

Cerebral Palsy Foundation Briefing

26 August 2009

It is really great to welcome you here this evening and I extend an especially warm welcome to Professor Alastair MacLennan who tonight will deliver the inaugural research briefing for the Cerebral Palsy Foundation.

Before Professor MacLennan takes the stage, it is important for the scene to be set and context given to this inaugural briefing by tracing the Cerebral Palsy Foundation's journey thus far.

The Foundation was officially launched in 2005 by the then Prime Minister, The Hon. John Howard, to mark The Spastic Centre's 60th birthday year.

The goal set for the Foundation was to raise a corpus of \$50 million to support the best and most meaningful cerebral palsy research here in Australia and overseas, and to invest in and capture the best research minds in our quest to piece together the puzzle that is cerebral palsy.

So, with a most generous bequest from the late Elsie Thompson and a half million dollar donation from the Commonwealth Government through the then Prime Minister, the Foundation was launched.

It is important for me to emphasise how critical it was back then, and now, not only to support the best research, but to actually have a real hand in steering the research agenda, nationally and internationally. By taking the reins, so to speak, we could ensure that our investment would be targeting those critical prevention and intervention projects that would move us and indeed the world, closer to the achievement of our vision.

The Cerebral Palsy Foundation dares to dream that the day will come when no child will be born with cerebral palsy. A tomorrow when no child will have to live with cerebral palsy!

We are unapologetic about our vision and unashamed of our ambition to be a key player in the world of cerebral palsy research.

To position the Foundation as a leader, if not the leader, and to ensure a strategic role in guiding the research agenda world-wide, our Cerebral Palsy Institute, headed up by Dr Iona Novak and Senior Research Fellow, Sarah McIntyre conducted a landmark Delphi study to ascertain the priorities of the top cerebral palsy researchers from all over the globe and to hear the views and opinions about research from people with cerebral palsy themselves and their families.

Interestingly enough, people living with cerebral palsy identified prevention research as their highest priority.

That Delphi study, a world first, developed a solid research agenda and it is against the agenda's priorities, especially those that target prevention, that grant applications are evaluated for funding.

In this way, we can steer research to the outcomes that will ensure the Foundation holds true to its vision, maintains its strategic direction and cements its importance on the world stage.

In 2006, the Foundation awarded its first round of research grants and scholarships to nine researchers – a total investment of \$359,000.

In the same year, a valuable partnership with the National Health and Medical Research Council was formed to co-fund selected projects, thus extending research investment and capacity.

In 2007, a further \$350,000 was allocated to innovative research projects, and the Cerebral Palsy Institute, funded by the Cerebral Palsy Foundation, launched the Australian Cerebral Palsy Register. This database, now the largest in the world, will expand our understanding of cerebral palsy, and provide a brilliant platform for research both here and around the world.

In 2008, a total of \$400,000 was granted to researchers, and the Foundation partnered with the School of Medicine of the University of Notre Dame, Australia to relocate its Cerebral Palsy Institute within the St Vincent's research precinct in Darlinghurst.

The move took place earlier this year, and with a NSW Government infrastructure grant of \$3 million, a more permanent home for the Cerebral Palsy Institute will be established into the future.

Another milestone achievement has been the creation of the Chair of Cerebral Palsy, through the generous support of Macquarie Group Foundation and a Federal Government grant.

The Macquarie Group Foundation Chair of Cerebral Palsy, as it will be known, will be located here within the School of Medicine at the University of Notre Dame, and will lead and direct national and international research. The successful appointee announcement will be made shortly.

In February this year, the Cerebral Palsy Institute hosted the 3rd International Cerebral Palsy Conference, a first for the southern hemisphere and widely described as the best conference ever. We hosted over 1,400 delegates from 40 different countries, bringing together the world's leading researchers. As a result, a new and long-awaited spirit of international collaboration has emerged.

The conference was sponsored by Allergan, the NSW Department of Ageing, Disability and Home Care, and the Cerebral Palsy Foundation.

We are delighted that Anthony Avvenevole from Allergan is with us tonight.

The Foundation has also formed a fabulous partnership with Avant, Australia's leading provider of medical indemnity insurance. Avant will provide \$2 million to further research projects.

This is a most significant investment and we are thrilled that Mark Williams from Avant has also joined us tonight.

By the end of 2009, the Cerebral Palsy Foundation will have awarded nearly \$2 million in research grants.

Our vision for cerebral palsy research, and the gift of one generous and compassionate woman, have already led to achievements beyond our imagining just four years ago.

These achievements would not have been possible without the outstanding support of our partners, sponsors and donors who inspire and motivate us in our mission.

And it is here that I pay special tribute to Bill Bartlett, Chairman of the Foundation's Council of Governors and team. Their leadership in attracting people to our cause, has been outstanding.

Once again, I would like to welcome you and thank you for sharing our vision - "A future without cerebral palsy."

Marelle Thornton AM

PRESIDENT – The Spastic Centre

DIRECTOR – The Cerebral Palsy Foundation