



RESEARCH AUDIT

2004 - 2014



RESEARCH
AUSTRALIA

“Australian scientists are playing a leading role in the worldwide battle to solve multiple sclerosis. The elimination of the disease is within reach – it is just a matter of when.”

Mr Simon McKeon AO,
Patron, MS Research Australia and 2011 Australian of the Year

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Created with generous support from the Macquarie Group Foundation



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MS Research Australia Research Audit 2004 – 2014.
MS Research Australia, Sydney.

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RESEARCH AUDIT

2004 – 2014



Dr Linda Ly, Brain and Mind Research Institute, University of Sydney

CONTENTS

| | |
|--|----|
| Foreword by Professor Bill Carroll | 4 |
| Introduction by Mr Simon McKeon AO | 5 |
| Introduction by Dr Matthew Miles | 6 |
| Executive Summary | 7 |
| Letter of support: Federal Minister for Health | 8 |
| Letter of support: State Minister for Health | 9 |
| 1 An overview of MS | 11 |
| 2 History of MS research in Australia | 16 |
| 3 MS Research Australia: a new approach to MS research | 17 |
| 4 Research Milestones 2004 – 2014: the Research Audit | 21 |
| Milestones in the MS Research Australia journey | 22 |
| Letter of support: National Health and Medical Research Council | 46 |
| 5 Achievements resulting from research funded by MS Research Australia | 49 |
| Letter of support: Research Australia | 50 |
| 6 Future developments and directions | 51 |
| 7 Acknowledgements | 54 |
| 8 References and key readings | 55 |



**PROFESSOR
BILL CARROLL**

Foreword

As the Chairman of MS Research Australia's International Research Review Board and former Chair of the MS Research Australia Research Management Council, it is clear that MS Research Australia's research investment has played a pivotal role in energising MS research in Australia. From humble beginnings, MS Research Australia is now the focal point for Australian research in MS, and this research audit celebrates the great accomplishments of MS Research Australia and its affiliated scientists. By striving to create focal points of research strength in all states of Australia, we have built a collaborative framework that is used now and will be expanded by future generations of researchers.

We are delighted that over 150 MS research grants have been awarded since 2004, and particularly thrilled with the research outcomes that have been achieved as a result. This level of research funding helps create the essential leverage for further funding, helping us to become the largest national not for profit provider of MS research funding in Australia.

I would like to acknowledge those who will be leading MS Research Australia's research governance into the future, including Professor Simon Broadley who will be taking over the important role of Chairman of the Research Management Council, Associate Professor Helmut Butzkueven who will be our new Progress in MS Research Scientific Conference Convenor, and Associate Professor Mark Slee who will oversee the MS Research Australia incubator grant program. All of these roles are critical to our success, and it is very pleasing to be able to see these important roles for MS Research Australia in such capable hands.

Of course, none of the remarkable developments undertaken by MS Research Australia would have been possible without the commitment, dedication and selfless contributions of all those who have served as Board Members, staff, and advisors over the past ten years, in some cases, longer. These people will figure within this publication and will also take quiet satisfaction in knowing that they have set MS Research Australia on the right path to benefit all people with MS. Finally, it appears to me that MS Research Australia has also been the catalyst for the MS family of MS Societies in Australia to develop a national view of the problems facing people with MS. It is remarkable, although no accident, that over a similar period of time there is now emerging a desire for all elements of the MS network to have a common set of goals and actions for both research into and care of people with MS. State societies have made outstanding contributions in many ways to MS Research Australia for a long time.

It has been a privilege to be part of the MS Research Australia journey.

Professor Bill Carroll

Chairman MS Research Australia International Research Review Board
MS Research Australia Board Member
Clinical Professor of Neurology, Sir Charles Gairdner Hospital, Perth
Vice President World Federation of Neurology

Introduction

As Founding Chairman of MS Research Australia from 2004 to 2010 and Board Member until 2012, it has been rewarding to see the organisation grow, prosper and achieve the outcomes it has over the past ten years. MS Research Australia has done a tremendous job encouraging and funding the very best MS researchers in the country to pursue their various fields of endeavour. This is vital as it's going to take a global effort and resources to find a cure for MS.

Many people have made MS Research Australia the success it is today, such as former Research Management Council Chair Professor Bill Carroll, our inaugural Executive Director Mr Jeremy Wright, past and continuing Board Members, and employees. Thanks also go to the late Mr Ian Ballard and the F5M+ community, Mr and Mrs Roy and Carol Langsford OAM, Professor Jim McLeod and the various MS state societies who have also been instrumental in the achievements of MS Research Australia.

In 2010, I handed the Chairmanship over to Mr Paul Murnane, a highly experienced investment banker and champion of the not for profit sector. Paul's family history of MS makes him perfectly positioned to understand many of the personal aspects of MS while excelling in the leadership of a "for purpose" organisation. After I left the Board in 2012, I was humbled to be asked to become Patron, thus enabling me to continue an involvement with MS Research Australia.

My personal experience with MS helps me appreciate the great work that is continually emerging from MS researchers in Australia. What is key, however, is that MS Research Australia's research funding over the last decade has tried to target the wide spectrum and complexity of disease, clinical signs and severity, which make MS such a challenge. MS Research Australia is a key catalyst for the rapid recent progress in our understanding of the factors underpinning the development of MS.

The work that MS Research Australia has supported has no doubt benefitted those with the relapsing and remitting form of the disease, and I am proud of the fact that we now have ten very sound treatment options for people with this form of MS. Progressive MS continues to confound us, and MS Research Australia is doing its bit to address this by joining and committing significant funds to the International Progressive MS Alliance in 2014, along with the USA, UK, Italy, Denmark and Canada.

For many years, Australia has produced some of the best scientific and medical researchers in the world, and our MS researchers are no exception. As a nation, Australia has undeniably generated substantial benefits from research. The overarching vision for health and medical research should be one where research is properly embedded in all aspects of healthcare delivery. "Better health through research" is consistent with our aspiration for Australia to build and maintain the world's best and most efficient health system.



Mr Simon McKeon AO

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



**MR SIMON
MCKEON AO**



**DR MATTHEW
MILES**

Introduction

As the Chief Executive Officer of MS Research Australia since 2013, I am inspired by the accomplishments of those who have shaped this organisation over the past decade.

Reflecting on the achievements highlighted in this document, the most striking result is the breadth of outcomes – the discoveries and benefits that have been brought to people with MS, their families and carers. Since 2004, MS Research Australia has supported many talented researchers by helping them to apply their expertise and scientific knowledge to ensure people with MS can lead better lives.

Many of these achievements would not have been possible without the generosity of all the supporters making tremendous impact on research investment into MS research in Australia. In particular, all of the state MS Societies, the Trish MS Research Foundation, CharityWorks for MS, and the Foundation Five Million Plus community fundraising groups have played a vital role in the success of MS Research Australia funding initiatives.

It is the support of donors, trusts and foundations, the Australian Federal and State Governments and our networks that have allowed us to achieve our goals since 2004. We strongly value our partnership with each of these groups and look forward to many shared achievements in the future. We would particularly like to acknowledge the Macquarie Group Foundation for their valued funding support to produce this important document.

We also rely greatly on the countless number of volunteers, as well as the significant number of corporate groups, companies and individuals who provide invaluable pro bono services each year.

At its core, 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 those who teach and mentor the professionals and the researchers of tomorrow.

We are grateful to all those who have made the past ten years possible.

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
Executive Committee Member, International Progressive MS Alliance

In 2014, Multiple Sclerosis Research Australia celebrates its 10th anniversary. Starting as a small organisation in 2004, it has grown to be Australia's principal non-government national organisation dedicated to both funding and coordinating MS research in Australia, as part of the worldwide effort to unravel the complexity of MS.

The primary mission of MS Research Australia is to accelerate research towards the prevention, better treatments and, ultimately, a cure for MS.

MS research in Australia

Before MS Research Australia's inception in 2004, MS research in Australia was uncoordinated and inadequately funded.

In 2004, MS Research Australia was established with the aim to revolutionise and revitalise the way MS research was conducted in Australia. In ten years, MS Research Australia has vastly increased the amount of funding available to researchers from all around Australia, and supported the development of several directed research platforms.

Importantly, MS Research Australia's activities have also been a catalyst to significantly increased funding of MS research from key Australian research funding bodies such as the National Health and Medical Research Council and the Australian Research Council.

Research Audit survey

MS Research Australia conducted a research audit to determine if key research output from the past ten years has adequately addressed the strategic objectives during this time.

Researchers who were awarded one or more grants from MS Research Australia between 2004 and 2013 were surveyed to identify the key outcomes resulting from their funding support.

The survey results highlighted key organisation achievements, such as dramatically increasing the funding dedicated to MS research in Australia and establishing a number of major collaborative platforms, but also many game-changing research breakthroughs, including new gene discoveries, novel research tools and methods, several patents and biomarkers that are changing the face of MS clinical practice.

MS research beyond 2014

MS Research Australia is rightly proud of all that has been achieved, but there is still much work to do. The cause and cure of MS remain elusive, despite major breakthroughs in the laboratory and advances in clinical therapy settings.

MS Research Australia will continue to focus on outcomes-based research, identifying gaps in treatments and symptom management options, and providing infrastructure, including staff and databases. In addition, MS Research Australia is now in a better position to refine and modify its strategic focus in the future, while maintaining many of the strategies that have made the previous ten years successful. Future goals aim to accomplish even more consumer-focused and outcomes-driven research, and to enhance a position as Australia's top national research funding organisation dedicated to MS.

EXECUTIVE SUMMARY

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



**THE HON PETER DUTTON MP
MINISTER FOR HEALTH
MINISTER FOR SPORT**

Dr Matthew Miles
Chief Executive Officer
Multiple Sclerosis Research Australia
PO Box 625
NORTH SYDNEY NSW 2059

Dear Dr Miles,

I am writing to congratulate you on the 10th anniversary of the establishment of Multiple Sclerosis Research Australia.

Since 2004-05, the Australian Government has provided over \$2 million in funding to support MS Research Australia undertake research towards prevention, better treatments and a cure for multiple sclerosis. I commend MS Research Australia in establishing other funding streams for Multiple Sclerosis research, to reduce its reliance on government funding, with strong partner relationships established with other bodies including corporations, Multiple Sclerosis state societies, trusts, foundations, other organisations and donors. I understand that this has resulted in over \$14 million being raised for research funding and is further evidence that MS Research Australia is the largest national not-for-profit supporter of Multiple Sclerosis research in Australia.

Australia's research efforts towards effective treatments and a cure for Multiple Sclerosis have furthered our global understanding of the disease and given hope for an Multiple Sclerosis-free future.

Congratulations to MS Research Australia on this achievement.

Yours sincerely

PETER DUTTON



The Hon Jillian Skinner MP

Minister for Health
Minister for Medical Research

M14/5054

Dr Matthew Miles
Chief Executive Officer
MS Research Australia
National Office
100 Miller Street
NORTH SYDNEY NSW 2059

Dear Dr Miles,

Please accept my warmest congratulations on the achievements MS Research Australia has made over the past 10 years. I have great admiration for MS Research Australia and am proud of the strong partnership between your organisation and the NSW Government.

The MS Research Australia Brain Bank at the Brain and Mind Research Institute and the NSW MS Clinical Trials and Research Network have been funded by the NSW Government for many years and are producing many positive outcomes for people with MS.

As NSW's first Minister for Medical Research, it is my goal to establish NSW as a global centre of excellence for medical research. Working with organisations such as yours is crucial to achieving this goal.

I am confident MS Research Australia will continue to lead MS research into the future.

Yours sincerely

Jillian Skinner MP



Dr Scott Byrne, University of Sydney

Multiple sclerosis (MS) is a common central nervous system disorder affecting more than 2.3 million people worldwide. MS can be debilitating, chronic and progressive, and there is no known cure.

There is no known cause of MS, but many genetic and environmental factors have been shown to contribute to its development.

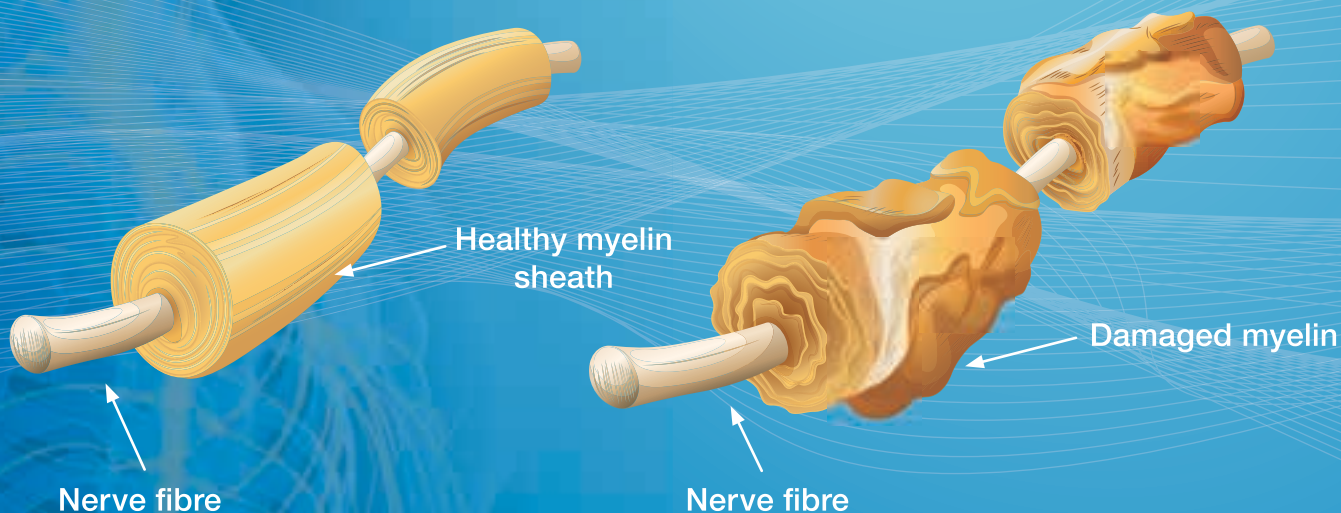
In MS, the body's own immune system mistakenly attacks and damages the fatty material – called myelin – around the nerves. Myelin is important for protecting and insulating nerves so that the electrical messages that the brain sends to the rest of the body travel quickly and efficiently.

As the myelin breaks down during a MS attack – a process called demyelination – patches of nerves become exposed and then scarred, which render the nerves unable to communicate messages properly and at risk of subsequent degeneration. This means that the brain cannot talk to other parts of the body, and a loss of motor skills, vision and cognitive ability, among other symptoms, can result.

1

AN OVERVIEW OF MS

MS is the most common acquired chronic neurological disease in young adults in the world. It affects more than 23,000 Australians and 2.3 million people worldwide.



The triggers for multiple sclerosis are currently not known, and there is no cure, but every day we are making new progress.

MS can manifest in two different ways: relapsing-remitting and progressive MS.

The incidence of MS is increasing in children and teenagers.

Around the globe, every hour, someone is diagnosed with MS.

1.1 Features of MS

The symptoms of MS are different for each person, sometimes they even vary within the same individual.

Symptoms of MS can include fatigue, difficulty walking or doing tasks, visual problems, memory changes and chronic pain. For most, MS is characterised initially by periods of relapse and remission, whereas for others it has a progressive and unrelenting pattern. For everyone, it makes life devastatingly unpredictable.

Because of the variety and vagueness of symptoms – many of which are common with other nervous system disorders – there is no specific test for MS. Rather, an individual showing symptoms of MS will likely undergo several specialised tests, including magnetic resonance imaging (MRI) and, less commonly, cerebrospinal fluid testing.

MS manifests in different ways with two different forms now recognised, based on the course of the disease:

- > Relapsing-remitting or bout-onset MS affects 85% of people first diagnosed with MS. This means that acute attacks happen that may last for days, weeks or months, but are followed by a period of less severe or no symptoms. Attacks may occur every one or two years, depending on the person.
- > Progressive MS is characterised by a person's slow, progressive accumulation of disability, but with no relapses or reversal in condition. This type affects about 10-15% of people first diagnosed with MS, and eventually affects almost all of those initially presenting with relapsing-remitting MS.

1.2 MS around the world

In 2013, there were globally about 2.3 million people living with MS – an increase from 2.1 million people in 2008. MS affects people in all regions, but the prevalence is highest in North America and Europe; prevalence is lowest in sub-Saharan Africa and East Asia.

The prevalence of MS also varies according to latitude, so that countries further away from the equator have a higher prevalence of MS compared with those closer to the equator. This finding has led to the current hypothesis that a lack of sunlight and vitamin D contribute to the causes of MS.

On average, around the world, twice as many women than men are diagnosed with MS, but researchers are not sure why this happens. In some countries, this is even more skewed: women are affected three times as often as men in East Asia, and in America this difference is about two-and-a-half times as many women. In all regions of the world, this sex difference is increasing.

Worldwide, the average onset age is 30. People can be diagnosed at any age, although it is usually in early adulthood.

The Multiple Sclerosis International Federation has estimated that about 7,000 people under the age of 18 are currently living with MS, although the true number of cases is likely to be higher (MSIF 2013). The International Paediatric MS Study Group reports that symptoms have been seen in babies as young as 12 months. The number of new cases of paediatric MS is also increasing each year (IPMSSG 2007).

1.3 MS in Australia

In 2009, 23,700 people in Australia were estimated to be living with MS (ABS 2009). In Australia, MS affects about three times more women than men, which is higher than the global average.

The geographical or latitudinal gradient pattern of MS – that is, the increasing prevalence in populations the further they live from the equator – is most striking in Australia and New Zealand. The prevalence is higher in the southern states than in northern states and territories – rates of MS are much higher in Hobart than in far north Queensland (Figure 1.1).

MS is usually diagnosed in a person's 20s or 30s, and women are three times more likely to be affected than men.

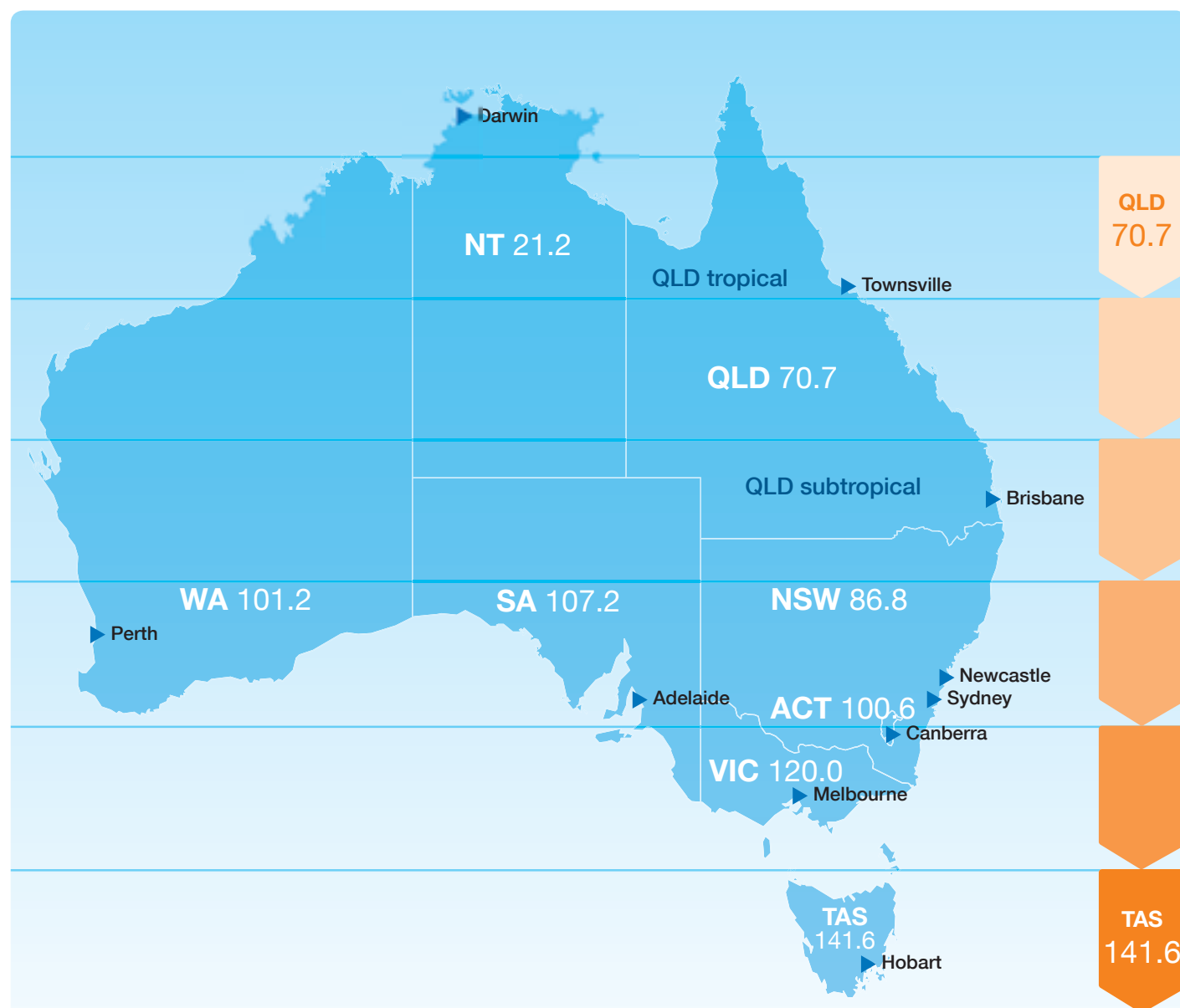


Figure 1.1 Adjusted rates of the prevalence of MS in Australia (per 100,000 people) according to Australian prescription data.

Source: *Economic Impact of MS in 2010*, Covance and Palmer (2011).

The Needs Analysis and Economic Impact Report, produced by MS Research Australia, provided new insight into many issues of key importance to people with MS in Australia.

The loss of quality of life in those living with severe MS is comparable to those who are living with end-stage cancer or a major stroke.

1.4 Social and economic impacts of MS

Most diagnoses are given in early adulthood (that is, in the 20s and 30s). The impact of a diagnosis can be dramatic, as it often affects young parents, those thinking about starting a family, or pursuing their career. It can also mean many years of living with uncertainty or managing a chronic, unpredictable, progressive condition.

For some, a MS diagnosis may come as a relief, because their symptoms are finally explained and they can start addressing them. However, for others, it can generate a lot of uncertainty.

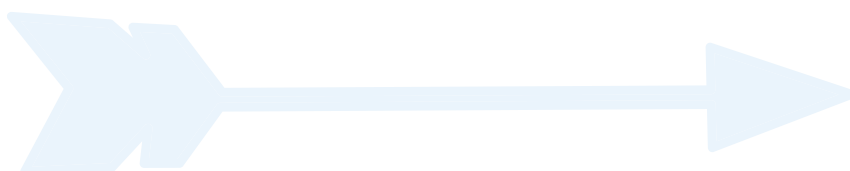
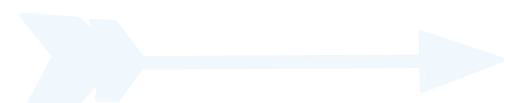
To help minimise the social impacts that come with living with MS, much research funding is allocated to studying the social and practical aspects of MS. Research platforms such as the Australian MS Longitudinal Study are providing information that has and will be used for service planning and advocacy for those with MS – for example, information on employment, economic impact and service needs have been gathered via the study. MS is often also associated with a substantial ongoing financial impact, such as for medicines, home and car modifications, as well as transport and support services (Covance and Palmer, 2011).

A needs analysis conducted through the Longitudinal Study in 2012 revealed that people with MS have a substantial need for information and advice on financial issues and benefits, as well as psychosocial support and assistance with transport and respite care (McCabe et al., 2012).

Findings such as these are of great practical importance to those living with MS and the organisations that support them.

The economic impact of MS increases as the disease worsens in severity and has significant impact on quality of life. The *Economic Impact of MS in 2010* report (Covance and Palmer, 2011) revealed that people with MS have about a 20 per cent reduction in quality of life, which reaches about 50 per cent once the disease becomes severe. This is comparable with those who are living with end-stage cancer or a major stroke (Covance and Palmer, 2011). However, with the improved treatments and better methods for symptom management that are being developed by MS researchers, quality of life is already greatly improved and can only get better for those living with MS.

There is significant community support for research aimed at alleviating the social and economic impacts of MS as well as for biomedical research that targets better treatments and a cure. This, combined with ever-increasing research funding, provides a great deal of hope for those currently living with MS and their families.



1.5 Public opinion on MS research investment

Researching the cause of MS is a valuable component of prevention. Genetics, epidemiological and environmental factors and their interaction need to be investigated further, as does neurobiology and immunology. Improved understanding in these areas will lay the foundation for new treatments that are safer and targeted directly to the source of the disease. Clinical trials will be a crucial part of all aspects of MS research. The social impact of MS has been and can be further improved by research into services, programs and policies.

A 2011 Newspoll study (Figure 1.2) provided insight into the key aspects that the community felt should be the priority targets for investment in MS.

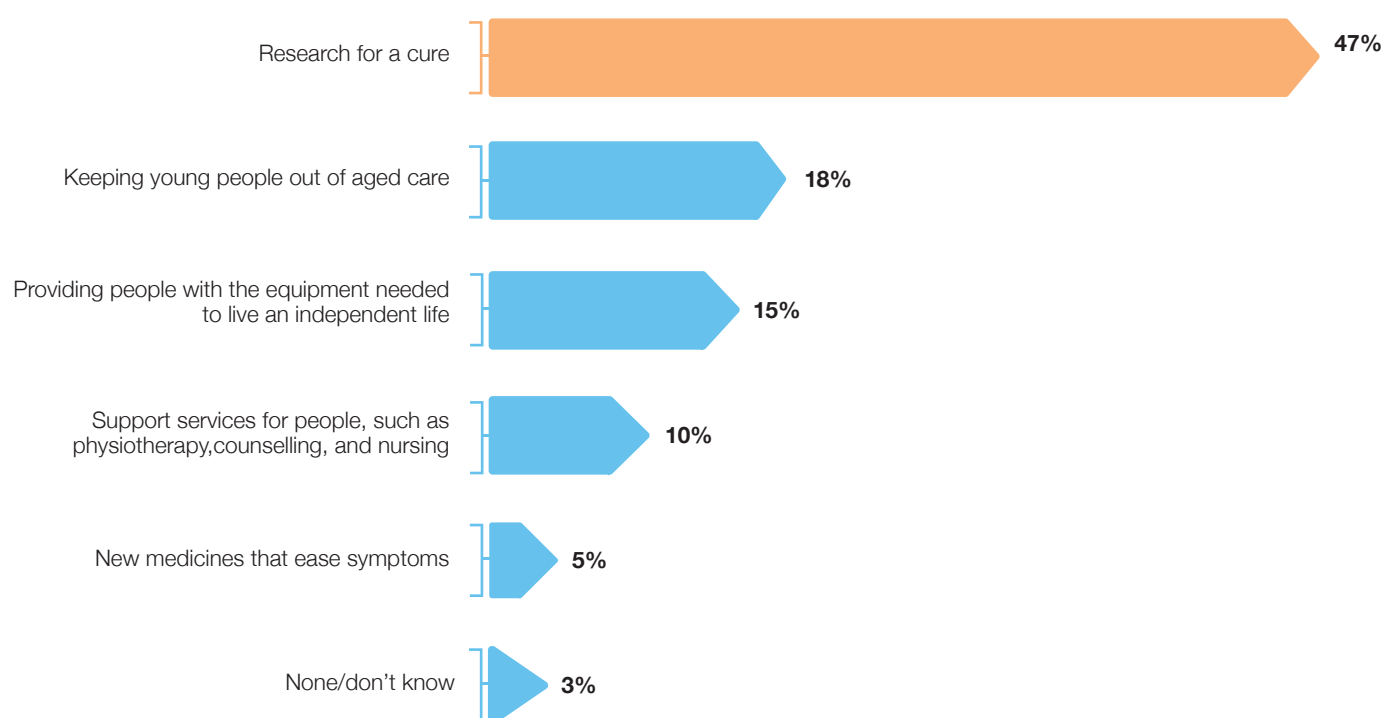


Figure 1.2 Public opinion on what area a donation of \$100 would be best spent for MS

Source: Newspoll (2011).



2 HISTORY OF MS RESEARCH IN AUSTRALIA

The world's first MS society – the National Multiple Sclerosis Society – started in New York, United States, in 1948. Australia was the fourth country to form a MS society of its own.

2.1 Australian MS Societies

The Australian MS Society was established in 1956 to advocate for and support people living with MS. The following decades saw the establishment of Societies in each state and territory.

For the first 30 years of their existence, state-based MS Societies contributed small funding amounts to researchers in their own jurisdiction. The first known MS Society research grant in Australia was in 1963.

In 1983, the National MS Research Foundation was established to allocate funds to research nationally. During the 1980s, MS Societies started to contribute to this fund and, in 1995, it reached more than \$800,000. However, due to increasing commitments to maintaining client services, the MS Societies' focus on research eventually waned, and by 2003 the research funding had dwindled to about \$440,000 – not enough to make a significant national impact on MS research and translational medicine.

Before 2004, MS research lacked a common national direction, and received very little funding.

MS Research Australia was to change this.

2.2 MS research before 2004

Historically, much medical research has been siloed, where researchers would study the discipline they were expert in, without much cross-talk between disciplines and institutions. This approach was common for all medical research, not just MS research.

Despite these limitations, much important work was undertaken before 2004. Australia has always been home to world-class experts in many areas of MS research, including immunology, genetics, neurobiology and integrated medicine.

Previously, the competitive funding model made collaboration more difficult, and duplication of research efforts inevitably existed. Nationally coordinated MS research networks and collaborations were more difficult to establish, affecting the number of high-quality collaborative outcomes. The complex nature of MS makes cross-disciplinary collaborations especially important for bringing diverse expertise to a project.

Before 2004, MS research lacked a common national direction, and received very little funding. MS Research Australia was to change this.

3.1 The early years

In 2002, in response to the MS Societies' limited research funding and in parallel with a move to a national federation of MS societies, the idea of MS Research Australia was first raised. The Directors and CEOs of several state Societies started discussing the need to recommit to research funding via a new business model. MS Research Australia would lift and coordinate the national MS research effort by establishing 'virtual institutes', and aim to identify cause(s) and cure(s). Also at this time (2003) Booz Allen was asked to provide a report on the potential to enhance MS research in Australia – and provided a blueprint for a new organisational focus.

All this provided the impetus for MS Research Australia to be formed, as an attempt to overhaul the way MS research was done in Australia.

In 2004, the National MS Research Foundation was converted into MS Research Australia, with changed goals, roles, and governance. Its first strategic objectives were to develop major sponsorship campaigns, establish the governance structure and a portfolio of research projects, and recruit researchers to establish new virtual research centres. MS Research Australia wanted to substantially increase available funding and realign the MS research effort. This would require a focused MS research campaign and a revised research structure.

3 MS RESEARCH AUSTRALIA: A NEW APPROACH TO MS RESEARCH



Former Prime Minister The Hon. John Howard OM AC
and Betty Cuthbert AM MBE at the launch of
MS Research Australia

(Canberra, Australia, August 2004)

By 2005 – 2006, the research investment had nearly doubled to more than \$1 million – the highest allocation MS researchers had seen in ten years. The public profile had risen, and an active Board of Directors had been established. Several important partnerships had been initiated that would come to make a vital contribution to supporting MS research, including the Trish MS Research Foundation and the grassroots fundraising body Foundation 5 Million.

3.2 A new approach to MS research

The founding objectives of the organisation required a new approach to MS research – a challenge that produced an innovative solution.

MS Research Australia and the researchers would establish a network of national research institutes, clinicians, and other specialists and researchers from around the country who all worked together. In this way, research infrastructure and data could be shared. Granting schemes would encourage collaboration, and focus on large-scale programs and projects that were comprised of multidisciplinary teams.

MS Research Australia would provide research strategies and direction, funding, governance and communication.

MS Research Australia would change the face of multiple sclerosis research in Australia.

The original research agenda included five research streams:

- > Neurobiology and MS
- > Immunology and Virology
- > Genetics and Epidemiology in MS
- > Clinical Trials
- > Social and Applied Research

The immediate research questions focused on the genetics of MS, the blood-brain barrier, and repair and regeneration.

This approach aimed to contribute to MS on a worldwide scale, build on Australian strengths and, importantly, provide benefits to people with MS by making research breakthroughs. Australia would be actively searching for a cause, aggressively identifying new treatments, and addressing the symptoms of MS. Researchers would see a much higher level of commitment to MS research, new opportunities to collaborate and exchange ideas, and more stable funding.



"Research is no longer exploratory and searching for the right questions; rather, it is focused on topics that are relevant to key disease mechanisms and increasingly yielding results. MS Research Australia has been closely involved with these successes in creating a portfolio of activities that reflects commitment to education and research and one that supports people who can best advance the subject wherever they are based in Australia. No one who has participated in the biennial Progress in MS Research symposia will fail to be impressed by the enthusiasm and commitment of the Australian research community, and by the many successes that their work has yielded.

MS Research Australia has had the vision and energy to embrace all of these endeavours and we can be sure that the next decade will be as successful as the last in realising its scientific and humanitarian aims."

Internationally renowned clinician scientist **Professor Alastair Compston**, Professor of Neurology, University of Cambridge, UK.

MS Research Australia Strategic Objectives 2004 – 2013

Founding objectives: 2004 – 2005

- 1 Establish Research Management Council and International Research Review Board
- 2 Increase research spending nationally
- 3 Develop and support key multi-centred platforms and 'virtual centres'
- 4 Establish a fully 'peer reviewed' portfolio of projects

Ongoing objectives: 2005 – 2013

- 5 Establish and maintain the MS Research Australia website to encourage interest for health professionals, researchers, people with MS and donors
- 6 Invest in the most productive areas of new research while supporting existing research commitments based on Australia's strengths and expertise
- 7 Allow for the flexibility for investigator-initiated research to develop into MS Research Australia-directed projects and thereby generate a higher proportion of proactive research
- 8 Foster the development of researchers in the MS field via secure career paths



Dr Edwin Lim, Macquarie University

In just ten years, MS Research Australia has grown from a small organisation to an important and well respected national funder of MS research in Australia. In 2012, Booz and Company Management Consulting Services conducted a strategic intent analysis for MS Research Australia and identified a research audit and resource map as key deliverables to inform future strategic direction.

To evaluate MS Research Australia's contribution to the MS research landscape and outcomes in Australia, an internal audit was conducted to assess all research funding programs and activities. In addition, surveys were conducted of all previously funded researchers who were awarded one or more grants from MS Research Australia between 2004 and 2013.

This survey captured information from 55 MS researchers, relating to 72 of 154 grants awarded over this period, and encompassing 66% of the total funding awarded (more than \$9.4 million worth of funding).

The survey asked researchers about outcomes arising from their MS Research Australia funding, including any additional funding received as a result; any career progression and mentorship; novel tools, techniques or methods developed; and many other measures of research achievement. In compiling the results of this survey, the key objective was to specifically examine how these outcomes address the original strategic goals of the organisation since 2004 (listed on page 19).

MS Research Australia grants have been awarded across Australia, and platform projects incorporate researchers from both Australia and New Zealand, providing support for the best MS researchers within all the major universities, institutes and hospitals.

4 RESEARCH MILESTONES 2004 – 2014: THE RESEARCH AUDIT

MS Research Australia works with leading medical research institutes in Australia and New Zealand



Milestones in the MS Research Australia journey

Pre-MS Research Australia

- > 1975: National Multiple Sclerosis Society of Australia peak body formed
- > 1981: First national prevalence survey of MS by Professor Jim McLeod and colleagues
- > 2000: National Multiple Sclerosis Society of Australia became MS Australia
- > 2000: Australian MS Longitudinal Study established
- > 2002: MS Australia Annual General Meeting – representatives of MS state-based Societies made the decision to establish MS Research Australia in 2004
- > 2002: Ausimmune Study established to investigate environmental factors in MS

MS Research Australia 2004

- > MS Research Australia officially launched in Canberra, with seed funding from the Australian Government Department of Health
- > First Chairman Mr Simon McKeon, the MS Research Australia Board and the Executive Director Mr Jeremy Wright were appointed
- > Research Management Council (funding) and International Research Review Board (strategy) formed, chaired by Professor Bill Carroll
- > Memorandum of Understanding established with The Trish MS Research Foundation to act in partnership

2005

- > Australian MS Longitudinal Study and Ausimmune Study both receive support from MS Research Australia
- > Grass roots fundraising group Foundation 5 Million established and members elect to fund research under the auspices of MS Research Australia
- > Incubator grant program initiated to encourage testing of new research ideas

2006

- > First Betty Cuthbert Scholarship announced in partnership with the National Health and Medical Research Council
- > Over \$1 million invested in research in 2005 – 2006, more than double previous years commitments

2007

- > Ausimmune Study published latitudinal gradient findings, providing foundation for further research into vitamin D and its effects on MS
- > The Ausgene group was established to investigate genetic links to MS (soon to become ANZgene with the addition of DNA samples from New Zealand)
- > First Progress in MS Research Conference, Melbourne, November 2007

2008

- > Over \$2 million invested in research in 2007 – 2008
- > New evidence links the Epstein Barr Virus with MS
- > MS Research Australia Brain Bank established, based at the University of Sydney

2009

- > First ANZgene discovery of two genes associated with MS
- > MS Clinical Trials Network and NSW Research Network initiated
- > Progress in MS Research Conference, Sydney, October 2009
- > Macquarie Group Foundation MS Research Australia/UK MS Society Fellowship awarded

Milestones in the MS Research Australia journey

2010

- > New Chairman Mr Paul Murnane appointed
- > MS Research Australia *Five-year Impact Report* published
- > National awareness campaign *Kiss Goodbye to MS* began
- > Proteomics of MS platform established
- > ANZgene discovery of two small gene regulatory molecules (microRNA)
- > *Economic Impact of MS in 2010* produced by researchers at the Menzies Research Institute Tasmania and Covance health economists, supported by Macquarie Group Foundation

2011

- > MS Research Australia former Chair and current Board Member Mr Simon McKeon named Australian of the Year
- > ANZgene together with the International Multiple Sclerosis Genetics Consortium discover 57 MS risk genes
- > Haematopoietic Stem Cell Transplant (HSCT) Registry formed
- > Progress in MS Research Conference, Melbourne, October 2011

2012

- > Needs Analysis conducted – Australian MS Longitudinal Study surveyed 2,900 people
- > MS Research Australia Brain Bank relocated to Brain and Mind Research Institute, Camperdown, Sydney
- > Significant breakthrough in immune system control from researchers at the University of Adelaide
- > *Kiss Goodbye to MS* becomes national fundraising campaign

2013

- > Vitamin D Prevention Trial (PrevANZ) commences, bringing together multi-disciplinary team to identify safety, efficacy, and dosage of vitamin D to prevent MS
- > ANZgene contributes to International MS Genetics Consortium discovery of further 48 MS risk genes
- > Australian Competitive Grants Register – Category 1 accreditation for MS Research Australia grants
- > Second Chief Executive Officer, Dr Matthew Miles, appointed
- > New Research Management Council Chair, Professor Simon Broadley, announced
- > McKeon Review of Health and Medical Research published
- > Largest ever Progress in MS Research Conference held in Sydney, November 2013

2014

- > MS Research Australia 10-year anniversary; total research funding exceeds \$22 million, awarded via more than 150 grants since 2004, and 8 major platform projects
- > A total of 815 MS Research Australia Brain Bank pledges and 45 brain and tissue donations received
- > MS Research Australia joined International Progressive MS Alliance as a managing member, with Professor Bill Carroll appointed to Scientific Steering Committee
- > Mr Simon McKeon AO awarded the Australian Academy of Science 2014 Academy Medal
- > After nine great years, Foundation Five Million Plus joins forces with *Kiss Goodbye to MS* campaign

Founding OBJECTIVE



Establish a Research Management Council and International Research Review Board

A founding objective of MS Research Australia was to establish two key panels that will facilitate robust and transparent research strategy for the organisation.

The *Research Management Council* and the *International Research Review Board* were both established in 2005, and, since then, both panels have made immeasurable contributions to the success of MS Research Australia research investments.

- > The Research Management Council oversees funding allocations for MS Research Australia investigator-driven research.
The Research Management Council is comprised of MS researchers and research specialists from related disciplines.
- > The International Research Review Board helps to guide MS Research Australia's research strategy and direction, to best leverage Australia's strengths in contributing to the global research direction.
The International Research Review Board plays a vital role in identifying promising future targets for directed research (streams and platforms).

The function and goals of these panels are constantly being refined and strengthened, to ensure the MS Research Australia funding model is among the most robust and transparent of all medical research organisations.

Governance and Management



Since 2004, MS Research Australia has funded more than \$22 million in Australian research endeavours. This includes more than 150 separate investigator-led research grants in all states and territories, totalling more than \$14 million overall, with an additional \$8 million allocated to directed collaborative research projects known as platforms.

MS Research Australia has been supported by more than 11,700 donors, including several individuals who have contributed more than \$100,000. Figure 4.1 shows the income sources of MS Research Australia since 2005, including several avenues for fundraising, support from the state MS Societies, federal and state government support, pharmaceutical industry grants, and bequests.

Founding OBJECTIVE



**Increase research
spending nationally**

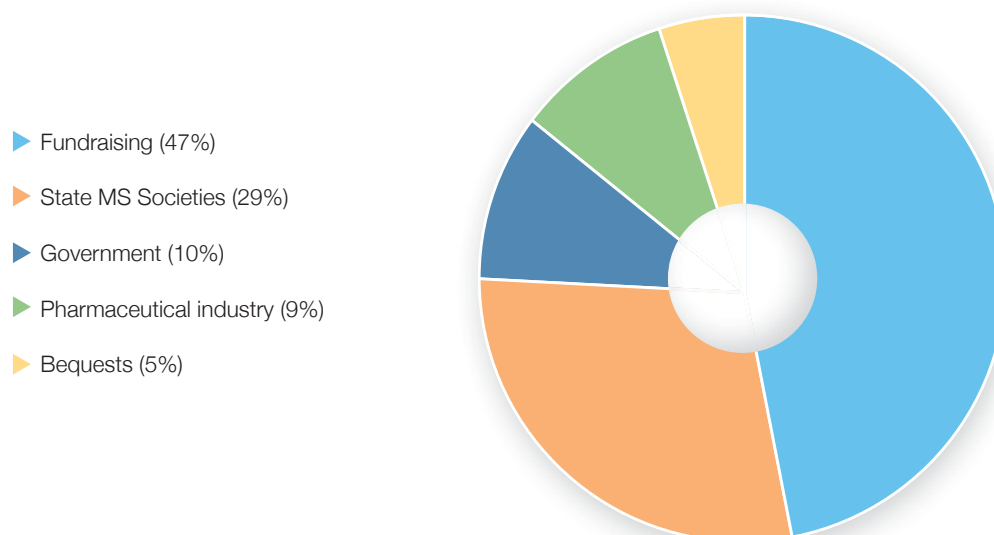


Figure 4.1 How MS Research Australia is funded: income sources 2005 – 2014

Data source: Audited MS Research Australia financial accounts

Through targeted fundraising and a solid research funding strategy, MS Research Australia has successfully and substantially increased Australian research investment into discovering the triggers, treatments, and a potential cure for MS.

Each year the available funding amount has increased – from \$440,000 in the 2004 financial year to more than \$3 million in the 2013 financial year (Figure 4.2).

In addition to fundamental support from government grants and the state MS Societies, an important aspect of the huge growth in funding allocated to MS research has arisen from MS Research Australia's community fundraising initiatives. This includes Foundation 5 Million (since 2005) and Kiss Goodbye to MS (since 2012), in addition to partnerships with organisations such as the Trish MS Research Foundation and CharityWorks for MS, and support from numerous trusts, foundations, and high net-worth individuals.

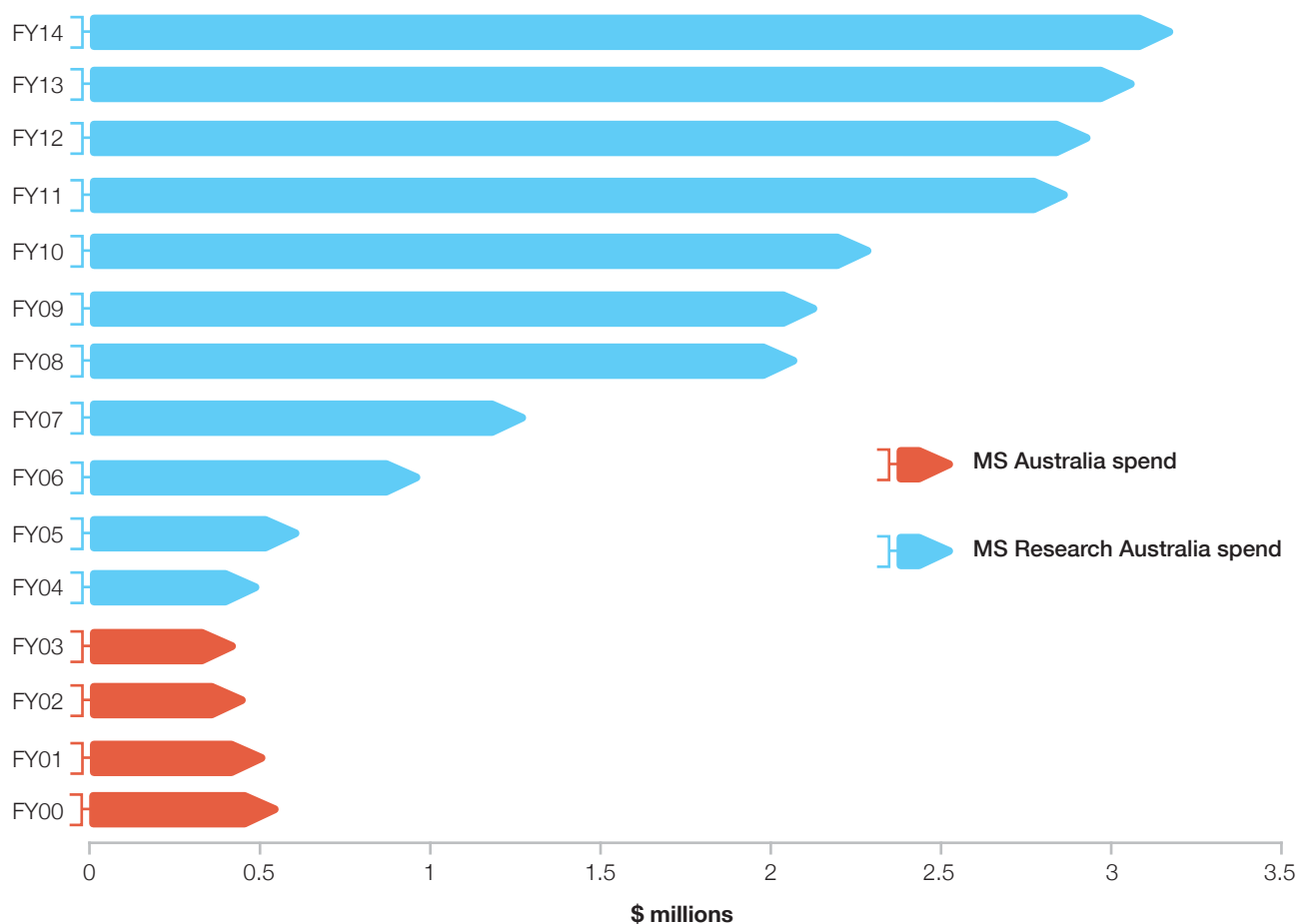


Figure 4.2 MS Research Australia growth of investment into MS research, 2000 – 2014 financial years

MS Research Australia is dedicated to accelerating Australia's contribution to the worldwide research effort for MS by raising the profile of MS as a national priority for research funding and attracting further funding into the field.

Figure 4.3 illustrates the growth of national funding investment by MS Research Australia, and other major funding bodies, most notably the National Health and Medical Research Council, which is the largest funder of MS research in Australia.

Since 2004, research investment into MS in Australia (including both MS Research Australia funding, and other major funding bodies such as the National Health and Medical Research Council) has increased to *five times the original spend*.

Importantly, this nationwide growth in funding support is also reflected in the Australian research output in the same period. Since 2004, both the quality and quantity of research produced by Australian academics has grown enormously, both from MS Research Australia support and through other funding sources.

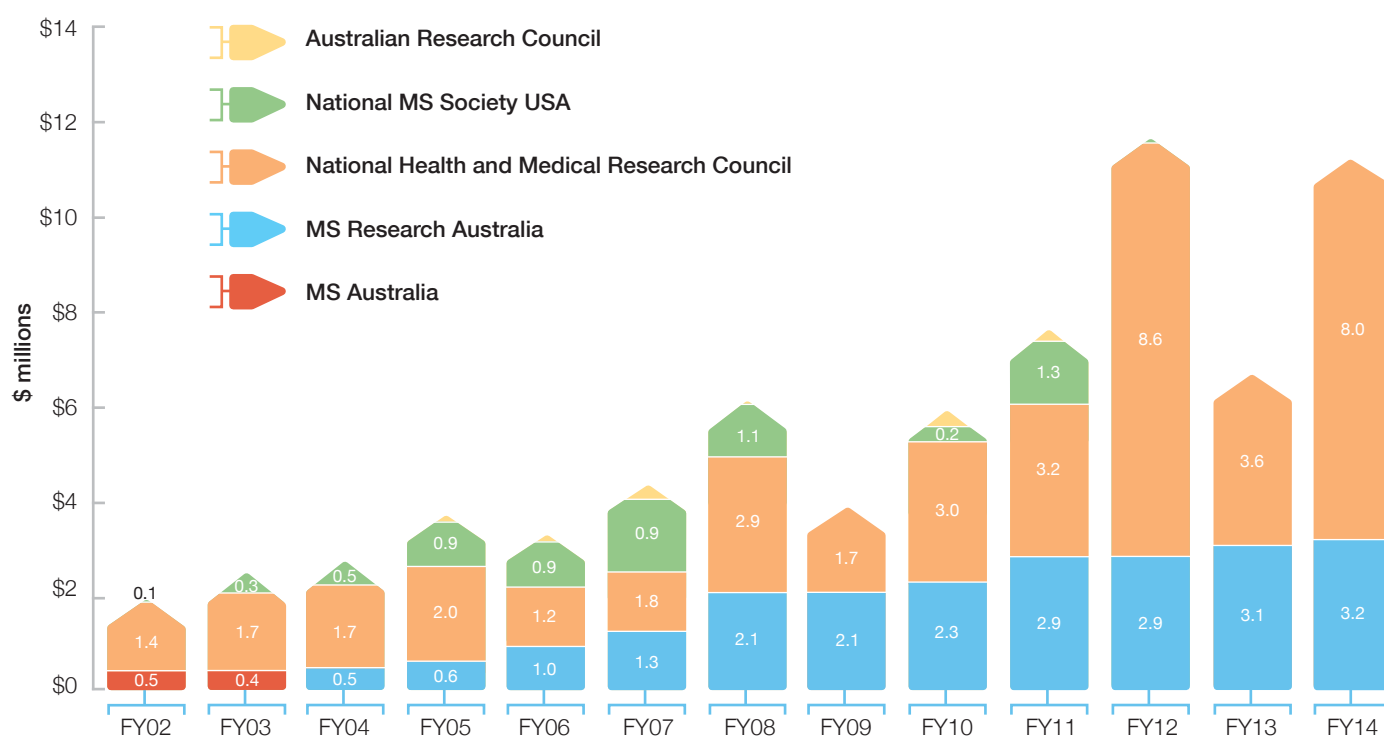


Figure 4.3 National spending on MS research by external funding bodies, 2000 – 2014 financial years

The number of MS-related articles published by Australian researchers has generally increased since 2004 (Figure 4.4).

Peer-reviewed research articles are an important way for academics to share their research with a wide audience, and enable researchers to build on and extend the discoveries being made by their peers around the world. These articles are the cornerstone of academia and an important measure of research productivity.

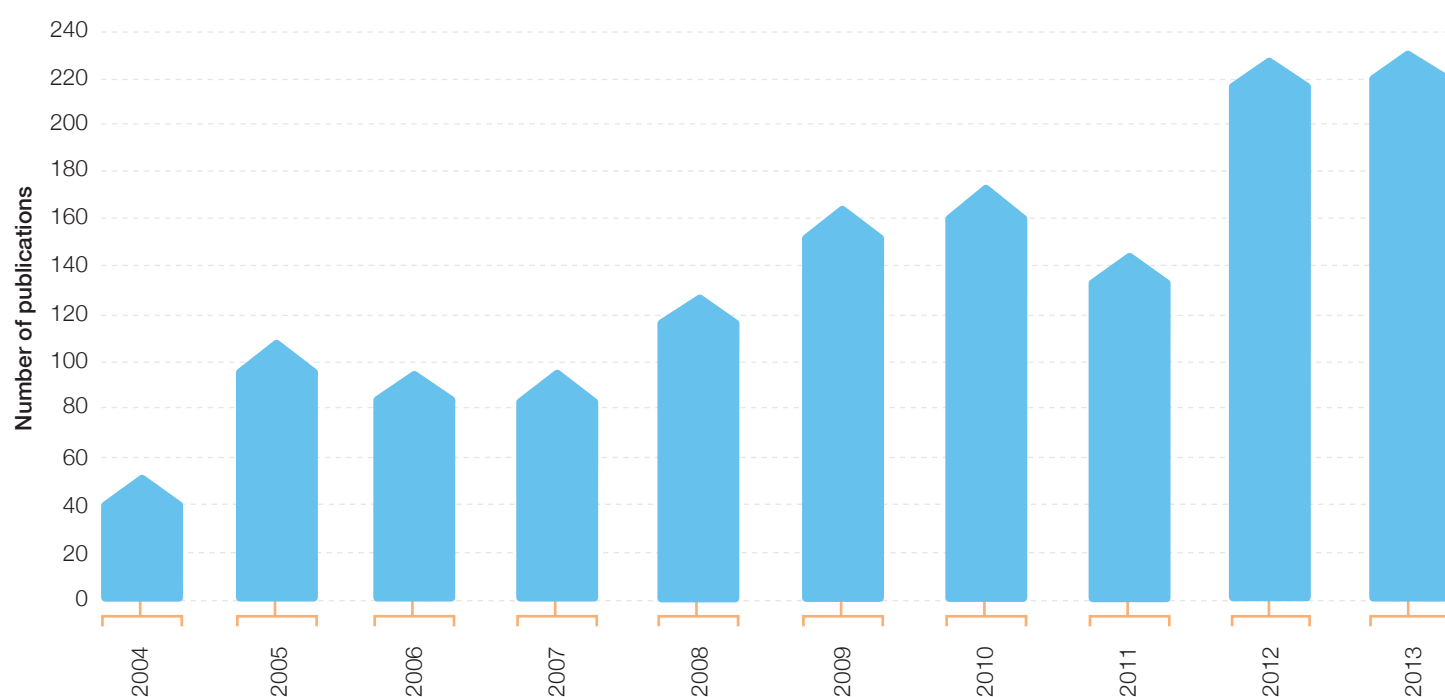


Figure 4.4 Number of Australian MS-related peer-reviewed publications, 2004 – 2013

Source: Thomson Reuters Web of Science (2014)

The expansion of Australian research productivity has been not only in *quantity*, but also in *quality*.

The number of citations of Australian MS-related journal articles published between 2004 and 2013 has substantially increased (Figure 4.5), demonstrating the excellence of the published research.

The number of times research papers are cited by other academics is an important measure of the impact of the article. Rising numbers of citations means that researchers around the world are referencing articles published by Australian researchers, showing that their international peers respect their findings and are building on their discoveries to pursue promising and productive lines of research.

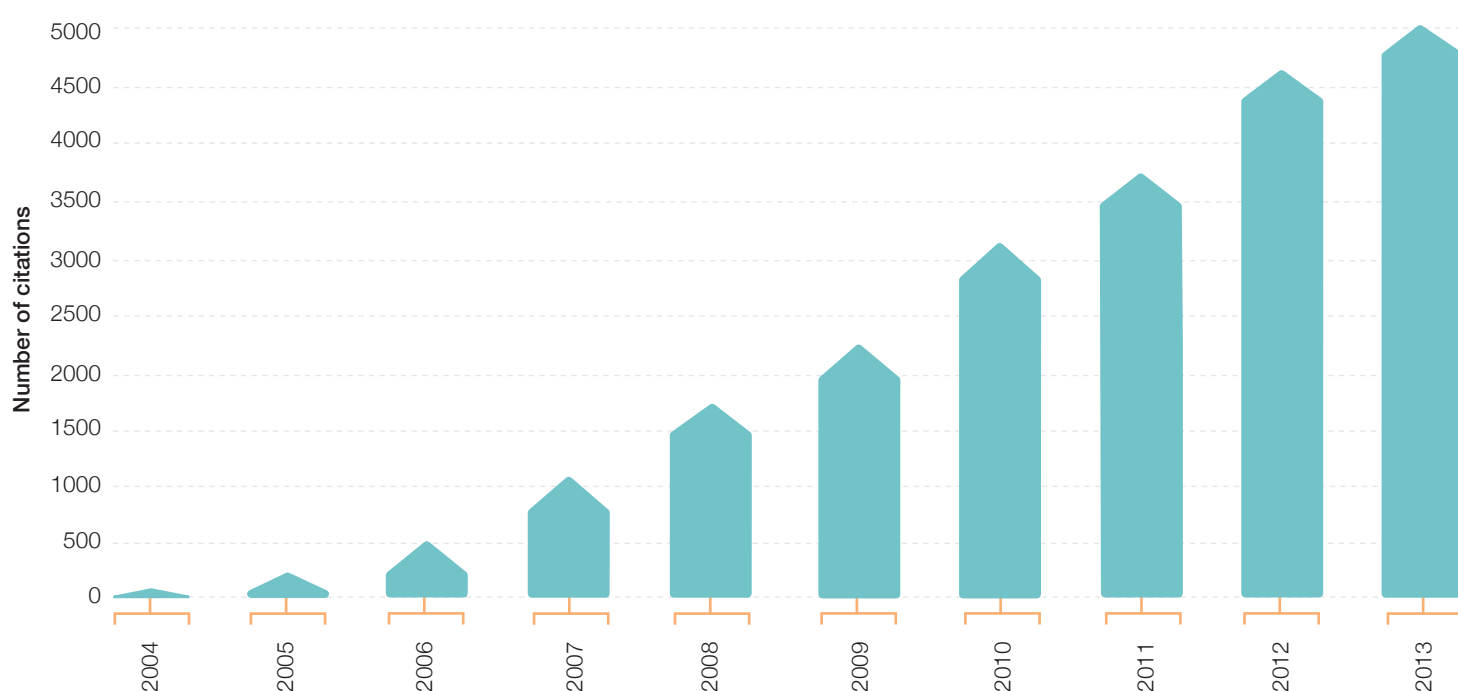


Figure 4.5 Number of citations of Australian MS-related peer-reviewed publications, 2004 – 2013

Source: Thomson Reuters Web of Science (2014)

30

Founding OBJECTIVE



Develop and
support multi-centred
platforms and
‘virtual centres’

MS Research Australia facilitates the development of collaborations and directed research platforms using Australia’s strengths, to undertake research that no single researcher could achieve alone.

Since 2004, MS Research Australia has developed a number of major platform projects that reflect the research strategy of the organisation and extend beyond the original ‘virtual centres’. Platform projects are intended to generate ‘blue sky’ research and develop major infrastructure or collaborations that will provide maximum benefit for people in Australia living with MS.

| MS Research Australia Platform Projects | Initiated in |
|--|--------------|
| Australian MS Longitudinal Study | 2000 |
| Ausimmune | 2002 |
| ANZgene (formerly Ausgene) | 2005 |
| MS Brain Bank | 2008 |
| Clinical Trials Network | 2010 |
| Proteomics | 2010 |
| Haematopoietic Stem Cell Transplant Registry | 2011 |
| PrevANZ | 2012 |

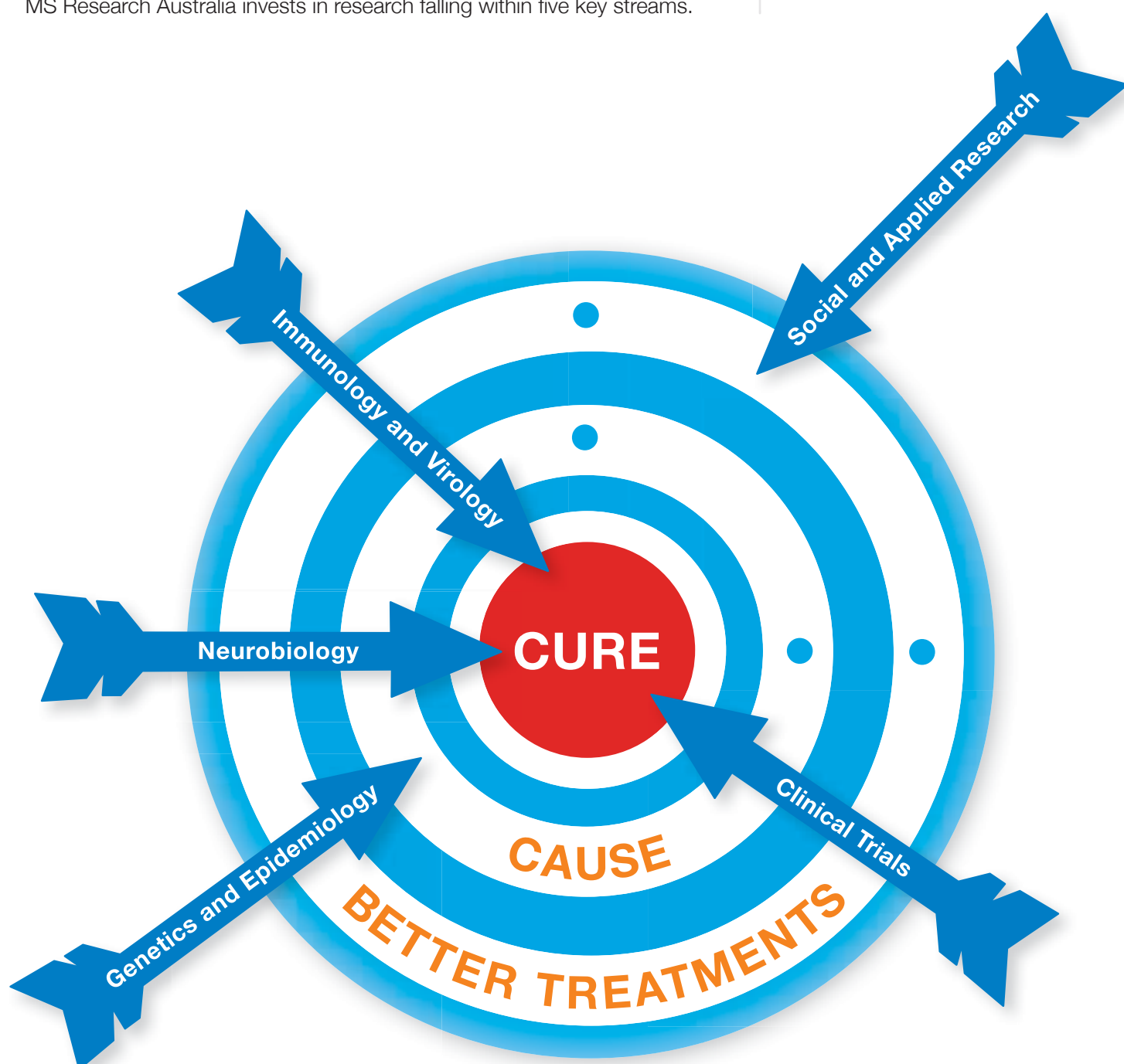
These projects have had many successes, including major breakthroughs in understanding the genetics of MS (see page 33); translating biological findings into new clinical options for treating or preventing MS (see page 41); creating several invaluable resources and data repositories that may be used by researchers around the world for years to come (see page 45); and widening our understanding of the social and environmental factors influencing MS and improving the lives of people with MS (see page 38).



Dr Che Fornusek, University of Sydney

MS Research Australia's scientific agenda focuses on funding research that will increase understanding of the biology driving MS, how to stop MS progression, and how to repair existing damage to reverse disability. This is a medium to long-term strategy and requires meticulous investigation and patience. In the short term, MS Research Australia also funds clinical, applied and social research to improve symptom management approaches and reduce the impact of MS on daily life.

To address the significant unknowns that remain in our understanding of MS, MS Research Australia invests in research falling within five key streams.



To accelerate progress towards the key research priorities, MS Research Australia is dedicated to funding high-quality projects falling within these streams. A substantial proportion of funding is allocated to each of these groups (Figure 4.6), although some types of research are more expensive or time consuming to conduct and require more substantial investment.

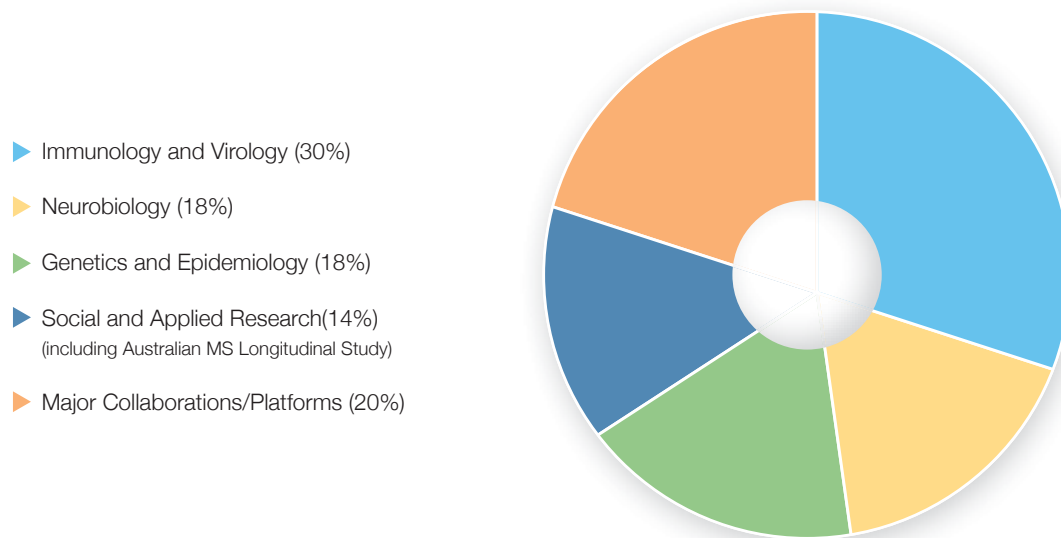


Figure 4.6 Allocation of funds by research stream, 2004 – 2013 financial years

Crucially, these research streams also align with the three themes guiding MS Research Australia's goals: identifying the triggers for MS, developing better treatments (both pharmaceutical and psychosocial) to improve the lives of people with MS, and finding a cure for MS via the repair or regeneration of cells.

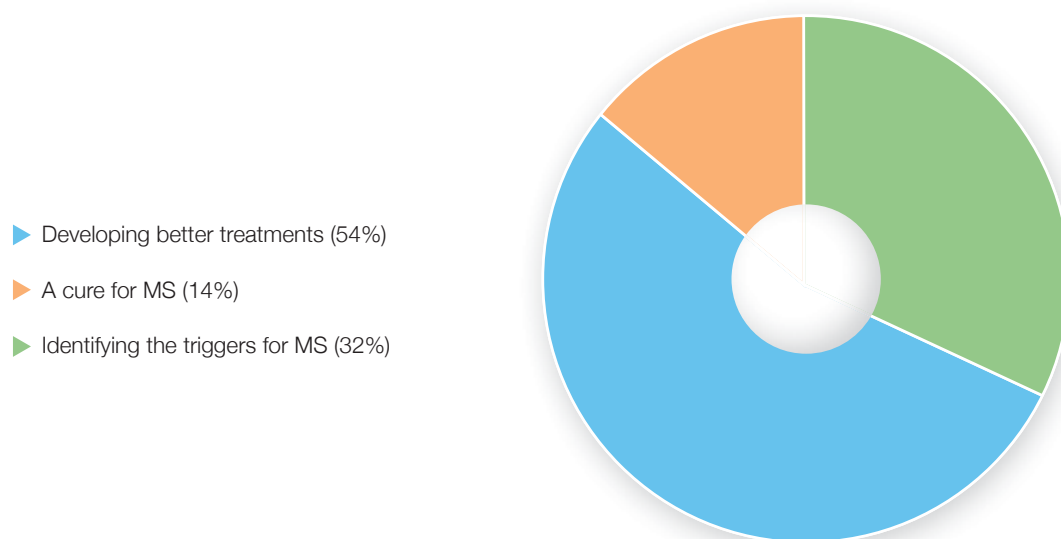


Figure 4.7 Allocation of funds by theme, 2004 – 2013 financial years

It is clear from Figure 4.7 that a large proportion of research to date has focused on novel therapies and identifying triggers for MS, as we strive to understand the complexities of the illness.

- > As global understanding of MS increases dramatically every year, we have identified **a key need for future investment dedicated specifically to finding a cure for MS**. This is a key outcome of the MS Research Australia Strategic Plan for 2014 – 2016.

Expanding our knowledge of MS genetics

The MS Research Australia ANZgene MS Genetics collaborative platform was established in 2005. Since then, the group has made a number of major contributions to some of the largest human genetic studies ever undertaken, aiming to identify the common genetic variants that may contribute to the cause of MS.

In 2004, we knew of only a handful of genes that may contribute to a person's susceptibility to developing MS. By collecting and pooling DNA samples, members of the ANZgene collaboration considerably increased their power to sift through a huge amount of genetic data from people with MS.

Led by a group of some of Australia's eminent genetic and immunological researchers, the ANZgene study, published in the prestigious journal *Nature Genetics* in 2009, was a world-first discovery of two new MS genes.

ANZgene became an important partner in the global effort through the International MS Genetics Consortium (IMSGC) incorporating 21 countries, with landmark breakthroughs in 2011 and 2013 that were published in *Nature* and *Nature Genetics*, respectively, that substantially added to our knowledge of MS genes. Together the papers identified over 110 genes that are associated with vulnerability to MS.

These breakthroughs bring scientists much closer to understanding the cause of MS and developing more effective, targeted treatments. They have also refined our understanding of the genetic risk factors and could be used to predict MS susceptibility in the future. The outstanding achievements of ANZgene would not have been possible without the support of over 2,000 people with MS around Australia and New Zealand who generously donated DNA samples.

Professor Graeme Stewart AM, from the University of Sydney and Westmead Millennium Institute, gave some insight into the future directions for ANZgene: *"With all these genes discovered, MS research enters a new phase. Each MS gene is a potential window into understanding the cause and unlocking the mystery of MS. Each also provides a potential new target for developing better drug treatments and new approaches to finding tests that personalise therapy choices. These goals require a detailed understanding of how each gene alters immune function in a way that increases the risk of developing MS."*

Professor Stewart also commented on the reasons ANZgene has been so successful: *"The reasons for this remarkable success include a deep, shared commitment to ensure that the benefits of the genetic revolution are extended to people living with MS and the unique and productive partnerships between and among MS researchers across Australasia, galvanised and nurtured by MS Research Australia. MS Research Australia's financial investment has leveraged major external funding and has been rewarded by outstanding scientific success."*



Founding OBJECTIVE



Establish a fully
'peer reviewed'
portfolio of projects

Grant applications to MS Research Australia are sent for rigorous external peer review by international experts before being reviewed by the Research Management Council, to identify the highest-quality applications to allocate funding.

- > The majority of MS Research Australia grants have been listed as Category 1 funding on the Australian Competitive Grants Register. These are considered a prestigious award, enabling institutions to leverage further infrastructure funding.
- > Only twelve medical/health-related not for profit entities in Australia are accredited with Category 1 funding and have similarly robust research management processes.

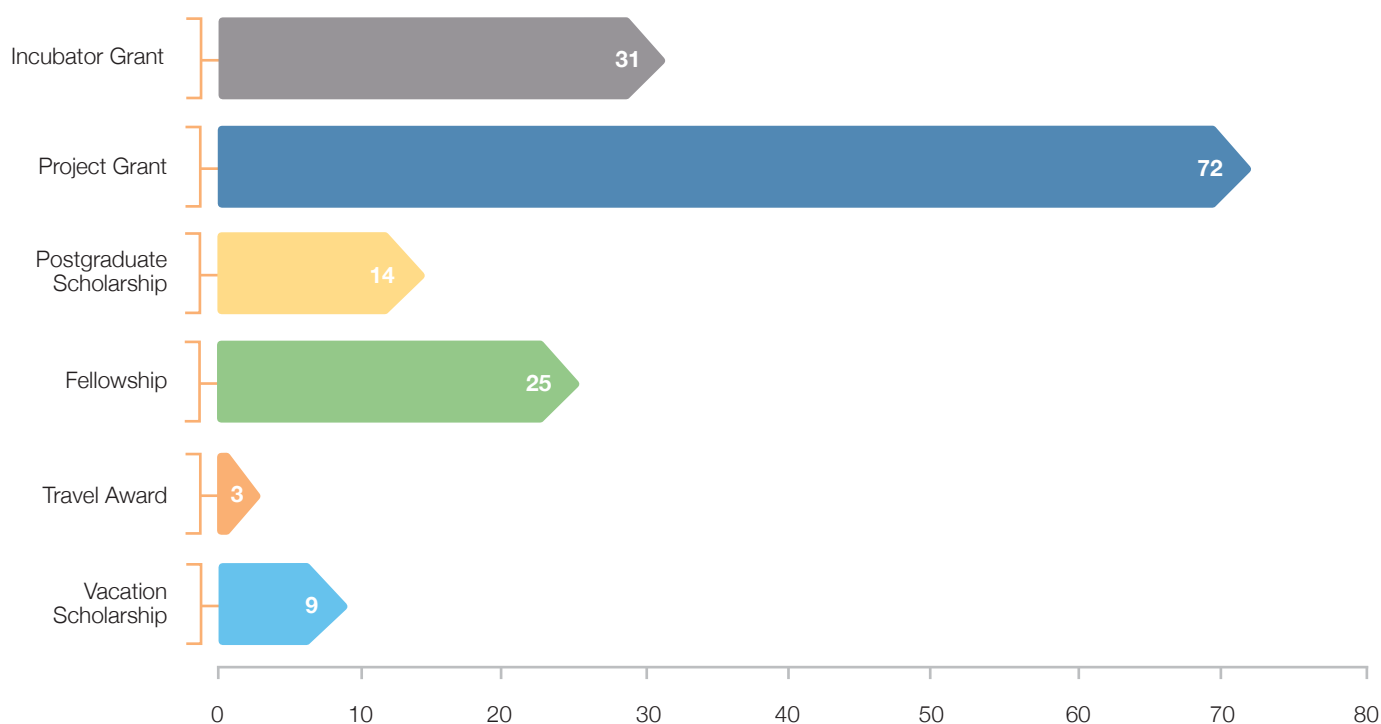


Figure 4.8 Number of each type of grant awarded since 2004

Figure 4.8 shows how frequently each type of MS Research Australia grant has been awarded since 2004.

Project grants represent the most frequent award, followed by incubator grants and fellowships. By also considering the proportion of funding allocated to each of these grant types (Figure 4.9), a pattern emerges regarding the level of commitment needed to support the different types of research.

While the most frequently funded (project grants) are also allocated the highest proportion of funding, the incubator grants stand out as a highlight. These small grants allow researchers to gather pilot data on new research ideas, and provide seed funding for unusual, novel, or 'left field' ideas to identify promising new research avenues. These grants have been awarded to 31 recipients for a total cost only 4% of the total research spend. However, incubator grants have a very high impact for getting new research ideas off the ground and leveraging substantial further funding (see more page 39).

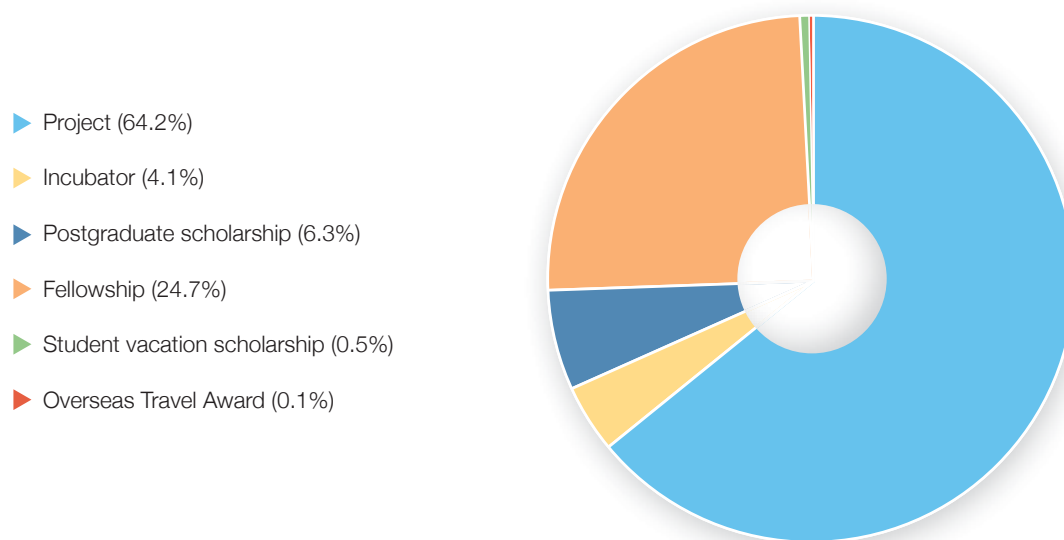


Figure 4.9 Allocation of funds by research grant type, 2004 – 2013 financial years

Researchers – then and now

Dr Phu Hoang is a researcher based at Neuroscience Research Australia (NeuRA) and a senior physiotherapist at MS – ACT/NSW/VIC, working at the important interface between allied health and academic research. Since 2004, Dr Hoang has been a co-investigator on numerous MS Research Australia-supported incubator projects, studying muscle function and the key factors affecting a person's risk of falling. At completion of his PhD, Dr Hoang was awarded a National Health and Medical Research Council Post-doctoral Health Professional Research Training Fellowship (2009 – 2013) to examine prevalence and characteristics of muscle contracture among people with MS.

Dr Hoang has since built on these findings and was awarded a MS Research Australia Project Grant (2011) and MS Research Australia Post-doctoral Fellowship in 2014 to support his research into an exercise program aiming to reduce falls and improve mobility in people with MS. This research has the potential to inform clinical practice and management strategies and to have a significant impact on the day-to-day quality of life for people living with MS.



Dr Phu Hoang
Neuroscience Research Australia

Ongoing 2005 – 2013

OBJECTIVE



Establish and maintain the MS Research Australia website to encourage interest for health professionals, researchers, people with MS and donors

MS Research Australia has several forums for communication and engagement, of which the website (www.msra.org.au) is a cornerstone.

- > The MS Research Australia website represents a key forum through which research updates and project summaries are communicated to a wide audience (Figure 4.10).
- > In addition, sister sites dedicated to platform projects (MS Research Australia Brain Bank, Clinical Trials Network) provide specific services to stakeholders, such as information on participating in current clinical trials.
- > Regular e-mail communications to researchers keep them informed of grant rounds, conferences, workshops and collaborative opportunities.

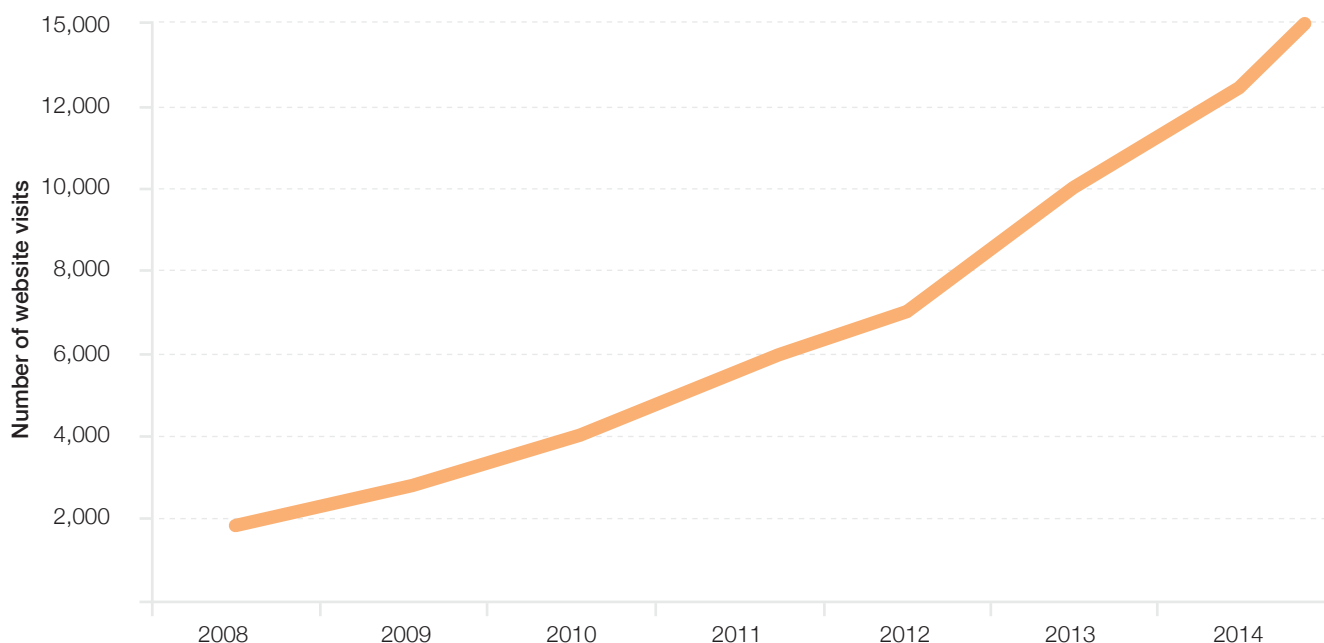


Figure 4.10 Average number of visits per month to the MS Research Australia website, 2008 – 2014

- > Regular research updates are also disseminated through the quarterly *NEXT* newsletter and the monthly *MS WIRE* e-newsletter, with a combined circulation approaching 20,000.
- > At the end of the first ten years, a MS Research Australia survey of newsletter recipients highlighted that around 95% of the 338 respondents rated these publications (*NEXT* and *MS WIRE*) as either “very good” or “good”.
- > With a rapidly expanding social media presence, MS Research Australia has a vital position in engaging a wide target audience about MS research updates in Australia and globally.
- > Website interest reaches the tens of thousands each month, making MS Research Australia ideally positioned to disseminate information throughout the global MS community. Interestingly, 27% of the website audience is now made up of international visitors (Figure 4.11).

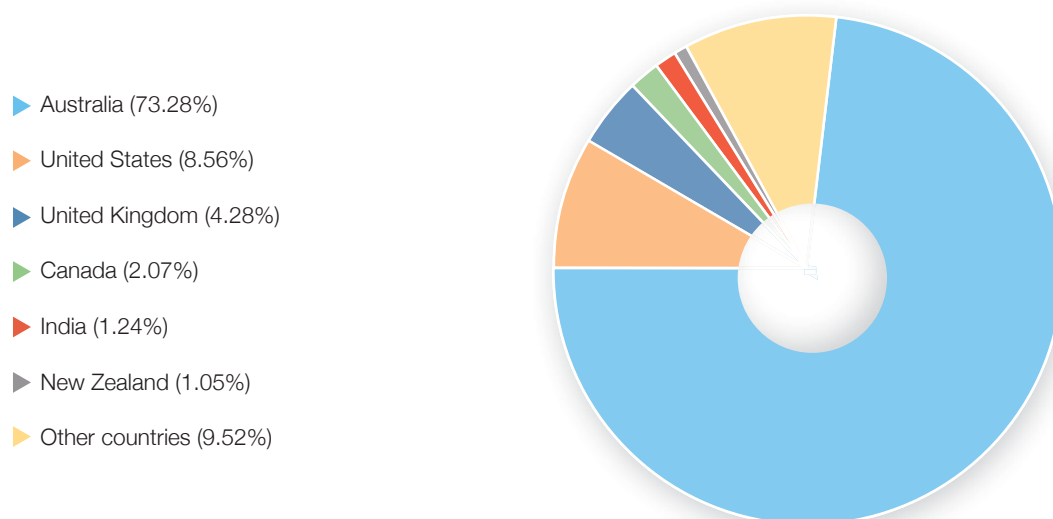
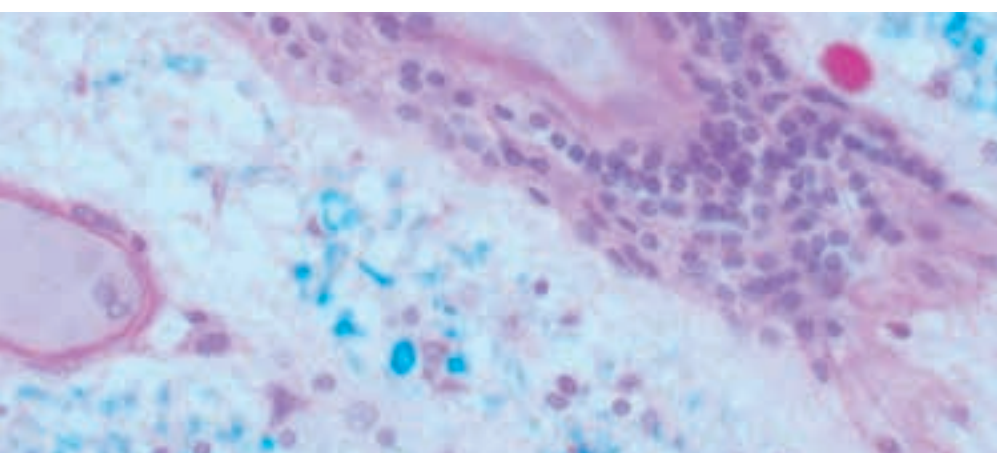


Figure 4.11 MS Research Australia global website audience in 2013



White matter brain tissue, stained to highlight cells

Image source: Dr Antony Harding and Associate Professor Michael Buckland, MS Research Australia Brain Bank, Brain and Mind Research Institute, University of Sydney

27% of the MS Research Australia website audience is now made up of international visitors.

Changing the face of MS in society

Australian MS researchers have shown that disclosure of a MS diagnosis to an employer is actually associated with higher levels of job retention. This important and surprising finding is a recent outcome from the MS Research Australia-funded Australian MS Longitudinal Study (AMSLS). The AMSLS, also known as the MS Life Study, was led by Dr Rex Simmons at Canberra Hospital until his retirement in 2014, and is now led by Dr Ingrid van der Mei from the Menzies Research Institute Tasmania. This study is an inter-disciplinary research platform that gives people with MS a voice in matters of importance to them, through scientific surveys designed by professional researchers in appropriate fields.

In addition to publishing numerous studies and surveys, the AMSLS has underpinned two major reports, including the *Economic Impact of MS in 2010*, and an analysis of the key needs identified by Australians with MS in 2012. Both documents have provided key advocacy tools for representing people with MS in Australia. A major finding from the Economic Impact Report was that people with MS were losing their employment mainly because of disabling symptoms of the disease, rather than because of 'workplace' factors such as inflexibility or discrimination. Fatigue was cited as the primary reason 70% of Australians with MS had left paid employment.

Following on from these findings, a 2012 MS Research Australia incubator grant led by Dr Pieter Van Dijk and Dr Andrea Kirk-Brown from Monash University, in collaboration with Dr Simmons, used the AMSLS data and found that those who had disclosed their diagnosis were more likely to be in current employment, and were also more likely to be employed for a longer time.

The AMSLS is helping to improve the quality of life for people with MS in Australia; a report from Dr Michael Summers from MS Australia in 2009 reported that 90% of people with MS had heat sensitivity and spent far more on air conditioning than the general population. This resulted in successful lobbying to government and policy-makers to obtain financial subsidies and other assistance for heat-intolerant people with MS.

These and many other important findings are continually arising from the AMSLS study. This is an ongoing research project providing practical data and insight that can shape future policy and service development, and most importantly make real improvements to the lives of Australians living with MS.



Dr Ingrid van der Mei
Menzies Research Institute Tasmania

MS Research Australia has made a priority of focusing on research investments that will capitalise on Australia's research strengths, to obtain maximum benefit and more productive outcomes from the research, and thus generate real progress and results for people with MS.

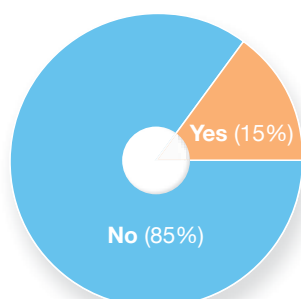
The Research Audit survey respondents highlighted a pivotal role of MS Research Australia in providing foundation support to get research projects off the ground, and this support was then leveraged to obtain additional funding for future work.

One important measure of the success of this initial investment is called the *multiplier effect* – the ability to gain further funding as a result of progress made using MS Research Australia funding.

The MS Research Australia multiplier effect averages 5:1 for all the projects that have been funded. This means that for every \$1 invested in MS research, the recipient researchers were able to leverage an average of 5 times that amount through securing other prestigious awards such as National Health and Medical Research Council or Australian Research Council grants.

Figure 4.12 highlights the breadth of funding leveraged to either continue or build on MS Research Australia-supported work. A total of 40% of respondents indicated they had received additional (primarily government) funding to either continue or extend on MS Research Australia-supported work.

Additional MS Research Australia funding



Additional external funding

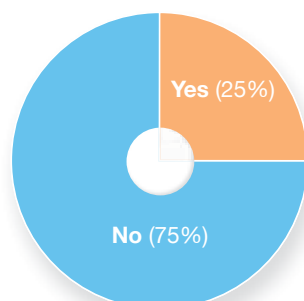


Figure 4.12 Additional funding obtained to support further work originally funded by MS Research Australia

Incubator grants are a highlight of the MS Research Australia funding model, providing cost-effective funding for novel, pilot research with huge potential for future development and leverage:

- > The Research Audit analyses found that the success rates for overall recurrent funding from the National Health and Medical Research Council gives the incubator grants a stunning multiplier factor of 27 on average.

Ongoing 2005 – 2013 OBJECTIVE



Investing in the most productive areas of new research while supporting existing research commitments, based on Australia's strengths and expertise



Investing in Australia’s strengths and expertise has, since 2004, been a key goal of MS Research Australia’s funding strategy.

Capacity building is an important way that this investment will return good results:

- > Australia has a critical mass of expertise in MS, as well as more broadly across domains of immunology and other fields of medical and applied research.
- > Two thirds (66%) of our survey respondents report other research interests in addition to MS (Figure 4.13).
- > These diverse research strengths are crucial to ensure MS research is at the forefront of the latest ideas, technologies and resources. It allows expertise from other research fields to inform potential new avenues of importance in MS.
- > For example, the recent ANZgene discoveries of key genes involved in MS were also found to overlap with several other autoimmune disorders such as Juvenile Diabetes, Inflammatory Bowel Disease, Rheumatoid Arthritis, and Crohn’s disease. Researchers with broad expertise may lead to new research to explore these biological commonalities.

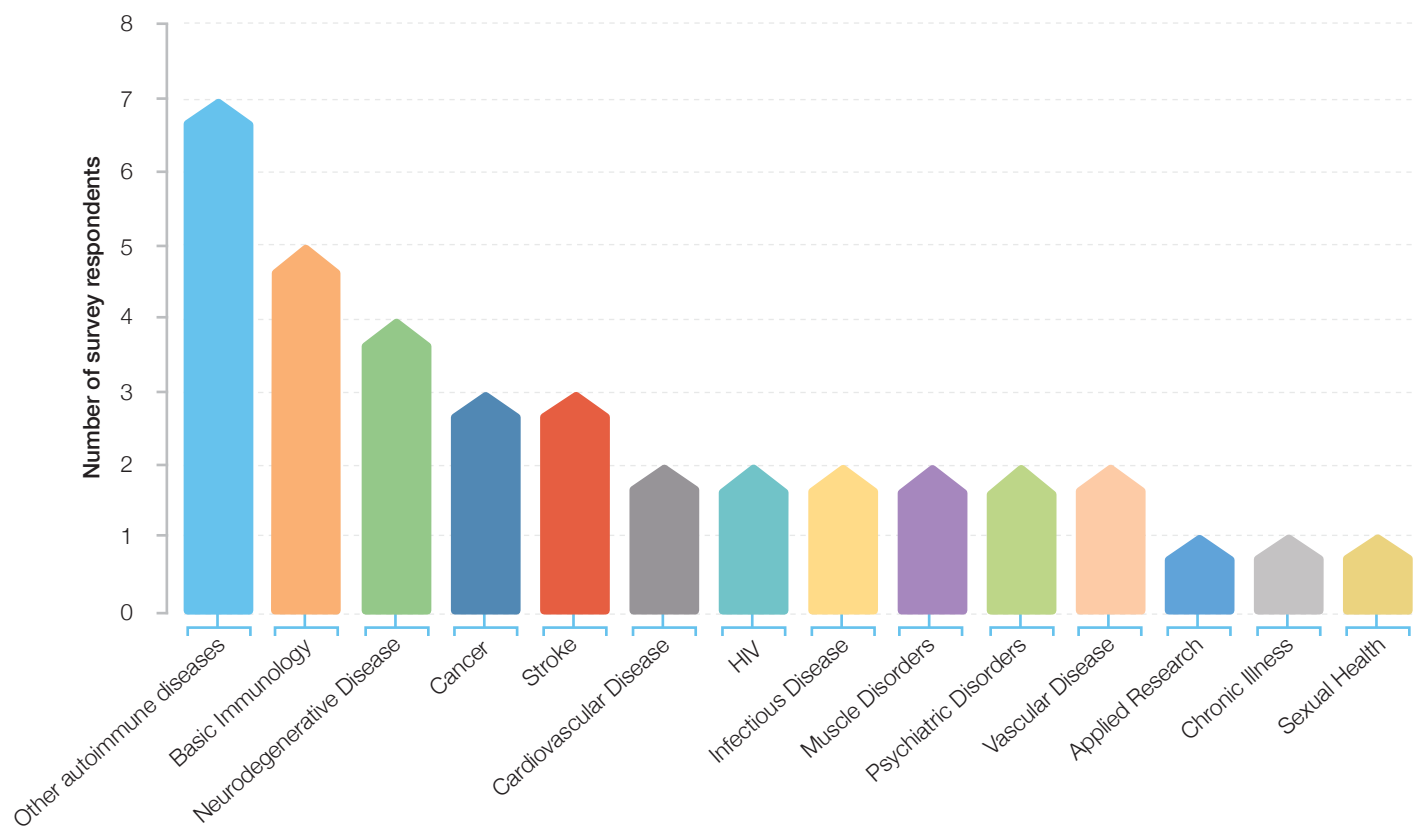


Figure 4.13 Diverse interests of MS Research Australia-supported researchers

Translating research findings into new clinical avenues for MS

The MS Research Australia Vitamin D Prevention Trial, or PrevANZ, is a world-first clinical trial platform aiming to explore whether vitamin D supplementation can prevent MS in those at risk of developing the disease.

There is now an accumulation of strong evidence for the role of vitamin D deficiency in MS. Several MS Research Australia platform projects contributed important knowledge – for example, the internationally important Ausimmune Study found a gradient in the number of people with a first demyelinating episode across different locations in Brisbane, Newcastle, Geelong and Hobart.

Variations in genes involved in the vitamin D metabolism pathway have also been implicated in susceptibility to MS, as shown by the first key breakthrough from the ANZgene MS Genetics Platform, while vitamin D deficiency has also been shown to be associated with a higher rate of relapses in people with established MS.

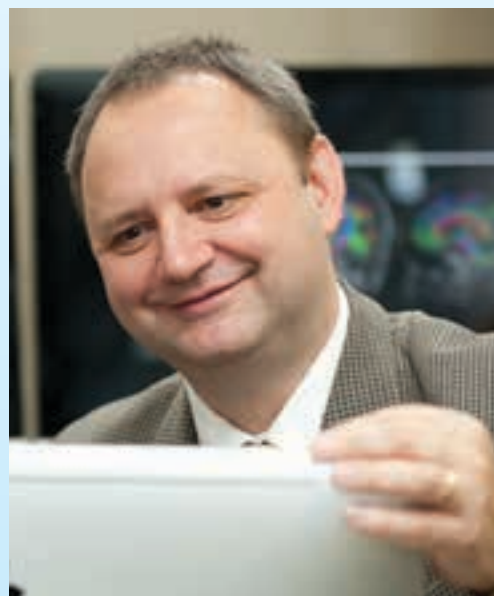
The PrevANZ study builds on the results of these studies, and is the first clinical trial to test which dose, if any, of vitamin D supplementation can prevent a diagnosis of MS in those people at the highest risk. The study will test three dosage levels of daily oral vitamin D3 supplements against placebo in 240 people following a first episode of symptoms that may be a precursor to MS.

PrevANZ commenced recruitment in June 2013, and will run for four years until 2016. It is expected that results will be available in 2017. This trial represents the largest single investment that MS Research Australia has ever made, and is a very important step forward for the translation of early epidemiological and genetic findings into clinical research.

The trial is being coordinated and funded by MS Research Australia, and has been made possible by generous support from state MS organisations, particularly MS Western Australia, MS Queensland, and MS Tasmania, as well as numerous trusts and foundations, including Foundation 5 Million, the Trish MS Research Foundation, and the John T Reid Charitable Trusts.

One of the early recipients of MS Research Australia support was Associate Professor Helmut Butzkueven. He was supported by the inaugural Betty Cuthbert Post-doctoral Fellowship co-funded by the National Health and Medical Research Council and the Trish MS Research Foundation in 2006. Since then, he has received numerous accolades, been promoted to Associate Professor, and successfully built on this support to receive further funding from MS Research Australia and external funding bodies, most recently including a prestigious five-year Practitioner Fellowship from the National Health and Medical Research Council.

Associate Professor Butzkueven leads a University of Melbourne and Royal Melbourne Hospital MS research group and manages people with MS in two large public hospital MS clinics in Melbourne as a Neurologist. He is the managing director of MSBase, an independent international clinical registry tracking MS outcomes in more than 31,800 people with MS. This platform is facilitating clinical research collaboration among academic clinicians worldwide. As well as making many research discoveries in his own right, he is a chief investigator of the PrevANZ Vitamin D MS Prevention Trial, and has contributed significantly to the highly successful ANZgene MS Genetics Consortium and the MS Research Australia Clinical Trials Network.



Associate Professor Helmut Butzkueven
University of Melbourne and Royal Melbourne
Hospital

The capacity to attract and retain quality researchers will ensure both sustainability and growth in Australian MS research output in the future:

- > 94% of researchers in the Research Audit survey reported that they still had a research interest in MS after receiving MS Research Australia funding (Figure 4.14), including a large proportion of young and early-career researchers.
- > Those who moved out of MS research did so because their research interest led elsewhere, particularly those researchers who developed research methods or techniques that are not disease specific and may be examined in other illnesses.

“After receiving MS Research Australia funding, do you still research MS?”

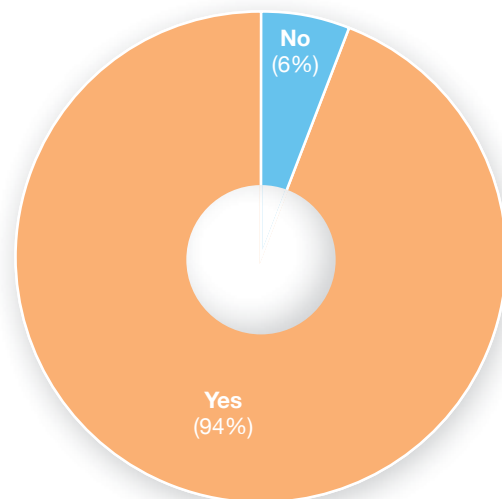


Figure 4.14 Building research capacity and encouraging research retention

Broad international collaborative network

Researchers report that their MS Research Australia funding resulted in the development of a wide range of Australian and international collaborations, including many outside the MS field into other domains of science and medical research (Figure 4.15):

- > This development of collaborative networks is vital to maximise the sharing of resources, techniques, and ideas. This will enable capacity building of individuals, research teams, and institutions.

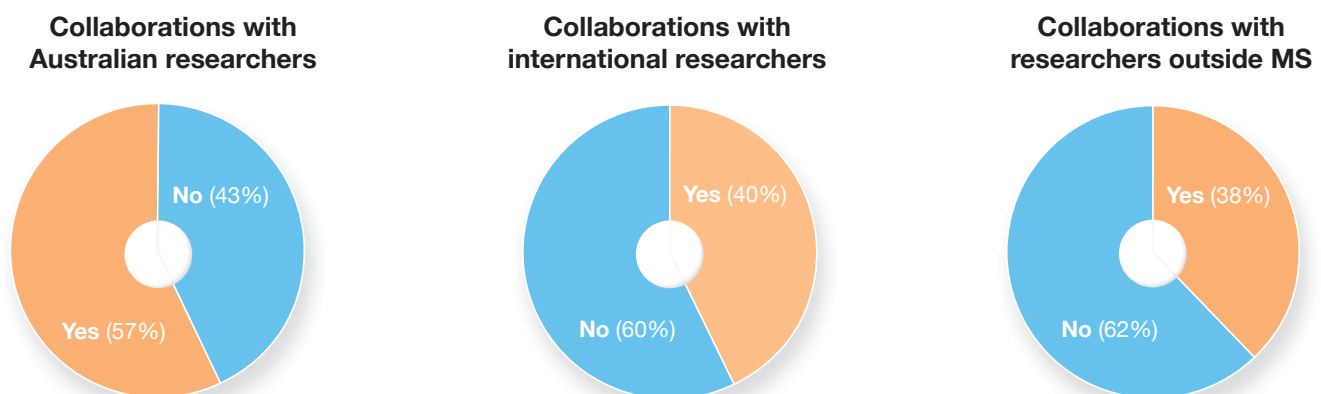


Figure 4.15 National and international collaborations established via MS Research Australia-supported work

Several investigator-led projects have evolved into major research platforms of MS Research Australia, and achieved outcomes that have shaped the way we understand MS.

For example, the major Vitamin D Prevention Trial has resulted from years of cumulative investigator-driven work as well as significant findings from several MS Research Australia platform projects, enabling the translation of findings from pre-clinical to clinical research with the potential to influence clinical practice (see page 41).

Over the last decade, the measures of success in not for profit organisations such as MS Research Australia are increasingly focusing on outcomes related to productive output such as research effectiveness and resource building, rather than focusing on the typical measures of fundraising revenue.

In these terms, both investigator-driven projects and directed research platforms supported by MS Research Australia have been extraordinarily productive since 2004, with many tangible research outcomes making a real difference in the MS world and beyond (see overleaf).

Ongoing 2005 – 2013 OBJECTIVE



Allow the flexibility for investigator-initiated research to develop into MS Research Australia-directed projects and thereby generate a higher proportion of proactive research

“As one of the world’s leading MS organisations, the scientific experience, financial resources and expertise that MS Research Australia can bring to the International Progressive MS Alliance will add enormous strength to the initiative. There are already considerable research efforts underway that will align with the work of the Alliance, such as the MS Research Australia Brain Bank and the MS Clinical Trials Network.”

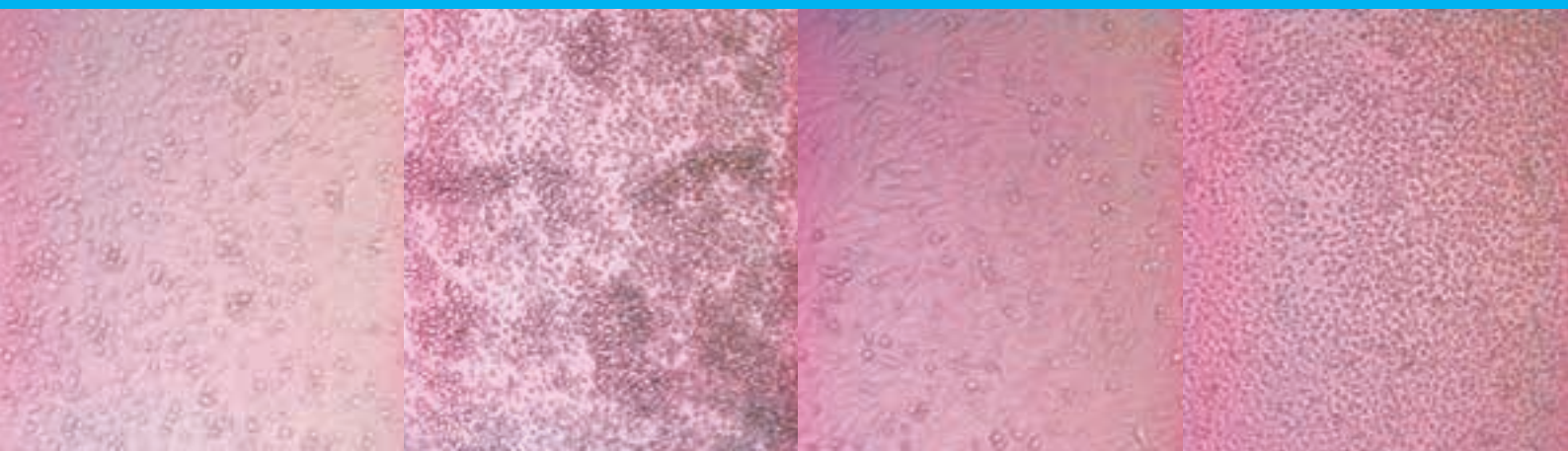
Professor Alan Thompson, Chair of the Scientific Review Committee for the International Progressive MS Alliance. Professor Thompson is a Fellow of the American Academy of Neurology, Vice-Dean at University College London and an international authority on MS.

INTERNATIONAL PROGRESSIVE MS ALLIANCE

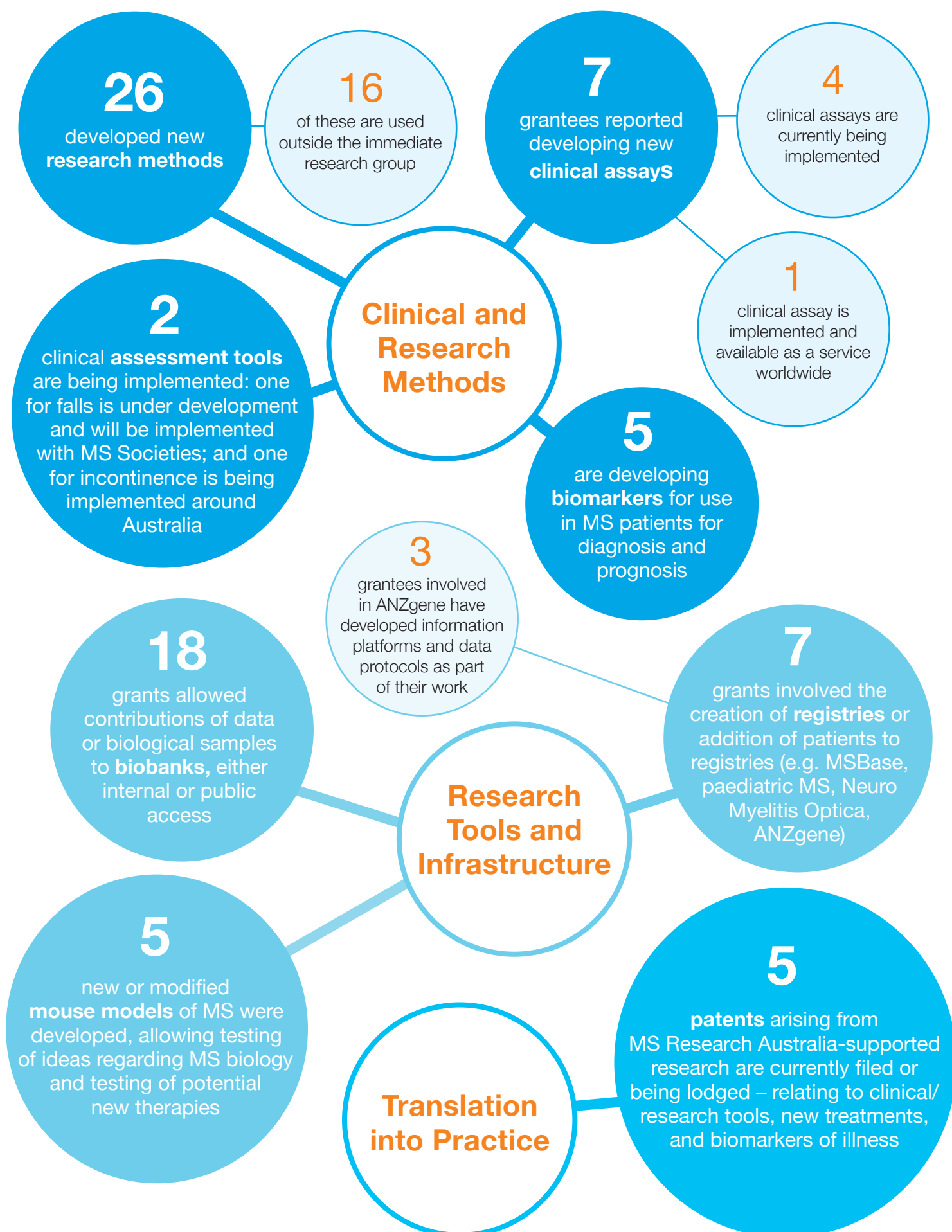
CONNECT TO END PROGRESSIVE MS

High-resolution images of different types of nerve cells and their connections

Image source: Associate Professor David Booth, Westmead Millennium Institute and University of Sydney



With their MS Research Australia funding, the surveyed researchers reported many new research outcomes. These include new methods for biomedical and applied research and for clinical assessment, novel research tools and new infrastructure, as well as new avenues for translation into practice.



Sharing research resources

MS Research Australia Brain Bank

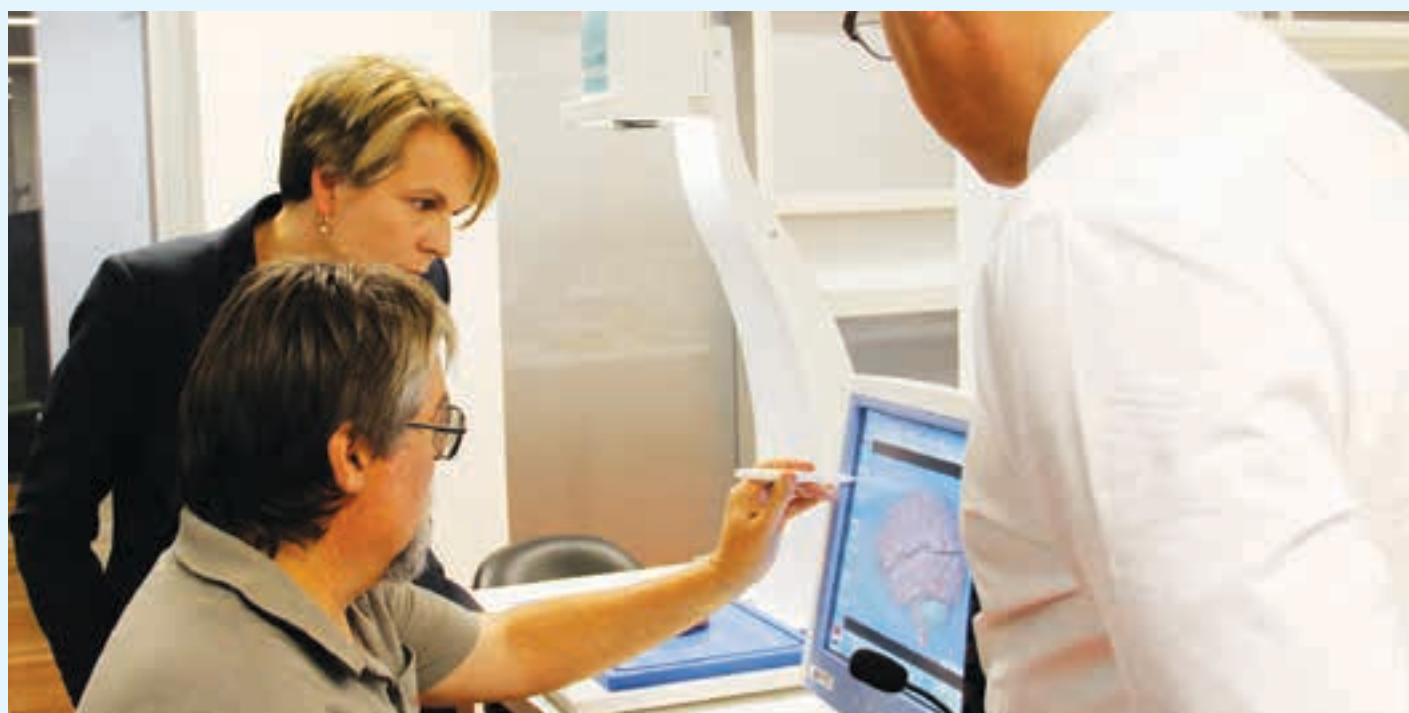
The MS Research Australia Brain Bank is a national tissue bank and donor program helping researchers around Australia to undertake groundbreaking research into MS.

Through a partnership with the Australian Brain Bank Network, the MS Research Australia Brain Bank is able to register individuals with MS around the country to donate their brain and spinal cord when they pass away. Researchers around the country may apply to access tissue for use in important research projects.

Established in 2008, the MS Research Australia Brain Bank has a huge responsibility. People with MS, in bequeathing tissue for scientific research, are making a final gift to others with MS and their families. They hope that their gift will lead to better treatments, improved understanding and ultimately a cure for others. More than 800 people have now pledged to donate their brain to the facility.

The MS Research Australia Brain Bank moved to the Brain and Mind Research Institute at the University of Sydney in 2012 and has provided tissue to a growing number of Australian research projects.

The MS Research Australia Brain Bank was established with invaluable support from the NSW Government Office for Health and Medical Research, Trish MS Research Foundation, University of Sydney, Collier Charitable Fund, FIL Foundation, Levy Foundation, and numerous other trusts, foundations, and generous individuals.



MS Research Australia Brain Bank funding launch in 2013 with former Health Minister Tanya Plibersek

MS Research Australia Brain Bank Manager Dr Antony Harding and Co-director Associate Professor Michael Buckland show Tanya Plibersek exciting technology used by the MS Research Australia Brain Bank

The MS Research Australia Proteomics Platform

The Proteomics Platform is a national research project aiming to discover the proteins involved in the development of MS. Established in 2010 as a major national MS collaboration between the University of Adelaide, Monash University, the University of Queensland and the Sir Charles Gairdner Hospital in Perth, this platform is an Australian first, and one of the first of its kind in the world.

Led by Professor Shaun McColl, the MS Research Australia Proteomics Platform was co-funded by the Australian Research Council and aimed to develop state-of-the-art proteomics technologies for the Australian MS research community, and use the technology to identify specific molecular changes in the central nervous system that correlate with different stages of disease in MS.

The results of this research will lead to the identification of new proteins that can be targeted for the development of new therapies and diagnostics for MS. The Proteomics Platform has established facilities that are available for collaborative research among the MS academic community.

The Proteomics Platform has resulted in a number of highly successful new collaborations and exciting research findings that have great promise for furthering our understanding of MS.



Australian Government
National Health and Medical Research Council



Dr Matthew Miles
Chief Executive Officer
Multiple Sclerosis Research Australia
PO Box 625
NORTH SYDNEY NSW 2059

Dear Dr Miles,

One of the primary objectives of the National Health and Medical Research Council (NHMRC) is to provide support for important and worthwhile research in Australia, which has helped Australian researchers to make a substantial contribution to health and medical research in the context of the global international research effort. The work of Australian researchers in the field of MS is making an impact worldwide.

A priority of NHMRC's Strategic Plan is to work with partners to address Australia's health research challenges. In partnership with the Research Management Council of MS Research Australia, the NHMRC has supported Multiple Sclerosis (MS) research projects throughout Australia and fostered collaboration among some of the country's top MS researchers.

This partnership allows the NHMRC and MS Research Australia to provide complementary support for ongoing projects and identify pioneering new research priorities. In the past three years alone, the NHMRC have awarded grants totalling over \$16 million to further the work of MS Research Australia-affiliated researchers.

Importantly, MS Research Australia represents one of only twelve not-for-profit medical research foundations eligible to award prestigious Category 1 funding, listed on the Australian Competitive Grants Register, and the only institute on this register dedicated specifically to supporting MS Research.

MS is a complex and highly debilitating disease, for which our understanding has been progressing rapidly. Sustained research investment will ensure this progress continues in Australia and worldwide in the quest for prevention, treatment, and a cure for MS.

I congratulate the researchers and other stakeholders involved in the production of this Audit.

Yours sincerely

Professor Warwick Anderson AM
Chief Executive Officer

WORKING TO BUILD A HEALTHY AUSTRALIA

Career progression is a measure of individual success and is strongly linked with the calibre of research funding and research output that the individual has achieved. It is also vital for the development of excellence in MS research and the retention of talented researchers in the field.

Competitive grant funding awards play an important role in career progression. Many survey respondents reported making significant career progression since receiving the MS Research Australia funding.

- > 36% of respondents indicated they are currently at a higher career stage than at the time of receiving MS Research Australia initial funding.
- > 15% of funding recipients reported progressing from early stage researchers (PhD candidate, Post-doctoral researcher) to mid-career researchers (Senior Lecturers, Associate Professors).

Comparing Figure 4.16 and Figure 4.17, there is a clear difference in the career stage of researchers when they received funding, compared with their career stage at the time of the Research Audit survey in 2014.

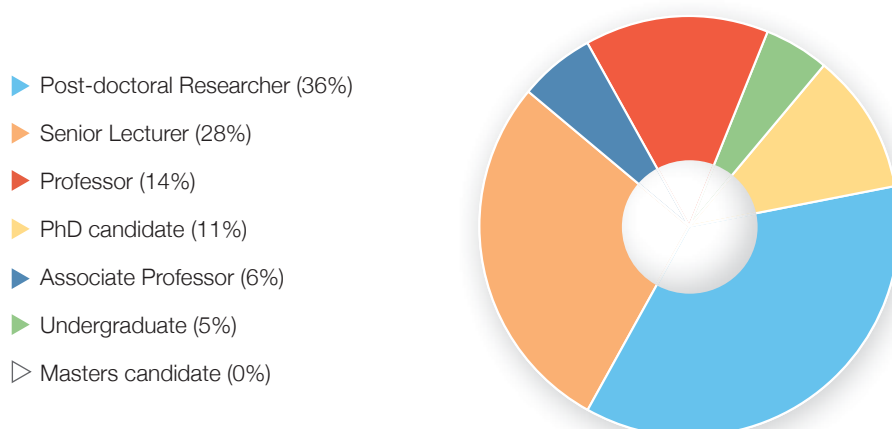


Figure 4.16 Career stage at the time of MS Research Australia funding

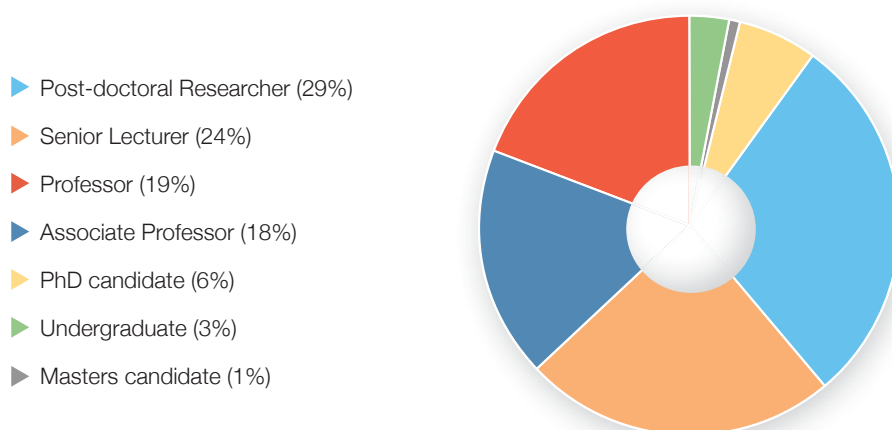


Figure 4.17 Career stage at the time of the Research Audit survey

Ongoing 2005 – 2013 OBJECTIVE



Foster the development of researchers in the MS field via secure career paths

Researchers – then and now



Associate Professor David Booth, from Westmead Millennium Institute, and Co-chair of the ANZgene Platform was recently awarded a prestigious Senior Research Fellowship for 2015 from the National Health and Medical Research Council. This follows on from his MS Research Australia Senior Research Fellowship 2010 – 2014.

Training the MS research ‘stars’ of tomorrow

Encouraging the career development of MS Research Australia-supported individuals is only one part of the story.

Career development is not only enabled by directly funding researchers to achieve their goals, but these gains are magnified when these researchers are encouraged and supported to share their knowledge, expertise and insights with newer generations of researchers.

Training young researchers and retaining them in the MS field builds the much needed expertise and critical mass of research capacity needed to drive those key discoveries and maximise the chance of identifying and realising the research pathways that will lead to the greatest gains for MS.

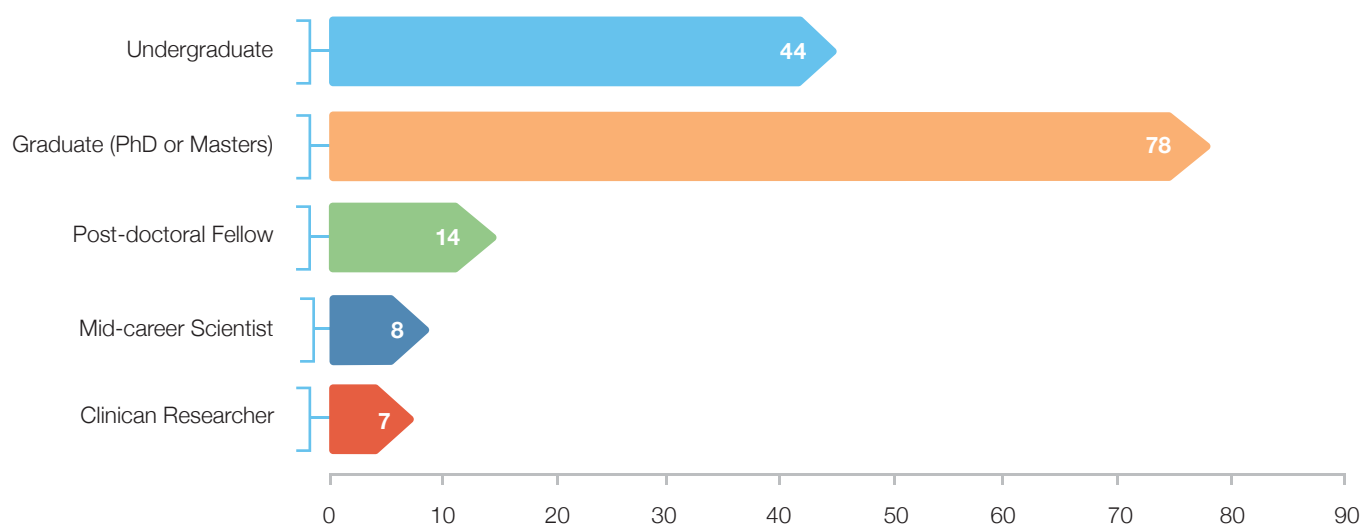


Figure 4.18 Number of trainees supervised by MS Research Australia-supported researchers, 2004 – 2014

Researchers – then and now

Dr Natalie Payne is an early-career researcher working with esteemed MS researcher Professor Claude Bernard at the Australian Regenerative Medicine Institute, Monash University, Melbourne. Dr Payne was awarded a MS Research Australia postgraduate scholarship during her PhD tenure from 2007 to 2010, supported by the Trish MS Research Foundation. During this project, Dr Payne undertook groundbreaking work studying stem cells derived from fatty tissue and their therapeutic effect in mice with a MS-like disease.

Since completing her PhD, Dr Payne has continued her work in this promising field of research and was recently awarded an Ian Ballard Travel Award, named after the founder of Foundation 5 Million Plus, which supports researchers to travel internationally to learn new techniques and present their research findings to international colleagues. Dr Payne is also collaborating with Dr Iain Comerford and Professor Shaun McColl at the University of Adelaide on their MS Research Australia-funded project aimed at inhibiting white blood cell entry to the central nervous system using laboratory models of MS and human stem cells.



Dr Natalie Payne
Monash University

Many exciting research breakthroughs have characterised the Australian MS research landscape over the past decade. A selection of some key achievements that have changed the way we think about MS today are highlighted below:

In 2007, the Ausimmune Study published findings describing a latitude gradient in Australia for prevalence of early demyelination. This landmark study provided the foundation for future work into the role of vitamin D.

In 2009, MS Research Australia awarded the first ever international Fellowship dedicated to MS research in collaboration with the MS Society in the United Kingdom, to strengthen worldwide collaboration on MS research.

In 2011, the Economic Impact of MS report identified that 50% of the economic impact of MS is due to reduced employment for people with MS and their families.

In 2012, researchers funded by MS Research Australia at the University of Adelaide made a significant breakthrough in finding new ways to control the immune system in MS.

In 2012, the Australian MS Longitudinal Study surveyed almost 2,900 people with MS to determine their needs, building a significant track record of making a tangible difference in service planning and advocacy for people with MS.

In 2012, researchers from Monash University discovered that blocking a protein involved in nerve fibre breakdown may preserve brain tissue in MS.

In 2013, the vitamin D MS Prevention Trial (PrevANZ) started recruiting participants across Australia and New Zealand, bringing together evidence on the role of vitamin D in MS via Ausimmune, ANZgene and other MS Research Australia-funded projects, and will be the largest of its type in the world.

In 2011 and 2013, an international consortium of researchers including the ANZgene MS Genetics Platform made substantial breakthroughs in identifying 110 genes associated with susceptibility to MS. In 2006, only a handful of genes were known.

New discoveries are occurring every day that give more insight into how these genes work, and their possible role in MS and immune system dysfunction.

In 2013, researchers from the Sydney Children's Hospital Westmead found that antibodies could differentiate among children with different types of demyelinating disease, resulting in the development of new clinical tools guiding treatment decision making.

In 2014, 45 brains have been donated to the MS Research Australia Brain Bank and the Australian Brain Bank Network around Australia since 2008, allowing new research into MS using gold standard technology.

In 2014, University of Queensland researchers published new evidence for involvement of the Epstein Barr Virus in MS.

5 ACHIEVEMENTS RESULTING FROM RESEARCH FUNDED BY MS RESEARCH AUSTRALIA



Dr Matthew Miles
Chief Executive Officer
Multiple Sclerosis Research Australia
PO Box 625
NORTH SYDNEY NSW 2059

Dear Dr Miles,

Research Australia is a nation-wide alliance of 160 members and supporters, advocating for health and medical research as a key priority for Australia's future. MS Research Australia is a long-standing and valued member of this alliance, helping to ensure that Australia is influential in the ground-breaking health and medical research discoveries emerging around the world.

Research Australia advocates for greater national and state investment in health and medical research from all sources. MS Research Australia provides vital support for this goal by funding national collaborations that utilise expertise from research centres and universities across Australia. The promotion of Australia's global position in health and medical research is a fundamental goal of both Research Australia and MS Research Australia.

In pursuit of a society that is well informed and values the benefits of health and medical research, MS Research Australia has made an invaluable contribution both to promoting high-quality cutting edge research, as well as strengthening the knowledge and awareness of MS research in Australian society.

The work of Australian researchers has enabled our understanding of MS to continue accelerating yearly. I commend MS Research Australia and all its affiliates for their commitment to finding a cure for MS, and the outstanding progress made since 2004.

Yours sincerely

Elizabeth Foley
CEO & Managing Director

Moving forward: MS Research Australia strategy 2014 – 2016

MS Research Australia is proud of these achievements, but its work is not done. As an organisation, MS Research Australia continues to strive for 'freedom from MS', which requires transitioning to priority-driven and outcomes-focused research, prioritising research in consultation with people with MS and collaborating with researchers in other disease areas.

The Research Audit has been a crucial exercise to reflect on the achievements of the past ten years and confirm that, over this time, the ambitious founding goals have been realised. However, the Audit has also provided an opportunity to identify targets for the future.

In this context, the Research Audit survey respondents were asked to list the key funding targets that they felt would be most valuable for future priority (Figure 6.1).

The top responses were:

- > Project funding and incubator grants
- > Increased salary support
- > Platform funding for progressive MS
- > Infrastructure

While more project and people support are clearly important to keep promising lines of research going, the respondents also identified that they need more access to 'hard to get' funding types that allow them to work together and share resources. Over 50% of respondents report a primary need for greater investment into infrastructure – the development of bio-banks and registries that are accessible on a national level, as well as collaborations or networks that encourage the sharing of resources.

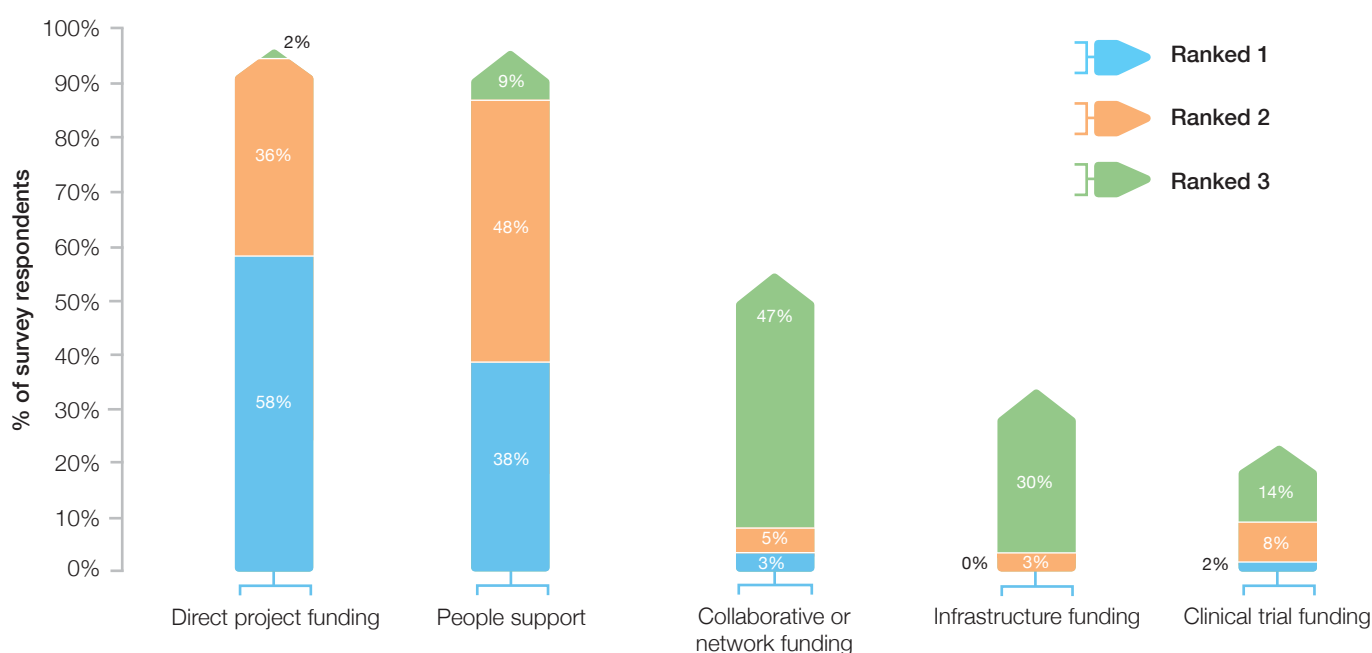


Figure 6.1 Survey respondents identified key priorities for future funding targets

6 FUTURE DEVELOPMENTS AND DIRECTIONS

Given the exciting breakthroughs, developments and achievements highlighted in this report, MS Research Australia is now in a strong position to be able to strategically shift focus, while maintaining momentum in current strengths.

The current model by which MS Research Australia operates will be adapted in the following five ways:

- > Increasing funding of research that targets potential cures for MS and is directly related to the gaps in our knowledge of MS
- > As part of a global alliance, focusing on progressive MS research where no approved treatment options currently exist
- > Incorporating the views and needs of people with MS even further into the governance of the organisation
- > Placing an even stronger focus on outcome-driven research
- > Placing a continued but enhanced emphasis on financial stability, sustainability and transparency in MS research information and research governance

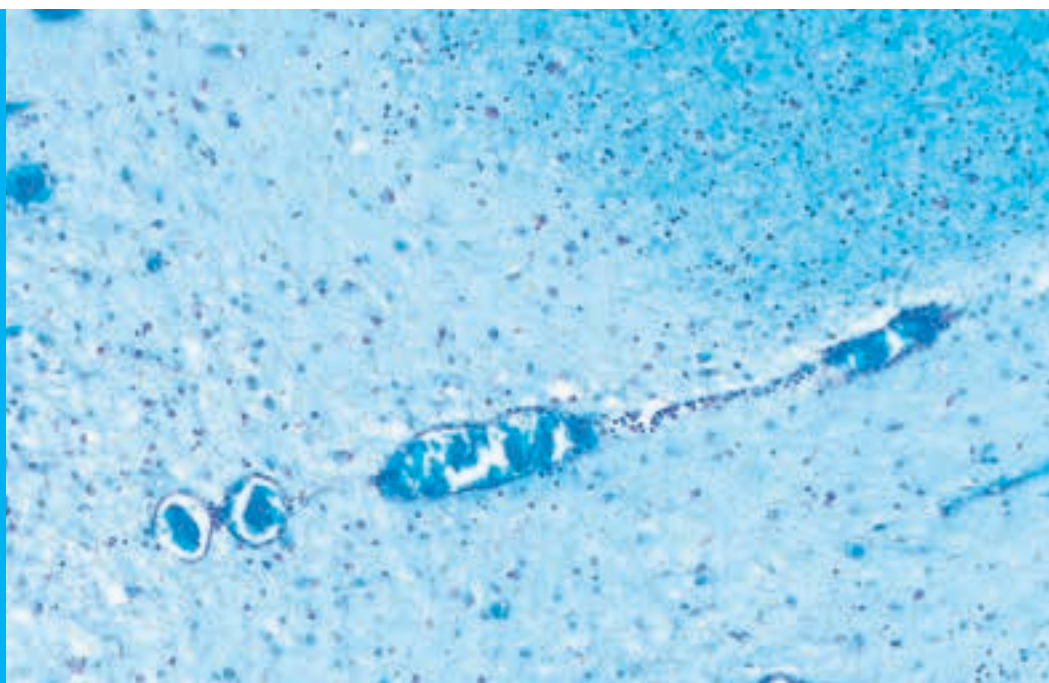
Based on the Research Audit analysis, several key targets have been defined that will accelerate filling the research gaps and strengthen Australia's contribution in the international endeavour to solve MS.

In response to these priorities, in 2014, MS Research Australia has committed funding and expertise to the International Progressive MS Alliance. This is a global initiative aiming to fast track new discoveries to help people with progressive MS.

MS Research Australia has refined its strategic objectives for 2014 – 2016, from those of establishment to those that build on the achievements of the past ten years. A detailed Strategic Plan has been developed and is available on the MS Research Australia website. MS Research Australia remains focused on finding a cure, and strengthening already strong collaborations – nationally and internationally.

MS lesioned tissue in the white matter of the brain, stained to highlight cells

Image source: Dr Antony Harding and Associate Professor Michael Buckland, MS Research Australia Brain Bank, Brain and Mind Research Institute, University of Sydney



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

| | |
|---|--|
| 1 | MS Research Australia will be laser focused in finding a cure for MS through funding the best research |
| 2 | MS Research Australia will strengthen active collaborations, maintain a national focus and distribution, and greatly expand its global relevance |
| 3 | MS Research Australia principles for activity will be consumer focused |
| 4 | MS Research Australia principles for activity will be outcome focused |
| 5 | MS Research Australia will continue to be a financially sustainable, accountable, trusted and transparent organisation delivering best-practice standards in the medical research sector |

7

ACKNOWLEDGEMENTS

The creation of this document was generously supported by a grant from the Macquarie Group Foundation.

The creation of this document was a recommendation by Booz and Company (now known as Strategy&) management consulting services company, from a strategic intent analysis conducted for MS Research Australia in 2012.

We gratefully acknowledge Thomson Reuters for providing access to the Web of Science database allowing compilation of some report content.

Many thanks go to the researchers who completed the Audit survey and contributed to compiling the document content.

We are also extremely grateful to the individuals whose images appear throughout the document:

- > Dr Heidi Beadnall, Brain and Mind Research Institute, University of Sydney
- > Associate Professor David Booth, Westmead Millennium Institute
- > Associate Professor Michael Buckland, Brain and Mind Research Institute, University of Sydney
- > Ms Therese Burke, Westmead Hospital
- > Associate Professor Helmut Butzkueven, University of Melbourne
- > Dr Scott Byrne, University of Sydney
- > Associate Professor Russell Dale, University of Sydney and the Children's Hospital Westmead
- > Dr Che Fornusek, University of Sydney
- > Dr Antony Harding, Brain and Mind Research Institute, University of Sydney
- > Dr Phu Hoang, Neuroscience Research Australia
- > Professor Trevor Kilpatrick, University of Melbourne
- > Mr Jae Young Lee, Monash University
- > Dr Edwin Lim, Macquarie University
- > Dr Linda Ly, Brain and Mind Research Institute, University of Sydney
- > Dr Fiona McKay, Westmead Millennium Institute
- > Dr Ingrid van der Mei, Menzies Research Institute Tasmania
- > Dr Julia Morahan, MS Research Australia
- > Dr Simon Murray, University of Melbourne
- > Dr Natalie Payne, Monash University
- > Dr Stephen Petratos, Monash University
- > Associate Professor Mark Slee, Flinders University
- > Professor Graeme Stewart, Westmead Millennium Institute

Particular thanks to Dr Antony Harding, Associate Professor Michael Buckland, Associate Professor David Booth, and Associate Professor Michael Barnett for the provision of scientific images used throughout the document.

We acknowledge the talented individuals who contributed to the creation of this document:

- > Biotext science information consultants www.biotext.com.au
- > Lisa Petroff Design lisapetroff@bigpond.com
- > Benjamin Lee Photography www.benlee.com.au

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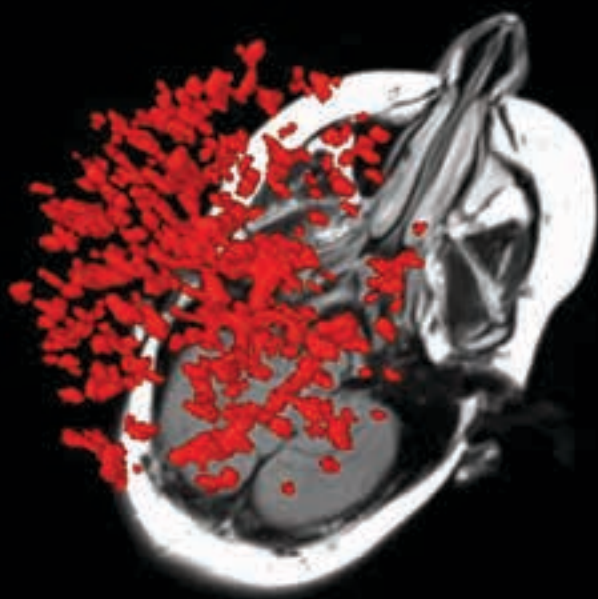
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8

REFERENCES AND KEY READINGS



3D image of MS lesions in a single patient

Image source: Associate Professor Michael Barnett, MS Research Australia Brain Bank, Brain and Mind Research Institute, University of Sydney



Professor Trevor Kilpatrick, University of Melbourne



**RESEARCH
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