

# STRATEGIC PLAN 2014 - 2016



“Accelerating Australian research to identify better treatments, the cause and the cure for multiple sclerosis.”



RESEARCH  
AUSTRALIA



As Chairman of MS Research Australia, I am inspired by the progress that has been made in the 10 years since establishment. MS Research Australia is taking every step towards accelerating improved treatments, identifying the cause and ultimately finding the cure for multiple sclerosis (MS).

MS Research Australia is the research arm of the peak body, MS Australia. The two national organisations work collaboratively with the state societies which service the needs of people with MS. From an Australian standpoint it is of paramount importance that the two national organisations work cohesively on important areas such as advocacy, media and communications where research intersects with government policy as well as being a key influencer of current and future government directions in the MS research space. This collaborative approach also has the ability to bring our MS research successes to a wider audience.

The Board of MS Research Australia acknowledges the importance of this strategic plan and believes the goals and plan adequately reflect our mission. In our leadership role we will ensure that MS Research Australia works towards the implementation of the clear goals that are set out.

With a personal connection to MS, I indeed have a vested interest in the research outcomes. I am certainly encouraged at what has been achieved to date and look forward to what the next few years will reveal. Leading researchers are now saying that the elimination of MS is definitely within our sights, it's not a matter of "if", but a matter of "when".



Paul Murnane

Chairman, MS Research Australia



## A MESSAGE FROM THE CHAIRMAN, MS RESEARCH AUSTRALIA

“...the elimination of MS is definitely within our sights, it's not a matter of “if”, but a matter of “when”.”



## A MESSAGE FROM THE CHIEF EXECUTIVE OFFICER, MS RESEARCH AUSTRALIA

It's heartening to think that MS Research Australia has funded most, if not all, of the best MS researchers in the country based at many of the leading Universities, medical research institutes or hospitals across our nation. However, what is most important when reflecting on that funded research is the outcomes, the discoveries and benefits that have been brought to people with MS, their families and carers.

We have been able to support these talented researchers by helping them to apply their expertise and scientific knowledge to ensure people with MS can lead better lives. Like many fields of medical research, Australia is particularly strong in MS and we should all be proud that Australian researchers have been instrumental in some of the recent breakthroughs that have been made.

We have actively supported many young Australian MS researchers, as well as our established higher profile academics, created pockets of research strength that have greatly diversified and enhanced our Australian MS research.

However, we still have much to learn about MS – recent advances in imaging, bioinformatics, neurology, genomics, epigenetics and knowledge of immune function give us an insight in to what is still to come from upcoming MS research. The next couple of years will see us take on a stronger position globally as we work to tackle critical issues such as progressive MS.

We are sincerely grateful to have such generous and engaged supporters who have made this all possible. Although there are too many to thank in this message, I would like to make reference to the unwavering support from the state MS societies, the Trish MS Research Foundation and the Foundation Five Million Plus community fundraising group who have played an important, valued and critical part in our success.

It is the support of donors, trusts and foundations, the Federal and State Governments and our networks that allows us to achieve our goals. We continue to need your help and we enjoy being a valued partner with you all.

We also rely greatly on the countless number of volunteers as well as the significant number of corporate groups, companies and individuals who provide pro bono services which when tallied would add up to a dollar figure in the hundreds of thousands each year.

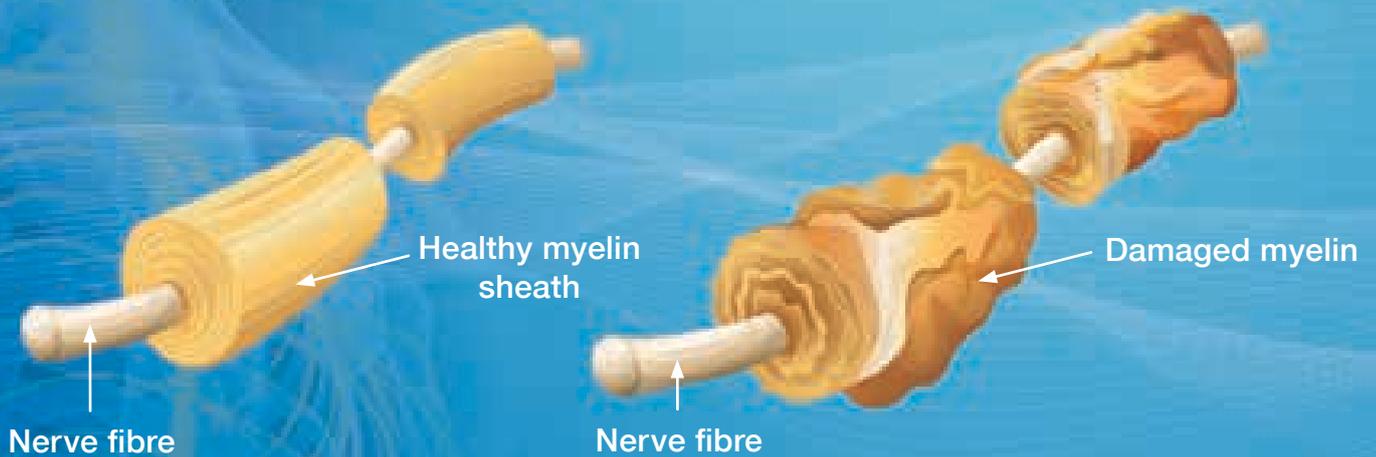
At its heart, MS research is about people, the people who benefit from research, the talented people who conduct MS research; people who work as professionals in the system and who teach and mentor the professionals and the researchers of tomorrow.

Our success depends on the wonderful commitment of a small team, and the involvement of Australian and International MS researchers who, amongst other things, contribute to our platforms, research councils, steering groups, collaboratives, networks and research conferences. Their individual and collective contribution to the organisation makes it what it is.

We thank you all very much.

A handwritten signature in dark ink that reads "Matthew Miles". The signature is fluid and cursive.

Dr Matthew Miles  
Chief Executive Officer



MS Research Australia is the only non-government national organisation dedicated to funding and coordinating multiple sclerosis (MS) research in Australia, as part of the worldwide effort to solve MS.

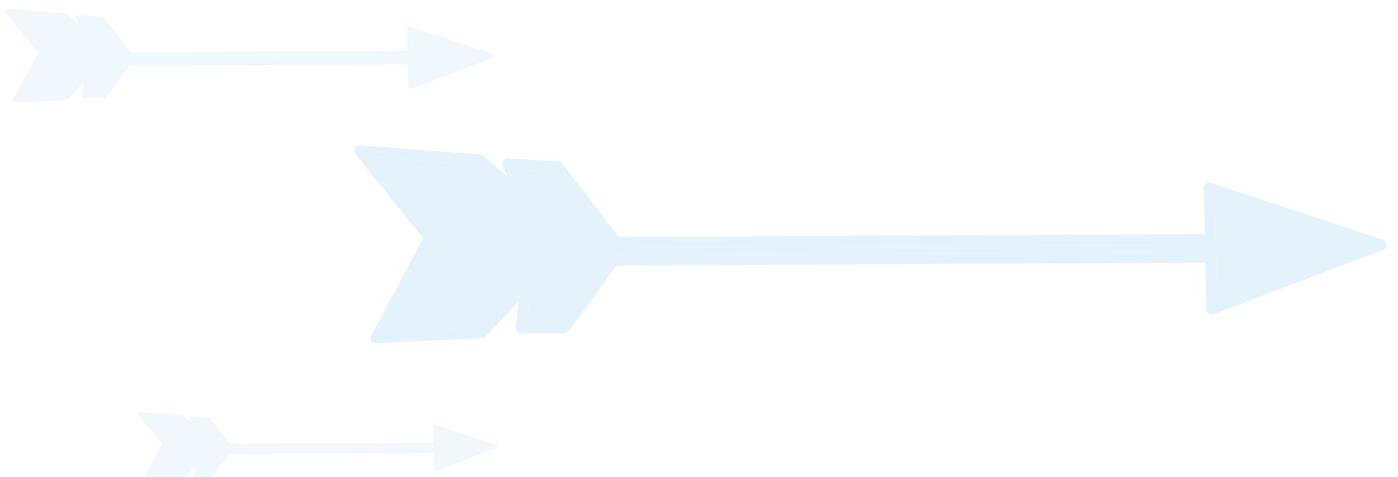
Our mission is to accelerate research towards the prevention, better treatments and ultimately a cure for MS.

## WHO IS MS RESEARCH AUSTRALIA

### What is MS

MS is the most common neurological disease affecting young Australian adults. With the average age of diagnosis being only 30 years of age, it affects three times more women than men. We do not know the exact cause and there is no known cure.

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. The symptoms of MS are different for each person; sometimes they even vary within the same person. Common signs include fatigue, difficulty walking or doing tasks, sight problems, memory changes and chronic pain. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive and unrelenting pattern. For everyone, it makes life devastatingly unpredictable.



# MS RESEARCH AUSTRALIA FUNDING MODEL

MS Research Australia's research strategy aims to accelerate research activity in areas where Australian scientists can have the greatest impact in worldwide MS research. Close partnerships have been established to encourage collaboration between Australia's leading medical research institutions. The research is focused on three main areas; to better diagnose and treat MS, to predict and prevent MS and to propagate cell repair and regeneration.

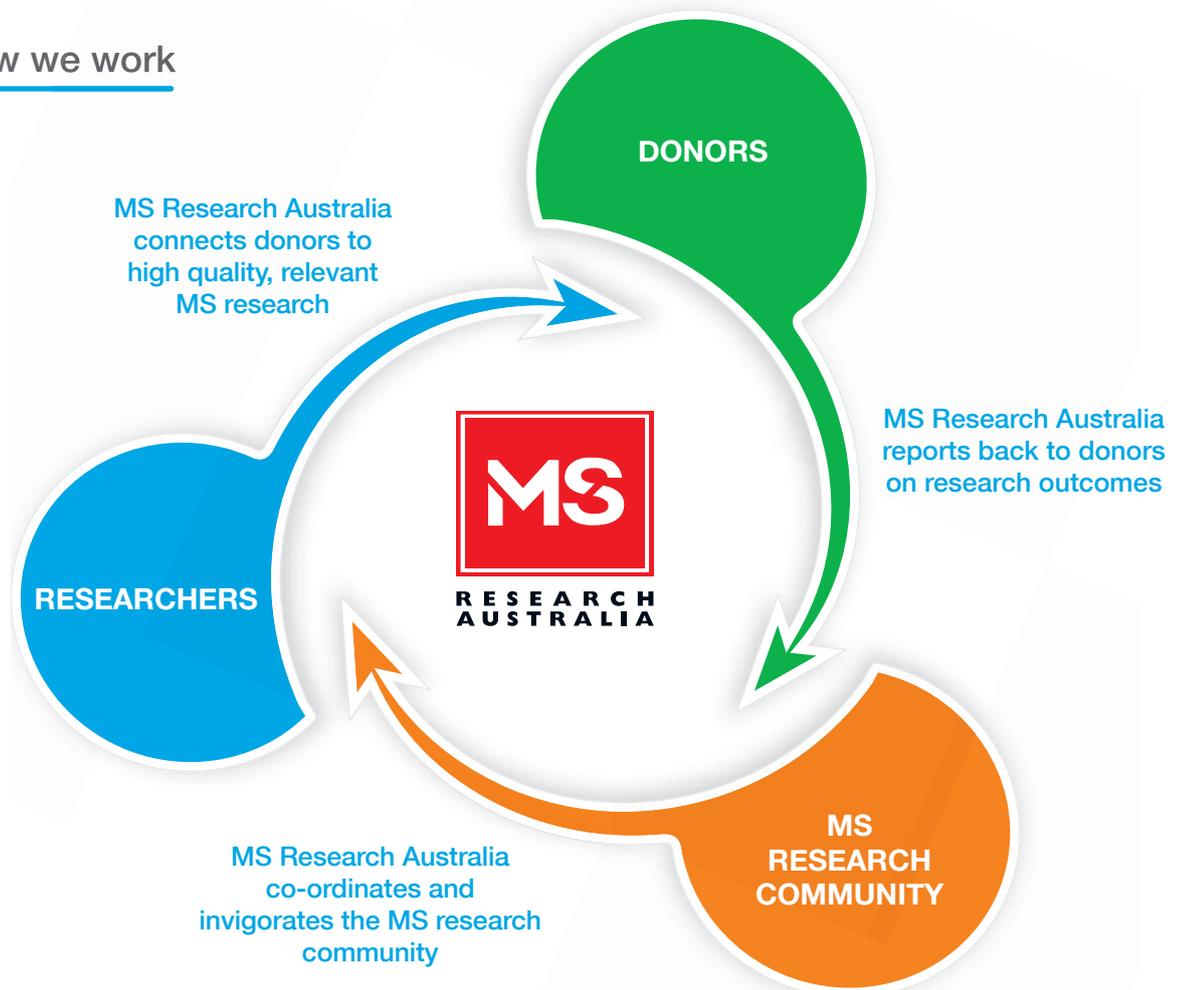
With the guidance of a scientific committee, MS Research Australia facilitates collaborations and research platforms using Australia's strengths, such as the MS Research Australia Brain Bank, the Vitamin D MS Prevention Trial, the Australian MS Longitudinal study and ANZgene, as well as funding investigator-driven research projects through an annual grant round.

MS Research Australia seeks financial contributions to support the research strategy by engaging support from state based MS societies, public donations, trusts and foundations, private philanthropic donors, grants, corporate partnerships, bequests and community fundraising. Our fundraising strategy links potential donors and sponsors with specific research projects of interest to them.

To further develop funding opportunities, MS Research Australia also works closely with the National Health and Medical Research Council (NHMRC), the Government's peer-reviewed medical research funding agency.

Together with a robust governance structure, MS Research Australia believes this approach will result in further significant breakthroughs in the knowledge and effective treatment of MS and major steps toward understanding the cause and developing the cure.

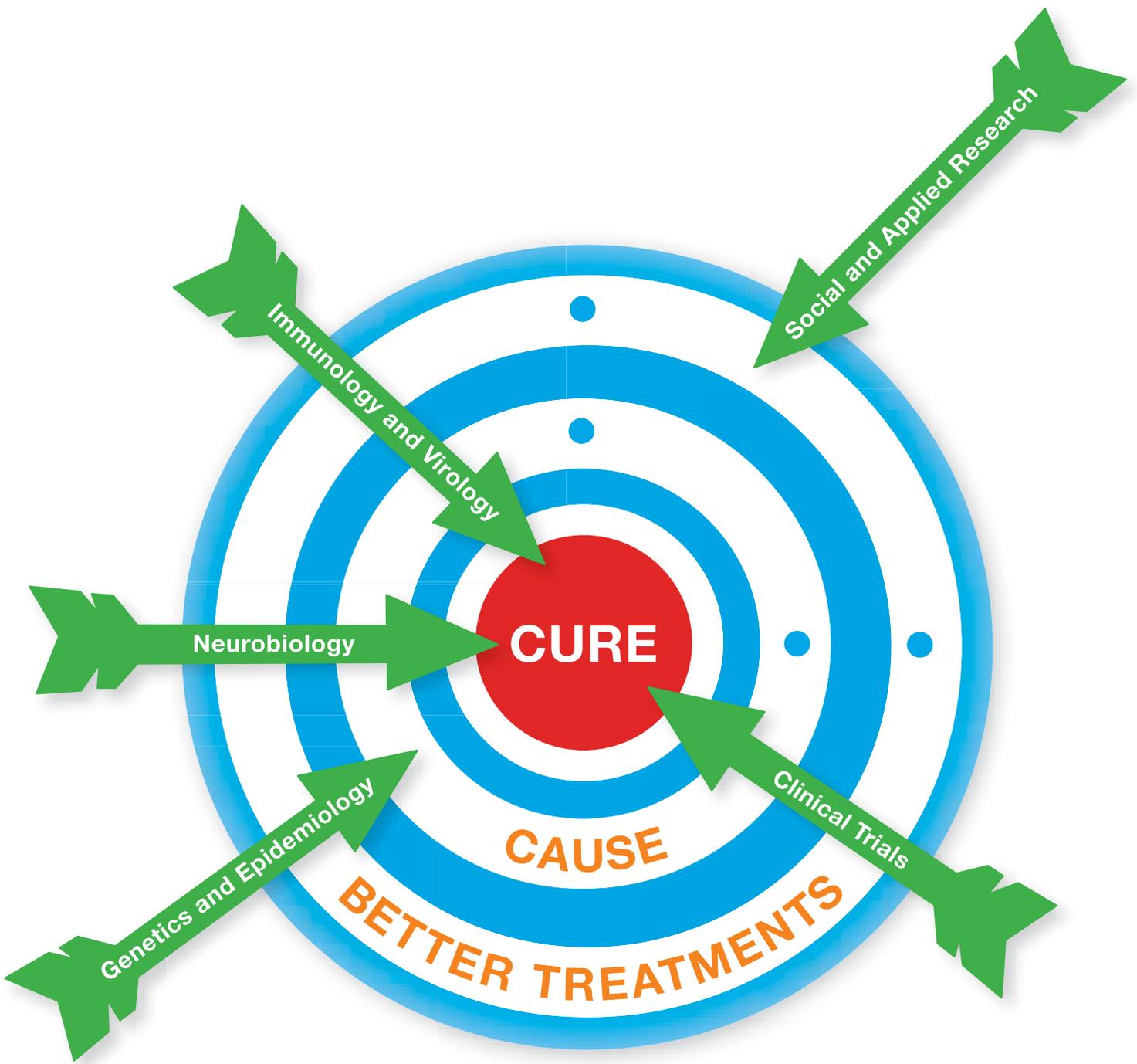
## How we work



# MS Research Australia works with Australia's leading medical research institutions

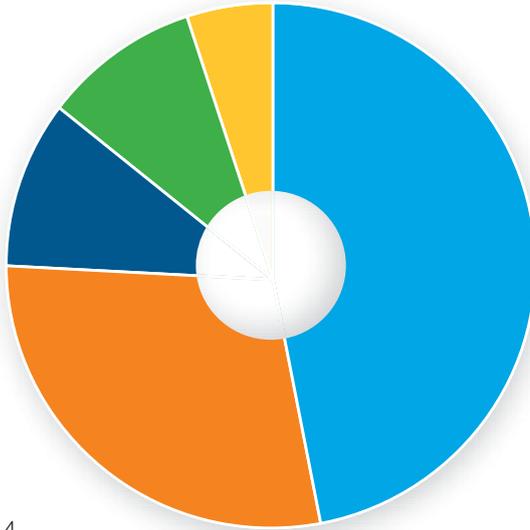


# Research Streams



## Funding Sources

- Fundraising (47%)
- State MS Societies (29%)
- Government (10%)
- Pharmaceutical (9%)
- Bequests (5%)

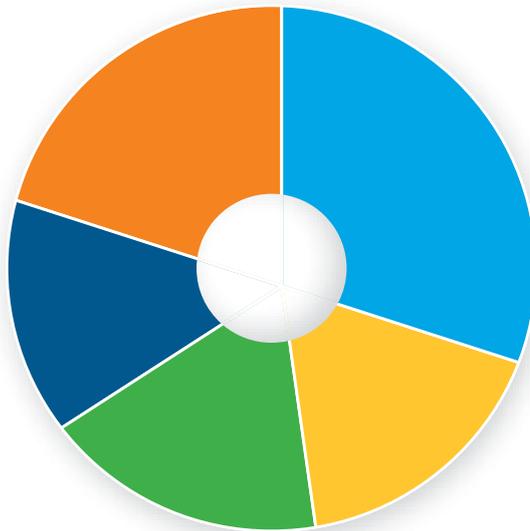


\*Snapshot of income sources 2005 – 2014

## HOW MS RESEARCH AUSTRALIA IS FUNDED

## Allocation of funds by research streams

- Immunology & Virology (30%)
- Neurobiology (18%)
- Genetics & Epidemiology (18%)
- Social & Applied (14%)  
(including Australian MS Longitudinal study)
- Major Collaborations/ Platforms (20%)

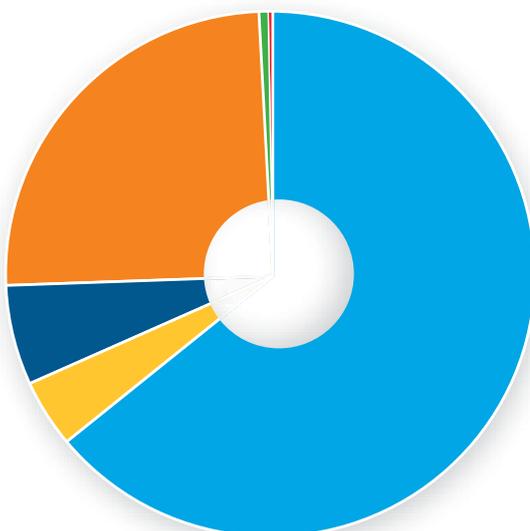


\*Snapshot of funds allocated 2004 – 2013

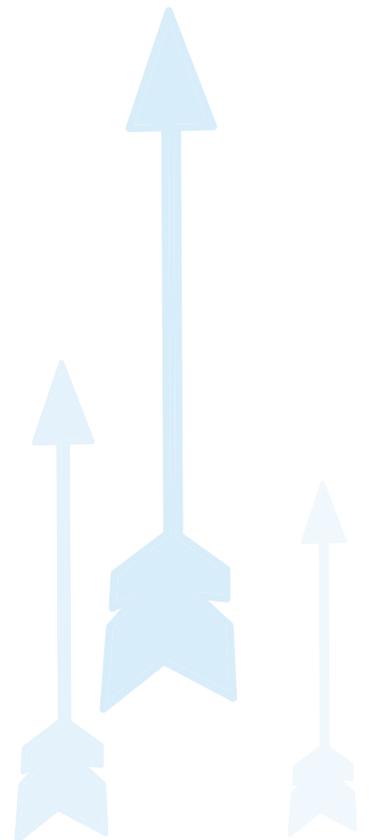
## HOW MS RESEARCH AUSTRALIA ALLOCATES FUNDS

## Allocation of funds by research grant

- Project (64.2%)
- Incubator (4.1%)
- Postgraduate scholarship (6.3%)
- Fellowship (24.7%)
- Student vacation scholarship (0.5%)
- Overseas Travel Award (0.1%)



\*Total of grants awarded 2004 – 2013





## MS RESEARCH AUSTRALIA PATRON

### Mr Simon McKeon AO

Mr Simon McKeon AO is the Executive Chairman of Macquarie Group's Melbourne office and specialises in mergers and acquisitions. He is also Chairman of AMP and CSIRO. Mr McKeon was the Founding Chairman of MS Research Australia from 2004 – 2010 and has been Patron since 2010.

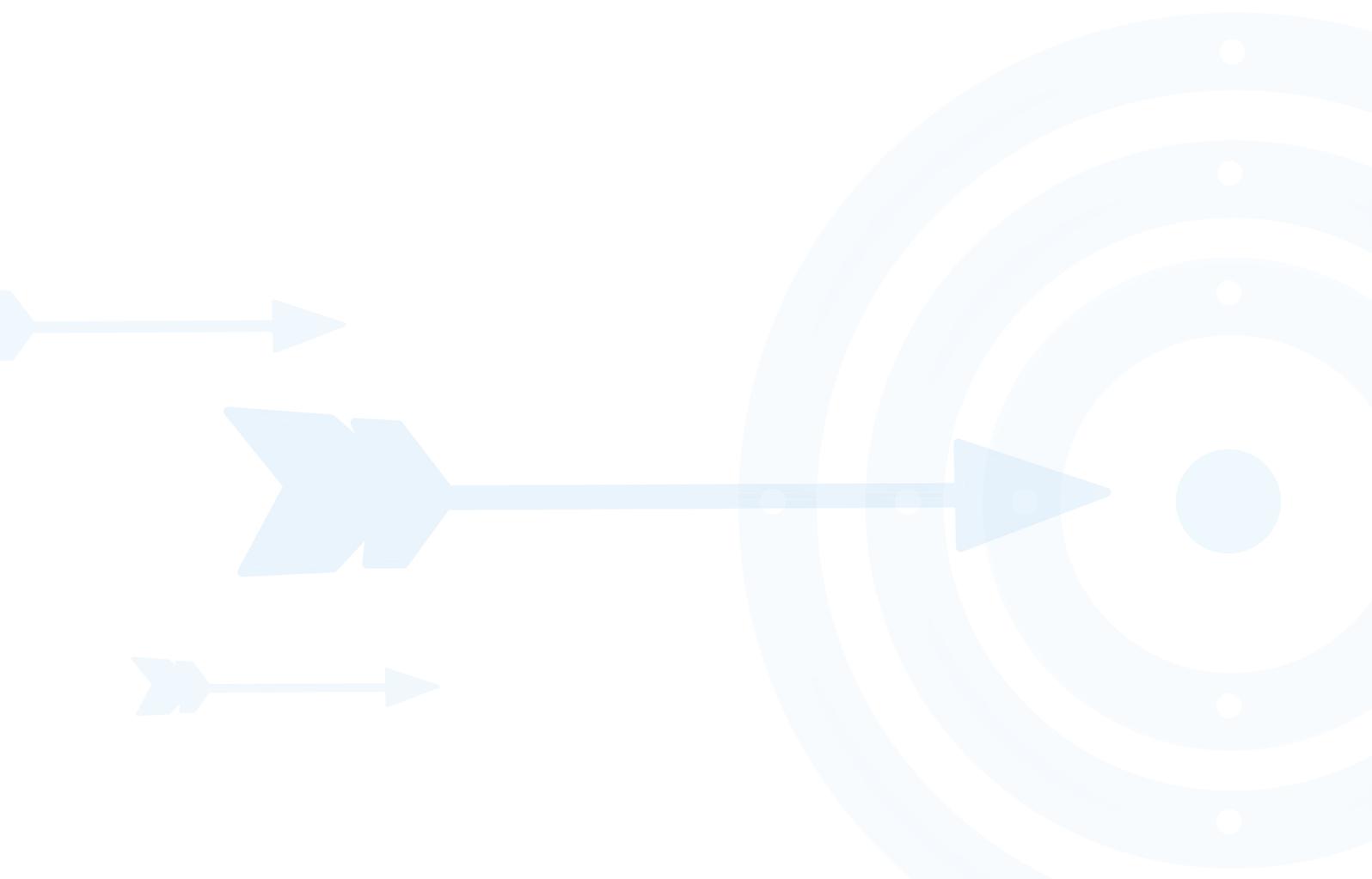
He was a director of World Vision Australia from 1994 - 2005. He also served on the board of World Vision's International's Vision Fund from 2004 - 2012 which has the responsibility for World Vision's micro-economic development activities.

Mr McKeon was recognised in 2011 as *Australian of the Year* for his humanitarianism.

During 2012, he chaired the Strategic Review of Health and Medical Research, an independent review of health and medical research in Australia which recommended a 10-year strategic health and research medical plan for the nation.

He has also served on the Federal Government's Human Rights Grants Scheme Advisor Panel and AusAID's Business Engagement Steering Committee.

For his contribution to MS Research Australia, McKeon received the John Studdy Award which is MS Australia's highest honour.



MS Research Australia employs a rigorous and robust governance structure that aims to identify and resource Australian research that will be the most effective in addressing our mandate for prevention, better treatments and a cure for MS.

MS Research Australia draws on scientific and management expertise from members within our governance structure including:

## MS RESEARCH AUSTRALIA'S GOVERNANCE



Chairman  
**Mr Paul Murnane**

**The Board of Directors** hold overall responsibility for the direction and management of Australian MS research initiatives. Their directives involve scientific advice prepared by the International Research Review Board and provide direction for future grant investments.



International Research Review Board Chairman  
**Professor Bill Carroll**

**The International Research Review Board** identify the promising areas of Australian research that complements the world-wide effort. This develops the strategic direction and focus for the allocation of funding for Australian research.



Research Management Council Chairman  
**Professor Simon Broadley**

**The Research Management Council,** are a multi-disciplinary team responsible for recommending grant allocations, monitoring and reviewing applications.



Chief Executive Officer  
**Dr Matthew Miles**

**The Chief Executive Officer** implements the strategic direction and, with the assistance of key staff, helps to coordinate the research and funds to translate the strategy into productive scientific programs.



Incubator Grants Chair  
**Associate Professor Mark Slee**

**The Incubator Grants program** provides essential seed funding for the early stages of new research efforts and is run with the guidance and oversight of the Research Management Council.



Social and Applied Research Sub-Committee Chair  
**Dr Elizabeth McDonald**

**The Social and Applied Research Sub-Committee** is part of the Research Management Council and provides recommendations on social and applied research applications.



Progress in MS Research Scientific Conference Convenor  
**Associate Professor Helmut Butzkueven**

**The Progress in MS Research Conference** is a biennial opportunity for Australian neurologists and researchers to come together, present their latest findings and form contacts for potential research collaborations.

# CORE VALUES

**Honesty**

**Integrity**

**Transparency**

**Excellence**

In just ten years, MS Research Australia has grown from a small entity to a very important and well respected national funder of MS research in Australia. Through the grant review process, MS Research Australia has awarded 154 separate research grants across every state in Australia to junior and senior MS researchers at most of the leading Universities, Institutes and hospitals.

MS Research Australia grants are considered a prestigious award and have become highly competitive. The majority of the research grants are considered as Category 1 funding; which means that recipient universities can more easily leverage further research and infrastructure funds from other competitive sources, including government. Less than ten other not-for-profit entities in Australia have similar robust research management processes and provide Category 1 funding.

The multiplier effect averages 5:1 meaning that for every \$1 raised philanthropically or otherwise for MS research, the recipient researchers are able to leverage that figure (on average) up to five times that amount with other funding. The one year Incubator Grants, however, leverage a staggering 27 times the initial money granted.

## WHAT HAS BEEN ACHIEVED

### Important achievements and outcomes so far...

- Researchers funded by MS Research Australia identified that vitamin D may be a significant factor in determining a person's susceptibility to MS as well as other environmental factors
- The opening of the only dedicated MS brain and tissue donation program, the MS Research Australia Brain Bank, based at the Brain and Mind Research Institute to which over 770 people have pledged to donate tissue to the global research effort
- MS Research Australia is undertaking the largest prevention trial of its type in the world on whether vitamin D may be used to prevent MS before the disease is diagnosed
- Researchers involved with the MS Research Australia platform-ANZgene contributed to the international identification of genetic variations that determine a person's susceptibility to MS, unlocking some of the mysteries surrounding the disease. In 2006, only two genes were known
- The Longitudinal Study surveyed almost 2,900 people with MS, determining a huge range of outcomes for people with MS regarding issues such as employment, cooling, access to therapies and housing
- A global effort and push for effective medications that included MS Research Australia, has facilitated the development of five new therapies over the last ten years (including oral forms as well as traditionally injectable medications) for treating relapsing-remitting MS. Therefore greatly improving treatment options and outcomes
- Using real world data, Australian MS researchers and their international colleagues have shown that over the last 15 years, people with MS are reaching a similar level of disability eight years later on average. Therefore greatly improving the quality of life of people with MS.



## LOOKING FORWARD



Given these exciting breakthroughs, developments and achievements, MS Research Australia is now in a strong position to be able to strategically change tack whilst still doing the things that we have always done well. The model will be adapted in the following five ways;

- Increasing funding of research targeting potential cures for MS and research directly relating to the gaps in our knowledge of MS
- As part of a global alliance, there will be a focus on progressive MS research where no approved treatment options currently exist
- Incorporating the views and needs of people with MS even further in to the research governance
- An even stronger focus on outcome-driven research
- A continued but enhanced emphasis on financial stability, sustainability and a trusted source of the truth in MS research information and its governance



***Join MS Research Australia on this journey***



# THREE YEAR STRATEGIC PLAN

The 2014 – 2016 Strategic Plan of MS Research Australia is based around five key objectives:

1	To be laser focused in finding a cure for MS through funding the best research
2	Strengthening our collaborations, we will maintain our national focus and distribution but greatly expand our global relevance
3	The principles for MS Research Australia activity are consumer focused
4	The principles for MS Research Australia activity are outcome focused
5	To ensure that MS Research Australia is a financially sustainable, accountable, trusted and transparent organisation delivering best-practice standards in the medical research sector

# STRATEGIC OBJECTIVE

# 1



To be laser focused in finding a cure for MS through funding the best research

GOAL	OUTCOME	TARGET FOR 2016*
MS Research Australia research funding to be prioritised according to achieving freedom from MS	<ul style="list-style-type: none"> <li>Greater amount of research activity concentrating on accelerating cures for MS               <ul style="list-style-type: none"> <li>- reversal of disease process</li> <li>- stopping disease</li> <li>- repair of existing damage</li> <li>- prevention</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>40% of Research Management Council (RMC) funding to be allocated to accelerating cures</li> <li>Two out of three priority-driven research projects to concentrate on researching the cause and cure for MS</li> </ul>
Fund inspirational, creative, innovative and novel research ideas focussed on the cure	<ul style="list-style-type: none"> <li>Greater opportunity for novel and out-of-the-box ideas to provide evidence towards unanswered questions</li> </ul>	<ul style="list-style-type: none"> <li>Substantial award is funded for innovation decided through the RMC by the end of 2015</li> </ul>
We identify accelerators and enablers needed to bring national and global expertise to close research gaps	<ul style="list-style-type: none"> <li>Our Research Audit and Resource Map assists in identifying priorities to guide, but not replace investigator-driven research</li> <li>Research is united on where there is the greatest need globally</li> </ul>	<ul style="list-style-type: none"> <li>Accelerators and enablers guide created as a result of resource and research mapping</li> </ul>
Fund the best quality research	<ul style="list-style-type: none"> <li>Donors funds are allocated to the best quality research available</li> </ul>	<ul style="list-style-type: none"> <li>Revamped International Research Review Board provided guidance and endorsement of recent projects and future direction (by June 2015)</li> </ul>

\*unless otherwise indicated

GOAL	OUTCOME	TARGET FOR 2016*
We act as a strategic navigator - building and leveraging our strong research networks within MS and other comparable diseases	<ul style="list-style-type: none"> <li>Proposals are invited for collaborations between ourselves and other funding bodies through the strategic (accelerator) lens rather than case-by-case</li> </ul>	<ul style="list-style-type: none"> <li>Dual MS Research Australia /Juvenile Diabetes research workshop instigated (by December 2014)</li> <li>Research audit roadmap completed (by November 2014)</li> <li>Resource map completed (by February 2015)</li> <li>NSW Clinical Trials and Research Network expanded in to two other states</li> </ul>
We concentrate on the global unanswered question of progressive MS and the emerging issue of paediatric MS via collaboration	<ul style="list-style-type: none"> <li>As an important part of the global Progressive MS Alliance, we have an opportunity to fund global progressive MS research</li> <li>Work with paediatric MS research leaders to develop early data</li> </ul>	<ul style="list-style-type: none"> <li>Funding case for support for Progressive MS Alliance developed (by March 2015)</li> <li>MS Research Australia representation at all Progressive MS Alliance meetings</li> <li>Funding secured for a paediatric MS register</li> </ul>
Working closely with MS Australia, we develop and expand our engagement with MS International Federation (MSIF), Fast Forward and our international counterparts	<ul style="list-style-type: none"> <li>Common goals are defined globally and consideration given to joint structures and the sharing of resources</li> </ul>	<ul style="list-style-type: none"> <li>Meetings held with major global stake-holders (by December 2014) with recommendation report written (by June 2015)</li> </ul>

## STRATEGIC OBJECTIVE

# 2



**Strengthening our collaborations, we will maintain our national focus and distribution but greatly expand our global relevance**

## STRATEGIC OBJECTIVE

# 3



The principles for MS Research Australia activity are consumer-focused

GOAL	OUTCOME	TARGET FOR 2016*
The inclusion of consumer-perspectives as part of the research communication and review process	<ul style="list-style-type: none"> <li>• Research priorities take account of the needs and priorities of people with MS and their carers</li> <li>• Research outcomes are communicated in easy-to-understand language to consumer audiences utilising appropriate communication vehicles</li> </ul>	<ul style="list-style-type: none"> <li>• A lay member is included in the Research Management Council (RMC) processes (by November 2015)</li> <li>• All MS Research Australia-funded projects translated using social media</li> </ul>
The inclusion of consumer-perspectives in the research prioritisation process	<ul style="list-style-type: none"> <li>• Use of the Australian MS Longitudinal Study to identify research needs within the Australian MS community</li> </ul>	<ul style="list-style-type: none"> <li>• Establish a process to identify research needs within the agreed terms of reference of the Australian MS Longitudinal Study</li> <li>• Include research priorities in the January 2015 call for applications</li> </ul>

\*unless otherwise indicated

GOAL	OUTCOME	TARGET FOR 2016*
<p>Strategies for focused translation of discoveries in to practice are considered as part of the research prioritisation process</p>	<ul style="list-style-type: none"> <li>Increased translation of scientific discoveries achieved in MS creating better outcomes for people with the disease and their families and carers</li> <li>A clear strategy for MS research translation articulated</li> </ul>	<ul style="list-style-type: none"> <li>Separate report on translational outcomes instigated (by February 2015)</li> <li>Translational impact integrated in to grants process (by November 2014)</li> <li>Translational research expert invited on to the MS Research Australia Board</li> </ul>
<p>Research results are communicated in terms of their direct contribution to the prevention of MS, better treatments for MS or acceleration towards a cure for MS</p>	<ul style="list-style-type: none"> <li>Research concepts will clearly articulate how outcomes will accelerate progress towards freedom from MS creating greater transparency and opportunities for increased funding</li> </ul>	<ul style="list-style-type: none"> <li>New outcome metrics agreed and displayed clearly on home page of MS Research Australia website (by February 2015)</li> </ul>

## STRATEGIC OBJECTIVE



The principles for MS Research Australia activity are outcome focused

## STRATEGIC OBJECTIVE

# 5



To ensure that MS Research Australia is a financially sustainable, accountable, trusted and transparent organisation delivering best-practice standards in the medical research sector.

GOAL	OUTCOME	TARGET FOR 2016*
Increase our major donor giving portfolio whilst maintaining appeal to a range of different audiences	<ul style="list-style-type: none"> <li>Major donors matched to exciting research activity creating a virtuous cycle</li> <li>Increased and diversified revenue</li> <li>The opportunity to fund excellent research currently missing out on grant funding</li> <li>Grass-roots fundraising continues and enhances its emphasis on cause and cure of MS</li> </ul>	<ul style="list-style-type: none"> <li>Major donor revenue to increase by 30%</li> <li>Develop and implement a 3 year fundraising plan that complements that of the MS state societies</li> <li>Other funding revenue sources increase collectively by 15%</li> </ul>
Employ best-practice governance throughout MS fundraising and research activities	<ul style="list-style-type: none"> <li>Exemplary donor stewardship concentrates on what we do, how we spend it and what the outcome will be</li> <li>Strict clarity on research governance processes building further on a significant level of trust</li> <li>Enhance our position as focal point and owner of the truth regarding MS research</li> </ul>	<ul style="list-style-type: none"> <li>Donor satisfaction survey results increase by 20%</li> <li>Repeat givers increase by 20%</li> <li>Market analysis of MS Research Australia scientific reputation repeated</li> <li>International Research Review Board produce a governance report with global benchmarks</li> </ul>
Develop our brand profile, messaging and create a greater reach nationally and internationally	<ul style="list-style-type: none"> <li>MS Research Australia engaged appropriately across all borders</li> </ul>	<ul style="list-style-type: none"> <li>Implement new marketing and communications plan (by February 2015)</li> <li>Leadership Council strategy developed and implemented (by end 2014) and first meeting (by February 2015)</li> <li>Increased media coverage by 20%</li> <li>Increased website hits, e–communique and social media cut-through by 25%</li> </ul>

\*unless otherwise indicated

## TURNING VISION INTO REALITY

**MS Research Australia is poised to greatly expand the research effort and have a positive effect on all people affected by MS in Australia and worldwide.**





**RESEARCH  
AUSTRALIA**

**MS Research Australia**

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