

In 2014 MND Australia will ...

- **Lobby** the Federal Government to influence palliative, aged and disability sectors to ensure needs based care for people diagnosed with MND
- **Raise awareness** of MND nationally and internationally through promotional campaigns during MND Week and MND Global Day
- Through the MND Research Institute of Australia, **provide \$2 million** to support the best MND research
- Hold the national MND conference to **educate** the professional MND community and promote optimal quality of life of people with MND
- Further **develop** national information resources to support people with MND to live better for longer



**To contact your state MND association
freecall: 1800 777 175**

Phone: +61 2 9816 5322
Email: info@mndaust.asn.au
Web: www.mndaust.asn.au

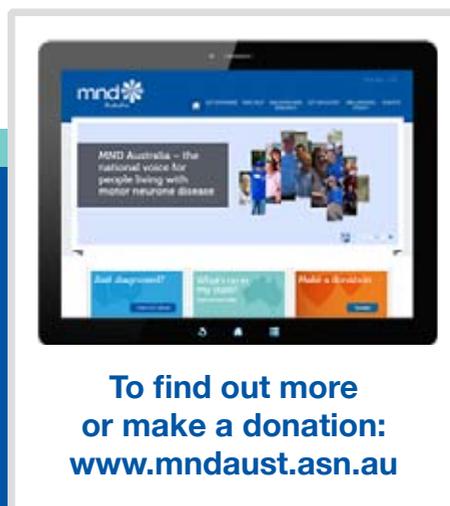
Stay up to date, subscribe to our newsletter

PO Box 990
Gladesville NSW 1675
AUSTRALIA

 /mndaustralia

 /mndaustralia

ABN 52 650 269 176



**To find out more
or make a donation:
www.mndaust.asn.au**

"MND Australia will continue to provide national leadership in defending the rights of all Australians with MND, maintain significant funding for the best research and keep the voice of the MND community strong."

**Carol Birks
National Executive Director**



Highlights 2012 - 2013



**Promoting motor neurone disease (MND)
care and research with a vision to
achieving a world free from MND.**

www.mndaust.asn.au

Thanks to generous gifts from our donors ...

During 2012–13, MND Australia in collaboration with state MND association members played an authoritative role in **promoting MND care and research to improve the lives of all Australians impacted by MND.**



- Advocated for the rights of all Australians with MND at a Roundtable on the interface between the National Disability Insurance Scheme and the aged care sector



- Adopted the five rights of people with MND petition that to date has the support of over 800 people



- 6th National MND Conference attended by 180 health professionals



- New MND Australia website



- MND Week and MND Global Day campaigns generated a flurry of social media activity assisting to raise awareness of MND



- Record \$2,014,000 awarded by MND Research Institute of Australia to grant recipients



- 22 new grants funding the best MND research in Australia



- Inaugural MND Australia Leadership Grant awarded to Associate Professor Ian Blair

As the national peak advocate for people living with motor neurone disease, MND Australia ...

Provides **trusted information**

The 6th National MND Conference was hosted by MND South Australia and attended by 180 health and community professionals from across Australia and New Zealand. Feedback from delegates indicated that the conference provided valuable information that they will use in practice to better care for people with MND.

Good quality information is vital to empowering people with MND to make decisions to help them live better for longer. By rethinking, redesigning and rewriting the MND Australia website we have assisted people in finding the information they need faster and more easily.

Raises **awareness**

MND Australia has used social media to connect with new audiences, particularly people aged 45 and under. The number of MND Australia Facebook fans has quadrupled in the last twelve months.

To mark MND Global Day, MND Australia launched the five rights petition in collaboration with the International Alliance of ALS/MND Associations. The online campaign encourages people to sign the petition to show their support for the rights of people living with MND to access appropriate and timely care. To date over 800 people have signed the petition.

Influences **policy**

In March 2013, the National Disability Insurance Scheme (NDIS) Bill was passed through Parliament. MND Australia played an authoritative role in championing the rights of all Australians living with MND by presenting feedback and submissions in response to the NDIS Scheme Bill 2012. The task is now to ensure that people diagnosed with MND when over the pension age are not disadvantaged compared with NDIS participants.

Promotes and funds the **best research**

The Motor Neurone Disease Research Institute of Australia (MNDRIA) funds more MND-related projects than any other organisation in Australia. Thanks to our donors, in 2013 a record \$2,014,000 was awarded to 22 top MND researchers from across the nation.

In addition, the inaugural MND Australia Leadership Grant (\$600,000 over four years) was awarded to Associate Professor Ian Blair to build a skilled team of MND researchers at Macquarie University's Australian School of Advanced Medicine. The Grant will provide the impetus to further research newly discovered MND genes and investigate how defects in these genes lead to the death of motor neurones.



MND in Australia:

- MND is a progressive, terminal neurological disease with no known cure or effective treatment
- Each day in Australia two people die from MND
- Each day in Australia two people are diagnosed with MND
- Average life expectancy is 27 months
- An estimated 1,900 people have MND in Australia

Find the full Annual Review: www.mndaust.asn.au/AnnualReview2012-13

"MND Australia continues to advocate for recognition of the special needs of MND carers, both through support from the NDIS and otherwise, for it is through the carers that much of the dignity and hope of people living with MND is given voice."



Ralph Warren
President

"The generosity of bequestors and donors has allowed MNDRIA to become the major force in driving MND research in Australia."



Janet Nash
Executive Officer Research