Research Update
Can cooling babies prevent cerebral palsy? Professor Lui investigates

Under The Microscope
Supporting research careers

Cerebral Palsy Follow-Up
New program reduces pain for children

Thank You
Supporters making a difference
Welcome to the first edition of Breakthrough for 2011.

Firstly, you may have noticed we have a new name. As a fully owned subsidiary of The Spastic Centre, we welcome their name change to Cerebral Palsy Alliance. Subsequently, our name has changed to the Research Foundation of Cerebral Palsy Alliance.

We may have a new name, but we remain committed to our original aims of funding research to find preventions and cure for cerebral palsy.

I am in a unique position as the Chairman of the Council of Governors for the Research Foundation of Cerebral Palsy Alliance. I think the most exciting part of this work is being able to make a difference. There have been many major steps forward during the last few years. It is exciting to know the work we support will impact not only on children in Australia, but also on children throughout the world. As an Australian, I am also proud this research push is being supported by an Australian organisation, and many of the world’s best researchers we support are locally based.

We are proud to say that in six years, we have funded more than 45 research projects in Australia and overseas valued at nearly $5 million. Funding these projects would have been impossible without the support of people like you.

We rely on your donations and are pleased to announce the development of a new level of support recognition. To recognise those who have donated more than $1 million, we have introduced the Platinum level of support. Three organisations are the inaugural representatives at this level – Avant, Macquarie Group Foundation and the NSW Government. Their support makes a significant difference.

According to the United Nations, it is estimated that 20 per cent of the world’s poor are persons with disabilities. Cerebral palsy is the most common physical disability in childhood, and 17 million people around the world have cerebral palsy. If we can support research to prevent and ultimately find a cure for cerebral palsy, we will have made a contribution to the global community.

If you can help or would like further information, please contact our Partnerships Manager, Marisa Chilcott.

Bill Bartlett
Chairman, Cerebral Palsy Foundation

GOVERNOR SPOTLIGHT

James Hodgkinson is a member of the Council of Governors of the Research Foundation and founder of the 20/twenty Challenge - a fundraising event that purchases mobility and communication equipment for children with cerebral palsy.

Ten years ago, James’ nephew Alex was born with cerebral palsy. For James, the challenges faced by his sister and her family were made particularly poignant when his own healthy son was born just three months before Alex.

‘My heart broke for Penny and her family. Having my own healthy son, I felt guilty and was very conscious of not presuming I knew what Penny and her family needed.’

Listening to his sister discuss the problems of sourcing specialised equipment inspired James, with long time friend Ross Elice Flint, to launch the now hugely successful 20/twenty Challenge.

The event is a physical and fundraising challenge that requires participants to complete a 2km swim, a 20km walk and a 3km kayak paddle.

To date, James and his team of supporters have raised close to $3 million, which has provided more than 1,500 items of life-changing mobility and communication equipment.

James was instrumental in securing support from the Macquarie Group Foundation for the establishment of the Macquarie Group Foundation Chair of Cerebral Palsy.
Professor Nadia Badawi is one of Australia’s leading authorities on cerebral palsy. She believes a breakthrough is imminent, and is encouraging researchers around the world to help us find ways to prevent and cure cerebral palsy.

As the Macquarie Group Foundation Chair of Cerebral Palsy, my priority is to encourage the best researchers in Australia and around the world to look for causes of cerebral palsy that can be prevented, and one day find a cure.

For decades, we have thought this was a non-preventable and incurable condition, and I think the time has come to change our way of thinking about cerebral palsy.

Surprisingly little money has been spent in research into cerebral palsy. Now with the help of the Research Foundation of Cerebral Palsy Alliance, we can target money from donors like you into the most promising research.

I would say that the time for cerebral palsy research has come.

Many things that in the past were a death sentence or led to chronic disability are now, as a result of research breakthroughs, eminently treatable. Childhood cancers, tuberculosis and rheumatic heart disease can now be treated because of medical research. However, cerebral palsy remains an area that many researchers have largely ignored.

“I believe that significant breakthroughs in the area of cerebral palsy are imminent.”

Thanks to your support of cerebral palsy researchers, we can now identify some of the causes of cerebral palsy, such as genetic conditions and some infections.

Some of the most exciting news of the last 10 years has been the confirmation that magnesium sulphate can help prevent cerebral palsy in babies who will be born pre-term.

We also know a lot more about neural protection, neuroregeneration, and of course, we know there is the very promising research into the effectiveness of stem cells repairing damaged brain tissue.

Cerebral Palsy Alliance is a unique collaboration between generous supporters such as you, people with cerebral palsy and their families, researchers and health care professionals.

Together, we are an alliance like no other and we are committed to making significant breakthroughs.
It is now clear that perinatal hypoxic ischaemic encephalopathy (HIE), often referred to as lack of oxygen at birth, is a major cause of death and disability in babies born at term or close to term. In context, however, only up to 10% of babies with cerebral palsy have an injury around the time of birth. For most, the cause is unknown with the injury occurring sometime during pregnancy.

Professor Kei Lui is head of Newborn Care at the Royal Hospital for Women in Randwick NSW. He is leading a PhD project to evaluate the long-term outcomes for survivors of HIE.

Professor Lui’s project received funding from the Research Foundation’s 2010 Balnaves Doctoral Research Scholarship.

The scholarship is valued at $81,000 over three years, and will allow Professor Lui and his doctoral student to compare and determine whether therapeutic hypothermia can reduce cerebral injury and improve neurological outcomes for babies born with HIE.

There is now evidence from randomised controlled trials conducted in both Australian and international hospitals that therapeutic hypothermia (cooling) may prevent or minimize the long-term consequences of brain injury, such as cerebral palsy due to HIE.

Therapeutic hypothermia involves reducing a baby’s body temperature to 33 – 34 degrees by using cool packs. The baby is then transferred to a neonatal intensive care unit where its temperature is maintained at this narrow margin for a period of three days. For optimum neurological outcomes, it is crucial the treatment is initiated within six hours of birth.

Professor Lui believes therapeutic hypothermia is one of the most exciting treatments available for preventing disabilities such as cerebral palsy.

‘Studies are showing us that the earlier we can cool the baby, the
Further to our magnesium sulphate cover story in the last issue, Breakthrough is pleased to announce the awarding of a $249,999 AVANT Innovative Research Grant from the Research Foundation of Cerebral Palsy Alliance to Professor Caroline Crowther.

Professor Crowther’s team created the world’s first clinical guidelines for the use of magnesium sulphate as a therapy for preventing cerebral palsy in infants born prior to 30 weeks gestation.

The Research Foundation grant will allow Professor Crowther and her team to continue their work as part of a project called WISH (Working to Improve Survival and Health for babies born very preterm). The project will run for three years. It will track the use of magnesium sulphate in hospitals throughout Australia and ensure it is used optimally to improve the health of babies born early.

FROM DONATION TO ACTION

Thanks to your generosity, Professor Lui and his team can now:

- Utilise and link data from neonatal intensive care databases and other population data collections
- Engage health economist and epidemiologist consultants in the design of methodology and statistical analysis
- Attend and present at interstate and international meetings and conferences.

How can you make a difference?

There are a number of cerebral palsy researchers needing your support to continue their work.

If you’d like to help researchers find the answers to cerebral palsy phone Marisa Chilcott on (02) 9479 7286 or email mchilcott@cerebralpalsy.org.au

better chance we have of preventing life-long brain damage. This means that parents should expect that if cooling is induced within six hours, their baby’s chance of survival increases while the chance of major disability decreases.’

Hospitals throughout the world have been using therapeutic hypothermia equipment since 2007 and the results have been encouraging. However, when rolling out a new treatment to the wider community, it is vital that researchers evaluate from a population perspective the long-term neuro-developmental outcomes for individuals who have already received the treatment.

Professor Lui says although therapeutic hypothermia has been shown to be a very promising treatment, it is now essential to utilise much larger sources of population data to accurately evaluate the long-term outcomes for survivors.

With any implementation of new and exciting treatment, it’s vital to obtain evidence to demonstrate efficiency and evaluate the outcome. In this case, it’s important to determine if therapeutic hypothermia would lead to a reduction of mortality and life-long disabilities such as cerebral palsy.

To achieve this, Professor Lui’s and his team have established key partnerships with neonatal hospitals throughout Australia, New Zealand and Canada as well as the research team of Cerebral Palsy Alliance and the Australian Cerebral Palsy Register.

Each has agreed to share their data with Professor Lui’s team to help them determine and compare neurological outcomes, recommend educational opportunities for staff using equipment and evaluate the economic implications of implementing therapeutic hypothermia as a protocol treatment throughout all hospitals.

The findings and finalisation of this PhD project are expected by the end of 2012.
With more cerebral palsy research projects now underway than ever before, the Research Foundation’s Career Development Awards are proving to be a sound investment for donors.

To encourage talented researchers in both Australia and overseas to focus their career’s work in the field of cerebral palsy, the Research Foundation has created The Career Development Awards. This year’s inaugural recipients are a great example of the diversity of talented researchers who are now working in this area in Australia. Thanks to your support, these researchers can continue their important work to find the answers to cerebral palsy.

Dr Flora Wong - $40,000 over two years
Consultant Neonatologist at Monash Newborn, Monash Medical Centre.
Senior Research Fellow at the Department of Paediatrics and The Ritchie Centre, Monash University
Dr. Wong’s research interests are in newborn cerebral pathophysiology, cerebral blood flow and oxygenation in relation to brain injury in newborn infants undergoing intensive care.

She has expertise in the application of Near Infra-red Spectroscopy to examine the cerebral pathophysiology in both animal and clinical studies, employing a translational paradigm. Her project will focus on investigations of the mechanisms of newborn brain injury, and the development of cotside monitoring and neuroprotective strategies.

Dr Rod Hunt - $100,000 over 4 years
Director, Neonatal Medicine, The Royal Children’s Hospital
Senior Research Fellow, Murdoch Children’s Research Institute.
Senior Fellow, The University of Melbourne.
Dr Hunt has spent four years completing his PhD with Professor Terrie Inder looking at the role of hormones in brain development in babies born preterm.
As the Director of the Newborn Intensive Care Unit at The Royal Children’s Hospital in Melbourne, Dr Hunt has an on-going interest in the development of the newborn brain and the way it recovers from injury.
He is currently working on studies to improve outcomes from hypoxic ischaemic encephalopathy and will soon oversee a multi-centre study in Australia to determine whether the treatment of seizures in the newborn period can improve developmental outcomes for children who have a range of brain injuries.
Cerebral Palsy Alliance employee and PhD student at The University of Notre Dame Australia, Cathy Morgan has been offered the chance to study a critically important area of cerebral palsy.

Mrs Morgan has been awarded a scholarship from the National Health and Medical Research Council (NHMRC) jointly funded by the Research Foundation of Cerebral Palsy Alliance and the Balnaves Foundation. Her research focuses on improving the movement skills of young infants with cerebral palsy, and has the potential to have long-term benefits for children with the condition.

Mrs Morgan said her research aims to improve our understanding about the effectiveness of newer interventions, which assist older children’s movement, by applying them to infants.

‘There is a growing body of research which indicates that the first two years of life are a critical window for brain development,’ Mrs Morgan said. ‘The infant brain has great capacity to develop and change, so it’s important that motor problems are identified and treated early. This research aims to test the effectiveness of goal-directed training and enriched environments for young infants with cerebral palsy.’

Head Researcher with Cerebral Palsy Alliance, Dr Iona Novak, said the PhD project was of critical importance and would not have been achieved without the partnership with The University of Notre Dame.

‘Thanks to this partnership a number of new post graduate students, such as Mrs Morgan, have chosen cerebral palsy for their doctoral and honors studies,’ said Dr Novak.

Director of the Office of Research at Notre Dame, Associate Professor Peter Dean said Mrs Morgan’s project underpins the importance of research collaboration; as demonstrated by the involvement of Cerebral Palsy Alliance, the University and NHMRC.

‘This special relationship reflects the University’s commitment to support high quality research and build partnerships in the health sector,’ said Dr Novak.

For more information about supporting the work of cerebral palsy researchers, phone 1300 551 137 or visit www.cpresearch.org.au

A big thank you to Eagle Boys Pizza!

Leading Australian pizza maker Eagle Boys Pizza has recently selected the Research Foundation of Cerebral Palsy Alliance as its charity partner. The partnership includes $50,000 for a research scholarship, which will fund the work of researchers at the Australian Cerebral Palsy Register.

‘We were looking for a charity partner where we could make a real difference to Australian families. When we learnt how many families cerebral palsy affects each year we thought this was an organisation which really needed our support,’ said Todd Clayton, CEO of Eagle Boys Pizza.

The first recipient of the Eagle Boys Research Scholarship is Hayley Smithers-Sheedy. Hayley is a Research Officer with the Australian Cerebral Palsy Register.

Hayley’s role is to integrate cerebral palsy data from cerebral palsy registers in each state and territory of Australia for multiple research purposes including monitoring the incidence and prevalence of cerebral palsy, better understanding the causes of cerebral palsy, planning services, and evaluating preventative strategies.
It's time to dust off your sneakers and tracksuits and join us for the annual Cerebral Palsy Challenge – a team fundraising activity that raises much needed dollars for children living with cerebral palsy.

Many children experience daily chronic pain resulting from hip dislocation, severe contractures and scoliosis. This pain greatly impacts on their lives, and can make simple movements such as walking and standing difficult.

The Research Foundation of Cerebral Palsy Alliance is currently setting up the Cerebral Palsy Follow-Up (CPUP) Program; a comprehensive assessment and surveillance program that a Swedish study has already proven will eliminate chronic pain through early detection and intervention.

By helping the Research Foundation expand the CPUP program in Australia, you will significantly improve the lives of children and families living with cerebral palsy.

Now, thanks to the health care program developed in southern Sweden, a number of these problems can be better addressed. Of the 258 children who participated in the Swedish study, none developed hip dislocation; contractures were reduced by 70 per cent and orthopaedic surgery decreased from 40 per cent to 15 per cent.

No other program around the world has been able to achieve results even close to this. It represents a significant breakthrough for children with cerebral palsy and their families.

Central to the program's success are twice yearly assessments of children under school age, and an extensive cerebral palsy research database. Information such as a child's measurements and current treatments will be entered into the database.

The Australian CPUP program's data base will be the world's largest resource of up-to-date information, and will ensure health professionals can detect problems and implement interventions much earlier than ever before.

However, to continue building the Australian CPUP program a further $100,000 is required. Funding would also accelerate the implementation of the program, and therefore benefit more families sooner.

Your generosity will ensure children with cerebral palsy will not have to endure unnecessary and prolonged pain.

If you would like to support the Cerebral Palsy Follow-Up Program, phone Marisa Chilcott (02) 9479 7286.

The Cerebral Palsy Challenge is a pedometer-based activity where teams of four track their daily steps or other fitness activity, and record them on a personalised web page. To participate, you don't have to just walk – you can run, cycle, swim, even play bowls to notch up your daily steps.

Once registered, participants will receive a Challenge pack that includes helpful hints and two pedometers. Fundraising has also been made easy with tools and payment facilities available via the website.

Participants can choose where they would like their funds to go - either towards research or for purchasing essential therapy services and equipment for children with cerebral palsy.
Despite raising two young children with a third on the way, Dionne and Darrel Cross have already agreed to sign up to this year’s Cerebral Palsy Challenge. Motivating the couple is their two year-old daughter Katelyn who has cerebral palsy.

‘Neither of us had even heard of cerebral palsy before Katelyn was born. We think it’s important to do as much as we can to raise awareness, and help Cerebral Palsy Alliance continue to provide children like Katelyn with the services they need.’

And if anyone thinks caring for a newborn will stop Dionne in her tracks, think again. ‘I will just put the kids in a pram and walk to reach my daily quota. This is a great way for me to get my fitness back, and I’m going to give it my best shot - if I can do it, anyone can!’

Register today at www.cerebralpalsychallenge.org.au or phone Jane Richmond on (02) 9479 7273.

A FAMILY URGES FOR YOUR SUPPORT

Mum Kelly Ferguson is a strong supporter of early intervention, and hopes donors will support the new Cerebral Palsy Follow-Up Program.

‘My husband, Andrew and I are strong believers in early intervention. Despite doctors telling us our son Bailey may not walk, talk or go to school, we decided to pursue a range of early intervention programs to improve his quality of life.

For many years, Bailey received a wide range of services from Cerebral Palsy Alliance (formerly known as The Spastic Centre). Our family firmly believes that had it not been for these early intervention programs, Bailey’s life today would be very different. Bailey will have cerebral palsy for life but now, 12 years later, not only is Bailey talking and walking, he will also soon be attending a mainstream high school.

If the community can help set up the Australian CPUP program, it will be money well spent. This information is a vital tool for therapists working with children with cerebral palsy. You cannot underestimate the huge difference in quality of life that is possible for these kids if they receive the right treatment as early as possible. To give children with cerebral palsy a better chance at life and alleviate their pain would be such a great thing to do.

The Australian Cerebral Palsy Follow-Up Program is absolutely required by families living with cerebral palsy.’

Kelly Ferguson
THANK YOU

YOUR SUPPORT OF RESEARCH IS CHANGING THE FUTURE OF CEREBRAL PALSY

International Presentations
Australian researchers continue to make their mark on the world stage. Sarah McIntyre presented her data on causal pathways to cerebral palsy in term infants at the meeting of the American Academy of Cerebral Palsy and Developmental Medicine in Washington DC. Dr Novak (above) co-presented the International Consensus Statements for Botulinum toxin published in the European Journal of Neurology. Dr Novak also presented the early pilot work on ways to improve the participation of children with physical disabilities.

Giant Influence
Associate Professor Eve Blair (left) and Professor Nadia Badawi are receiving significant international attention for their seminal work into the prevention and cure of cerebral palsy. Their research is so well regarded, that Dr Gary Hankins recently referred to both as the ‘giants of cerebral palsy research’ in his keynote address at the prestigious annual meeting of the American Academy of Cerebral Palsy and Developmental Medicine in Washington DC.

Assoc. Prof. Eve Blair is author of the landmark text, ‘Cerebral Palsies: Epidemiology and Causal Pathways’, and Professor Nadia Badawi’s early research into Neonatal Encephalopathy and risk factors for cerebral palsy continues to be of international importance in the cerebral palsy research field.

Bulls & Bears Trophy Charity Golf Day
Inspired by a family whose son has cerebral palsy, JBWere’s John McCarroll initiated this annual event to fund the Bulls & Bears 12 month scholarship. For the past three years, the event has supported the work of Dr Alicia Spittle (above) from the Murdoch Children’s Research Institute. Dr Spittle’s research looks at the impact of early intervention on brain development of premature babies.

Career Honoured
Earlier this year, Professor Alastair MacLennan AO was appointed an Officer of the Order of Australia for distinguished service to medicine as a leading researcher and practitioner in the areas of obstetrics and gynaecology and the causes of cerebral palsy, to medical education and to professional development. Professor MacLennan has been the recipient of a number of grants from the Research Foundation of Cerebral Palsy Alliance.

Sail4Palsy
Real estate agent, Peter Hodgson (third from right) recently sailed 350km in a catamaran from Townsville to Cairns to raise funds for cerebral palsy research. Motivated by big sister Karen who has cerebral palsy, Peter raised $15,000 from friends, family and more than 25 local businesses as well the Twin Cities’ Leo’s Club and Lions Q2 District to fundraise for research projects across the world into the prevention and cure of cerebral palsy. Joined by mate David Lindsay, the fleet completed the journey over one week.
Advancements in the treatment of cerebral palsy greatly improved Ethan’s life. Sadly, they could not save it.

If we can find out why children like Ethan are born with cerebral palsy, we can develop better treatments for this disability. We could prevent children from being born with cerebral palsy in the future. We could even find a cure.

The Research Foundation of Cerebral Palsy Alliance is the only dedicated funding body for research into the prevention and cure of cerebral palsy in the world.

We have identified 7 crucial research projects that require urgent funding – and could change the lives of people with cerebral palsy and their families forever.

A gift from you today could help fund this crucial research and help us come closer to a world without cerebral palsy.

Please accept my gift of:

☐ $25  ☐ $50  ☐ $100  ☐ My choice $ ________________

I enclose a ☐ Cheque  ☐ Money order for the sum of $ ________________

OR please debit my  ☐ Mastercard  ☐ visa  ☐ AMEX

__________________________
Name on card

__________________________  Expiry Date ________________
Signature

__________________________  Mobile ________________
Email

“Losing Ethan has been the single most devastating thing to happen in our lives. If a medical breakthrough could be found for this, I would be ecstatic.”

Shannon Clough – Ethan’s Mum

Privacy

Thank you for considering our communication. We at Cerebral Palsy Alliance really value the relationship with you. We wish to keep in touch with you and keep you informed about our work. It is only with the support of people like you that we can continue helping people with cerebral palsy.

We recognise the importance of your privacy and the safeguarding of your personal information. We are careful with all your details and will use them to contact you about issues we believe will be important to you. If you do not wish to receive further communications from Cerebral Palsy Alliance please call us on (02) 9479 7200 or tick this box ☐

Finding more people such as you to help individuals with cerebral palsy is incredibly important. Occasionally we’d like to work with other charities who are involved in the environment, animal welfare, the arts, human rights, health and welfare, medical research or international aid. We’d like to allow them to write to you in return for them allowing us to write to their supporters. These charities would only keep your contact details if you respond to them. If you are happy for us to do this now but change your mind in the future, you may let us know and we’ll note this on your record.
Thank You!
WE CAN’T DO IT WITHOUT YOU.

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