



# NEXT



THE OFFICIAL NEWSLETTER OF MULTIPLE SCLEROSIS RESEARCH AUSTRALIA

## \$1.9 million for new MS research grants

**MS Research Australia is proud to announce that nearly \$1.9 million in funding has been awarded to 22 new Research Management Council approved research projects.**

These outstanding research projects encompass a range of MS fields and will be able to commence this year as a direct result of this funding round. With the major collaborative platform projects and ongoing projects from previous years, MS Research Australia's research portfolio now totals 52 active research projects.

'We are very grateful to our all of our donors, supporters, our funding partners, the state MS Societies, the Trish MS Research Foundation, Charity Works for MS and many others for making it possible to invest in such a broad range of projects,' said Dr Matthew Miles, MS Research Australia Chief Executive Officer. 'We are proud that 2015 will represent another great year for investigator led MS research and look forward to ground breaking outcomes arising from this work.'

New biomedical grants will cover a range of fields, including studies investigating the genetics of MS, furthering our understanding of the association of vitamin D with MS risk, and deeper exploration of the role of the Epstein Barr Virus in MS. Several projects have a key focus on promoting repair and remyelination of the nerve cells of the brain and spinal cord.

Dr Fabienne Brilot-Turville and Associate Professor Russell Dale from the Kids Research Institute, NSW received a three-year grant to continue their investigation of antibodies to the myelin

oligodendrocyte glycoprotein (MOG) in children and adults at risk of blindness.

MS Research Australia plays a vital role in increasing the capacity for MS research in Australia by supporting the career development of promising young MS researchers. This year, Dr Jessica Fletcher from the University of Melbourne received a three year post-doctoral fellowship, awarded in partnership with the Trish MS Research Foundation. Dr Fletcher will investigate new methods for promoting myelin repair and preventing disease progression. Dr Melissa Gresle, also from the University of Melbourne has received a Charity Works for MS/MS Research Australia post-doctoral fellowship to investigate how MS risk genes might influence the behaviour of immune cells to contribute to MS susceptibility.

New social and applied research has also received funding, including a pilot

study by Dr Ollie Jay at the University of Sydney, investigating body temperature regulation in people with MS during physical activity. A significant project by Professor Andrew Palmer, from the Menzies Institute for Medical Research, will develop a statistical modelling tool to identify the treatments for relapsing-remitting MS that are the greatest value for money, with a goal to improve outcomes and optimise the use of limited healthcare resources.

Associate Professor Ingrid van der Mei at the Menzies Institute for Medical Research also received a grant to support new work that is crossing the boundaries of social and biomedical research, aiming to identify key risk factors for primary progressive MS and compare these with the known risk factors for relapsing-remitting MS.

MS Research Australia has funded over 170 research projects over the last decade and committed nearly \$24 million to MS projects and collaborative platforms.

For a snapshot of all new research funded this year please turn to page 3 or visit [www.msra.org.au](http://www.msra.org.au) ■





# Relationship and Planned Giving Coordinator

Neil Robertson joined MS Research Australia in 2005 as the Foundation Five Million (F5m) Campaign Coordinator. More recently, Neil has moved into the exciting new role of Relationship and Planned Giving Coordinator.

Neil's dedication to MS research started when he was just 10 years old. His mother was diagnosed with MS and he became her primary carer. At this young age he began to assist his mother with the day to day uncertainties that this mysterious disease brings. However, he wanted to do more to help and this started his life long passion to find a cure for MS. He started fundraising for MS UK by parachute jumping, bike riding and organising a ball in memory of his mother when she passed away in 1992.

Before joining MS Research Australia, Neil gained valuable experience in the printing industry. Although he enjoyed this deadline driven industry, his desire to contribute to the world of MS research was far greater. When the opportunity arose to join the MS Research Australia team in 2005, he jumped at the chance.

Together with the late Ian Ballard, Neil assisted with the formation of F5m, a fundraising initiative which aimed to raise over \$5 million in gross revenue towards MS research. F5m exceeded this goal in 2011 and has now raised much more than originally anticipated.

'I am very proud of what we have achieved with this grass-roots fundraising initiative, raising over \$7.7million. From the launch event at Wynyard Park on 2 November 2005, you could sense that something very special was beginning to take shape. The sense of community and the can do attitude proved to be the major factor in the success of F5m' said Neil.

'The most rewarding experience was the formation of the F5m+ Funds Steering Committee, which consisted entirely of people with MS who had fundraised for MS research. This committee selected approved MS Research Australia projects to direct F5m funding. For people who live with this debilitating disease and who have worked hard to fundraise, being involved in the funding direction is absolutely empowering.'

Neil has now moved into the new role of Relationship and Planned Giving Coordinator, which will include managing MS Research Australia's bequest program as well as regular giving.

Neil said 'having cared for my mother and now with other close family members living with MS, I am passionate about raising funds to ensure the collaborative efforts of researchers across the globe will lead us to a cure. In fact, my career ambition is to be unemployed – when a cure for MS is discovered of course!'

If you are interested in supporting MS Research Australia, please contact Neil directly on 1300 356 467. Together you can establish the best way to develop your involvement and support. ■



Neil Robertson

## A word from our Chief Executive Officer

In this issue of NEXT, we are proud to announce our commitment of \$1.9 million in funding to new Australian MS research projects. This is an increase of over 20% from the 2013/4 figure.

Along with our additional and ongoing funding of existing MS research projects – including our research platforms, major collaborations and our significant commitment to progressive MS research – we are confident that 2015 will be another exceptional year, bringing us one step closer to solving MS.

It is now imperative that we obtain the funding support to fulfil these commitments. On page 7 you will read about the importance of donating and fundraising for MS research. It is your contributions that enable MS Research Australia to fund these high quality MS research projects. We are dedicated to fast-tracking all MS research in Australia to find better treatments, prevention and ultimately a cure.

In this issue you will be able to read about the 22 new MS research projects funded this year, including several project highlights.

In addition, we also asked two of our valuable MS community members to speak about their experiences of being an observer at the recent Research Management Council meeting, where the crucial decisions on who receives our funding are made each year.

Lastly I would like to introduce you to a member of our dedicated team, Neil Robertson, who is our new Relationship and Planned Giving Coordinator. ■

Dr Matthew Miles

## A bequest to MS Research Australia

However large or small, your bequest to MS Research Australia will make a difference. For further information or to request a copy of the information brochure please contact us on **1300 356 467**, [bequest@msra.org.au](mailto:bequest@msra.org.au) or [www.msra.org.au/bequest](http://www.msra.org.au/bequest)





RESEARCH AUSTRALIA

# SNAPSHOT

## PROJECTS STARTED IN 2015 FUNDED BY MS RESEARCH AUSTRALIA

GENETICS & EPIDEMIOLOGY

### IDENTIFYING THE TRIGGERS FOR MS

#### Hunter Medical Research Institute, NSW

Associate Professor Jeanette Lechner-Scott is looking at how the environment affects gene activity in the immune system.

#### Telethon Kids Institute, WA

Professor Robyn Lucas will profile the role of components of the Vitamin D pathway in risk of MS.

#### Westmead Clinical School, University of Sydney, NSW

Dr Sanjay Swaminathan is exploring the mechanisms of how the Epstein-Barr Virus (EBV) may lead to the development of MS.

#### University of Sydney, NSW

Dr Fiona McKay is investigating how MS risk genes may interact with EBV infection to contribute to the development of MS.

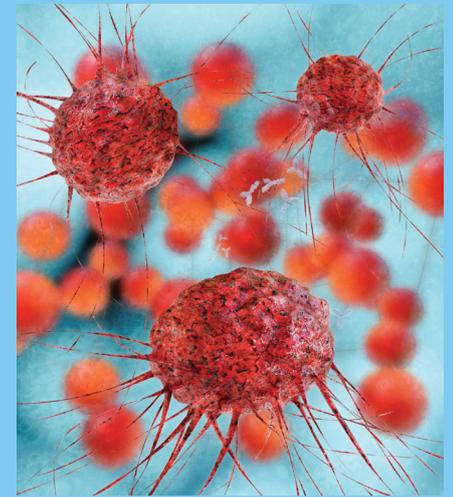
### DEVELOPING BETTER TREATMENTS

#### University of Melbourne, VIC

Dr Melissa Gresle is testing how MS risk genes influence the activity of other known immune system genes.

Associate Professor Helmut Butzkueven will investigate how key genes of interest affect the immune system in MS.

### A CURE FOR MS VIA REPAIR OR REGENERATION OF CELLS



NEUROBIOLOGY

#### Brain and Mind Research Institute, NSW

Dr Cheryl Li will use the MS Research Australia Ian Ballard Travel Award to visit the lab of Professor Jonathan Mill at the Institute of Psychiatry, King's College London, to learn new techniques for analysing DNA in brain tissue.



#### University of Melbourne, VIC

Ms Sanuji Gajamange is testing a new type of brain scanning technique that is very sensitive to identifying neurodegeneration.

#### Baker IDI Heart & Diabetes Institute, VIC

Professor Karlheinz Peter is investigating the role of platelets in MS inflammation and the potential use of platelet imaging for the early detection of MS.

#### University of Melbourne, VIC

Dr Holly Cate will study novel ways to create a more conducive environment for myelin repair in the brain.

Dr Jessica Fletcher is searching for new ways to increase myelin production in MS.

#### University of Adelaide, SA

Ms Jasmine Wilson will investigate ways that tooth stem cells may assist repair in MS.

#### Australian Regenerative Medicine Institute, VIC

Dr Natalie Payne is profiling reprogrammed stem cells to harness the genes that are expressed during development to promote repair.

#### Florey Institute of Neuroscience and Mental Health, VIC

Professor Trevor Kilpatrick is profiling a specific nerve cell receptor to understand its role in encouraging myelin repair.

IMMUNOLOGY & VIROLOGY

#### Institute for Immunology and Infectious Diseases, WA

Dr David Nolan is researching how the EBV interacts with the immune system in MS.

#### University of Sydney, NSW

Mr Sherman Siu is analysing antibodies to identify different subtypes of demyelinating disorders.

#### University of New South Wales, NSW

Mr Paul Wilcox is studying the immune system to understand the mechanisms behind the 'remission' period in relapsing-remitting MS.

#### Kids Research Institute, NSW

Dr Fabienne Brilot-Turville is developing a diagnostic tool for bilateral and relapsing optic neuritis.

#### Telethon Kids Institute, WA

Mr Will Kermode will examine the effects of exposure to UV radiation on the immune system via bone marrow cells in mice.



SOCIAL & APPLIED RESEARCH

#### Menzies Institute for Medical Research, TAS

Associate Professor Ingrid van der Mei is investigating the risk factors for Primary Progressive MS.

#### Menzies Institute for Medical Research, TAS

Professor Andrew Palmer will develop a tool to identify the treatments that are greatest value for money for relapsing-remitting MS.

#### University of Sydney, NSW

Dr Ollie Jay will employ novel techniques to study heat regulation in people with MS during physical activity.

KEY

INCUBATOR GRANT

FELLOWSHIP

SCHOLARSHIP

PROJECT GRANT



Associate Professor Jeannette Lechner-Scott

## Understanding gene-environment interactions in MS risk

**Despite significant advances in treatment options for relapsing-remitting MS, the disease mechanisms remain unclear. MS is known to be autoimmune in nature, but what triggers disease onset is still not completely understood.**

Associate Professor Jeannette Lechner-Scott, from the Hunter Medical Research Institute in Newcastle NSW, was recently awarded a three year project grant from MS Research Australia, to support her work identifying non-genetic risk factors that may be associated with vulnerability to MS.

Over the past ten years, a number of genetic and environmental factors have been associated with an increased risk of developing MS, including over 110 genetic variants, viral infections such as the Epstein-Barr virus, and other environmental factors (such as latitude and exposure to sunlight).

More recent research has been moving towards detailed investigation of the interaction between genes and the environment, known as epigenetics. The term 'epigenetics' describes a variety of external factors that influence the way DNA code is read by cells, without changing the actual DNA sequence. Associate Professor Lechner-Scott's new study aims to examine the role of epigenetics in MS onset.

In an earlier study, her team isolated

immune and blood cells from people with MS and healthy individuals, and looked for differences in one particular type of epigenetic change, called DNA methylation.

DNA methylation refers to the 'bookmarking' of DNA with chemical tags. This process helps to regulate the level of gene activity, by identifying which genes are switched on or off. Researchers can study the levels of DNA methylation and identify differences among individuals. DNA methylation can be modified by a variety of environmental factors, and therefore provides a connection, linking the influence of both genes and environment on health and disease.

Associate Professor Lechner-Scott's research team discovered significant changes in the DNA methylation profiles of people with MS compared to healthy controls, and determined that the majority of these changes were clustered around one key region of DNA, a region which is known to regulate the immune system.

In this new project, the aim is to further study the changes identified in this region and assess what effect these changes might have on various features of MS such as onset, progression, and severity.

This study will be undertaken in collaboration with esteemed genetics

researchers from around Australia. Co-investigators on the project include colleagues Professor Rodney Scott and Dr Rod Lea from the Hunter Medical Research Institute, Associate Professor Helmut Butzkueven from the University of Melbourne, and Professor Bruce Taylor from the Menzies Institute for Medical Research in Tasmania.

This innovative study is one of the first methylation studies in MS. This type of epigenetics represents the next generation of genetic research – studying the non-genetic factors that influence the activity of genes and DNA.

The internationally respected team of researchers working on this study are key members of MS Research Australia's ANZgene consortium which includes geneticists from around Australia and New Zealand. The ANZgene consortium has, since 2007, worked with international colleagues to completely change our understanding of MS.

Associate Professor Lechner-Scott also took part in the recent tenth anniversary celebrations of MS Research Australia, filming a mini-documentary where she discusses the momentous changes in the outlook and prognosis of MS over the past ten years. ■

# Travel award supports genetics research using Brain Bank tissue

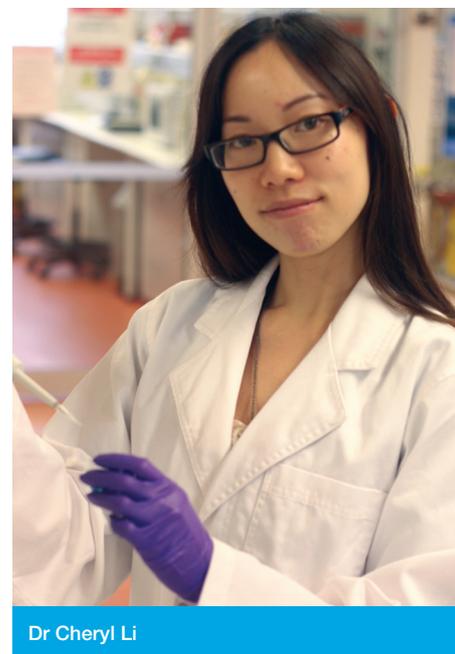
The MS Research Australia Ian Ballard Travel Award has this year been awarded to an early career researcher, Dr Cheryl Li, who will travel overseas to learn techniques for analysing DNA extracted from brain tissue. Dr Li works with Associate Professor Michael Buckland, the co-director of the MS Research Australia Brain Bank, based at the Brain and Mind Research Institute at the University of Sydney.

Dr Li's work involves analysing genes that are active in the brain tissue from people who had MS, in order to understand what may be causing the disease. Using tissue donated to the Brain Bank, Dr Li aims to use specialised analysis techniques to study the genes that are switched on and off in the brains of people with MS and compare this with brain tissue donated by healthy individuals.

Dr Li will travel to the laboratory of Professor Jonathan Mill at the Institute of Psychiatry, King's College London, who is a world-renowned expert in the genetic study of post-mortem tissue samples.

While visiting Professor Mill's lab, Dr Li will undertake extensive DNA profiling of the tissue from 12 people with MS who donated their brains to the UK Brain Bank. Dr Li will study the tissue from a specific region of the brain – the thalamus – which has been shown to be important in MS.

Brain donation is an incredibly valuable gift that people with MS can make, to enable new breakthroughs in medical research. Dr Li's project will help us to understand the genes that may be incorrectly switched on or off in the brain of people with MS, in order to identify what may trigger the disease, and also to identify new targets for the development



Dr Cheryl Li

of innovative new treatments. This work highlights the value of studying human tissue to deepen our understanding of the genetics of MS and how this affects the structure and function of 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. ■

## MS community input into the grants funding process

The awarding of new MS Research Australia grants, this year totalling almost \$1.9 million in funding, is the result of an extensive grant review process undertaken by the MS Research Australia Research Management Council.

The Research Management Council (RMC) is a multi-disciplinary team of fourteen clinicians and researchers with extensive expertise in a range of fields relevant to MS research. The Council is responsible for reviewing grant applications and recommending funding allocations. Applications are also reviewed by at least two international experts and their assessments are taken into account by the Council. A key factor being considered is not only the scientific quality of the project, but the relevance and potential impact of

the research to make a real difference for people with MS.

Also in attendance at the RMC proceedings are two invited observers who attend on behalf of the MS community. These individuals are well informed about both MS and the research process and bring a dedication and passion for furthering Australian MS research efforts.

At the 2014 RMC meeting, the observer roles were filled by key members of the Australian MS research fundraising community.

Carol Langsford OAM, is the co-founder and Chairman of the Trish MS Research Foundation. Carol and Roy Langsford lost their daughter Trish to a severe form of MS, at the age of just 30 years.

Carol says 'I was extremely impressed

the first time I attended a Research Management Council meeting and in fact, the process far exceeded all my expectations. It is really comforting to know that the very thorough and rigorous process ensures only the highest quality research is eligible for funding.'

The second observer in attendance this year was Mike Hemingway. Mike was a founding member of the Foundation 5 Million grassroots fundraising initiative and, along with his wife Katrina, in 2014 organised a team to walk the breadth of the UK and raised over \$220,000 for the Kiss Goodbye to MS campaign.

Mike says 'As a person with MS I feel privileged to be a part of the RMC process and to see the broad range of discussions where every application gets a fair hearing, in order to choose the research projects that will have the best value for people with MS. Leaving the meeting, I always feel incredibly energised and optimistic about the future of MS research in Australia.' ■

# Studying the interaction between gene activity and the Epstein-Barr virus

Dr Sanjay Swaminathan from Westmead Clinical School and the University of Sydney was recently awarded an MS Research Australia Incubator Grant for 2015, to investigate the mechanisms of how the Epstein-Barr virus (EBV) may alter the immune response and contribute to the development of MS, by measuring the levels of micro RNA (miRNA) in immune cells.

In recent years, miRNA has been recognised as an important way that genes are regulated and controlled. Our genes are encoded in DNA, but RNA is essentially a chemical copy of DNA that acts as an intermediate step in the process of 'reading' the DNA code in cells. Most RNA molecules contribute to the building of the proteins that form the components in the cell's machinery. However, miRNAs are small fragments of RNA that play a role in regulating the activity of genes – helping to switch genes on or off.

As well as being produced by cells in the body, miRNA are also known to be produced by viruses such as EBV that have a 'latent' period where the virus lies dormant in the body. In these cases, miRNA can have a significant influence on increasing virus activity.

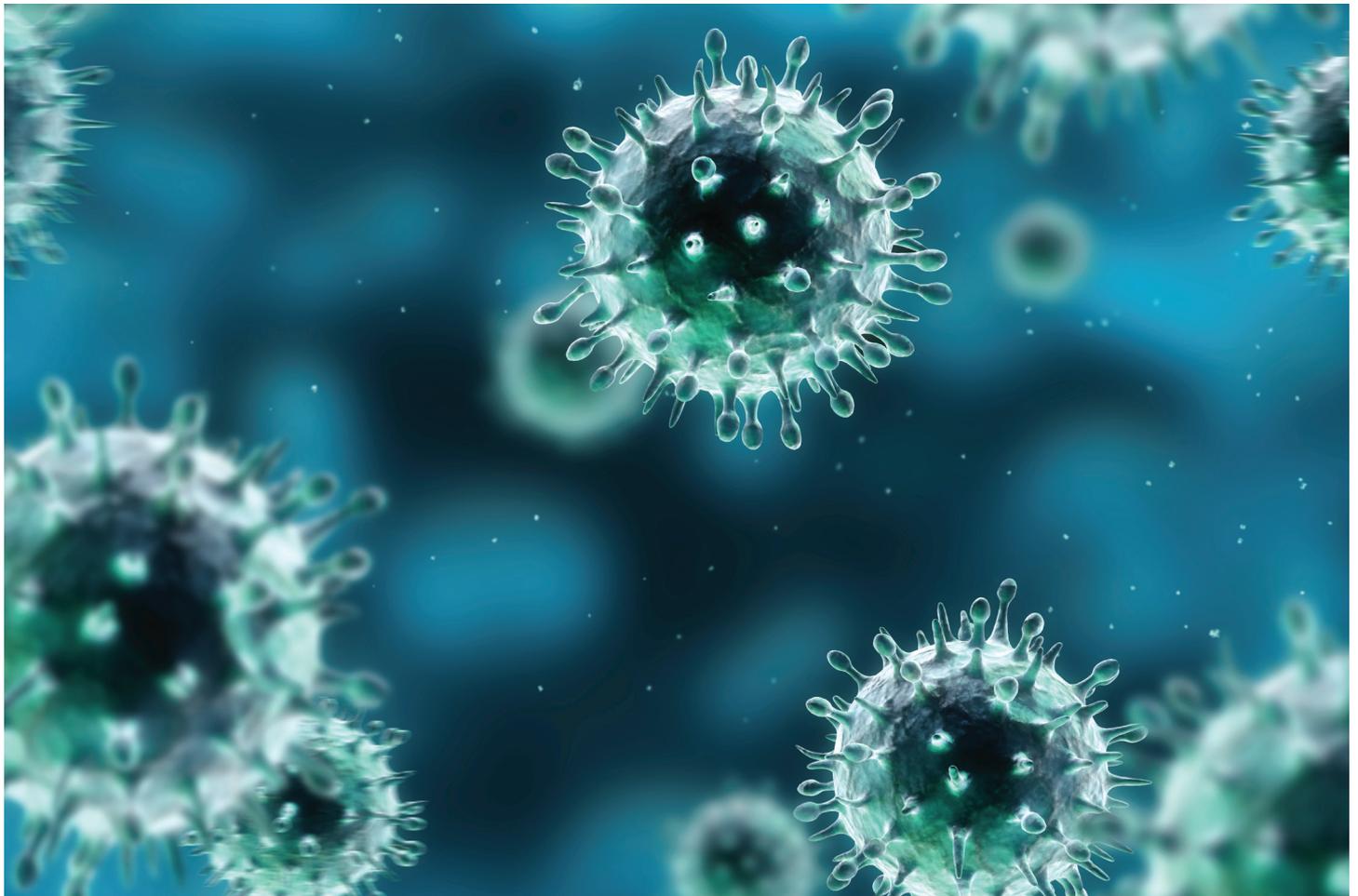
The aim of Dr Swaminathan's project is to measure the miRNA that is derived from EBV in key groups of immune cells, including B cells and T cells. Currently there are 44 miRNA that have been identified as coming from EBV. In this study, each of these 44 miRNA will be compared to see if the levels in the body are different between people with MS and healthy individuals.

Those miRNA fragments that do show differences between the two groups of people will then be studied in further detail using computer-based statistical analysis tools (bioinformatics), to learn more about their function and what role they may play in the relationship between EBV and MS. Further analysis will then aim to manipulate the levels of these miRNA and study the effects on immune cell functioning.

Another study recently published in the *Journal of Molecular Neuroscience*, from Polish researchers, has looked at the possibility that miRNA may be useful as a marker of disease activity in MS, by comparing whether the miRNA levels are different when a person is in remission compared to during an active relapse.

The researchers found that certain miRNA fragments were significantly more likely to be expressed during remission, while other miRNA fragments were correlated with more frequent relapses. These findings support the utility of miRNA as a potential marker that may be useful in practice to detect disease activity and measure treatment outcomes.

Dr Swaminathan's new MS Research Australia-funded project represents a highly novel approach to understanding the mechanisms of how EBV may alter the immune response and contribute to the development of MS. This project could identify new ways of targeting the EBV virus with a view to altering MS disease progression. ■



# How is MS Research Australia funded?

In just over a decade MS Research Australia has grown from a small organisation to the largest national not-for-profit funder of MS research in Australia. We have invested \$23.9 million into Australian MS research endeavours which are making a significant contribution in the worldwide effort to solve MS.

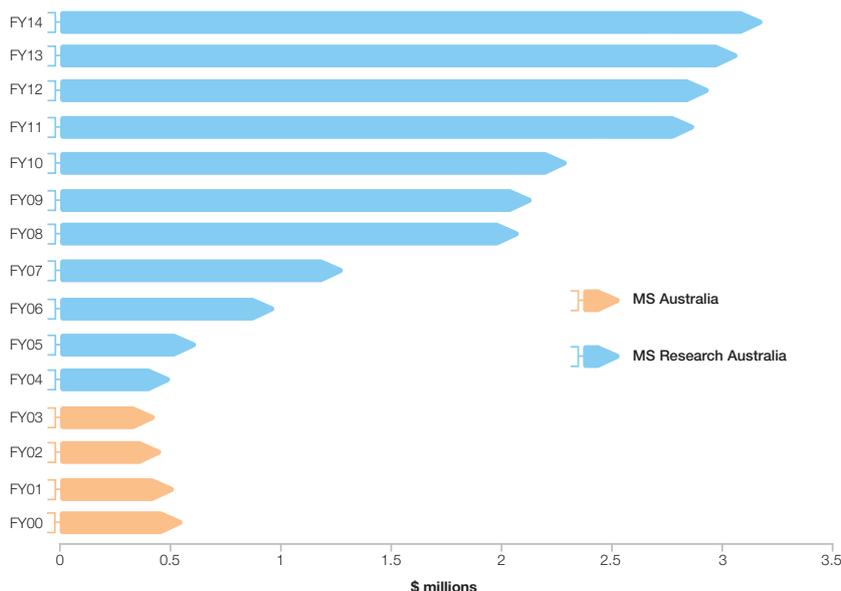
MS Research Australia has directed more than \$15.9 million into individual MS research projects and an additional \$8 million towards longer-term, collaborative research projects known as platforms, such as the Australia and New Zealand wide genetics consortium – ANZgene.

In order to meet our funding commitments, MS Research Australia relies on a diverse range of financial support, ensuring a reliable and long-term income stream to keep the research momentum going. Much has already been achieved in terms of understanding MS and developing better treatments options, but ultimately we want to find a cure and we are dedicated to making sure that happens.

Financial support from individuals and corporate organisations is absolutely vital in funding our research grants, and over the past decade MS Research Australia has received contributions from many generous donors. The pie chart (right) shows all income sources, with fundraising contributing to 47% of total funds raised. The fundraising category includes donations from individuals, corporate organisations, trusts and foundations, the Kiss Goodbye to MS campaign and our previous fundraising campaign Foundation Five Million Plus.

The state MS societies continue to grant vital financial support to MS Research Australia, although their main focus is on providing support services for people living with MS. Bequests are also becoming an emerging source of valuable funds. Grants are sought from both federal and state Government as well as pharmaceutical companies and these help to cover our operational expenses as well as a portion of some of our large, multi-year, MS research platforms.

All income sources are vital to ensure MS Research Australia can continue to increase funding to support the best MS research in Australia.



Above: Growth of investment into MS research, 2000-2014 financial years

Below: How MS Research Australia is funded: income sources 2005-2014



One of the key trends in philanthropy over the past decade has been for major donors to request reports on the impact of their donation in terms of research outcomes. Not-for-profit organisations are also expected to provide significant detail around the efficiency of their operations (such as the ratio of operational costs to funds raised). In order to meet these donor expectations, MS Research Australia aims to ensure transparency in all our operations and funding. Full financial information is available via the MS Research Australia website, as are details on all our funded research projects. Each of the currently funded project pages is updated with an annual progress update. In addition to the updates on the website and via our various newsletters, MS Research Australia provides an impact report to those donors who provide major grants to specific projects. These impact reports detail exactly what has been achieved with their donation, both

in terms of research discovery and the impact it will have for people with MS.

There are many ways to support and contribute to MS Research Australia from fundraising to making a donation, regular giving or leaving a bequest. The team are always happy to work with you to establish the most appropriate way for you to get involved.

One method of support is the Kiss Goodbye to MS campaign coming up in the month of May, which calls on you to 'wear, dare and share' to raise vital funds for MS research. For more details on how you can get involved, visit [www.kissgoodbyetoms.org](http://www.kissgoodbyetoms.org). The Kiss Goodbye to MS campaign has recently been recognised as a national finalist in the Fundraising Institute of Australia (FIA) National Awards for Excellence. If you are interested in discussing a specific area of MS research to direct a personal contribution, please contact our team on 1300 356 467. ■



Above: Megan after the Ocean Swim with the crew from Umina Surf Life Saving Club; Above right: Megan and Brian Healey with the Hon. Bronwyn Bishop

## Megan is Kissing Goodbye to MS

Megan Healey is one of the 23,000 Australians living with MS. Although Megan is wheelchair-bound with a progressive form of MS, she doesn't want to be defined by her disability. Since 2013, Megan has been committed to championing MS awareness and raising funds for MS research – and this year is no exception.

Megan is completing her own Bucket List as her fundraising idea for the Kiss Goodbye to MS campaign 2015. Already she has completed several items from the list. In January, the Umina Surf Lifesaving Club rallied around Megan to help her complete a 3km ocean swim from Palm Beach to Whale Beach in Sydney, by towing her through the surf on a jet ski mat. In addition, Megan has

already ticked jet skiing and flying in an ultralight plane off her list.

'Although research is starting to be geared towards progressive MS, a cure could be years away and my decline is so rapid that my young family and I may not have the time to wait. I want to challenge myself to do some fun things before it is too late and also promote MS research to make it better for others,' Megan says.

In 2013, Megan drove her ride-on lawnmower from Melbourne to Sydney (M to S) as part of the Kiss Goodbye to MS campaign and raised over \$50,000. Her determination and drive don't let the progression of her MS hold her back and this is what inspires so many to join her in fundraising for MS research through Kiss Goodbye to MS.

Now is the time to join like-minded people to fundraise in May for MS research. To get started:

1. Register as a fundraiser online at [www.kissgoodbyetoMS.org](http://www.kissgoodbyetoMS.org)
2. Add details about how you would like to fundraise: for example, wear red lipstick for a day in May; hold an office morning tea or fundraising dinner; participate in a challenge and ask others to sponsor you. Whatever you would like to do, do it for MS research.
3. Update your fundraising page with a photo and details about why you are fundraising for MS research.

For more information, please visit [www.kissgoodbyetoMS.org](http://www.kissgoodbyetoMS.org) or email [kgtms@msra.org.au](mailto:kgtms@msra.org.au) ■

## 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:

**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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