

## International Progressive MS Alliance project updates

The International Progressive MS Alliance has brought together MS organisations and researchers from around the world to tackle progressive MS. By 2019, the Alliance will have invested A\$31 million (€22 million) into progressive MS research. MS Research Australia is proud to be a managing member of the Alliance.

The International Progressive MS Alliance identified a number of priority areas to tackle the barriers to treatment and outcomes for people with progressive MS. These include understanding the mechanisms which underlie how MS becomes progressive, devising new ways to measure progression so we can design and conduct shorter, faster clinical trials and develop and evaluate new therapies for progressive MS.

In 2014, the International Progressive MS Alliance awarded their first 'Challenge Awards' to encourage scientific innovation, and 'Infrastructure Awards' to promote data sharing and knowledge management. Over \$1.6 million in funding went to 22 projects from nine countries, including one to Dr Steven Petratos from Monash University in Australia. The full progress report of these projects has now been released via the Alliance website and shows researchers making ground against progressive MS.

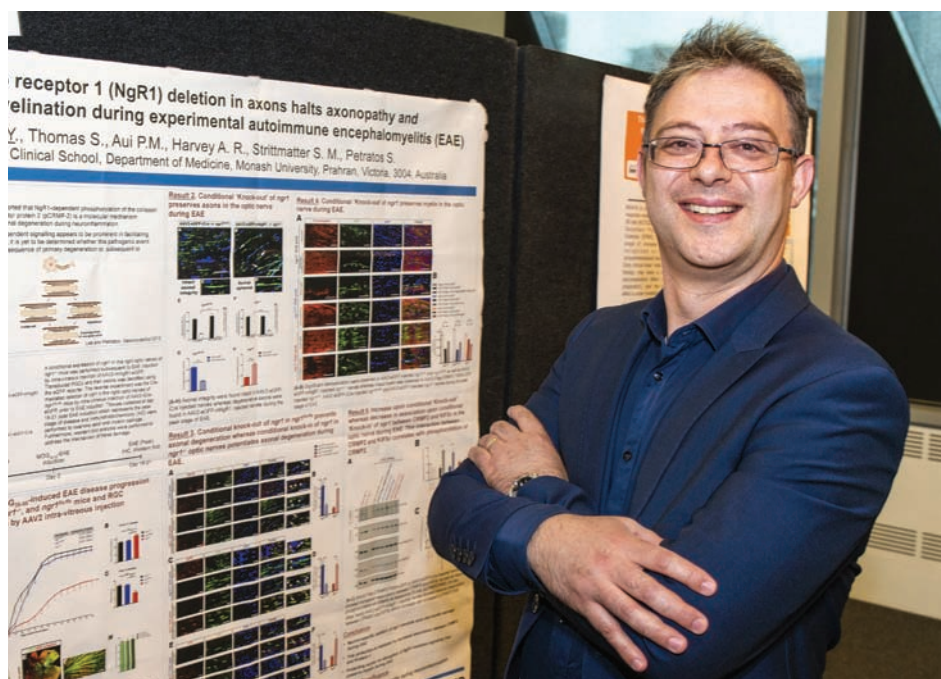
Progress has been made on numerous fronts, with projects in this round looking to improve clinical trials for progressive MS and associated outcome measures, biomarkers (measurable indicators) of progression, genetic studies,

rehabilitation trials, new disease models, and research to better understand the cellular mechanisms which underlie progression. Particular highlights include the development of a smartphone app to track walking speed and other measures in progressive MS clinical trials by Professor Paul Matthews at Imperial College London and the discovery of a potential blood biomarker that can distinguish between slow and rapid disease progression by a research group led by Charlotte Teunissen from the University Hospital Vrije Universiteit-VUMC in the Netherlands.

Dr Petratos, who undertook the only Australian-led project from this round of funding, was investigating the role of a molecule called Nogo-A in nerve fibre damage in progressive MS. The researchers were aiming to block Nogo-A by delivering agents directly to the brain and spinal cord to hopefully limit MS-like disease in laboratory models of MS. The research team investigated the role of the Nogo-A related gene (known as NgR1) in nerve fibre degeneration and found that by blocking this gene they could limit nerve fibre damage and the subsequent neurodegeneration.

The International Progressive MS Alliance is currently assessing the full proposals for their next grant round, where they are looking to award a large €4.2 million grant over 4 years to fund Collaborative Networks of scientists to accelerate progress in the Alliance priority areas.

For further information on the Alliance please visit the website [www.progressivemsalliance.org](http://www.progressivemsalliance.org) ■



Dr Steven Petratos, Monash University.



## A word from our Chief Executive Officer

**Despite significant advances in treatment options for relapsing MS, unfortunately people living with progressive MS are still left without treatments. Clearly, that is not good enough.**

To combat this, MS Research Australia has joined with a number of MS organisations from around the world and the MS International Federation to form the International Progressive MS Alliance. The Alliance is the most ambitious collaborative project the global MS movement has ever embarked on and we are dedicated to find answers and develop solutions to end progressive MS. In this issue of NEXT we highlight some of the research progress updates from the first round of Alliance grants and over the coming months we look forward to informing you of the Alliance Collaborative Network Awards, which will unite research teams from different corners of the world to further accelerate the research progress.

In this issue, Dr Simon Murray's research looked at new ways to stimulate myelin repair. MS Research Australia's initial investment in Dr Murray's research has enabled him to further leverage the funding with a three year grant from the National Health and Medical Research Council.

We are proud our funding model is continuously providing a multiplier effect which currently averages at 5:1 for all projects funded. This means that for every \$1 invested in MS research via our funding, the recipient researchers were able to leverage an average of five times that amount through other prestigious award programs. The solution to when only a very modest amount is available for MS research in this country is to make that money work as hard as possible. ■

**Dr Matthew Miles**

## Anne Bennett joins the board

MS Research Australia welcomes Anne Bennett as a newly appointed MS Research Australia Board Director. Anne is the Executive General Manager of Wealth Digital and Direct Service at NAB.

Anne has almost 20 years' experience in financial service organisations working in large corporate and program leadership and strategy and transformation leadership roles. She is passionate about driving systems, process, organisational and operating model change. Her experience includes digital, contact centre, and functional and operational transformations at both Westpac and NAB, across business banking, global investment banking and wealth sectors.

Paul Murnane, Chairman, MS Research Australia said that 'an important salient point about Anne's background that fits with our evolving Board, is her lengthy experience in transformational change and broad general management, where client focus and digital technologies have been key. We believe that her expertise will be important for all aspects of the



Anne Bennett.

activities of MS Research Australia but especially relevant towards our Kiss Goodbye to MS campaign which has a strong digital marketing approach. Anne and her team have already been incredibly knowledgeable and helpful.'

'We look forward to having Anne as a key Board Director for MS Research Australia to help guide us through the next digital age.' ■

## Raising vital funds for MS research

**After graduating with a Bachelor of Health Science and Master of Public Health from Western Sydney University, Samantha Rosenfels initiated a volunteer internship with MS Research Australia. Samantha initially worked with both the research team and with the Kiss Goodbye to MS campaign.**

After six months Samantha was successfully appointed to the team as the Development and Events Coordinator. In this role Samantha manages a range of events, including the biennial Progress in MS Research Conference and public lectures as well as being responsible for the grant applications schedule seeking philanthropic and grant funding for MS Research Australia activities.

'I found organising the conference and public lectures to be incredibly rewarding, as I was privileged to hear from leading Australian MS researchers and could see first-hand their dedication to working in the MS research field' said Samantha.

Samantha's role at MS Research Australia not only allows her to facilitate events for people with MS, but also to work with the fundraising team to raise vital funds for MS research. ■



Samantha Rosenfels.





## Overcoming heat sensitivity

Our bodies are like an amazing air conditioning unit, and much like an air conditioning unit, it has to be able to sense the temperature and then calculate whether to switch on the heating elements, or switch on the fans and cooling elements to keep our core body temperature of 37°C (our external temperature of the skin is much more variable). But unlike an air conditioning unit which has switches and microprocessors, it is our central nervous system that determines whether we are hot or cold, and then relies on our nerves to transmit the resulting instructions to the body. If the central nervous system determines we are hot, it

instructs our bodies to produce sweat and increase blood flow to the body's periphery to lose heat. If we are cold, our bodies reduce the blood flow to our extremities, it shivers and we get goose bumps, all in an attempt to keep us warm.

Up to 80% of people with MS experience what is called heat-related fatigue, also known as the Uhthoff's Phenomenon. This occurs when their body temperature increases more than 0.5 degrees and they experience a worsening of their symptoms. Once their body temperature is normalised, signs and symptoms tend to improve. Dr Ollie Jay, at the University of Sydney, has been investigating this

phenomenon in a successful pilot study funded by MS Research Australia.

In this study, Dr Ollie Jay, took 21 participants, 12 with MS and 9 without and put them in a state of the art atmospheric controlled exercise chamber in the Thermal Ergonomics Laboratory at the University of Sydney. This allows the researchers to carefully control all aspects of the climate including the temperature, air flow, and humidity. The participants then exercised to increase their body temperature and as they did so their ability to sweat and regulate their blood flow around their periphery was analysed. The team found that following exercise, people with MS had a reduced ability to regulate their temperature, resulting in about a 0.5 degree increase in body temperature. This was associated with a reduction in sweating and a reduced skin blood flow response, compared to people without MS, which reduces heat dissipation from the skin surface to the surrounding environment via evaporation.

Interestingly, the team also discovered that the perception of temperature in people with MS is altered. They placed items of different temperatures on the skin of participants, and their perception of different temperatures was measured. They found that the ability to perceive different cold stimuli is blunted in people with MS.

These results show that MS affects thermoregulation in two ways. First by affecting the sensing or perception of temperature differences, and secondly MS appears to subdue the body's attempt to shed the excess temperature.

Typically people with MS try to minimise their exposure to hot environments and reduce exercise to minimise their symptoms worsening. However, there is mounting evidence to suggest regular exercise can be beneficial for people with MS with improvements in the sense of well-being, reduced fatigue, and improved walking abilities. As such, regular physical activity can be seen as an important component of an overall disease management plan. Therefore it is important to understand Uhthoff's Phenomenon, in an attempt to hopefully overcome heat sensitivity in people with MS. ■

# Clinical trials; you may be able to help from your home

For many people, the term clinical trials conjures up the image of trialling new pharmaceutical drug treatments. However, clinical studies can encompass far more. The term clinical trials is broad and includes research studies that explore whether a therapeutic strategy, symptom management regime, psychological intervention, or lifestyle modification is safe and effective. Trials are essential in bringing patients evidence-based care that allows them to live well with their MS.

Trials are very varied and can involve

as little as filling in a questionnaire online, right through to participating in a study testing a new drug or compound. But they are all designed to ensure the scientific validity and reproducibility of the results.

Trials normally have a specific population they are looking to recruit, whether it be people at a particular stage of their disease, age, gender or the types of treatment they have undergone. Typically, researchers initially enrol a small number of volunteers into what is called a pilot study. The pilot study determines the feasibility of a larger

trial and helps develop the methods the trial will use. The next stage is to recruit larger numbers, and after that, conduct comparative studies on a larger scale to determine a final result.

A quick look at MS Research Australia's [mstrials.org.au](http://mstrials.org.au) website illustrates the varied nature of trials. A few examples of trials currently enrolling are;

- The use of vitamin D in preventing the risk of MS
  - Whether whole body vibration treatment improves gait and reduces falls in people with MS
  - Help-seeking behaviours and depressive and anxiety symptoms in individuals with MS
  - Brain function in relapsing-remitting MS patients who have recently commenced particular MS treatments
- These are only a small selection of trials listed on the MS trials website. Despite the varying nature, they are all designed to deliver evidence on which to base future decisions about treatments and interventions.

There are multiple benefits of participating in these trials, it can provide people with early access to treatments, it can help develop better treatments and interventions for the future, and it can lead to a better understanding of MS. Visit the MS trials website and get involved in a study suitable for you. ■



## Australian research devising new ways to repair myelin

The symptoms of MS result from damage to the myelin layer that insulates nerve fibres, in part due to a loss of the cells which produce myelin, known as oligodendrocytes. In the early stages of MS, damaged myelin can be repaired by natural processes, but during the progressive phase of the disease, this repair process fails, leading to the slow but progressive decline that can occur in later stages of the disease. Current treatments for MS suppress the immune system, but do not aid repair of myelin, so this is an area where research into therapeutic options is sorely needed.

One strategy for repair in MS is to somehow enhance the natural ability

of the remaining oligodendrocytes to stimulate repair. Dr Simon Murray, from the University of Melbourne, received a project grant in 2014 with funding support from the grass-roots fundraising campaign Foundation 5 Million Plus to look at new ways to do just that. Dr Murray and his team are focussing on a molecule called 'brain derived neurotrophic factor' or BDNF, which is known to be involved in the laying down of myelin during development. The researchers were interested in whether BDNF might also be able to repair myelin after damage in adult brains.

The team has discovered that BDNF can assist with the repair of myelin in a number of ways. Using laboratory models

of MS to examine the direct effects of BDNF on cells in the brain, the researchers showed that not only is it able to restore myelin, but also increases the number of myelin-producing cells in the brain, which in turn increases the capacity of the brain to naturally repair the damage.

They also tested the effect of a number of molecules which act like BDNF on the animal models. While these molecules act in a similar way to BDNF, crucially, they are easier to produce, making them a more attractive option for future treatment development. They have shown that one of the chemicals, called TDP6, boosts myelin repair in a similar way to BDNF, making this an appealing drug candidate. Dr Murray and his team will continue to investigate other molecules which mimic BDNF over the next year.

The researchers are now performing specialised experiments to determine the exact mechanisms which underlie



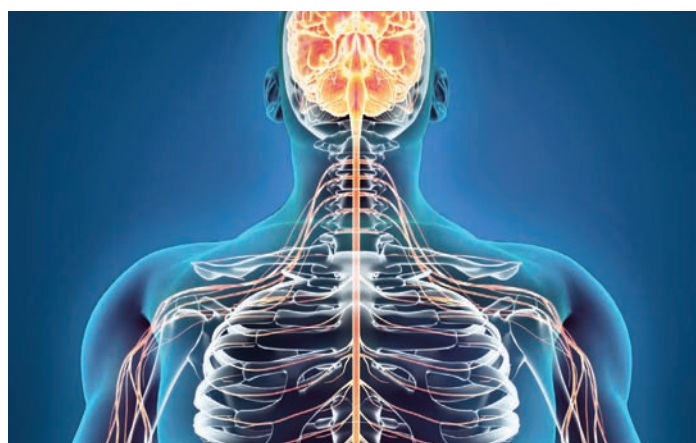
# Donated MS tissue used to identify a new target of immune attack in MS

MS is thought to be caused by a person's own immune system mistakenly attacking components of the brain and spinal cord. The exact target of the immune attack in MS is currently unknown and is thought to be different in every person. Identifying what the immune system is targeting in MS has been a long held focus of MS research and would lead to a better understanding of MS processes allowing more accurate therapies against this attack to be designed.

Researchers from Sweden have recently published the results of a study in the prestigious international journal *Proceedings of the National Academy of Sciences* which has used MS tissue to identify a completely new autoimmune target in the MS brain.

The scientists screened the blood of 2,169 people with and without MS for over 380 protein fragments (a tell-tale sign that the protein had been targeted by the immune system), to identify whether there were particular proteins in the blood of people with MS that were not present in the people without MS. They discovered one protein that was increased in the MS group. Anoctamin 2 forms part of a chloride channel (a gateway through which chloride molecules can pass in and out of cells) and also interacts with the major risk gene of MS, further underlining its potential importance in MS.

Next, the researchers looked at where anoctamin 2 was located in the brain, looking at tissue from brains affected by MS and comparing it with unaffected tissue. In a very interesting series of experiments, they found that anoctamin 2 was located both inside and very near to, areas of damage in MS and was clustered together in little groups, known



as aggregates, which often occur when proteins incorrectly assembled due to disease processes.

The use of MS brain tissue in this study was critical to its success. It showed that there are differences in the blood that are truly reflective of changes in the brain tissue during MS. In the scientific paper the authors state 'Brain and spinal cord tissue, and in particular the MS lesion tissue forming the actual site of the disease, is an outstanding source to search for specific markers of disease related mechanisms'. This study highlights the value of studying human tissue to deepen our understanding of the cause of MS and identify blood based markers for use in research and to develop new treatments.

To register your interest in becoming a donor with the MS Research Australia Brain Bank, visit [www.msbrainbank.org.au/register](http://www.msbrainbank.org.au/register) or call 1300 672 265. ■

the myelin repair stimulated by BDNF. Dr Murray and his team have presented their findings at a number of scientific conferences with publications expected soon. Due to the success of this research, Dr Murray has also been awarded funding from the National Health and Medical Research Council to continue this work over the next three years.

This work is vitally important, as avenues which promote myelin repair offer a good chance for treatment options for the progressive phase of MS. While many treatments are available for the relapsing remitting form of MS, none are currently available for progressive MS. This treatment gap has been recognised as a priority for research by the global MS community, and in 2013 the International Progressive MS Alliance formed to tackle progressive MS. To read more about the Alliance and MS Research Australia's involvement please see page 1. ■



Dr Simon Murray, University of Melbourne.



Maureen T. Corrigan, author and MS Research Australia supporter.

## The power of a bequest

**During September, MS Research Australia will be working with the Include a Charity campaign to highlight the vital role that bequests play in our community. In particular how incredibly valuable a bequest to MS Research Australia is to ensure vital MS research can be funded and the value of creating a lasting contribution towards a world free from MS.**

No matter how large or small, a bequest to MS Research Australia will make a difference. It will allow Australia's leading MS researchers to focus their attention on finding the cause and cure for MS. Medical research is moving rapidly and each new discovery takes us closer to a world free of MS.

Maureen T. Corrigan, author and MS Research Australia supporter, recently spoke to us about her mother, Noeleen's motivation to include MS Research Australia in her Will. Maureen was a medical practitioner, working in a broad range of healthcare roles, from general practitioner to CEO, and retired early because of her MS. She was diagnosed with secondary progressive MS in 2006 and that was when her new life started. Maureen began to pursue her other passions, especially travel and writing. She wrote articles for the Victorian Government Office for Disability and a book about travelling with a mobility scooter which has just been published, *Unexpected Rewards: Travelling to the Arctic with a Mobility Scooter*.

Maureen said 'I was very touched by my mother's bequest to MS Research Australia. I knew she cared about me and she tried to do everything she could to help me with all aspects of my life. Her donations took things to another level for me. Mum was doing the best she possibly could for me even after her death'.

Maureen's brothers, Dennis and Phillip Corrigan, also spoke of the caring and positive person that their Mum was. They said 'Mum was very positive and encouraging, full of hope and support. She wanted her bequest to contribute to research to help others with MS. She said 'Inch by inch anything is a cinch' and hoped her contribution would allow even a small inroad into breaking down MS.'

'Mum would have wanted her bequest to help people living with MS to be more informed and encourage them to be positive that someday through everyone's contributions however large or small, bit by bit, inch by inch, the eventual cause and cure gets closer by the day.'

When re-arranging her finances, Maureen also made the decision to donate to MS Research Australia via regular monthly contributions. Maureen thought more seriously about which groups she would regularly support and came up with five different organisations in various sectors. MS Research Australia was one of them.

Expert commentators in philanthropy have noted that there are very strong links between bequests and medical research, particularly from those affected by the disease. Many bequestors noted that their motivation was to 'ensure that others affected didn't have to go through the same thing.' While this desire for bequests to support medical research is strong, a recent analysis of the nationwide bequest income received by Australian MS charities revealed that 96.3% was bequeathed to critical MS services whilst 3.7% was bequeathed directly to MS research.

Maureen felt that she was aligned with MS Research Australia in a number of ways. She commented 'I had MS, I was a doctor with a science background, and evidence-based research and treatments were important to me. I also enjoyed reading about the research that was happening. It gave me hope that maybe one day the progression of my MS could be stopped completely or that something could be found to reverse the effects. Even if it wasn't me that MS Research Australia helped, it would be able to help others in the future.'

'MS Research Australia provides hope and information. Hope for the future that our MS might improve or stop progressing permanently. Information, so that we better understand what we are dealing with. Knowledge is power'.

If you would like more details about leaving a bequest to MS Research Australia, please call Neil Robertson on **1300 356 467**, request a brochure or visit **[www.msra.org.au/bequest](http://www.msra.org.au/bequest)** ■







Kiss Goodbye to MS has even reached Antarctica. Photo above: Casey Station, Windmill Islands, Antarctica.

## Changing the MS research fundraising landscape

**MS Research Australia's fundraising initiative Kiss Goodbye to MS looks set to change the landscape of MS research around the world.**

In 2016, Kiss Goodbye to MS expanded its wings and officially became a global initiative. This is exciting as more funding for research is desperately needed to continue the current momentum of research and treatment success which has developed over the last decade.

The success of Kiss Goodbye to MS as a low cost and high return fundraising campaign galvanised MS International Federation (MSIF) and its member countries, who saw its potential as a vehicle to increase the funding available for research globally.

Kiss Goodbye to MS has already been adopted by 11 countries. In 2017 it will continue to expand into other countries such as the UK and Canada. While it is wonderful to have an Aussie-founded campaign adopted as the first global MS research initiative ever, the truly exciting factor is the new funds that will be generated for research into MS around the world.

The 2016 global target for Kiss Goodbye to MS is US \$1 million and together we have reached US \$840,000. Donations are still being received in Australia and many other countries like Denmark and Ireland, so we are confident that the global target will be reached before the end of the year.

Kiss Goodbye to MS has brought together thousands of internationals who are passionate about raising funds for

research. In an era where globalisation and digitalisation is making the world a smaller place, with diminishing geographical boundaries, the international MS community is more aligned than ever before. The introduction of a united global campaign will also help bring the world together to enhance MS research, and tap into new and exciting funding opportunities. It will also provide a unique vehicle for countries who have never previously fundraised for MS research and it creates new advocates to ensure better access to standard MS treatments are available in other parts of the world. We welcome this development as it strengthens the global MS community and gives them a voice.

Following the growing engagement on social media from the community and international celebrities, we saw countries such as India and Greece join the global movement. Given that different countries have different level of resources they can contribute to the campaign, the campaign was made available for each country to implement as they saw fit. The only condition was that the fundamental message behind Kiss Goodbye to MS must remain, that is the message of hope, empowerment and positivity.

In some countries 'red lips' and 'kissing' are culturally sensitive, which meant a few countries were initially hesitant to join. However as India closely watched the global roll out, they decided to hold a small pilot event, which the Indian community embraced. Following that success, India not only continued to fundraise with

Kiss Goodbye to MS in 2016, but have confirmed that they will run a month-long campaign in January 2017.

Similarly, the Greek MS Society initially indicated that they would not be involved given the country's economic instability, however, the Greek MS community convinced them otherwise. Thanks to the hashtag #KissGoodbyeToMS on social media and the groundswell of activity in that country, the Greek MS Society were compelled to embrace the initiative, started fundraising and have also committed to the 2017 campaign.

However, it is Ireland who have stood out. They ran a three month Kiss Goodbye to MS campaign, despite initially planning to only run a four week campaign. The success and engagement from Ireland has mirrored the outstanding enthusiasm we have seen in Australia, and we look forward to watching the Irish campaign grow.

With each country becoming more passionate about the campaign, it is exciting to see some good-natured competitiveness developing between countries. Australia is determined to hold our place on the leader board!

The global success of Kiss Goodbye to MS across language and cultural barriers proves, that social media has the power to transcend boundaries and can overcome even seemingly insurmountable differences. In Australia we are proud to see our campaign grow to such success, but more so, we are excited about the new source of funding for research into MS. Importantly, it creates new, strong and powerful voices in MS organisations and jurisdictions large and small, in the global fight for equity of access to new research, techniques and treatments for MS. ■



Belinda Hutchinson AM, Chancellor, University of Sydney, Len Russell, MS Research Australia and Dr Michael Spence, Vice Chancellor, University of Sydney.

## Leading Australian university recognises MS contributions

**MS Research Australia is honoured to be inducted into the Founders' Circle of the University of Sydney.**

The Founders' Circle celebrates the remarkable contribution of philanthropy to the University and recognises donors and not for profit funding bodies, like MS Research Australia, who have the vision to make a difference through substantial giving.

Over the past decade MS Research Australia has directly contributed over \$5.2 million to 40 MS research projects at the University of Sydney. Most of our grants awarded were classified as competitive Category 1 research grants which provides the University's MS researchers with significant leverage to seek further funding from prestigious

Government Award programs. Currently MS Research Australia's funding model provides a multiplier effect of 5:1 for all projects funded. This means that for every \$1 MS Research Australia invests into MS research the recipient researchers have been able to leverage an average of five times that amount through additional award programs.

Since 2008, MS Research Australia has also worked in a joint partnership with the University of Sydney to manage the world class research resource, the MS Research Australia Brain Bank, which is based at the Brain and Mind Centre, Camperdown.

Hosted by the Chancellor, Belinda Hutchinson AM and Vice Chancellor, Dr Michael Spence, the Founders'

Circle ceremony inducted 21 generous individuals and organisations who have supported the university across a number of academic, research and building projects. This combined financial support has played an important part of ensuring that the University of Sydney continues to be a place of exceptional learning, harnessing the talents of the best and brightest researchers and ensuring the campus has world class facilities.

Vice Chancellor, Dr Michael Spence, said that the funding of research at the university, by organisations such as MS Research Australia, benefits both the university as well as medical research across a wide area of disciplines. The ability to leverage more of the government's public funds for areas such as medical research is becoming more and more important as the costs of research increase substantially.

Large universities have an endless array of medical research fields and endeavours that they can concentrate on. It is critical that MS Research Australia continues to promote research into all elements of MS, keeping it front of mind for our academic leaders. This in turn, gives people affected by MS, comfort that the very best minds are working tirelessly on finding breakthroughs.

MS Research Australia recognises that the funds we distribute to research such as that at the University of Sydney is only made possible through the generous support of our donors. MS Research Australia is committed to progressing research to developing better treatments, identifying prevention strategies and ultimately discovering cures for MS. ■

## 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

### Contact details

Title:  First name:   
 Surname:   
 Address:   
 Suburb:  State:  Postcode:   
 Phone:  Mobile:   
 Email:

### Payment method:

- ☐ Cheque (made payable to MS Research Australia)
- ☐ Direct Debit Request (copy of service agreement can be provided on request)  
 Financial institution:   
 BSB number:   
 Account number:   
 Account holder's name:
- ☐ Credit Card  
 Mastercard ☐ Visa ☐ Amex ☐  
 Credit card number:   
 Exp:  CVV:   
 Name on card:   
 Signature:

