



# NEXT



THE OFFICIAL NEWSLETTER OF MULTIPLE SCLEROSIS RESEARCH AUSTRALIA



## MS Research Australia joins the fight to change the lives of millions

**MS Research Australia has joined the USA, UK, Italy, Denmark, Spain and Canada in a global alliance to end progressive MS.**

The International Progressive MS Alliance is the most ambitious collaborative project the international MS movement has ever embarked upon. Renowned researchers from multiple disciplines and countries (including Professor Bill Carroll from Australia), will guide the development and implementation of the Alliance's research priorities and investments.

Dr Matthew Miles, Chief Executive Officer, MS Research Australia, says that 'working in isolation on an issue such as progressive MS risks duplicating efforts or making only slow progress on promising research which could lead to a breakthrough. This Alliance is aimed at fast-tracking those important discoveries'. MS Research Australia will contribute €765,000 (A\$1.1 million) to the Alliance over the next three years.

The Alliance will fund the best global

projects that target key challenges in progressive MS research: better understand progression; design shorter, faster trials that measure patient outcomes; conduct trials to test agents; and to develop and evaluate new therapies to manage symptoms.

Impressively the initial call for the International Progressive MS Alliance research projects generated over 195 applications from researchers representing 22 countries - clearly showing the power of a global approach.

Mike Hemingway, a person with MS and the Chairman of the fundraising initiative Foundation 5 Million Plus (F5m+), said 'The F5m+ funds allocation committee, comprising of people with MS, were unanimous in its endorsement of funding the first year's subscription to the Alliance on behalf of MS Research Australia. This is such an important project as developments in the area of understanding progressive MS have been slow and, given that many people with

MS will end up with a form of progressive MS, it is vital that more priority is given to understanding and treatment.'

When asked about MS Research Australia's involvement, Professor Alan Thompson, the Chair of the Scientific Review Committee for the Alliance was emphatic. 'As one of the world's leading MS organisations, the scientific experience, financial resources and expertise that MS Research Australia can bring to the Alliance will add enormous strength to the initiative'. Professor Thompson, a Fellow of the American Academy of Neurology, Vice-Dean at University College London and an international authority on MS adds that 'there are already considerable research efforts underway that will align with the work of the Alliance such as the MS Research Australia Brain Bank and the MS Clinical Trials Network.'

'I'm delighted to hear of this wonderful initiative', says Stewart MacLennan. 'I experienced my first symptoms of MS 28 years ago. Since then I've gradually lost much of my independence; particularly my ability to walk. I'm aware of the work and progress scientists are making internationally, as well as ours here in Australia. I'm convinced that working in collaboration we are destined to see some very exciting outcomes which will slow down the progress of the disease and before too much longer lead to the cure we all wish for'.

MS Research Australia joins as a managing member, with a key role in the Executive Committee which leads all aspects of the Alliance and will contribute technical advice and expertise. MS Research Australia will also continue to fund the best progressive MS research in Australia as has been done over the last decade. This focus on progressive MS is one of the key priorities identified in our Strategic Plan 2014-2016, available at [www.msra.org.au](http://www.msra.org.au) ■



# Development and Events Manager at MS Research Australia

**Mandy Lee has been working in fundraising and event management in the not for profit sector for over 12 years, with the last five at MS Research Australia.**

Prior to coming to Australia, Mandy worked in fundraising and events for Crisis UK, the Royal Society of Arts and the Zoological Society of London. She arrived in Australia in 2009 and has been with MS Research Australia ever since.

Mandy's role is to manage MS Research Australia's fundraising and events operations, ensuring we have the funding we need to fund as many MS research projects as possible. Her role ranges from writing grant applications to organising high profile events, media launches and meeting with donors.

'I really enjoy my role at MS Research Australia as it enables me to use my strong organisational and communication skills to make a real difference for people with MS'.

'Key achievements in my time at MS Research Australia are the establishment

of the Kiss Goodbye to MS campaign as a national fundraising activity and the development of the MS Angels group. These two activities alone have raised over \$2.5 million towards MS research and I am sure will raise even greater funds in the future'.

Through my role at MS Research Australia I have met many inspirational people with MS, their friends and families, not to mention talented MS researchers, who are absolutely focussed on finding a cure. I truly believe that if we all work together we can ensure that a cure will be found sooner rather than later – so we can ultimately Kiss Goodbye to MS once and for all! ■



## A word from our Chief Executive Officer

**The International Progressive MS Alliance will ensure a collaborative approach to research, ensuring duplication is avoided and that important discoveries are fast tracked. This year's grant allocations will be announced at the joint American and European Committee for the treatment of MS meeting being held in Boston, USA.**

In this issue of the NEXT newsletter we provide an update on the exciting work of a young researcher, PhD student Mr Jae Young Lee, who under the supervision of Dr Steven Petratos, is making great progress in exploring methods to prevent the degeneration of myelin and nerve fibres in MS.

Also of great significance is the recent academic workshop we co-hosted with the Centre for Advanced Imaging at the University of Queensland. It was a unique forum which brought together experts (from Australia and overseas) in both imaging and MS to discuss the development of more sophisticated imaging techniques. We believe that advanced imaging has significant potential in earlier diagnosis of MS as well as tracking the progression of the disease.

I would like to introduce you to Mandy Lee, our Development and Events Manager. She is a valuable member of the MS Research Australia team.

Lastly I would like to thank those of you who participated in the recent readership survey, your comments and suggestions have been very insightful and will guide in refining our future editions. ■

**Dr Matthew Miles**

## Readership survey results

The recent readership survey revealed the MS NEXT is well regarded, receiving a 95% satisfaction rating of 'very good' or 'good'. 84% read most or all of the articles and the most popular sections are the Australian and worldwide MS research discoveries, updates on MS clinical trials, MS Research Australia funded projects and the MS Research Australia Brain Bank.

When asked specifically what readers liked most, an overwhelming majority detailed the informative and interesting research updates, the relevance of the articles, the ease of reading and the quality of the writing.

The results of this survey are encouraging and will be used to enhance and improve our various communication publications. ■



### VALE Louise Kurczyk

Australia's MS community was saddened to learn of the sudden death of a passionate and dedicated Clinical Nurse Consultant and researcher. Ms Louise Kurczyk provided outstanding and personal mentorship to MS nurses around Australia in improving the identification and treatment of continence symptoms, and she was a recipient of a MS Research Australia project grant. Her colleagues and MS nurses around Australia will continue her work on this important project.

Our thoughts are with Ms Kurczyk's family, friends and colleagues at Monash University's Eastern Clinical Research Unit at Box Hill Hospital.



# MS Research Australia becomes a key health and medical research partner

Research Australia is an alliance of 160 members and supporters advocating for health and medical research in Australia. Independent of government, Research Australia's activities are funded by its partners, donors and supporters from leading research organisations, academic institutions, philanthropy, corporates and others representing the interests of the broader community.

'We are thrilled to be able to announce that MS Research Australia is our latest collaborator to become a **Health and Medical Research Partner** with Research Australia,' said Ms Elizabeth Foley, CEO and MD of Research Australia.

MS Research Australia has become one of 28 Health and Medical Research Partners and joins the likes of Victor Chang Cardiac Research Institute, the Brain and Mind Research Institute, JDRF and the Orygen Research Centre.

'There is strong alignment between the two organisations and we look forward to continuing our collaboration on items of mutual interest to do with medical research, specifically related to MS,' said Dr Matthew Miles.

Research Australia believes strongly

that Australia is the home of world-leading research. Our research seeks not only to address the health problems faced by Australians, it also contributes to global research as well as assisting our neighbours in the Asia Pacific region.

'MS is a devastating disease and the most commonly acquired neurological disease in young adults in the world. MS Research Australia is an important non-government funder of MS research,

in fact, the largest national organisation of its kind in Australia. The advances that have been made, over the last decade, in our understanding of MS has increased exponentially under their guidance' said Ms Foley. ■



Elizabeth Foley and Dr Matthew Miles

## Partner Profile



The John T Reid Charitable Trusts is a family foundation, created by the late Sir John Reid. For over 50 years, three generations of family members have proudly continued his generous legacy. Sir John's philanthropy had as its basis that support from his Charitable Trusts allowed good people to get on with their own good

work for the benefit of the community.

The John T Reid Charitable Trusts has been a generous supporter of MS Research Australia since 2006 when they made a significant contribution to help start up the ANZgene MS genetics research platform.

The ANZgene platform is a national, collaborative effort between a multi-disciplinary team of neurologists, geneticists, bioinformaticians and molecular biologists, coordinated by MS Research Australia. It was set up in 2005 as part of a global initiative to identify the genes that influence disease susceptibility and the progression of symptoms in MS. Knowing what these genes are and what they do is vital in helping researchers to understand the causes of MS and its progression.

Since the establishment of ANZgene, we have gone from knowing just a handful of genes implicated in MS to over

110. Researchers are now painstakingly investigating each and every gene to understand the mechanisms behind an individual developing MS.

One key finding of the ANZgene project is the discovery that genes involved in the metabolism of vitamin D are implicated in MS. This correlates with epidemiological research showing that reduced exposure to sunlight (which contains vitamin D) results in an increased risk of developing MS. Armed with this important information, MS Research Australia recently set up the world first MS Prevention Trial (PrevANZ) to investigate whether supplementation with vitamin D can prevent high risk individuals from developing MS. The John T Reid Charitable Trusts has also supported this important clinical trial.

MS Research Australia is very grateful to the John T Reid Charitable Trusts for their ongoing and generous support. ■



Jae Young Lee

## Studying new methods to prevent disease progression

**A team at Monash University in Melbourne are making great progress exploring novel methods for preventing the degeneration of myelin and nerve fibres in MS. This work has important implications for preventing the progressive degeneration that causes accumulating disability in many people with MS.**

Dr Steven Petratos, and PhD student Mr Jae Young Lee, are using novel approaches to explore whether the

damage to the protective myelin sheath surrounding nerve fibres in MS could be avoided, by targeting a molecule that has been linked with the structural degeneration of nerves.

Mr Lee currently holds a MS Research Australia Postgraduate Scholarship, supported by the Trish MS Research Foundation. This is an exciting project and the laboratory of Dr Petratos provides an excellent training ground for the young researcher. The team is making great

progress, having already published some results and more papers are currently being prepared for publication.

Collaborations with researchers from the University of Toronto, Canada and Yale University in the US, have previously identified that a pathway involving a molecule known as the Nogo Receptor (NgR) may play a role in the earliest stages of nerve fibre damage in a laboratory model of mice with MS-like disease. They have also shown that blocking this pathway can limit the extent of nerve damage.

Mr Lee has now been able to show that blocking the action of NgR was also associated with significantly less damage to the myelin surrounding the nerve fibres in these mice. These findings provide confirmation that the NgR influences the structure of both nerve fibres and the surrounding myelin, and suggests that it may be a useful target to pursue in human studies to assess its potential as an intervention to prevent MS progression.

To further understand the role of NgR and its effects on brain structure and nerve fibres, Mr Lee and Dr Petratos have developed genetically modified mice that also lack a crucial gene involved in the NgR pathway. Their early results indicate that these mice tended to show less severe symptoms following induction of MS-like disease, but also have specific differences in the structure of their myelin and nerve fibres. This work should lead to new possibilities to develop drugs that may protect myelin and nerves in MS and holds great promise for preventing the progression of disability in MS. ■

## Our world-first Vitamin D trial update

**Over the last decade MS Research Australia has supported several important Australian studies that have contributed to the considerable body of evidence that vitamin D deficiency is associated with increased risk of developing MS. However, if vitamin D supplementation is to be adopted as an early, preventative intervention for people at high risk of developing MS, rigorous evidence for optimum dosage, efficacy and safety is required from a carefully designed randomised controlled trial.**

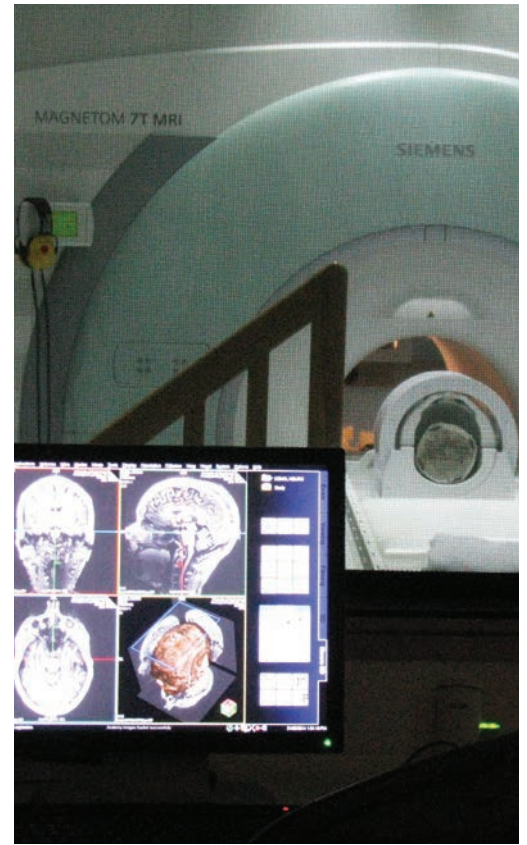
Australia has a critical mass of expertise in this field and MS Research

Australia has worked with these researchers to develop the vitamin D MS Prevention Trial (PrevANZ). It is a phase IIb randomised controlled trial of oral vitamin D supplementation in people who have experienced a first demyelinating event. The trial is funded by MS Research Australia, with the support of the state MS Societies, including significant contributions from the MS Society of WA, MS Queensland, Trish MS Research Foundation, Foundation 5 Million Plus and other trusts and foundations.

After a period of preparation for the trial in which protocol, ethics approvals and regulatory requirements were finalised,

trial sites have been progressively set up, with the first patient enrolled in June 2013. 20 sites have now been established in MS clinics around Australia and New Zealand with the final site, the Wesley Research Institute in Brisbane, coming on board in May 2014. Enrolment of patients has been progressing steadily and the PrevANZ Steering Committee is working with their colleagues to increase awareness of the trial and ensure that recruitment of participants continues to grow to reach our target of 240 patients in the trial. Results are expected in 2017. For more information visit [www.msra.org.au/prevanz](http://www.msra.org.au/prevanz) ■





## A better window into the brain

**Magnetic Resonance Imaging (MRI) scans of brain and spinal cord perform a vital role in the diagnosis and care of people with MS. However, earlier diagnosis, treatment decisions, clinical trials for progressive MS, and research could all benefit from the development of more sophisticated imaging techniques.**

MS Research Australia recently teamed up with the Centre for Advanced Imaging at the University of Queensland to run a workshop on Advanced Imaging in MS. The workshop brought together experts in both imaging and MS to discuss a range of techniques and explore their use in research and in the clinic.

The Centre for Advanced Imaging houses state-of-the-art imaging equipment including one of only two 7 Tesla human MRI scanners in Australia (most clinical MRI scanners have a magnet strength of 1.5 or 3 Tesla). The centre is staffed by a multi-disciplinary team including biologists, chemists, mathematicians and engineers.

This made the Centre for Advanced Imaging an ideal partner for MS Research Australia to achieve one of its key strategic goals to leverage strong collaborative networks within the field of MS and other comparable fields of endeavour to advance research into MS.

It is now recognised that lesions seen using standard MRI scans correlate poorly with the level of clinical disability seen in individuals with MS. Studies using post-mortem brain tissue also show that damage occurs in the grey matter in MS and even 'normal appearing white matter' seen in MRI scans may be affected.

Thus there is a pressing need to improve techniques to 'see' what is happening in the brains of people with MS in real time.

Participants at the workshop discussed how measures of brain tissue loss (atrophy), particularly in certain areas of the brain, are

increasingly being used to monitor the course of MS in clinical trials. However, atrophy measures, are currently less useful for monitoring individual patients due to the high variability and need for repeat scans over longer time periods.

The development and use of radioactive chemicals for use in positron emission tomography (PET) scans is gaining momentum, and Australia has been strong in this area. Professor Andrew Katsifis from the Royal Prince Alfred Hospital in Sydney and international keynote speaker Professor Paola Piccini from Imperial College London, UK, described the development and use of a new generation of PET markers for microglia, the resident inflammatory cells of the brain. Microglia are thought to play a key role in progressive MS, but also appear to be activated very early in the course of the disease.

With progress being made in the development of experimental medications that aim to promote myelin repair and protect the neuronal axons from permanent damage, there is a great need for reliable scanning tools to accurately measure myelin and axon integrity.

Great headway was made at the workshop in meshing the needs of MS researchers with the capabilities of the scanning specialists and several possible collaborative research avenues were identified.

Professor David Reutens, Director of the Centre for Advanced Imaging and Professor Bill Carroll, Chair of the MS Research Australia International Research Review Board, were extremely pleased with the level of 'intellectual ferment' stimulated by the workshop. The workshop revealed the strengths that Australia can apply to the pursuit of the key biological and clinical questions needed to improve diagnosis, treatment and prevention of disease progression in MS. ■

# Understanding spinal cord lesions in progressive MS

**An article published in the international journal *Glia* gives new insight into the structure of lesions in the spinal cords of people with progressive MS.**

Researchers from the Lyon Neuroscience Research Centre in France recently undertook a study of spinal cord tissue donated to the MS Tissue Bank at Imperial College in London by 16 people who had either a primary or secondary progressive form of MS.

As nerve cell damage accumulates in MS, regions of the brain and spinal cord lose the protective myelin coating around nerves ('demyelination') resulting in lesions, also called plaques, of damaged tissue. In this study, the researchers aimed to analyse the damaged nerve cells within the spinal cord, looking specifically at the tissue immediately surrounding a lesion in the spinal cord, known as 'peri-plaque' regions.

Some previous studies have found that the peri-plaque regions may show signs of damage and demyelination similar to the lesion itself; however, very few previous studies have measured the degree of demyelination in these regions, or the profile of immune system involvement in this area.

The spinal cord is of key interest

because it shows increasing damage as MS progresses, and the extent of spinal cord lesions is more strongly associated with level of disability than brain lesions. Using special staining techniques, the researchers identified that the extent of demyelination in peri-plaque areas in the spinal cord extended further than previously thought.

The researchers analysed the molecular 'signature' of immune system activity in the peri-plaque regions, and reported subtle alterations in a number of different cell and protein types that may contribute to the observed demyelination. They found that these areas of tissue contained immune molecules known to inhibit the repair and remyelination of nerve cells, and also had increased activity of several immune-related genes. Furthermore, the researchers found that the peri-plaque regions were associated with low-level inflammatory activity predominantly from resident support cells of the brain, rather than immune cells that infiltrate the spinal cord from the blood. The finding suggests that these cells may contribute to progressive loss of myelin and the failure of myelin repair that gradually spreads beyond the initial lesion.

The researchers suggest these peri-plaque areas might contribute to some of the neurological disability reported by people with progressive MS, and represent a potential target for the development of new treatments aiming to limit the spreading of tissue damage and myelin degeneration.

This study highlights the value of studying human tissue to deepen our understanding of the structure and causes of MS lesions and how these lesions might affect nerve functioning in the brain and spinal cord.

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** ■



## Do you want to participate in MS research?

**For people with MS wishing to get directly involved in research into MS, there are many different ways to participate, ranging from completing a short survey to a more lengthy commitment with multiple clinical visits.**

There are research studies aimed at improving our understanding of MS, clinical trials to test new medications, studies that evaluate and improve the services available for people with MS and surveys to understand the social, economic and psychological challenges of living with MS.

The MS Research Australia Clinical Trials Network website provides information on the various trials available and the recruiting criteria. Visit **[www.mstrial.org.au](http://www.mstrial.org.au)**

### **Currently recruiting:**

- The Australian MS Longitudinal Study investigates the issues of practical importance to people living with MS. Participants receive regular surveys covering a range of issues. For more information visit **[www.msra.org.au/amsls](http://www.msra.org.au/amsls)**.
- A clinical trial is currently underway looking at whether approved MS medication fingolimod (Gilenya) has different effects in people in the early stages of MS who have previously been on other MS medications, compared to people new to MS medications. Another experimental oral medication siponimod, which is chemically related to fingolimod, is also being tested in both relapsing remitting and secondary progressive MS.
- While most MS medications are not recommended for use in women who are planning pregnancy or are pregnant, there are sometimes pregnancies that are exposed to MS medications. Collecting data on the outcomes of these pregnancies is vitally important and Pregnancy Registries are currently running for a number of MS medications.
- A number of physiotherapy studies are also underway to improve walking and balance and prevent falls in people with all forms of MS. ■



# F5m+ to join the Kiss Goodbye to MS campaign

When Foundation 5 Million Plus was established in 2005, the vision was to raise \$5 million for MS research. Through the hard work of truly remarkable people, that vision was realised and then exceeded with a total of \$7.3 million being raised to date. This includes the fundraising of the Trish MS Research Foundation, Charityworks for MS, the MS Angels and the MS Saints.

Over the last year, F5m+ supporters have also been strong advocates for the Kiss Goodbye to MS campaign. Kiss Goodbye to MS symbolises exactly what F5m+ wants to happen - we all want to Kiss Goodbye to MS once and for all. This fun and empowering new campaign has grown from a simple awareness activity to a national fundraising campaign which encourages everyone to get involved. Most importantly all funds raised through Kiss Goodbye to MS are directed to vital MS research.

With this in mind, F5m+ has decided to support Kiss Goodbye to MS to form one dedicated community fundraising campaign for MS Research Australia. By pooling resources we can focus on funding top quality research into MS, reduce costs and ultimately concentrate on finding a cure.

Founding F5m+ member Mike Hemingway said 'My journey with

F5m+ began when I was looking for something to help me understand life with MS. It empowered me to contribute to the search for a cause and cure for MS. I felt like I was fighting back and taking control over something over which I had no control. More than that, F5m+ put me in touch with a group of like-minded, positive, can-do people who wanted to fight and wanted to find a cure. I am so pleased to see F5m+ come together with Kiss Goodbye to MS, so much so that my wife Katrina and I are leading a walking group across England this year to fundraise

under the Kiss Goodbye to MS brand'.

Carol Langsford OAM, Lina Marrocco OAM and Jacqui Tracey, long time members of F5m+ all agree 'F5m+ has been a wonderful organisation, it has been an organisation of people with MS, their family and friends, making a difference by fundraising. Not only did we fundraise but we were also a support network for each other. The Kiss Goodbye to MS campaign perfectly matches our desire as a group to rid the world of this illness and we are looking forward to leveraging this exciting brand in the future!' ■



## Foundation 5 Million Plus



Charityworks for **MS** presents  
*ms research gala. ball*  
Saturday 18 October 2014

**Million Dollar DREAMS**  
*Dream for a cure*

7:00pm  
Peninsula, Docklands, Melbourne  
[www.charityworksforms.org.au](http://www.charityworksforms.org.au)



**Trish**

Please join us for The Trish Ball and assist us  
**KISS GOODBYE TO MS**

13th September 2014  
6:30pm

Grand Ballroom, Hilton Sydney  
[www.trishmsresearch.org.au](http://www.trishmsresearch.org.au)



## Trekking across England to Kiss Goodbye to MS

One of the Kiss Goodbye to MS campaign top fundraising teams are currently walking 303kms across the UK to raise funds for MS research.

The Wainwright's Coast2Coast MS Walk team are motivated by friendship and determination to see an MS cure. The team organiser, Katrina Hemingway says, 'I wanted to set a challenging walk that would mimic the challenges of living with MS... I had a vision of people joining me for the walk to raise money for research and better therapies for MS and am just

over-awed by the team that has arisen.'

This team is made up of both Australians and British people, most are walking the full distance and several are joining for parts of the walk. Many of the walkers have a close connection with MS, including two determined walkers, Debbie and Dianne who are living with MS. 'I want to be a part of finding the cure for MS... and us helping to raise this money brings that cure a step closer.' Debbie said.

After months of hard training,

fundraising with BBQs, cake stalls, dinners and trivia nights the team have started their incredible journey. All team members fully funded their own trip and committed to fundraising towards the team goal of \$200,000.

MS Research Australia are inspired by the determination and effort from all team members and wish them the best of luck for the walk!

The Wainwright's Coast2Coast MS Walk is a challenging 303km walk across Britain over 12 days. From St Bees on the west coast it traverses three national parks – the majestic Lake District, the beautiful Yorkshire Dales and the expansive North York Moors – before finishing on the east coast at Robin Hood's Bay.

To support this inspiring team, go to [www.kissgoodbyetoms.org](http://www.kissgoodbyetoms.org) and like Kiss Goodbye to MS on Facebook for all the latest news. ■



### Campaign Update

- Over \$737,000 raised this year for MS research
- 33,000+ Facebook likes
- Instagram followers increased 112% since 2013

## Help us find a cure for MS

**Donate** (Donations over \$2 are tax deductible)

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

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

### Contact details

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

**Thank you for supporting MS Research Australia with your generous donation.**

Please return by post to:

**PO Box 625, North Sydney NSW 2059**

You can also donate online at:

**[www.msra.org.au](http://www.msra.org.au)**

### Payment method:

- ☐ Cheque (made payable to MS Research Australia)
- ☐ Please debit my ☐ Mastercard ☐ Visa ☐ Amex

Credit card number:

Exp:  CVV:

Name on card:

Signature:



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