

30 YEARS OF COMMUNITY AND SUPPORT

Almost thirty years ago, in the offices of Dr Brian Somerville, Marjorie and Bill Harrap received the devastating news that Bill was suffering from amyotrophic lateral sclerosis (ALS, a motor neurone disease). Instead of giving way to despair, the Harraps turned their gaze and energies outwards, focussing on what could be done to set up a support network for people facing similar struggles with ALS and motor neurone disease.

Around their kitchen table, the Harraps gathered a small group of friends — Lynette and Alex Henderson, Denise and Colin Crundwell, Dawn and Don Thew — who

became the committee members of the Amyotrophic Lateral Sclerosis Society of Australia (registered December 9, 1981), with Dawn Thew acting as President, and Dr Somerville as Medical Adviser.

This small circle of volunteers worked to identify patients with motor neurone disease who would benefit from the information, support, and community that they provided. Membership grew steadily. The Society is now the Motor Neurone Disease Association of NSW (MND NSW) and calls the MND NSW Centre, at Gladesville, home.

1981



Marjorie Harrap, responsible for the genesis of the ALS Society in 1981, still volunteers at the MND NSW Centre once a week, bringing her warmth and wisdom to our staff and members.



1987



Dawn Thew, President of the Association for its first seven years, moved on to found the MND Research Institute of Australia in 1987, serving as its Chairperson for its first eight years, assembling key researchers in each State and facilitating their collaboration.



1981 - The Amyotrophic Lateral Sclerosis Society of Australia is formed in NSW.

1982 - The first edition of Forum.

1985 - The Society moves into its first business premises and recruits a volunteer staff.

1988 - The NSW Society is renamed the ALS-Motor Neurone Disease Association (MND Association).

1982 - Seminar of ALS with Mr. Eames Bishop from the ALS Society of America as guest speaker.

1983 - The seminar *ALS and Research* brings members and researchers together for the first time.

1987 - The ALS Research Foundation is established (since renamed the Motor Neurone Disease Research Institute of Australia).

1989 - The first meeting of Australian MND organisations is hosted by the Association in Adelaide.

From its homely roots, the Association has grown to offer a wide range of services and to participate in a wide range of activities.

A key objective of the Association since its inception is the provision of accurate and easily understood information for people with MND and their carers. Happily, the results of the biannual member's survey conducted in November 2009 indicate that the Association is performing well in this effort. Eighty eight percent of members surveyed rated the overall support and information provided by the Association as good or very good (see Figure 1). Eighty five percent of carers surveyed agreed (see Figure 2). In particular, ninety one percent of those surveyed appreciated the content of Forum, rating the Association's newsletter as good or very good (see Figure 3).

A larger goal — to actively fund and facilitate research in the area of motor neurone disease, with the aim of finding a cure — has also been realised with the foundation of the MND Research Institute of Australia in 1987. In 1995, the first Scientific Conference on MND Research in Australia was held at the Walter & Eliza Hall Institute in Melbourne. And today, the MND Research Institute continues to support dedicated MND scientists with seeding grants and research monies.

Also as an outcome of effective fundraising — particularly a ball held in honor of HRH the Duchess of York when she opened the MND NSW Centre then based at Concord in 1995 — the Association has been able to build and expand an equipment pool. This has become a vital resource offered by the Association to its members, 92% of whom rate the Association's equipment loan pool as being good or very good in meeting their needs (see Figure 4).

Just as valuable is the Family Support outreach program, a resource custom-designed around the home and residential care needs of our members as identified by a comprehensive needs assessment survey conducted in 1999. It is gratifying to see that 92% of members surveyed rated the ability of their Regional Advisor to provide support and information as they've needed it as good or very good (see Figure 5).

But perhaps the most telling testimonial to the value of the Association to its members, nearly 30 years after its birth around a kitchen table, is the answer to the simple question: would you recommend MND NSW to other people living with MND? To which 94% of members surveyed responded with a resounding 'yes' (see Figure 6.)

1993



Hari Singh, MND NSW's first employee, became the Association's Executive Officer in 1993, accepting a minimal salary for 20 hours per week, and working another two days per week without being paid. This dedication saw him working beyond retirement age in his pursuit of a Family Resource Centre for people with MND. He reluctantly retired in 2003.



1995



Janet Nash joined the Association in 1995 as our first — and for a while, only — Patient Care Coordinator. For over a year, Janet provided support to people with MND all around NSW single-handedly, as regional advisor, equipment and information officer! She continued on as Research and Information Coordinator until 2005, the year she commenced as Executive Officer of the MND Research Institute of Australia.



1991 - The second bi-annual Conference for MND Associations leads to the formation of the MND Association of Australia (MNDAA).

1993 - The Medical Advisory Panel is formed to provide the Association with expert advice and to evaluate the services provided to members.

1995 - The Blue Cornflower is introduced as the national emblem for MND. The Association's equipment pool expands, and new MND literature is introduced.

1997 - The first Family Support Outreach Worker is appointed. Regional seminars to educated health care professionals is introduced.

1999 - support "Frien NSW"

1990 - The first MND Awareness Week is celebrated in April, successfully raising awareness of the disease.

1992 - The Association adds "of New South Wales" to its name, to delineate itself from MNDAA.

1995 - The Association changes its name to MND Association of NSW Inc. and adopts a new constitution. The Duchess of York opens the Association's new offices at Concord Hospital.

1996 - A Development Officer is appointed to plan programs supporting the home care of people with MND in NSW.

1998 - The Association's staff expands to include four part-time Family Support Workers, a dedicated fundraiser, and an administrative assistant.

Figure 1: The overall support and information provided by MND NSW is:

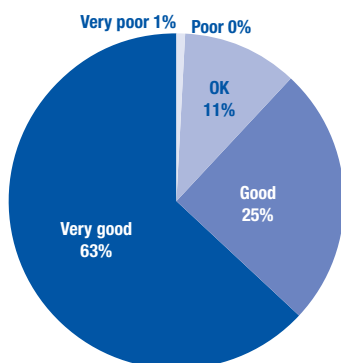


Figure 2: The support and information from MND NSW for me as a carer is:

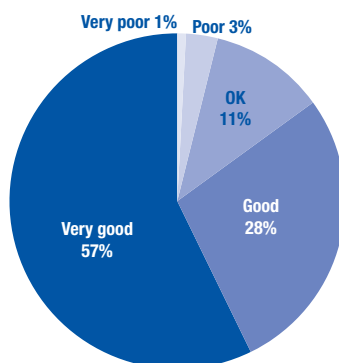


Figure 3: The content of the MND NSW newsletter Forum is:

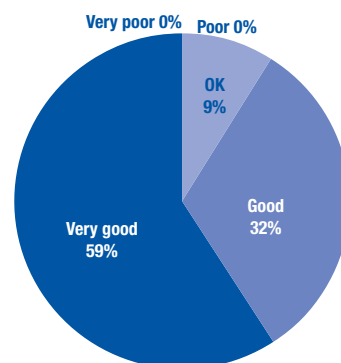


Figure 4: Ability of the equipment from the loan pool to meet my needs is:

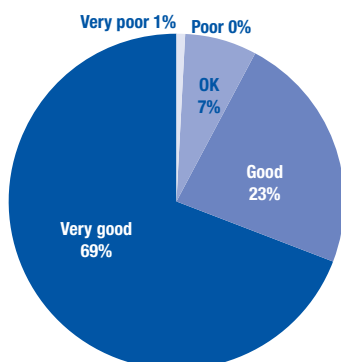


Figure 5: The ability of my RA to offer support and information as I have needed it is:

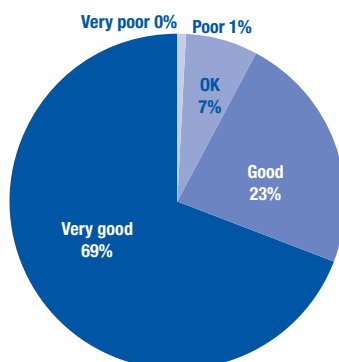
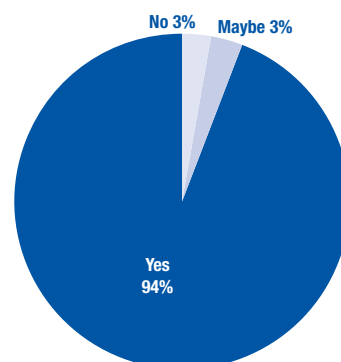


Figure 6: Would you recommend MND NSW to other people living with MND?



1996



Anita Richter was employed in 1996 to conduct a needs survey of people with MND and their carers. The results of this survey formed the framework of our Family Support Service. Anita also developed the Care for Carers program — a spectrum of care, education and support for MND carers.



1999



Kevin Langdon was elected as a member of the Board of the MND Association in 1990, became Vice President in 1992 and played a very active role as President from 1993 until December 2003. In 1999, Kevin was awarded the OAM in recognition of his service to people living with MND. He has been invaluable in providing insights from the perspective of a person living with MND.



- Regional support groups — introduced.

2000 - Cornflower Blue Day is introduced. The Family Support Service provides outreach to five regions throughout NSW.

2002 - Care for Carers funding is made available.

2005 - National Annual Conference is established..

2006 - The first regional office is established, in Newcastle.

1999 - Go live of the MND NSW website.

2001 - An Equipment Assistant is appointed.

2004 - Special Interest Groups were formed to keep health and community care professionals up to date

2005 - A bi-annual survey to members is inaugurated, a survey of health professionals started in 2009.

2010 - The Association works to raise \$500,000 to fund increased services in regional and remote areas of NSW.

Where to now?

Our 30th anniversary marks an important milestone for MND NSW, one at which we can all take pride in how much has been accomplished. But the Association cannot rest on its laurels. As we move into our fourth decade, increasing client demand means we must continue to invest in our programs and services in support of people living with MND and their families.

Recently, we launched the MND 30th Anniversary Appeal. Our goal is to raise \$700,000 to replace aging equipment from our equipment loan program, expand our Regional Advisor Family Support Services, maintain our Telephone Helpline; and ensure our Medical Research Programs continue to look for a cure for MND.

We hope you will consider supporting this 30th Anniversary Appeal. Your loyal and generous support is needed more than ever. Here are just a few ways you can make a difference:

- \$120,000 would enable the purchase of 10 motorised wheelchairs, replacing old ones and increasing the number we could loan to clients to maintain a sense of independence
- \$90,000 would allow us to loan 25 new motorised hospital beds needed in the homes of families with someone living with MND
- \$42,000 funds the purchase of 6 communication devices which allow a person with MND to communicate even when the ability to speak is lost
- \$6,250 enables us to answer over 100 calls for help to our MND Telephone line every month
- \$10,000 could replace 10 aging wheelchairs with new wheelchairs for us to loan to clients
- \$80,000 would support 30 families in regional NSW with a Regional Advisor
- \$70,000 keeps our medical researchers looking for a cure.

These are just a few ways you could support the MND 30th Anniversary Appeal. If you wish to discuss other ways to help, please contact our CEO, Graham Opie on 02 8877 0914.

