

PREVENT TREAT CURE

Annual Impact REPORT 2017



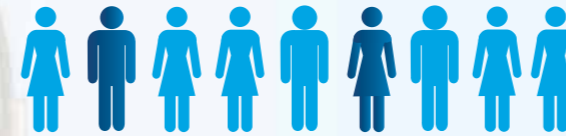
RESEARCH
AUSTRALIA

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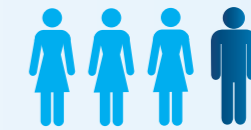
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The latest about MULTIPLE SCLEROSIS (MS)

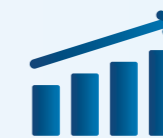
25,000+ Australians are living with MS



Of every 4 Australians diagnosed with MS 3 will be women



More than 2.3 million people worldwide live with MS



Over 1 million people live with the progressive form of the disease

What is multiple sclerosis (MS)

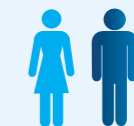
MS is the result of damage to myelin – a protective sheath surrounding nerve fibres of the central nervous system. When myelin is damaged this interferes with messages between the brain and other parts of the body.

MS Research Australia

MS Research Australia is dedicated to funding, coordinating, educating and advocating for MS research as part of the worldwide effort to solve MS.



MS is caused by a complex interaction between genetic and environmental factors



Every day between 1 and 2 Australians are diagnosed with MS



MS is different for everyone no two people will have the same severity or combination of symptoms



30-40 The average age of diagnosis



People with MS are at the heart of our organisation.



“Winning awards reinforce the credibility of an organisation by the rigorous analysis of operations and financials required.”



We often talk about the change in landscape for many people with MS and how drastically it has changed over the past 20 years. As a carer for my wife, Annie, who has MS, and as someone who has worked in the not-for-profit sector for over 20 years and with MS Research Australia for 10 years, I am reasonably attuned to describing that change.

Annie was diagnosed 21 years ago, but experienced symptoms from the age of 18. I have seen how MS research has progressed over this time; the increase in treatments, diagnosis and the sheer volume of research being conducted. It is making a significant difference and MS Research Australia is largely involved in this rapidly changing landscape.

This year, and by any metric, we have undoubtedly had our most successful year to date, both financially and in terms of being instrumental in bringing the global MS community closer together. This has included our pivotal role as a managing member on the International Progressive MS Alliance, our leadership and Board roles with

MSIF and with various international MS research collaborations, and, of course, the MS Research Australia-founded Kiss Goodbye to MS fundraising campaign, which has now been adopted globally.

These are all exciting opportunities and initiatives that take time, drive and focus. They also take dedication, shared values and a belief that you are on the right track to lead such collaborations. I applaud the commitment of MS Research Australia staff who work tirelessly to contribute to our mission and goals.

With \$8.3 million raised this year, it allows us more than ever before to invest in the best MS research, to continue our role in education, coordination, research advocacy and facilitation - nationally and increasingly, globally.

However, there are dark clouds approaching. Analysis has shown that the 'research gap' between what is currently available for MS research annually versus what is actually needed, will blow out to over \$10 million annually within a relatively short period of time. This

is increasingly worrying for us, not only to ensure our own fundraising manages to increase to cover that shortfall, but to keep our best and brightest MS researchers in Australia, and, in MS. Over 75% of Australian MS researchers who left the profession in 2017 cited a lack of funding as their primary reason for leaving.

As one of the 7 million Australians who know someone with MS, it's a devastating issue that is very close to my heart. But to make this insidious disease go away completely, we need everyone to care. MS Research Australia is the platform to bring all Australians to that point so that we can ultimately cure MS. It won't be a singular weapon, it will be a multi-faceted attack. But it's achievable in our lifetime if we commit ourselves and be laser-focussed on this cause.

Paul Murnane

Chairman, MS Research Australia

The MS Research Australia 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 Advisory,
family connection to MS



Tanya Branwhite

Financial and investment market



Anne Bennett

Digital Communications



Professor Graeme Stewart

Clinical Immunologist,
Professor of Medicine



Mike Hemingway

Financier and molecular biologist,
direct connection to MS



Graham Tribe

Corporate Management



Dr Annette Carruthers

General Practitioner,
direct connection to MS



David Simmonds

Audit, Finance & Risk



Richard Bergman

Risk and Cyber Investigations,
family connection to MS

“ MS Research Australia has been able to increase the initial MS research contribution figure 10 fold in just 13 years. ”



MS Research Australia has continued to go from strength to strength and the organisation's ongoing success in 2017 has been the much-needed boost the MS community needed.

Formed in 2004, to address the endemic lack of funding for MS research in Australia, MS Research Australia has achieved a 10 fold increase in research funding in just 13 years.

As the Founding Chairman and now Patron, it has been wonderful to see not only the funding quantum to research but, more importantly, the impact of that funding for people with MS both nationally and globally.

From a strategic standpoint, we have seen the number of therapies available to people with the relapsing form of MS in Australia increase from just a couple of options to 12. There has been a drastic reduction in the number of hospitalisations due to MS on a global scale (by over 70%) and an improvement in employment outcomes for the majority of people with MS. A global push for early diagnosis and the corresponding improvement in outcomes for people diagnosed earlier and quicker has also driven a reduction in the time

from first symptoms showing to definitive diagnosis.

These improvements only happen because of the funding contributed to quality research and because we have the people, resources and expertise to facilitate national and global collaborations. The focus, hard work and drive of many people have led to these improvements.

I would like to acknowledge the incredible and tireless work of Founding CEO, Jeremy Wright and Founding Research Chairman, Professor Bill Carroll who have been absolutely instrumental in the success we have seen.

Many of the successful research structures, governance initiatives and some of the fundraising opportunities and collaborations were set up at a very early stage. Over the past four years, MS Research Australia's CEO, Matthew Miles, has carried that desire, drive and expertise forward with a supportive Board of diverse and experienced individuals. They need to implement both a global and collaborative approach with like-minded organisations, which was identified by Matthew very early on in his appointment as CEO.

This has been implemented very successfully through his hard work and determination in recent years.

Going forward, there is a lot of work still to be done. We need to find ways to repair the damage done, find additional and effective treatment options for people with MS and of course, prevent MS from developing in people in the first place. These are the large and complex areas that must be addressed and it will only be through collaborating with the best and brightest minds, wherever they are, that we will uncover the ultimate results we all long for.

Mr Simon McKeon AO

Patron, MS Research Australia and 2011 Australian of the Year
Co-author 'McKeon Review on Health and Medical Research'



Dr Scott Byrne,
Researcher,
The University of Sydney

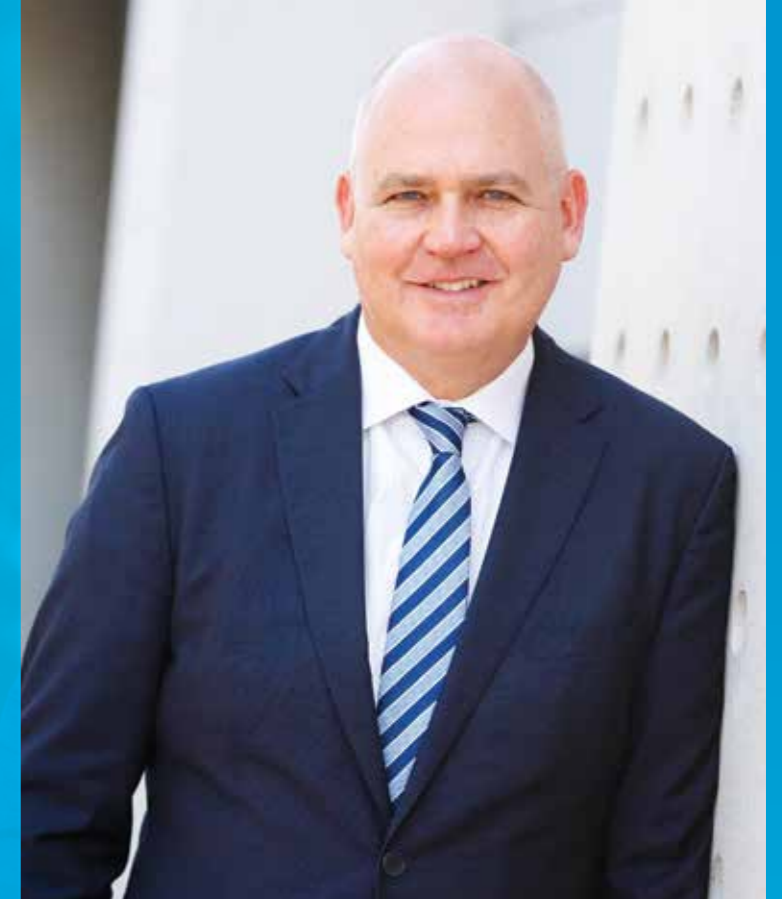


Therese Burke,
MS Nurse

“

Our goal has been to always fund great ideas and leverage that funding.

”



If there is one breakthrough story in 2017 that really defines and epitomises MS Research Australia, it's most certainly the world-first discovery of a blood biomarker for MS. This discovery has the potential to be the first-ever blood test to differentiate between the different subtypes of MS. Led by Australian researchers, Professor Gilles Guillemin, Dr Edwin Lim, Professor Bruce Brew and their colleagues. This story hit the front page of The Australian newspaper in early 2017 and received over 1 million hits on the ABC website. It wasn't long before the news went worldwide.

What's really important to understand about this breakthrough is that it originated from a single \$15,000 MS Research Australia incubator grant. These year-long grants fund 'out of the box ideas' and provide a chance for our researchers to test a theory and get pilot data on their research direction. The area of research that led to this discovery was not well developed in MS at all, but it

took the expertise and foresight of our Research Management Council (RMC) to see its potential future implications for the MS community down the track.

We hope that our funding reaches this sort of milestone for all MS researchers, especially ones at a young age. Most importantly, we hope that this blood test becomes an important clinical test and tool for neurologists to use, a prognostic indicator and more for people with MS.

It continues to be an absolute pleasure working with my MS colleagues around the world as a participating member of the International Progressive MS Alliance and the MSIF Board. Our global research collaborations are aiming to find treatments for progressive MS and together we are providing more than hope - we are seeing progress. We have also been able to partner with global MS researchers, industry, regulators and biotech to continue the search to find real solutions for people with progressive forms of disease.


Finally, in 2017 it was thrilling to see the first ever drug approved for use in patients with primary progressive MS. After decades of having no options available, this is an important milestone in the world of MS. We now feel confident that more solutions for people living with progressive diseases are not only possible in a short timeframe, but likely. When they occur, they simply must be affordable and accessible to all.

Dr Matthew Miles

CEO, MS Research Australia
Executive Committee Vice Chair,
International Progressive MS Alliance
Board Director,
MS International Federation

OVERALL RESEARCH AT A GLANCE

 **24 NEW** research grants @ \$2.046 million

 **42** investigator-led projects currently being supported by MS Research Australia

 **\$825,000** inc GST Department of Health grant awarded to underpin research operations and core fundraising activities

Research breakthrough  **world-first blood test** that can distinguish between the different types of MS



1,050 people from the MS community completed the research priority survey. Research priorities identified were:
a) Finding a cure for MS via repair and regeneration
b) Developing better treatments for MS
c) Preventing MS



New grant online application platform developed



MS research updates and presentations to people affected by MS, stakeholders and health professionals across Australia

 In partnership with JDRF Australia, we established the **Australian Immunological Alliance** – a collaboration of non-for-profit organisations



International research efforts and local advocacy leads to **first ever treatment approved** by the TGA for primary progressive MS

“

If it wasn't for MS Research Australia, my research wouldn't have got off the ground.

– Professor Gilles Guillemin

”

OVERALL RESEARCH HIGHLIGHTS

✓ MS Research Australia grants are classified as **Category 1 competitive funding**

54+ universities and research institutes funded

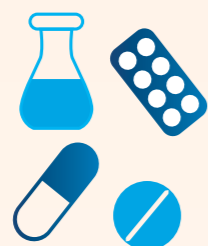


900+ Australian researchers and clinicians working on MS

Funding and coordinating **7 major research collaborations/platforms**



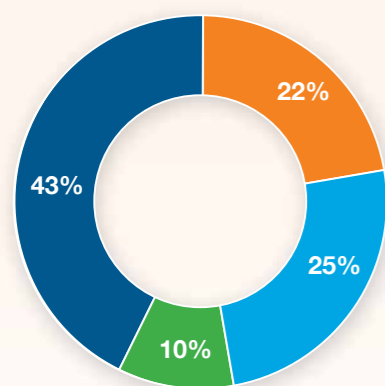
12 treatments now available for people living with MS



Established the first ever **vitamin D MS Prevention Trial**

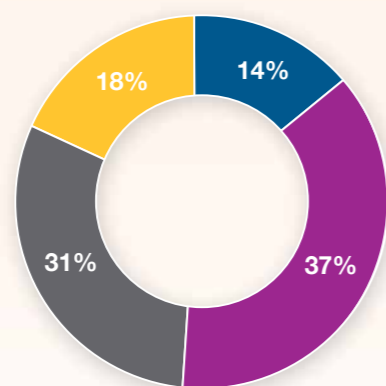


RESEARCH FUNDING ALLOCATIONS



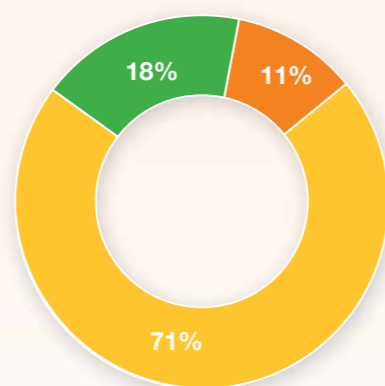
Research funding

- Investigator-led projects
- National research collaborations
- Fellowships and scholarships
- International research collaborations



Research streams

- Genetics & Epidemiology
- Immunology
- Neurobiology
- Social & Applied Research



Research focus

- Developing better treatments
- Identifying the triggers of MS
- A cure for MS via repair or regeneration

World-first discovery

An MS Research Australia incubator grant of just \$15,000 was the catalyst for a major international study, led by Australian researchers Dr Edwin Lim, Professor Gilles Guillemin and Professor Bruce Brew. They have discovered the first-ever blood biomarker – a chemical identifier in the blood to distinguish the different types of MS.

MS has three recognised forms; relapsing remitting MS, secondary progressive MS and primary progressive MS. The various forms of MS are likely to be due to different changes in the immune system and have very different outcomes and treatment implications. Traditionally, distinguishing between MS subtypes and confirming diagnosis has been a lengthy and challenging process requiring an array of tests. The good news is that this process looks set to change, thanks to this blood biomarker breakthrough.

Not only does this research open up the possibility of a test to discriminate between the types of MS, but there is potential it might also provide key insights into the changes that go on at a cellular level leading to the different forms of MS. This would enable the development of further, targeted, treatment options for people with MS.

The researchers believe a quick and accurate blood test could be a reality in the next 2 years and it also has potential implications for diseases such as Alzheimer's, Parkinson's and Motor Neuron Disease.

Professor Guillemin explains "This is a significant discovery because it will facilitate the ability to quickly and simply diagnose the three types of MS and will allow clinicians to adapt their treatment for MS patients more accurately and rapidly."



Professor Gilles Guillemin and Dr Edwin Lim, Macquarie University



They have discovered the first-ever blood biomarker – a chemical identifier in the blood to distinguish the different types of MS.



The outstanding research outcomes from this project led to an MS Research Australia Fellowship for Dr Edwin Lim and further funding from the National Health and Medical Research Council (NHMRC), which is another role of the incubator grant programs – to help leverage additional funding and other opportunities.

Dr Matthew Miles, CEO of MS Research Australia, explains the importance of this research and why MS Research Australia got behind it with a grant: "We have been excited to be part of the translation of this fundamental research into a potential clinical blood test. This has the clear capacity to be the first ever blood biomarker for the prognosis of MS, and in doing so will meet one of the real unmet needs in the clinical management of MS."



Dr Fiona McKay,
Researcher,
The University of Sydney

Determining MS research priorities

In 2016, the MS community were consulted for their opinion on the MS research priorities here in Australia. The MS Research Australia survey was designed to capture the views of the MS community, while discovering which areas of MS research are considered important by people directly and indirectly affected by MS, as well as health professionals and researchers.

MS Research Australia believes it is critical to incorporate the views of the MS community into their research strategy.

There were 1,058 survey participants, including 774 people who have MS, 219 who have a direct connection to MS (through a family member or friend) and 65 participants who are MS health or scientific professionals.

After evaluating the results, the top MS research priorities were clearly identified as:

- **Finding a cure for MS** (via repair and regeneration of cells)
- **Better treatment of MS** (relapses and disease progression)
- **Preventing MS**

MS Research Australia has incorporated the above priorities, into their ongoing research strategy to ensure that the Australian research they fund aligns directly with the needs and wants of the MS community.



Dr Hamish Campbell, MS Research Australia



Dr Kaylene Young and Professor Bruce Taylor, Menzies Institute for Medical Research

“
This Fellowship pairs a laboratory and a clinical researcher side-by-side, to fast-track ground-breaking research and to accelerate its translation from the laboratory into clinical reality.
 ”

Innovative new ideas

In late 2016, MS Research Australia successfully secured generous funding from the Macquarie Group Foundation that enabled the launch of an inaugural MS Research Australia-Macquarie Group Foundation Paired Fellowship. This Fellowship pairs a laboratory and a clinical researcher side-by-side, to fast-track ground-breaking research and to accelerate its translation from the laboratory into clinical reality.

Applications opened in early 2017 and a panel of five independent MS experts assessed each application based on the applicants' track record, their research relevance to MS, its translational impact and importantly, what would be gained from the paired team.

The panel concluded that whilst all of the applications were very strong, with programs of enquiry highly relevant to people with MS, there was one team that particularly stood out - Dr Kaylene Young (laboratory researcher) and Professor Bruce Taylor (neurologist and MS researcher) from the Menzies Institute for Medical Research at the University of Tasmania. The pair became the inaugural recipients of the Fellowship, which commenced on 1 September 2017.

Dr Kaylene Young's and Professor Bruce Taylor's research program is focused on two significant discoveries:

- The first is the identification, via clinical research, of genetic mutations associated with the development of MS. The team will investigate the effects of these genetic changes in the laboratory, with the aim of finding interventions that can be tested clinically to target these genetic mutations.
- The second avenue of research builds on Dr Kaylene Young's discovery that non-invasive transcranial magnetic stimulation can be used to promote myelin repair. Over the course of the Fellowship, Dr Kaylene Young and Professor Bruce Taylor will work together to translate these findings into a series of clinical trials to determine whether this treatment is safe and effective for people with MS.

The Fellowship addresses one of the key recommendations made in the 2013 McKeon Review into Health and Medical Research, which suggests that more clinicians need to participate in research, to help reduce the time it takes for patients to clinically benefit from research. For people with MS the Fellowship means they will reap the benefits of life-changing research much sooner.



Dr Grant Parnell, The Westmead Institute for Medical Research

Opening the door to cross-disease research projects

Dr Grant Parnell, from Westmead Institute for Medical Research, was the recipient of a unique Fellowship jointly funded by MS Research Australia and JDRF Australia, with the support of the Macquarie Group Foundation.

This unique Fellowship has led to the development of new collaborations across disease fields and opened the door to further cross-disease research projects.

Dr Grant Parnell has been deeply investigating the shared genetic and environmental risk factors for developing MS and Type 1 Diabetes (T1D), to ultimately improve our understanding of both conditions.

As a result of his Fellowship research, Dr Parnell reviewed the evidence that in both MS and T1D it is common for people to have experienced a viral infection prior to developing either disease. There is also a latitude effect for the risk of developing both diseases, with the risk increasing the further away from the equator you live. These factors - viruses, UV light and vitamin D - may all play a role in modulating the activity of the immune system, increasing its activity and the chance it may mistakenly attack a person's own body.

Genes in humans can have small variations between one person and another. Dr Parnell's work pulled together all the information that has been gathered to date on the gene variations that affect the risk of developing either T1D or MS. Many of these genes are important in cells of the immune system, and their activity is affected by the amount of vitamin D in a person's body. To extend this research Dr Parnell has also looked closely at the DNA from a small group of people with both MS and T1D. He found several unique features, including the complete absence of a key gene variation known to increase the risk of MS, but which protects against T1D.

Further analysis of the novel genetic features identified will provide important information for our understanding of the biology of both diseases, but may ultimately help in developing new therapies for both diseases and in screening people diagnosed with either MS or T1D, to predict the risk of developing the other disease.



“
This unique Fellowship has led to the development of new collaborations across disease fields and opened the door to further cross-disease research projects.
 ”

Purpose driven collaborations

The Australian Immunological Alliance is a purpose-driven collaboration between a broad range of 15 not-for-profit organisations who all have a deep interest in improving the diagnosis, treatment, outcomes, funding and awareness of immune and autoimmune diseases and disorders.

The Alliance was formed as a result of the combined MS/Type 1 Diabetes research project conducted by MS Research Australia and JDRF Australia. Both organisations are founding members of the Alliance and the other members include:

- Allergy and Immunology Foundation of Australasia
- Arthritis Australia
- Australasian Society for Clinical Immunology and Allergy
- Autoimmune Resource & Research Centre
- Asthma Australia
- Brain Foundation
- Coeliac Australia
- Crohns & Colitis Australia
- IDFA
- Lung Foundation Australia
- Lupus support groups
- Rheumatology Association Australia
- Thyroid Foundation



Members of the Australian Immunological Alliance

The purpose of the Alliance is to improve the quality of life and outcomes for people who live with immune and autoimmune conditions. This is achieved through:

- Focusing on what Alliance members can collectively achieve, in addition to each organisation's own mission, priorities and activities
- Increasing the profile of immunological diseases in Australia
- Educating clinicians, funding bodies, government decision-makers, patients and the broader community about the collective impact of immune and autoimmune disorders
- Seeking to better understand the strengths and gaps in current research and clinical knowledge of immune disorders and their treatments – including prevalence in the population and the multiple diagnoses of immune diseases in individuals and families
- Encouraging and facilitating research to address the many gaps in our existing knowledge and strengthening our understanding of the common biological mechanisms underlying immune and autoimmune disorders

What has become clear for the Alliance is that the data and information detailing how many people in Australia have immunological conditions and what the annual cost to the Australian health system is, does not exist. One of the Alliance's initial goals is to determine this vital information.

All Alliance members acknowledge the Macquarie Group Foundation for their ongoing support, innovative ideas and focus on fostering collaboration.

“

The purpose of the Australian Immunological Alliance is to improve the quality of life and outcomes for people who live with immune and autoimmune conditions.

”



Key government grant renewed

Since MS Research Australia's inception, government grants have provided crucial organisational income to help reduce administrative costs and maximise funding available for MS research projects.

In 2017, MS Research Australia were pleased to announce a renewed commitment of \$825,000 from the Commonwealth Department of Health over the next 3 years (2017 – 2019).

This signature grant, which commenced in 2004, initially enabled MS Research Australia to establish itself and has since been renegotiated every 3 years. With much advocacy and hard work on both sides, this important Commonwealth grant will continue to underpin many of MS Research Australia's research administration, facilitation and fundraising activities.

Dr Matthew Miles, CEO of MS Research Australia explains the importance of this funding: "The funding from the Commonwealth Department of Health has been important in many ways in helping us achieve our recent MS successes, in both a national and, increasingly, global setting. With a modest organisational team of 13 people, this has allowed us to do much more for the MS research community and people affected by MS, than we ever thought would be possible."



Dr Bernd Merkel, Dr Tobias Merson and Dr Lisa Melton

The research team at MS Research Australia, led by Dr Lisa Melton, provides detailed biannual progress reports to the Commonwealth Department of Health on the team's achievements in-line with the agreed targets. This reporting process encompasses various commitments, including conference and workshop participation, facilitation of national collaborative research platforms, engagement with global collaborators, communication of research progress to the MS community and strengthening of fundraising activities.

MS Research Australia will continue to advocate strongly for further opportunities to partner with state and federal government departments to support MS research in Australia. Sustained government funding, both to MS Research Australia and the broader MS research community, remains critical for our shared mission of better treatments, prevention of MS and ultimately finding a cure.

First treatment for primary progressive MS approved in Australia

A new MS medication called Ocrevus – treating both relapsing and progressive MS – reached the end of its development pipeline in 2016. Ocrevus was granted marketing authorisation by the Therapeutic Goods Administration (TGA) in Australia (and other regulatory bodies globally) in 2017.

The International Progressive MS Alliance, of which MS Research Australia is a managing member, has played a key role in advocating with regulatory agencies worldwide about the pressing need to accelerate access to treatments for people with progressive MS, including medications like Ocrevus.

Professor Alan Thompson, Chair of the Alliance's Scientific Steering Committee, explains why:

"We are encouraged by the continued focus of the regulatory agencies and the progress being made to bring forth treatments for this disabling form of MS. One cannot underestimate the importance and impact of the very first treatment for primary progressive MS – this is the crucial first step in finding ever more effective treatments for everyone with progressive MS."

Within Australia, MS Research Australia helped advocate for a successful submission to the Australian Pharmaceutical Benefit Advisory Committee (PBAC), advocating for a reimbursement listing for Ocrevus on the Pharmaceutical Benefits Scheme (PBS) for relapsing remitting MS.



Professor Alan Thompson, University College London Hospital

FUNDRAISING AT A GLANCE



Celebrating 10 years of long standing support from Macquarie Group Foundation, ISPT, AFA Foundation, Perpetual Trustees

Charity partner of the **Sohn Hearts and Minds Investment Leaders Conference**



More than **\$850,000** in pro bono services

Large grant received to fund the **2017/8 Economic Impact Report** on MS

Over \$1million received from **Trusts and Foundations**



MS Research Australia engages with over **130** Trusts and Foundations



15% increase in regular givers

Increased focus on **work place giving programs**



Largest singular gift of **\$1.5million** from an individual

4106 donations received from individuals and regular givers

MS Angels have raised over **\$1 million** for research into MS



Increase of **54%** of confirmed bequestors



We are inspired to raise much needed funds for research into MS. The search for a cure provides hope for patients and families like ours, living with the challenges of MS. We are at a pivotal moment where researchers are making significant progress. We all need to get behind this cause to ensure we can live in a world free of MS.

– Millie and Sarah Horton

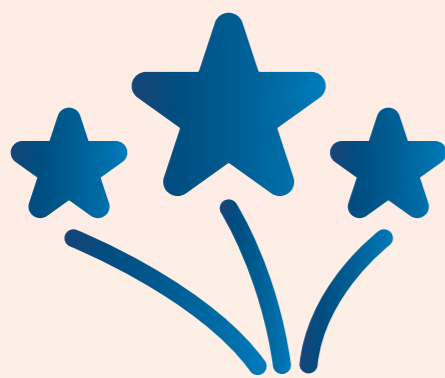
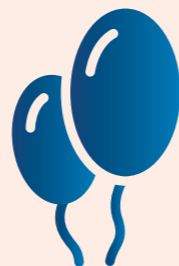


Kiss Goodbye to MS FUNDRAISING HIGHLIGHTS

Kiss Goodbye to MS raised
\$1,160,000
for MS research



205
brand new
fundraisers



Melbourne fundraisers
Camilla and Sarah Horton
launched the inaugural
MS Charity Ball raising
\$517,762



Increasing support
from individuals aged
18-24



270
community fundraisers
run, dance or hold events



30 groups
participated in community
affiliated events like
**City2Surf and
The Colour Run**

Red Lab Coat Day
engaged **200**
researchers nationally



Cost of fundraising ratio
remains exceptionally low at
12 cents
of every dollar raised

Kiss Goodbye to MS - the only national campaign raising funds for MS research

Kiss Goodbye to MS is an Australian founded initiative that calls on the MS community to raise funds and awareness for ongoing research into MS.

Kiss Goodbye to MS is a social media based campaign, with the majority of marketing initiatives centred around social media activation. The community and the world have embraced Kiss Goodbye to MS, including Australian and international celebrities and media personalities showing their support and using the campaign hashtag #KissGoodbyeToMS on social media. Kiss Goodbye to MS has grown from a successful awareness campaign to a 'first of its kind' global initiative that has transcended cultural and linguistic boundaries.

Kiss Goodbye to MS has three core campaign values:

- 1. Fundraising for MS research**
- 2. Focusing on a positive future for people with MS, with a campaign about hope**
- 3. Empowering people with MS, their friends and families to participate in fundraising regardless of their physical ability or geographic location**



Kerrie Newton



Kiss Goodbye to MS Ambassadors

“

Kiss Goodbye to MS is a campaign about hope, that together we can accelerate research into MS.

”



Kiss Goodbye to MS Charity Ball

Sarah and Millie Horton are identical twin sisters on a mission. Their mum was diagnosed with MS before they were born and as the girls grew up they watched her symptoms get progressively worse. Millie and Sarah's passion and determination is palpable, and on April 1, 2017 they held the Kiss Goodbye to MS Charity Ball which raised just over \$500,000 for research into MS. The Kiss Goodbye to MS Charity Ball was the biggest single fundraising event ever for MS Research Australia.

For Millie and Sarah, who both work in the investment banking world, their event was about hope for their mum and hope for every single person living with MS. They are a force to be reckoned with and in Millie and Sarah's own words "the strength of our mum has always been, and continues to be, our motivator".



Dr Steven Petratos & team, Monash University

Red Lab Coat Day

Red Lab Coat Day is an initiative of MS Research Australia and launches the Kiss Goodbye to MS campaign annually. Red Lab Coat Day asks Aussie and international MS researchers to switch their traditional white lab coats for bright red Kiss Goodbye to MS coats and then publish a picture, with the hashtag #RedLabCoatDay to their social media profiles. Universities and institutions around Australia and globally got on board in 2017 with more than 300 researchers proudly donning a red coat. This is a fun way for researchers to be involved with Kiss Goodbye to MS and raise awareness for the importance of the work they are doing, and for the community to send messages of thanks to the incredible researchers who have dedicated their careers to better understanding MS.



Tav to The Top

In 2017, a group of mates, also known as the 'Tav to The Top' boys, were inspired by their friend who is living with MS. They committed to doing something significant that would financially support research into MS. One member of the group suggested riding to the highest point in Australia and despite none of the men ever really having cycled before, the idea stuck. Over 5 days and almost 500km this incredible group cycled from Nowra on the NSW South Coast to Mount Kosciuszko, raising \$74,000 along the way.



Golf Day

The Coopers Brewery Foundation decided to make a difference by raising much needed funds for research into MS, and they chose their annual golf day at the Kooyonga Golf Club in South Australia to get the fundraising started. The annual golfing event brings together staff and clients from Coopers, with a total of 128 golfers participating and getting into the spirit of the day by wearing red. The day was a massive success and raised \$113,019 for Kiss Goodbye to MS.

"The Coopers Brewery Foundation is passionate about supporting organisations that are making profound impacts in medical research. MS is a disease that has affected some of us in the Coopers community and we are proud to be working with MS Research Australia to help bring us one step closer to finding the cure." - Melanie Cooper.



Celebrity support

The hashtag #KissGoodbyeToMS was popular amongst MS Research Australia supporters, with over 15,500 people using the hashtag on Instagram alone. Everyday Australians, bloggers, influencers, musicians, actors, media personalities and sportspeople were posting for the cause.

In 2017 MS Research Australia received incredible support from Jennifer Hawkins, Megan Gale, Leisel Jones and Natalie Bassingthwaite who all posted red lippy selfies and a message about Kiss Goodbye to MS.



Pro bono partnerships

Pro bono partnerships are crucial to the success of MS Research Australia ensuring the Kiss Goodbye to MS campaign and operational costs remain low. Whether it be through professional services, volunteering, donated goods or discounted services - every single bit makes a world of difference. Over the past financial year, MS Research Australia received over \$850,000 in pro bono support, which is testament to the generous contributions being made by the broader community.

One of MS Research Australia's longest standing pro bono partnerships is with Cube PR – affectionately known as the 'dream team'. Cube PR have been working side by side with the MS Research Australia team on the Kiss Goodbye to MS campaign for many years, helping to raise awareness through securing social media coverage and media features across various outlets. This incredible team contribute their expertise free of charge, which MS Research Australia is extremely grateful for.

Corporate partnerships

Corporate philanthropy means more to MS Research Australia than just funding dollars. Whilst it accounts for up to 22% of total gross income, the additional benefits come from both pro bono support and professional engagement opportunities.

The Macquarie Group Foundation has been one of the most important philanthropic foundation supporters of MS Research Australia since its establishment, and is largely invested in many of the organisation's greatest achievements.

Lisa George, Global Head of the Macquarie Group Foundation explained: "We think it's important to contribute to a national organisation which has a clear mandate and history of excellence in research governance. We do this through financial support and by using the skills of Macquarie staff to help the team at MS Research Australia. Donors like to see how their support has been utilised and MS Research Australia is able to deliver on that by readily reporting on the outcomes of funded research."



Lisa George, Global Head of the Macquarie Group Foundation

The Macquarie Group Foundation recognises innovation and recently funded two unique Fellowships. A joint Fellowship between MS Research Australia and JDRF which led to an important finding of a genetic overlap between MS and type 1 diabetes, and a Paired Research Fellowship - the first of its kind in Australia - where a laboratory and clinical researcher work side by side to fast track research by accelerating its translation from the laboratory into clinical reality.



Dr Heidi Beadnall, BMRI, The University of Sydney

Sohn Hearts and Minds Investment Conference

The Sohn Hearts and Minds Investment Conference is inspired by the prestigious Sohn New York Conference and hosted by the Sohn Foundation, attracting and inspiring world leaders in the finance field with investment minds generously donating their time and ideas.

This Conference is innovative and unique to Australia, and MS Research Australia was thrilled to be chosen as one of the four charity partner organisations in 2017.

Key speakers from around the world descended on Sydney's Opera House to pitch stock tips and ideas to a full house and proceeds from ticket sales, donations and sponsorships was contributed to the charity partners.



Sara Donaldson & friend,
Kiss Goodbye to MS Ambassador

COMMUNICATIONS AT A GLANCE

Number of people reached across all social media **4,550,621**   

 Website International audience **34%**

Developed **3 NEW** redesigned state of the art websites 

 **144,623** reached via website


 Increase of organic traffic by **43%** across all websites

Social media traffic increased by **39%** to Kiss Goodbye to MS website

 Total probono media coverage value is estimated at **over \$3 million**

 E-Newsletter open rate above average at **32%**

15,500 people have used the hashtag **#KissGoodbyeToMS** on Instagram

 **20** high profile celebrities and bloggers support Kiss Goodbye to MS on Instagram

 Globally streamed **our first ever research live update event**

 On World MS Day **100,835** people saw one of our social media posts

 **Community consultation** conducted on digital media strategy

“ For me, writing is a passion. But being able to use that passion to bring awareness to the work that MS Research Australia advocates is a privilege. To think that something I write may influence those who can give - or those that need hope - is very powerful.
 – Jillian Kingsford Smith

”

AWARD WINNING HIGHLIGHTS



MS Research Australia Team

Over the past financial year MS Research Australia has been honoured to win six prestigious awards;

- **Telstra 2017 Australian Charity Award**
- **Telstra 2017 NSW Business of the Year**
- **Telstra 2017 NSW Charity of the Year**
- **The Australian Charity Awards, 2017 Outstanding Achievement**
- **Fundraising Institute of Australia, 2016 Most Effective Creative Campaign**
- **Fundraising Institute of Australia Awards, 2016 Special Event Award**



Receiving such awards is not only acknowledgment of MS Research Australia as a sector leader, but is also an important component of their communications strategy. Being a finalist or award recipient allows MS Research Australia to differentiate itself from other not-for-profits, and to raise awareness of MS, elevate their brand, research projects and mission through positive media coverage, donor and employee communications.

These recent awards have been particularly positive for MS Research Australia's reputation

due to the criteria in which they were judged on. MS Research Australia's robust and transparent processes, innovative approach, governance policies, and international collaboration activities have been judged and recognised as part of these awards' application processes.

Being recognised in this way, through an official third party endorsement, positions MS Research Australia as an expert in their field.





Members of the MS Research Australia team

Listening to the community

In order for MS Research Australia to connect with and educate stakeholders, they put a large emphasis on consulting with the MS community. This community typically includes people living with MS, their families and loved ones, researchers, neurologists, clinicians, nurses and psychologists.

MS Research Australia has embraced the approach of seeking involvement from the public in order to develop and review their communication processes. This included making well informed decisions, increase stakeholder satisfaction and be an example of best practice displayed through quality governance and transparency.

Over the past year MS Research Australia engaged in a wide variety of consultation processes to gain new information and test ideas. These processes allowed MS Research Australia to ask questions, listen to suggestions and get insightful access to the issues their community faces and information they would like to receive. Some of these information gathering processes included MS Research Australia's newsletter readership survey, focus groups, one-on-one interviews, newly diagnosed survey and case study analysis. By adopting a range of techniques MS Research Australia maximises their capability to become extremely well informed and to set clear and achievable objectives.



The community consultation has influenced the entire organisation from the strategic planning processes, committees and right through to the communications.

One such change is the inclusion of guest contributors to the newsletter to broaden the range of information provided and present a variety of perspectives. This past year has seen insightful articles from Jillian Kingsford Smith, a best-selling author and person with MS, Dr Ollie Jay, a senior lecturer and researcher at the University of Sydney, Professor Robyn Lucas, an epidemiologist at ANU, Dr Suzi Clafin, a researcher and Professor Bruce Taylor, a clinical researcher both at the Menzies Institute for Medical Research.

Embracing the digital landscape

MS Research Australia prides itself on being technologically savvy and continually embracing the growing digital landscape we all live in. This is demonstrated not only through their state-of-the-art website, social media presence and paperless workspace but also through their willingness to be early adopters of new technologies.

The digital landscape removes geographical boundaries allowing MS Research Australia to reach a global audience. Analytics reveals that the 34.44% of the website audience are international.



In 2017, for the first time, MS Research Australia invited people from across the world to live-stream their *Progress in MS Research Live Update*. Connecting the MS community with leading MS researchers and experts in real time. Questions submitted from the registered attendees were addressed and relevant MS research information was presented in an easy to understand and engaging format. Previously held as a public lecture, the new live video streaming format allowed viewing from any location.



The video streaming project was made possible with the pro bono support of Go Collaborate, headed-up by Producer and person with MS, Tara King. MS Research Australia became involved with Tara and her team following an interview they conducted with Dr Lisa Melton for a television series they were working on.

Following the success of the live update, and as part of the new communications strategy, they will be able to continue to build on and develop additional digital projects, short videos and researcher interviews.

Having access to informative and user friendly information (such as videos) at the click of a button is a major part of MS Research Australia's communications approach. It allows the organisation both a cost-effective mechanism for conveying engaging research updates and progress, and an excellent platform for creating awareness and educating the public about MS and the organisation's progress.

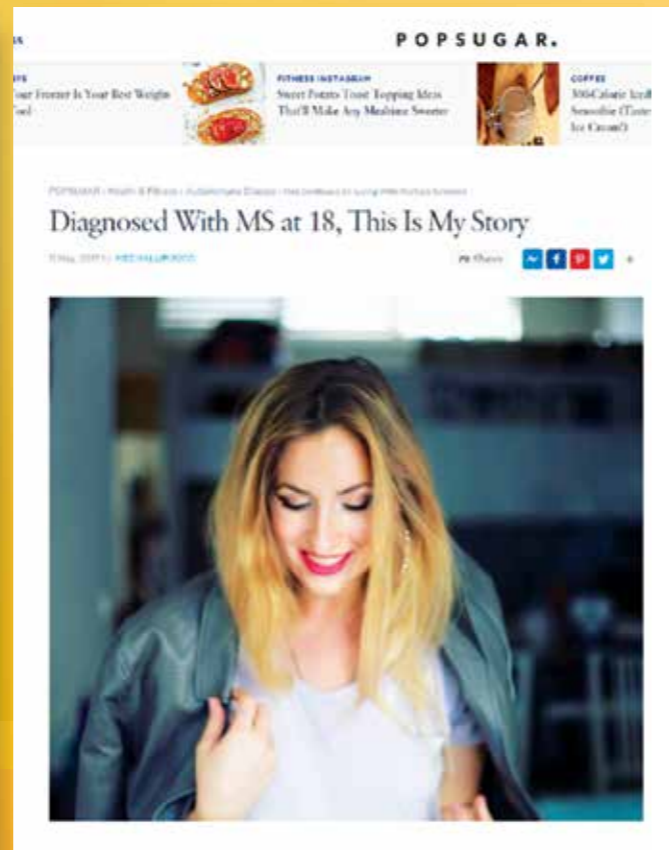
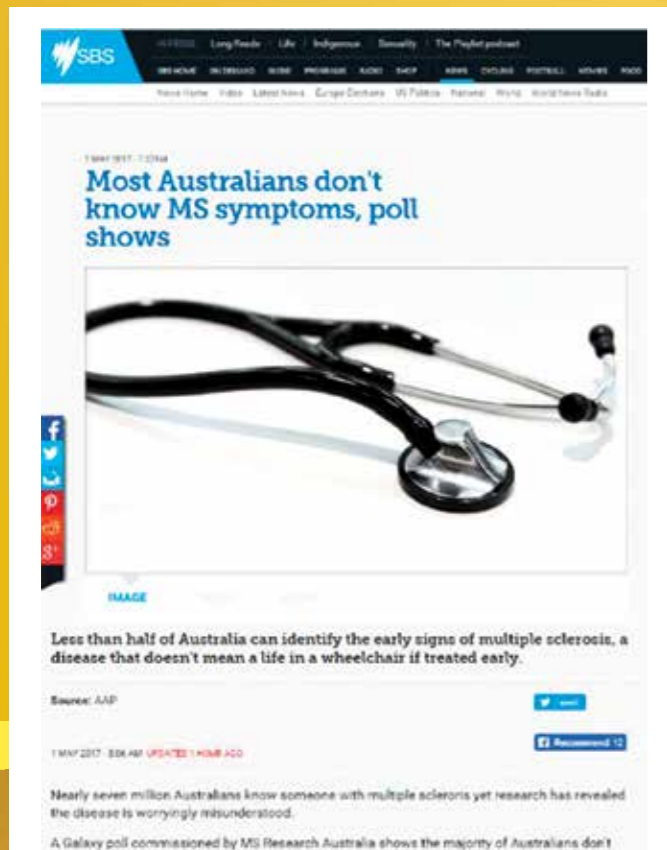
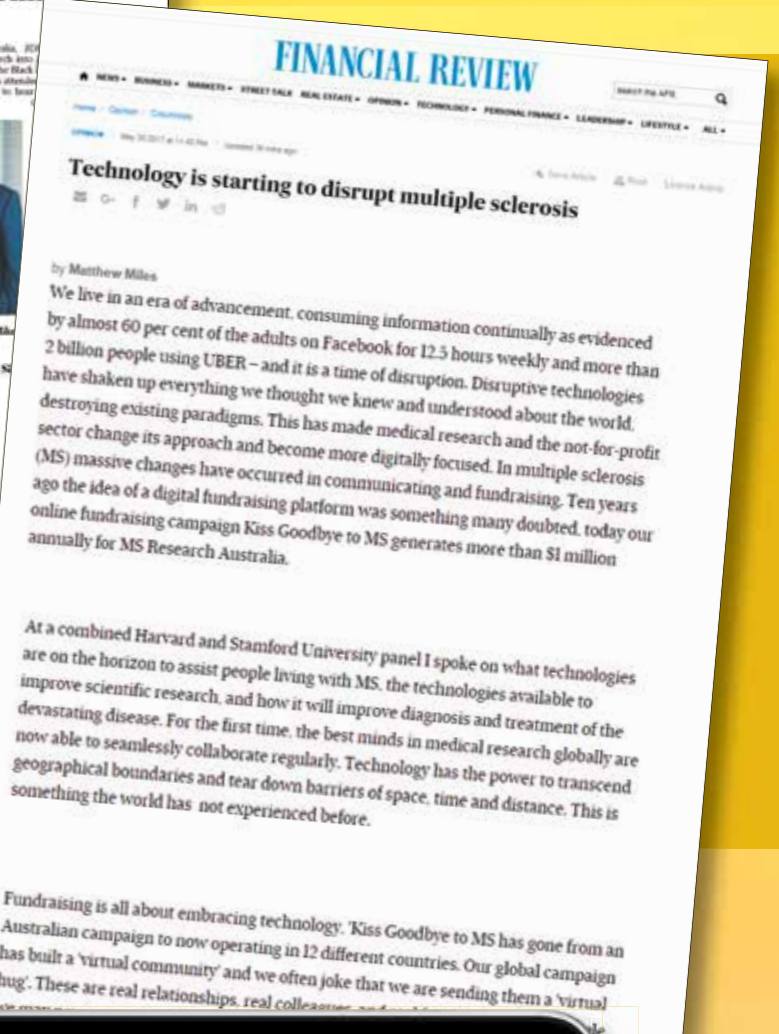
As our community spends more and more time on laptops, mobiles and tablets, MS Research Australia has made it a priority to reach out and connect digitally and to adopt and engage with new technologies to remain relevant in the sector.

“

Having access to informative and user friendly information (such as videos) at the click of a button is a major part of MS Research Australia's communications approach.

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HITTING THE HEADLINES



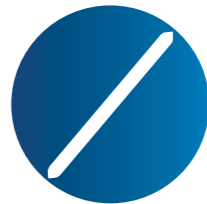


Global research HIGHLIGHTS AT A GLANCE



MS Research Australia has committed **AU\$1.1 million over 3 years** to the **International Progressive MS Alliance** to help fast track the type of discoveries that can truly change lives for people with progressive MS

Instrumental in advocacy leading to the fast track treatment of **Ocrevus**, the only primary progressive MS treatment currently approved



Worked with MSIF and other global leaders to develop the new **MSIF 2017 to 2021 strategic plan**



MS Research Australia **contributes annually** to the MSIF



MS Research Australia asked to write the global **MSIF research news**



Participated in **2017 MSIF Research Staff Network Conference** – working together to identify opportunities for global and research collaboration



Researchers collaborated with MS Research Australia to report back to the Australian MS community on ECTRIMS news and outcomes

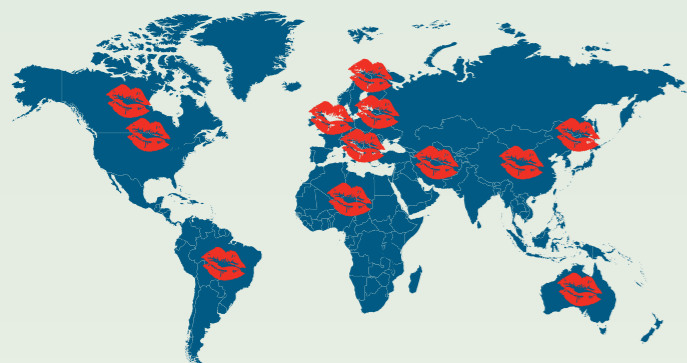
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Through participating in this collaboration, MS Research Australia are leading the way in making the global MSIF movement’s strategy a reality. MS Research Australia are setting a superb example which we will use inside the movement to get the other member organisations to join in on research and other global collaborations.

– Peer Baneke, CEO MSIF

”

Kiss Goodbye to MS GLOBAL HIGHLIGHTS



12 countries participated in Kiss Goodbye to MS and it is continuing to grow

No matter what language you say it in...



Kiss Goodbye to MS is officially global!

Kiss Goodbye to MS has attracted a global audience through its positive messaging. Founded in 2014, the campaign's success, has provided critical funding and the ability for MS Research Australia to join the global fight to end Progressive MS.

Australia is now able to stand united with the other large players in the MS world to find treatments, and ultimately a cure for Progressive MS. In 2016, Kiss Goodbye to MS became a global success story, raising AU\$1.45 million for research into MS. In 2017, the global campaign involved 12 countries coming together for the same goal... to bring us closer to finding a cure for MS.

Every country runs the campaign in their own way, but it doesn't really matter if you say 'Kiss Goodbye to MS', 'Kys Sclerose Farvel' or 'Dire Adieu A La SEP', it is the end goal that the whole world is now focused on, freedom from MS.

- 15,500 thousand people posted #KissGoodbyeToMS around the world!
- Kiss Goodbye to MS is the first global MS fundraising campaign ever!
- 12 countries participate – each country runs the campaign in their own way!
- Born in Australia, Kiss Goodbye to MS is now raising funds for research into MS around the world!



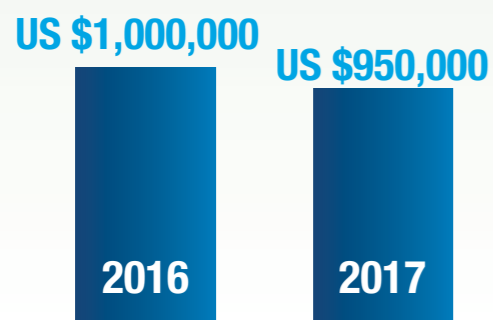
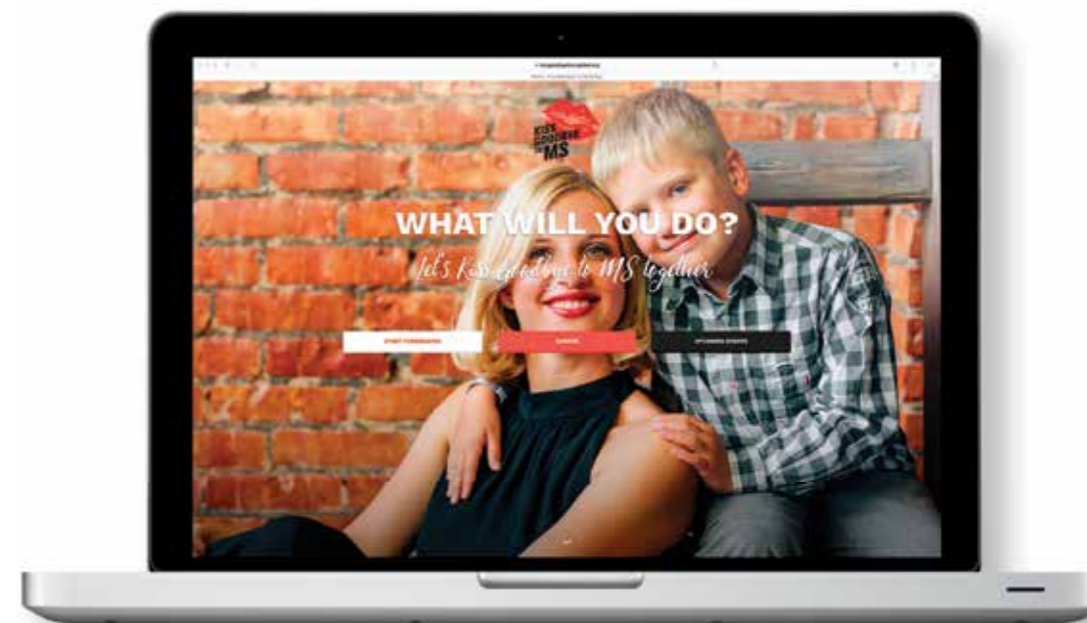
Kiss Goodbye to MS is the first global MS research fundraising campaign
Red Lab Coat Day adopted internationally



Our target in 2017 was
US\$1,500,000



In 2016 our global **Kiss Goodbye to MS website** was born – telling the story of Kiss Goodbye to MS to the world!



Raised by the campaign so far!



15,500
people globally engaged with and posted the hashtag #KissGoodbyeToMS

International Progressive MS Alliance

For the first time in the history of MS research, a global alliance of 16 countries have joined forces to form the International Progressive MS Alliance to help find solutions for people with primary and secondary progressive MS.

Those living with progressive MS, like all people with MS, do not care where in the world the breakthroughs, discoveries and advancements come from – as long as they happen expeditiously and of benefit to all people with MS. The Alliance is working towards making this a reality.

The opportunity, power and determination of this global collaboration cannot be overemphasised. It has already provided well over €23 million in funding for progressive MS research and its success has come about by bringing the best MS research and clinical minds together. This laser-focused attention on the end goal of finding treatments for progressive MS is enhanced by ensuring people with MS are an integral part of the work of the Alliance.

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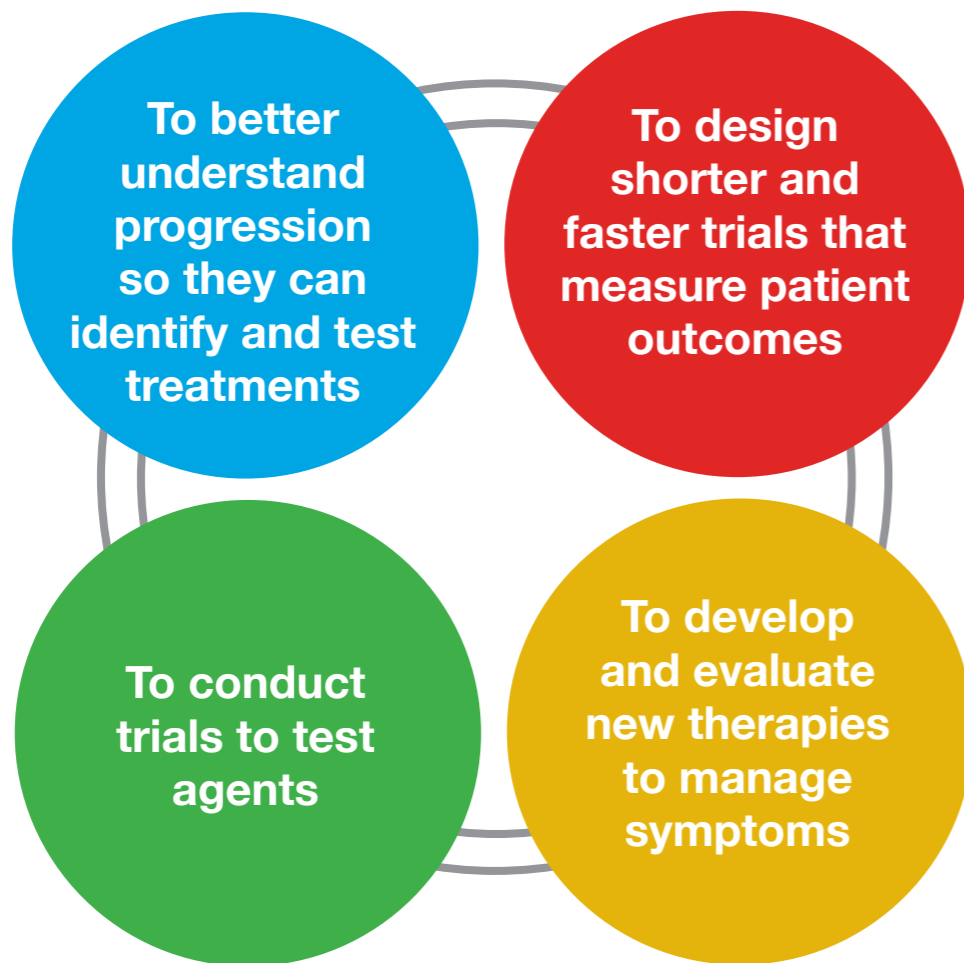
The opportunity, power and determination of this global collaboration cannot be overemphasised.

”



Alliance Executive Committee

The Alliance's four main focus areas include:



“

... In the philanthropic world you're looking at the toughest problems that exist. The reason why they are important problems is that they've resisted the intellect and the money being thrown at them over the years and they haven't been solved ...

– Warren Buffet

”

MS Research Australia is a managing member of the Alliance and represented on the Scientific Steering, Executive, Communications and Fundraising committees. Cyndi Zagieboylo from the US MS Society chairs the Executive Committee and Dr Matthew Miles, CEO of MS Research Australia is the Vice Chair.

“In fact, we all share the single-mindedness, collegiality and resolve that is desperately needed to help solve one of the great mysteries in MS. There are hurdles, barriers and minefields along the way but this global collaborative is absolutely the right tool, and probably the only tool possible, to face that challenge. We are better together” said Dr Matthew Miles.

The Alliance is one of the few international medical research collaborations to directly involve the pharmaceutical industry and the drug regulating bodies.

INTERNATIONAL
PROGRESSIVE MS ALLIANCE

CONNECT TO END PROGRESSIVE MS

Multiple Sclerosis International Federation

The Multiple Sclerosis International Federation's (MSIF) focus on galvanising the MS community, while allowing specialists in particular areas of MS research to lead and convene their collaborative country partners. This approach is paramount to the advancement of MS research and treatments.

Here are some of the ways MSIF act as a catalyst for the global MS community:

Capturing MS data

One example of MSIF's role in empowering project leads is through the Italian MS society-led platform called International Patient Reported Outcomes (IPRO), which captures and analyses data from people with MS

The Australian MS Longitudinal Study (owned and run by MS Research Australia) inputs into the research platform, along with many global patient reported outcome (PRO) registries. Each contributor to the platform is focused on sharing information and ideas, helping to reduce replication and widen the possibilities for breakthroughs in MS.

Kiss Goodbye to MS

MS Research Australia jumped at the chance to take *Kiss Goodbye to MS* to the world, when approached by MSIF with the idea. Now in 12 countries, the campaign has gone from strength to strength, particularly in countries with smaller MS communities. The aim is to scale the campaign over the coming years.

Keeping connected

The global MS research network, convened by MSIF, is another key forum charged with keeping the global MS community attuned to research activity in all corners of the world. This network enables members of the community to tackle opportunities - such as potential new treatments for MS - together, and to work collectively on areas of interest to everyone, such as reaching consensus on research metrics and identifying gaps in MS knowledge.



Manuela, person affected by MS, Germany

Thanks to the team

MS Research Australia would like to acknowledge Dr Lisa Melton, Head of Research for her work on the International Progressive MS Alliance Scientific Steering Committee, global MS research network and data access. Lisa and her team also provided research articles for the MSIF research newsletter during the year.

Thanks to Petricia Augustus, Head of Communications, Marketing and Operations, who works tirelessly as a member of the Alliance's communications team. And thanks to Richelle King, Campaign Manager, who co-led the global roll-out of *Kiss Goodbye to MS*.



Susan, person affected by MS, USA



From the day I first joined MSIF, the *Kiss Goodbye to MS* campaign stood out as one of the most exciting things happening around the world. Whenever we've talked to our members there has been real excitement.

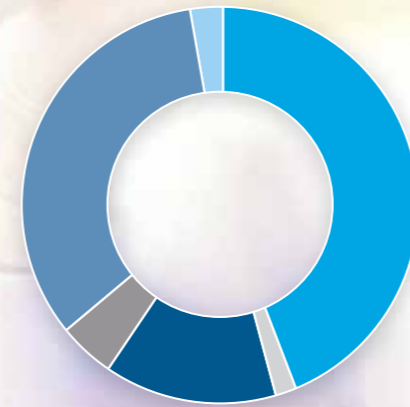
– Luke Thomas, Head of International Fundraising at MSIF



Brian, person affected by MS, USA

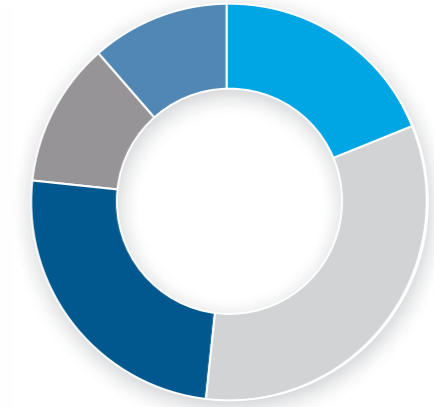
FINANCE AT A GLANCE

- MS Research Australia finished 2017 in a solid financial position by raising record funds for MS research, a 51.9% growth compared to 2016.
- In this financial year, around 66.5% of all revenue came from MS Research Australia fundraising sources whilst 33.5% was from the various state-based MS groups.
- 70% of the total MS state society contributions to research came from MS WA.
- MS Research Australia, overseen by significant finance and investment expertise on our Board, continued to implement its conservative investment strategy focused on protection of capital and risk minimisation, and its investment portfolio generated investment earnings of \$210,000 representing a return of approximately 3.63% during the year.



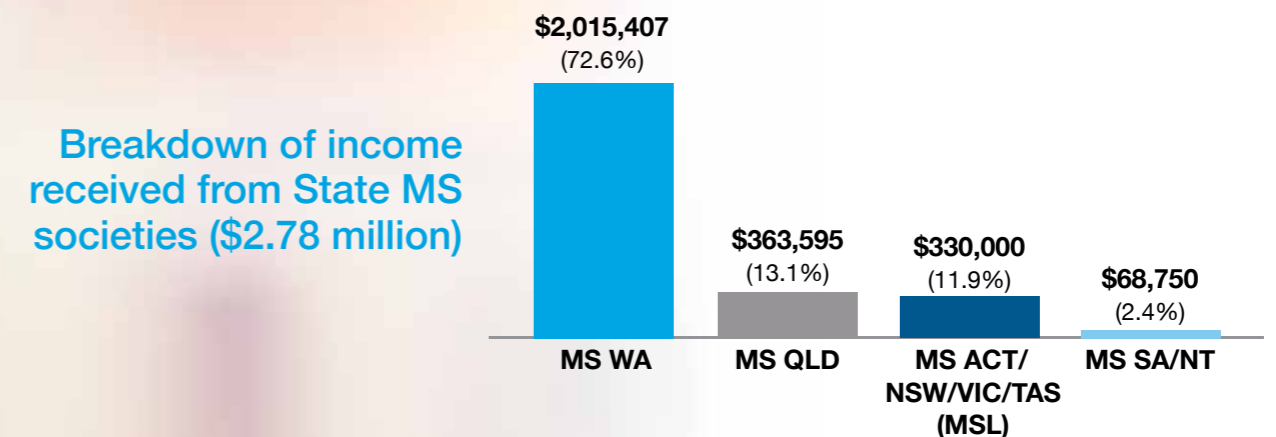
Income \$8.3 million

- Donations / Fundraising (44.5%)
- Bequests (1.5%)
- Kiss Goodbye to MS Fundraising campaign (13.8%)
- Grants from government (4.3%)
- State MS societies (33.5%)
- Other (2.5%)



Expenditure \$5.1 million

- MS Research Grants Funded (32.7%)
- MS Research Collaborations/ Platforms/Support Funded (25.1%)
- MS Research Advocacy/Awareness/ Education/ Mission delivery (11.9%)
- Cost of Fundraising (19.0%)
- Administration (11.3%)



The MS Research Australia fellowship allows me to commit to my goal and also work with Professor Bruce Taylor to be able to achieve better outcomes for people with MS. I can be more ambitious with my planning and goals because I have that guarantee of support.

– Dr Kaylene Young



2016/2017 FINANCE HIGHLIGHTS

Our fundraising
cost kept low
at 12 cents of
every dollar raised



\$2.046 million
committed to
**new research
grants**



81 cents
of every dollar
raised goes towards
**funding and
facilitating
MS Research**



\$50.4 million
raised since 2004
based on audited
financials



\$1.5 million
single donation received
from a key donor

\$5.6 million
committed to
**future ongoing
research projects**



\$3.3 million surplus
is earmarked towards future research
into MS

\$31.9 million
invested into funding and facilitating
MS research since 2004



\$825,000 inc GST
Government grant secured



Total staff headcount of
14 with 13.36 on a FTE basis

42 current MS research
projects supported



Fundraising income raised
during the financial year of
\$8.09 million



Visit the Australian Charities and Not for Profits Commission (ACNC) for detailed financial records of MS Research Australia's 2017 year.



Dr Antony Harding,
MS Research Australia Brain Bank Manager



**RESEARCH
AUSTRALIA**

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