mnd ✻ 2019

New South Wales

Looking back on more than this year

Day of Hope and Remembrance

A message from the CEO

It is that time of year again when we usually take stock and look back to see what your support has helped us achieve. Usually, the period in question is the closing financial year, but occasionally it pays to take a longer view. It can be both enlightening and motivating to remember what we have been able to achieve together, as part of a bigger picture. As our founder, Marjorie Harrap, was fond of saying: "From little acorns, oak trees grow".

It is therefore with great pride that I invite you to revisit our beginnings with me—to step out of the oak tree's shade and take a moment to contemplate how it grew to such robustness. Of course, there is still much work to be done; more growth to be pursued. And, whatever progress we have made comes too late for many of our members but we will never give up.

To all those who have lost loved ones and friends to MND, on behalf of our board and staff, I extend our deepest sympathy. I pledge our continued commitment, support and service towards improving the daily living of our members and their carers—and in pursuit of the ultimate goal of a cure.

Graham Opie
Chief Executive Officer

1981

Marjorie Harrap's husband Bill is diagnosed with Amyotrophic Lateral Sclerosis (ALS). Their doctor, Dr. Brian Somerville, suggests that Marjorie and Bill get an association to support ALS sufferers started.

The inaugural meeting of the Amyotrophic Lateral Sclerosis Society of Australia is held in the Harraps's home with a Management Committee of 8 volunteers. They knew nobody with MND, other than Bill.

Marjorie Harrap and Dawn Thew with Eames Bishop

1982

Granted registration as a charity. The first newsletter is published. "Seminar on ALS" given by Mr. Eames Bishop, President of the ALS Society of America, draws 200 attendees. By the end of the year, the Society supported 151 members, including 49 people with MND. An American booklet and fact sheets are adapted for the Australian market by Dr. Somerville.

1983

Seminar "ALS and Research" brought together researchers and members for the first time.

Lions Clubs pledged support for MND organisations. This made it much easier for people with MND to obtain much-needed equipment.

1985

The Society moved into first rented premises. Moya Tarrant became our first Volunteer Coordinator.

1987

A separate entity for research purpose, the ALS Research Foundation (later renamed the Motor Neurone Disease Research Institute of Australia), is formed. The Society passed over to the new Foundation $49,876 for research.

The first ALS Video is made for the informational library.

170 vs. 8

We currently have 119 registered volunteers, with 170 volunteers involved in MND Week 2019.

27 vs. 1

From the first newsletter, the MND NSW list has grown to twenty-seven general information and MND management publications, in in addition to our regular e-newsletters which have a current circulation of 1350.

600 vs. 49

Current MND NSW membership is 600 with MND.

2136 vs. 4

From just 4 manual wheelchairs in 1981, there are now 2136 items stocked in the FlexEquip equipment library. Equipment was provided to 371 individuals last financial year.

$1.5m vs. 50k

Since 2010, MND NSW has invested $1.5M of raised funds in supporting research.

76 vs. 1

You can now find 76 informational videos posted at the MND NSW YouTube channel, www.youtube.com/user/mndnsw

1989
All Australian MND organisations come together for the first time and decide on a common National Awareness Week.

1990
The first Awareness Week is celebrated with a seminar at the University of NSW, followed by a visit from the Duchess of York.

The first volume of "Recipes for Those with Swallowing Difficulties" is published.

Marjorie Harrap with the Duchess of York

1991
The first support group (Illawarra) formed.

14 vs. 1
Today, there are 14 regional MND NSW support groups meeting regularly.

1993
Mr Hari Singh joins as part-time Office Manager, becoming first employee of the Society.

1994
The Society is renamed the MND Association of NSW.

MNDA Newcastle/Hunter Region becomes a Support Group. The Central Coast Support Group is also formed in September.

Graham Opie and Janet Nash

1995
We welcome our first Care Coordinator, Janet Nash.

Ice Bucket Challenge

2005
We welcome our current CEO, Graham Opie.

2007
The first Walk to d'Feet MND is staged in Sydney. That year there are also 10 community-organised events.

9 vs. 1
85 vs. 10
This past year saw 9 Walk to d'Feet MND events and 85 community-organised fundraisers.

2019

Other numbers from this past fiscal year:

236 — People newly diagnosed with MND in NSW

760 — People with MND who interacted with us this year

9706 — Contacts made via the Info Line (email, phone, letter)

>10,000 — People who visited the MND Website

368 — People with MND or their families who attended an education or other MND event

160 — Allied health professionals who attended the MND Special Interest Group workshop

444 — People who attended in-service training sessions for organisations caring for people living with MND.

With your continued support we can achieve so much more

Although it is rewarding to see the progress we have made this year in the context of what we have achieved over the longer term, continued progress would not be possible without your support. Please consider becoming a donor, a volunteer, a community event organiser or a public awareness ambassador.

You can 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. You can also submit proposals to fundraise on our behalf. (Of course, you can always phone us at 02 8877 0999, if you prefer). Bequests and major gifts also help ensure our success over time. If you would like to make a major gift to MND NSW in your lifetime or in your will, please contact Kym Nielsen at 02 8877 0999 or kymn@mndnsw.asn.au for a confidential discussion.