

MULTIPLE SCLEROSIS AUSTRALIA

2017 Federal Pre-Budget Submission

17 January 2017

Deidre Mackechnie
Chief Executive Officer

Multiple Sclerosis Australia
Level 19 Northpoint Building,
100 Miller St
NORTH SYDNEY NSW 2060
T: 02 8413 7977
F: 02 8413 7988

Executive summary

Multiple Sclerosis (MS) is a debilitating disease of the central nervous system. It is the most common chronic neurological condition affecting young adults in Australia.

- Affects more than 23,000 people throughout Australia
- 1,000 more people diagnosed every year
- Average age of diagnosis is between 20 to 40 years old
- 75% of people diagnosed are women

Economic impact of MS is considerable

- Total cost of MS in Australia is \$1.04 billion per year
- \$500 million is due to lost productivity
- Replacement cost of informal care provided to Australians with MS is \$125m
- 50-80% of people with MS cease to work full time within 10 years of diagnosis
- Australians with MS pay \$78m per year out of their own pockets for medication and treatment

Our aspirations

The standard of medical treatment of MS in Australia is one of the best in the world. People with MS need this to be coupled with a comprehensive and coordinated multi-disciplinary approach to better manage their chronic condition:

- We want people with MS to be diagnosed and treated as early as possible to minimise disease activity and reduce the progression of their disease.
- We want ongoing specialist care and support to reduce the impact on the healthcare system by minimising the need for crisis interventions.

Quality of MS management should not be contingent on which state the person lives in.

Our two requests for the 2017 Federal Budget will advance these aspirations and:

- **Reduce the impact of MS on the individual, their family and carers; and on the disability and aged care sectors** by enabling them to stay in employment longer and slowing the progression of disability. This will delay the need for them to access funded supports like the NDIS and potentially enter residential care.
- **Reduce the impact of MS on the healthcare system** by decreasing presentations to emergency departments, reducing hospital admissions and length of stay; and reducing the burden on GPs and Neurologists
- **Improve the quality of life, health and wellbeing** of all people diagnosed with MS
- Support and advance **research to stop MS**

Whilst the two following budget requests are independent of each other, there is great synergy of systemic impact for people with MS as indicated by these outcomes.

Budget Request 1

A strategy to ensure all people with MS in Australia have **access to the care coordination, support and expert advice of a specialist MS Nurse**

\$1 million over 3 years

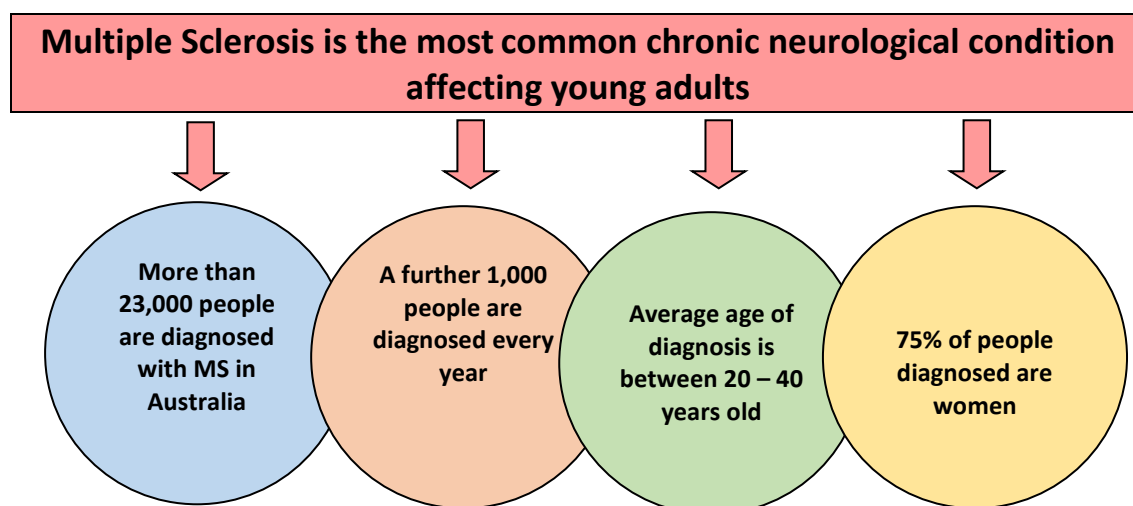
Budget Request 2

Implementation of an **integrated therapeutic strategy** with the potential to **minimise disease activity and maximise lifelong brain health** for those with MS

\$15 million over 3 years

Multiple Sclerosis Australia: 2017 Federal Pre-budget submission

ABOUT MULTIPLE SCLEROSIS



Multiple Sclerosis (MS) varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it is a progressive decline over time. For all, it is life changing.

Symptoms can include severe pain, walking difficulties, debilitating fatigue, partial blindness and cognition problems.

There is no known cause or cure.

An Economic Impact study of MS (Palmer, 2011) stated that, “the typical course of MS is initially relapsing-remitting, with symptoms partially or completely disappearing during remissions. However, after about 10 years, the majority of people enter a secondary progressive phase and disability gradually accumulates. For a smaller group, the disease course is primary progressive, with ongoing worsening of the initial presentation. Many of these people with MS develop other chronic conditions in the course of the disease.”¹

There have been several studies of the prevalence of MS in Australia over the years and each of these studies reported a latitudinal gradient of MS prevalence. That is, the number of people with MS per head of population in Australia is much higher in Tasmania than in Queensland as shown in the table below.

Prevalence of MS (per 100,000) by prescription²

NSW	VIC	QLD	SA	WA	TAS	ACT	NT
86.8	120.0	70.7	107.2	101.2	141.6	100.6	21.2

¹ Palmer A., *Economic Impact of MS in 2010 Australian MS Longitudinal Study*, September 2011, page 7.

² Covance & Menzies Research Institute. *Economic Impact of Multiple Sclerosis in 2010; Australian Longitudinal Study*. Prepared for MS Research Australia. North Ryde: Covance Pty Ltd. 2011

ECONOMIC IMPACT³



The economic impact of MS is significant, with direct and indirect costs impacting the person with MS, their family and the wider community. Improved management will enable people with MS to remain in employment longer, reduce the burden on carers and minimise both the systemic and individual healthcare costs.

A COMPREHENSIVE APPROACH

People with MS require a greater investment in research to seek better treatment, prevention and repair of damage to the nervous system. Equally important is a comprehensive approach to management of people with MS across all tiers of the federal, state, territory and local jurisdictions.

We want to create articulated pathways of diagnosis, treatment, care and support, with an emphasis on consumer-directed care, recognising that families and carers can only do so much.

We want to ensure people with MS are diagnosed and treated as early as possible, minimising the need for crisis interventions and avoiding people being placed in residential care.

Our two budget requests for the 2017 Federal Budget will advance these aspirations.

³ Covance & Menzies Research Institute. *Economic Impact of Multiple Sclerosis in 2010; Australian Longitudinal Study*. Prepared for MS Research Australia. North Ryde: Covance Pty Ltd. 2011

Budget request 1: MS Nurse Pilot Project

1.1 Purpose of funding

Establish a pilot project to create a solid, sustainable system that ensures all people with MS in Australia have access to the care, support and advice provided by a specialist MS Nurse.

1.2 Period of funding

Three year period from 1 July 2017 to 30 June 2020

1.3 Need for funding

The critical importance of the role of the MS Nurse is well understood⁴ and is pivotal to:

- mitigating against and slowing disease progression (and consequent progression to significant functional impairment) and improved symptom management which in turn leads to:
 - a reduction in reliance on federally funded supports such as the National Disability Insurance Scheme (NDIS) and the Disability Support Pension (DSP)
 - employment retention and enhanced workforce participation
- avoiding unnecessary emergency department presentations or admissions to hospital
- reducing length of hospital stays
- reducing demands on time of GPs and neurologists by acting as first point of contact for queries and concerns and providing post appointment follow up
- supporting clinical trials of MS treatments in Australia
- generating income for clinical activity
- responding to the particular, unique needs of people living with MS

A study undertaken in the UK in 2015 titled, *Impact of Proactive Case Management by MS Specialist Nurses on Use of Unscheduled Care and Emergency Presentation in MS* showed that by increasing specialist MS nursing hours per week, and implementing a care pathway in the emergency department for patients with MS who did present, there was a reduction in utilisation from a mean of 2,700 bed-days per year (2002-2006) to a mean of 198 bed-days per year (2007-2013)⁵.

Anecdotal evidence indicates there are currently gaps in providing comprehensive access to MS specialist nursing services across Australia and that people with MS have a less than optimal experience in the accident and emergency departments of hospitals. Multiple Sclerosis Australia is currently working with the MS Nurses Association of Australasia to determine the geographic areas of need, and the optimum number of MS specialist nurses required to meet this need. There are currently less than 100 MS Specialist Nurses in Australia.

Changed funding streams, mainly due to the loss of government block funding, consequent to the introduction of the NDIS; plus loss of pharmaceutical company funding due to changes in legislation, have led to a significant reduction in the number of MS Nurses funded by MS societies in Australia. Innovative attempts are being introduced to continue services through Nurse Advisor roles using 'telehealth' methods, funded through donations and bequests which does not provide for a certain future.

⁴ United Kingdom Multiple Sclerosis Specialist Nurse Association. *Multiple Sclerosis Specialist Nurses: Adding Value and Delivering Targets*. Stevenage, UK:UKMSSNA: 2006.

⁵ Leary, A., Quinn, D., Bowen, A. *Impact of Proactive Case Management by Multiple Sclerosis Specialist Nurses on Use of Unscheduled Care and Emergency Presentation in Multiple Sclerosis*, International Journal of MS Care, Consortium of Multiple Sclerosis Centers. 2015

The establishment of this pilot project will ensure a career pathway for the MS Nurse specialist is well established and sustainable into the future.

1.4 Funding amount and arrangements in future years

\$1 million: establishing 10 MS Nurse positions plus funding for a project coordinator role

	2017-18	2018-19	2019-20
MS Nurse pilot project cost	\$400k	\$300k	\$300k

- The 10 MS Nurse positions will be established in MS Clinics in geographic areas of need, based on MS population distribution and “hot spot” areas where gaps in service have been identified (such as in Hobart and Canberra).
- Pilot project funding will enable MS specialist training in the nurses first year of employment
- Ongoing funding for each role will come from the health service.
 - MS Clinics that wish to participate in the pilot project will need to guarantee the ongoing funding of an MS Nurse role to qualify to participate. (This will be an attractive offer to MS Clinics, as the first year of salary and training is paid through the pilot project funding.)
 - An important component of the role of the Project coordinator is to negotiate and put in place this arrangement.

1.5 Link to other models of success

An excellent model of success to which this proposal could be compared is the McGrath Breast Care Nurses. These nurses ensure ongoing support for people being treated for breast cancer and their model of operation is very similar to that envisaged for the MS Nurse specialist.

This model of care ensures physical, psychological and emotional support to individuals, their families and carers commencing at diagnosis and continuing throughout treatment.

1.6 Outcomes proposed

Cost savings are potentially enormous through:

- Slowing of disease progression and consequent call on disability support programs including the NDIS
- Increased support for clinical trials of MS treatments and other MS research initiatives; potentially leading to substantial developments in this important area of research plus further economic gains
- Reduced pressure on workload of GPs and Neurologists treating people with MS
- Reduced presentations to accident and emergency departments
- Reduced admissions and length of stay in hospital

1.7 Governance arrangements

Multiple Sclerosis Australia is governed by a 12 member Board of Directors, and has in place all necessary processes and documentation to provide evidence of sound governance practices such as a Strategic Plan, Risk Register and audited financial statements. Multiple Sclerosis Australia, along with our partner MS Research Australia and our state member organisations have an established track record of meeting Australian Government funding guidelines, reporting and risk assessments.

We would be very pleased to provide any additional material in support of this proposal.

CASE STUDY 1

Tasmanian resident ANDREW Potter was diagnosed with MS aged just 23. A year into his marriage, the MS diagnosis came as a shock to both Andrew and his new wife, Jane. Within six months he had lost sensation in the lower half of his body and was confined to a wheelchair.



Why having an MS nurse is important to me

Through hard work and determination, Andrew gradually was able to walk again and regain some control of his body. They had two daughters, Grace and Nicola, and he was starting to manage life with the neurological condition. But eight years later, Andrew's MS worsened at a rapid rate and, at the advice of his neurologist, Andrew then commenced two years of chemotherapy to try and put his MS into remission. The treatment had severe side effects making Andrew unable to work and putting strain on the family's finances. Jane found a job to cover home loan repayments while Andrew became a stay-at-home dad while continuing to deal with the side effects of chemotherapy.

The chemo had limited success and Andrew's MS progressed with ongoing, sporadic double vision, extreme levels of fatigue and an uncontrollable tremor. He also experienced bowel and bladder management challenges, non-specific neurological pain and sensory loss in his hands and parts of his body. New medical treatments available in Australia have assisted Andrew to manage his MS; he regained much improved health and he is able to work part-time.

Andrew said: *"For me, a nurse is vital for now and into the future. Whilst right now I'm very well, my MS brings with it the challenge of looking well when you're not; MS may well strike you at any time and have everlasting repercussions. I can work with my nurse, knowing that their expert knowledge will help me to better manage my symptoms and keep me well; able to stay in work and playing my part as husband and dad."*

Budget request 2: Brain Health Project

2.1 Purpose of funding

Implement the recommendations of the Brain Health Project; a therapeutic strategy with the potential to minimise disease activity and maximise lifelong brain health for those with MS.

The *Brain Health: Time Matters in Multiple Sclerosis* report presents consensus recommendations on diagnosis, therapeutic strategies and improving access to treatment in MS. The core recommendation is that the goal of treating MS should be to preserve tissue in the central nervous system and maximize lifelong brain health by reducing disease activity.

The report was developed by an international multidisciplinary group of experts. It summarizes the evidence and consensus findings from structured discussions with clinicians, researchers, specialist nurses, health economists and patient groups, all with expertise and experience in the area of MS. It presents an expert, evidence-based position for policy recommendations aimed at improving outcomes for people with MS.



A full copy of the *Brain health: Time Matters in Multiple Sclerosis* report is available at www.msbrainhealth.org/report.

This project, managed and overseen by Multiple Sclerosis Australia and Multiple Sclerosis Research Australia, will build on the work of the research team behind the Brain Health project, to systematically address each of the recommendations in the report to support full implementation.

2.2 Period of funding

Three year period from 1 July 2017 to 30 June 2020

2.3 Need for funding

Multiple sclerosis has a profound personal, social and economic impact. Recent years have seen rapid developments in diagnostic criteria, treatment options and monitoring procedures in MS, as well as an improved overall understanding of the disease by medical researchers. Major policy changes are needed, however, to translate these advances into better outcomes for people with MS and those who care for them.

Implementing the Brain Health recommendations will:

1. Enable targeted health policies to minimise delays in the diagnosis of MS and in the time to treatment initiation as these can result in irreversible disability progression (e.g. prompt referral by GPs to neurologists).
2. Encourage healthcare professionals to set goals for treatment and ongoing management that aim for the best possible outcome for every person with MS (e.g. ensure that MS healthcare professionals can take the time to monitor disease activity, agree on and implement standard data collection techniques, protocols and data sets).

3. Encourage healthcare professionals and healthcare providers to consult the most robust evidence base possible, and generate further evidence, to inform decisions creating optimal therapeutic and management strategies for MS (e.g. carry out economic evaluations of therapies and other healthcare interventions from a societal perspective).

2.4 Funding amount and arrangements in future years

\$15 million allocation: support project management and education of healthcare professionals

	2017-18	2018-19	2019-20
Brain Health project implementation	\$5m	\$5m	\$5m

2.5 Outcomes proposed

- Minimise disease activity and maximise brain health thereby reducing the burden on individuals, carers, families and the healthcare system
- Improve the quality of life, health and wellbeing of all people diagnosed with MS
- Minimise overall cost to health, aged care and disability sector, especially to reduce numbers of people with MS needing to access the NDIS and the Disability Support Pension (DSP)
- Improve symptom management leading to improved workforce participation and employment retention of people with MS
- Minimise crisis situations and reduce the burden on hospital emergency departments
- Minimise the number of people admitted to hospitals and aged care facilities

2.6 Links to strategies and priorities of the Medical Research Future Fund (MRFF)

The MRFF released its Innovation Strategy and Innovation Priorities in November, 2016.

The Brain Health Project proposal links directly to a number of the MRFF strategic platforms, namely:

- **Strategic and international horizons** - through the Brain Health Project's globally collaborative and long-term research nature and Australia's ability to provide leadership in MS research
- **Health services and systems** – through the Brain Health Project's suite of proposed policy recommendations to improve MS diagnostic and treatment processes
- **Capacity and collaboration** – through the Brain Health Project's intention to implement recommendations that involve multi-disciplinary teams of health professionals, national bodies, healthcare providers, patient groups and government agencies.
- **Trials and translations** – through implementing the Brain Health Project recommendation to consult the most robust evidence base possible, and generate further evidence to make good decisions about therapeutic and management strategies for MS.

2.7 Governance arrangements

Multiple Sclerosis Australia is governed by a 12 member Board of Directors, and has in place all necessary processes and documentation to provide evidence of sound governance practices such as a Strategic Plan, Risk Register and audited financial statements. Multiple Sclerosis Australia, along with our partner MS Research Australia and our state member organisations have an established track record of meeting Australian Government funding guidelines, reporting and risk assessments.

We would be very pleased to provide any additional material in support of this proposal.

CASE STUDY 2

ASTRID Edwards was diagnosed with relapsing remitting MS at the age of 32. Faced with the uncertainties of life with MS, she started blogging about life with chronic disease. Already engaged in her own healthcare, the Brain Health: Time Matters report means a new approach to treatment of her MS.



What the Brain Health: Time Matters report recommendations mean to me

"I was diagnosed with MS in late 2013. My diagnosis was swift by MS standards – less than a month between the onset of symptoms and the MRI results. I experienced ascending bilateral paresthesia (in other words, numbness and tingling on both sides of my body) that began in my feet and crept up to my abdomen. I thought I was going mad. I couldn't feel my own body properly. After weeks of this, as well as a day in ER and a night in hospital, an MRI indicated MS.

The generalist neurologist put my MRIs up on the wall and pointed to the lesions in my brain. She said I would feel sad about my diagnosis. And then she said she would book me in with another neurologist, and if I was lucky I could see him in a few months. That was it. No treatment for the relapse I had just experienced, not even an information booklet. I was sent home.

I am now a National Advocate for MS Australia, and based on the conversations I have with other people with MS, such an experience is relatively common. There is an assumption, even by practicing neurologists, that there is no short term intervention that can help someone experiencing an MS relapse.

But there is. And the Brain Health: Time Matters report makes this clear. The report recommends that major public policy changes are needed to translate recent advances in the diagnosis and treatment of MS into improved outcomes. The first of these recommendations arrests me each time I read it – it recommends minimising delays in the time to treatment initiation as this can result in irreversible disability progression.

In my case, the system had no intention of minimising my time to treatment, and it thus left me with an increased chance of irreversible disability progression. I remain unsure if the generalist neurologist who diagnosed me even knew there was such an option.

But I was lucky. A medical professional friend took matters into her own hands. Within two weeks she found an MS neurologist in a different hospital and begged him to see me. To his everlasting credit, he took me on and remains my neurologist to this day.

His approach differed from the first hospital, and is an example of the Brain Health: Time Matters report in action. He immediately began treatment for the relapse I was recovering from, and scheduled tests to determine the best management and treatment plan for me.

The first hospital did not treat me, or even mention the possibility of treatment. The second hospital did. It is my hope that all hospitals and neurologists get on board with the Brain Health: Time Matters report. If they do, we can improve long term outcomes for people with MS."

Astrid became a National Advocate for MS Australia in March 2015. She blogs about life with MS at www.LadywithMS.com.

About Multiple Sclerosis Australia

Multiple Sclerosis Australia (MSA) is the national peak body for people living with multiple sclerosis in Australia. Our role is to work alongside our research partner MS Research Australia, on behalf of all state and territory based member organisations, to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration
- Research

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with MS, their carers and the broader MS community.

Our Vision

Is consistent with the vision of the Multiple Sclerosis International Federation – **'A world without MS'**

Our Mission

MSA will support our members and work towards meeting the needs of people with MS, their families and carers. We will facilitate a national comprehensive representation of the Member organisations through advocacy and communication.

Our Purpose

On behalf of our members and people with MS, our purpose is to develop:

- **Research:**
Supporting ongoing research to pursue further knowledge in targeting prevention, improving treatment, enhancing quality of life and ultimately, to find a cure.
- **Advocacy and Awareness:**
Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about change to the lives of people living with MS.
- **Communication and Information:**
Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member organisations and our key stakeholders.
- **Support for our member organisations:**
As MS specialists providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, that addresses their changing needs.
- **International Collaboration:**
Representing the MS cause and promoting collaboration with our domestic and international partners.



17 January 2017

Hon Arthur Sinodinos AO
Minister for Health and Aged Care (Acting)
Minister for Sport
PO Box 6022
House of Representatives
Parliament House
Canberra ACT 2600

(By email to: Minister.sinodinos@health.gov.au)

Dear Minister Sinodinos,

Allocations from the Medical Research Future Fund

As part of the 2017 Federal Budget process, Multiple Sclerosis Australia understands that you will be determining the first allocations from the Medical Research Future Fund (MRFF).

Multiple Sclerosis Australia is seeking an allocation of \$25 million, from the MRFF, to Multiple Sclerosis Research Australia for the purpose of funding areas of research that have the best chance of finding a cure for Multiple Sclerosis (MS) in the near future.

Why is this necessary?

A cure for MS is possible within our lifetime. It is a distinct possibility that it will be this generation of scientists and political leaders who make MS an historical footnote, but this is dependent upon adequate funding being invested in this effort.

That is why the establishment of the \$20 billion MRFF in April 2014, was so publicly welcomed by Multiple Sclerosis Australia. There has undoubtedly been great progress in the fight against MS over the last decade. We anticipate a contribution from this fund would catalyse this momentum and significantly advance ground-breaking research in conditions such as MS.

It is important that any allocation of funding is invested wisely. To this end Multiple Sclerosis Australia, on behalf of Multiple Sclerosis Research Australia, seeks assistance with prioritised funding for a number of peer-reviewed, promising, signature areas of research that will boost the chances of finding a cure.

What will this do?

As proposed, the MRFF will build to a \$20 billion perpetual fund, providing annual disbursements of \$1 billion by 2022-23. The MRFF is intended to have a transformational impact on long-term future health and medical research in Australia and, through this, the efficiency and effectiveness of the Australian health system.

Multiple Sclerosis Research Australia implements an informed and robust scientific agenda to accelerate advances that will prevent, better treat and ultimately cure MS. It focuses on funding research that will increase understanding of the biology driving MS and discovering how to stop the triggering of the disease. It also has a primary aim to investigate how to repair existing damage caused by MS. This is a medium to long-term strategy and it requires extensive funding, collaboration and coordination.



In the short term, Multiple Sclerosis Research Australia funds clinical research that measures the benefits of alternative symptom management approaches. Social research through the Australian MS Longitudinal Study measures the physical, social and economic impact of MS on Australians for advocacy and service development purposes.

The following promising areas of research will significantly boost the chances of finding a cure for MS:

1. Investigating compounds or those research directions, including stem cells, that show promise in the repair of what was once thought to be irreparable damage to the myelin sheath and nerves caused by MS.
2. Strengthening the role Australia now plays in leading the global fight to find a cure for progressive MS – a form of MS normally associated with a higher level of disability, lower quality of life and a comparatively higher health burden on the Australian health system.
3. Boosting the world's largest Vitamin D clinical trial investigating whether Vitamin D may be given to prevent MS. Over 240 patients will be recruited to look at not only the effectiveness of Vitamin D in preventing MS for people who have had a first clinical attack, but also the effective dose needed.
4. Investigating the genetic links between MS and other autoimmune diseases such as Juvenile Diabetes (type 1) to help unlock the mysteries of immunological diseases in general. Breakthroughs will potentially benefit over 145,000 people in Australia and millions worldwide.

Both Multiple Sclerosis Australia and Multiple Sclerosis Research Australia would be very pleased to provide additional information or material to assist with your understanding of these promising areas of research, and we look forward to hearing the outcomes of your deliberations.

Yours sincerely,

A handwritten signature in black ink that reads 'Matthew Miles'.

Dr Matthew Miles
Chief Executive Officer
MS Research Australia

MS Research Australia
Level 19, Northpoint Building
100 Miller Street
North Sydney NSW 2060
T: 8413 7900
Multiple Research Sclerosis Australia
ABN: 34 008 581 431

A handwritten signature in black ink that reads 'Deidre Mackechnie'.

Deidre Mackechnie
Chief Executive Officer
MS Australia

MS Australia
Level 19, Northpoint Building
100 Miller Street
North Sydney NSW 2060
T: 8413 7931
Multiple Sclerosis Australia
ABN 51 008 515 508