



NEXT



THE OFFICIAL NEWSLETTER OF MULTIPLE SCLEROSIS RESEARCH AUSTRALIA

Identifying the MS research priorities – have your say

MS research covers a range of fields, encompassing immunology, neurobiology, genetics and epidemiology as well as stretching across clinical and allied health disciplines. Research into MS aims to address both treatment of the disease and the management of its many symptoms.

Each year, MS Research Australia is only able to fund a portion of the many worthy research projects presented. It is, therefore, crucial that we focus our efforts and our donors' funds not only on the strongest research projects and the most capable researchers, but also on those projects that are viewed as a priorities within the MS community.

In conjunction with the Board of Directors and a panel of expert research advisors, MS Research Australia has developed a targeted research strategy and a robust governance process. You can read more about our research strategy and governance process on our website.

Our approach has been to support Australia's strengths within the context of the global MS research effort, build the Australian MS research network and tackle a number of broad research goals. These include research into how to better diagnose and treat MS (including managing symptoms and promoting rehabilitation), to predict and prevent MS and to develop strategies to promote cell repair and regeneration.

MS Research Australia invites applications from individual research teams, as well as supporting major 'platform' projects in which a national collaborative effort can provide the

impetus and power to make discoveries not possible for individual research teams working alone. As our recent Research Audit Report showed, significant progress has been made against these goals since our inception, but there is still a great deal of work to be done.

As part of the MS Research Australia strategic plan and research strategy, feedback and consultation is being sought to understand which of the many different areas of MS research are considered important by people directly and indirectly affected by MS, as well as health professionals and researchers.

MS Research Australia is laser focused on being mission driven and putting people with MS at the epicentre of its activities. This project is just one of the initiatives in our umbrella strategy of "listening to people with MS".

This research priorities survey has been prepared using tried and tested methods

aligned with successful surveys used by the Multiple Sclerosis Society UK (MS UK) in addition to extensive consultation with people with MS, MS Australia, international MS organisations, the MS Research Australia Board and the MS state societies.

It is a priority for MS Research Australia to incorporate the views of the Australian MS community to guide our research strategy into the future.

MS Research Australia is inviting Australians with MS, their friends, family and carers, doctors, MS staff, nurses and researchers to join in the discussion about the priorities in MS research by participating in this survey.

To take part in the online survey please go to www.surveymonkey.com/r/MSResearchAustralia. The survey will remain open until 30 June 2016. Your opinion will help the future of MS research ■





A word from our Chief Executive Officer

In this issue of NEXT, we seek your feedback via an evidenced based survey that will be distributed widely to our stakeholders. The survey is designed to help inform our future MS research priorities. We would like to understand which of the many different areas of MS research are considered important by people directly and indirectly affected by MS. The article on page 1 provides the online survey link and details on the importance of this survey. We encourage you to participate and help guide our research strategy into the future.

“Red Lab Coat Day” successfully launched this year’s Kiss Goodbye to MS campaign. It was a unique opportunity for our key MS researchers to not only actively participate in the awareness raising of Kiss Goodbye to MS but also to promote the importance of ongoing funding into MS research. It is also a day when the MS community can connect with the researchers via social media and post messages of appreciation and encouragement. Thank you to everyone who got involved and helped to make the launch of Kiss Goodbye to MS 2016 so successful.

One of the two great trends in the NFP sector nationally and globally is the ever-present rise of the digital age. This is particularly evident in fundraising, which is easily facilitated on your mobile device, and an important mechanism to receive trusted information, updates and to become involved. The other trend is the increasingly strong call for enhanced NFP transparency. We have tried to address both points in this issue with further information on how MS Research Australia is building digital media in to everything it does, but also some relevant information on our facts, figures and costs. Once completed, our new website will be the one-stop shop interface for all of this information and for showing the impacts that we have had. ■ **Dr Matthew Miles**

New board members

MS Research Australia is pleased to announce the appointment of two new members to the Board of Directors, Dr Annette Carruthers and Mr David Simmonds.

Following the direction of the Australian Institute of Company Directors “best practice principles for good not-for-profit governance”, the MS Research Australia Board has been undergoing a skills and diversity based refresh to ensure we have the best team possible representing the national MS research organisation and guiding the strategic direction. Additional board announcements will be made within the next few months.

Medically trained as a general practitioner, Dr Carruthers has comprehensive experience in patient care, clinical risk management and quality improvement in health services. She is an experienced non-executive director on a number of significant boards including organisations within financial services, health, infrastructure and aged care.

In particular she holds board appointments on the ASX-listed NIB Holdings, Catercare Pty Ltd and the Hunter Infrastructure and Investment Advisory Board. Annette has a special interest in risk management and is the Chair

of the NIB Risk and Reputation Committee. She is a member of the NSW Medical Experts Committee Avant Pty Ltd, conjoint senior lecturer in the School of Medicine and Public Health at the University of Newcastle and was most recently appointed as the Vice President of the MS Australia Board.

David Simmonds is a Chartered Accountant and has over 30 years of professional audit experience in a number of sectors including media, technology, property, funds management and not-for-profit.

David is currently an Audit Partner and Professional Practice Director for the global giant Ernst & Young, with responsibility for quality oversight of technical audit matters. He is also a member of their Accounting and Auditing Policy Committee which advises on the regulatory environment.

‘Their strong interest in MS research, their experience and capabilities will be a real benefit to developing and strengthening the strategic direction of MS Research Australia. We warmly welcome both Annette and David to the Board and I look forward to the positive contributions they will make,’ said Mr Paul Murnane, Chairman, MS Research Australia. ■



Dr Annette Carruthers.



Mr David Simmonds.



Researchers join in the fun with Red Lab Coat Day



Red Lab Coat Day shines a light on the faces behind some of Australia's leading research efforts into MS. There are currently over 850 researchers and clinicians based at more than 54 universities and research institutes focused on MS, who are all committed to making MS Research Australia's vision of freedom from MS, one step closer to a reality.

Red Lab Coat Day is a unique opportunity for our Australian MS researchers to join in the fun that is Kiss Goodbye to MS. On April 29, 160 researchers from all around Australia ceremoniously threw away their traditional white lab coats in favour of red Kiss Goodbye to MS coats. Digital media was flooded with pictures of MS researchers in their Red Lab Coats, promoting awareness for the importance of accelerating MS research. You can follow the team photos by searching the hashtag #RedLabCoatDay on twitter.

Red Lab Coat Day is a celebration

of ongoing research into MS, and the incredible progress that has been made over the last decade. The day is a fantastic opportunity to profile the need for ongoing funding into research, to which Kiss Goodbye to MS is crucial. There was significant media interest in Red Lab Coat Day this year, including an article in The Courier Mail and the Canberra Times, which outlined the urgent work that these researchers are undertaking, as well as the need for continued funding. Despite extensive and ongoing research into MS there remains no cures for this disease which affects 23,000 Australians.

Each year our Kiss Goodbye to MS team is inundated with messages and support directed to the MS researchers in Australia and around the world who dedicate their careers to better understanding MS. To connect our Australian MS researchers with the Kiss Goodbye to MS community we created Red Lab Coat Day.

On Red Lab Coat Day the Kiss Goodbye to MS community were encouraged to

repost the Red Lab Coat Day images from our research teams with their message of appreciation. The result was an incredible display of gratitude, and humbling for the researchers to be recognised in this way.

Dr Matthew Miles, Chief Executive Officer of MS Research Australia said, 'We are well positioned to make even more breakthroughs in this disease. We are absolutely committed to making MS manageable for everyone in our lifetime and finding ways to reverse the damage done. We can't do this without all of the research teams around Australia.'

'The only real part missing is the funding. There is a desperate need to give our best MS researchers all the tools they need to make that vision become a reality. Kiss Goodbye to MS is crucial to this,' Dr Miles said.

Red Lab Coat Day is a celebration of commitment and dedication. Commitment from researchers around the world to solving MS, and dedication from the Kiss Goodbye to MS community who work tirelessly to raise funds for research into MS. Both parties are key to the advancement of MS research and Red Lab Coat Day places emphasis on the area where it is desperately needed. ■

Increasing transparency in the NFP sector

An overview of revenue, expenditure, achievements and challenges

Over the last decade MS Research Australia has been dedicated to increasing the amount of funding to support the best MS research in Australia to achieve the mission of finding better treatments, the cause and cures for MS. Since inception MS Research Australia is proud to have invested more than \$16 million into investigator led research projects and \$10.2 million into longer term, collaborative research projects which we call research platforms. This is a total of over \$26 million.

The average yearly contribution to MS research has increased from \$450,000 per annum in 2000 to \$3.3 million in 2015. MS Research Australia remains the largest non-government funder of research into MS, and in 2015 the organisation allocated a larger financial contribution to MS research than the federal government. Approximately \$4 million in research funding is budgeted for in the financial year (FY) 2016 – a significant 21% increase in research spending from the previous year despite a challenging funding environment.

In order to ensure that MS Research Australia can continue to commit to this level of funding, there is a strong reliance on a diverse range of financial support. 75% of the total annual funding received comes from direct fundraising relationships with individuals, trusts and

foundations, corporate organisations and some support from government. Whilst 25% of our revenue is from state MS societies.

Whilst government, corporate and pharmaceutical support has remained constant, there has been a drop in state society support of MS research as a percentage of the total income. There is also a drop in bequest income from the previous decade which often is a highly variable source of funding.

In FY2015, MS Research Australia allocated 74% of the total expenditure directly to funding MS research. Of this, 27% was for investigator-led projects recommended by the MS Research Australia Research Management Council, 24% on major collaborative research projects (including the Vitamin D Prevention Trial, the MS Research Australia Brain Bank and ANZgene), 18% on Fellowships or Scholarships which support the best MS researchers and 6% on MS research operational costs to support the facilitation of our national and global research initiatives. The small MS Research Australia research team coordinate, facilitate and provide secretariat support for eight national collaborative research platforms as well as all of the investigator-led research grants. MS Research Australia is currently funding a staggering 46 ongoing investigator-led MS research projects.

The MS Research Australia Research Management Council (RMC) consists of leading MS experts who review all grant applications and recommend funding allocations to the Board. The RMC follows a robust research governance process, which is one of the most well-thought of in the industry and unashamedly copied by similar medical not-for-profit (NFP) organisations.

MS Research Australia is only one of twelve national NFPs in the medical research sector to be deemed a Category 1 funder of medical research, and the only one that funds MS research. The advantage of Category 1 funding is the leverage opportunities it provides to researchers, particularly when seeking further funding from other sources of competitive funding. It also helps to keep our best MS researchers in the country and not lose them to larger overseas institutions.

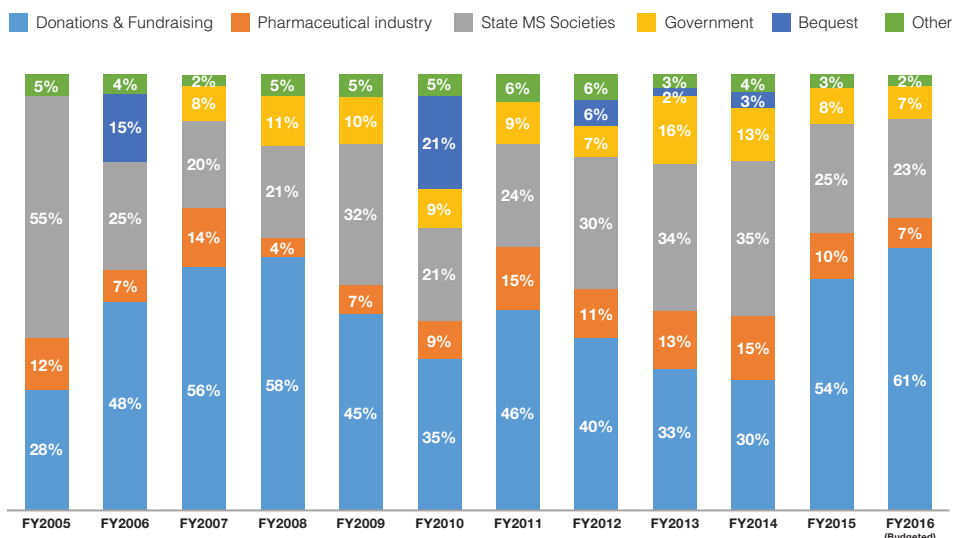
The other main sources of competitive Category 1 funding for MS research is the National Health and Medical Research Council (NHMRC) and the Australian Research Council (ARC), although with its broader remit, historically the ARC has been a less frequent funder of MS research.

The graph on the right illustrates the growth in total funding for MS research over the last 15 years provided by MS Research Australia (including the MS Australia contribution over 2002-2004), the NHMRC and other external funding bodies. MS Research Australia's funding has consistently increased over this time, with the NHMRC remaining relatively constant with the exception of 2012 and 2014. In 2016 MS Research Australia is set to fund more MS research than the NHMRC.

In 2015, the American MS Society (NMSS) provided over \$50 million to MS research, which is well over 20% of their total revenue. They have a plan in place to increase this even further over the next 5 years. The Canadian MS Society has just mandated that 60% of the entire expenditure of the national organisation must be spent on MS research whilst 40% will be spent on services for people with MS.

INCOME SOURCES 2005-2016

SOURCE: AUDITED MS RESEARCH AUSTRALIA FINANCIAL ACCOUNTS



In FY2015, the total revenue collected from all MS organisations in Australia, (the state societies, MSA and MS Research Australia) was \$106.9 million, from this amount \$3.8 million (or 3.5%) goes directly to fund the best research or facilitate the coordination of research in to MS whilst approximately \$56.1 million (or 52%) goes to MS services and the support costs associated with providing those services.

The MS landscape has been comprehensively and irreversibly transformed by the progress in research and therapeutics. Over the last 15 years, people are being diagnosed earlier and quicker, and disability milestones are being reached almost 8 years later on average. A Canadian study found that hospitalisations due to MS in 2011 had declined by over 75% compared to the 1984 figure.

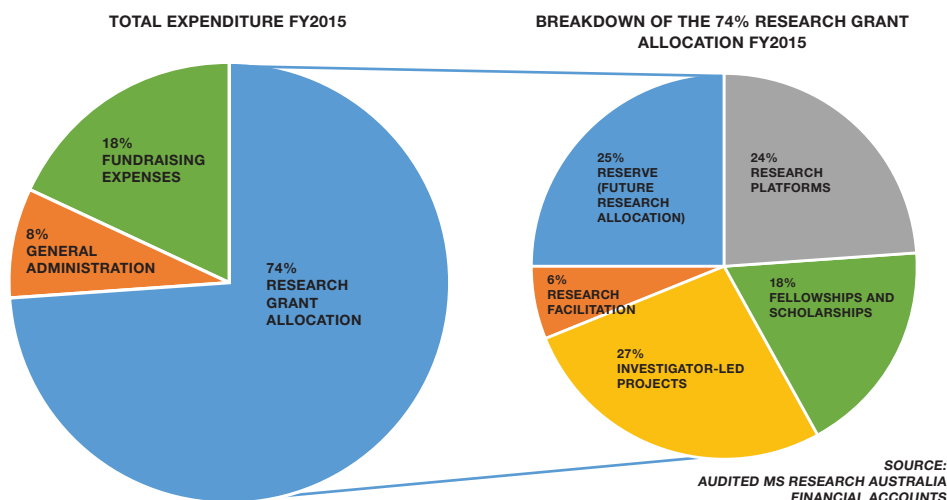
The number of treatment options for relapsing MS has increased five-fold with more on the way.

However, more research is desperately needed, particularly into the progressive forms of MS. To this end MS Research Australia has committed to support the International Progressive MS Alliance which is leading an aggressive global push to advance treatment options for progressive MS. More research is also needed to improve disease management, to reverse damage and to prevent MS. We now need, more than ever, to double the research efforts to ensure that the momentum that has been built up over the last decade is not lost.

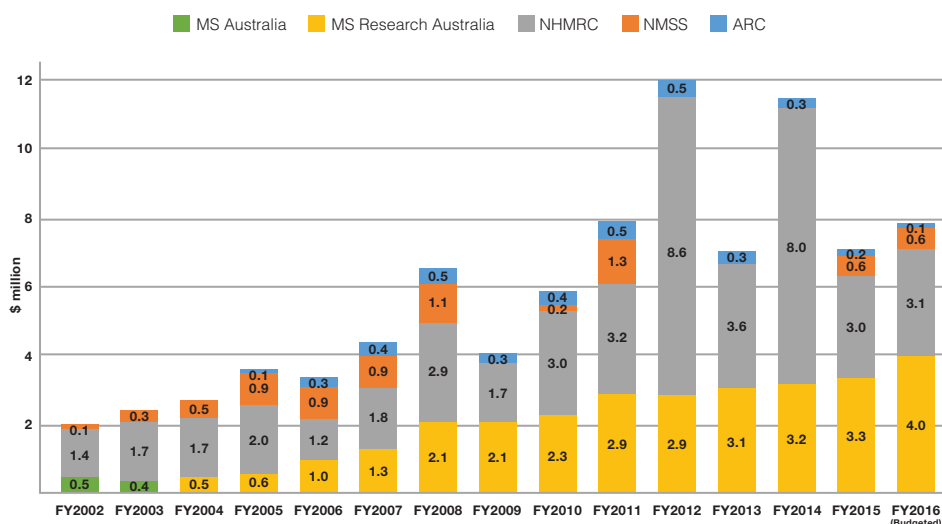
As a direct result of MS Research Australia funding, there have been many significant research outcomes including new methods developed for both biomedical and applied research and for clinical assessment, novel research tools, new infrastructure and new avenues for translation into practice. Australia has contributed to a number of exciting research breakthroughs in MS. This includes the role of environmental factors in MS, further evidence of the way Epstein Barr Virus is involved in MS, the identification of 110 genes associated with the susceptibility to MS and new ways to control the immune system.

What is evident from the data is that the funding of MS research in this country has significantly improved since MS Research Australia was inaugurated in

EXPENDITURE BREAKDOWN 2015



NATIONAL SPENDING ON MS RESEARCH BY MS RESEARCH AUSTRALIA, NHMRC AND OTHER EXTERNAL BODIES (2002-2016)



2004. The vast majority of the funding for MS Research Australia activities has come from our own fundraising and supporter network. Since 2010, MS WA has been the largest contributor to MS research amongst the MS state societies. MS Research Australia, via its research funding, has had significant impacts on the lives of people with MS in Australia and worldwide.

Unfortunately, we anticipate that funding for MS research in Australia over the next three years will be greatly challenged by:

- A likely trend of a plateauing in NHMRC funding for MS research in Australia according to valued sources and data.
- The static nature of funding from other federal and state government sources of revenue.
- The Medical Research Future Fund (MRFF) is now more of a longer term proposition and the quantum of funds that will be invested in medical research

is markedly reduced from what was first proposed.

- An increased reliance on MS Research Australia for funding from Australian researchers which will create an increasing need to spread the net further with individual donors, major donors, PAFs, trusts and foundations, bequests and campaign fundraising. The increasing need for further advancements in therapeutic options, especially for progressive MS, will require a doubling of the research effort. We greatly risk losing our best MS researchers in Australia if they cannot find adequate funding for their research.

In order to continue with the level of funding commitment, and keep the Australian MS research momentum on its trajectory, much more financial support is needed. A lot has already been achieved in understanding MS but there remains a lot more to do. ■

Good vibrations – can they improve balance in MS?

MS Research Australia is currently funding several clinical trials that are testing interventions to better manage some of the symptoms of MS. These include a number of approaches to improve mobility and reduce the risk of falls for people with MS. Other studies are assessing psychological interventions for depression and anxiety, and new approaches to exercising for people with higher levels of disability or heat sensitivity.

In the latest round of MS Research Australia grants, Dr David Kennedy was awarded an Incubator Grant to investigate whether exercises combined with whole-body vibration can improve mobility and balance and reduce falls in people with MS.

Whole-body vibration is thought to increase the amount of sensory information that gets delivered to the nerves in the spinal cord to help the nerves better control muscle activity and movement. While previous studies have investigated the effects of whole body vibration for mobility in MS, most have been too small to provide

clear evidence of whether whole-body vibration is more effective than standard exercise.

Dr Kennedy will test whether a home-based exercise regime combined with whole-body vibration is more effective to improve mobility outcomes and reduce falls in people with MS compared to the same exercise regime without whole-body vibration.

Given that about 60% of people with MS will suffer at least one fall per year and more than 30% will suffer three or more falls within a twelve month period, this study will address a feature of MS that can significantly affect both safety and quality of life.

Dr Kennedy aims to recruit 104 people with MS to perform exercises over a twelve week period. This study is unique in that it has a home-based setting, which will have greater 'real-life' relevance for people with MS.

Dr Kennedy's study is currently recruiting in Sydney. Other symptom management studies, including a trial to treat ankle contractures (stiff ankles) are also recruiting in Sydney, Melbourne and Brisbane.



These studies provide participants with the opportunity to access innovative approaches to symptom management as well as contributing to the development of new treatments that may benefit the wider MS community. To learn more about these studies and other clinical trials visit www.msresearch.org.au ■

Determined to make a difference



Tanja Edwards joined MS Research Australia in early 2015 and has quickly become an integral team member. Whilst initially employed as the Database Administrator, Tanja has demonstrated her versatility and now also assists with financial administration and event management.

Tanja graduated in 2014 with a Bachelor of Commerce from Macquarie University, majoring in International Business. Prior to joining MS Research Australia, Tanja gained significant experience volunteering in a number of charities whilst also working in the hospitality industry as a conference coordinator.

Whilst volunteering, Tanja quickly realised her passion and dedication to help others and then targeted her career towards the not-for-profit sector.

Tanja said 'For me, when I wake up in the morning I am excited to go to

work and I think that's quite rare. I really enjoy my role at MS Research Australia as it enables me to use my strong organisational and communication skills to help make a difference for people with MS. The MS Research Australia team is small but everyone is hands on and willing to help one another. We have a positive organisational culture and that is very important to me.'

With her event management experience Tanja was well placed to run this year's Red Affair dinner. 'I was really excited to be able to help organise this event. This is a big event in the Kiss Goodbye to MS calendar, raising over \$55,000. This is the 5th year this event has been held and I was thrilled to have been a part of it. I am very proud of the work that MS Research Australia does for people living with MS and I am delighted to be using my skills to help make a difference.' ■



Associate Professor Michael Buckland, Co Director and Dr Antony Harding, Manager, MS Research Australia Brain Bank.

Tissue from MS Brain Bank put to good use

The MS Research Australia Brain Bank has been operating for over eight years across Australia, and has built up a large collection of tissue specifically for use in MS research. Experts in MS identify and classify MS brain lesions in the donated tissue at different disease stages.

This carefully classified tissue is then made available for researchers around the world to use to answer research questions about the biology of MS that cannot be resolved in any other way.

An independent MS Research Australia Brain Bank Scientific Advisory Committee review requests to use the tissue in research projects to ensure the proposed use is ethical and scientifically sound.

Tissue from the MS Research Australia Brain Bank is being used in a number of projects both in Australia and overseas looking at different aspects of MS pathology and cover a wide range of research areas. Topics include the identification of factors in the brain which promote nerve regeneration and investigation of the cells involved in encouraging myelin repair, to determine why these processes fail in later MS. Other projects are looking at how damage is wrought differently in progressive MS compared to relapsing remitting MS, and the role of genetics in progressive forms of disease. Research projects are also studying the interactions between genetic and environmental factors that could underpin MS onset and progression and looking for corresponding biomarkers to develop safe and simple tests for use in the clinic.

This work would not be possible without the support of people with MS and their families. To find out more about the MS Research Australia Brain Bank, phone 1300 672 265 or visit www.msbrainbank.org.au ■

Lifestyle factors influence on disease course and disability

Dr Steve Simpson Jnr, from the Menzies Institute for Medical Research, has recently concluded his three year MS Research Australia Fellowship, with valued funding support from MS WA, looking at the role that lifestyle factors play in an individual's disease course and disability. Using information collected from large groups of people with MS in Australia who have been followed over a number of years Dr Simpson has teased out a number of important factors which are related to disease course in MS.

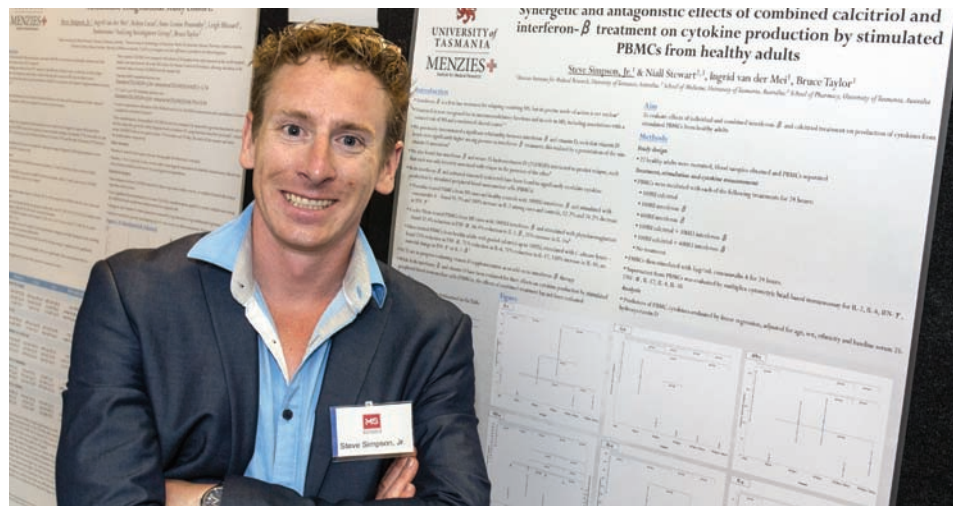
Working with his collaborators, Dr Simpson looked at the role of lipids in MS and identified that higher body mass index (or BMI) was associated with greater disability and disability progression but not with relapses in established MS. Dr Simpson also examined the rates of anxiety and depression in early and established MS, investigating the role of stress and quality of life in MS. He showed that anxiety and depression were higher in people at early stages of the disease and that these rates were similar to those in established MS.

Dr Simpson showed that the effects of sunlight and vitamin D depend on an individual's genetics and that vitamin D levels can be predicted by latitude and higher sun exposure in early MS. However this association drops off as disease progresses, suggesting that living with MS also has an effect on sun exposure behaviours in some individuals.

Dr Simpson's genetic research focussed on the different role of genes in predicting

relapses compared with disabilities.

Dr Simpson achieved a great deal in his fellowship, publishing an outstanding 21 papers with many more underway. This research will help inform the clinical care of people with MS and enable further research into the role of lifestyle factors in MS. Dr Simpson also supervised a number of postgraduate students during the course of his fellowship, further building the capacity for MS research in Australia. Dr Simpson will now continue to use these large MS cohorts to investigate the many lifestyle factors that influence MS in individuals. ■



Dr Steve Simpson Jnr, Menzies Institute for Medical Research.



Dr Fiona McKay, Westmead Institute for Medical Research.

Researchers identify genetic tag for treatment response

MS Research Australia's Incubator grants provide short-term funding for new and innovative ideas in MS research. They gather pilot data to support larger research projects in the future. Dr Fiona McKay, from the Westmead Institute for Medical Research, received an incubator grant from MS Research Australia in 2015, with generous funding support from the Trish MS Research Foundation, to undertake a genetic study that hopes to confirm a potential biomarker for treatment response in people with MS.

Dr McKay's research focussed on four genes which play a role in immune cells involved in responding to infection by Epstein-Barr Virus (EBV), an established

environmental risk factor for MS. Dr McKay has recently published her findings on two of these genes, known as EOMES and TBX21 in the scientific journal *Clinical Immunology*.

EOMES and TBX21 are genes which control the activity of many other genes and they have far reaching effects. Dr McKay's team confirmed that these genes have lower activity levels in the blood of people with MS in comparison to people who do not have MS. The researchers termed this the ET profile.

The genes are predominately active in specific immune cells in the blood and Dr McKay carried out an analysis of the related protein levels in immune cells taken from people with MS and showed

that the ET profile has a functional effect on the immune cells.

Using blood samples taken from the same individuals six months apart, the researchers also showed that the ET profile is stable over time and therefore may provide a useful biomarker for MS.

Interestingly, the researchers demonstrated that the ET profile changed according to treatment. While there were considerable differences between individuals on any particular treatment, the most consistent findings were for those people on Natalizumab (Tysabri). In this group, the ET profile was greatly increased compared to people with MS who were not on treatment and their ET profile looked more like the profile seen in healthy people. This suggests that the ET profile may be a useful test to show in real-time whether an individual is responding to a treatment rather than waiting over a longer period to see whether further relapses or MRI lesions emerge.

Further work is now needed to determine whether changes in the ET profile in the same individuals over time, for example before, during or immediately after treatment with an MS therapy, may be useful as a clinical biomarker to predict a person's response to MS therapies.

MS Research Australia's analysis showed that, on average, recipients of incubator grants have been able to leverage the initial grant funding amount by a staggering 27 times with other sources of competitive research funding. With the level of funding available for MS research incredibly challenged, this is a good example of our funding being put to hard work. ■

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
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- ☐ Cheque (made payable to MS Research Australia)
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Account number:

Account holder's name:

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Mastercard ☐ Visa ☐ Amex ☐

Credit card number:

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