



15
year
anniversary

MS WIRE

THE OFFICIAL NEWSLETTER OF MULTIPLE SCLEROSIS RESEARCH AUSTRALIA

Innovative ways to use MRI



In January, MS Research Australia announced the successful grant recipients for 2019, totalling over \$1.75 million in new funding.

The new grants cover a range of topics from fundamental laboratory research to new interventions to help people with MS manage their symptoms. Magnetic resonance imaging (MRI) plays a crucial role in the diagnosis and treatment of MS and four of the 20 new grants have focussed on innovative ways to use MRI to better understand MS, rather than simply as a clinical tool.

Dr Chenyu Wang and Dr Justin Garber, both from the University of Sydney will be working to deploy MRI analysis in new ways to track the progression and severity of MS.

Dr Chenyu Wang, an engineer with a PhD in imaging and signal processing, will be undertaking a Postdoctoral Fellowship into the use of MRI as a way to monitor silent disease progression in people with MS – that is disease activity that does not lead to immediate symptom changes but may contribute to the ultimate burden of the disease in the brain. Dr Wang will develop an MRI platform to track changes over time and across different brain regions to measure how an individual's disease is progressing and responding to treatment. This fellowship is a great example of capturing researchers from diverse fields and getting them to use their knowledge in new ways to help solve MS.

Dr Justin Garber's Postgraduate Scholarship, with thanks to funding support from the Trish MS Research Foundation, will allow him to investigate what drives brain cell loss in people with progressive MS. Dr Garber is a consultant neurologist working with people with MS as

well as contributing to research into MS. He will explore ways to track nerve cell changes using MRI and create a map of connections within the brains of people with progressive MS. It is hoped this technique will provide a simple way to measure progressive disease activity for use in clinical trials and in clinical practice to determine if a treatment is working within a shorter timeframe.

Dr Saadallah Ramadan is a magnetic resonance physicist and biochemist who has worked for many years overseas leading the development of new techniques in MRI. Now at the University of Newcastle, he will use his MS Research Australia Incubator Grant to develop MRI techniques to track changes associated with fatigue in MS. Fatigue is one of the most commonly reported symptoms, occurring in over 80% of people with progressive MS. Effective ways to manage fatigue is a huge unmet need and Dr Ramadan's work will form part of a pioneering clinical trial that will be looking at whether supplements which boost cellular energy production can combat fatigue and depression in MS.

Finally, one of our Ian Ballard Travel Awards this year has gone to **Dr Ai-Lan Nguyen**, from the University of Melbourne, who will visit colleagues at the University of Genoa in Italy to collaborate on techniques to improve the use of MRI. Dr Nguyen, who is a practicing MS neurologist, aims to develop a consistent way of analysing MRI so that the data can be pooled and analysed in large international studies effectively irrespective of where in the world the images were taken. This will be a great benefit for the use of MRI in clinical trials with sites in different locations around the world, as well as directly improving the information obtained from individual MRI scans to support the care of people with MS in the clinic.

All four researchers we are funding are targeting progressive MS and have in common the use of specialised MRI and image analysis to better understand MS progression and track symptoms.



Dedicated to accelerating MS research for over 15 years

2019 is an important milestone for MS Research Australia as we celebrate 15 years of significantly changing the MS landscape in Australia and dedication to our critical mission of accelerating and coordinating MS research.

In our short 15-year history we have become the largest not-for-profit funder of MS research in Australia, with over \$44.3 million invested in funding and facilitating vital research and 274 research grants awarded, overseen by an independent Research Management Council. Our competitive category 1 funding processes provide a prestigious funding source which our MS researchers can more easily leverage with other sources of funding. This often increases our initial investment in research five-fold!

We are also proud to manage and coordinate a large number of major collaborations and research programs including the MS Clinical Trials Network,

the Australian MS Longitudinal Study, ANZgene and the MS Research Australia Brain Bank. Such collaborations are futile without innovation and we are delighted to have attracted talented researchers to the MS field by providing seed funding to allow researchers to prove a principle in their research and launch a promising new line of investigation.

The milestones achieved include the development of 7 new clinical tests, 5 patents and 26 new research methods to name just a few. The research investment growth is noteworthy as we all know that research is the only hope for a cure. To attain that goal takes both time and vital funds.

Our beginnings were quite humble. By 2002, the MS state societies' annual research funding allocation had nearly halved to \$444,000 per annum in total. This was due to a focus on and the pressures of maintaining client services. Those research funds that were being provided annually were being spread too thinly over an increasing number of projects and in a largely uncoordinated way, to have a major impact on MS research in Australia. There was an urgent need to recommit to MS research funding through a new business model and with this impetus, MS Research Australia was formed in 2004.

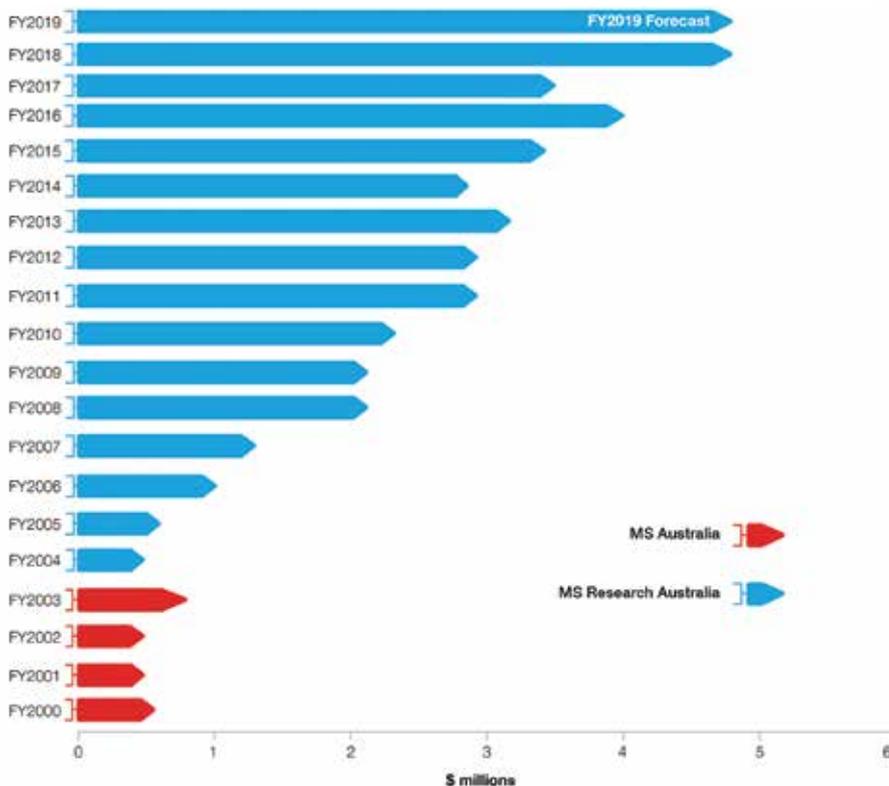
The chart opposite identifies the growth of investment into MS research. It's impressive to report that the annual funding has grown from \$500,000 in 2004 to over \$4.8 million in 2018, which is a **massive 860% growth**. Our ambition is to continue to grow this funding momentum until we eliminate MS once and for all. Our Board-approved goal is to provide \$15 million every year to fund the best Australian MS research.

The progress made in such a short space of time is remarkable and has only been made possible by the wonderful support received from you and the MS community. However, there is clearly much work that is yet to be done.

Supporting MS Research Australia means that you are solely supporting the best and most competitive MS research. Our role is very simple to understand yet extremely complex to implement. With the support of the community, corporate organisations, philanthropists, trusts/foundations, government and state-based MS societies we are confident that we will stop and reverse the effects of MS in our lifetime.

Dr Matthew Miles, CEO

MS Research Australia growth of investment into MS research (\$ Millions)



Note: FY2019 is a budgeted figure.



RESEARCH AUSTRALIA

SNAPSHOT

PROJECTS STARTED IN 2019 FUNDED BY MS RESEARCH AUSTRALIA

IDENTIFYING THE TRIGGERS FOR MS

NEUROBIOLOGY



DEVELOPING BETTER TREATMENTS

- Brain and Mind Centre, NSW**
Dr Cheryu Wang will use MRI to monitor silent disease progression in MS.
- Perron Institute for Neurological and Translational Science, WA**
Ms Lillian Toomey is investigating whether damage to myelin support cells drives MS at a molecular level.
- Brain and Mind Centre, NSW**
Dr Justin Garber is using MRI to track disease and severity in progressive MS.
- University of Newcastle, NSW**
Dr Saadallah Ramadan is investigating how MRI can be used to evaluate the treatment of fatigue and depression in MS.
- University of Melbourne, VIC**
Dr Ai-Lan Nguyen is travelling to Genoa to form a collaboration that aims to improve clinical decisions and care, using MRI in MS.

A CURE FOR MS VIA REPAIR OR REGENERATION OF CELLS

- University of Melbourne, VIC**
Dr Junhua Xiao is investigating how nerve cells influence myelin repair in the brain.
- University of Melbourne, VIC**
Dr Simon Murray is investigating ways to promote myelin repair in the brain.
- University of Sydney, NSW**
Associate Professor Anthony Don is determining the biological pathways that promote the creation of new myelin in MS.
- Monash University, VIC**
Dr Steven Patratos is developing novel drugs to promote neuroprotection and repair in progressive MS.

GENETICS & EPIDEMIOLOGY

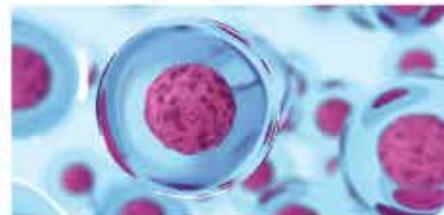
- Hunter Medical Research Institute, NSW**
Professor Rodney Scott is identifying markers of gene activity that are associated with disease onset and severity.
- Menzies Institute for Medical Research, TAS**
Dr Yuan Zhou is travelling to Boston to develop a pipeline for the analysis of sex chromosomes in MS.



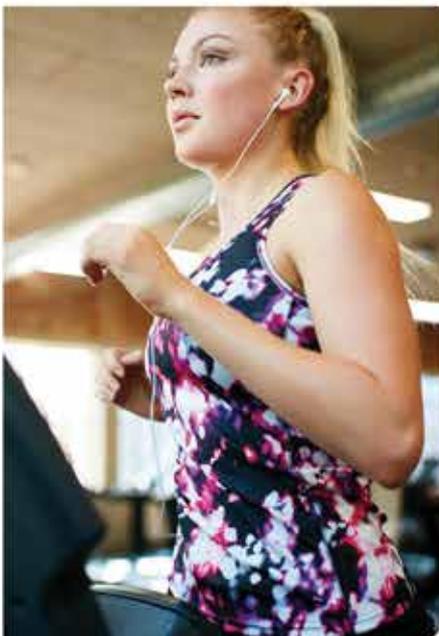
IMMUNOLOGY

- Westmead Institute for Medical Research, NSW**
Professor David Booth is developing a test in immune cells for individual vitamin D response.

- University of Queensland, QLD**
Dr Stefan Blum is developing a test to personalise treatment with the MS medication, natalizumab.
- Monash University, VIC**
Dr James Harris is exploring how a specific molecule, macrophage migration inhibitory factor (MIF) regulates inflammation in MS.



SOCIAL & APPLIED RESEARCH



- University of Melbourne, VIC**
Professor Mary Galea is tracking walking and balance changes in people with MS.
- Curtin University, WA**
Dr Lucinda Black is identifying dietary factors that reduce the risk of onset and early disease progression in MS.
- Menzies Institute for Medical Research, TAS**
Ms Alice Saul is examining the role of diet in symptoms and progression of MS.
- University of Wollongong, NSW**
Dr Yasmine Probst is creating new methods to analyse food and nutrient intake in MS.
- Australian National University, ACT**
Dr Jane Desborough will develop a toolkit for scientists and people with MS to work together on collaborative MS research.
- Curtin University, WA**
Dr Lucinda Black will be travelling to Southern California to conduct research into the relationship between diet and the risk of MS.



KEY

- PROJECT GRANT
- FELLOWSHIP
- SCHOLARSHIP
- INCUBATOR GRANT
- TRAVEL AWARD

Investigating the link between diet and MS

Many people with MS modify their eating habits to become more aligned with some diets that are promoted as being beneficial to MS. However, more research is needed to clearly identify whether there are concrete connections between diet and the risk, onset and progression of MS, and how to manage these connections for the best outcomes for people with MS.

This topic actually formed a large part of the discussion that took place between leading researchers and stakeholders at the MS Research Australia hosted Modifiable Lifestyle Factors Workshop held last year.

Now, in the latest funding round for grants starting in 2019, MS Research Australia is pleased to be supporting several high calibre new research projects which will be focussed on the link between diet and MS.

All three researchers we are funding are aiming to provide evidence to improve the strength and accuracy of data, and research techniques in this important field.

This will enable clinical trials to further test dietary strategies that show promise, and aid the development of evidence-based dietary guidelines for people with MS and those at high risk of MS.



Dr Lucinda Black,
Curtin University, WA

In a rare occurrence, Dr Lucinda Black has been successful with two MS Research Australia grants in this round. She has been awarded a Postdoctoral Fellowship and an Ian Ballard Travel Award, with thanks to the funding support from MS WA.

Over the next three years, Dr Black will investigate whether specific foods or nutrients can help reduce the risk of disease onset and progression in MS. Her work will be based on dietary intake information and blood samples from people with the earliest signs and symptoms of MS, collected through long standing studies in Australia the AusImmune study and the US MS Sunshine Study. This study will look closely at the impacts of dietary factors such as following a Mediterranean diet, consuming foods with anti-inflammatory properties, and blood levels of omega-3 polyunsaturated fatty acids and other fats, to determine their effects on MS onset. Through the Travel Award, Dr Black will be able to extend and deepen collaborations with the US researchers and establish the best protocol for their shared data analysis.

Over the next three years, Dr Black will investigate whether specific



Ms Alice Saul,
University of Tasmania, TAS

Ms Alice Saul has been awarded a Postgraduate Scholarship to look into generating robust evidence on the role dietary factors play on MS progression. Ms Saul will collect information on dietary patterns, quality of diet, and inflammation seen in people with MS. She will go on to determine whether MS outcomes

such as disability progression, relapses and symptom severity are influenced by the various dietary factors in her study.



Dr Yasmine Probst,
University of Wollongong, NSW

Dr Yasmine Probst has been awarded an Incubator Grant to improve the methods of researching diet in MS. Incubator Grants enable researchers to get new research ideas and techniques off the ground. Until now, dietary research in MS has been mostly conducted using techniques used in large population

studies, rather than studies designed using protocols developed specifically for MS.

The MS specific methodologies developed from this project will be tested by applying them to data from the US and New Zealand. Validating these methods on food data across various countries means that results can be compared and best practice can be developed globally.



Impaired sweating may contribute to heat sensitivity in MS

Despite having a similar core temperature to those without MS while resting and exercising, people with MS showed a significantly reduced sweat response which may in part explain the heat-related fatigue and other symptoms experienced by people with MS.

The majority of people with MS (over 80%) experience sensitivity to heat, which presents as heat-related fatigue and the worsening of previous MS symptoms such as vision complications, muscle control, bladder or bowel control and pain. As a result, people with MS may avoid exercise and physical activity, particularly in warm conditions, to avoid increasing their core temperature. However, this can prevent people with MS from obtaining sufficient levels of exercise, which has been shown to be beneficial in managing symptoms and improving the general well-being of those with MS.

The worsening of symptoms with increasing core body temperature is also known as Uhthoff's Phenomenon and is traditionally thought to relate to heat slowing the conduction of nerve signals through areas where myelin has been lost. However, in a MS Research Australia-funded project, Associate Professor Ollie Jay and Ms Georgia Chaseling from the University of Sydney have been investigating whether heat sensitivity in MS might be a result of changes in the ability to regulate core body temperature in MS.

Associate Professor Jay and Ms Chaseling have been using more sensitive and accurate techniques to measure core temperature than used in previous studies, and looked at sweating and blood flow to the skin in people with and without MS at rest and during exercise in carefully climate-controlled conditions. In the first of two papers they showed that people with relapsing remitting MS (RRMS) do not show any difference in core temperature at rest compared to those without MS.

However, building on this study, they then went on to demonstrate that people with MS have a significant reduction in the sweat response while exercising in warm conditions compared to people who do not have MS. While people with MS showed a reduced sweat response, they did not show any impairment in another natural cooling mechanism, blood flow to the skin, compared to people without MS. Despite the reduced sweating, the overall increase in core body temperature as a response to exercise was surprisingly the same as the control

“However, building on this study, they then went on to demonstrate that people with MS have a significant reduction in the sweat response while exercising in warm conditions compared to people who do not have MS.”



Georgia Chaseling and study participant in the Thermal Ergonomics Laboratory, University of Sydney

group, suggesting that other mechanisms to maintain core temperature may be switched on in people with MS.

While more research is needed to further understand this different temperature regulation response in people with MS, the researchers suggest that damage to the central nervous system (CNS) in MS may result in the signals from the brain not reaching the skin's cooling systems. The researchers also suggest that having to activate other body mechanisms to keep the core cool may place an extra burden on the body, contributing to the worsening of disease symptoms. Further research is needed to confirm this theory.

A better understanding of the causes and mechanisms behind heat sensitivity in MS will help experts develop the most effective evidence-based recommendations for people with MS to exercise within safe limits and find new ways to mitigate the effects of heat during physical activity.

Safe as houses, a wise investment towards a cure for MS

Recently MS Research Australia benefitted from the sale of a suburban house as a result of a generous supporter including us in her Will.

Her wonderful generosity to leave a percentage of her Estate (residual) rather than a fixed amount (pecuniary) to MS Research Australia has ensured that the value of the final contribution has substantially increased from the original point in time when she prepared her Will. This is mainly due to the increase in property values over time.

The increasing trend of including a gift in your Will to a favourite charity is providing charities across the nation with critical, much needed financial support. We encourage our supporters to consider including MS Research Australia in their Will when it comes time to update it or draw up a new one with the assistance of your chosen legal professional.

The generous decision our Melbourne supporter made by leaving a percentage of her Estate will enable MS Research Australia to fund another vital MS research project, putting her legacy to work and driving forward the mission to eradicate this disease.

Leaving a gift in your Will is a great way to support MS Research Australia, the largest national funder of



vital MS research. All gifts no matter how large or small can make a difference and we always encourage you to keep your loved ones as the highest priority and keep them informed of your intentions of leaving a gift in your Will towards your chosen charity. Any charitable gifts in Wills of property, stocks and shares are exempt from capital gains tax which is a benefit to all involved. Gifts in Wills can be very unique and not always a residual or pecuniary nature. Some collectors of art or jewellery have left valuable pieces

to their charity of choice. Also funds are allocated to MS Research Australia from a family trust or a private ancillary fund, which has sometimes been set up to administer philanthropic giving to Deductible Gift Registered organisations.

Research has revealed that only 7% of Australians who are considering leaving a gift in their Will to a chosen charity, will actually do so.

The impact of donating or leaving a valuable gift in a Will to MS Research Australia cannot be overstated as it will contribute to the worldwide collaboration to ultimately stop and reverse the effects of MS.

If you have chosen or are thinking about nominating MS Research Australia in your Will, please do let us know of this important decision by contacting:

**Neil Robertson, Relationship and Planned Giving Coordinator on
1300 356 467 or bequest@msra.org.au**

LEAVE YOUR
LIMITS BEHIND.

THE MAY 50K

#KissGoodbyeToMS



Are you ready to leave your limits behind? *Join* The May 50K!

This May we would like to invite you to help Kiss Goodbye to MS by signing up for our new fundraising activity – The May 50K!

Throughout the month of May we are challenging you to walk or run 50 kilometres, leave your limits behind and fundraise for life changing research into MS.

After six years of diverse and very creative ‘do it yourself’ style fundraising for Kiss Goodbye to MS, and almost \$5 million raised for MS research, it’s now time for a new challenge! This May, Australians can run or walk 50km over the entire month, at the time and place of their choosing whilst raising funds to support research into MS. We’ve identified a need to re-vamp the campaign a little to live up to your demand for rapid change within the space of MS research. We love that you don’t accept the status quo and **The May 50K** is embracing your determination, willpower and attitude!

Since 2000, the treatment options for MS have increased from only one to twelve available treatments, and that’s all

thanks to people just like you, working hard to ensure we can keep funding research into MS. Research is the key to changing the future of MS, and we’ve accepted the challenge to do this within our lifetime. We know you’ve got it in you to go the extra km and be an active part of the change this May.

The May 50K is your chance to test your limits, get fit and support a brighter future for MS this May. Wherever you live, whatever your fitness level, you can decide when, where and how to complete your 50 kilometres. You might decide to monitor and track your progress via a fitness app. You can do **The May 50k** by yourself, with friends and family or get together a team with your work colleagues. Let’s get fit this May and raise vital funds for research into MS.

Every step you take, every kilometre you clock, takes us closer to finding a cure for MS. You can help Kiss Goodbye to MS by joining **The May 50k** this May. Together we will change the future of MS and leave MS where it belongs, behind us.

Find out more about **The May 50K** at: www.themay50k.org

(P.S If you love ‘do it yourself’ style fundraising, don’t worry this option is still available!)

Board announcement

After twelve years on the Board of MS Research Australia, and nine of those as Chairman, Paul Murnane has recently decided to step down.

It is with both sadness and gratitude that we farewell Paul from the Board. Paul joined the MS Research Australia Board in 2007, and was an extremely active influencer of the MS family of organisations for 22 years previously. Paul's unwavering dedication to MS research and the MS community can be seen from the incredibly vital role he has played in the setting up, the direction and unprecedented growth of MS Research Australia.

Under Paul's leadership, MS Research Australia has grown to be the largest national not-for-profit funder and coordinator of MS research in this country, investing more than \$44.3 million in world class MS research including, 274 research grants and a significant number of world-first national and global research collaborations. Paul's global business outlook encouraged MS Research Australia to develop a significant presence in the international MS research environment, an area to which MS Research Australia is now firmly entrenched.

Whilst we farewell Paul from the Board, we know that he will remain closely involved and will work with us in an advisory capacity whenever called upon. Paul's wife, Annie, is living with MS and he has been dedicated to this field since she was diagnosed 37 years ago. He has built up a

database of literally hundreds of contacts in Australia – from MS researchers, politicians, MS donors, Board members from similar organisations, key influencers, members of the media, people living with MS and their close friends and families. He remains close to those that are now well into their MS journey but equally approachable to those that have been recently diagnosed with MS. Time and time again, the friends and families of someone recently diagnosed with MS have sought Paul out as a sounding board for advice, guidance and reassurance.

During his tenure, Paul has seen a dramatic change in the landscape for people living with the disease. A rapid change from when diagnosis was often difficult to impossible and treatments were non-existent or few, to a time just two decades later, where we have 12 treatments registered for relapsing MS and one for primary progressive MS. Since 2016, we have also seen the start of the massive changes that will come for service delivery associated with MS due to the rollout of the NDIS.

We can also now announce the appointment of Richard Bergman to the position of Chair and Tanya Branwhite as Deputy Chair. Both Richard and Tanya have served as non-executive Board Directors of MS Research Australia for a number of years and have been



Paul Murnane

contributing to and guiding the strategic research direction to fast track research to stop and reverse MS in our lifetime.

Richard is currently a Partner at PwC and has over 17 years' experience working with senior executives and Boards to manage risk, financial crime and cybercrime and balance the risks of cyber with the upside of the rapid adoption of digital.

Tanya is the Head of Portfolio construction at the NSW Treasury and one of the most senior women in the Australian financial markets. She has over 25 years' experience both in equities research and funds management and as an investment analyst.

We thank both Richard and Tanya for accepting such critical positions on the Board. Their valuable wealth of knowledge and expertise coupled with the solid team of Board directors will continue to propel MS Research Australia on our audacious mission to live in a world free of MS.

HELP MS RESEARCH AUSTRALIA FIND A CURE FOR MS

Donate (Donations over \$2 are tax deductible)

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

- Make a one off donation of \$
- Make a monthly donation of \$
- Learn more about leaving a gift in my Will

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