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We welcome to our final edition of Breakthrough for 2013.

When cerebral palsy was first described in 1861 by surgeon Dr William Little, the prognosis for anyone diagnosed with the condition was bleak.

Now, more than 150 years later, thanks to the efforts of researchers throughout the world, the independence and community participation of people with cerebral palsy is far greater than Dr Little and his colleagues probably ever thought possible.

Although this progress is admirable, it’s only in the last decade when we’ve seen some of the most promising research discoveries that medical experts have begun to believe cerebral palsy may not be the incurable condition we’ve all thought it to be.

Cerebral palsy is the result of an injury to the brain. So, it’s no coincidence that this marked change in opinion has come about at a time when science is revealing more about the brain’s potential to repair, recover and reorganise itself after an injury.

Another research area generating widespread interest is stem cell therapy, which has shown extraordinary promise for repairing injured brain cells. In response to this interest, the Research Foundation of Cerebral Palsy Alliance recently co-hosted a free Stem Cell and Cerebral Palsy Forum (see page 3 for the full story).

This special event was also live streamed, allowing people from across the globe to tune in and hear the latest developments in stem cell research and what it means for cerebral palsy.

The impact of these emerging fields of research has been the increasing number of researchers and patients wanting to know more about the new treatments that may be available in the near future.

And it’s this type of ongoing collaboration that we hope will be so important if we are to achieve further breakthroughs in cerebral palsy research. A great example of this was seen at our second Prevention and Cure Cerebral Palsy Summit in Washington D.C., USA (page 5) where researchers throughout the world met to discuss the direction of future research to treat babies diagnosed with neonatal encephalopathy (NE), a condition that leads to cerebral palsy.

History has shown what a difference can be made when cerebral palsy research receives the funding and attention it needs to achieve breakthroughs. But for research to continue unveiling important discoveries, we need people like you whose support makes it possible for researchers to continue their work.

A parent of a child with cerebral palsy once said “without research we are no closer to a cure” - a sentiment I now believe resonates with many in the community, not just people directly affected by cerebral palsy.

Thank you for having the vision to join us in our quest to improve our understanding of cerebral palsy.

Thank you.

Bill Bartlett
Chairman

Research Awards

Researcher Awarded Top Scholarship

Cerebral Palsy Alliance’s Head of Research, Associate Professor Iona Novak has been awarded a Fulbright Scholarship – one of the world’s most prestigious educational scholarships - to further her work in stem cell research.

Recognised for her research which is aimed at finding a cure for cerebral palsy, Iona’s Fulbright Scholarship will allow her to establish and lead an American-Australian Cerebral Palsy Stem Cell Consortium called Xcellerate utilising American stem cell researchers and Australian cerebral palsy registers.

Rob White, CEO of the Research Foundation of Cerebral Palsy Alliance says the organisation is extremely proud of Iona’s achievement.

“Iona is one of only 26 Australians to be recognised as a Fulbright Scholar in 2013.

I believe her project will help accelerate the rate of research and breakthroughs that will directly benefit people with cerebral palsy,” he said.

Iona’s scholarship will enable her to spend four months working in the highly regarded Stem Cell, Child Neurology and Cerebral Palsy Research Faculty at the University of California San Francisco (USCF).

Her project will involve collaborating with leading American stem cell researchers and institutions including the California Institute for Regenerative Medicine, Salk Institute, Duke University, University of Toronto, Columbia University, Oregon Health and Sciences and the University of Texas.

The Fulbright Program is a program of competitive, merit-based grants for international educational exchange for students, scholars, teachers, professionals, scientists and artists created by U.S Senator J. William Fulbright and the U.S Government in 1946.

Under the Fulbright Program which operates in over 155 countries, competitively selected Australians receive a scholarship to study, conduct research, or exercise their talents in the USA.

Associate Professor Iona Novak

Governor Spotlight

Before establishing Australia’s most recognised online experience company redballoon.com.au, Naomi Simson was a leading corporate marketer with companies including IBM, KPMG, Ansett and Apple.

Since 2001 redballoon.com.au has sold almost two million experiences and for five consecutive years has been named as a ‘B&W Great Place to Work’.

In 2008 Naomi received the National Telstra Business Women’s Award for Innovation and in 2011 she was awarded the Ernst and Young Industry Entrepreneur of the Year Award.

Naomi is a leading motivational speaker, authors one of Australia’s top 15 Business Blogs and is a LinkedIn Influencer, dispensing knowledge with an audience of 200 million members.

Naomi has a long standing commitment to philanthropy and community work, and Cerebral Palsy Alliance is a cause close to her heart. ‘I believe that prevention is better than cure. It is a fact that the impact of cerebral palsy is felt by many Australian families including my own.

Iona’s project will be so important if we are to achieve further breakthroughs in cerebral palsy.

Bill Bartlett
Chairman

Diary Date

Research Briefing – Thursday 31 October 2013 – Museum of Sydney

Each year the Research Foundation of Cerebral Palsy Alliance hosts two research briefings to showcase current developments in cerebral palsy research.

Past presenters have included a number of Australian and international cerebral palsy experts including stem cell pioneer, Professor Alan Trourson, Macquarie Group Chair of Cerebral Palsy, Professor Nadia Badawi, Associate Professor Nick Evans from the Royal Prince Alfred Hospital, Sydney and Prince Alfred Hospital, Sydney and Australian cerebral palsy registers.

Professor Euan Wallace from the Ritchie Centre at the Monash Institute of Medical Research. For more information about our next research briefing or to book a seat, contact Louise Reeson on 02 9975 8934.

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Stem Cells – A Treatment for Cerebral Palsy?

Readers can now watch and listen to a webcast of the recent Stem Cells & Cerebral Palsy: The Promise & The Progress public forum, jointly hosted by Cerebral Palsy Alliance, Stem Cells Australia and the NSW Stem Cell Network.

More than 200 people attended the forum on 21 May 2013, which was live streamed throughout the world, to hear an expert panel of clinicians and scientists discuss the latest developments in stem cell research and cerebral palsy.

The panel included Professor Euan Wallace, Associate Professor Megan Munsie and the Research Foundation of Cerebral Palsy Alliance’s Associate Professor Iona Novak, also discussed investigations into the possibility of later this year beginning Australia’s first clinical cord blood trials in search of a breakthrough treatment for cerebral palsy.

Associate Professor Iona Novak, Head of Research with Cerebral Palsy Alliance and 2013 Fulbright Scholarship recipient (see page 2) for her work into stem cell research, says it is vital that Australian families are updated on what’s fact and what’s fiction in stem cell science.

‘Parents are urged to be cautious of considering embarking on costly and clinically unproven stem cell treatments overseas for their children with cerebral palsy’, Assoc Prof Novak said.

‘The health and wellbeing of the person with cerebral palsy are paramount, which is why we urge families to be patient whilst we undertake exciting investigations into holding evidence-based clinical stem cell trials here in Australia. ‘Results coming from a recent South Korean study certainly offer the first possibility of using cord blood and erythropoietin for treatment of cerebral palsy and we are keen to integrate these findings into our plans to later this year begin two Australian clinical stem cell trials.’

The recent clinical trial in South Korea (Umbilical Cord Blood Therapy Potentiated with Erythropoietin for Children with Cerebral Palsy: A Double-blind, Randomized, Placebo-Controlled Trial, Dr Kyunghoon Min) has raised the possibility that cord blood along with erythropoietin (which increases red blood cell numbers) could one day be used to treat and ultimately prevent cerebral palsy.

Speaking from personal experience at the forum was Stephen Archer, who in November 2010 took his then 5-year-old son Zac to North Carolina for cord blood treatment for his cerebral palsy.

“We researched stem cell treatments thoroughly. Given our belief that cord blood treatment wouldn’t cause Zac any harm, we went ahead in the hope it would provide him with improved movement and reduced impact from his cerebral palsy”, Stephen said.

“We don’t believe we have seen any great improvement in Zac since he was treated. However, with some of his cord blood remaining, we would consider the possibility of similar treatment within a clinical trial setting.’

Associate Professor Megan Munsie from Stem Cells Australia welcomes the possibility of stem cell clinical trials in Australia and urges parents to think twice about participating in unproven treatments overseas.

“There is no doubt that stem cell research around the world is entering an exciting new phase with possible new therapies for many conditions now being investigated in clinical trials. We still have so much to learn about stem cells. We need more than hope that stem cells will work, we need evidence and participating in clinical trials is the best way to find out whether stem cell research can deliver the longed for benefits for generations to come’, she said.

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Stem Cell Treatment

Push for Australian Trials

Australian researchers are hoping to conduct the country’s first clinical trial to evaluate the effectiveness of stem cell treatment for people with cerebral palsy. Conducting a clinical trial in Australia will allow families to access safe and rigorous research at home, rather than travelling overseas to purchase unproven and unmonitored treatments.

Individuals and families interested in participating in these trials should email the Cerebral Palsy Register: cpregister@cerebralpalsy.org.au for more information.

These types of trials are very expensive and the Research Foundation of Cerebral Palsy Alliance is seeking support to fund these important local trials.

Contact Jen Wight on 02 9975 8769 for information on how to support these trials.
Cerebral Palsy Prevention and Cure Summit 2013

Australians unite world experts in search of best treatment for babies at high risk of cerebral palsy.

More than 40 researchers from across the globe recently met at the second Cerebral Palsy Prevention and Cure Summit, hosted at the National Institute of Health by IMPACT for CP (the International Multidisciplinary Prevention and Cure Team for Cerebral Palsy) in Bethesda Maryland, USA.

Australia’s top cerebral palsy experts met with researchers from the USA, Canada, the UK, the Middle East and Africa to discuss ways to investigate best practices for treating babies diagnosed with neonatal encephalopathy (NE), a condition that leads to cerebral palsy.

In Australia, there are approximately 33,000 people with cerebral palsy, and around 20% of these were diagnosed with NE as newborns.

Recent studies (Hypothermia for Neonatal Hypoxic Ischemic Encephalopathy, Togin 2012) have shown that cooling the infants within six hours of birth to 33-34 degrees celsius for a period of 72 hours reduces mortality and development of cerebral palsy in one in six of these cases. However, for the remaining five in six of these cases, additional therapeutic interventions are required.

A number of adjuvant therapies being trialled in Italy, France, Egypt and the US will be shared at the Summit. These include the use of human growth hormone EPO, magnesium sulphate and other treatments.

Currently, an estimated 17 million people around the world live with cerebral palsy.

“The initial CP Summit in 2011 is starting to show real results, following the agreement to combine global efforts around cooling therapy for term babies at risk of cerebral palsy,” said Neil Balnaves, Chairman of The Balnaves Foundation which is sponsoring the Summit.

“It is real progress that evidence suggests this treatment alone may stop the development of CP in one out of every six of these babies,” he added.

Professor Nadia Badawi from Cerebral Palsy Alliance says global collaboration at the Summit will keep researchers informed on the progress of the different approaches to treating NE.

“Such collaboration will particularly help the five in six babies who don’t respond to cooling therapies”, Professor Badawi said. “We can combine our individual learnings to hopefully fast-track best practices, helping millions of at-risk babies.”

Summit delegates were also updated on the use of video to identify babies at high risk of cerebral palsy. The General Movements Assessment (GMs) involves careful and expert examination of video recordings of babies with NE or prematurity. Abnormal GMs allow us to identify the baby as being at very high risk of cerebral palsy.

“The use of the General Movements Assessment in all NICUs across NSW to enable all specialists to use the General Movements Assessment, the General Movements Assessment in all NICUs throughout NSW to enable all specialists to use the General Movements Assessment, the General Movements Assessment provides a window to identify babies who will benefit the most from accessing vital early intervention therapies for cerebral palsy”, Cathy said.

“We could one day even see smart phones being used to help video at-risk babies, supporting the vital work done in intensive care units.”

Cerebral Palsy Alliance’s hosting of the 2011 and 2013 World Summits and the General Movements Assessment training of NICU specialists throughout NSW have been funded by ongoing support from The Balnaves Foundation, established in 2006 by philanthropist Neil Balnaves AO.

“I think it is appalling that although cerebral palsy is the most common physical disability in childhood, less than $US5million worldwide was spent last year on research to find a cure”, said Mr Balnaves.

“Breakthroughs in cerebral palsy prevention and cure will come, but not without increased Government and philanthropic support”, he said.

“Ongoing support such as that from The Balnaves Foundation is what allows us to continue our research, ensure vital global collaboration, and ultimately drive our results”, said Professor Nadia Badawi.

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Donor support has been crucial to the development of a surveillance and follow up program aimed at reducing chronic pain in children born with cerebral palsy.

CP Check-Up

Two years ago, Breakthrough first reported on a Swedish surveillance and follow up program that had proven it was possible to eliminate hip dislocations, and reduce chronic pain caused by contractures and other orthopaedic problems in children born with cerebral palsy.

Now, thanks to the generosity of donors, researchers at the Research Foundation of the Cerebral Palsy Alliance have developed a similar program called CP Check-Up to help improve the quality of life for the 50% of Australian children born with cerebral palsy who experience chronic pain.

While the Swedish program focussed on investigating the effects of cerebral palsy on a child’s upper and lower limb development and nutrition, the Australian CP Check-Up program has expanded its assessment criteria to also include pain, sleep, communication, cognition and learning as well as parent and child well-being.

Based on the success of the Swedish model, Australian researchers are confident the CP Check-Up program’s focus on early identification will ensure Australian families will benefit from similar results.

The CP Check-Up program requires children aged 0-6 years to attend twice-yearly assessments by Cerebral Palsy Alliance’s therapy teams during which vital details such as their measurements and treatment history are entered into an extensive cerebral palsy database.

Petra Karlsson is a Research Project Officer at the Research Foundation of Cerebral Palsy Alliance. Petra worked on the Swedish program and has been working on CP Check-Up since 2011. She says donor support has been critical to the program’s development, in particular the database. ‘Our supporters, in particular UBank, who has donated $100,000 towards the program, have made it possible for us to develop and build the database and implement CP Check-Up much earlier than we had originally envisaged.’

A child’s support team (including health professionals such as physiotherapists, occupational, speech and recreation therapists, psychologists, doctors etc) can then access and analyse the information on the database, from which a report is generated, which can help them identify problems early.

By identifying problems early, the clinicians can then work with families to develop and prioritise goals, plan and provide timely treatments. This may reduce time spent on hospital waiting lists by proving the urgency of a particular intervention and start the process of applying for equipment funding earlier.

Petra Karlsson says the information on the 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 to see what works best and make similar treatment recommendations for other children. This sort of information is particularly useful for parents considering invasive interventions such as surgery.’

To date, parent feedback on the program has been positive says Petra. ‘Parents are particularly pleased with how the CP Check-Up program has facilitated greater communication between therapy teams and families regarding their child’s development, prognosis, shared goal settings and intervention plans with other services such as hospitals.’

CP Check-Up is funded by the Research Foundation of Cerebral Palsy Alliance.

Stats Update – Cerebral Palsy in Australia

The Australian Cerebral Palsy Register (ACPR) has just released its second report on the current status of cerebral palsy in Australia.

Featuring the country’s most accurate and complete source of statistical information on cerebral palsy, the Australian Cerebral Palsy Register Report 2013 has for the first time been able to cautiously report on trends in Australia.

The 2013 Report has identified four groups that, statistically, have a greater risk of cerebral palsy:

1. Males – males are at a greater risk of having cerebral palsy
2. Premature babies – prematurity is associated with higher rates of cerebral palsy
3. Small babies – Low birth weight is associated with higher rates of cerebral palsy
4. Twins, triplets and higher multiple births – Prematurity is associated with higher rates of cerebral palsy

11% of children with cerebral palsy were from a multiple birth, whereas the rates of multiple births are only 1.7% in the Australian population.

The ACPR is a research database featuring data provided by each of the state and territory registers, and it is one of the few national cerebral palsy registers in the world. The aim for the ACPR is to be a source of data that will support research relating to:

- monitoring of cerebral palsy
- identifying interventions that effectively improve quality of life
- identifying causal pathways to enable prevention

Benefits of CP Check-Up Program for Families

• Re-assurance - regularly monitoring means that potential problems can be detected earlier than before
• Peace of Mind – success is possible as seen by results of Swedish program
• Less Surgery – children are less likely to develop painful secondary conditions that require invasive interventions
• Improved wellbeing – regular appointments helps parents and children feel more in control about future treatment planning

To make a donation to the CP Check-Up program, contact Tracey Jordan at tjordan@cerebralpalsy.org.au
Impact for CP

One of the outcomes of the first Prevention and Cure Cerebral Palsy Summit in 2011 was the creation of the International Multidisciplinary Prevention and Cure Team for Cerebral Palsy (IMPACT for CP) - a research network committed to accelerating breakthroughs for cerebral palsy research.

The steering group for IMPACT for CP includes some of the world’s leading cerebral palsy experts such as Professor Donna Ferriero, Dr Jan Brunstrom, Dr Linda de Vries, Professor Nadia Badawi, Associate Professor Iona Novak, Research Fellows Sarah McIntyre and Cathy Morgan who all attended the second Prevention and Cure Cerebral Palsy Summit held earlier this year.

Among the aims of the group is to encourage and facilitate collaboration and data sharing between cerebral palsy researchers throughout the world, and develop information on recommended protocols and common data elements for future trials. This information will soon be available on a new website currently undergoing development.

Since forming, the IMPACT for CP group has also achieved consensus regarding global research priorities. These priorities have now been organised into topics including neonatal encephalopathy, the focus of this year’s Summit in Washington D.C., after which a number of attendees expressed an interest in working with other researchers through the IMPACT for CP group.

Other research areas the group have deemed a priority include (but not limited to), birth defects, stroke, neuroregeneration, early identification and intervention and CP Registers and surveillance.

Rob White, CEO of the Research Foundation of Cerebral Palsy Alliance which is funding IMPACT for CP, says collaboration of the best minds in cerebral palsy research is pivotal to future breakthroughs.

“When researchers can work together, share data and agree on the next steps in the various research programs, the answers to cerebral palsy will be found more quickly, and possibly in our lifetime.”

AIMS OF IMPACT for CP:

• Develop a shared research plan outlining goals and research priorities
• Support efforts to expedite research translation: between basic science and clinical trials then into the community/hospital environment to change clinical practice
• Provide a forum for informal mentoring and support between researchers
• Support strategic research through this network, other similar networks and further collaborations.
• Support the work of CP Registers
• Connect investigators to enable data sharing
• Provide standardised data collection tools and outcome definitions to support prospective and longitudinal data collection that can be more easily shared, compared and pooled
• Explore opportunities for collaborative research
• A coordinated effort to seek funding

A group of budding researchers from Brisbane Girls Grammar School have ‘stepped up’ to support cerebral palsy research by joining this year’s Steptember campaign - a 4 week health and wellness initiative to raise funds for Cerebral Palsy Alliance and cerebral palsy research.

The Research Foundation of Cerebral Palsy Alliance hopes to top last year’s record of 1100 teams registering by the time Steptember begins on Wednesday 4 September.

With the girls from Brisbane Girls Grammar School already supporting the work of cerebral palsy researcher Hayley Smithers-Sheedy on the CMV newborn blood spot study, it was a natural ‘step’ for them to support Steptember says Mrs Lynne Mungomery the school’s Service Coordinator.

‘Hayley has given our students a great insight into what it’s like to work in the field of cerebral palsy research and shown us all how our fundraising dollars can make a real difference. Girls are encouraged through our service program to really be involved with the charities and causes they support, to advance understanding in the wider community and demonstrate leadership.

Steptember is a great opportunity for our school community to continue its support and help raise awareness about cerebral palsy to our own personal networks.’

CEO of the Research Foundation of Cerebral Palsy Alliance, Rob White says Steptember is about engaging all Australians in becoming actively involved in supporting fellow Aussies with CP.

33% of children with cerebral palsy can’t walk, and 20% can’t talk. With the help of Steptember teams across Australia, we can continue supporting vital research to help us find answers and support for people with cerebral palsy and their families.

Brisbane Girls Step Up for Cerebral Palsy Research

Steptember
– 4 September to 2 October 2013

Here’s how you can get involved

Diarise Steptember
– Wednesday 4 September
– Wednesday 2 October

Register a team at www.steptember.org.au of four people

Start and record your daily steps / activity levels by wearing a pedometer

Walk 10,000 steps a day to reach the top of 7 mountain summits in the online virtual mountain climbing course

Promote Steptember to your colleagues, friends, family etc.

Use the online step converter to convert your favourite activity into steps (there are 40+ activities you can do!)

For more information contact Marie Gamble on 02 9975 8765.
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