



IMPLEMENTATION PLAN

for



A Roadmap
to Defeat
Multiple Sclerosis
in Australia



**RESEARCH
AUSTRALIA**



AUSTRALIA





Dr Sarah Spencer

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The Hon. Greg Hunt presenting at the *Roadmap to Defeat Multiple Sclerosis in Australia* launch event



Left to right: Senator David Busby, Simon McKeon AO, Jillian Kingsford Smith, Deidre McKechnie, Astrid Edwards, The Hon. Greg Hunt and Dr Matthew Miles.

Foreword from The Hon Greg Hunt MP

Multiple sclerosis (MS) is the most common chronic disease of the central nervous system among young Australians. It affects more than 25,000 people in Australia and is 3 times more common in women than in men.

When they should be thinking of careers, starting a family, travel or just living life to the fullest, up to 10 Australians each week will be informed of a diagnosis which may challenge some of those dreams.

We are galvanised and genuinely captivated by the degree of progress that we have seen in offering much better treatments to halt MS, and improved ways to diagnose the disease and emerging treatments for progressive MS, that have been introduced largely over the last 10 years. However, we are also aware of the significant work that is still ahead of us to ensure that everyone with MS has effective treatment options, not just some, and that MS is managed most effectively to optimise quality of life.

Thanks to an army of people living with MS, our very best Australian MS researchers, neurologists, nurses and allied health professionals and the national organisations – MS Research Australia and MS Australia – working collaboratively with each other and the Commonwealth Department of Health, we now have a Roadmap to Defeat MS and this document, the National Implementation Plan for A Roadmap to Defeat MS which provides a tactical and cohesive strategy for exactly how we will achieve that goal of ending MS. On the following pages, you will find the blueprint to tackle MS in a multi-pronged attack. Through more high-quality medical research, cutting edge clinical interventions, new collaborative programs of research and better management and care of people living with MS.

The Government is committed to support research initiatives that would improve health outcomes and quality of life of patients with devastating conditions, such as MS.

This comprehensive plan was developed over more than 9 months by a truly dedicated team. I wish to particularly thank all of those living with MS that have been part of this plan by sharing their own experiences with me and other parliamentarians and by participating in multi-stakeholder events that showcase how feasible it is for us to collaborate to stop and reverse MS. The national research organisation – MS Research Australia – may have set both audacious and time bound goals – but they are attainable. All of the experts are united in that assertion. Now is not the time to rest on our laurels or pat ourselves on the back for the last 10 years of stellar progress, now is the time to finish the job.

It is my sincere hope that this National Implementation Plan for A Roadmap to Defeat MS will serve to change the lives of people living with MS, their friends and families now and in to the future. I look forward to all state and territory governments also playing a part in the overall goals, objectives and actions of the plan. Now is the time to act with momentum firmly swinging in our favour.

The Hon. Greg Hunt MP
Minister for Health

About the Implementation Plan

Background

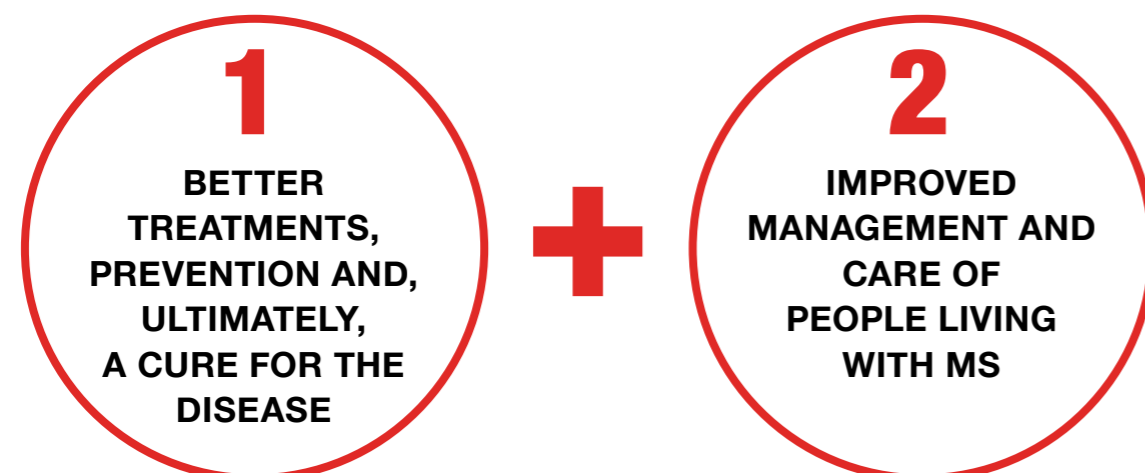
A *Roadmap to Defeat Multiple Sclerosis in Australia* was developed due to a request from the Commonwealth Health Minister, the Hon. Greg Hunt MP. He officially launched the Roadmap in Canberra on World MS Day 2018.

The launch event included a key note introduction from Mr Simon McKeon AO, Founding Chairman and now Patron of MS Research Australia and 2011 Australian of the Year. Mr McKeon led the 2013 strategic review on health and medical research in Australia known as the McKeon Review.

As someone living with MS himself, Mr McKeon has been a strong supporter of increased research funding for people living with MS. Following the launch, the Roadmap received bipartisan government support and the Health Minister committed to work with both MS Australia and MS Research Australia to develop an implementation plan to ensure that the momentum on this important initiative continued at pace.

Overall objectives

The overall objectives of the *Implementation Plan for A Roadmap to Defeat Multiple Sclerosis in Australia* addresses the two fundamental needs of people with MS in Australia.



How the Roadmap works

What is paramount to the success of such an audacious plan is the singular, comprehensive and cohesive oversight and implementation of all the elements of this plan.

MS Research Australia and MS Australia, whilst working with their key implementation partners, have the core capabilities, expertise, staffing, knowhow and relationships with MS researchers both nationally and globally, to perform that critical role. In bringing together the implementation plan for the Roadmap it was identified that the work needed to achieve our first goal of better treatments, prevention and ultimately, a cure for the disease, could be streamlined under three broad objectives. The original priorities of the Roadmap have been aligned with these objectives to accelerate implementation.

Many elements of this plan align with the priorities of the Medical Research Future Fund MRFF and intersect with MRFF activities and key considerations. However, a piecemeal approach will be inefficient and will not allow us to build the momentum and coordination necessary to accelerate progress and deliver solutions to people with MS within an acceptable time frame.

FUNDING REQUIRED TO IMPLEMENT THE ROADMAP

Total investment of \$55 million

- \$20 million for innovative pre-clinical and clinical research studies on nerve repair and protection to minimise the impact of all forms of MS.
- \$12 million investment over ten years in competitive and prestigious researcher programs to retain, sustain and grow the pool of high quality researchers in Australia; individuals who have excelled or show potential to excel in MS research.
- \$5.5 million to develop and improve infrastructure aimed at optimising personalised management and prevention of MS.
- \$3 million to improve the secondary prevention of MS by addressing modifiable lifestyle risk factors.
- \$8 million to support national clinical trials and Australian arms of international clinical trials.
- \$2.5 million to support and implement clinical studies that aim to prevent MS.
- \$2 million to expand access to Autologous Haematopoietic Stem Cell Transplant (AHSCT) for MS.
- \$2 million investment to establish, build and audit national care pathways.

Funding Source

\$30 million
investment from the **Medical Research Future Fund** and other **Federal Government** funding sources over 10 years.

\$5 million
from the **Commonwealth Primary Health Network** funding.

\$20 million
commitment from **MS Research Australia** to part match the government funding of MS research.



Mike Hemingway, diagnosed with MS in 2003,
Kerrie Newton, diagnosed with MS in 2008 and
Emma Giunti, diagnosed with MS in 2010

What is multiple sclerosis (MS)?

MS is the most commonly acquired neurological disease in younger adults around the world with over 2.3 million people affected.

More than 25,600 Australians live with MS and over 7.6 million Australians know or have a loved one with this potentially debilitating disease.

MS is the result of damage to myelin – a protective sheath surrounding nerve fibres of the central nervous system. When myelin is damaged, this interferes with messages between the brain and other parts of the body. The symptoms of MS are different for each person; sometimes they even vary within the same person. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern. For everyone, it makes life unpredictable.

25,600+ AUSTRALIANS
are living with MS



30-40
The average
age of diagnosis

Of every **4** Australians diagnosed with MS



3 WILL BE WOMEN

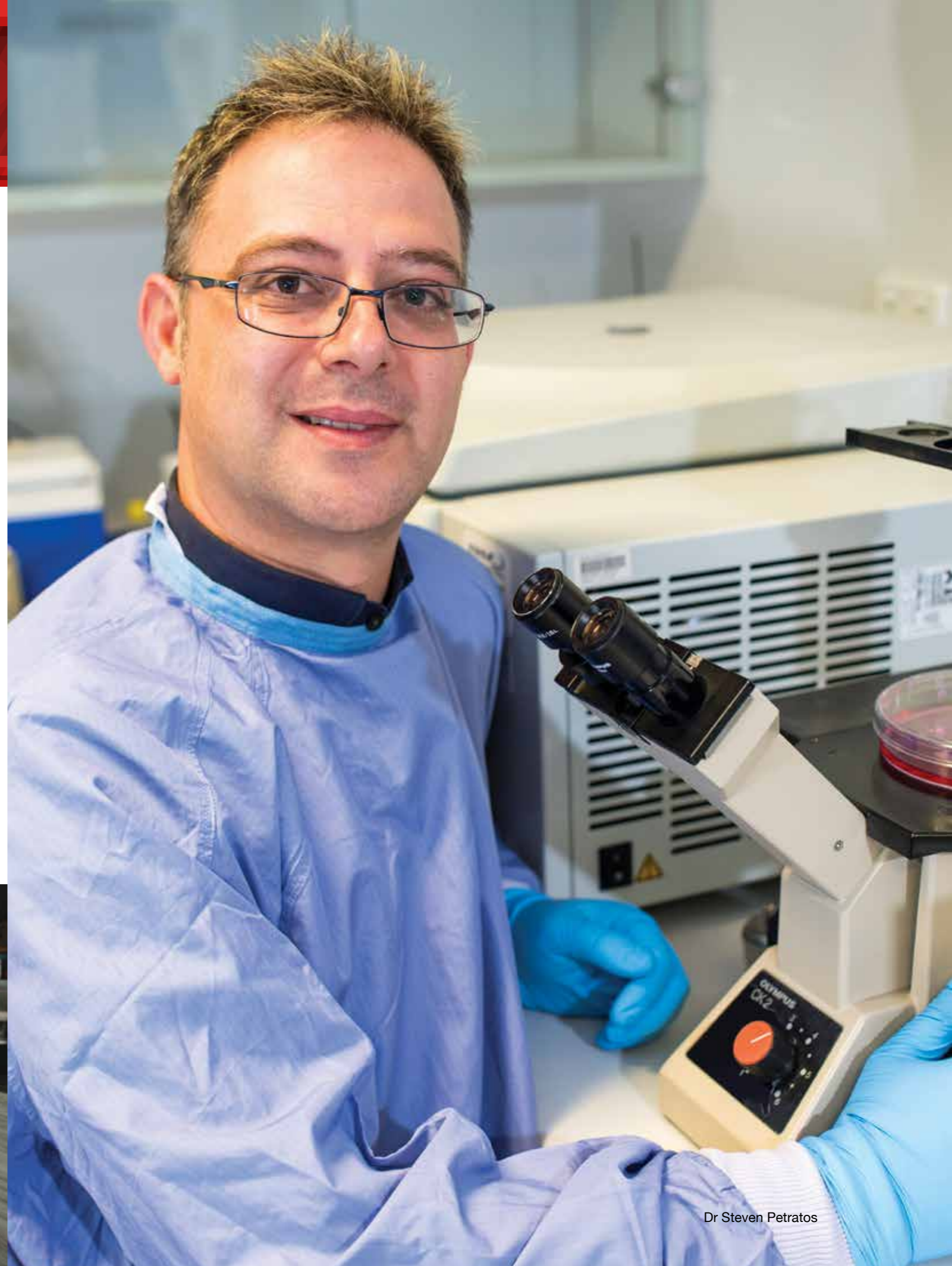


Key MS facts & figures

- MS causes significant disruption and can cause chronic disability to people in the prime of their lives and therefore has a substantive health burden and economic cost to the Australian health system.
- The prevalence of MS in Australia has increased by over 20% since 2010 – yet experts predict that 90% of MS cases could be preventable.
- 10 people on average are diagnosed with MS every week.
- The average age of diagnosis is between 30-40 and around 75% of those affected with MS in Australia are female.
- There is overwhelming evidence that MS is caused by an autoimmune process with both genetic and environmental contributors.
- The direct and indirect costs to the Australian community are increasing and now exceed \$1.75 billion every year. Nearly 32% of this figure is through the lost wages for Australians living with MS and their carers.
- 12 therapies are available for relapsing MS but treatment response varies enormously and methods to target and personalise treatment to optimise management and prevent disability accumulation are urgently needed.
- Only one therapy has been approved by the Australian Therapeutic Goods Administration (TGA) for progressive forms of MS, but is yet to be PBS-listed. Solutions to stop and reverse the progress of MS for people with progressive forms of MS are urgently needed.
- Australia has a mid to high incidence of MS compared with other countries, with 105 Australian people in every 100,000 having a diagnosis of MS. As with the global prevalence of MS, there is a significant latitudinal gradient in MS prevalence in Australia, where the prevalence of MS in Tasmania is double that of Queensland¹.



Renee Coffey, diagnosed with MS in 2011



Dr Steven Petratos



Time for action

A concerted, cohesive program of work has been identified that will accelerate solutions for people with all forms of MS, across the full spectrum of MS from primary prevention to halting and reversing disability for those most severely affected.

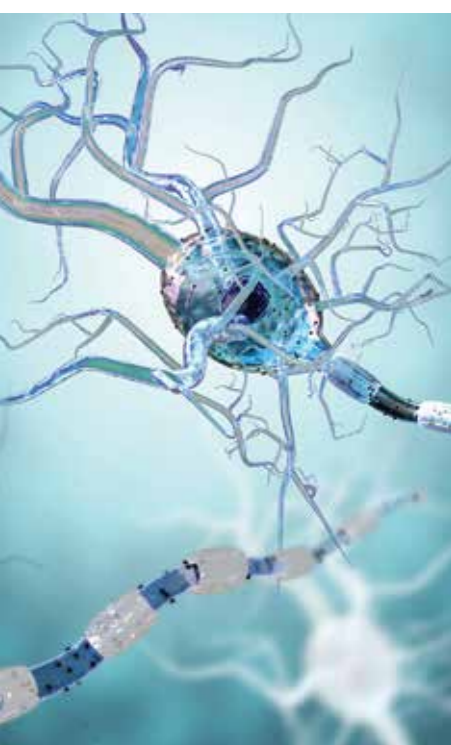
Whilst there are positive signs that the landscape is improving for people with MS in Australia thanks to research and treatment successes, on average, the quality of life indices of the Australian MS population remains 31% less than the Australian population norm.

The economic costs associated with MS per annum have increased by 41% since 2010.

However, importantly, robust scientific evidence exists which suggests that up to 90% of MS cases may be preventable².

Key recommendations from our recent report, *The Health Economic Impact of MS in Australia in 2017*, noted that:

- Interventions to prevent people from developing MS are crucial;
- Improving early diagnosis and affordable access to effective treatments are essential;
- There should be a continued focus on managing symptoms and supporting people with MS and their carers in employment;
- Quality of life of people with MS could be significantly improved through effective and specific interventions;
- Interventions and support to help people with MS to maintain physical health as they age will also improve quality of life for older people with MS.



There is significant evidence that there has been more progress in MS than in any other neurological disease in the world. However, with the serious burden for people with MS and the community, in terms of both quality of life and economic impact, there is still a great need for urgent action.

Australian collaboration

Australian MS research has a rich and successful history with significant research strengths in many different Universities and medical research institutes. Many of our talented MS researchers are amongst the world's best and global leaders in their fields of MS research. Australia has been involved with, or led, many of the world's most successful MS research collaborations over the last two decades, with the majority of national collaborations having been funded and facilitated by MS Research Australia, whose track record in leading and coordinating major collaborative efforts in MS research is second to none.

MS Research Australia has also worked closely with the National Health and Medical Research Council (NHMRC) over the last decade, often co-funding MS research projects. MS Research Australia is a category 1 funder of research, the only national MS not-for-profit organisation in Australia to be able to provide prestigious grant funding of this nature.

Moreover, this funding model has allowed MS researchers to leverage funding from other competitive sources. On average, researchers receiving our category 1 funding are able to leverage further competitive and philanthropic funds by a factor of 5 times the original investment. This is increased to 27:1 for our successful incubator grant applicants.

MS Research Australia achievements

- The largest trial of its kind in the world studying vitamin D and MS prevention (PrevANZ);
- The support of the Australian New Zealand MS Genetics Consortium (ANZgene) which led to the discovery of two major MS risk genes and contributed to the discovery of now over 200 gene variations through the International MS Genetics Consortium;
- In addition to these two collaborations, the funding and coordinating of a further 6 major research platforms to bridge knowledge gaps;
- Initiation of the first ever Australian MS Longitudinal Study (AMSLS) tracking patient-reported outcomes in MS – a study that has transformed advocacy and support for people with MS in Australia;
- A world-first blood biomarker discovery to help differentiate between the different types of MS;
- First ever joint research fellowship awarded by MS Research Australia in partnership with JDRF Australia to identify the common genetic pathways in MS and type 1 diabetes driving autoimmunity in both diseases;
- Funding of over 270 research grants awarded by MS Research Australia;
- In excess of \$44.3 million committed to MS research by MS Research Australia;
- Funding to over 50 Universities and medical research institutes in Australia; and
- Helping to build the capacity for MS research in Australia with a critical mass of over 900 clinicians and scientists focusing on MS in Australia.



Established the first ever
VITAMIN D
MS Prevention Trial



900+
Australian researchers
and clinicians working
on MS



OVER 270
research grants awarded by
MS Research Australia



International collaboration

MS Research Australia, MS Australia and Australian MS researchers play an integral role in the global efforts to solve MS.

MS Research Australia and MS Australia are active participants of the international federated body called the Multiple Sclerosis International Federation (MSIF). Over 40 MS organisations throughout the world are, or have been, involved with the global federation. It has given people affected by MS, MS societies, organisations and researchers from all over the world a chance to successfully collaborate together on items of global importance to people with MS, including research, treatment access, support, services and quality of life.

MS Research Australia and Australian MS researchers have been involved in numerous global initiatives that are making huge strides in improving our understanding of MS and the treatment of MS. Examples of this include:

- The International MS Genetics Consortium in which Australian MS researchers played a pivotal role.
- MS Research Australia joined the world-first International Progressive MS Alliance as a managing member – a global success story in accelerating treatments for progressive forms of MS.
- Melbourne based team founded and managed the largest clinical MS database in the world, called MSBase.
- A wealth of individual collaborations between Australian MS researchers and their global counterparts.
- MSIF global research team collaborations including the International Patient Reported Outcomes (PROs) initiative seeking to harmonise and collaborate on the collection and use of PROs for research, clinical trials, drug approvals and clinical management of MS.

Fundraising for MS research

National or global research programs can only function with adequate funding. In 2012, MS Research Australia launched its fundraising platform called *Kiss Goodbye to MS*. The campaign has now become the signature fundraising initiative for the global federation and has been rolled out in over 13 countries throughout the world. The Kiss Goodbye to MS campaign has a large social media footprint throughout the world and has proved to have significant traction with younger people affected by the disease no matter where in the world they live.

Top three research priorities for MS

In 2016, MS Research Australia undertook a large-scale survey of people affected by MS in Australia to ascertain their research priorities. Well over 1000 people responded to the survey. This large sample size was endorsed as being highly representative of the Australian MS population by senior epidemiologists at the Menzies Institute for Medical Research.

The survey results conclusively revealed that the **top three research priorities** for people affected by MS in Australia are:

1 FINDING A CURE FOR MS
via repair and regeneration

2 BETTER TREATMENTS and MANAGEMENT
of MS

3 PREVENTION
of MS

These priorities are the same regardless of where along the journey of MS people are: whether they are newly diagnosed or have lived with the condition for years, or whether they are mildly or severely affected by MS.

OBJECTIVE 1

Better treatments, prevention and, ultimately, a cure for the disease

There are three overarching priorities that will deliver the research outcomes for people with MS in Australia. Each of these priorities are interlinked to the overall Roadmap to Defeat MS in Australia.

The priorities are:

1. **Build research capability and capacity:** through fellowships and clinician-researcher grants;
2. **Harness and improve collaborative research efforts through infrastructure:** a nationally funded infrastructure for deeply characterised patient cohorts, interlinking clinical and patient reported data and biobanks, available to all researchers; and
3. **Clinical trials and clinical trial enabling infrastructure:** to accelerate new treatments and ultimately find a cure for and prevention of MS.



Dr Kaylene Young

Priority 1 – Build Research Capability and Capacity

Introduction

Invest in and expand promising signature areas of best quality, competitive and impactful research for MS through targeted research grants and capacity building through innovative fellowship schemes.

Destination

Capacity and capability is expanded and coordinated in signature areas of research with significant progress towards a cure via the repair and regeneration of cells.

Aims

There are two key aims (please see details in table below):

- Stimulating the translation of strong Australian discovery research on myelin repair and neuroprotection for MS into pre-clinical and clinical studies by developing a targeted program for research into these agents;
- Building the workforce and capabilities needed to achieve this, including developing strong connections between laboratory and clinical research, industry and other stakeholders through expansion of fellowship, paired fellowship and incubator programs.

1.1 \$20m for innovative pre-clinical and clinical research studies on nerve repair and protection to minimise the impact of all forms of MS.

ACTIVITY	DETAIL
New and innovative pre-clinical and clinical studies on myelin repair and nerve protection for MS.	Establish a fund for a targeted call for applications for innovative pre-clinical and clinical studies of novel myelin repair and neuroprotection interventions and the biomarkers and assays required to monitor drug efficacy in trials. The grant program will fund a portfolio of projects with clinical and commercial potential and bring them to proof-of-concept stage ready for further commercial investment.
Further research and development of the most promising preclinical and clinical outcomes from the above activity.	Establish a fund to provide follow-on funding to support further research and development of the most promising outcomes of the above projects.



1.2

\$12m investment over ten years in competitive and prestigious researcher programs to retain, sustain and grow the pool of high quality researchers in Australia; individuals who have excelled or show potential to excel in MS research.

ACTIVITY	DETAIL
Expansion of the successful competitive paired fellowship program (clinician and researcher working together as a pair), dedicated to translational research to better treat, prevent and find a cure for MS.	Establish a fund to continue to support new competitive paired fellowships. MS Research Australia's unique Paired Fellowship program was established in 2017 to facilitate cutting-edge clinical research by funding a Senior Research Fellow and dedicated research time for a Clinical Practitioner Fellow to collaborate on a shared program of research that will accelerate translation of research outcomes into clinical practice.
Investment in longer-term competitive and prestigious senior research fellowships and senior clinical practitioner fellowships to allow their promising research programs the time to come to fruition.	Expand MS Research Australia's signature senior research fellowship (for laboratory researchers and clinicians) program to enable them to focus on long-term research programs.
Expansion of the existing one-year incubator grants designed to stimulate innovative research.	Expansion of the incredibly successful MS Research Australia Incubator grant program to fund a larger number of small pilot grants of \$25,000 each which allow researchers to get innovative new 'out of the box' ideas and discoveries off the ground. These grants on average leverage 27 times the original investment through follow on grants.

Priority 2 – Harness and Improve Collaboration through Shared Infrastructure

Introduction

Collaboration in the MS research space in Australia is incredibly well established and effective. With further integrated funding and coordination, MS Research Australia is well positioned to capitalise on this and support our Australian experts to drive home the progress and momentum that has been achieved to date and make a lasting difference for people living with MS.

Enormous strides in understanding the risk factors for MS, developing treatments and measuring disease outcomes have been made. It is in these areas that increased investment in shared infrastructure and further collaboration will be most valuable. With a concerted effort we can use these advancements to ensure that the management of MS is targeted, optimised and personalised – the right treatment, for the right person, at the right time – and that we translate our knowledge into the causes of MS to prevent MS and the consequences of MS (primary and secondary prevention).

The 2016 Focussed Workshop of the European Committee for Treatment and Research in MS (ECTRIMS)² concluded that:

- 60% of MS cases could be prevented if smoking, vitamin D, obesity and glandular fever were addressed;
- 90% of MS could be prevented if an Epstein Barr Virus (EBV) vaccine was also developed.

Destination

Research collaboration and infrastructure are boosted to improve diagnosis, prognosis and treatment selection for a personalised approach to the management of MS and ultimately up to 90% of new cases of MS are prevented.

Aims

There are two key aims (please see details in the table overleaf):

- Develop national data and registry infrastructure, including cross-disease approaches, to coordinate the collection and analysis of data on individual diagnostic, prognostic, and preventative factors to personalise treatment and target prevention of MS.
- Collaborate nationally and internationally to develop and test strategies to minimise the impact and prevent the consequences of a diagnosis of MS.



2.1

\$5.5m to develop and improve infrastructure aimed at optimising personalised management and prevention of MS.

ACTIVITY	DETAIL
Identify at-risk individuals and identify diagnostic, prognostic and treatment response biomarkers through the establishment of a national registry and data research platform.	Both primary and secondary prevention strategies will be most successful if combined with methods to definitively identify the most at-risk individuals. Develop and coordinate a national collaborative research platform to utilise existing and emerging evidence to develop integrated genetic, clinical, imaging and fluid biomarker signatures and algorithms to enable screening and stratification of populations with, and at risk of MS to feed into trial designs and treatment strategies.
Enabling platforms for clinical trials.	Develop a shared national coordination and infrastructure platform for MS clinical trials in Australia to maximise access, efficiency, comparability and data use from clinical trials for MS – to be integrated with the shared data and registry infrastructure in the above activity and articulated with international MS clinical trials platforms and consortia.
Develop international collaborative links to address glandular fever and an EBV vaccine.	Work nationally and internationally to drive a focussed international effort to develop and test an EBV vaccine. This is likely to include identifying the most promising vaccine candidate(s), developing a feasible multinational trial design to evaluate efficacy for MS prevention and identifying funding sources to conduct the necessary large, population-based MS prevention study.
Expansion of the Australian Immunological Alliance model to collaborate on common areas of research to identify triggers and prevention strategies for autoimmune, immunological and neurological diseases.	Support the ongoing work of the Australian Immunological Alliance with support costs and a common fund to ensure momentum and progress on common research priorities. Develop a similar approach on common research priorities with other neurological diseases.

2.2

\$3m to improve the secondary prevention of MS by addressing modifiable lifestyle risk factors.

ACTIVITY	DETAIL
Address smoking, obesity, physical activity for the primary prevention of MS.	Establish and support the development and integration of communications and behaviour change support targeted at high risk populations and monitor ongoing MS diagnoses in the target population via the registry infrastructure. Partner with public health initiatives to develop, trial and evaluate effective behaviour change interventions for smoking prevention and cessation and obesity prevention in high risk populations and monitor outcomes via a targeted registry.
Target secondary prevention of MS via the adoption of a brain healthy lifestyle for people with the earliest signs of MS.	Work nationally and internationally to develop and implement a strategy targeting adoption of recommendations on modifiable lifestyle factors, with a focus on smoking, diet, physical activity, obesity and other identified risk factors including co-morbidities, associated with worse outcomes in MS. Ongoing research to develop and test robust and pragmatic lifestyle interventions for optimal brain health in people with MS and those at high risk of MS.



Priority 3 – Clinical Trials to cure and prevent MS

Introduction

While a range of medications are available for people with relapsing forms of MS and one single medication has recently been approved by the Australian Therapeutic Goods Administration (TGA) for primary progressive MS, these medications are not effective for all people with MS and can come with a host of risks and side effects. There remains an urgent need to increase treatment options for people with MS, especially for progressive MS. Work is underway worldwide to address this and there is gathering national and international momentum towards clinical trials in a number of innovative areas for MS.

Funding is needed to ensure that Australians living with MS can fully participate and gain access to these clinical trials. In particular, there is intense activity in the development and testing of repurposed medications and other interventions with low commercial interest but potentially high impact for people living with MS. Not least, the significant momentum being driven by the International Progressive MS Alliance, of which MS Research Australia is a managing member will soon see numerous progressive MS clinical trials coming down the pipeline. This includes a range of emerging cell and gene based therapies for MS. Concerted funding is needed to support innovative clinical trials in Australia and Australian participation in international trials of these up and coming agents for the treatment of MS.

Clinical trials are also the only way to answer the question of whether MS can be prevented in those at risk. Australian research in this area is strong and it is paramount that we complete ongoing clinical trials on whether vitamin D or UV could be used to prevent conversion to MS. Analysis of these trials alongside other international evidence will underpin the development of guidelines for clinical practice for at risk populations.

In addition, support for infrastructure and collaboration is needed to enhance access to Autologous Haematopoietic Stem Cell Transplant (AHSCT) as a treatment for MS. This therapy is currently offered at two centres in Australia as part of clinical observational trials and access needs to be greatly improved for those for whom it is appropriate.

Destination

Australia plays a leading role in clinical trials for MS treatments and Australian participation in international trials is enhanced, leading to earlier access to treatments for Australians with MS. Clinical trial activity determines the role for environmental factors in the prevention of MS.

Aims

There are three key aims (please see details in the table opposite):

- Supporting innovative clinical trials for promising drug targets for relapsing and progressive MS.
- Expand clinical trials and access to cell based and gene based therapies for MS.
- Enhance access to AHSCT through the development of centres of excellence.

3.1

\$8m to support national clinical trials and Australian arms of international clinical trials.

ACTIVITY	DETAIL
Grant program for innovative clinical trials for progressive and/or relapsing MS relating to promising drug targets or interventions.	Establish a competitive fund for collaborative investigator-led, clinical trials for relapsing and progressive MS including both national trials and Australian arms of international trials. Consideration will be given to pharmaceutical and non-pharmaceutical interventions, and should include the development and validation of assays, biomarkers and tools for monitoring treatment outcomes in clinical trials, stratifying patients and optimising a personalised approach to treatment.
Expand Australian research-driven, clinical trial activity relating to innovative cell and gene-based therapies for MS.	Establish a competitive fund to support Australian clinical research centres to participate in international collaborations for the development and trialling of innovative, emerging cell- and gene-based therapies for MS, with initial priorities to include AHSCT, mesenchymal stem cells, and cell-based therapies targeting established risk factors and disease mechanisms in progressive MS.

3.2

\$2.5m to support and implement clinical studies that aim to prevent MS.

ACTIVITY	DETAIL
Address low vitamin D and UV.	Complete the ongoing Australian clinical trial into the prevention of MS using vitamin D (PrevANZ) and analyse results in concert with international vitamin D trials and the Australian PhoCIS UV trial. Develop guidelines on appropriate vitamin D supplementation and safe UVB exposure for the general population and at risk populations. Conduct registry-based evaluation of implementation and efficacy of these guidelines. Support international working group to explore primary prevention trials for MS.



3.3

\$2m to expand access to Autologous Haematopoietic Stem Cell Transplant (AHSCT) for MS.

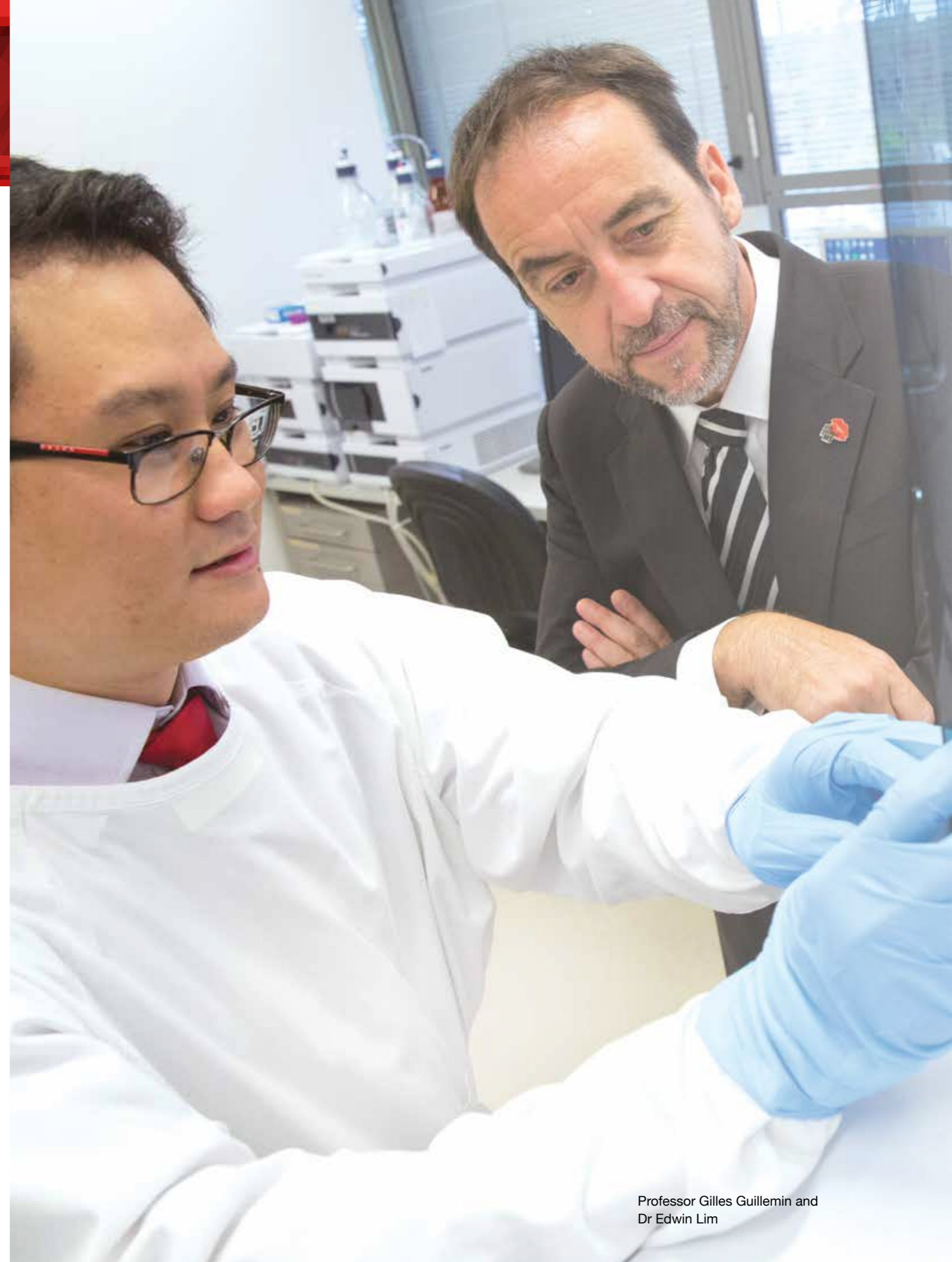
ACTIVITY

Expanding access, via research-driven centres of excellence, to AHSCT for people living with MS where this is deemed the optimal approach.

DETAIL

Establish and support a research platform and network for AHSCT for MS. The platform will include support for a national network of centres of excellence providing AHSCT for MS in Australia. The network will be supported with ongoing registry infrastructure to facilitate data-gathering and research.

Explore collaboration with and support for international trials to expand access to treatment trials of AHSCT for people with MS in Australia and contribute to the international data-gathering on this treatment modality.



Professor Gilles Guillemin and Dr Edwin Lim

OBJECTIVE 2

Improved Management and Care of People living with MS

Introduction

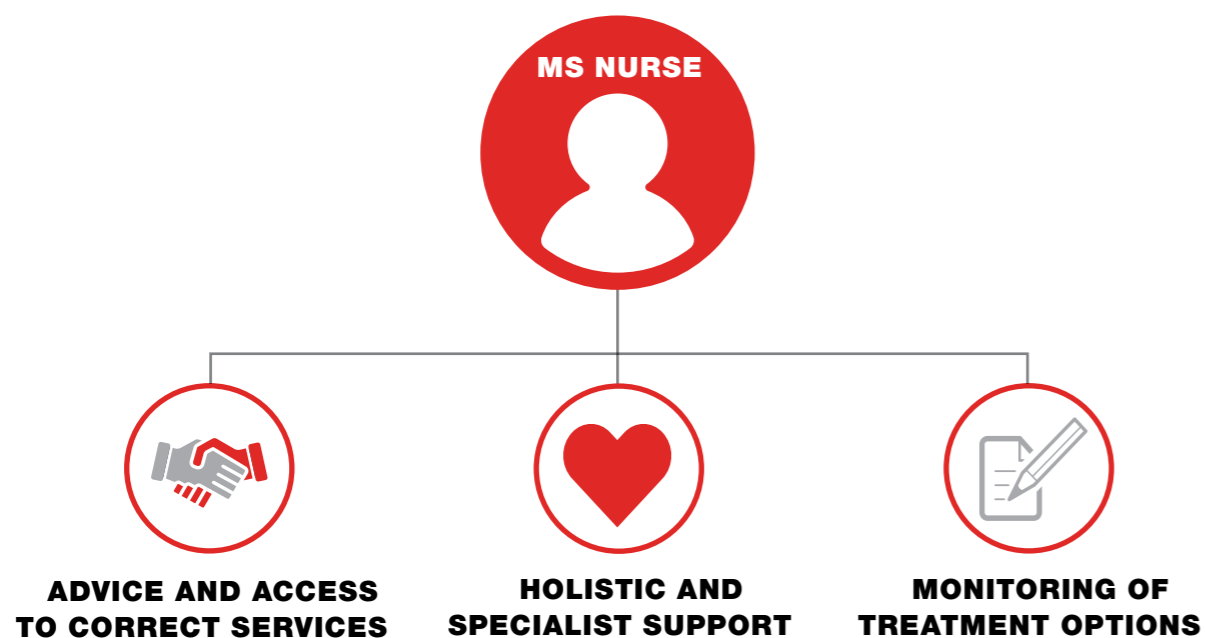
Ensure all people with MS have access to the best possible models of care from onset of symptoms, through diagnosis and ongoing treatment and management, including monitoring of treatment efficacy.

Improving the management of people affected by MS will be achieved by the outcomes of some of the activities in Priority 1 & 2. This will be further enhanced by investment in the health care team that supports people living with MS (Priorities 3 & 4) to optimise treatment, minimise disease and disability progression and assist in maintaining quality of life including employment.

\$2 million will be used to establish, build and audit vital national care pathways, including the development of the health care team integral to these care pathways.

Foundational to an optimal MS health care team is the specialist MS Nurse.

Multiple Sclerosis Specialist Nurses (MSSNs) are an established and essential part of the multidisciplinary team of specialist health professionals supporting people with MS. They play a key role in information, advice and support for patients, family and carers, at the point of diagnosis and ongoing.



MSSNs provide holistic and specialist support in symptom management and are the key support that assists the patient and their family to navigate a complex number of service systems (health, disability, community and aged care), to access the right support at the right time. They work closely with medical staff in providing practical and individualised information for patients to make informed choices on treatment options best suited to their MS and lifestyle. They also assist with safety and monitoring reporting which is crucial to avoid serious adverse reactions especially in respect to several of the newer disease modifying therapies.

Research nationally and internationally has highlighted the economic argument for employing specialised nurses in the management of chronic diseases³.

Research articles that demonstrate a clear economic argument to employ MSSN include the 2015 ten year retrospective evaluation study conducted in the UK, which found that the introduction of a proactive nurse-led management and rapid response service of MSSNs in one health area - including the implementation of a care pathway in the emergency department for patients who present with MS - was associated with a reduction from a mean of 2700 bed-days per year to a mean of 198 bed days per year⁴.

Additionally, there is clear evidence of patient preference for the use and perceived value of MSSNs⁵.

Destination

Access to early interventions and the most effective treatment therapy is well established.

- Optimal models of MS care pathways are well established.
- The time taken from onset of symptoms to diagnosis, treatment and adoption of a brain-healthy lifestyle is significantly reduced.
- Evidence-based lifestyle interventions are well understood by clinicians and adopted by people living with MS.
- Number of MS Nurses in Australia is dramatically increased.

Aims

There are four key aims that encompass this objective:

- Recognising the critical importance of early diagnosis, early treatment and appropriate monitoring.
- \$2m investment to establish, build and audit national care pathways.
- Empower patients and clinicians with evidence based information on the role of lifestyle factors for a holistic approach to managing MS.
- Expand the number of specialist MS nurses in Australia to support effective disease and symptom management in the primary care setting.



1 Recognising the critical importance of early diagnosis, early treatment and appropriate monitoring.

ACTIVITY	DETAIL
1.1	<p>Increase understanding of MS within primary health and across the wider community to expedite diagnosis and referral to an expert in MS, as per the recommendations of the international consensus initiative, <i>Brain Health: Time Matters in MS</i>.</p> <p>Work with the Primary Health Networks, Health Pathways team, GPs and other health care peak organisations to increase awareness of MS symptoms and the benefits of early diagnosis, treatment and adoption of a brain-healthy lifestyle. This will include developing and promulgating evidence-based ‘best practice’ care pathways and disseminating material such as the “<i>Brain Health: time matters in multiple sclerosis</i>” guide as widely as possible.</p> <p>Continue broad-based advocacy and communications work to improve understanding of MS in the broader Australian community, with a particular emphasis on the importance of recognising symptoms early, expediting diagnosis and treatment and adopting a brain-healthy lifestyle.</p>

2 \$2m investment to establish, build and audit national care pathways.

ACTIVITY	DETAIL
2.1	<p>Establish, build and audit national care pathways to support decision-making by healthcare professionals and their patients.</p> <p>Fund a dedicated project manager to work with the Primary Health Network, Health Pathways team to implement the recommendations of the <i>Brain health: time matters in multiple sclerosis</i> international consensus standards for the management of MS with a focus on diagnosis, treatment and lifestyle change.</p> <p>Work with Primary Health Networks, MS Nurses Australasia, ANZAN MS Neurologists, patients and MS clinics to evaluate, audit and adjust pathways of care to achieve the internationally established standards of best practice in MS diagnosis and management.</p>
2.2	<p>Increase access to diagnostic tools including blood tests and magnetic resonance imaging (MRI).</p> <p>Partner with other peak organisations to advocate and lobby for increased affordable access to diagnostic tools such as blood tests and MRIs by building on recent commitments to increase the number of MRI machines across Australia,</p> <p>Urgently address the cost of these tests for patients, to ensure cost is not a barrier to obtaining a diagnosis and close monitoring of treatment response and disease progress.</p>
2.3	<p>Enhancement of widely-accepted and best practice prescription of currently available MS medications to enable the individuality of the disease to be matched by tailored and optimal treatment.</p> <p>Building on the work detailed in 1.1 on the opposite page, work with the Primary Health Networks, GP and other health care peak organisations to increase awareness by both health care providers and people newly diagnosed with MS, of the various MS treatment options available.</p>



3 Empower patients and clinicians with evidence based information on the role of lifestyle factors for a holistic approach to managing MS.

ACTIVITY	DETAIL
3.1 Provide patients and clinicians with evidence based information on the role of lifestyle factors in MS.	Building on the outcomes and resources developed as part of Objective 1, we will utilise a range of on-line and social media channels to provide healthcare professionals with contemporary, evidence based information on the role of lifestyle factors on brain health to assist in adoption at the point of diagnosis.
3.2 Continue to develop the evidence in this area and minimise the impact and progression of the disease.	Partnering with existing public health programs to promulgate evidence for the impact of lifestyle factors on the management of MS to increase adherence and long term gains, with consideration for the unique challenges for people living with MS (including the specific barriers of physical, cognitive, mental health and fatigue symptoms that accompany a diagnosis of MS).

4 Expand the number of specialist MS nurses in Australia to support effective disease and symptom management in the primary care setting.

ACTIVITY	DETAIL
4.1 Implement a range of contemporary mechanisms, including telehealth, to enable MS specialist nurses (MSSNs), to provide specialised support and care to people with MS in rural and remote locations, either directly or via local health professionals to assist in coordinating a multidisciplinary care approach to achieve optimal MS patient outcomes.	<p>Collate evidence as to the efficacy of a range of contemporary mechanisms in improving access and specialised support for people living with MS in rural and remote Australia.</p> <p>It is anticipated that the intervention of a MSSN will improve MS patient outcomes such as quality of life, employment stability, delay in progress of disability, plus reduced requirement for high needs care.</p>
4.2 Implement a project to provide evidence of the impact of specialist nurse support in neurologist-led MS clinics. This project will utilise a clinic currently without an MS nurse to establish baseline data on key measures including symptom management, accident and emergency presentations, hospital stays and the prevention of disease progression, prior to establishing an MS nurse in that setting and collecting evidence of the impact of the MS nurse role.	<p>Establish an advisory group of key health professionals and peak bodies to design a project to support the implementation of this specialist role.</p> <p>The MS specialist nurse will monitor and proactively manage MS patients through coordination of services, strengthening referral pathways and assisting with support for advanced therapies.</p> <p>This project will gather data to build on the evidence base described in the introduction to this section of the Plan, and provide a value proposition, further demonstrating the benefits of employing specialist MS nurses.</p>
4.3 Identify and establish data collection systems to build an evidence base regarding the most effective nursing interventions to improve symptom management, provide effective multidisciplinary care, delay and minimise disease progression and empower the person with MS to maintain the best possible health and wellbeing.	Work closely with MS Nurses Australia and other MS peak bodies to develop, adopt and promulgate an Australian model of MS care, including best practice guidelines and established standards for treating, supporting and caring for people with MS in Australia.

Next Steps and Early Priorities

Once adequate funding has been secured to ensure the Roadmap to Defeat MS fulfils its objectives, the following is suggested:

Step 1: Establish an Implementation Oversight Group

- Establish an Implementation Oversight Group to facilitate and monitor the implementation of the Roadmap. This group will consist of the following members:
 - Representative from MS Research Australia Board
 - Representative from MS Australia Board
 - MS Research Australia CEO or nominated representative
 - MS Australia CEO or nominated representative
 - MS Clinician
 - MS Biomedical Researcher
 - MS Social and Applied Researcher or Allied Health Professional
 - Industry/Commercialisation Expert
 - Consumer advocate (2 people)

MS Research Australia and MS Australia will manage implementation of the Roadmap with the Implementation Oversight group, supported and advised by subcommittees as required for individual initiatives.

Step 2: Implementation oversight group to take action

Immediate and early implementation of the Roadmap will include:

- Calling for a series of competitive Requests for Funding Applications (RFAs) via the robust, current and impactful mechanisms of MS Research Australia, specifically targeting the key identified MS research priorities areas (gaps and opportunities), these are:
 - Advancing Australian strengths in myelin repair and neuro-protection research.
 - Better understanding the underpinning cellular mechanisms of MS progression.
 - Enhancing translational Australian research designed to provide treatments and interventions for people living with progressive MS.
 - Modifiable lifestyle factors in MS management, symptom management interventions for fatigue, pain and cognition in MS.
- Competitively enhancing the translational research and clinical trial capacity of current and potential therapies for MS including Autologous Haematopoietic Stem Cell Treatment (AHSCT) and other cell based therapies aimed at supporting and increasing areas of existing clinical and research strengths in Australia.
- Establishing a competitive and robust research translational grants program to specifically support investigator-led pre-clinical (proof of concept) and clinical trials of novel MS therapies including re-purposing medications for myelin repair and neuroprotection.
- A collaboration between MS Australia and MS Research Australia on advocacy and awareness using evidence-based interventions to change public policy leading to earlier intervention, and prevention of the development and progression of the disease.
- Establishing a model high quality care pathways for MS and working with the Primary Health Networks across Australia in their local implementation.
- Implement a working party to progress development of research into the impact of lifestyle changes on the progress of MS.
- Expand the current MS specialist nurse project to develop an evidence base for growth of the MS nursing workforce.
- Establish best-practice monitoring, oversight and milestone developments.



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For more information about research into multiple sclerosis and the work of **MS Research Australia**, please contact: **1300 356 467** or visit **www.msra.org.au**



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