MS RESEARCH AUSTRALIA

# ANNUAL IMPACT REPORT 2018

PREVENT TREAT CURE

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MS
RESEARCH AUSTRALIA

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# 01.
# INTRODUCTION

## LATEST ON MULTIPLE SCLEROSIS

**3 OUT OF 4**
AUSTRALIANS DIAGNOSED WITH MS ARE WOMEN

**25,600+**
AUSTRALIANS ARE LIVING WITH MS

**30 YEARS OLD**
IS THE AVERAGE AGE OF AN MS DIAGNOSIS

**$1.75 BILLION**
THE ESTIMATED COST TO THE AUSTRALIAN COMMUNITY

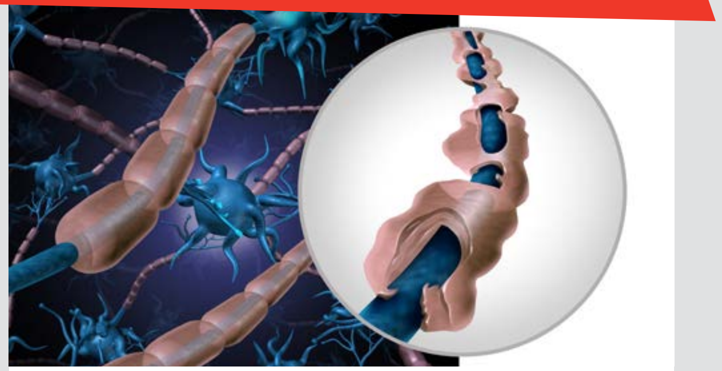
**MORE THAN 2.3 MILLION**
PEOPLE LIVE WITH MS WORLDWIDE

**10+**
PEOPLE ARE DIAGNOSED WITH MS EVERY WEEK ON AVERAGE

**MS AFFECTS MORE YOUNG PEOPLE THAN ANY OTHER ACQUIRED CHRONIC NEUROLOGICAL DISEASE**

### WHO IS MS RESEARCH AUSTRALIA ?

MS Research Australia is the largest national not-for-profit organisation dedicated to funding, coordinating, educating and advocating for MS research as part of the worldwide effort to solve MS.



### WHAT IS MULTIPLE SCLEROSIS (MS)?

MS is the result of damage to myelin, a protective sheath surrounding nerve fibres of the central nervous system. When myelin is damaged this interferes with messages between the brain and other parts of the body.

Every case is different – the progress, severity and specific symptoms of MS are different for everyone.

# CHAIR, CEO & PATRON WELCOME

**Thank you for reading our 2017/18 MS Research Australia impact report. We are proud to be the largest not-for-profit (NFP) funder and facilitator of multiple sclerosis (MS) research in Australia.**

This year, we have decided to combine our Board Chair, CEO and Patron message. While our three respective roles are very different, there is a great sense of collaboration, shared values and laser-focus towards a common purpose – keeping people affected by MS at the centre of MS research and everything we do.

## RECOGNITION OF OUR ACHIEVEMENTS

2017/18 year was one to be proud of, winning the Telstra Australian Charity Award and the Telstra NSW Business of the Year (the first NFP to ever win this business award), as well as the Australian Charity Award for Outstanding Achievement for the fourth year running!

We were also able to raise important awareness about MS not only within Australia but globally, with events in Washington DC and New York. These events allowed us to shine a light on our wonderful global MS research collaborations and also highlight the stellar Australian MS research that is providing answers for people living with MS here in Australia and further afield.

## BREAKTHROUGHS AND SUCCESSES

MS Research Australia was thrilled to be able to allocate another $2.8 million to fund the best and most competitive MS research projects in Australia via our independent Research Management Council (RMC). This resulted in 26 new projects and brings our total funding of MS research to over $37 million since inception.

Over nearly a decade we have contributed more than $1.2 million to Epstein-Barr Virus (EBV) research conducted by Professor Michael Pender so that his discovery could one day be tested in people living with MS. Thanks to wonderful additional support from MS Queensland, that became a reality in 2018 with an EBV clinical trial and announcement of promising safety data for a potential home-grown treatment for progressive MS.

We have also invested $100,000 in research at St Vincent's Hospital in Sydney to better understand how Autologous Haemopoetic Stem Cell Transplant (AHSCT) works in MS.

This is the site of the largest observational clinical trial on AHSCT occurring in Australia. We now know that a type of T cell thought to be important for inflammation in MS was wiped out and that there was also a sustained rise in other immune cells that work to dampen down and regulate the immune system.

By comparison, these changes were not seen in patients who received the same AHSCT for a cancer called lymphoma. This suggests that in people with MS, AHSCT not only works by turning off the attack on the myelin seen in MS, but also may restore the immune system's ability to regulate itself. MS Research Australia continues to invest in its AHSCT registry which aims to better understand the whole process to help improve outcomes for people with MS.

## LARGE-SCALE PROJECTS

We worked on a large number of big-ticket items this year, a few of which are highlighted below:

- An exciting, once-in-a-lifetime 'audaciously feasible' blueprint to 'stop and reverse MS'. Working with the PwC Impact Assembly, the plan involves people living with MS, our best MS researchers, donors, government, MS Australia, state societies and stakeholders.
- Work started on a strategic platform funded by one of our key philanthropic donors to help younger people recently diagnosed with MS navigate the myths, misconceptions and untruths based around MS and MS research.
- Collaboration with the Commonwealth Government and MS Australia on a 'roadmap' approach for stopping, reversing and eventually, ending MS. The $55 million implementation plan requests $35 million from the Commonwealth Government with the remaining $20 million to come from MS Research Australia and its supporters.
- Launch of the MS Research Australia *Health Economic Impact of MS in 2017 Report* by the now Prime Minister, the Hon. Scott Morrison MP in Canberra. Whilst the direct and indirect cost of MS to the Australian economy has blown out to more than $1.7 billion annually, there were some extremely encouraging results for people living with MS on employment outcomes and evidence that high-efficacy therapies are making a significant impact on people's lives.


*L-R: Paul Murnane, Chair, Matthew Miles, CEO and Simon McKeon AO, Patron*

## A CLEAR FOCUS ON HOW WE USE FUNDS RAISED

We are blessed with more than 37,700 valued donors and we would like to thank every one of you. We will highlight just a few below:

### *KISS GOODBYE TO MS "RIDE FOR A CURE"*

Three brothers and their cousin (whose father Rob lives with progressive MS) rode 1000km on horseback across the wilds and deserts of Mongolia. Known as the world's longest horse race, they toiled under extreme weather and riding conditions to raise nearly $200,000 for Kiss Goodbye to MS – they should be so proud of what they have achieved in raising much needed funds for MS research.

### *PETER AND MARGARET ABOUD*

Peter, who is living with MS and his wife Margaret have been running a golf day in the Blue Mountains for over 11 years, raising and facilitating donations of $130,000 for MS research – a really huge effort and we are so very thankful for their support!

### *SOHN HEARTS AND MINDS INVESTMENT LEADERS CONFERENCE*

The largest single-day charity event in Australia raised over $350,000 for MS Research Australia this year. As a founding-recipient charity not only do we benefit financially, we have also been able to collaborate with fellow recipients such as the Black Dog Institute (a medical research institute and global leader in translational mental health research) to develop one of our signature videos highlighting depression/anxiety and MS.

### *TRISH MS RESEARCH FOUNDATION*

This year saw the wonderful Trish MS Research Foundation raise almost $5 million, a staggering effort given that the Foundation is 100% volunteer run!

**MS RESEARCH AUSTRALIA IS THE LARGEST NFP FUNDER OF MS RESEARCH IN THE COUNTRY WITH OVER $37 MILLION INVESTED IN FUNDING AND FACILITATING MS RESEARCH SINCE 2004. IN THIS PAST YEAR OVER $3.8 MILLION HAS BEEN ALLOCATED TO NEW PROJECTS AND COLLABORATIVE PLATFORMS**

## WORKING TOGETHER

MS Research Australia is proud to be a managing member of the International Progressive MS Alliance, an unprecedented global effort making inroads on designing shorter, faster clinical trials and testing new agents with the hope of developing and evaluating new therapies to manage symptoms of progressive MS.

Jon Strum, whose wife Jeanne lived with progressive MS, said that being part of the Alliance is “the most meaningful and important work that I’ve ever done in my life”. A great accolade and something that many of us at MS Research Australia also feel. Our thanks also go to MSWA for their commitment to this initiative.

Global roll out of the Australian-founded Kiss Goodbye to MS campaign continued with 15 countries now raising funds for MS research via this innovative digitally-focussed platform. Realising our 2017-19 goal of 15 participating countries highlights the success of the campaign.

The first-ever therapy was registered for primary progressive MS, with Australia the second country in the world to get on board. We very much hope that by next year’s impact report, we will be able to provide you with news on the other therapies in the pipeline to help people with both primary and secondary progressive MS.

Closer to home we worked with CharityWorks for MS on their stellar Melbourne Charity Ball, re-established our small but vital grants with both the Commonwealth and NSW Health Departments and continued to work with 14 other immunological charities in The Australian Immunological Alliance.

It’s been a great year and MS Research Australia continues to be effective and influential in what it does.

**Paul Murnane, Chair, Matthew Miles, CEO and Simon McKeon AO, Patron**

*L-R: Paul Murnane, Chair, Matthew Miles, CEO and Simon McKeon AO, Patron*

# BOARD

The MS Research Australia Board of Directors give their time voluntarily and work together to guide the direction and management of MS research initiatives in Australia. Each Board Director is highly skilled and brings a diverse range of experience to the team.

**PAUL MURNANE, CHAIR**
CORPORATE ADVISOR, FAMILY CONNECTION TO MS

**TANYA BRANWHITE**
FINANCIAL AND INVESTMENT MARKET SPECIALIST

**ANNE BENNETT**
DIGITAL COMMUNICATIONS EXPERT

**PROFESSOR GRAEME STEWART AM**
CLINICAL IMMUNOLOGIST, MS RESEARCHER FOR 40+ YEARS

**MIKE HEMINGWAY**
FINANCIER, MOLECULAR BIOLOGIST, DIRECT CONNECTION TO MS

**DAVID SIMMONDS**
AUDIT FINANCE AND RISK SPECIALIST

**RICHARD BERGMAN**
RISK AND CYBER INVESTIGATIONS EXPERT, FAMILY CONNECTION TO MS

**DR GEOFF CUMMING**
HEALTHCARE AND TECHNOLOGY SPECIALIST, FAMILY CONNECTION TO MS

**PROFESSOR HELMUT BUTZKUEVEN**
NEUROLOGIST, MS SPECIALIST FOR 20+ YEARS

## 02.

# RESEARCH

## RESEARCH AT A GLANCE

**$3.8 MILLION**
TOTAL RESEARCH EXPENDITURE INCLUDING COLLABORATIVE PLATFORMS

**26 NEW**
RESEARCH GRANTS AWARDED

**7 SUBMISSIONS**
TO GOVERNMENT AND OTHER BODIES ADVOCATING ON BEHALF OF PEOPLE WITH MS

**$2.8 MILLION**
ALLOCATED IN THE LARGEST GRANT ROUND TO DATE WITH PROJECTS RUNNING FOR 3-4 YEARS

**47**
INVESTIGATOR-LED PROJECTS CURRENTLY FUNDED

**12 NEW INCUBATOR**
GRANTS AWARDED, PROVIDING SEED FUNDING TO NEW INNOVATIVE RESEARCH IDEAS

**LARGEST EVER BIENNIAL PROGRESS IN MS RESEARCH CONFERENCE HELD WITH ATTENDANCE INCREASING BY 38.5%**

### MODIFIABLE LIFESTYLE FACTORS

We held the first ever Modifiable Lifestyle Factor Workshop bringing together 45 international and national clinicians, researchers, service providers and people affected by MS to discuss current evidence and research.

RENEWED FUNDING SUPPORT FROM NSW HEALTH FOR THE MS RESEARCH AUSTRALIA CLINICAL TRIALS AND RESEARCH NETWORK

ALL GRANT APPLICATIONS SUBMITTED AND REVIEWED THROUGH THE NEW ONLINE GRANTS PORTAL

# TACKLING TREATMENTS FOR PROGRESSIVE MS

**Major inroads towards a treatment for progressive MS have been made with Professor Michael Pender and Professor Rajiv Khanna releasing encouraging preliminary results from a world-first clinical trial.**

Professor Michael Pender, a neurologist and researcher from The University of Queensland and Royal Brisbane and Women's Hospital has spent much of his career investigating the relationship between Epstein-Barr virus (EBV) and MS.

MS Research Australia is proud to have supported Professor Pender and his team since 2005, awarding over $1.2 million during that time in a bid to support research that tackles one of the greatest unmet needs in MS research – progressive MS. Despite huge advancements in the treatment of relapsing remitting MS previous attempts to develop treatments for progressive MS have fallen short, leaving people with progressive MS without treatments and without hope.

Professor Pender's research group have shown that people with MS have a reduced number of T cells capable of killing EBV-infected B cells, compared with people who do not have MS. This led to the idea that boosting a person's ability to kill EBV-infected cells might help treat MS.

Based on these findings, Professor Pender teamed up with Professor Rajiv Khanna from QIMR Berghofer Medical Research Institute to lead a study into a new therapy called autologous EBV-specific adoptive immunotherapy in the hope of discovering a new treatment for progressive MS.

A small phase I safety trial was conducted in 2017 to evaluate the safety and feasibility of using a patient's own EBV-specific T cells to treat progressive MS. The trial was funded through a grant in partnership between MS Research Australia and MS Queensland and other philanthropic support to QIMR Berghofer Medical Research Institute.

**7 OF THE 10 PARTICIPANTS SHOWED A CLINICAL IMPROVEMENT ON THE TESTS OF NEUROLOGICAL DISABILITY**

Professor Khanna developed a technique that takes the patient's own T cells from the immune system and primes them to recognise and kill EBV-infected B cells by exposing them to an EBV vaccine. The T cells are then reintroduced to the patients by intravenous infusion.

This very small study was first and foremost designed to identify any safety issues with the treatment, yet the clinical signs of improvement noted are encouraging. Seven of the 10 participants showed a clinical improvement on the tests of neurological disability and none of the 10 people experienced any serious side effects as a result of the treatment.

"One person with secondary progressive MS showed striking improvement," Professor Pender said. "This participant had a significant increase in ambulation. Lower leg spasms that had persisted for 20 years resolved."

"Of course, much more research needs to be done with larger numbers of participants to confirm and further evaluate these findings, but the results add to the mounting evidence for a role of the EBV infection in MS and sets the stage for further clinical trials."

Professor Khanna is now collaborating with biotechnology company Atara Biotherapeutics to conduct a larger trial of an 'off-the-shelf' version of this treatment.

The study was a collaboration between the QIMR Berghofer Medical Research Institute, Royal Brisbane and Women's Hospital and The University of Queensland in Brisbane, Australia.

*Main image: Professor Rajiv Khanna and trial participant Louise Remmerswaal. Photo courtesy of QIMR Berghofer Medical Research Institute.*

*Right: Professor Michael Pender at the study findings event.*

# UNLOCKING WAYS TO REPAIR MYELIN

**With the potential to reverse the symptoms of MS and prevent further damage to exposed nerve fibres, MS Research Australia has identified myelin repair and regeneration as a key focus area for MS research.**

In MS, the immune system mistakes myelin, the conductive coating around nerve fibres in the brain and spinal cord, as a foreign invader and attacks it, gnawing away at the protective layer. The resulting damage disrupts the nerve signals, slowing the signal or stopping it altogether. Myelin can be repaired naturally, but this process is incomplete.

Now scientists supported by MS Research Australia, in partnership with the Trish MS Research Foundation, have made a fundamental discovery that could unlock ways to boost the natural repair of myelin in the brains of people with MS.

The team led by Dr Tobias Merson, from ARMI at Monash University Victoria, in collaboration with Assistant Professor Ben Emery at Oregon Health and Science University USA, found that stimulating nerve cells in the brain promotes the laying down of myelin around these nerve cells. This repaired protective layer allows neurons to then work more effectively to transmit electrical signals around the body.

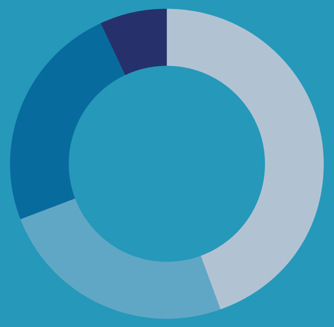
Matthew Miles, CEO of MS Research Australia, said "this is exciting research, understanding the natural processes by which the brain insulates individual nerve fibres will help us develop much-needed MS treatments that hopefully would lead to the restoration of nerve communication and potentially could mean a reversal of symptoms for people with MS."

While it is still early days this is an important step forward that may pave the way for us to manipulate myelin. Therapeutic approaches that increase the activation of certain nerve cells may be coupled with medications that may promote remyelination, reducing or potentially reversing disability in a person with MS.

# ORGANISATIONAL RESEARCH HIGHLIGHTS

2004-2018

RESEARCH FUNDING



- ● Investigator-led projects 44%
- ● National research collaborations 25%
- ● Fellowships & Scholarships 24%
- ● International research collaborations 7%

RESEARCH STREAMS

- ● Immunology 31%
- ● Genetics & epidemiology 29%
- ● Neurobiology 25%
- ● Social & applied research 15%

RESEARCH FOCUS

- ● Developing better treatments 58%
- ● Identifying the triggers of MS 30%
- ● A cure for MS via repair or regeneration 12%

WORKED WITH MORE THAN 900 MS RESEARCHERS AND CLINICIANS

ESTABLISHED AUSTRALIA'S ONLY MS DEDICATED BRAIN BANK FACILITY

ESTABLISHED A COMPREHENSIVE REGISTRY, TRACKING AHSCT TREATMENT FOR MS

16 YEARS – THE LONGEST RUNNING MS LONGITUDINAL STUDY IN AUSTRALIA

MS RESEARCH AUSTRALIA GRANTS ARE CLASSIFIED CATEGORY 1 COMPETITIVE FUNDING

$37 MILLION INVESTED INTO FUNDING AND FACILITATING MS RESEARCH SINCE 2004

# UNDERSTANDING AHSCT COULD BE TREATMENT KEY

Autologous Haematopoietic Stem Cell Therapy (AHSCT) has garnered worldwide interest as a possible treatment option for MS.

*Dr Jennifer Massey*

It has been used to treat a small percentage of people overall with MS in Australia and internationally, with good results for some with relapsing MS. However it does carry risks and international clinical trials and studies have shown that it is not effective or suitable for everyone with MS.

Limited formal research has been conducted globally on AHSCT as a treatment for MS, which is why MS Research Australia has worked to make it a research priority. In addition to funding and directing the AHSCT Registry, MS Research Australia has supported a recent study by Dr Jennifer Massey in Sydney.

AHSCT (also known as bone marrow transplant) is an immunosuppressive chemotherapy treatment combined with reinfusion of blood stem cells to help re-build the immune system. Prior to undergoing chemotherapy, haematopoietic (blood and immune) stem cells are isolated from the person and then returned following the chemotherapy treatment to aid the regrowth of the immune system.

The aim of AHSCT is to 're-boot' the immune system so that the immune cells that attack the brain and spinal cord are removed and replaced with a regenerated immune system. This process of removal and re-booting of the immune system seems to benefit some patients with highly inflammatory MS that has not responded to other MS therapies and in some cases a prolonged remission has been achieved.

> **LIMITED FORMAL RESEARCH HAS BEEN CONDUCTED GLOBALLY ON AHSCT AS A TREATMENT FOR MS, WHICH IS WHY MS RESEARCH AUSTRALIA HAS WORKED TO MAKE IT A RESEARCH PRIORITY**

Dr Jennifer Massey, an MS Research Australia-supported researcher and her colleagues at the St Vincent Hospital in Sydney have now published results from their eight-year study of AHSCT in people with relapsing-remitting and secondary progressive MS, which aimed to determine at a cellular level how the immune system regenerates after AHSCT.

The study examined the numbers of different types of immune cells following AHSCT and whether differences in these cells could be used to predict which patients would gain the most long-term benefit from the treatment.

The study showed that a year after AHSCT, the attacking types of immune cell in MS were still wiped out and that there was a sustained rise in other immune cells that work to calm and regulate the immune system.

Study participants included 20 people with relapsing-remitting MS and 15 with secondary progressive MS, who had failed to respond to at least two previous therapies for MS. Researchers tracked evidence of disease activity via relapses, brain lesions and disability progression for an average of three years post-treatment.

In the overall group of people in the study, 60% showed no evidence of disease activity for up to three years after AHSCT, while the people with relapsing-remitting MS did better, with 70% showing no disease activity. 73% of participants had no disability progression during the follow-up period, and 13 people had improvements, however eight people had their disease continue to progress, two with relapsing-remitting MS and six with secondary progressive MS.

Encouragingly, 83% of participants had no new or enlarging lesions at their last MRI scan and 96% showed no active lesions.

The results are similar to those seen in other international studies in that they confirm that people with relapsing-remitting MS respond better to AHSCT than those with secondary progressive MS.

Dr Massey's research into immune cells adds to an international body of work aiming to produce guidelines for the use of AHSCT in the treatment of MS. It will also help us to understand how the treatment works at the immune system level and potentially lead to other strategies to reset the immune system that do not require such intensive chemotherapy treatments. MS Research Australia will continue to support efforts to understand how AHSCT can add to the treatment options for MS.

# MS THERAPIES IMPROVE EMPLOYMENT

**People with MS often report leaving the workforce or reducing their level of employment due to their symptoms.**

The financial impact of this reduced employment places a substantial burden on individuals, families and the wider community with the *Health Economic Impact of MS in 2017 Report* putting the cost of lost productivity at $0.56 billion/year.

Thankfully, research published in 2016 by Dr Pieter Van Dijk and his team at Monash University, together with Associate Professor Ingrid van der Mei using data from MS Research Australia's Australian MS Longitudinal Study (AMSLS), showed that the gap in employment rates between people with MS and the general population is closing and is now within 4% of the general population.

Funded by MS Research Australia, the AMSLS is a survey-based research study that has been running since 2002. The study is designed to provide data of practical use for improving the lives of Australians living with MS and facilitating the provision of services and advocacy for people with MS.

Now, researcher Jing Chen, Associate Professor Ingrid van der Mei, and their colleagues at the Menzies Institute for Medical Research have delved deeper into the data from the AMSLS to explore whether the use of disease-modifying therapies has played a role in this improvement in employment retention for people with MS.

Published in the prestigious *Journal of Neurology, Neurosurgery, and Psychiatry*, the study showed that people on high-efficacy disease-modifying therapies were 2-3 times more likely to report improved employment outcomes than those on the lower-efficacy first generation MS treatments.

The results showed that while many participants did not report any changes to their employment outcomes, the users of high-efficacy therapies (mainly represented by fingolimod and natalizumab) were 2.84 times more likely to report an increased amount of work, 3.14 times more likely to report an increased work attendance and 2.5 times more likely to report improved work productivity compared to those who used β-interferons and glatiramer acetate.

Importantly, this study indicates that newer generation MS medications are having a positive effect on the quality of life of people with MS, allowing them to maintain health and keeping them well enough to stay fully active and productively employed.

PEOPLE ON HIGH-EFFICACY DISEASE-MODIFYING THERAPIES WERE 2-3 TIMES MORE LIKELY TO REPORT IMPROVED EMPLOYMENT OUTCOMES

# MODIFIABLE LIFESTYLE FACTORS WORKSHOP

**Identified as a key area in the 2016 Research Priorities survey, modifiable lifestyle factors typically include diet, environmental exposures, exercise and stress.**

People with MS can take control of these factors to help manage and even minimise the impact of MS on their lives, providing a sense of empowerment and hope.

Recognising this fundamental need, MS Research Australia felt that bringing people together to discuss current knowledge and challenges for research would be the best way to accelerate progress and promote collaboration to improve outcomes for people with MS.

Held in May 2018, the workshop was attended by clinicians, allied health professionals, people living with MS, MS organisations and researchers who specialise in a range of fields and diseases. The aim was to explore the potential role of modification of lifestyle factors in preventing MS onset, preventing disease activity and disability progression, and improving overall quality of life.

Funded by a generous grant from Novartis Australia, the event allowed both research professionals and other members of the MS community the opportunity to come together to share their expertise and experiences and discuss topics such as nutrition, wellness, physical activity and MS risk factors such as sunshine and vitamin D.

Speakers and delegates from around the world included epidemiologist Professor Robyn Lucas from Australian National University, Professor George Jelinek from the University of Melbourne, Professor Terry Wahls from the University of Iowa, USA and dementia researcher Professor Kaarin Anstey from University of NSW.

Dr Lisa Melton, Head of Research at MS Research Australia said, "We wanted to explore how we could capitalise on our Australian strengths and international connections to extend our current knowledge. We need to translate the current evidence we have on MS risk factors into effective interventions to improve outcomes and quality of life for people with MS."

The workshop produced key outcomes and actions including the need to provide consistent guidance to people with MS based on the best-available evidence about modifiable lifestyle factors. Following the workshop, MS Research Australia is working with experts in the field and people with MS to develop and produce these guidelines.

*Right: Professor Robyn Lucas, Australian National University*

*Top: Professor Helmut Butzkueven addressing conference attendees*
*Above: Dr Riccardo Saccardi from Florence*

# PROGRESS IN MS RESEARCH
# BIENNIAL CONFERENCE

**MS Research Australia is dedicated to building the MS researcher community, retaining up and coming researchers in the MS field and stimulating collaboration.**

Key to this goal is the biennial Progress in MS Research Conference – a valuable opportunity for MS researchers and PhD students to access global insights and expertise within an Australian setting.

Australia's only dedicated MS research conference, organised by MS Research Australia, took place in Sydney in October 2017 and was the largest in its 13-year history, with over 180 registered participants, 23 oral presentations and 50 research posters.

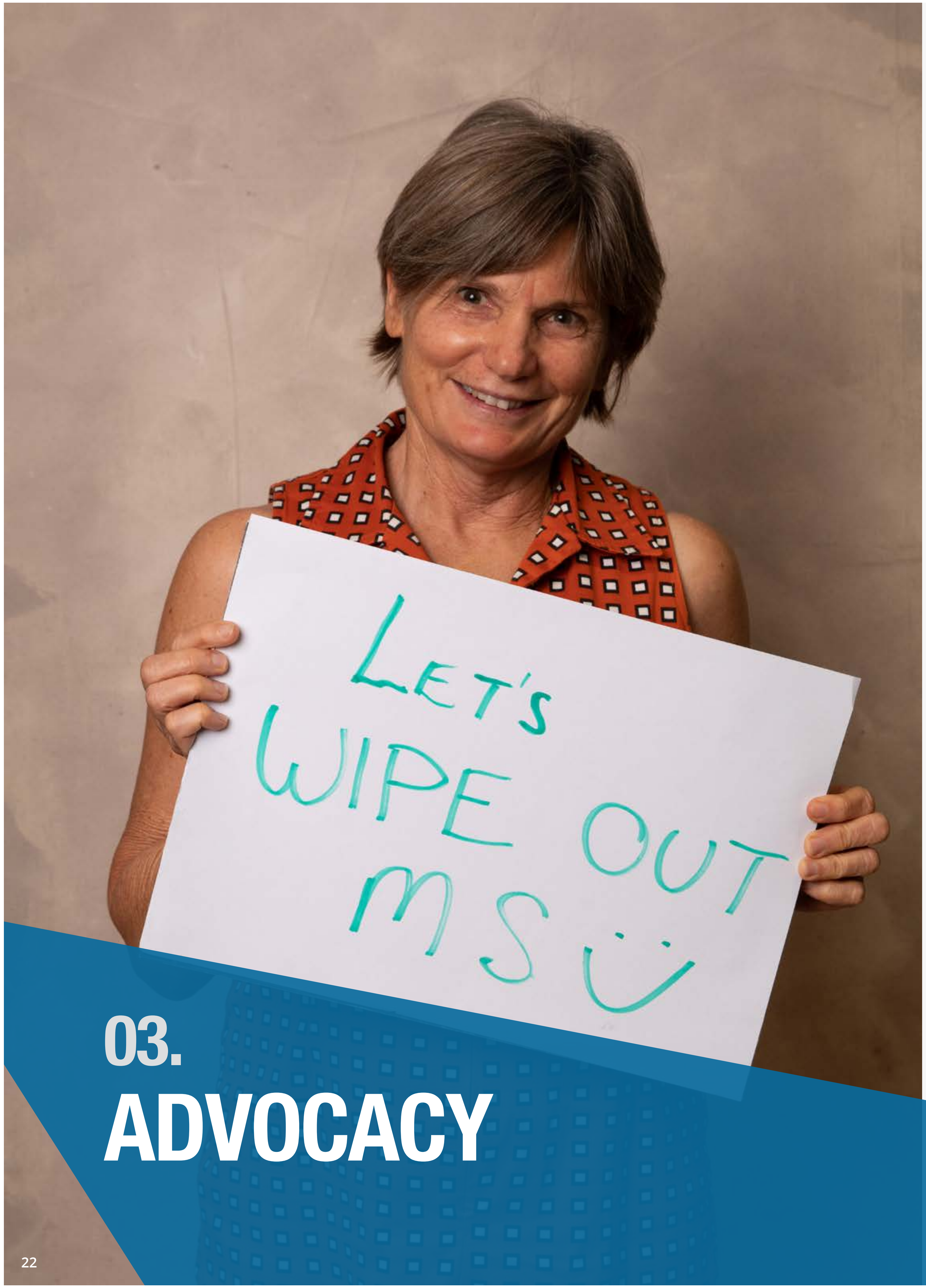
Researchers, clinicians, nurses and allied health professionals came together from different fields to share their research findings, network and establish collaboration opportunities.

Highlights included Dr Riccardo Saccardi from Florence, Italy sharing the experience of the European Bone Marrow Transplant Registry in the use of chemotherapy with autologous haematopoietic stem cells transplant (AHSCT) for MS and Professor Jack Antel from Montreal, Canada discussing his collaboration with neurosurgeons to obtain living human myelin producing cells for studing myelin repair in the laboratory.

Professor Jan Lünemann from Zurich, Switzerland and local keynote speaker, Professor Stuart Tangye, from the Garvan Institute, Sydney, gave an overview of how both clinical experience and laboratory-based research have provided enormous insights into the biology of B cells and their role in MS, while Associate Professor Leigh Charvel from New York University discussed the most useful tests to easily and accurately monitor changes in cognition over time.

Our thanks go to Professor Helmut Butzkueven, conference convener, and the conference committee, Dr David Darby, Royal Melbourne Hospital, Associate Professor John Moore, St Vincent's Hospital, Sydney, Associate Professor Ingrid van der Mei, Menzies Institute for Medical Research, Hobart and Professor David Booth, Westmead Institute for Medical Research, Sydney, for putting together such an excellent program.

*Right: Members of the conference committee*



# 03.

# ADVOCACY

## ROADMAP TO END MS

**MS Research Australia was excited to collaborate with the Commonwealth Government and MS Australia on a 'roadmap' approach for stopping, reversing and eventually, ending MS.**

The *Roadmap to Defeat MS* was developed with input from people living with MS, our best MS researchers, donors, government, MS Australia, state MS societies and other stakeholders to work out exactly how we 'stop and reverse MS'.

Launched on World MS Day at Parliament House by Health Minister Greg Hunt, the roadmap was built on two fundamental needs of people with MS – better treatments, prevention and, ultimately, a cure for the disease and improved support for the management and care of MS.

THIS ROADMAP WAS DEVELOPED TO WORK OUT EXACTLY HOW WE 'STOP AND REVERSE MS WITHIN 10 YEARS'.

Largely MS research-based, the implementation plan sets out what is needed within the next 10 years to ensure that we can prevent and ultimately defeat MS and ensure that people living with MS have effective and appropriate management and interventions.

The Roadmap brings together all of the components in to an 'audaciously feasible' blueprint that covers three key objectives: stop MS and find a cure, prevention of MS and improved management of MS.

Securing bipartisan support for the plan is essential with an estimated implementation cost of $55 million.

This figure calls for a $30 million investment from the Medical Research Future Fund (MRFF) and other Federal Governmental funding sources over 10 years and a further $5 million from the Commonwealth Primary Health Network funding to establish, build and audit national MS care standards that support decision-making by GPs, neurologists and other healthcare professionals.

To demonstrate the benefits of collaboration, MS Research Australia will commit $20 million to part match the government funding of MS research; $10 million over a 10-year time period from annual revenue and $10 million from major donors and a fundraising campaign based on community support to 'stop and reverse MS'.

MS Research Australia and MS Australia will now develop an implementation plan for the roadmap to ensure greatest impact and best-practice reporting back to Government and other supporters. This in-depth plan is due to be released in 2019.

*Left: Simon McKeon AO, Patron , Jillian Kingsford Smith, Advocate, the Hon. Greg Hunt MP, Commonwealth Health Minister & Matthew Miles, CEO at the Roadmap to Defeat MS launch event*

# GOVERNMENT SUBMISSIONS

**MS Research Australia, in conjunction with MS Australia, advocates on behalf of people with MS to certain government agencies and other regulatory bodies.**

One of the ways we achieve this is by advocating for affordable access to clinically proven medications and interventions via the Pharmaceutical Benefits Advisory Committee (PBAC), commenting on regulatory changes via the Therapeutic Goods Administration (TGA) and making submissions to relevant public consultations.

This year MS Research Australia made seven advocacy submissions on behalf of people with MS, including a submission to the Senate Community Affairs References Committee inquiry into the availability and accessibility of diagnostic imaging equipment around Australia.

We also made a submission to the TGA consultation on the introduction of the 'Black Triangle Scheme' which relates to adverse event reporting for new medications.

Five submissions were also made to the PBAC advocating for affordable access to new MS medications, including the first medication shown in clinical trials to have efficacy in delaying disability progression for people with primary progressive MS – Ocrevus.

MS Research Australia will continued to advocate for affordable access to Ocrevus, a medication registered for the treatment of relapsing and primary progressive forms of MS by the Therapeutic Goods Administration (TGA) to reduce the frequency of relapses and delay progression of physical disability. So far Ocrevus has only been approved for PBS reimbursement for relapsing remitting MS – we are still working hard to advocate for a listing for people with primary progressive MS.

Mavenclad, an oral treatment for relapsing-remitting MS, was considered by PBAC and then added to the Pharmaceutical Benefits Scheme (PBS) in December 2018. Mavenclad, whose generic name is cladribine, selectively targets the immune cells that play a role in MS. Its inclusion on the PBS means Australia now has 12 approved and subsidised disease-modifying therapies for relapsing remitting MS, making it one of the very few countries in the world to have such ready access to treatment.

# BIPARTISAN SUPPORT WITH ADVOCACY AGENCY

**One of MS Research Australia's strategic initiatives is to increase support from government and state-based funding bodies, and to advocate for an increased focus on research and better treatments for people with MS.**

Securing bipartisan government support is crucial to this mission and to the success of major advocacy projects such as the *Roadmap to Defeat MS* and the *Health Economic Impact of MS in 2017 Report* (page 25).

This year we made significant inroads in building this support with the appointment of advocacy agency, Barton Deakin.

Barton Deakin is a respected advocacy agency that will assist us with analysis of government and help us make the most effective submissions and presentations to the government. Their work with us mainly covers our approaches to the Commonwealth Department of Health.

Barton Deakin have a related partner, Hawker Britton, who assists us with our engagement with the Labour side of government.

Not only have we had numerous events where the Prime Minister, the Hon. Scott Morrison MP and Health Minister, the Hon. Greg Hunt MP, has attended but we have engaged successfully and proactively with the opposition Health Minister, the Hon. Catherine King. Both Greg and Catherine attended the launch of our *Roadmap to Defeat MS*.

Barton Deakin was instrumental in assisting the brain cancer collective receiving a $100 million boost for brain cancer research. We are hoping they can do similar things for MS.

# HEALTH ECONOMIC IMPACT OF MS IN AUSTRALIA

**In 2018 we launched the first comprehensive review of MS in Australia in nearly eight years. Prime Minister, the Hon. Scott Morrison MP (Treasurer at the time) was on hand to release the MS Research Australia Health Economic Impact report in Canberra.**

Just over 12 months in the making, the report provides a clear description of the economics around MS and is an incredibly valuable tool used by MS organisations, researchers, clinicians and a range of advocacy organisations.

Commissioned by MS Research Australia, funded by a generous donor and prepared by the Menzies Institute for Medical Research, University of Tasmania, the report shows how many Australians are now living with MS, the costs of the disease from an individual and societal perspective, and the quality of life indices for individuals living with MS.

Findings from the report show that while the number of Australians living with MS has risen by 20% to 25,600, the course of the disease is shifting with more people able to stay in work and needing less care and support as a result of changes in treatment and management strategies.

**THE TOTAL ECONOMIC COST OF MS TO THE COMMUNITY NOW STANDS AT $1.75 BILLION**

The report suggests that the 20% increase in the number of Australians living with MS is largely due to more people living with MS for longer, rather than a strong increase in the incidence. Women continue to represent more than three quarters (78%) of those with MS in Australia.

"The introduction of new generation disease-modifying therapies (DMTs) with improved efficacy over the past few years has had profound effects on the management of the disease and also on the costs of MS," comments Professor Andrew Palmer, Health Economics Research Unit, Menzies Institute for Medical Research, University of Tasmania.

"We can't take our foot off the pedal, as while there are positive signs, we need to maintain the momentum and continue to make improvements in the management and care of MS, including interventions aimed at stopping the relapses and preventing the progression of MS, so we can reduce the human and economic burden even further."

The total economic cost of MS to the community now stands at $1.75 billion – an increase of $500 million since 2010 when it was $1.24 billion (in 2017 dollars), but now only 32% of that cost is due to lost employment for people with MS compared to 50% in 2010.

*David Alexander, Barton Deakin, Paul Murnane, MS Research Australia Chairman and Matthew Miles, MS Research Australia CEO*

## 04.

# FUNDRAISING

## FUNDRAISING AT A GLANCE

CELEBRATING **10** YEARS
SUPPORT FROM WOMEN'S NETWORKING GROUP MS ANGELS

MORE THAN **$300K**
WORTH OF PROBONO SUPPORT IN FUNDRAISING

**$565,310**
RECEIVED FROM TRUSTS AND FOUNDATIONS

MORE THAN **$158,000**
RECEIVED FROM OVERSEAS DONATIONS

**2**ND YEAR
AS CHARITY PARTNER OF THE SOHN HEARTS AND MINDS INVESTMENT LEADERS CONFERENCE

MORE THAN **$3.5** MILLION
COMMITTED BY TRUSTED FUNDING PARTNER TRISH MS RESEARCH FOUNDATION OVER THE LAST 14 YEARS

**THE GENEROUS SUPPORT OF DONORS AND FUNDRAISERS DELIVERED MORE THAN $3.8M OF FUNDRAISING INCOME**

**62%**
INCREASE IN GIFTS IN WILL INCOME

**132%**
INCREASE IN CORPORATE SUPPORT FOR THE PROGRESS IN MS RESEARCH CONFERENCE

**18%**
INCREASE IN WORK PLACE GIFTS

**17%**
INCREASE IN DONATIONS RECEIVED FROM REGULAR GIVERS

# PARTNERING TO FIND A CURE

**The Trish MS Research Foundation is one of MS Research Australia's most important partners, offering unwavering support since our inception 14 years ago.**

The Foundation is staffed solely by volunteers who give their time and resources so that every dollar raised can be placed into research – this year that figure reached almost $5 million donated to MS Research Australia over the course of the partnership.

Roy and Carol Langsford OAM established the foundation in 2000 in honour of their beloved daughter Trish, who was diagnosed with MS at just 23. Trish was an elite sportswoman representing NSW and Australia in cricket whose life was sadly cut short at the young age of 30 due to an aggressive and rapidly progressing form of MS.

Dedicated to finding a cure and preventative strategies for MS and to ensure that no one else would have to go through the same experience as their daughter, the Trish MS Research Foundation sought to establish close links with MS Research Australia.

Each year the foundation hosts a number of fundraising events, including their annual gala ball which features MS research updates from MS Research Australia researchers and shares stories of those living with MS.

"When we launched the Trish Foundation in December 2000, we felt that not enough funding was being put into research, particularly to find the cure or a preventative strategy for MS, and so consequently, down the track, when MS Research Australia was launched, we were absolutely thrilled, because obviously the common goal means that the cure will be part of a collaborative effort," said Carol Langsford OAM.

"The robust grant review process of MS Research Australia ensures that only the strongest research projects are considered. MS Research Australia then presents us with funding opportunities which are reviewed by the Trish Foundation's Honorary Scientific Research Committee and approved by the Board."

Over the years the Trish MS Research Foundation has contributed to many important research projects including providing initial funding to the MS Research Australia Brain Bank, which has become an invaluable resource for MS researchers in Australia and research that resulted in the first blood biomarker test for MS.

MS Research Australia is extremely grateful to Carol and Roy Langsford and the Trish MS Research Foundation for their commitment to MS research and finding a cure for MS.

Left: Roy and Carol Langsford OAM

# INVESTMENT LEADERS SUPPORT MEDICAL RESEARCH

**We were once again incredibly grateful to be involved in the Sohn Hearts and Minds Investment Leaders Conference, Australia's largest, single-day charity event aimed at inspiring the investment community to support medical research.**

Taking place in late 2017, the event raised over $350,000 for MS Research Australia, which will be used to fund the best quality MS research projects in Australia.

Four charities were selected to take part in the highly acclaimed event – the Victor Chang Cardiac Research Institute, the Black Dog Institute, MS Research Australia and JDRF Australia. These charities were chosen based on their high-impact research and expertise in their respective fields of heart disease, depression, multiple sclerosis and type 1 diabetes. With all profits going directly towards medical research, it was important to the event organisers to involve charities who had the ability to make a real and tangible difference with the funding.

The conference brought together the best minds in the investment community for a series of Ted-X style presentations with the proceeds of ticket sales, corporate partners and philanthropists donated to the four charities. Prime Minister at the time, Malcolm Turnbull MP addressed the 550 strong crowd, speaking about anonymous giving and the differences between government funding and philanthropy. "Australia needs investors like you – people willing to reach beyond what we think is possible, in science, in business and in philanthropy" said Mr Turnbull.

The Sohn Hearts and Minds Investment Leaders event was the brainchild of well-known activist investor, Company Director of The Centre for Independent Studies and Board member of the Victor Chang Cardiac Research Institute, Dr Gary Weiss. He was inspired by similar events overseas such as the Sohn Conference and the Robin Hood Investors Conference, that both started in New York.

We wholeheartedly thank Matthew Grounds, Chair of the Victor Chang Cardiac Research Institute and Gary Weiss who have been the brains and driving force behind the event. Not only has MS Research Australia's involvement led to some desperately needed funding, it has built some fantastic research and awareness collaborations between the four charities.

Top: MS Researcher Dr Kaylene Young speaking at the conference

# LEAVING A LEGACY
# STEWART & LESLEY MACLENNAN

**Stewart MacLennan had experienced symptoms of what turned out to be progressive MS since 1985. He was not diagnosed until 12 years later when, as a result of an MRI, doctors delivered the diagnosis.**

Stewart had worked as a journalist and filmmaker at the ABC before founding his own multimedia company.

In 2000 he was forced to sell his business largely as a result of the impact that progressive MS had and continues to have, on his life. Since his diagnosis like so many others who have MS, he and his family have experienced enormous pressure physically, emotionally and financially.

He and his wife Lesley have agreed that leaving a 'Gift in Will' to MS Research Australia in their respective wills is the best possible way to help support the search for a cure and to leave a lasting legacy.

Stewart and Lesley are passionate about doing all that they can to prevent MS in the future and want to encourage others to consider supporting MS Research Australia through a gift in their Will (bequest).

Stewart is a dedicated advocate for supporting medical research, especially in Australia, where we're among the global leaders in terms of medical breakthroughs and have some of the best researchers in the world. He chooses to support MS Research Australia as he believes that our level of governance and reporting, ensures we are well on track to achieving our mission.

"I am convinced that every penny that goes to MS Research Australia is going to be very well invested as they have a robust mechanism for investing funds efficiently and giving reports to those donating so they are aware of where their funds are going," explained Stewart.

"The team at MS Research Australia are happy to share ideas for the type of projects your funds could potentially support and can provide progress reports of these projects to your loved ones."

Stewart believes that everyone can leave a gift in their Will no matter how big or small. He would like to ask that people living with MS and those that work in the MS area, that in addition to considering their own 'Gift in Will', they actively encourage others in their life to contemplate taking similar action to support MS Research Australia.

"Ask your grandparents, your parents, ask friends of your grandparents to consider it – let them know just how much of a difference it can make to the lives of people who have MS today and those that might be unlucky enough to develop it in the future."

*Left: Stewart MacLennan*

# MAKING A DIFFERENCE
# THROUGH PHILANTHROPY

**The Harper Bernays Charitable Trust is an incredibly important MS Research Australia partner, providing a consistent source of funding through its clients' charitable funds for the past 10 years.**

The Trust advises and assists its clients with their philanthropic efforts, working with its clients to develop a 'giving strategy', choose projects to support and determine their involvement.

Committed to making a difference through philanthropy, the Trust manages charitable monies for a number of families who provide ongoing support to MS Research Australia, either through donations or in their Will.

One of the Trust's clients has been supporting MS Research Australia since 2008, allowing us to continue accelerating Australian research, particularly in the area of MS genetics, where Australia has been taking a lead in identifying a number of MS genes. This is helping enormously in the development of diagnostic tools and patient-specific treatments.

The Harper Bernays Charitable Trust, through their clients' ongoing support has allowed us to expand our portfolio of research projects focused on prevention, MS cell repair and cell regeneration, helping us move towards a shared goal of finding a cure for MS.

In addition to financial support, charities assisted through the Trust are subject to rigorous evaluation of their operations and governance. This independent auditing provides an extra measure of assurance for MS Research Australia as a kind of external 'stamp of approval'.

MS Research Australia would like to thank the Harper Bernays Charitable Trust and all of their clients who have continued to support Australian MS research.

## KISS GOODBYE TO MS
## FUNDRAISING HIGHLIGHTS

240 CITY 2 SURF RUNNERS MADE IT TO THE FINISH LINE

9 RESEARCH LABS PARTICIPATED IN THE BATTLE OF THE LABS

4 COUSINS RACED THE MONGOL DERBY RAISING NEARLY $200,000

90,000 LIKES ON FACEBOOK

2 GALA DINNER EVENTS ORGANISED BY KISS GOODBYE TO MS RAISED $116,000

$3,358 RAISED ON AVERAGE BY OUR KISS GOODBYE TO MS FUNDRAISERS

123% INCREASE IN FUNDING FROM THE YEAR PRIOR

51% INCREASE IN WEBSITE USERS DURING MAY

## RED LAB COAT DAY
## CELEBRATES OUR MS RESEARCHERS

We launched Kiss Goodbye to MS with over 20 research institutions across Australia and colleagues as far afield as the Netherlands, Ireland and New Zealand switching their usual white lab coats for red ones in celebration of Red Lab Coat Day.

Held on May 1, Red Lab Coat Day is our way of saying ‘thank you’ to MS researchers across the world and highlighting the significant contributions and invaluable work of our Australian researchers towards finding a cure for MS!

This year, we asked our researchers from Australian universities to create a video showcasing their passion, dedication and hard work towards MS research as part of the ‘Battle of the Labs’ competition.

Nine brilliant videos were submitted, with the public voting for their favourite on the Kiss Goodbye to MS website. The videos were watched over 8,300 times and 2,695 total votes were submitted!

The ‘Battle of the Labs’ winner was announced during World MS Day on 30 May. Congratulations went to the University of Technology (UTS), Sydney who surprised everyone with their creative dance performances in and outside the lab and earned an outstanding 917 kisses (votes).

Following the announcement, Alessandro Castorina, Head of the UTS lab said: “Thank you everyone! It was a fun initiative but more importantly it sends a message of hope to the MS community that there are scientists in Australia and at UTS, who are working towards a solution for this disease.”

MS Research Australia would like to thank all the wonderful labs that participated in the ‘Battle of the Labs’ and all the researchers who posted photos and boomerangs on Red Lab Coat Day using the #KissGoodbyeToMS hashtag.

We were again blown away and inspired by our researchers’ passion and commitment, helping us get closer to finding a cure for MS every single day. Thank you for doing such important work!

*Top: Associate Professor Fabienne Brilot-Turville and her team*

# RIDING THE TOUGHEST RIDE FOR MS RESEARCH

**In August Ed, Rob and Jack Archibald and Henry Bell took on the Mongol Derby, the world's longest and toughest horse race to raise vital funds for Kiss Goodbye to MS and MS research.**

Stretching 1000km and consisting of unpredictable terrains, extreme temperatures, high chances of wild animal encounters and an unmarked course, the race was recreated to mirror Genghis Khan's infamous horse messenger system that was used in 1224.

Finishing the race as a team, was the ultimate way to end an amazing year-long adventure for the four who took on the wild challenge for their father and uncle Rob Bell, who's living with primary progressive MS and is wheelchair bound.

The Mongol Derby was not only a huge personal challenge for the men, but also an opportunity to raise money and awareness for a cause that is close to their heart and has affected their family so profoundly.

The Bell's previous knowledge of MS was very little. Henry, Rob's son said: "There were no family traces of MS, we only knew one person with it. To be honest, we did not know enough about the disease to realise how scary the proposition of dad living with MS was. However, over time, we understood the severity of the disease and were a little scared that there was such limited treatment available".

The determination and mental strength that Rob shows on a daily basis kept the guys going on their two-week adventure.

"Persistence and a never give up attitude is what Rob has taught me", said Ed, "Being able to deal with unyielding difficulty, as he does, made our 10 days and 1000km nothing in comparison".

Despite sore muscles, frustration over slow or bucking horses, hunger and unpredictable weather conditions the cousins raised over $189,325 for Kiss Goodbye to MS – the biggest Kiss Goodbye to MS fundraiser for 2018!

L-R: Rob Bell, Ed Archibald, Henry Bell & Jack Archibald

**Kiss Goodbye to MS Ambassador Katrina Hemingway lives with MS every day, but she doesn't have MS herself.**

Her husband Mike does, and it was for him and everyone else living with MS that she decided to take on England's most difficult National Trail, the Pennine Way.

Steeped in history, Britain's Pennine Way marches 268 miles along the rocky backbone of England, providing one of the country's most demanding long-distance walks – and one of the most satisfying to complete.

Together with her sister Belinda and brother in-law Neil, Katrina took on the trek to raise awareness and funds for Kiss Goodbye to MS and MS Research Australia.

In the lead up to the event Katrina said that the Pennine Way would be a walk in the park compared to living with MS. Her husband Mike's symptoms vary and since his diagnosis in 2003, the two tackle MS the only way they know how – together.

"Raising vital funds for continued research will hopefully lead to better therapies, improved quality of life, hope and ultimately a cure for the 2.3 million people worldwide, including my wonderful husband Mike, currently living with MS," said Katrina.

After walking 430km in only 16 days, experiencing everchanging terrains, sore feet and blisters and the cruel English weather, Katrina, Belinda and Neil completed their epic adventure in June. They raised over $22,000 for MS research, an amazing effort!

*Left: Neil Robertson, Katrina Hemingway and Belinda Robertson take on Pennine Way*
*Above: Katrina Hemingway and sister Belinda Robertson on the trail*

# A TATTOO IS PERMANENT BUT MS DOESN'T HAVE TO BE

**"A tattoo is permanent – but MS doesn't have to be" That is the statement Jess Rudd and best friend Renee Coffey stood by to raise awareness and funds for vital MS research.**

In 2011, Renee was in her office when she felt a sensation on her ribs, resulting in an intense constricting feeling by the end of the week.

The weeks that followed were difficult and Renee was in a constant battle with the ever-changing symptoms that came with MS. In early 2015, a follow up MRI revealed more disease activity, confirming her diagnosis with MS.

"When I was diagnosed, the first person I called was Jess," she said. "We have been through a lot together and I knew she would be there for me."

Now as young mothers, Jess and Renee didn't have time to climb a mountain or compete in a marathon as a fundraiser. Instead, they decided to get matching tattoos.

The idea came with a simple thought: "What is multiple sclerosis? It's the multiple scarring of the nervous system and we thought scars...tattoo?!"

They decided to start a public donation vote on whether they should get matching tattoos on World MS Day or not. The vote that raised the most money for either 'Yes' or 'No' would seal their fate.

Jess said, "Renee is one of ten Australians a week to be diagnosed with MS and it's quite a difficult thing to live with because you don't know when it's going to strike. You can have these episodic spells that can see your face paralyse, or you can lose speech and it can hit you at any angle at any time and when you're working full time and trying to raise children, it can be very difficult".

So, what did the public decide? The votes were very close until the last minute when a generous anonymous donation of $6,000 pushed the 'No' vote ahead in the final minutes. With a sigh of relief, the duo raised an incredible $33,359 by putting their skin on the line.

*Left & main: Jess Rudd and Renee Coffey*

# 05.

# COMMUNICATIONS

## COMMUNICATIONS AT A GLANCE

**15,230** NEW USERS TO THE KISS GOODBYE TO MS WEBSITE IN MAY

MORE THAN **32%** INCREASE IN OUR TWITTER AUDIENCE

**43,885** VIEWS OF KISS GOODBYE TO MS GAME FACE ACTIVATION VIDEO

MORE THAN **214,000** WEBSITE VISITORS

**30%** AVERAGE NEWSLETTER OPEN RATE (HIGHER THAN INDUSTRY BENCHMARK)

MORE THAN **92,000** PEOPLE ENGAGED WITH OUR FACEBOOK CONTENT

EACH EDITION OF THE MONTHLY NEWSLETTER DISTRIBUTED TO OVER 15,000 SUBSCRIBERS

**1** IN **5** MS RESEARCH AUSTRALIA WEBSITE VISITS CAME FROM SOCIAL MEDIA

MORE THAN **9,000** WORLD MS DAY CAMPAIGN RESEARCH VIDEO VIEWS

WON THE **2018** AUSTRALIAN CHARITY OUTSTANDING ACHIEVEMENT AWARD FOR THE 4TH CONSECUTIVE YEAR

**5** RESEARCH REPORT VIDEOS PRODUCED

MORE THAN **60,000** PEOPLE REACHED BY OUR WORLD MS DAY POST

**12.5%** INCREASE IN MEDIA COVERAGE INCLUDING AFR, SMH, THE AUSTRALIAN, THE AGE AND THE COURIER MAIL

# ENHANCING OUR DIGITAL PRESENCE

**MS Research Australia is dedicated to ensuring that our research information is communicated across a variety of platforms to maximise reach within our community.**

This year we have focussed on increasing our digital presence and embracing more engaging formats such as video, infographics, podcast and live stream.

We introduced an extremely well received monthly Research Report video series, dedicated to exploring and explaining research happening in Australia and around the world. The series interviews researchers from many different specialties about their research and how their findings may help people with MS in the future, covering topics such as AHSCT and Mesenchymal Stem Cells. With over 2,700 views across YouTube and Facebook this year, we expect this figure to continue to increase as our audience becomes more aware of the series.

Seeing how our audience really engaged with our video content, we developed a social media campaign for World MS Day in May called 'Up Close and Personal with our Researchers'. This involved sharing a series of short videos and individual profiles of our MS researchers covering questions such as why it's important to fund MS research, why researchers chose to study MS and what the future of MS looks like. Video views across YouTube and Facebook totalled over 9,300 demonstrating the power of communicating our messages via a more dynamic format.

Taking the video format to the next level, we hosted our first ever live streamed event, 'Progress in MS Research Live update'. This connected the Australian and international MS community with MS researchers and experts in real time. We encouraged audience participation by putting their questions to the panel of researchers, creating a more inclusive feel and ensuring that people living with MS got the most out of the event. For those who were unable to live stream due to time zone differences, an 'on demand' video was made available shortly after the event concluded.

While we have found that videos are a great way to communicate with our audience, it is important to ensure that the content of our communications are on track, up to date and meeting the needs of the community, so we regularly consult with people living with MS and experts in the communications and digital fields.

One such expert who has worked closely with us this year is leading journalist and author Jillian Kingsford Smith who lives with MS and regularly writes for us. We are also lucky enough to work with globally recognised TV producer and person living with MS, Tara King, who consults with us and assists us on a number of projects. Complementing this expertise is Anne Bennett, one of our valued Board Directors and a leading digital and technologies expert, who also provides valuable guidance and advice.

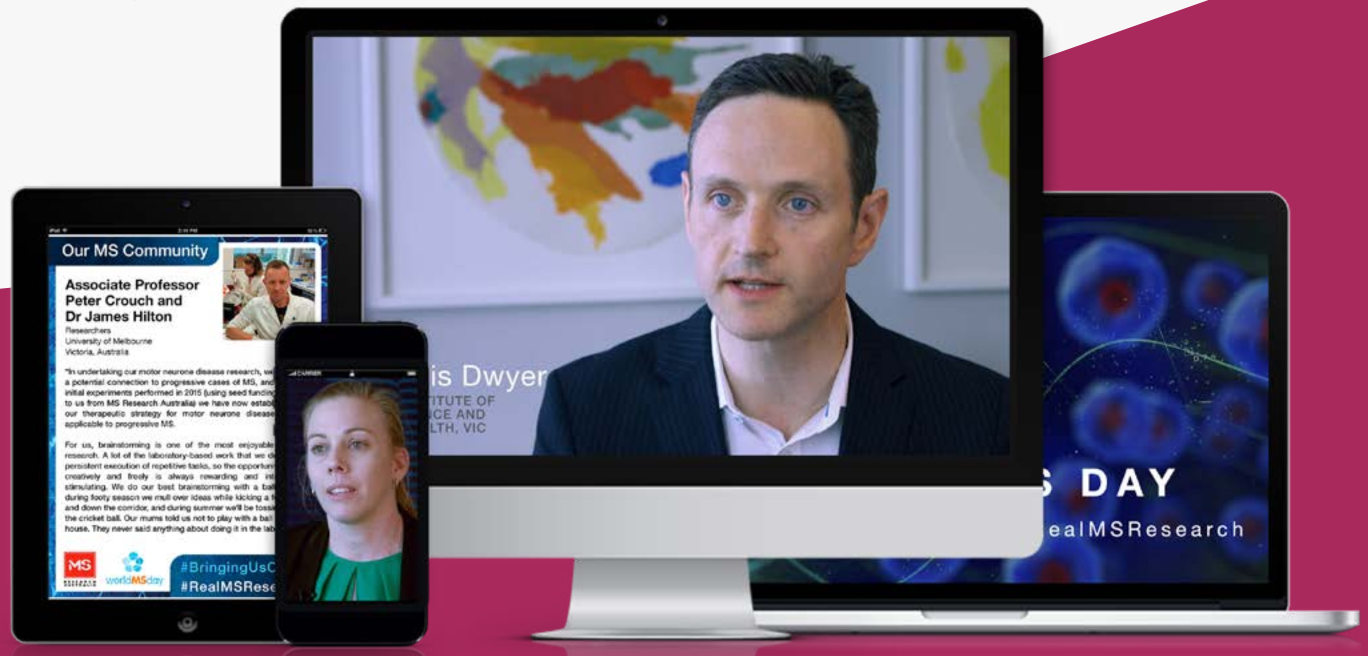
Another of our key communication channels is the MS Wire, our regular e-newsletter, which is sent to more than 13,500 people each month and consistently achieves open-rates of around 30% – better than average for the not-for-profit industry. Our audience continues to reaffirm that the content is of great interest to them, with one reader recently stating, "I wanted to say the content looks excellent and is so relevant and valuable to an MS person like me. Keep up the good work!"

Our website continues to be the place to go for the latest research news and information and embracing digital platforms has also helped us increase our global presence, sharing our first-class research with the world.

As in previous years the majority of our website visitors are based in Australia (approximately 85%), however it is exciting to see that the information and news we post is also being consumed across other English-speaking countries including the United States, United Kingdom, Canada and New Zealand. While these four countries made up almost 15% of our website audience, we also have occasional visitors from places such as India and several other European countries.

A fifth of this website traffic is being driven by our social media channels, which we continue to grow. Social media is proving to be one of the most timely and dynamic ways to communicate with our audience and we are increasing our presence steadily on Facebook, while our Twitter audience has increased by 32% over the past year.

Looking to the year ahead, we are keen not only to maintain the content quality of our research communications but also to enhance the ways in which we communicate. We have some exciting projects in the pipeline, meanwhile look out for more videos and visually dynamic content across all of our digital platforms.



# HITTING
# THE HEADLINES

MS Research Australia has continued to hit national media headlines with a 12.5% increase in media coverage this past year.

## Mum swoops in as saviour

BRIAN BENNION
brian.bennion@news.com.au

A LAST minute donation by Australia's former first lady helped save her daughter and her friend from the tattoo artist in a charity fundraiser.

Jessica Rudd, the daughter of former prime minister Kevin Rudd, and her childhood friend Renee Steenstra had pledged to put to a public vote whether they should get a tattoo — all in the name of charity.

The pair raised $33,209 for MS Research Australia for World MS Day last Wednesday.

At the request of the organisers, Kiss Goodbye to MS, the polls closed early, sending a flurry of last-minute votes, with their mothers leading the charge and former "first lady" Therese Rein taking to social media with "time to vote no".

With 1½ hours left to decide, the yes vote had taken the lead, just $373 ahead.

But in the final hour Ms Rein added $1000 to the no vote, with the comment: "So proud of both of you. But Dianne and I both think that you have quite enough on your plates without getting inked."

Jessica Rudd had earlier thought the yes vote would have sent them to the tattoo studio, saying, "Who would vote no?"

In thanking their supporters she said: "Can't quite believe we are walking away without tatts! With over $30k donated to researchers, we are stoked with the result."

Ms Steenstra said they were overwhelmed by the support of the campaign.

The opening of the voting had seen the women's fathers voting yes and their mothers voting, and campaigning, for a no vote.

Ms Rein had voted no with a $200 donation.

Mr Rudd then voted yes with a $500 donation.

It all got serious when an anonymous donation of $10,000 stoked up the yes vote. Then an anonymous $6000 donation came in for no, making the vote even.

**Can't quite believe we are walking away without tatts!**
Jessica Rudd

Childhood friends Renee Steenstra and Jessica Rudd raise $33,209 for MS Research Australia as ambassadors for Kiss Goodbye To MS. PICTURE: AAP/RENAE DROOP

**THE COURIER MAIL**
COVERAGE OF FUNDRAISERS JESS & RENEE

## Cash drought brings on MS research brain drain

*We are losing our best and brightest young scientists*

JILLIAN KINGSFORD SMITH

The Innovation Nation, the Smart State, the Clever Country ... a host of expressions easily roll off the tongues of our policymakers and educators. And while we can collectively feel smug at our smartness, the real truth is that we are facing a brain drain in Australia that will render devastating effects and have far reaching ramifications.

Late last year, the Australian Society for Medical Research released a report revealing that one in four scientific leadership positions and about 670 research positions — about a sixth of the sector's human capital — had been stripped away from Australia since 2011.

To add insult to the injury, ASMR president Sarah Meachem, said more than 80 per cent of those surveyed were considering leaving scientific research for another career. It doesn't take a rocket scientist to acknowledge that the lack of career opportunities and job

their quest to solve a puzzle. The field itself can be tremendously rewarding and in recent years the MS community has triumphed in many groundbreaking wins. Our scientific superheroes are not leaving for lack of lustre.

Australia has started to become a magnet for brilliant young researchers around the world. With high mobility, immense creativity and high productivity, those early career researchers are the engines of future prosperity. But the success in creating the conditions for young scientists to be attracted to Australia comes with big challenges. For the vast majority of them, we can't find funding.

But most worrisome is that it's predominantly the mid-career scientists who are put in a position where they have to rethink their professional options.

MS Research Australia and the ASMR have surveyed why researchers have left or would consider leaving research and it's unequivocally because of a lack of funding. Similarly, a 2016 report by Professionals Australia shows Australia risks losing the best and the brightest scientists from medical research institutes

financial commitments; housing, families and education. And I imagine scientists at this level can't help but be affected by seeing the lifestyles their peers in different industries are leading, no doubt with far greater financial freedom. To put it into perspective, a dedicated researcher in Australia is likely to be paid less than an executive assistant in the CBD.

Unlike other developed countries, we're not experiencing a migration of our brightest minds in medical research. Instead we're experiencing an evaporation.

So let's bring this closer to home and ponder the effects a brain drain will have on the MS community.

The potential costs of brain drain on MS research can be great: while I find the loss of skills for Australia troubling, my greatest fear is the loss of ideas and innovation. We already know what a complex disease multiple sclerosis is to solve. In among trying to understand the cause of it, we're also aiming to develop more refined treatments, explore the possibility of repair and in our wildest dreams a preventive measure.

This is the time in the history

**THE AUSTRALIAN**
JILLIAN KINGSFORD SMITH OPINION PIECE

HEALTH MATTERS
SEAN PARNELL

## Neurological battle touches a nerve

Neurological conditions are caused by damage to the brain, spinal cord or other nerves, and can have a range of symptoms and degrees of severity. Definitions vary, but some of the most commonly diagnosed conditions are epilepsy, which can occur from birth, and dementia, which is becoming increasingly common with an ageing population. In its latest update on the impact and causes of illness and death, the Australian Institute of Health and Welfare found 6.8 per cent of the 2011 disease burden was a result of neurological conditions, more common among women and older age groups. These are the health problems that continue to plague us as a population and, in some cases, end up killing us. In 2011, dementia cases made up 49.4 per cent of neurological conditions, now likely a majority, followed by epilepsy (14.6 per cent). Thankfully, great work is being done around the world to improve diagnosis and treatment options. Hopefully, these diagnoses will become less of a burden on patients and ultimately such conditions may be able to be avoided altogether or managed into submission.

Parkinson's disease has quite overt symptoms, particularly tremors and shaking, but its cause is more complex and mysterious.

In *The Medical Journal of Australia* recently, Simon Lewis from the University of Sydney's Brain and Mind Centre wrote of global efforts to

Motor neurone disease is fatal and progresses rapidly, but exactly how quickly someone will deteriorate has been hard for doctors to determine.

Researchers at the University of Queensland Centre for Clinical Research have discovered that patients who use more energy at rest are more than twice as likely to die within 12 months of assessment.

"One of the hallmarks of MND is that cellular metabolism in muscle and nerve cells goes haywire, a phenomenon that could impact on whole body energy use," says researcher Frederik Steyn.

Shyuan Ngo, the Scott Sullivan MND research fellow at the UQ Australian Institute for Biotechnology and Nanotechnology, says the finding will help manage disease progression and potentially lead to new treatments targeting the cellular process of energy use.

UQ's Queensland Brain Institute, together with the company NuNerve, is working on a potential drug therapy for use in clinical trials next year. It blocks a protein known as EphA4 and is intended to protect motor neurones and delay progression of the disease.

Multiple sclerosis is an auto-immune condition affecting the central nervous system, but half of the population don't realise the link, according to a survey by MS Research Australia.

**THE AUSTRALIAN**
HEALTH MATTERS FEATURE

The Sydney Morning Herald

POLITICS FEDERAL RESEARCH

## Research leaders plead for charity funding certainty

By Mathew Dunckley & Dana McCauley
9 November 2018 — 4:07pm

Former Australian of the Year Simon McKeon says the future of $9 billion earmarked for a landmark medical research funding body should not be skirted by the major parties heading into the next election.

Mr McKeon, who is the patron of MS Research Australia and headed the review that led to the establishment of the multibillion-dollar Medical Research Future Fund (MRFF), said both sides of politics needed to affirm their commitment to the funding in an environment where uncertainty about money was a major concern.

Simon McKeon, patron of MS Research Australia and Suzi Carp, chairman of Murdoch Childrens Research Institute JOE ARMAO

The fund was established in 2013 and so far has received about $11 billion. The most recent budget has committed to provide another $9

**SYDNEY MORNING HERALD**
COVERAGE OF PATRON SIMON MCKEON

*Main image: Matthew Miles, MS Research Australia CEO on The Today Show, Channel 9*

*Right: Coverage of the Kiss Goodbye to MS Mongol Derby fundraisers on Sunrise, Channel 7*

## 06.

# COLLABORATING FOR IMPACT

## MS INTERNATIONAL FEDERATION

**The Multiple Sclerosis International Federation (MSIF) is a unique global network of over 49 MS organisations, people affected by MS, volunteers and staff from around the world who share a vision of a world without MS.**

MS Research Australia continues to be heavily involved in MSIF with CEO Matthew Miles a member of the MSIF Board and several of our staff participating in either the MSIF fundraising committee, scientific committees or communication teams.

This year we were extremely proud to have been approached by MSIF to write the research articles for their monthly global research newsletter called *MS Research News*.

To be given this opportunity to strengthen our involvement with MSIF is an honour. It demonstrates the level of international trust and respect shown for our organisation, as well as recognition of our willingness to readily collaborate with other organisations in the global mission to find a cure for MS.

Peer Baneke, CEO MSIF said, "Through participating in this collaboration MS Research Australia are leading the way in making the global MSIF movement's strategy a reality in so many ways."

"MS Research Australia are setting a superb example which we will use as much as we can inside the movement to get as many of the other member organisations to join in on research and other global challenges," said Peer.

Global collaborations are a significant part of our strategic plan and we are looking forward to working with MSIF to bring accessible research news directly to MS organisations from around the world to help ensure that the huge world-wide research effort and advances in MS are shared as widely as possible.

## COLLABORATION HIGHLIGHTS

- CO-HOSTED 100 YEARS OF MATESHIP EVENT IN USA WITH NATIONAL MS SOCIETY
- INSTRUMENTAL IN NEW INTERNATIONAL PROGRESSIVE MS ALLIANCE COMMUNICATIONS STRATEGY
- CO-LED & MANAGED THE GLOBAL KISS GOODBYE TO MS CAMPAIGN
- KEY STAFF PRESENTED AT 2018 MS INTERNATIONAL FEDERATION CONFERENCE
- 5 MS RESEARCH AUSTRALIA STAFF CONDUCTING INTERNATIONAL PROGRESSIVE MS ALLIANCE LEADERSHIP ROLES
- MEMBER OF MS INTERNATIONAL FEDERATION BOARD & MEDICAL & SCIENTIFIC ADVISORY BOARD
- $2.4 MILLION COMMITTED OVER 6 YEARS TO INTERNATIONAL PROGRESSIVE MS ALLIANCE
- INSTRUMENTAL IN INTERNATIONAL PROGRESSIVE MS ALLIANCE STRATEGIC PLANNING FOR 2018 AND BEYOND

# NATIONAL RESEARCH COLLABORATIONS

**MS Research Australia works hard to fund and support major national collaborations to accelerate progress in key areas of Australian research.**

We do so through a 'platform' approach which ensures that we complement the world-wide research effort without duplication, fund a highly focused initiative with clear goals and timeframes and identify potential obstacles and solutions to overcome them quickly.

This approach allows researchers and MS research centres around Australia and New Zealand to collaborate on major bodies of work that other funding agencies often don't have the right grant mechanisms to fund or are considered 'too risky' to fund, but have the potential to yield the greatest outcomes for people with MS.

The platform approach was introduced very early on following the inception of MS Research Australia and we have been instrumental in the establishment and ongoing support of a number of successful national research collaborations, including the following:

## THE AUSTRALIAN MS LONGITUDINAL STUDY

Initiatilly established at Canberra Hospital in 2002, the study is owned by MS Research Australia, with researchers at the Menzies Institute for Medical Research (University of Tasmania) commissioned to run the study. It is the longest running MS study in Australia and gathers data on patient reported outcomes and issues of practical importance to people living with MS via regular surveys. Results from the study most recently demonstrated that use of higher efficacy MS medications is associated with better employment retention for people with MS and underpinned much of the data used to develop the *Health Economic Impact of MS in 2017 Report*.

## THE PREVANZ VITAMIN D MS PREVENTION TRIAL

Sponsored and managed by MS Research Australia, the trial is overseen by a team of clinicians and researchers from Australia and New Zealand with expertise in MS neurology, MS clinical trials, endocrinology and epidemiology. The trial is testing whether vitamin D supplementation can prevent MS in people who are at very high risk. Running since 2013 the trial is set to be completed in 2020.

## THE ANZGENE MS GENETICS CONSORTIUM

With funding and coordination support from MS Research Australia, a group of neurologists, geneticists and immunologists have been working together, since 2007 to study the DNA of people with MS to find clues about the causes and mechanisms of the disease. As well as making their own significant discoveries they have collaborated with the International MS Genetics Consortium to help in the discovery of now over 200 genetic variations that contribute to the risk of MS. ANZgene also recently initiated an international collaboration to further mine DNA samples held in their collection using new genetic technology platforms to reveal new information about the genetics of MS.

## THE MS RESEARCH AUSTRALIA BRAIN BANK

Established in 2008 the Brain Bank is a collaboration between MS Research Australia, the University of Sydney, and Sydney Local Health District. The Brain Bank collects post-mortem human MS tissue for use in research to investigate the causes of and develop a cure for MS. The collection now houses over 100 brains and tissue has been used to support over 20 research projects conducted all around the world.

We are incredibly proud that our platforms approach has changed the way MS researchers can carry out MS research in Australia.

# INTERNATIONAL PROGRESSIVE MS ALLIANCE

**MS Research Australia has continued to strengthen our involvement with the International Progressive MS Alliance, a multi-country strong global alliance formed to address progressive MS.**

The Alliance brings together global stakeholders to help unravel the complexities of this frustratingly complex form of MS. Unfortunately, people with primary or secondary progressive MS have not had many of the incredible benefits that successful MS research has brought to those with the relapsing form of the disease - something the Alliance strives to change.

The Alliance focuses on four priority research areas:

- Better understand progression in MS
- Design shorter, faster clinical trials
- Conduct trials to test agents
- Develop and evaluate new interventions to manage symptoms

As one of six managing member organisations, MS Research Australia is integrally involved in the Alliance. CEO Matthew Miles is Vice Chair of the Alliance Executive Committee while Professor Bill Carroll, Neurologist and Chair of MS Research Australia's International Research Review Board and Dr Lisa Melton, MS Research Australia's Head of Research are both members of the Scientific Steering Committee.

This year members of the Executive Committee and the Scientific Steering Committee for the Alliance attended a strategic planning session in London. Following this intensive period of planning the Alliance has now begun to implement several new initiatives to build on the work already underway.

Our very own Dr Lisa Melton has been appointed staff Co-Chair on one of these initiatives, tasked with looking at experimental medicine trials that will provide both biological information about the mechanisms of progressive MS as well as advancing potentially impactful therapies.

Other initiatives will be looking at biomarkers to better track progression and measure repair, and improved symptom management and rehabilitation for people living with MS.

The Alliance has already committed over €52 million to research in to progressive MS, in the hopes of finding breakthroughs and encouraging more international collaborative research efforts.

*Right: Members of the Alliance Executive Committee & Scientific Steering Committee at a strategic planning session in London*

# US AND AUSTRALIAN COLLABORATION CELEBRATED

**MS Research Australia co-hosted an event to celebrate the collaborative work of MS Research Australia and the United States' National MS Society (NMSS) as part of the Australian and US '100 Years of Mateship' program.**

Held at the Australian Embassy in Washington DC, the evening showcased both the Australian and the American MS research efforts, as well as the work of the International Progressive MS Alliance to nearly 100 guests. The event was made possible due to the amazing generosity and support of the Telstra office in New York City, who covered the majority of costs.

First speakers at the event were MS Research Australia CEO, Matthew Miles, and CEO and President of the US NMSS, Cyndi Zagieboylo. As the Vice Chair and Chair of the Executive Committee of the International Progressive MS Alliance respectively – they used this opportunity to talk about the complementary strengths of Australian and US research over the last 15 years including much of the research efforts on understanding both genetic and environmental factors of MS.

Matthew and Cyndi emphasised the need to find solutions, and eventually a cure, for people living with primary and secondary progressive MS and highlighted how global research efforts led to breakthrough therapy Ocrelizumab, the first ever registered treatment for primary progressive MS in Australia, the US and Europe.

World leader in developing new treatments for MS, Professor Stephen Hauser, was the keynote speaker at the event, sharing the incredible 20-year journey of Ocrelizumab, from the earliest concepts, to the registration and FDA approval for both forms of MS.

Recipient of two of the biggest accolades in MS research – the Charcot Award and the Dystel Prize, Professor Hauser has been recognised for his scientific work that challenged the current thinking about MS, and his discoveries have opened new therapeutic avenues for highly effective treatments for MS. Without Professor Hauser's understanding of the role of genetics and immune B cells in MS diagnosis, Ocrelizumab therapy may not exist today.

While many researchers initially did not agree with his theory of the role of genetics and immune B cells in MS, Professor Hauser spoke of the Australian researchers that had faith in his theory and collaborated with him to bring Ocrelizumab to fruition or had actively collaborated on related projects. These Australian researchers included the likes of Professor John Prineas, Professor Graeme Stewart AM, Professor Michael Barnett and Professor Bruce Taylor amongst many others.

Professor Hauser also acknowledged the important role that the Australian individuals living with MS played in the early days of research, by participating in clinical trials relating to the new therapy.

A huge thanks must go to the Office of the Australian Ambassador, the Hon. Joe Hockey and the Minister, Anthony Turfett as well as the Embassy team for making this overseas event a reality. Our thanks also to Telstra Global, based in New York, for sponsoring the event.

# AUSTRALIAN IMMUNOLOGICAL ALLIANCE

**MS Research Australia is proud to be the current chairing member of the Australian Immunological Alliance, a group of not-for-profits representing immunological diseases who work together to fight for common goals, learn from each other's experiences and bring about more rapid change for the people we represent.**

The idea for the Alliance was born out of the success MS Research Australia had working with JDRF Australia on a research project on the common risk factors and genetics of MS and type 1 diabetes. This spurred MS Research Australia and JDRF Australia to discuss the idea further with senior leaders at the Macquarie Group Foundation and broaden this idea to include other organisations working with related diseases.

Since then Alliance members have met to determine direction, develop the charter and guide ongoing activities, providing valuable collaborative and learning opportunities along the way.

Together the Alliance have developed a shared narrative that reflects the experience of people with immunological and autoimmune diseases in Australia that the Alliance can use for shared advocacy and awareness, effectively boosting the voices of individual organisations beyond that of their single disease group.

This narrative was used when the Alliance made a submission to the Commonwealth Government's priority setting consultation for the Medical Research Future Fund 2018-2020. This joint submission was a collaborative effort that highlighted the need for research across the represented conditions to be prioritised within the Medical Research Future Fund.

The Alliance also plans to collaborate on shared research initiatives, particularly common gaps and areas of common interest across the immunological and autoimmune conditions represented.

**THE IDEA FOR THE ALLIANCE WAS BORN OUT OF THE SUCCESS MS RESEARCH AUSTRALIA HAD WORKING WITH JDRF AUSTRALIA**

In 2018, Alliance members participated in a survey to identify these perceived research gaps with results currently being collated and analysed to identify research that will be of most value.

It is hoped that the next stages of the Australian Immunological Alliance will provide forward momentum for joint research projects and further develop the Alliance as a significant shared platform that provides value to its members' efforts to improve outcomes for people with immunological and autoimmune conditions across Australia.

*Left: Ian Smith, USA National MS Society Chief Research Officer Dr Tim Coetzee, Professor Stephen Hauser, USA National MS Society CEO and President Cyndi Zagieboylo, MS Research Australia Chairman Paul Murnane, MS Research Australia CEO Matthew Miles*

*Right: Matthew Miles, CEO MS Research Australia & Mike Wilson, CEO JDRF Australia*

## KISS GOODBYE TO MS
## GLOBAL HIGHLIGHTS

MORE THAN $4.5
MILLION RAISED
GLOBALLY SINCE 2016

9 RESEARCH TEAMS
CREATED 'BATTLE OF
THE LABS' VIDEOS

15 COUNTRIES, 5 CONTINENTS
& 9 LANGUAGES INVOLVED IN
KISS GOODBYE TO MS

3 COUNTRIES
CELEBRATED RED LAB
COAT DAY

MORE THAN 18,000
PEOPLE USED
#KISSGOODBYETOMS
ON INSTAGRAM

400,000 PEOPLE REACHED
WITH GLOBAL GAME FACE
VIDEO

# KISS GOODBYE TO MS
# TAKES ON THE WORLD

**The Kiss Goodbye to MS global community continued to embrace our Aussie-founded campaign, working side by side as part of the worldwide effort to raise funds for MS research.**

The first MS campaign to ever have a global footprint, Kiss Goodbye to MS has raised more than $4.5 million in just three years.

This year has been our biggest Kiss Goodbye to MS campaign yet, with 15 countries across the globe getting involved. We again joined forces with Canada, United States, Norway, Finland, Denmark, Spain, UK, Netherlands, Greece, Ireland, France, New Zealand and were thrilled to welcome Egypt and Lebanon.

Researchers from the Netherlands, Ireland, New Zealand and Australia changed their white lab coats to red ones for Red Lab Coat Day which kicked off Kiss Goodbye to MS and MS awareness month on May 1.

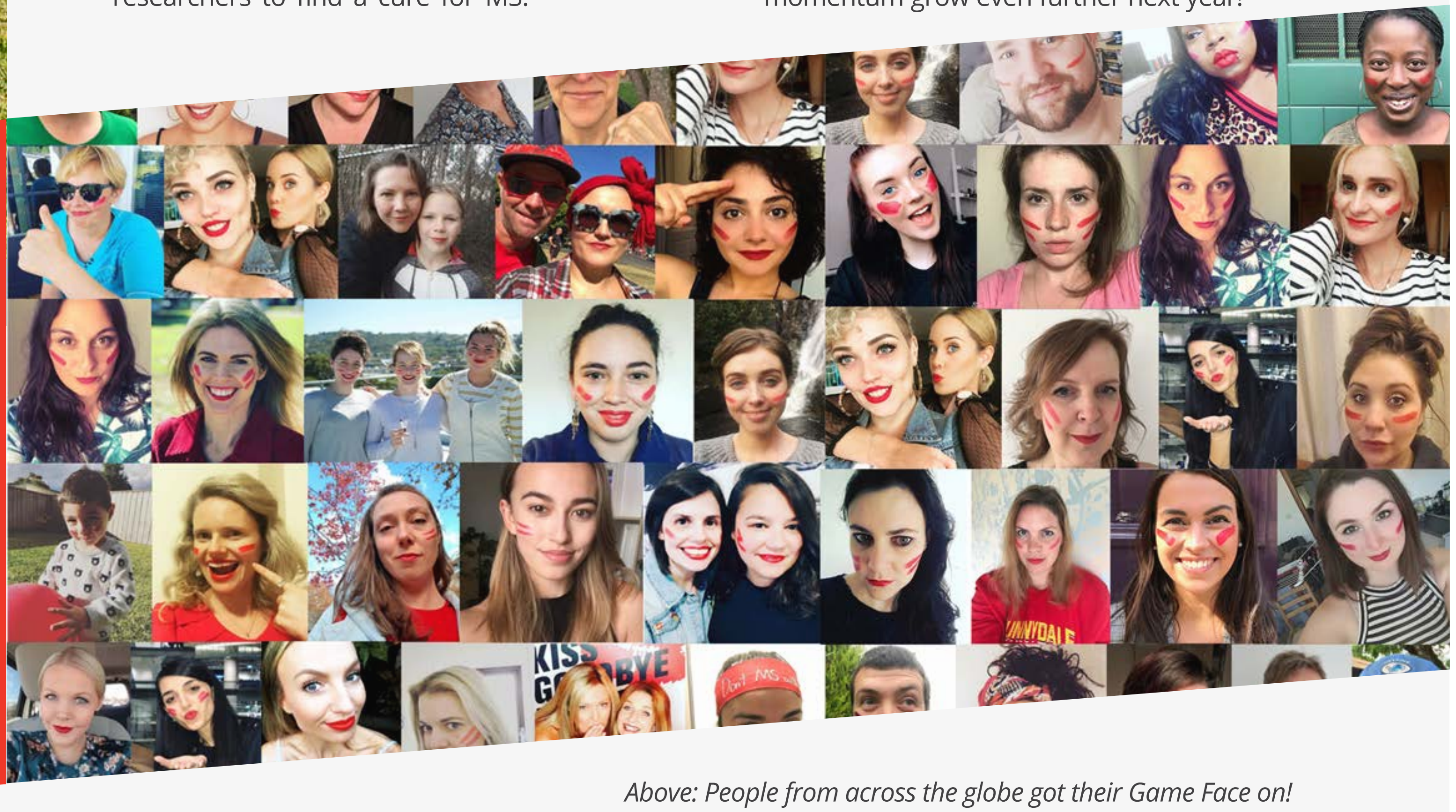
Red Lab Coat Day is our annual day where we stop for a moment to say thank you to our MS researchers across the world and highlight the significant contributions and invaluable work of our Australian researchers to find a cure for MS.

Another highlight of this year's campaign saw our Kiss Goodbye to MS community across the world put on their 'game face' to raise awareness for MS research and reach over 400,000 people on social media.

People with MS put on their game face every single day, often hiding their many invisible symptoms which come with the disease. We challenged our global community and received hundreds of photos of people applying their game face – young and old, at home or while surfing, our MS Squad took it to the next level and surprised us with their creativity.

Our global game face video was watched over 400,000 times on social media and the #KissGoodbyeToMS hashtag was used over 18,800 times on Instagram, showing that our global community is truly united and stronger than ever before.

We are looking forward to seeing our global momentum grow even further next year!



*Above: People from across the globe got their Game Face on!*

## 07.

# FINANCE

## FINANCE AT A GLANCE

**$6.6 MILLION**
INCOME, FINISHING 2018 IN A SOLID FINANCIAL POSITION

**$300K SURPLUS**
RECORDED FOR THE FINANCIAL YEAR

**66.1% OF ALL REVENUE**
CAME FROM MS RESEARCH AUSTRALIA FUNDRAISING

**$206K**
IN INESTMENT EARNINGS, A RETURN OF APPROX. 2.6%

**MORE THAN $200K**
INCREASE IN BEQUEST INCOME

**30.6% INCREASE**
IN RESEARCH EXPENDITURE THIS FINANCIAL YEAR

VISIT THE AUSTRALIAN CHARITIES AND NOT-FOR-PROFIT COMMISSION (ACNC) FOR DETAILED FINANCIAL RECORDS OF MS RESEARCH AUSTRALIA'S 2017/2018 FINANCIAL YEAR

**$5.5 MILLION**
COMMITTED TO FUTURE ONGOING RESEARCH PROJECTS

**$1.957 MILLION**
COMMITTED TO NEW RESEARCH GRANTS

**$61.9 MILLION**
RAISED SINCE 2004 BASED ON AUDITED FINANCIALS

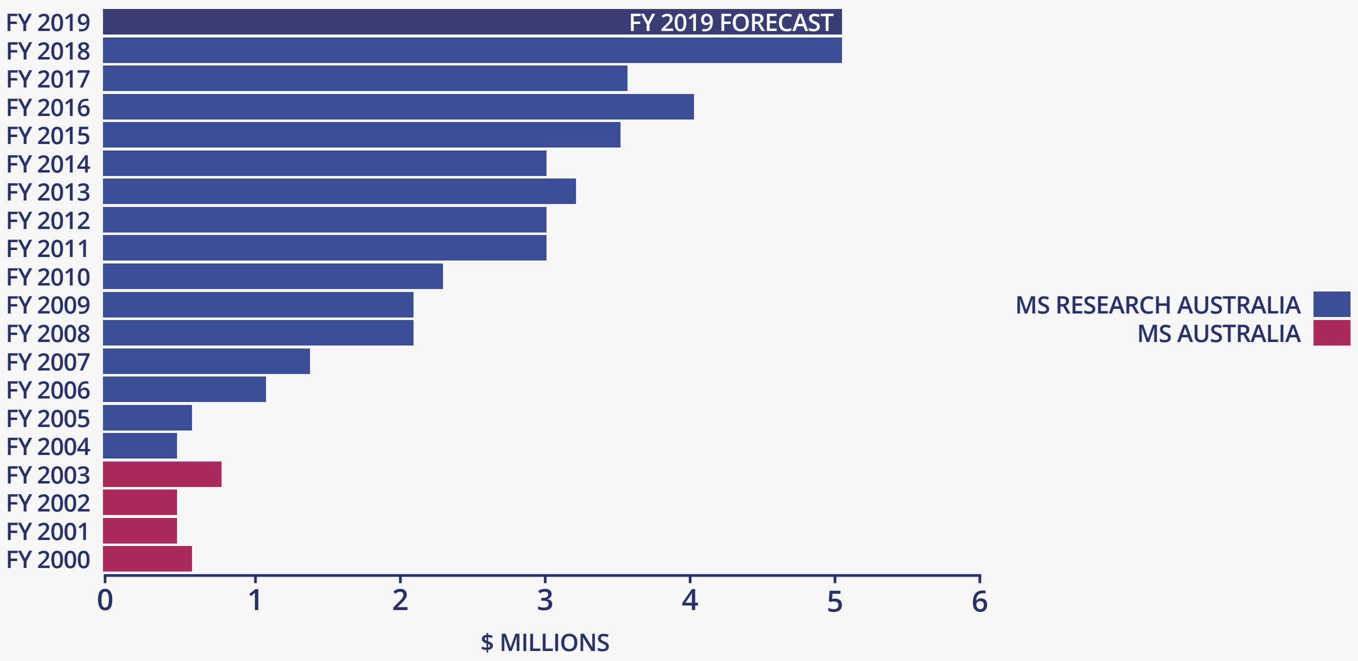
**77C OF EVERY DOLLAR**
RAISED GOES TOWARDS FUNDING & FACILITATING MS RESEARCH

**13 TOTAL STAFF**
WITH 11.4 ON A FTE BASIS

**$1.5 MILLION**
RECEIVED FROM MS WA

# GROWTH OF INVESTMENT INTO MS RESEARCH

2000-2019 FINANCIAL YEARS ($ MILLIONS)



# INCOME & EXPENDITURE

**INCOME**

- Donations/fundraising 41.5%
- State MS Societies 33.9%
- Kiss Goodbye to MS fundraising 12.3%
- Bequests 5%
- Grants from Government 4.2%
- Other 3.1%

**EXPENDITURE**

- Collaborations/platforms/funded 35%
- Grants funded 25.9%
- Advocacy/awareness/education/mission delivery 15.3%
- Cost for fundraising 12.4%
- Administration 11.4%

# SUPPORT FROM THE STATE MS SOCIETIES

**33.9%** OF ALL REVENUE WAS RECEIVED FROM THE VARIOUS STATE-BASED MS GROUPS

**STATE MS SOCIETY SUPPORT**

- MS WA $1,500,000
- MSL (MS ACT/NSW/VIC/TAS) $330,000
- MS QLD $380,595
- MS SA/NT $25,000

RESEARCH AUSTRALIA

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