

A Roadmap to Defeat Multiple Sclerosis in Australia



Objective

People with MS have two fundamental needs:

1. Better treatments, prevention and, ultimately, a cure for the disease
2. Improved support for the management and care of MS

This Roadmap sets out what is needed **within the next 10 years** to ensure that we can prevent and ultimately defeat MS. And we want to ensure that everyone with MS has effective and appropriate management and interventions.

FUNDING OBJECTIVES:

A Total Investment of \$55 Million

- > A **\$30 million investment** from the Medical Research Future Fund (MRFF) and other Federal Governmental funding sources over 10 years.
- > To demonstrate the benefits of collaboration, **MS Research Australia will commit \$20m in total to part match the government funding of MS research**; \$10m over a 10 year time period from annual revenue and \$10m from major donors and a fundraising campaign, building on previous successes and community support, to 'Stop and Reverse MS'.
- > **A further \$5m** from the Commonwealth Primary Health Network funding is sought to establish, build and audit national MS care standards that support decision-making by GPs, neurologists and other healthcare professionals and to ensure people with MS adopt a brain healthy lifestyle.

Why is this important?



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

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



There is overwhelming evidence that MS is caused by an **autoimmune** process with **both genetic and environmental contributors**.



The average age of diagnosis is only 30 and around 75% of those affected with MS in Australia are female.



MS causes significant and 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 direct and indirect costs to the Australian community are increasing and now exceed **\$1.9 billion every year**. Nearly 50% of this figure is through the lost productivity of Australians living with MS and their carers.



1. Stop MS and Find a Cure

What needs to be done?

Invest in and expand promising signature areas of best quality, competitive and impactful research to find the cure for MS.

Our number 1 priority is:

1. \$20m for innovative, pre-clinical and clinical research studies on nerve repair and protection to minimise the impact of all forms of MS.

2. \$12m investment 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, to include:

- > Expansion of the competitive and successful paired fellowship program (clinician and researcher working together as a pair), dedicated to better treatment, prevention and finding a cure for MS
- > Investment in longer-term competitive and prestigious senior research fellowships and senior clinical practitioner fellowships to allow promising research the time to come to fruition
- > Expansion of the existing one-year incubator grants designed to stimulate “innovative” research.

3. \$10m grant program capable of supporting national (and Australian “arms” of international) translational research collaborations. This will be for innovative clinical trials for progressive and/or relapsing MS relating to promising drug targets or interventions.

- > Expanding access, via research-driven centres of excellence, to Autologous Haematopoietic Stem Cell Transplant (AHSCT) for people living with MS where this is deemed the optimal approach.
- > Expand Australian research-driven, clinical trial activity relating to Mesenchymal Stem Cell Treatment (MSCT) for people living with progressive and/or relapsing MS.

DESTINATION

Signature areas of research are expanded with significant progress towards a cure via the repair and regeneration of cells.

Achieved through expansion and extension of existing and new MS research activities:

- Pre-clinical and clinical trials on nerve repair for MS
- Competitive paired fellowships
- Senior research fellowships and senior clinical practitioner fellowships
- One-year incubator grants
- National translational research collaborative grant programs
- Access to AHSCT treatment, and clinical trial activity for MSCT



2. Prevention of MS

What needs to be done?

Addressing smoking, Vitamin D deficiency, obesity and glandular fever will prevent 60% of MS cases.

If we also develop a vaccine against the Epstein Barr Virus (EBV), we could prevent 90% of MS cases.

1. \$8m to undertake high quality research to facilitate the primary prevention of MS through a focus on determining the genetic and environmental factors that contribute to the development of MS, to include:

- > Completing the Vitamin D MS prevention trial coupled with utilising the outcomes of the UVB light therapy trial to reduce the MS risk in susceptible people
- > Working with our global research partners on an EBV vaccine
- > Developing and implementing a strategy targeting lifestyle changes, with a focus on smoking, diet and obesity in high risk populations
- > Funding for expansion of the Australian Immunological Alliance work to further research commonalities with other immunological diseases on triggers and prevention

2. \$3m to improve the secondary prevention of MS through a strategy to encourage people who have experienced an initial MS event to adopt a brain healthy lifestyle including avoiding smoking, limiting alcohol intake, maintaining a healthy diet, keeping physically active, and keeping their minds active.

DESTINATION

Ninety percent of MS cases are prevented.

- Genetic and environmental factors contributing to MS are determined and measures to address them are implemented
- An EBV vaccine is developed and administered
- Brain-healthy lifestyle factors are well understood and adopted by people who have had an initial MS event



3. Improved Management of MS

What needs to be done?

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 efficacy.

1. Recognising the critical importance of early diagnosis and early treatment in minimising the impact of MS, 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, Brain Health:Time Matters in MS

2. \$2m investment to establish, build and audit national care pathways to support decision-making by healthcare professionals and their patients, including:

- > Access to diagnostic tools including blood tests and Magnetic Resonance Imaging (MRI)
- > 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

3. Empower patients and clinicians with information on appropriate evidence-based lifestyle interventions and continue to develop the evidence in this area, crucial to providing an holistic approach to managing MS, and minimising the impact and progression of the disease.

4. Expand the number of specialist MS Nurses in Australia to promote effective condition and symptom management and prevent the progress of MS in the primary care setting by:

- > Empowering people with MS to maintain the best possible health and wellbeing
- > Working with GPs and medical specialists to support and coordinate multidisciplinary care
- > Monitoring and proactively managing MS patients to minimise crisis events, accident and emergency presentations, avoid or minimise hospital stays, and delay and minimise or prevent the progress of disability through coordinating services, strengthening referral pathways and assisting with support for advanced therapies.

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



Implementation and Next Steps

What needs to be done?

1. MS Australia and MS Research Australia will manage implementation of the Roadmap:

- > Supported and advised by the proven and robust MS Research Australia research governance mechanisms currently in place for all MS research-related activities to ensure greatest impact and best-practice reporting back to Government and other supporters. An Expert Advisory Group will oversee the pathways to better care and management.

2. Immediate and early implementation of the Roadmap will include:

- > 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
- > 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 Australian cell-based therapies (including Autologous Haematopoietic Stem Cell Treatment (AH SCT), Mesenchymal Stem Cell Treatment (MSCT) and EBV-related) 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
- > 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



For more information about this Roadmap, multiple sclerosis in general and the work of **MS Australia**, please contact: **1300 010 158** or visit **www.msaustralia.org.au**

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**