



# *A world without MS*

Strategic Plan 2022-2026



### Acknowledgement of Country

MS Australia acknowledges the traditional custodians of country throughout Australia, and their continuing connection to land, sea, and community. We pay our respects to them and their cultures, and to Elders past, present and emerging.

### About MS Australia

MS Australia is Australia's national multiple sclerosis (MS) not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia represents and collaborates with its Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS

### About MS

MS is a condition of the central nervous system, interfering with nerve impulses within the brain, spinal cord, and optic nerves.

In MS, the body's own immune system mistakenly attacks and damages myelin, a fatty material that protects and insulates 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.

There is no known single cause of MS, but many genetic, environmental and behavioural factors contribute to its development. These can include genetics and ethnicity, gender, viral infection, climate and sun exposure, vitamin D, smoking, stress, diet and physical activity and various other factors.

**64%** of people with MS use a disease modifying therapy (DMT), an increase of 40% since 2010



More than **25,600** Australians live with MS

MS affects more *young adults* than any other acquired chronic neurological disease



Nearly **3** million people live with MS worldwide



**3** out of **4** Australians diagnosed with MS are *women*

Average *age of diagnosis* is between **20-40** years old



**\$1.75** billion is the estimated cost of MS to the Australian community in 2017

**1-2** Australians are diagnosed with *MS* every day



## *Strengthening our resolve for research and advocacy*

On behalf of the MS Australia Board, I am delighted to present the MS Australia 'A world without MS: Strategic Plan 2022–2026'.

A single national body now represents Australians living with MS after an extensive review of our governance and operations in 2019 and 2020. The MS Australia Board endorsed an independent expert's recommendation to bring MS Australia and its research subsidiary MS Research Australia together, which heralds a new era for people living with MS. In the shadow of a tough operating market for not-for-profits following a series of major national structural and regulatory reforms, the review identified ways to better meet the current and future needs of people living with MS and the ongoing pursuit for a cure.

The resultant changes mean MS Australia is becoming a more robust and efficient organisation. This has also strengthened our resolve and capacity to advance our research agenda alongside our tireless advocacy for people living with MS. The governance realignment is nearly complete, and with the appointment of Rohan Greenland, MS Australia's new CEO, we are excited about the future. In particular, the implementation of our inaugural Strategic Plan and greater sustainable partnerships with our state and territory Member Organisations, consumers, carers, researchers, institutions, and other stakeholders.

This Strategic Plan has drawn on extensive feedback from people living with MS, their family members, friends and others affected by MS. I am delighted that so many stakeholders trusted us and shared their views. Some 3,000 people responded to our 2021 Research and Advocacy Priorities Survey – an incredible result and quite possibly the largest point in time feedback from the Australian MS community! Many others participated in dynamic focus groups and feedback sessions. We also heard from health professionals, our member organisations, staff and key stakeholders in our networks in Australia and overseas. I am confident that our process has been robust, inclusive and well informed. I want to thank everyone who participated in our strategic planning process.

Significantly, the most important priority identified during the feedback process is for us to supercharge funding for research. It is the pinnacle and aligns with our mission to accelerate research toward the prevention, better treatments and a cure for MS. You will see this priority permeates a large part of our strategic intent.

In closing, I would like to thank all Australians who have directly and indirectly contributed to MS Australia's agenda to advocate for all people living with MS and carers and supercharge our research agenda to find the cure. I look forward to working with each and every one of you, keen to help ensure MS Australia's future success.

**Associate Professor Des Graham**  
President, MS Australia



## *Putting people with MS at the centre of all we do*

I am deeply honoured to have joined MS Australia at such an important time in its development. Its mission is critical to the lives of over 25,600 Australians who are living with MS, to their families and others affected by MS, and to the MS community.

MS Australia has an enviable reputation as an organisation that supports world-class research, provides much needed and practical assistance to people living with MS and advocates with passion for the people it serves.

Our new Strategic Plan looks to a future that builds on that reputation and will help achieve our ultimate goal, a world without MS.

A key feature of our new Strategic Plan is to put people with MS, their families, friends, and others affected by MS at the centre of all we do. The voice of people living with, and affected by MS is central to all our work and to how we think about and prioritise the future of our research and our advocacy work.

Every strategic priority and goal are underpinned by a range of activities, each of which has a timeframe, measure and target. Progress against activities will be reported to the Board at regular intervals. This robust, integrated framework ensures our Board, staff, volunteers, and supporters can link their own contribution to the overall success of MS Australia.

We are now on an unstoppable journey to put MS where it belongs, behind us.

**Rohan Greenland**  
CEO, MS Australia



*Vision*

# A WORLD WITHOUT MS

*Mission*

Our mission is to empower people with MS to live well through:

- Research to treat, prevent and cure MS
- Advocacy to drive change
- Education to improve awareness and outcomes

*Values*

Our values are at the heart of how we work.

<b>Collaborative</b> We are stronger together, able to accomplish more in partnership	<b>Dynamic</b> We are agile, positive and responsive, allowing us to efficiently achieve our purpose	<b>Consumer-centred</b> We put people with MS and those affected by MS at the centre of all we do
<b>Trusted</b> We conduct ourselves with integrity, respect, reliability and fairness	<b>Evidence-based</b> Our work is underpinned by robust evidence and expertise	

*Strategic priorities and goals*

Our strategic priorities and goals are grouped under five pillars:

<b>Research</b> <ul style="list-style-type: none"> <li>• Fund the best research to find cures for MS, prevention &amp; better treatments</li> <li>• Fund the best research to manage MS &amp; improve quality of life for people living with MS</li> <li>• Facilitate translation &amp; implementation of research outcomes</li> <li>• Build the capacity of the research workforce</li> <li>• Collaborate with partners nationally &amp; globally to maximise outcomes</li> </ul>	<b>Advocacy</b> <ul style="list-style-type: none"> <li>• Supercharge funding for MS research</li> <li>• Improve the quality of life for people with MS, their carers &amp; others affected by MS through every stage of the MS journey</li> <li>• Boost access to health services &amp; trusted information</li> </ul>	<b>People living with MS, their carers, friends &amp; family</b> <ul style="list-style-type: none"> <li>• Develop a foundation Roadmap for collaboration with the MS community</li> <li>• Enhance our advocacy agenda through evidence from people with MS &amp; those affected by MS</li> <li>• Embed engagement and participation by people with MS, their carers &amp; those affected by MS</li> <li>• Ensure the MS community has a strong voice into governance, research, policy &amp; advocacy, education &amp; awareness</li> </ul>
<b>Governance &amp; Operations</b> <ul style="list-style-type: none"> <li>• Continuously improve the organisations financial model</li> <li>• Strengthen the research program's governance</li> <li>• Strengthen organisational governance</li> <li>• Enhance coordination &amp; communication with our Member Organisations</li> </ul>	<b>Education &amp; Awareness</b> <ul style="list-style-type: none"> <li>• Be the leading, trusted provider of MS information</li> <li>• Strengthen collaboration with partners</li> <li>• Strengthen education &amp; awareness programs</li> <li>• Ensure the MS community has a voice in education &amp; awareness activities</li> </ul>	



## Research



<i>Strategic Priorities</i>	<i>Goals</i>
<b>Fund the best research to find cures for MS, prevention and better treatments</b>	Fund innovative, high-quality research according to the research priorities identified by our community
	Fund research building on our strengths, avoiding duplication and encouraging collaboration
	Facilitate national collaborative research platforms according to the research priorities identified by our community
	Fund research through our rigorous, expert reviewed funding assessment model
<b>Fund the best research to manage MS and improve quality of life for people living with MS</b>	Fund innovative research to improve management strategies for MS
	Fund research into the management of MS, building on our strengths, avoiding duplication and encouraging collaboration
	Facilitate national collaborative research platforms to improve management strategies for MS
	Fund research through our rigorous, expert reviewed assessment model
<b>Facilitate translation and implementation of research outcomes</b>	Facilitate translation and implementation of research findings into the community
	Partner with other organisations to translate research with respect to clinical and informal care
	Partner with Member Organisations to create awareness and implementation of research outcomes
<b>Build the capacity of the research workforce</b>	Support the development of the research profession and workforce through an annual conference
	Fund scholarships and fellowships to support researchers at all career stages
	Fund innovative collaborative opportunities for clinicians, researchers and people with MS to work together
<b>Collaborate with partners nationally and globally to maximise outcomes</b>	Collaborate with aligned research organisations in relevant immunological and neurological conditions
	Collaborate with the international community on priorities for MS research to accelerate outcomes
	Clearly define our international role to maximise the value of our partnerships

## Advocacy



<i>Strategic Priorities</i>	<i>Goals</i>
<b>Supercharge funding for MS research</b>	Advocate for increased funding of research that aligns to the research priorities of the MS community
	Advocate for increased funding of research to improve management of MS and quality of life for people living with MS
	Advocate for increased funding for the translation and implementation of research findings into the community
	Advocate for increased funding for MS researchers in Australia to build capacity for MS research
	Partner with aligned research organisations investigating other relevant neurological and immunological conditions
	Partner with global MS research alliances to maximise outcomes
<b>Improve the quality of life for people with MS, their carers, family and friends through every stage of the MS journey</b>	Improve access to National Disability Insurance Scheme (NDIS) and optimise NDIS packages
	Improve support and services for all people with MS
	Advocate for improved access to aged care services for people living with MS
	Improve residential support options for young people with high care needs
	Challenge stigma in the workplace
	Strengthen our relationship with the Neurological Alliance Australia
<b>Boost access to health services and trusted information</b>	Strengthen our relationships and alignment with allies and partners to progress advocacy goals
	Enhance our well-established National Advocates program
	Improve access to specialist MS neurologists, MS nurses and relevant allied health professionals including in rural and remote areas
	Develop and implement models of care to facilitate speedy diagnosis, access to an expanded range of treatments and ongoing management of MS
	Ensure people with MS and their healthcare team are informed about MS treatments, management and care, including through the appointment of an MS Australia Chief Neurologist

## People living with MS, their carers, friends and family



Strategic Priorities	Goals
<b>Develop a foundation roadmap for collaboration with the MS community</b>	Collaborate closely with Member Organisations on issues relevant to people with MS, carers, family and friends
	Ensure policy positions recognise the diversity of needs and aspirations of all people with MS
	Partner with other organisations with common interests including peak consumer and carer bodies
<b>Enhance our advocacy agenda through evidence from people with MS and those affected by MS</b>	Recognise that people with MS and those affected by MS have unique experiences and separate needs that are captured through a robust evidence base
	Ensure our advocacy agenda is informed by our consumer and carer community
<b>Embed people with MS, their carers, family and friends within the organisation</b>	Ensure people with MS, carers, family and friends are embedded in the organisation
	Adopt a set of principles to underpin an effective participation model
	Ensure a flexible, safe, respectful and adaptive workplace, that is easily accessible and responsive to the needs of stakeholders
<b>Ensure the MS community has a strong voice into governance, research, policy and advocacy, education and awareness</b>	Establish a panel of people with MS, carers, family and friends to provide guidance on research, policy and advocacy
	Adopt a process for dissemination of information to inform consumers and carers how their participation influences governance, research, policy and advocacy

## Governance and operations



Strategic Priorities	Goals
<b>Continuously improve the organisations financial model</b>	Implement a leaner financial model
	Align the investment structure to the Board's risk appetite
<b>Strengthen the research program's governance</b>	Ensure that the Research Management Council's Governance framework is one of continuous quality improvement
	Support the research agenda by providing financial reporting that furthers the quality of the research reporting
<b>Strengthen organisational governance</b>	Implement a framework that continuously reviews and strengthens the effectiveness of the organisation's governance, including annual reviews of the Board and Directors performances.
	Develop and embed a people and culture framework that embodies the mission, vision and values of the organisation

## Governance and operations

	Foster a working environment of diversity, inclusion, flexibility and wellbeing
	Work towards MS Australia becoming a gold standard employer for people with MS and other neurological or autoimmune conditions
<b>Enhance coordination and communication with our Member Organisations</b>	Integrate fundraising activities with our Member Organisations
	Strengthen the framework supporting financial arrangements to continuously seek more efficient processes and outcomes
	Develop opportunities to integrate, share and build on infrastructure and resources

## Education and awareness



Strategic Priorities	Goals
<b>Be the leading, trusted provider of MS information</b>	Clearly present MS information and education, research updates and advocacy information that are accessible and relevant to the entire MS community
	Grow our position as the leading, trusted source of MS information and education
	Enhance communication channels with all our stakeholders
<b>Strengthen collaboration with partners</b>	Collaborate with Member Organisations, international alliances and local partners to develop streamlined and consistent information and campaigns
	Collaborate with like-minded partners to increase reach and engagement with the MS community
	Collaborate with aligned immunological and neurological organisations to present information that is accessible and relevant to the community
<b>Strengthen education and awareness programs</b>	Develop educational and awareness-raising programs and material that provides information, tools and resources for the MS community
	Utilise the most relevant digital communications channels to ensure accessibility and inclusion for all people with MS, carers, family and friends
	Provide information and resources to assist people with MS, their carers, family and friends to monitor and manage their health and wellbeing including a focus on mental health
<b>Ensure the MS community has a voice in education and awareness activities</b>	Consult with people with MS, their carers, family and friends as active participants in education and awareness programs
	Involve people with MS, their carers and others affected by MS as active participants in education and awareness programs
	Ensure education and awareness programs are representative and inclusive of the MS community



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