

2018

A year of **steps**, **leaps**



A message from the CEO

It recently came to my attention that there is a theory of productivity called "incrementalism," sometimes defined as belief in change by degrees.

For all of our members struggling with MND, such a faith — and the patience and perseverance that accompanies it — is a daily necessity. I thought this perspective would make a useful lens through which to review our past fiscal year. However, in looking for small steps forward, I was pleasantly surprised to see that, in fact, in many places we have advanced by leaps and bounds. I am both proud and grateful to share this review with you: proud of what, together, we have been able to accomplish, and grateful because it is almost entirely the outcome of personal, direct involvement and action on the part of so many of you.

The summary of this year's achievements is most efficiently communicated by using graphs. However, behind every bar and every pie-slice, there is human effort and commitment. The sidebar on this page gives us a glimpse of this, by sharing an exemplary story.

Of course, whatever progress we have made comes too late for many of our members. I am ever mindful that there is still so much more to be done, and that we must do it with the greatest urgency. To all those who have lost loved ones and friends to MND, on behalf of our board and staff, I extend our deepest sympathy.

Graham Opie
Chief Executive Officer

and bounds

Small steps make a big difference

In March 2014, Baden's grandmother Nicola was diagnosed with MND. After seeing first-hand how MND NSW assisted her during her deterioration, Baden and two of his school friends, Will and Cameron, thoughtfully decided to hold a fundraiser at school. They organised a raffle and the sale of MND merchandise, and raised \$1,000 for MND NSW.

The boys were nominated for an award from the Independent Primary School Heads Association (IPSHA) and invited to participate in the IPSHA Social Action Expo in July 2017. They gave a presentation about Grandma Nicola's journey with MND, raising awareness about the disease, and also shared their experience and ideas for successful fundraising.

Unfortunately, Grandma Nicola passed away in August 2016 and was unable to witness Baden's big day. She would have been proud, as we are, of Baden, Will and Cameron for their remarkable achievements.



Baden, Will and Cameron

Greater community involvement



This year saw a huge increase in community involvement, surely the ultimate driver of much of the progress we have made. Throughout the year and across NSW and the ACT, sports charity days, school fundraisers, ice bucket challenges, cake bakes and craft fairs, galas, dinners and dances were organised to raise funds for MND NSW. In addition, we saw many more people volunteering, both for MND Week/Blue Cornflower Day, and as a regular extension of our staff. A great vote of thanks to all of you who got involved.

Community events organised



Volunteers during MND week



Regular volunteers



More successful fundraising

As a result of this surge in community support, we have been able to raise more funds this year to invest in services for our members. Donations of hundreds, thousands, and even tens-of-thousands of dollars arrived from the above-mentioned community events, and each cheque was greatly appreciated. The increased number of volunteers during MND Week greatly improved our visibility and presence. Likewise, a greater turnout for MND Walk to d'Feet events led to both higher visibility and more funds raised. Last but not least, we were also the grateful recipients this year of a larger number of bequests.



Donations from community events*



Funds raised during MND Week*



Funds raised by Walk to d'Feet*



Bequests made to MND NSW*



*In thousands of dollars

Services for our members

Although we continue to contribute to the search for a cure, we are thankful that many organisations exist specifically to fund this research. Instead, our primary goal is to provide the support and services our members need to improve their quality of life. To that end, we invest heavily in the provision of advisory, informational and educational support in general, in Coordination of Support services to assist National Disability Insurance Scheme (NDIS) participants in getting the most out of their NDIS plans, and in helping members to navigate My Aged Care. Our FlexEquip program is also highly valued by members who wish to continue living at home, as it enables members with progressive disease to access a range of everyday equipment and aids as needs arise.

We are proud that in this past year the number of people who access our services has increased, and that based on the estimated number of people who are diagnosed with MND in NSW and ACT, approximately 98% are registered and actively involved with MND NSW.

Proportion of funds invested by program



Number of members registered



Funds invested in MND NSW support services*



*In thousands of dollars

We continue to need your support

All the progress that has been made would not be possible without the help of our community advocates and donors. You can voice your support for us at any time with a donation. 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. Bequests and major gifts can also advance our cause by leaps and bounds. If you would like to make a major gift to MND NSW in your lifetime or in your will, please contact Yvonne Hamilton, Supporter Liaison Officer, at 02 8877 0927 or yvonneh@mndnsw.asn.au for a confidential discussion.



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