

Priorities for research – listening to the MS community

Earlier this year we asked the Australian MS community, to let us know your thoughts on the priorities for the many different areas of MS research. The results are in, and we are enormously grateful to everyone who took the time to share their views.

We are pleased that 1,058 people participated in the survey. This included 774 people with MS, 219 people with a close connection to MS (friends and family) and 65 MS health and scientific professionals. Reassuringly, an independent analysis revealed that we had captured a representative sample of the Australian MS population.

Perhaps unsurprisingly, the top priority goals for MS research emerged as:

- **Finding a cure for MS** (via repair and regeneration of cells)
- **Better treating MS** (relapses and disease progression)
- **Prevent MS**

These top three goals were unanimous no matter what stage of the MS journey people are at and also across all groups within the MS community. Research to improve the management and care of MS (symptoms, services and support), and to improve the ability to predict and better diagnose MS, were lower priorities.

Within 'better treating MS' the community prioritised research relating to progressive MS, followed by better treatments to stop relapses. There was also interest in developing a better understanding of the safety and effectiveness of autologous haematopoietic stem cell transplant for MS.

One important and emerging theme was the priority people placed on lifestyle factors in managing the impact of MS, potentially reflecting people's desire to understand factors they may be able to control themselves, such as stress, lifestyle, diet and exercise. Overall, social and applied research to improve the

management and care of MS symptoms and rehabilitation was rated as a lower priority across the whole MS community. However, the people who are more severely impacted by their MS gave it a higher rating than others.

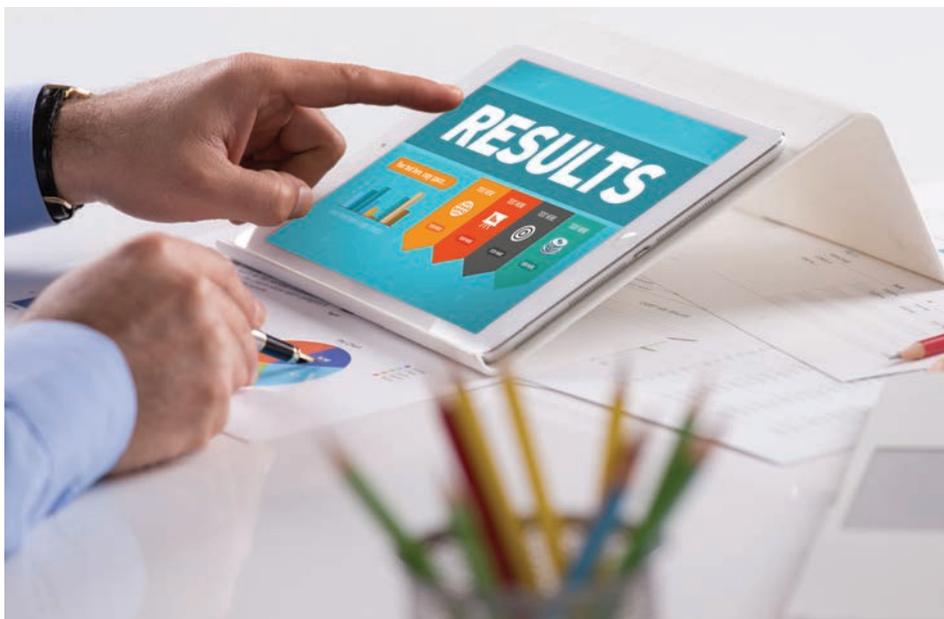
MS has many symptoms and it was imperative that MS Research Australia evaluated which symptoms the community regarded as needing the most urgent attention. The top responses were symptoms relating to walking and mobility, cognition, pain, fatigue, vision, speech and swallowing. There were some differences in the priorities identified by health professionals and friends and family. This needs closer examination as it may have implications for the provision of information, referrals and services in relation to the management of symptoms.

It is important to MS Research Australia that we work with the MS community to continue to fund the strongest Australian research that aligns with the community's needs and wants. A review of our funding over the past few years reveals that we are well aligned with the community, but there are some areas where our research strategy can be adjusted. This includes accelerating Australia's excellent research in myelin and nerve repair into clinical trials of new treatments, as well as translating the lifestyle factors identified in our strong epidemiological research into interventions to prevent MS and reduce its impact. Additional focus should perhaps be given to fatigue, cognition and pain management in MS.

We will delve deeper into these issues and all the findings from our survey in the coming months, and keep you informed of our progress to address these priorities. ■

View the report on our website

www.msra.org.au





A word from our Chief Executive Officer

We end this year with continued momentum towards a world without multiple sclerosis and an increased focus to find solutions for the progressive forms of MS.

MS Research Australia is one of the leaders in this pursuit and we are determined to push the research boundaries. We are exploring new opportunities and collaborations to ensure that we convene the best researchers around the globe and focus their attention on the MS research priorities.

By joining the International Progressive MS Alliance we are helping to drive this objective and this year has seen awards granted to three global collaborative research networks which demonstrated the highest potential to make crucial breakthroughs in understanding and treating progressive MS.

MS Research Australia has also conducted an extensive research priorities survey to ensure that our 2017 research direction and strategy is in line with community expectations. It is important that we continue to fund the strongest Australian research that aligns with the community's needs and wants. The top 3 priorities highlighted were the consistent focus on a cure, better treatments and prevention of MS.

We are also grateful to have been involved with the Sohn Hearts and Minds Investment conference. MS Research Australia was selected as one of four medical research charity partners for the conference due to our exceptionally robust strategic and research governance. It was a privilege to have been a part of the successful event which raised important funds for Australian medical research.

Thank you for your ongoing support over 2016, we wish you a happy and safe festive season. ■

Dr Matthew Miles

MS Research Australia and the global MS effort

Collaboration has become an important requirement for progress and achievement in business, industry and the not-for-profit sector. At MS Research Australia we are proud that collaboration has been one of our strengths and strategic direction since establishment in 2004.

We have adopted the philosophy that 'if you want to take small steps – compete, if you want to take giant leaps – collaborate.'

MS Research Australia has a good reputation in the sector as being proactive and successful in this arena, both nationally and now increasingly globally. This now includes collaboration with other Australian charities involving different diseases or disease groups and, of course, global MS organisations.

One of the first collaborative projects supported by MS Research Australia 10 years ago was the Ausimmune study, a multicentre Australian study, following over 300 people diagnosed with a first episode of MS, providing a greater understanding of the potential role of the Epstein Barr virus and confirmation of other environmental factors such as vitamin D, sunlight, smoking, diet and exercise.

Other large collaborations have included the ANZgene study, the Vitamin D MS Prevention trial and the MS Research Australia Brain Bank.

Most recently, MS Research Australia joined the International Progressive MS Alliance to increase the focus and research efforts into finding a solution for people with progressive MS. Not only has MS Research Australia invested financially in the Alliance, but as a managing member we have allocated a significant commitment of staff resources for the global working teams. Several key MS Research Australia staff, board members and representatives are playing active roles in the management of the Alliance, including the

executive committee, the scientific steering committee, the research work team, communications and fundraising team.

With 14 countries involved in the Alliance and the varying time zones, it often means our Australian team are joining teleconferences and meetings in the early hours of the morning or late at night, but the unanimous objective of ending the fight against progressive MS far outweighs any difficulties.

Globally A\$31 million (€22 million) has been pledged so far to the Alliance, and over 480 MS researchers from all over the globe were involved in the last funding round. This is an outstanding example of a global alliance with a common goal and shared values.

Another way we are looking to foster collaboration is by bringing together other immune disease research charities to foster sharing of ideas to accelerate research progress. Much of the progress in MS has been a direct result of investigation into the autoimmune field; this collaborative endeavour is clearly an incredibly valuable field of research. We have been thrilled to be able to convene a working group in this space and get significant participation.

One of the largest scale global collaborations is currently underway in research fundraising with 11 countries taking on the MS Research Australia-founded Kiss Goodbye to MS campaign. Nothing has been seen on this sort of scale before and it's exciting to see different countries around the world making the campaign their own and accessing additional funds for research.

MS Research Australia is committed to developing and exploring research initiatives and collaborations. We believe this will provide the ability to galvanise and convene the best researchers from around the country and globe and dedicate them to a common unmet need, a world free from MS. ■



New study shows benefits of current treatments for people with advanced MS

Contrary to the notion that current treatments only benefit early stage MS, new research has shown that taking treatments that modify the immune system can improve the disease course even in people with advanced MS.

Advanced MS affects people in different ways, and is very difficult to predict. A group of international scientists led by Australian researcher Nathaniel Lizak, of the University of Melbourne, has been using a large database of MS patients to investigate advanced MS. As the famous Sherlock Holmes once said 'it is a capital mistake to theorise before one has data'. The database called MSBase, is run from Australia and now follows close to 40,000 people with MS from over 72 different countries, making it the largest MS dataset in the world.

Published in the *Journal of Neurology, Neurosurgery and Psychiatry*, the study looked at people with MS who had more advanced scores on the EDSS scale. EDSS stands for

Expanded Disability Status Scale, and it is a method of measuring disability in MS. They identified 3,415 patients which were categorised as having advanced MS and tracked their disease progression using the clinical data. The researchers found that a person's early disease course did not predict their rate of progression once they had reached moderately advanced MS.

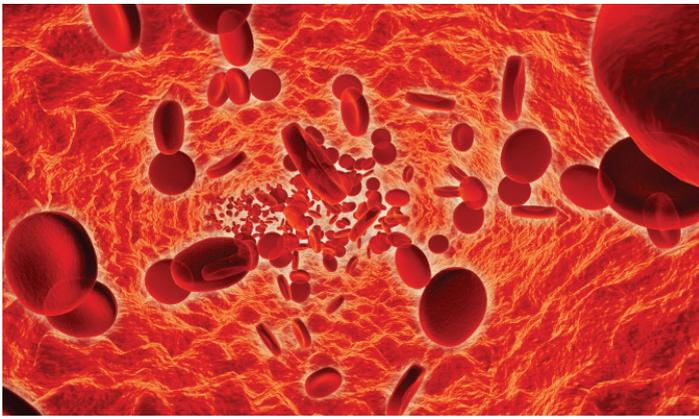
They also tested the effect of different treatments on the rate of progression in people with advanced MS. Here they found that with the current arsenal of treatments, there are opportunities to modify the disease course even at later stages of MS. They demonstrated that the use of current treatments does have benefits, and delays the increase in EDSS scores of people with advanced MS.

This is somewhat surprising, as it is often thought that treatments can only benefit people in the early stages of MS. It is thought that MS has different phases, and during the early phase, the physical effects of MS are mainly due to inflammation, whereas in the

later phases, they are due to the loss of nerve cells in the brain and spinal cord. Treatments used for MS generally target the inflammatory stage, which is why they can be effective early in the disease, when inflammation is most important. This research suggests that inflammation also plays a role in more advanced stages of MS.

It is important to note that this study didn't look at individual medications but rather the effect of modulating the immune system. Each immunomodulatory treatment works in a slightly different manner and given the hugely variable nature of MS no one medication is likely to suit all patients. It is important that you discuss your medication with your treating physician.

One great advantage of MSBase is the ability to look at the long-term effects of treatments and see what impact they are having over many years in real-life situations. MSBase is just one example of how Australian researchers are making a tremendous impact in the field of MS. ■



Clinical trials – determining the safety and effectiveness of treatments

There is a lot of interest in the MS community in the potential treatment option for MS known as autologous haematopoietic stem cell transplant (AHSCT). Research into this form of treatment for MS has been going on for some time now, and we are getting a clearer picture of how this intensive form of therapy may fit within the treatment landscape for some forms of MS.

AHSCT is a two-step treatment, consisting of chemotherapy (similar to what cancer patients receive for certain blood cancers), to kill off the majority of the immune cells followed by the reinfusion of blood cells to help try and re-build the immune system. More information on this treatment can be found on our website www.msra.org.au/AHSCT.

As for any medical treatment, there needs to be rigorous testing to show that it is effective and safe. Especially with diseases that can be as variable as MS, clinicians need to know which type of patient

is going to benefit, how to best apply the therapy, and how to avoid any potential complications or side effects. This type of information is typically ascertained in a multistage clinical trial process. The first stage is to assess whether it is safe. Then, using gold-standard randomised controlled trial designs, it is determined if the treatment effectively treats the disease and whether the trial treatment is better or equivalent to the current standard treatment options.

To date, AHSCT has been investigated in a number of international observational studies of groups of patients, and through some small or ongoing randomised trials. However, one of the difficulties in fully understanding the risks and benefits of AHSCT has been due to the variation in the way the studies have been carried out, including participants with different types of MS or levels of disease, and different forms of chemotherapy used. Variations in the way people are treated make proper comparisons difficult, which means it takes longer to reach a valid conclusion from the clinical trial results, and to use the data to achieve a change in hospital or government policy.

Encouragingly, evidence is growing that AHSCT may be a treatment option for a small proportion of people with MS, particularly younger people who are still in the active inflammatory stage of their disease and particularly for those who don't respond to other therapies. The clinical trials that have been conducted so far have also shown that it does not work for everybody, and there are considerable risks. Additionally, it is not yet known whether those patients who respond will have long-term protection against their MS symptoms returning. However, the current trials are giving us a clearer picture of this treatment and are leading to further refinement in its application and optimisation of the outcomes for patients receiving this treatment in the future.

Two observational clinical studies are running here in Australia, one in Sydney and the other in Melbourne; both are listed on www.mstrials.org.au.

For a list of other clinical trials occurring in Australia go to www.mstrials.org.au. Please speak to your neurologist or treating clinician for any information to do with treatment options and clinical trials that might be appropriate for you. ■

Administrator extraordinaire

Emma Bonehill joined MS Research Australia in 2015 as the Administration and Campaign Coordinator and has quickly become the anchor of the team. She is an efficient Administrator with over eight years' experience in a diverse range of organisations including finance, education and the not-for-profit sector.

After completing a Diploma in Business Administration, Emma worked for 3 years in an accountancy practice. Although enjoying the experience, Emma wanted to engage more with the community and hence took steps to obtain a role as a disability support worker.

MS Research Australia has enabled Emma to combine her professional work

experience with her genuine interest to work within the not-for-profit space. Emma's responsibilities include office management, travel and logistics, EA to the Chief Executive Officer, event support and coordination of the Sydney MS Angels.

The MS Angels are a group of well-connected women from the business community, dedicated to helping MS research in Australia. They donate their time and funds in a way that allows them to network with other interesting women.

Emma says 'Working for MS Research Australia has been a truly rewarding experience, as I get to work and communicate with so many inspiring people. I am motivated on a daily basis



to be surrounded by such generosity and empathetic people who are striving to make a difference within the MS community.' ■



Employment rates improving for Australians with MS

New research from Dr Pieter Van Dijk and his team at Monash University, together with Associate Professor Ingrid van der Mei of the Australian MS Longitudinal Study, supported by MS Research Australia, has shown that employment levels have improved for people with MS.

These findings are welcome news, in 2010 data from the Australian MS Longitudinal Study highlighted the significant difficulties for many people with MS in retaining employment in the years following a diagnosis. This data focussed the attention of MS organisations on advocacy and employment support for people with MS.

The new study, published in the *Multiple Sclerosis Journal* followed a group of 1260 people with MS who participated in the Australian MS Longitudinal Study annually over four years from 2010-2013, surveying them on their job retention, work roles and work environment.

Employment increased from 48.8% in 2010 to 57.8% in 2013. This reduced the gap in employment rates for people with MS compared to the general population from 14.3% in 2010 to 3.5% in 2013. This was mostly due to an increased number of men with MS employed full-time over this period. However, the number of men in full and part time employment remains significantly below that of the general

population. For women the gap has closed almost entirely.

Encouragingly, 95% of people with MS received requested changes in their role and 82% of people who asked for changes to their environment obtained them. Previous studies have also shown that disclosure of an MS diagnosis can help job retention in people with MS. Physical and mental fatigue topped the list of symptoms that impacted the most on work performance.

People also tended to overestimate their likelihood to leave work, with 16% reporting that they were likely to leave work in the next 12 months but the actual number of people leaving between 2010 and 2013 was 6%. Of those not working in 2010, 9.7% had returned to work in 2013.

This research complements the recent findings of the 2016 Global MS Employment Report that showed improved employment rates and work patterns for people with MS. The availability of effective disease modifying therapies, the stability of MS symptoms, and support from family and employers are likely to be key factors in enabling people with MS to stay at work longer. In addition to the financial benefits, participation in the workforce enhances self-esteem and social inclusion, which is good news for the overall wellbeing of people with MS. ■

Heavy metals in MS

In a new study published recently, tissue from the MS Research Australia Brain Bank was used. Led by Associate Professor Roger Pamphlett from the University of Sydney, to study the role of heavy metal accumulation in the spinal cord of people with MS and other neurodegenerative disorders.

Motor neurons, the cells in the brain and spinal cord that control muscle function and movement, can be injured and lost in MS and often in areas not affected by lesions. One factor that may contribute to this loss is the uptake of toxic substances from the environment such as heavy metals like mercury or silver.

The research used a technique called autometallography which allows researchers to see whether heavy metals are present within cells. Associate Professor Pamphlett examined spinal cord tissue samples from people with MS, as well as people who did not have any evidence of motor neuron damage. He found that heavy metals were present in motor neurons and also in a special class of nerve cells called interneurons, which relay electrical signals between different types of nerve cells.

It was found that in the normal ageing process heavy metals accumulate in nerve cells. However, if this accumulation was too great, or if people had other risk factors it may contribute to the loss of neurons. In particular, damage to interneuron types of cells can lead to nerve loss, as these cells normally help protect nerve cells, but removing interneurons short circuits this protection leading to nerve cell loss.

The use of tissue from people with MS is key to the success of this study, as only examining nerve cells from the spinal cord, in this case, can help answer the question of whether heavy metals or other environmental toxins are having an impact on MS and other neurodegenerative disorders.

If you would like more information about the MS Research Australia Brain Bank or would like to register to become a brain donor please phone 1300 672 265 or register online at www.msbrainbank.org.au ■



David Robertson, MS Research Australia supporter.

Why I give regularly

David became a regular donor to MS Research Australia to offer ongoing support to MS research and be a part of a sustained effort to find cures for MS.

David says 'As someone with MS, I have more than a little self-interest. Research funds in Australia are scarce and you can't expect everyone else to cover it. Recently I've seen a decrease in government funding and the community are mistaken to believe that the government will pick up the tab for everything. Organisations like MS Research Australia and the researchers they fund, need a regular income stream to plan their research with any certainty, and I'm happy to help meet that goal. Everyone with MS wants a cure to be found and the only way to achieve this is through research.

'For a small organisation, MS Research Australia delivers world class results. Through their website, newsletters and numerous research lectures I've watched the progress of a lot of the research they are funding.

'Research which offers the hope of better treatments and a cure is invaluable. If nothing else, it's nice to know there's someone out there working on it.'

Regular donations help MS Research Australia provide researchers the consistent funding and security to remain in the MS speciality. A regular donation is quick and easy to set up. To find out more or to set up your regular donation, please contact Neil Robertson, Relationship and Planned Giving Coordinator on **1300 356 467** or enquiries@msra.org.au ■

The philanthropic impact of giving

Corporate philanthropy means more to MS Research Australia than just funding dollars. Whilst it accounts for up to 22% of our total gross income, the additional benefits come from both pro-bono support and professional engagement opportunities.

Since our early and quite humble beginnings in 2004, MS Research Australia has had a significant, measurable and unequivocal impact on the lives of people with MS, both nationally and globally.

The Macquarie Group Foundation has been one of our most important philanthropic foundation supporters over that time, and is largely invested in many of our greatest achievements. The benefit to MS Research Australia from this support however, goes deeper than just the dollars. The ability to have staff engagement at all levels across both organisations is much appreciated. We have been pleased to meet with executive staff and Board members of Macquarie as well as receive the support of Macquarie staff. Macquarie has also hosted donor boardroom lunches and supplied volunteers to help organise Kiss Goodbye to MS events. The mutual reward that comes with such interactions has made us better at what we do.

Lisa George, Head of the Macquarie Group Foundation said 'We think it is important to contribute to a national organisation which has a clear mandate and history of excellence in research governance. The team at MS Research Australia are always more than ready to report on the outcomes of funded research. Donors like to see how their support has been utilised and MS Research Australia is able to deliver on that'.

Matthew Miles, CEO at MS Research Australia said 'it's rare to have the sort of relationship where the staff of a large corporate Foundation are so knowledgeable and engaged with what we stand for on so many levels. It is really encouraging and

humbling to be able to work with the Macquarie staff on a fundraising event such as a golf day and then report to the Macquarie Group Board or the Macquarie Group Foundation Committee in Martin Place and hear a similar level of understanding and enthusiasm for our work'.

MS Research Australia is incredibly grateful to the Macquarie Group Foundation for its support over the years. The number of projects and initiatives it has supported with us are numerous, but several of the most recent include: staff development and training workshops, hosting a not-for-profit autoimmune workshop to encourage collaborations and cross fertilisation of ideas to accelerate progress in the sector and funding Fellowships and research projects.

The Macquarie Group Foundation recognises innovation and recently its funding of a unique joint Fellowship between MS Research Australia and JDRF led to an important finding of a genetic overlap between MS and type 1 diabetes.

The Macquarie Group Foundation and MS Research Australia hope to be able to announce another MS research collaborative project very soon. This project looks set to be one of the most exciting we have worked on together thus far.

It is through the support of philanthropic organisations like the Macquarie Group Foundation that we can look to the future with confidence. ■





Kiss Goodbye to MS: bringing us one step closer to freedom from MS

At MS Research Australia our mission is clear – to accelerate research targeting the prevention, better treatments and to find a cure for MS. We are committed to this mission and to funding the best research in Australia. To do this, we rely on the support of the MS community, who come together to raise funds through the Kiss Goodbye to MS fundraising campaign.

In 2016, Kiss Goodbye to MS has raised over \$800,000 for research into MS and we haven't quite finished yet. We like to think of 2016 as the year our Aussie campaign hit its stride and found its place in the world, becoming a global fundraising campaign, in 11 countries. The global Kiss Goodbye to MS campaign has generated almost US\$1 million, which is just over A\$1.3 million for global MS research initiatives.

But we certainly can't take the credit for this incredible achievement. We couldn't have done this without our inspiring Kiss Goodbye to MS fundraisers who held events, baked cakes, shaved their heads, wore red lippy and entered fun runs. Together, you have raised crucial funds for research into MS – and we are so grateful for your support.

This year there have been hundreds of Kiss Goodbye to MS events held

around the world. We have now had over 12,000 posts using our hashtag #KissGoodbyeToMS on Instagram, and as of today 77,302 people like us on Facebook, and this number increases every day. More than 1,785 kilometres were run in Kiss Goodbye to MS singlets and \$58,000 was raised by the people who ran, walked and jogged in 23 community fun runs throughout the year.

And while these numbers are impressive, we still have a way to go. Kiss Goodbye to MS is committed to MS Research Australia's mission, and we will not stop raising funds until a cure is found.

MS Research Australia is proud to run Kiss Goodbye to MS as a low cost fundraising campaign. Our administration costs are at 21 cents in the dollar, well below industry averages, and we work hard to keep them there. The campaign relies on the power of social media and the community that supports Kiss Goodbye to MS. We do not invest in expensive advertising campaigns, but we rely on you to spread the word. Our campaign continues to be managed by one staff member who oversees the Australian campaign as well as co-leads the global initiative. The only reason we can run a low-budget, lean fundraising model is because of the power of our community.

One of this year's most memorable fundraising teams is a group of mates from the NSW south coast, who decided to ride to Mount Kosciuszko. These men were not avid bike riders, in fact most of them had never cycled more than 10km in their lives. But they were inspired by their best mate who is living with MS, and together they all committed to riding 410km and raising funds for Kiss Goodbye to MS. These incredible men not only made it to Mount Kosciuszko with very limited training and experience, but they also raised \$74,000 for Kiss Goodbye to MS. This team are now proudly holding the number one position on the Kiss Goodbye to MS leaderboard. It is this sense of community support, determination and mateship that is the core of what this campaign is all about.

As we wrap up Kiss Goodbye to MS for another year we want to remind you of the incredible difference you are making. This campaign has the ability to bring people together from all over the world and from different walks of life, and we are so excited to be entering 2017 with you. Whether you donated \$20, raised \$10,000, purchased merchandise or posted about Kiss Goodbye to MS on social media – thank you for believing in our dream of freedom from MS. Together we are one step closer. ■

Investment conference raises \$3 million for medical research

The influential Australian Financial Review journalist, Joe Aston, called the recent Sohn Hearts and Minds Investment conference a “triumph”, raising \$3 million for medical research.

MS Research Australia was honoured to be chosen as one of the four recipients of this game changing funding stream. The other charities were the Victor Chang Cardiac Research Institute, JDRF and the Black Dog Institute. The sold-out event was based on the Sohn investment conferences, which started in New York more than a decade ago. The event genesis here in Australia was largely thanks to two of Victor Chang Institute Board Members, Dr Gary Weiss and Chairman Matthew Grounds. In the end though, it took the largely volunteer and pro bono work of many to make it a success in an extremely short turnaround time.

MS Research Australia was represented by Chairman Paul Murnane, Board Director Tanya Branwhite and CEO Dr Matthew Miles who assisted in promoting MS Research Australia and the importance of more research funding into MS. Sydney-based neurologist and MS researcher Dr Heidi Beadnall gave a Ted X-style presentation on her MS research to the 600 strong audience that included the former Prime Minister Paul Keating and current NSW Premier Mike Baird.

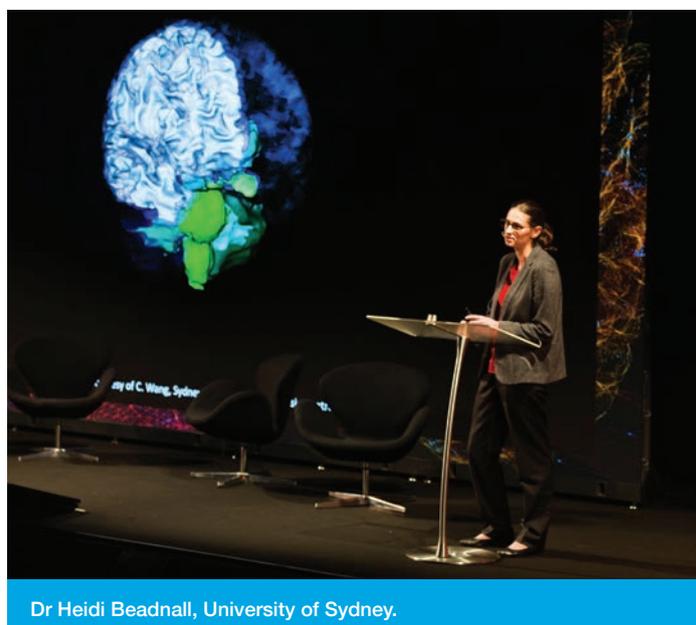
This is not the first time that the Australian business community has come together in an innovative way to plug the ever-increasing gaps between what funding for medical research (including MS) needs and what is available. However, it was certainly one of the most successful. It's very rewarding to see such extensive collaboration between different charities to improve funding for medical research.

Ian Narev, CEO of the Commonwealth Bank spoke about the critical importance of MS, heart disease, type 1 diabetes and depression research, and implored the audience to give generously to the four worthy causes.

The charities were selected on their robust medical research governance structures and the ability of each charity to make a real and tangible difference with the funding. The organisers had two other major important goals, one was to ensure that the vast majority of all funds raised from sponsorship and ticket sales went directly to medical research. The second was to garner sponsorship from iconic Australian companies that could also add valuable in kind contributions as well as dollars. To these points, virtually all costs associated with the day were covered by pro bono assistance, meaning the event had an impressively low fundraising cost ratio. Additionally QANTAS donated \$10,000 in free flights to each charity which will significantly help to reduce administration costs, therefore meaning more funds go directly to the research.

Our CEO was given significant coverage in both *The Australian* and on *Sky News*. Sincere thanks to our Patron and Founding Chairman, Simon McKeon AO, for being heavily involved in national media interviews during the lead up to the event and assisting in many other ways.

Plans are now underway for an even bigger and better event in 2017. ■



Help MS Research Australia find a cure for MS

Donate (Donations over \$2 are tax deductible)

To support MS Research Australia's vital work I would like to:

- Make a one off donation of \$
- Make a monthly donation of \$
- Learn more about leaving a bequest in my Will
- I have already made a bequest to MS Research Australia in my Will

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