



DECEMBER 2020

AMBER HOPES FOR A CURE IN HER LIFETIME



Amber was 33 when she found out she had MS. Like many in our community, this came as a big shock.

She was nursing her second child at remembers waking up with a numb hand, thinking that she had just "slept funny". But when the numbing effect started to creep to her foot was wrong. Amber saw her GP on and was diagnosed on Thursday.

"It was really quick for me. Between was six days, start to finish. My first question was, am I going to see my kids grow up?."

Not knowing anything about MS was Mark were quick to admit they hadn't dealt with anything like this before. As high school sweethearts, their life together was picture perfect close families, great jobs, and loved members of a tight knit community in Sydney's south. In the early days

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ADVANCING CELLULAR THERAPIES FOR MULTIPLE SCLEROSIS

MS Research Australia has made a significant commitment to accelerate autologous haematopoietic stem cell transplant (AHSCT) research for MS in Australia.

We are delighted to announce a strategic, five-year partnership with the St Vincent's Curran Foundation to advance cellular therapies for MS, including AHSCT. Together we are working to help establish the St Vincent's Hospital Sydney Centre of Excellence in Cellular Therapy.

The MS Research Australia and St Vincent's Curran Foundation partnership aims to accelerate research and treatment of people with autoimmune diseases as well as those with malignancies. For MS, it will hopefully help clarify who best responds to treatment, as well as ensure that people with MS can continue to access stem cell therapies under observational trial conditions. With increased attention in these areas, clinicians and researchers will have the opportunities and information to facilitate ground-breaking research into cellular therapies.

St Vincent's Hospital Sydney has been at the forefront of bone marrow and stem cell transplantation since 1975, when the very first bone marrow transplant for cancer treatment in Australia was undertaken. Since 2011, they have been using AHSCT in clinical trials as a treatment for MS.

"We are proud to support St Vincent's and the Centre of Excellence in Cellular Therapy. Our goal is to accelerate AHSCT research for MS here in Australia and we hope this model can be expanded to additional centres around Australia" said Dr Julia Morahan, Head of Research at MS Research Australia.

Cont. on pg 4



WATCH ON DEMAND HERE: MSRA.ORG.AU/EVENTS/LIVEUPDATE2020

A WORD FROM OUR CHAIR

ASSOCIATE PROFESSOR DESMOND GRAHAM



As 2020 comes to a close, two words come to mind: extraordinary and challenging.

The beginning of the year unfolded with devastating bushfires and then the COVID-19 global pandemic. The MS Research Australia team didn't waiver. They were determined to stay focused and even increased our commitments to MS research in this challenging environment.

Before COVID-19 we were undertaking steps to introduce a new governance model, merging MS Australia and MS Research Australia. The rationalisation of the two organisations has already reaped several efficiencies with more to come. Part of that process has been an extensive and thorough recruitment process to identify a new CEO to guide the newly focused and amalgamated MS Australia and I am proud to announce that advocacy and public affairs specialist Mr Rohan Greenland has been appointed. We look forward to him starting on the 14th December.

With a large number of people with MS taking immune modulating therapies, the emergence of the novel coronavirus did cause a lot of concern. The Board acted quickly to approve \$100,000 to enable Australian researchers to participate in an international data collaboration capturing information regarding COVID-19 and its impact on people with MS globally, this helped generate evidence based guidelines for people with MS and their health care teams.

Rolling lockdowns also put a number of MS research projects in jeopardy. We quickly made available an additional \$275,000 to a number of existing projects which were facing extensive disruptions and delays due to COVID-19. This allocation of financial support and time extension of a further six months will see the continuation and completion of these important investigations.

In the 2020 calendar year with your incredible assistance we raised over \$10.5 million to fund and facilitate major MS research projects and collaborations. The May 50K campaign was an unprecedented success and combined with our valuable donors and significant contributions from the SA/NT MS Society, MS Limited and MS WA we reached a record high fundraising year. At MSA and MS Research Australia we never forget that none of this is possible without everyday Australians contributing to improve the health and social outcomes of people with MS and in finding, the allusive cure.

Incredibly, The May 50K attracted over 26,500 participants and raised over \$6.6 million which will be invested in future ground-breaking MS research. This year also saw The May 50K launched globally as we work closer with our partner research organisations around the world to help pool the best brains and resources to enhance MS research around the world.

Another milestone was the PBS approval of siponimod (Mayzent), the first approved treatment for secondary progressive MS. There are now 14 MS medications available in Australia. This would not have been possible without incredible MS research being conducted around the world. Much work remains to be done and we will continue to advocate so that MS treatments can be listed on the PBS to ensure people with MS have affordable access to the widest possible choice of medications to treat their MS.

Lastly, as a person living with MS and Chair of the Board, I would like to take this opportunity to acknowledge your magnificent assistance and sincerely thank you for your support. I wish you a safe and prosperous 2021.

MS AUSTRALIA ANNOUNCES THE APPOINTMENT OF NEW CEO

The Board of MS Australia is pleased to announce the appointment of a new Chief Executive Officer to guide the newly focused and amalgamated MS Australia.

MS Australia Board President, Associate Professor Desmond Graham, recently announced the appointment of Mr Rohan **Greenland** as the organisation's new CEO.

Associate Professor Graham said, "After a very comprehensive recruitment process, the MS Australia Board is pleased to secure Rohan for the role, commencing on the 14th December"

"Rohan is an extremely impressive executive, who has dedicated his career to successfully advocating for better health outcomes for everyday Australians."

"In a tough environment for the not-forprofit sector, Rohan has the experience required to help MS Australia speak with one voice about care, research and advocacy and brings an established network of stakeholders which will help our message to be heard."

Rohan brings a track record of success, particularly in relation to public health advocacy and stakeholder engagement. The Board is confident he is the best person to advance MS Australia's core

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purpose: achieving the best possible outcomes for those living with MS now and in the future by enabling the delivery of care and support; funding research to seek a cure; and advocating for improved health and social outcomes and greater investment into the disease.

Rohan joins MS Australia from Palliative Care Australia where he has been CEO since February 2019. He also worked in senior advocacy roles at the National Heart Foundation for more than a decade; was Director Public Affairs at the Australian Medical Association; and was a political adviser to Australian national and territory ministers.

Mr Rohan Greenland said "I am deeply honoured and excited to join MS Australia at an important time in its development. Its mission is critical to lives of the 26,500 Australians who are living with MS, to their families and carers, and to the nation as a whole."

"MS Australia has an enviable reputation as a charity that supports world-class research, provides much needed and practical assistance to people living with MS and advocates with passion for the people it serves. I look forward to doing all I can to build on that reputation and help achieve its ultimate goal, a world without MS."

Associate Professor Graham said "on behalf of the Board, we would also like to acknowledge the hard work and strong leadership of both Deidre Mackechnie, the outgoing CEO of MS Australia, and John Blewonski, who has been Acting CEO of MS Research Australia, and extend our gratitude for their significant contributions to the MS community."

FUNDING FOR NEW DIGITAL TOOL



The National Health and Medical Research Council (NHMRC) has announced \$1.4 million in funding for an innovative MS patient-centred digital health care tool - InforMS - as part of their prestigious Partnership Projects program.

The University of Tasmania's Menzies Institute for Medical Research in partnership with MS Research Australia are developing InforMS to help people living with MS better manage their symptoms. This digital patient-centred health care tool will create a paradigm shift in MS self-care, clinical care and research.

Professor Ingrid van der Mei from the Menzies Institute, says that "InforMS will utilise modern monitoring technologies like mobile apps and wearables to collect valuable MS information. It will empower people living with MS by providing timely information to track their MS via their smart devices. This data can then be used to influence treatment decisions, monitor symptoms, and identify insights and disease trends to enhance MS research."

Information collected through the InforMS tool will be invaluable for future MS research and treatment. From greater insights into the day-to-day impacts of MS to the effectiveness of treatment, this innovative system will provide access to data that was once beyond the reach of researchers, clinicians, and people living with MS.

The first phase of the InforMS development project will utilise existing information from MS Research Australia's Australian MS Longitudinal Study (AMSLS) - a research platform comprising a registry of people living with MS and their selfreported data. This will be used as the building block from which the new InforMS tool is to be developed.

Chair of MS Research Australia, Associate Professor Desmond Graham states "This important project could never have come to fruition if it wasn't for the incredible support and involvement of several MS stakeholders. In particular MS Australia and the MS State Societies, Kiandra IT, Atlassian, and vital insight from people living with MS."

"MS Research Australia aspires to Stop and Reverse MS in 10 years and part of this exciting plan is to develop a patient-centred portal. The purpose of InforMS is to empower people with MS to be actively involved in the decision-making process around treatments and management of their MS - it does this through providing clinicians and patients with timely information, allowing them to be more responsive" said Associate Professor Graham.

The partnership funding will enable testing, optimisation and implementation of the new digital InforMS tool. For more information, head to our website: https://msra.org.au/informs/

Expert contributors to the InforMS project: Professor Ingrid van der Mei, Professor Bruce Tylor, Professor Andrew Palmer, Professor Christopher Leigh Blizzard and Professor Dianne Nicol, Menzies Institute for Medical Research; Professor Helmut Butzkueven, Dr Vilija Jokubaitis, Monash University, Professor Simon Broadley, Griffith University, Belinda Bardsley, MS Nurses Australasia.

CONTINUED FROM PAGE 1 ADVANCING CELLULAR THERAPIES FOR MS

"We look forward to progressing research to improve outcomes for people with MS".

In addition to MS Research Australia, singersongwriter Delta Goodrem has announced her philanthropic support for the Centre to significantly increase the research focus on cellular therapies for haematological cancers and MS.

WHAT IS AHSCT?

AHSCT, also known as stem cell transplantation or bone marrow transplant. can be used for the treatment of MS. Similar to the chemotherapy treatment used to treat blood cancers, AHSCT is used to kill off the immune cells in the body before reintroducing the patient's own (autologous) blood stem cells to rebuild the immune system. Blood stem cells, known as haematopoietic stem cells, are a type of adult stem cell found in the blood and bone marrow, and can generate new blood and immune cells.

The procedure involves:

- · Pre-treatment to release bone marrow stem cells into the blood
- Collecting or 'harvesting' the autologous Hematopoietic stem cells (AHSCs) from the blood of the patient
- Freezing (cryopreserving) the AHSCs in the laboratory until they are required
- Administering chemotherapy to kill the patient's current immune system (conditioning)
- Returning the thawed AHSCs to the patient by infusion into the veins, in an attempt to repopulate the immune system

High intensity supportive medical treatment is provided during and immediately after the transplant when there is a high risk of infection and bleeding disorders due to the intense immune suppression.

In MS, the immune system mistakenly attacks the brain and spinal cord. The aim of AHSCT for MS is to 're-boot' the immune system so that the "self-reactive" immune cells that are attacking the nervous system are removed and replaced with a regenerated immune system. This rebooted immune system is thought to be more self-tolerant and less likely to continue attacking the body.

DOES AHSCT REGENERATE NERVES IN THE BRAIN AND SPINAL CORD?

There is no evidence to suggest that AHSCT can repair nerve fibres. International



St Vincent's Haematologist Associate Professor John Moore and singer-songwriter Delta Goodrem



OUR GOAL IS TO ACCELERATE AHSCT RESEARCH FOR MS HERE IN AUSTRALIA AND WE HOPE THIS MODEL CAN BE EXPANDED TO ADDITIONAL CENTRES AROUND AUSTRALIA.



studies suggest that it is also unlikely there will be reversal of longstanding disability. In AHSCT, it is hoped that the regenerated immune system is less likely to attack the brain and spinal cord, but this does not contribute to repairing the damaged nerves.

Some people with MS may experience some reversal of disability following AHSCT, however, this is thought to be primarily the result of normal repair of myelin around intact nerves, which can occur once the inflammatory attack in the brain and spinal cord is suppressed.

Other types of stem cells have potential to grow or repair tissue in areas of the brain and spinal cord that have been damaged or destroyed. However, the use of these other types of stem cells in MS is still in the early stages of research, and has not yet been shown as an effective treatment for people with MS. Some private clinics are offering forms of stem cell therapy for MS and other diseases which claim to successfully regrow damaged tissue using stem cells derived from fat tissue. However, clinical data on these therapies are currently lacking.

WHO IS AHSCT SUITABLE FOR?

Australian hospitals and doctors are likely to recommend AHSCT as a possible treatment only if the other approved MS therapies are not working for an individual with MS, or other treatments cannot be used in an individual for other reasons. The international studies to date also suggest that AHSCT is unlikely to halt or reverse progressive forms of the disease, so it is not likely that AHSCT would be recommended as a treatment for patients with secondary progressive or primary progressive MS.

Each person's situation is unique, and individuals should consult their neurologist to consider the potential benefits, risks and side effects for their circumstances before making a decision.

WHERE IS AHSCT AVAILABLE IN AUSTRALIA FOR MS?

Currently the treatment is provided in Australia through three observational clinical trials, at St Vincent's Hospital, Sydney; Austin Health, Melbourne; and The Alfred, Melbourne; and by a small number of other centres on a case by case basis. These centres have strict eligibility requirements that have been set by the hospital ethics committees, and may only apply to a limited number of patients with MS. It is for this reason patients need to be referred to these centres by a neurologist, who can provide a detailed clinical history and magnetic resonance imaging (MRI) findings.

WHAT OTHER AHSCT RESEARCH IS MS RESEARCH AUSTRALIA FUNDING?

MS Research Australia has been actively supporting individual Australian research projects in AHSCT for many years. Currently we are funding projects at St Vincent's Hospital by Dr Jennifer Massey examining how immune cells that cause inflammation in the brain are altered by the treatment. She is also investigating whether immune cell markers can be used to predict who will have the most long-term benefit.

MS Research Australia (with the support of the MS WA) has been funding the Australian MS AHSCT Registry since ANOTHER
IMPORTANT QUESTION
THAT IS YET
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WITH THE NEW
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RELAPSING MS.

2012, and is working with haematologists and neurologists to gather and analyse further data on Australians with MS treated with this procedure. As an experimental treatment, it is critical that we gather data on the safety and effectiveness of AHSCT for people with MS.

The MS Research Australia AHSCT clinical registry has recently been transferred to St Vincent's Hospital Sydney. The team at St Vincent's are also responsible for the Australasian Bone Marrow Transplant Recipient Registry (ABMTRR), which

follows people who have undergone bone marrow transplants in Australia and New Zealand. The team at St Vincent's Hospital will link the ABMTRR with the prestigious and powerful MS clinical registry, MSBase to help accelerate research. If you are a person with MS who has undergone AHSCT either in Australia or overseas and want to be included in the registry, talk to your neurologist to be included via MSBase.

Another important question that is yet to be definitively answered is how AHSCT compares with the new generation, highly effective therapies available for relapsing MS. Associate Professor Tomas Kalincik with funding support from MS Research Australia is analysing data gathered through MSBase and other international clinical registers, to compare clinical outcomes of people treated with AHSCT to those treated with natalizumab, alemtuzumab, fingolimod or mitoxantrone. This will help build a more complete picture of the outcomes of AHSCT.

For more information on AHSCT please visit https://msra.org.au/ahsct/

To donate to support these important AHSCT research projects select AHSCT in the specific field of research on the donate page https://msra.org.au/donate/ or call Tim Roseman to discuss the funding and partnerships opportunities 1300 356 467 or troseman@msra.org.au

AUTOLOGOUS HAEMATOPOIETIC STEM CELL TRANSPLANT (AHSCT)



Administer pretreatment to release blood stem cells from bone marrow into the bloodstream



Collect the blood stem cells from the bloodstream



Freeze the blood stem cells in the laboratory until they are required



Administer chemotherapy to remove or partially remove the immune system



Return thawed blood stem cells by infusion into the vein



Provide supportive medical treatment for at least 4 weeks as the immune system rebuilds



AHSCT IS AN IMMUNOSUPPRESSIVE CHEMOTHERAPY TREATMENT COMBINED WITH REINFUSION OF BLOOD STEM CELLS TO REBUILD THE IMMUNE SYSTEM

CONTINUED FROM PAGE 1 AMBER HOPES FOR A CURE IN HER LIFETIME

of her diagnosis, they both felt like fish out of water.

"We didn't know anything about MS, except that it was really bad. We went home and started googling everything we could about it. And thankfully, there was lots of good information online and on the MS Research Australia website."

After finding out as much as they could, they started to feel more confident. They could see that treatments would help and that research breakthroughs were happening all the time.

Thankfully, after Amber started her first round of treatment some of her symptoms improved – although there was a downside, the steroids meant she could no longer breastfeed.

"I couldn't breastfeed for 12 hours at a time. Archer wouldn't take a bottle so Mark would take him for long walks at night and I would hear him crying as they came up the driveway. It was a really difficult time, managing a nine-month old, a two-and-a half year old and my MS."

IT WAS A REALLY DIFFICULT TIME, MANAGING A NINE-MONTH OLD, A TWO-AND-A HALF YEAR OLD AND MY MS.

Today, Amber says that MS affects her life in more "insidious ways" with her symptoms more frustrating than anything, especially the fatigue.

"Day-to-day, the fatigue is probably the biggest thing that can affect family life. I call my bad days 'MS days', where I can't get through everything. And those days make me feel like a pretty bad mum."



I'M REALLY PINNING MY HOPES ON A CURE.



Feeling like a "bad mum" and "worrying about the future" is common for me, says Amber. And her fears are real, like not being well for her family. Despite this, Amber's hopes are real as well – especially for a cure in her lifetime. She knows that treatments and potential cures are progressing all the time, thanks to MS research.

"I'm really pinning my hopes on a cure. I don't want my children to have to grow up dealing with a mum that has MS any more than I currently do. And I certainly do not want any of my children to grow up and develop MS either. If that means we need a cure, we need a cure."

Amber and Mark are thankful every day to those who donate to MS research because it's for people just like them. Donations in any amount provide a steady stream of funding for research to help us find cures and treatments that will change lives for MS families.

Amber and Mark's journey has been hard, but they know also it's made them stronger and there have been some wonderful times too since her diagnosis. In 2018, Amber and Mark welcomed a third child, Aden. Amber always wanted a big family so being able to have another baby was a dream come true!

You can give hope to people like Amber and Mark with a gift by donating here: msra.org.au/donate. If you'd like to discuss how you could do more to support our research, please contact Janene Gontier on 1300 356 467 or at jgontier@msra.org.au.





Despite the hardships and challenges this year brought for all of us, you, our Kiss Goodbye to MS family showed incredible resilience, determination and commitment to helping us accelerate research into MS.

With your support, Kiss Goodbye to MS is celebrating its biggest year yet! Together you've raised a record-breaking \$6.75 million for life-changing MS research - a huge achievement which will have a lasting impact on the lives of people living with MS. From the bottom of our hearts, thank you.

Let's take a virtual walk down memory lane to reflect on your MS research achievements...

YOU TRIPLED THE FUNDS RAISED **IN THE MAY 50K 2019!**

When thinking about The May 50K 2020, we're still pinching ourselves. This year, over 26,500 Australians took on the challenge to run or walk 50km throughout May and fundraise for life-changing MS research. That is more people than the 25,600 Australians living with MS! You ran, walked, cycled and arm cranked over 50 laps around the world, and raised a gobsmacking \$6.6 million to leave MS behind us.

Your astonishing efforts enabled MS Research Australia to fund project extensions for our most vulnerable researchers, whose invaluable work was affected by COVID-19. This vital funding lifeline has secured the completion of important MS investigations, all thanks to you.

YOU INSPIRED THE WORLD - THE **MOVEMENT WENT GLOBAL!**

Following last year's success of The May 50K in Australia, you inspired our global colleagues from the Multiple Sclerosis International Federation (MSIF) to pilot The May 50K across the UK, Canada, Ireland and the US. The challenge saw over 13,000 people leave their limits behind, raising a collective \$1.25 million for essential MS research and access to treatment – a huge accomplishment!

In less than two years, you've raised a breathtaking \$9.98 million across 5 countries in The May 50K. We can't wait to watch our Aussie born movement continue to grow globally, as part of the worldwide efforts to solve MS.

YOU WELCOMED FRASER ISLAND **AS A DOMESTIC ADVENTURE!**

With international travel on hold for the foreseeable future, we had to postpone the Kiss Goodbye to MS Tuscany Trek to 2021. Instead, we are exploring our Aussie backyard and launched our domestic fundraising adventure to Fraser Island!

A team of like-minded adventurers will join the challenge to walk 50km across the world's largest sand island for five days in September 2021. Together, you'll discover the diversity of Fraser Island, ranging from rainforests and gorges to lakes and beaches, whilst raising funds to power MS research.

Our determined Kiss Goodbye to MS Tuscany team also continued to soldier on, with over \$21,131 raised so far as they prepare for the 100km trek in late 2021!

There's a limited number of spots left on both adventures. If you'd like to make your travel dreams a reality and help us Kiss Goodbye to MS, get in touch on kgtms@msra.org.au.

YOU ARE CHANGING LIVES!

Thank you from the bottom of our hearts for continuing to pour your heart, love and energy into funding life-changing MS research. We see and appreciate every one of you and your tireless efforts to change lives. Thank you for everything you do.

Whether you participated in The May 50K, bravely shaved your head, set yourself a fitness challenge, held a birthday fundraiser, purchased our merchandise or followed us on social media - you are the heroes behind Kiss Goodbye to MS!

2020 will undoubtedly mark an unforgettable year in history. But for us, it's not because of COVID-19. It's because of the incredible passion and resilience you have shown during these unprecedented times. You are determined to leave MS behind for good - and together we will!

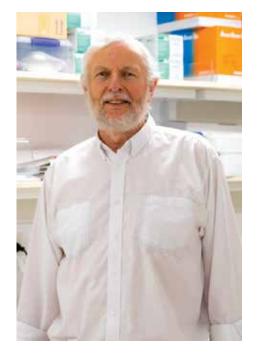
Bring on 2021, we can't wait to see what you've got in store for MS research!

Tanja & Shannen from the Kiss Goodbye to MS team

MEET THE RESEARCHER

PROFESSOR RAYMOND NORTON

MONASH UNIVERSITY, VIC



LET'S GET STARTED! TELL US AN INTERESTING FACT ABOUT YOURSELF...

I have had a long-term fascination with the ocean. Characterising new molecules from sea anemones and cone snails (both are venomous marine animals) remains a major interest of mine.

WHAT INSPIRED YOU TO GET INVOLVED IN MS RESEARCH?

For decades my research has been driven

by my desire to see the outcomes of my work have a positive benefit for human health and well-being. While there are numerous medicines available to treat MS, there are still people whose symptoms are poorly controlled. The opportunity to develop a new treatment option that could complement current therapies motivates my involvement in MS research.

WHAT DO YOU THINK HAS BEEN THE MOST EXCITING DEVELOPMENT IN MS RESEARCH?

New findings about the basis for MS and the associated pathologies offer opportunities for new therapeutic interventions.

TELL US ABOUT YOUR CURRENT RESEARCH PROJECT...

Several years ago, I was fortunate to be involved in determining the threedimensional structure and mechanism of action of a novel peptide from a sea anemone that inhibits a specific ion channel in a sub-class of lymphocytes that causes tissue damage in MS. Analogues of that peptide are about to enter Phase 2 clinical trials for a range of autoimmune diseases. More recently, we developed a new peptide, this time from a scorpion, that inhibits the same ion channel but is easier to make, more stable in the body, and much more selective (thus likely to cause fewer side effects). My project, in collaboration with Dr Natalie Trevaskis at Monash Institute

of Pharmaceutical Sciences (MIPS), will explore the ability of novel analogues of this peptide to remain in the body for longer, home to lymph nodes, where the harmful lymphocytes are produced, and enter the central nervous system to enhance the therapeutic benefits.

WHY IS YOUR RESEARCH IMPORTANT AND HOW WILL IT INFLUENCE THE UNDERSTANDING AND TREATMENT OF MS?

If we can generate long-acting analogues of our peptide that also enter the central nervous system, these peptides will become important new therapeutic leads for the treatment of MS as they act via a totally different mechanism of action from existing therapeutics for MS.

WHAT DO YOU ENJOY MOST ABOUT WORKING IN THE LAB AND WHAT ARE SOME OF THE CHALLENGES YOU FACE?

The most exciting aspect of our lab work is that it may lead to new treatments that improve the wellbeing of those with MS. The challenge is that moving a molecule from being an interesting focus of research to a new therapeutic lead is a huge and expensive task, so one has to accept that progress occurs in seemingly small steps. It also requires collaborations with a broad range of experts with complementary skills to our own.

HELP MS RESEARCH AUSTRALIA FIND A CURE FOR MS

Donate (Donations over \$2 are tax deductible)			Payment method:	
To support MS Research Australia's vital work I would like to:			Cheque (made payable to MS Research Australia)	3
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Make a monthly	donation of \$		Financial institution:	
Learn more about leaving a gift in my Will			BSB number:	81 43
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