



A message from the CEO

At MND NSW, we strive daily for progress. Progress towards a cure, certainly. But also progress in educating health care providers and the wider community about the challenges facing our members; progress in effecting legislative changes to help meet our members' needs; progress in the breadth of services we, ourselves, can offer; and progress in improving the quality of those services.

Sometimes such progress comes in leaps and bounds. Take our Walks to d'Feet, for example. Our very first Walk was organised in 2007, at Sydney Olympic Park. Two hundred and ninety one registrants participated—including 26 dogs. In the past twelve months, we've seen six Walks to d'Feet, including new events at Hunter and Illawarra, with 1951 members, family, friends and dogs walking together to support people with MND and defeat motor neurone disease, raising a total of \$162,168.

At other times, progress is slow and painstaking. It's a matter of determination: putting one foot in front of the other and being committed to conquering the mountain in small steps. Such has been our struggle to ensure disability coverage for all Australians, beginning with advocacy from the very inception of the National Disability Insurance Scheme (NDIS) to sustained voter mobilisation. The July 2013 announcement of DisabilityCare Australia is a big step in the right direction, but it excludes many of our members. Although it's progress, it only renews our commitment to ensuring that this coverage is expanded to include all our members regardless of age, or age at diagnosis.

So it's with pride that I share with you the gains we've made in 2013. Have we achieved all our goals? No. But we've made progress. And the steps that we've taken in this past year will bear fruit in the years to come, as we continue stepping forward.

Graham Opie
Chief Executive Officer

Walking the talk

The past 12 months has seen six great Walks to d'Feet MND, including inaugural events in two new locations: Illawarra and Hunter. These events raised a total of 162,168 much-needed dollars to support MND NSW and provided the opportunity for hundreds of people to happily 'walk the talk' and show their commitment to improving the future for our members. But these events were much more than great fundraisers.

Each Walk to d'Feet MND gave MND NSW members, family, friends and staff the chance to come together as a community. The walks were uplifting occasions of hope and solidarity, and raised greater awareness of MND among the general public.

Since the first Walk in 2007, the appeal of the Walks to d'Feet MND has just kept growing. We have learnt that local coordinators make all the difference to an event's success, so if you're interested in helping out in 2014, please us know. We've also learnt how to benefit from social media, specifically by encouraging participants to create and promote pages at Everyday Hero which could be accessed through mndnsw.asn.au

The effectiveness of this way of seeking sponsorship was especially notable for the Sydney Walk to d'Feet MND, where \$39,089 of the record \$50,661 raised—77%—was contributed through Everyday Hero.

So, expect to see more Walks to d'Feet MND in the coming year. These successful, vibrant, and just-plain-old-fun events have earned their place on the MND NSW calendar.



2012-13 Walks to d'Feet MND and new locations confirmed for 2013-14.

Port Macquarie
Sydney
Illawarra
Canberra
Hunter
Tweed-
Coolangatta
Wagga
Dubbo
Central Coast

Other community fundraisers

Although we're justifiably proud of the success of Walks to d'Feet MND, most of our community funding comes from ad-hoc events devised, organised and coordinated by our members and their family and friends. Without this generous—and often creative—community support, we would not be able to accomplish as much as we do. In the 12 months to 30 June 2013, community fundraising contributed \$347,883.25 to support people with MND. Thank you to everyone who inspired, organised, donated or participated!



Big leap or small bound?

Members, family, and friends who wrote to their local members of parliament about the National Disability Insurance Scheme, went to speak to them in person, or signed up to make themselves heard through Every Australian Counts, have finally seen tangible results of their action: on 1 July 2013 the long-awaited National Disability Insurance Scheme was formally launched as DisabilityCare Australia.

At first blush, the passing of the National Disability Insurance Scheme Act 2013, under which DisabilityCare Australia operates, was a huge leap forward. Certainly for all of us at MND NSW who have been working to see this come to pass, it was a longed-for victory. However, we are very aware that for many of our members, this first step will be too small or come too late.

In NSW, the roll out began in July this year in the Hunter local government area of Newcastle. The roll out continues across NSW on a schedule that will only see completion in July 2018. In ACT, the DisabilityCare roll out is not scheduled to begin until July 2014 and should be completed by July 2016.

Furthermore, DisabilityCare coverage for people with MND is restricted to members who were diagnosed before the age of 65 and are younger than 65 at the time that DisabilityCare commences in their area.

For our older members, or those living in areas that will only see coverage at the end of the roll out period, what should have been welcome news might have been, instead, a disappointment. But we would like to encourage all members to see this as a step in the right direction—and to keep up their spirits and their efforts. Continue speaking to your members of parliament, and rest assured that we will work to ensure that DisabilityCare is extended to include all Australians in need, regardless of age or age at diagnosis.

To find out more about DisabilityCare, including when it will reach your area, visit www.disabilitycareaustralia.gov.au

Letting their fingers do the walking

While on the topic of website downloads, our usefulness is rewardingly easy to track when our members let their fingers do the walking and come to us online. Here are some cumulative downloads to date of different informational resources we provide for our members—information we're pleased to see they and their communities find useful!

Downloads

• Motor Neurone Disease Some Facts	3941
• Motor Neurone Disease More Facts	2441
• Talking About Motor Neurone Disease For Friends	926
• Talking About Motor Neurone Disease For 8 To 12 Year Olds	705
• Talking About Motor Neurone Disease For Teens	686
• Talking About Motor Neurone Disease For Parents	680
• Talking About Motor Neurone Disease For Schools	627

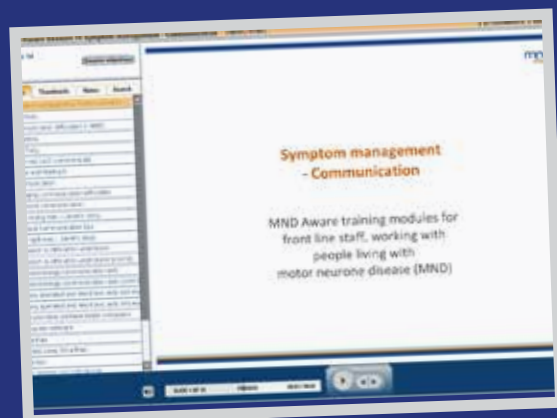
Leaping ahead: MND Aware

A key plank in our strategy to improve the outlook for our members is to educate health and community care professionals about motor neurone disease. To that end, we have developed training for health and community care professionals with funding from NSW Government Family and Community Services which gives care providers an overview of the disease, as well as specific information about proper care, symptom management and wellbeing, and the support needs of a person with MND.

In the 2012-2013 financial year, through face-to-face events such as regional health and community care professional trainings, we have educated an additional 467 healthcare professionals on the challenges facing our members. This is a more than four-fold increase in the number of health and community care professionals we've been able to reach, face-to-face, compared to 2011-2012.

In addition, our free online MND Aware training continues to be well subscribed. In the 2012-2013 financial year, we've had 3774 (worldwide) and 1,531 (NSW) module downloads of MND Aware training.


The success of the program has also been recognised on a national level. MND Aware is a finalist in the Improving Health Outcomes Award, part of the 2013 National Disability Awards. The award recognises achievement in supporting people with disability and maximising their ability to participate as equal citizens in society.



Stepping Up... *Meet five new champions of MND*




Associate Professor Ian Blair, MND Research Leader




The winner of a MNDA Leadership Grant, Dr. Blair will lead a multidisciplinary team of scientists in creating a new powerhouse of motor neurone disease research at the Australian School of Advanced Medicine at Macquarie University. They will further research into inherited forms of MND.

Olympic Gold Medalist, Brittany Elmslie, MND Australia Young Ambassador




After learning about the effects of motor neurone disease from a friend, Brittany took the initiative to approach MND Australia to see how she could help. Now the official MND Australia Young Ambassador, Brittany will use her considerable public profile to help raise awareness about MND and the plight of those affected by it.

Ironman and Triathlete, Nathan Johnston, MND NSW Ambassador




Nathan is a visually impaired resident of Helensburgh who has been in multiple endurance events over the years. Despite having only 8% sight, Nathan completed the Port Macquarie Ironman Triathlon in May, and the City2Surf in August with the Honourable Tony Abbott as his guide. Nathan's involvement with MND NSW began in 2012 when he volunteered as an organiser of the Burgh2Beach Charity Run for MND NSW. He has since become an official and invaluable MND NSW Ambassador.

Dianne Epstein, MND NSW Regional Advisor, Southern NSW and ACT



Our newest Regional Advisor, Dianne has had many years of experience working with people with disabilities, their carers, and families. With her love for country driving, you can expect to meet Dianne in the near future if you live in her region.

Deb Ward, MND NSW Regional Advisor, Inner West, Hills District and Southern Central Coast



Deb brings both extensive and diverse health system experience to her new role as an MND NSW Regional Advisor. She started as a physiotherapist in neuro-rehab and then worked in policy implementation, giving her excellent interpersonal and advocacy skills which will benefit our members.

Next steps

As always, there is much more work to do! As we look forward to 2014, we will be helping our members to understand DisabilityCare and any impact the roll out will have on them. We will continue in our advocacy work, with the aim of having DisabilityCare extended to all Australians in need. We will continue to focus attention and resources on the quest for a cure, and educate health and community care professionals and the greater public on the needs of our members. And we will provide day-to-day support, not only in the form of easily accessible information and equipment—but also in the form of invaluable human contact: from our regional advisors to our massage volunteers, to the friendly faces at our Walks to d'Feet MND.

You can help us in our efforts. Anything you can contribute financially would be greatly appreciated. Please go to "Donate" at www.mndnsw.asn.au to make a secure donation online with a credit card, or download a form to fill and send with your cheque in the mail. Of course, you can always phone us at 02 8877 0999, if you prefer. If you would like to make a gift to MND NSW in your will, please contact us on 02 8877 0999, or email admin@mndnsw.asn.au. We would love you to join our Blue Cornflower Society—invaluable benefactors who support the work of MND NSW.