



MND Australia Strategic Plan 2015 – 2018

Who are we?

MND Australia is the national peak organisation representing all across Australia who share the vision of a world without motor neurone disease. We work collaboratively with our member organisations, the state MND Associations, to influence policies and services at a national level and to advance research to ultimately end MND.

Our Vision

A world without motor neurone disease (MND)

Our Mission

To promote, influence and advance MND care and research to improve the lives of all Australians impacted by motor neurone disease.

Strategic Plan Objectives

As a national peak body, MND Australia:

- with our member organisations, promotes the delivery of equitable, quality services and support for people living with MND in Australia, their families and carers
- encourages and supports MND research that will identify causes and lead to better care, effective treatments, and ultimately a cure for MND
- supports inclusive relationships with our member organisations
- represents the interests of the MND community and our member organisations at the national level
- lobbies for excellence in all services provided for people affected by MND
- increases awareness of the issues facing people living with MND by coordinating the dissemination of information on MND and advocating with the Federal Government and the media
- creates reciprocal supportive and informative links with research organisations
- builds strategic alliances with other national and international bodies with aligned goals.

Values

MND Australia is committed to the following values:

- we act responsibly, maintain professional integrity and respect of the individual, and engage and collaborate with our members, our partners, researchers and the broader community, and
- we encourage and support innovation and research that improves opportunity and quality of outcomes for people living with MND.



Strategic Priorities 2015 to 2018

1. Review our governance, structure and policies to better support our member organisations
2. Influence government and other bodies to support the interests of people living with MND nationally
3. Promote, support and fund the best MND research that has the greatest chance of providing benefit for people living with motor neurone disease
4. Support State MND Associations in context of the National Disability Insurance Scheme to ensure the best outcomes for all people living with motor neurone disease across Australia
5. Promote community awareness and understanding of motor neurone disease and the State MND Associations
6. Advocate for consistent access to quality needs-based services and support for all people living with motor neurone disease in Australia
7. Ensure a more financially independent and sustainable national peak organisation
8. Liaise with international organisations, bodies and associations aligned to the MND Australia Objectives.

Priority 1:

Review our governance, structure and policies to better support our member organisations

We will:

- Carry out a review of the corporate and governance structure of MND Australia and make recommendations to the Board for implementation in 2015
- represent the views of our member organisations in our national advocacy and influencing work
- develop standards, processes and structures that facilitate greater support, integration and consistency across our member organisations
- develop and maintain effective processes and information flows to facilitate effective participation and engagement by member organisations and the broader community
- develop a directory of member services to be shared across member organisations
- maintain an effective and representative peak body through a well-managed, sustainable and accountable organisation.



Priority 2:

Influence government and other bodies to support the interests of people living with MND nationally

We will:

- influence government in policy development including meet and engage with relevant Federal Ministers and/or advisors and government departments and agencies, and contribute to Government inquiries
- promote awareness and recognition of the role and services provided by State MND Associations and their impact on the lives of people living with motor neurone disease
- develop and maintain effective partnerships, collaborations and strategic alliances including but not limited to the Neurological Alliance Australia, Coalition for the Advancement of Medical Research Australia, Palliative Care Australia
- lead national advocacy in collaboration with members and partners through developing national policies and position statements.

Priority 3:

Promote, support and fund the best MND research that has the greatest chance of providing benefit for people living with motor neurone disease

We will:

- encourage and support quality scientific, clinical, and social research
- support other research that benefits State Associations, service delivery and people living with motor neurone disease
- encourage national and international research collaborations
- optimise investment in research
 - together with State MND Associations, aim to grow donations to the MND Research Institute of Australia (MNDRIA) to \$4 million per annum by 2018
 - maintain donor engagement through bi-annual research appeals and newsletters to donors and subscribers
 - maintain optimal research governance
 - communicate research activities through plain language research updates circulated to members, community opinion leaders and media outlets; web-based research news updates; research case studies to demonstrate value of



MNDRIA seed funding; Research Australia; Annual scientific meeting

- support the further development of the Australian Motor Neurone Disease Registry and the MND Tissue Bank.

Priority 4: Support State MND Associations in context of the National Disability Insurance Scheme to ensure the best outcomes for all people living with motor neurone disease across Australia

We will:

- influence government and the National Disability Insurance Agency to ensure that the unique needs of people living with motor neurone disease are understood and met consistently across Australia
- continue influencing government for a national equitable approach to people aged 65 years and over living with motor neurone disease
- with the State MND Associations, advocate for appropriate levels of funding with the National Disability Insurance Scheme (NDIS) and development and implementation of NDIS Tier 2 service models and funding
- advocate for funding national NDIS-related projects that will benefit State MND Associations and the people they support.

Priority 5: Promote community awareness and understanding of motor neurone disease and the State MND Associations

We will:

- work with our member organisations to encourage and support a collaborative approach to setting shared communication goals and expectations
- provide national leadership by developing and implementing nationally consistent communication campaigns around community awareness and understanding of services provided by State MND Associations and of the needs of people living with motor neurone disease among key stakeholders
- work with our member organisations to produce joint communication campaigns with a national focus that aim to heighten the awareness of MND while maintaining member organisations' autonomy in communication and branding
- work towards building a stronger brand identity by using consistent key messages that highlight MND Australia's value proposition and standing as the national voice representing State MND Associations and people living with motor neurone disease in Australia



- lead and encourage collaboration with our member organisations to develop and support jointly beneficial national public relations and communication campaigns
- encourage, resource and support State MND Associations together with the national organisation to more effectively use social media to engage with their communities, particularly younger people, and online networking and fundraising communities.

Priority 6:

Advocate for consistent access to quality needs-based services and support for all people living with motor neurone disease in Australia

We will:

- coordinate the further development of shared MND information resources including web based and print
- disseminate quality evidence-based and best practice information through relevant media
- develop and promote national MND care pathways/models of care in collaboration with members and partners
- work with our member associations to respond strategically to the changes in NDIS and aged and health care
- work with our member associations to assist them in achieving equitable quality services for people living with motor neurone disease in Australia
- promote coordinated expert interdisciplinary care and advocate to support and further develop the network of multidisciplinary MND clinics across Australia and explore options for funding the clinic network
- promote national and international collaborations and partnerships through the MND Australia Travel Grant and other opportunities.

Priority 7:

Ensure a more financially independent and sustainable national peak organisation

We will:

- enhance giving opportunities without compromising the fund raising activities of the State MND Associations
- access Federal Government funding for identified programs



- develop national corporate relationships and partnerships without compromising the relationship building initiatives of State MND Associations
- support member organisations through national fundraising opportunities.

Priority 8:

Liaise with international organisations, bodies and associations aligned to the MND Australia Objectives

We will:

- engage with and support the International Alliance of ALS/MND Associations
- as an International Alliance member, actively contribute to the development of the Alliance and its programs
- provide timely updates to State MND Associations on trends in international ALS/MND association promotion, fundraising, services, marketing and information to improve their service delivery and outcomes in Australia
- develop collaborations with international partners and networks in the Asia and Pacific region through the Asia-Pacific network meetings and other opportunities.