Dame
  - Amount: $55,449
- Suzie Miller: Innovative Research Grant, Monash University
  - Amount: $82,154
- Dinah Reddinhough: Innovative Research Grant, Murdoch Children’s Research Institute
  - Amount: $145,375
- Jacques Coq-Oliver: Innovative Research Grant, National Centre for Scientific Research
  - Amount: $100,000
- Research Institute: People Support & Infrastructure
  - Amount: $405,097

#### 2009 – Total Research Funding $2,641,976
- Student Grants: Undergraduate Student Scholarships
  - Various NSW Universities
  - Amount: $4,500
- Jan De Groot: Emerging Researcher Grant, Telethon Institute
  - Amount: $2,200
- Australian CP Register: Innovative Research Grant
  - Cerebral Palsy Alliance
  - Amount: $150,000
- Emma Wilczek: Graduate Scholarships
  - Various
  - Amount: $1,500
- Jessica Westover: Graduate Scholarships
  - Various
  - Amount: $1,500
- Beren Gunisik: Graduate Scholarships
  - Various
  - Amount: $1,500
- Nick Evans: Innovative Research Grant, Royal Prince Alfred Hospital
  - Amount: $33,000
- John Gilroy: Doctoral Research Scholarship, Centre for Disability studies
  - Amount: $34,968

#### 2010 – Total Research Funding $1,949,727
- Giovanni Ciani: Conference Grant, University of Pisa
  - Amount: $10,000
- Andrea Guzzetta: Conference Grant, University of Pisa
  - Amount: $8,000
- Student Grants: Undergraduate Student Scholarships
  - Various NSW Universities
  - Amount: $9,000
- Paul Colditz: Innovative Research Grant, University of Queensland
  - Amount: $50,000
- Australian CP Register: Innovative Research Grant, Cerebral Palsy Alliance
  - Amount: $150,000
- Henry J Cowan: Student Grants
  - Various
  - Amount: $4,500
- Kei Lui: Doctoral Research Scholarship, University of New South Wales
  - Amount: $81,000
- Natasha Lannin: Post Doctoral Fellowship, Royal Rehab Centre
  - Amount: $258,546
- Paediatric Movement Analysis: Innovative research Grant, Sydney Children’s Hospital Network
  - Amount: $60,000
- Sarah McIntyre: Doctoral Research Scholarship, Cerebral Palsy Alliance
  - Amount: $10,000
- Sarah McIntyre: Doctoral Research Scholarship, Cerebral Palsy Alliance
  - Amount: $173,112
- CP Register: Innovative Research Grant, Cerebral Palsy Alliance
  - Amount: $70,000
- Nick Evans: Innovative Research Grant, Sydney Hospital Local Network
  - Amount: $50,000
- Graeme Polglase: Innovative Research Grant, Monash University
  - Amount: $151,185
- Tamara Yavno: Innovative Research Grant, The Ritchie Centre, Monash
  - Amount: $50,000
- Caroline Crawford: Innovative Research Grant, University of Adelaide
  - Amount: $250,000
- American ACAPDM: Conference Grant, American ACAPDM
  - Amount: $7,000
- Research Institute: People Support & Infrastructure
  - Amount: $557,384

#### 2011 – Total Research Funding $998,766
- Cathy Morgan: NHMRC Postgraduate Scholarship (Co-fund)
  - Amount: $116,564
- Micah Perez: Doctoral Research Scholarship, University of Qld
  - Amount: $45,000
- Danny Gilroy: Memorial Research Grant, University of Western Sydney
  - Amount: $1,500
- Flora Wong: Career Development Grant, The Ritchie Centre, Monash
  - Amount: $40,000
- Rod Hunt: Career Development Grant, Murdoch Children’s Res Institute
  - Amount: $100,000
- United Cerebral Palsy: Conference Grant, UCP Conference
  - Amount: $2,200
- IMPACT for CP Prevention & Cure Summit: Conference Grant, CP Summit
  - Amount: $103,000
- Student Grants: Undergraduate Student Scholarships
  - Various NSW Universities
  - Amount: $15,000
- Research Institute: People Support & Infrastructure
  - Amount: $575,702
## RESEARCHER TITLE INSTITUTION AMOUNT

### 2012 – Total Research Funding $1,442,004

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<th>RESEARCHER</th>
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<th>AMOUNT</th>
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### 2012 – Total Research Funding $3,552,362

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<tbody>
<tr>
<td>Koa Whittingham</td>
<td>Conference Grant</td>
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<td>Mary Tolcos</td>
<td>Conference Grant: Neuroscience Society AusNZ</td>
<td>Australian Neuroscience Society: perinatal brain injury symposium</td>
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<tr>
<td>Cheryl Jones</td>
<td>Career Development Grant</td>
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<td>Matthias Axt</td>
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<tr>
<td>Caroline Croxther</td>
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<td>Samantha Barton</td>
<td>Perinatal Society Conference Abstract Winner</td>
<td>The Ritchie Centre</td>
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<tr>
<td>James Andis</td>
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<td>Michelle Juarez</td>
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<td>Cathryn Croxther</td>
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<tr>
<td>Postgraduate Student Grant</td>
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<td>Rebecca Pelkasos</td>
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<td>Graeme Polglase</td>
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<tr>
<td>Bobbi Reiss</td>
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<td>An Massaro</td>
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<td>Ros Boyd</td>
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<td>University of Queensland</td>
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<tr>
<td>Tamara Yavno</td>
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<tr>
<td>Lee Barber</td>
<td>Avant Innovative Research Grant</td>
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</tr>
<tr>
<td>Caroline Croxther</td>
<td>Avant Innovative Research Grant</td>
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<td>$250,000</td>
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### RESEARCH ACHIEVEMENTS: GRANTS LISTING

#### 2012
- **Lachlan Thompson**: Avant Innovative Research Grant | University of Melbourne | $108,471
- **Claire van Eik**: Avant Innovative Research Grant | University of Adelaide | $298,996
- **Alexander Hoyn**: CP Challenge Research Grant | John Hopkins University | $53,200
- **Alastair MacIennan**: Innovative Research Grant | University of Adelaide | $800,000
- **Suzie Miller**: Career Development Grant | Monash Institute Medical Research | $50,000
- **Nigel Pannell**: Distinguished Researcher Award | Michigan State University | $50,000
- **Cally Tan**: Career Development Grant | University College London | $25,000
- **Glen Lichtswark**: Career Development Grant | University of Queensland | $25,000
- **Eve Blair**: Distinguished Researcher Award | Telethon Institute Child Health Res | $10,000
- **Student Grants**: Undergraduate Student Scholarships | Various NSW Universities | $18,000
- **William Walsh**: IMPACT for CP Summit | Conference Grant | CP Summit 2013, Bethesda USA | $1,120
- **IMPACT for CP Summit - NIH**: Conference Grant | NIH, Washington DC | $4,000
- **IMPACT NIE & NIE Summit**: Conference Grant | CP Summit, Washington DC | $71,000
- **Research Institute**: People Support & Infrastructure | | $809,652

#### 2014
- **Lachlan Thompson**: Avant Innovative Research Grant | University of Melbourne | $108,471
- **Claire van Eik**: Avant Innovative Research Grant | University of Adelaide | $298,996
- **Alexander Hoyn**: CP Challenge Research Grant | John Hopkins University | $53,200
- **Alastair MacIennan**: Innovative Research Grant | University of Adelaide | $800,000
- **Suzie Miller**: Career Development Grant | Monash Institute Medical Research | $50,000
- **Nigel Pannell**: Distinguished Researcher Award | Michigan State University | $50,000
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- **IMPACT for CP Summit - NIH**: Conference Grant | NIH, Washington DC | $4,000
- **IMPACT NIE & NIE Summit**: Conference Grant | CP Summit, Washington DC | $71,000
- **Research Institute**: People Support & Infrastructure | | $809,652
RESEARCH ACHIEVEMENTS:  
GRANTS LISTING  
(CONTINUED)

### RESEARCHER  
### TITLE  
### INSTITUTION  
### AMOUNT

#### 2015 – Total Research Funding $4,730,861

**Postgraduate Student Grant**

- **Conference Grant**
  - University of Sydney $500
- **Conference Grant, PSANZ Melbourne**
  - University of Auckland $1,250
- **Conference Grant, PSANZ Melbourne**
  - University of Queensland $1,250
- **General Movements Assessments**
  - Training Grant $17,000
- **General Movements Assessments**
  - Training Grant $30,000
- **General Movements Assessments**
  - Training Grant Children’s National Health Centre $2,200

**Henry J Cowan Student Grants**

- **Conference Grant**
  - University of Sydney $4,500
- **Student Grants**
  - Undergraduate Student Scholarships CSU, UoN, UWS, UCAN $9,000
- **Helen Liley**
  - Conference Grant University of Queensland $600
- **Westmead International Update**
  - Conference Grant Children’s Hospital Westmead $1,000
- **Stephen Back**
  - Conference Grant Oregon Health & Science University $5,000
- **IMPACT Stem Cell Summit**
  - Conference Grant CP Summit $50,000
- **IMPACT Neonatal Stroke Summit**
  - Conference Grant CP Summit $100,000

**Adrian Barnett**

- **Project Grant**
  - Queensland University of Technology $20,000

**Alison Spittle**

- **Project Grant**
  - Murdoch Childrens Research Institute $6,500

**Gulam Khandaker**

- **Project Grant**
  - Child Sight Foundation $14,400
- **AACPDM Project Grants**
  - Project Grant American Academy CP & DM $125,000
- **General Movements Assessments**
  - Project Grant Research Institute $105,000

**Peta Karlsson**

- **Project Grant**
  - Research Institute $25,000
- **Ju-Lee Oei**
  - Project Grant University of NSW $10,110
- **Shona Goldsmith**
  - Project Grant Research Institute $20,695
- **Greg Powell**
  - Project Grant JP Kapnek Trust $30,000
- **Ana Aradhna-Babarumani**
  - Project Grant Kings College London $38,376

**Emily Bain**

- **Project Grant**
  - University of Adelaide $23,500

**Angie Morrow**

- **Project Grant**
  - Children’s Hospital at Westmead $100,000

**Hayley Dickinson**

- **Project Grant**
  - Hudson Institute of Medical Research $230,000

**Mohammed Muhit**

- **Project Grant**
  - Child Sight Foundation $39,841
- **Graeme Polglase**
  - Project Grant Hudson Institute of Medical Research $123,395
- **Jonathan Morris**
  - Project Grant University of Sydney $42,416
- **Arlene D’Silva**
  - Project Grant Western Sydney University $14,940
- **Bryan Leaw**
  - Project Grant Hudson Institute of Medical Research $141,890

**Felicity Pidgeon**

- **Project Grant**
  - Northern Territory Department of Health $12,984

**Margaret Wright**

- **Project Grant**
  - University of Queensland $201,600

**Xun Li**

- **Project Grant**
  - University of Sydney $14,798

**Catherine Elliot**

- **Project Grant**
  - Curtin University $50,000

**David Winlaw**

- **Project Grant**
  - Children’s Hospital at Westmead $125,000

---

#### RESEARCHER  
### TITLE  
### INSTITUTION  
### AMOUNT

**Elizabeth Elliott**

- **Project Grant**
  - University of Sydney $19,525

**CRE-CP Leadership Program**

- **Career Development Grant**
  - Centre of Research Excellence for CP $100,000

**Hayley Smithers-Sheedy**

- **Career Development Grant**
  - Research Institute $10,500

**Barbara Lucas**

- **Career Development Grant**
  - George Institute for Global Health $2,725

**Xun Li**

- **Career Development Grant**
  - University of Sydney $75,000

**Michael Msall**

- **Career Development Grant**
  - University of Chicago $10,000

**Courtney McDonald**

- **NHMRC Early Career Fellowship (Co-fund)**
  - Hudson Institute of Medical Research $157,322

**Shani O’Brien**

- **NHMRC Postgraduate Scholarship (Co-fund)**
  - University of Queensland $53,802

**Jordan Nguyen**

- **Neurodisability Assist Grant**
  - PsyKinetic Pty Ltd $25,000

**Developing World Conference Grant**

- **Conference Grant**
  - ICP/EACD Conference, Stockholm $12,000

**Stem Cells in Umbilical Blood Infusion for CP**

- **Project Grant**
  - Murdoch Childrens Research Institute $200,000

**Stem Cells for CP**

- **Project Grant**
  - To be advised $460,000

**CP Genomics**

- **Project Grant**
  - To be advised $450,000

**Research Development**

- **People Support & Infrastructure**
  - Cerebral Palsy Alliance Research Foundation $280,000

**Research Institute**

- **People Support & Infrastructure**
  - $1,137,642

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**RESEARCH FOUNDATION**

10 YEARS OF DISCOVERY
Glossary of Terms

Epidemiology The branch of medicine dealing with the incidence and prevalence of disease in large populations and with detection of the source and cause of epidemics of infectious disease.

Genome A full set of chromosomes; all the inheritable traits of an organism.

Exome The portion of a gene or genome that codes for protein synthesis; the exons in the human genome.

Single Point Mutation An alteration in DNA sequence caused by a single nucleotide base change, insertion, or deletion.

Copy number variations A form of structural variation—alterations of the DNA of a genome that results in the cell having an abnormal or, for certain genes, a normal variation in the number of copies of one or more sections of the DNA.

Genetic sequencing The process of determining the precise order of nucleotides within a DNA molecule. It includes any method or technology that is used to determine the order of the four bases—adenine, guanine, cytosine, and thymine—in a strand of DNA.

Boccia A game similar to bocce, played by competitors who have a physical disability that requires the use of a wheelchair.

Magnetic Resonance Imaging (MRI) A technique that uses a magnetic field and radio waves to create detailed images of the organs and tissues within your body. Most MRI machines are large, tube-shaped magnets. When you lie inside an MRI machine, the magnetic field temporarily realigns hydrogen atoms in your body.

 Biomarkers A naturally occurring molecule, gene, or characteristic by which a particular pathological or physiological process, disease, etc. can be identified.

Prediction modelling A process used in predictive analytics to create a statistical model of future behaviour.

Botulinum toxin A (BoNT-A) An anti-spasticity medication used for children and adults with cerebral palsy. It is injected into muscles to temporarily decrease unwanted muscle tightness.

General Movements Assessment A quick, non-invasive and cost-effective way to identify neurological issues which may lead to cerebral palsy and other developmental disabilities. The assessment can be conducted from birth to three months of age. A distinct movement pattern that is evident in babies before birth (fetus from nine weeks) and after birth up to 18 weeks post-term. The movement pattern is one which the baby does spontaneously and without any external stimulation, such as a parent playing or talking to them.

Contractures A shortening of muscles, tendons and soft tissue, causing abnormal forces that limit motion and lead to joint deformity.

Scoliosis An abnormal lateral curvature of the spine.

Eye-gaze technology Technology that enables a person to use eye movements to operate a computer or tablet for communication.

Endogenous The substances and processes that originate from within an organism, tissue, or cell.

Neurogeneration The umbrella term for the progressive loss of structure or function of neurons, including death of neurons.

Stem Cell An undifferentiated cell of a multicellular organism which is capable of giving rise to indefinitely more cells of the same type, and from which certain other kinds of cell arise by differentiation.

Neuroimaging The process of producing images of the structure or activity of the brain or other part of the nervous system by techniques such as magnetic resonance imaging or computerised tomography.

Neonatal encephalopathy (NE) A syndrome in the neonate where neurological function is disturbed. The newborn infant may have respiratory problems, present as ‘flat’ with depressed reflexes, a sub normal level of consciousness and possibly seizures.

Perinatal hypoxic-ischemic encephalopathy (HIE) An oxygen deficiency for the infant, and there can be a number of reasons that the child does not get the required amount of oxygen. It can also happen when there is a problem with the umbilical cord (such as a prolapse or if it was pinched closed) or if the placenta separates from the inner wall of the uterus.

Perinatal / Intrapartum asphyxia The medical condition resulting from deprivation of oxygen to a newborn infant that lasts long enough during the birth process to cause physical harm, usually to the brain.

Neonatal The neonatal period is the transitional time from intrauterine to independent existence. Defined as approximately the first 4 weeks after delivery, the neonatal period is possibly the most tenuous in a human’s lifetime.

Obstetrics The area of medicine and surgery concerned with childbirth and midwifery.

Magnesium sulphate Given to pregnant mothers when they are at risk of very preterm birth. This can help protect babies from the brain injury that leads to cerebral palsy.

Expanding our reach to the developing world

In 2014 Dr Gulam Khandaker of the Sydney Medical School at the University of Sydney, in collaboration with the Child Sight Foundation (CSF) in Bangladesh, received a grant from Cerebral Palsy Alliance Research Foundation to establish a Cerebral Palsy Register in Bangladesh.

Following ethics approval in Australia and Bangladesh, the Bangladesh Cerebral Palsy (CP) Register study activities were commenced in January 2015 using the existing infrastructure of the Australian Cerebral Palsy Register to facilitate studies on prevalence, severity, aetiology, associated impairments and risk factors for cerebral palsy in Bangladesh. So far 342 children are currently registered with the majority having never previously received any assistive devices or rehabilitative services.

With an additional grant from Cerebral Palsy Alliance Research Foundation, in conjunction with TNA Solutions and Wheelchairs for Kids (WFK), many children in Bangladesh with cerebral palsy have now been provided with free wheelchairs. The first shipment of 121 wheelchairs was distributed to children listed on the Bangladesh CP Register in October 2015. There has since been another shipments with many more in plan for the future. This symbolises a new beginning, one with exciting new partnerships across the developing world.