

**Motor Neurone Disease Association of
Australia**

Strategic Plan 2006 – 2011

“A world free from the impact of MND”

November 2006





MND Australia, in its Strategic Plan provides the framework for endeavours over the next five years to ultimately enhance the quality of life for people living with MND.

- MND Australia's vision of "A world free from the impact of MND" is set in a time when there is no known cause, no cure and only interventions with limited effect. Current statistics show that every day more than one Australian dies of MND and a new person is diagnosed with this progressive and inevitably fatal disease.
- Our interim Goal is that "within 10 years, no person diagnosed with MND will experience high levels of unmet need"
- In outlining the five key objectives to be focussed on from 2006 to 2011, the plan will be the basis for prioritising actions and allocating costings, incorporated in the Business Plan.
- MND Australia actively seeks personal and financial support from the wider community to meet these objectives.
- The plan has been developed as a consultative process involving widespread discussion with members from all states via the delegates and with reference to similarly aligned organisations.

Current members are the State Associations for New South Wales, Queensland, South Australia, Tasmania, Victoria, Western Australia, and the ACT. Delegates are appointed by member associations to sit on the National Board. The executive officers are voted by the National Board Members. A National Executive Director was appointed in February, 2006.

The National freecall number is 1800 777 175. Calls to this number will divert to the state of origin of the call.

Associate Members are MNDA New Zealand, the Motor Neurone Disease Research Institute. MND Australia is also a member of the International Alliance of ALS/MND Associations and celebrates Global Awareness Day with countries around the world on June 21st.

Helen Sjardin – Howard, President MND
Australia



VISION:

“A world free from the impact of MND”

GOAL:

Within 10 years no person diagnosed with MND will experience high levels of unmet need.

PURPOSE:

By providing a national peak body for MND in Australia, MND Australia is committed to:-

- Lobby for excellence in all services provided to all people affected by MND
- Facilitate and coordinate dissemination of information
- Create reciprocal supportive and informative links with research organisations.
- Ensure increased awareness of the issues facing people living with MND
- Enhance the quality of life for people living with MND

VALUES:

- Our service is to people living with MND, above all else
- We can expect effective communication, openness, trust and respect of the individual and expect a fair hearing within our Association
- We support, encourage and value innovation that improves opportunity and quality of outcomes



OBJECTIVES:

As the National Authority on MND, MND Australia is committed to:-

1. Gain recognition as an effective PEAK body for MND in Australia
2. Inform policy that impacts on people living with MND nationally and internationally
3. Raise awareness of the issues faced by people living with MND
4. Attract funding at a national level to achieve our mission
5. Encourage and support research into MND

Strategy	Performance measure	Who	Due
1.3 Maintain a productive and supportive relationship with members and stakeholders	<ul style="list-style-type: none"> An effective and resilient communication process and procedures between MND Australia and the State Associations is established and maintained to minimise cost, duplication and misunderstandings 	NED/EMG/Board	Ongoing
	<ul style="list-style-type: none"> Support provided by MND Australia to State and Territory MND Associations if applicable to effect change and to promote equitable service provision 	NED/Board	Ongoing
1.4 Comply with all relevant laws and contracts	<ul style="list-style-type: none"> All relevant statutory and legal responsibilities are met in a timely fashion including ATO reporting 	NED/Treasurer	Ongoing
	<ul style="list-style-type: none"> All relevant contractual responsibilities are met in a timely fashion 	NED/Executive	Ongoing
	<ul style="list-style-type: none"> Policies and Procedures in place 	NED	April 2007
1.5 Maintain an organisational structure, finance and staffing that allow for effective achievement of mission	<ul style="list-style-type: none"> State Association funding to maintain the National Peak Body agreed and maintained by all State Associations 	State Associations	Ongoing
	<ul style="list-style-type: none"> Communication and collaboration maintained with other MND Associations, MNDRIA, International Alliance etc and required knowledge maintained 	NED/Board	Ongoing
	<ul style="list-style-type: none"> Orientation program/information package for new staff and board members reviewed and distributed as required 	NED	April 2007

Objective 2: Inform policy that impacts on people living with MND nationally and internationally

Background: There is a requirement to be informed on policy and current MND issues by establishing and maintaining effective links with government, non government organisations (NGOs) and MND Associations nationally and internationally.

Strategy	Performance measure	Who	Due
2.1 Review national policy that impacts on people living with MND	<ul style="list-style-type: none"> Understanding of current relevant national policy and issues 	NED	Ongoing
	<ul style="list-style-type: none"> Links made with relevant government departments/portfolios 	NED	Ongoing
	<ul style="list-style-type: none"> Links with other NGO's with related concerns 	NED	2007 onwards
2.2 Develop and disseminate policy responses in priority areas	<ul style="list-style-type: none"> Standard top and tail submission completed 	NED	April 2007
	<ul style="list-style-type: none"> Relevant MND Australia policies and procedures complied with 	NED	Ongoing
2.3 Gain representation on key advisory groups	<ul style="list-style-type: none"> Review of key advisory bodies undertaken 	NED	October 2007
	<ul style="list-style-type: none"> Relevant representation established 	NED	2008 onwards

<p>2.4 Actively contribute to International MND organisations to inform policy development</p>	<ul style="list-style-type: none"> • Membership and contact maintained with International Alliance • Symposium attended annually • Other relevant international organisations visited, reciprocal visits offered and information exchanged 	<p>NED</p> <p>NED</p> <p>NED</p>	<p>2006 onwards</p> <p>Dec 2007 onwards</p> <p>As the opportunity arises</p>
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Objective 3: Raise awareness of the issues faced by people living with MND

Background: To increase awareness of MND and MND Australia as a peak body for MND in Australia there is a requirement to enhance awareness within the community, media, charity, corporate and government sectors. The objective is to advocate on behalf of people with MND, their families and their carers to ensure equal access to the best possible care and support.

Strategy	Performance measure	Who	Due
3.1 Deliver a sustainable program of awareness and ongoing support of MND Australia in corporate and government sectors	<ul style="list-style-type: none"> • Marketing strategy developed • Partnerships established with National Corporate and Government organisations 	NED	June 2007 June 2007 onwards
3.2 Review and enhance a coordinated communications strategy	<ul style="list-style-type: none"> • Media strategy developed • List and contact made with valuable media outlets • Media releases developed and distributed in a professional and timely manner 	NED/PR consultants NED NED	Nov 2006 onwards As applicable
3.3 Establish a national corporate image for MND Australia as the peak body for MND in Australia	<ul style="list-style-type: none"> • Logo is utilised in all communications and at all levels 	NED/Board	Ongoing

Strategy	Performance measure	Who	Due
3.4 Identify and inform best practice/standards of care related to people with MND, carers and health and community care providers	<ul style="list-style-type: none"> • Best practice/standards of care prepared by EMG • Funding obtained to support implementation of minimal standards of care across Australia • National MND Conference held annually and promoted nationally and internationally • Opportunities for funding to support National MND Conference explored • Informed on evidence based best practice nationally and internationally across all disciplines related to MND 	EMG NED States NED NED	Dec 2006 Dec 2007 June 2007,8,9,10,11 Ongoing Ongoing
3.5 Enhance and support penetration of MND Week activities	<ul style="list-style-type: none"> • MND Week activities identified via EMG • Progress Call to Action Nationally 	EMG EMG	Ongoing annually

Objective 4: **Attract funding at a national level to achieve our goal**

Background: To attract funding at a national level to achieve our goal that within 10 years no person with MND will experience high levels of unmet needs there is a requirement to identify needs, relevant projects and sponsorship opportunities and to develop a professional marketing strategy.

Strategy	Performance measure	Who	Due
4.1 Identify needs, relevant projects and funding targets (Feasibility Study by Keogh on Funding options July 2005)	<ul style="list-style-type: none"> • Understanding of current MND State and Territory Association issues and service provision • Needs assessed • Projects identified • Proposals written • Marketing package prepared 	NED	Ongoing May 2007 June 2007 June 2007
4.2 Identify potential partners/sponsors/funders with aligned values and objectives	<ul style="list-style-type: none"> • analysis of priority, risk, likelihood, cost v benefit target undertaken • opportunities in Federal Government, corporations, charities identified • Annual MND Australia joint fundraiser with State associations 	NED NED/MNDANSW	April 2007 Ongoing Nov 2006
4.3 Build and maintain sponsorship/partnership/funding with relevant organisations that complement state activities	<ul style="list-style-type: none"> • Relationship with Sanofi- Aventis pursued • Funding received 	NED	Nov 2006 onwards

Objective 5: Encourage and support research into MND

Background: To encourage research into MND the MND Australia relationship with MNDRIA and other research bodies should be strong and supportive. It is vital that information related to MND research is disseminated widely and all opportunities for funding explored.

Strategy	Performance measure	Who	Due
5.1 Support scientific research of the highest quality	<ul style="list-style-type: none"> • Interaction/relationship with MNDRIA maintained and developed • MND Australia membership of MNDRIA actively maintained • Research policy reviewed annually and disseminated as required • MND Australia links with research bodies maintained/established 	<p>NED/MNDRIA</p> <p>Ned/Boards</p> <p>Ned/Board</p>	<p>Ongoing</p> <p>Ongoing</p>
5.2 Support and promote healthcare research	<ul style="list-style-type: none"> • Promote applications to MNDRIA for healthcare research grants 		

<p>5.3 Promote awareness, communication and collaboration across the broad scope of research</p>	<ul style="list-style-type: none"> • Hosting of International Symposium • Plain English research documents which can be attributed to MND Australia developed • Review Ask the Experts and Newly diagnosed kits – initiated with Sanofi Aventis • Information distributed to delegates and member Associations in a timely manner • Nina Buscombe Award (MNDA Vic) promoted to support attendance at conferences or study tours to enhance the quality of life of people living with MND • MND Australia Travel and study grant for MNDA Staff initiated and established 		
<p>5.4 Promote national funding for MND research.</p>	<ul style="list-style-type: none"> • Number of sources of funding identified • Submission prepared in consultation with MNDRIA • Contacts made with relevant government departments • Information/liaison assistance provided to possible recipients of funds. 		

