

2009



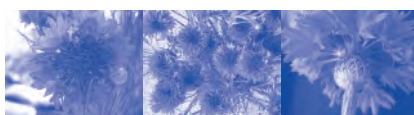
ENHANCEMENTS

through **partnerships**

The delivery of a strong, cohesive service to people with motor neurone disease requires a wide array of partnerships. These partnerships are not always obvious and start at community involvement, right through to government, non-government organisations and foundations. Often the service is delivered directly to the person with MND through organisations other than MND NSW. We would like to thank those partners, just a few of whom are mentioned in this publication.



Partnerships *with the Community*



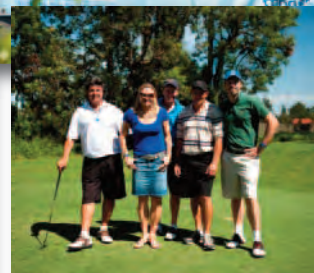
Partnerships with the community, corporate partners, trusts, foundations and individual donors help us to provide equipment and services for our members. These partnerships provide 80 percent of our recurrent funding each year.

Members of the MND NSW Circle of Courage are an exclusive group of donors who make an annual gift or monthly pledge. In 2008-09 these generous donors raised over \$48,000 for equipment and research.

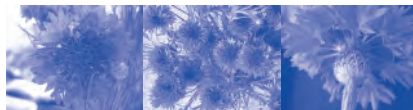
Over the past 12 months MND NSW has been assisted in a very special way by members remembering the Association in their will. These valuable gifts form a key part of the Association's long-term income and help us to continue to provide essential services and information, providing support and advice for people with MND.

Community partnerships have seen the establishment of annual events such as the Country Music Festival in Kurri Kurri, Valentine's Day Ball and the Monstar Cup. Now in its third year, the Monstar Cup golf day, held at Pennant Hills, has raised nearly \$170,000

Through the support of foundations including United Way Sydney and the Honda Foundation we have received funding to purchase additional equipment for loan to people with MND. This allows us to reduce waiting lists for equipment.



Partnerships *with Government*



NSW Department of Ageing, Disability and Home Care (DADHC)

DADHC has committed \$950,000 over five years to increase our vital equipment pool. This has led to decreased waiting periods and a more directed and innovative range of equipment.

We have continued to enhance our equipment pool in 2008-09 and as a result we have been able to meet the increasing demand as our membership grows. Our focus is to increase the availability of new technology and communication devices. During 2008-09 we provided 1,169 items of equipment to our members, an increase of over 16 percent from 2007-08. More than 250 members accessed equipment from the equipment pool during 2008-09.

DADHC's willingness to look further than the next financial year has allowed us to fill gaps in communication with and between our members, service delivery agencies and health and disability services (government and non government). Over the last two years DADHC has assisted in our ability to deliver education programs to people with MND, carers and health and community professionals through several avenues including:

- the National MND Conference, held in Sydney in June 2009
- a review of our health and community services education programs to enhance quality of education provided by MND NSW
- a member and carer regional education project enabling the provision of education programs to targeted areas across NSW.

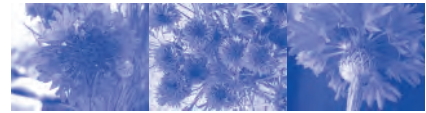
Additionally, the availability of priority access to DADHC Attendant Care Packages and High Needs Pool has resulted in a reduction in waiting time for these services to people with MND.

NSW Department of Health (DOH)

DOH has provided recurrent funding to MND NSW to assist in employment of regional advisors (RAs). Throughout New South Wales, RAs act as an essential conduit between people living with MND and their families, and health, disability and community services. RAs also conduct education programs for people living with MND, their families, carers and the professionals who help care for these groups.



Partnerships *with Non-Governmental Organisations*



Technical Solutions for Computer Access, Seating and Communication Service (TASC), a service of The Spastic Centre of NSW, is working with MND NSW to ensure our members have access to expert assessment and timely advice. TASC advise on options for equipment that may be suitable for our members, especially for those with loss of hand function and/or speech.

Another partnership developed this year with the HOME Hospice program links MND carers with their own HOME Hospice mentor who is an experienced volunteer providing support and guidance at the end of life.

DADHC provided additional one-off funds to Community Options in the 2005-2006 financial year for the development and implementation of a case management model that would be responsive to the needs of people with rapid neurological degenerative conditions including MND. A second allocation was made in the 2008-09 financial year.

Together with Multiple Sclerosis in NSW and Muscular Dystrophy NSW, MND NSW is a member of a consortium funded by DADHC to create and manage FlexiRest - an innovative respite program for people with MND, MS and MD. Funding amounts to \$1 million over four years.



MND NSW Service Enhancements

Enhancements through partnerships

Education

The provision of education about MND is an essential aspect of our services. It brings people together and contributes to the quality of care provided for people with MND. This year we provided 47 education sessions to 744 health, disability and community professionals. We are currently reviewing our education programs to better target these groups.

We have employed a Regional Education Project Officer to extend our education programs for members and their families in regional NSW. This includes Link and Learn, a two day residential program for carers that will be conducted during 2009-10. This program provides carers with much needed support and education to take on this unexpected and unfamiliar role as a result of a loved one being diagnosed with MND. Other programs will be developed specifically for our regional members during the coming year.

A new initiative has been the Information Line Advisor to provide information to our members, the newly diagnosed, family and friends as well as to health and community professionals. In 2008-09 we had 3413 calls to our Info Line, an increase of 950 calls from the previous year. We are also developing a guide to services to assist members understand health and community services and help access them.

Regional Advisors

The new Information Line position means that RAs are now able to spend more time directly on their member-related activities including home visits and liaising with service providers in the community. We have increased the number of visits to regional members from 10 field trips in 2007-08 to 18 in 2008-09. We delivered services to 501 people with MND, their families and carers during the year.

Conference for Allied Health Professionals

In June 2009 MND NSW hosted the 5th National MND Conference in Sydney. The high calibre of speakers attracted 246 health, disability and community professionals and health researchers from around Australia and New Zealand.

Day of Hope and Remembrance

This event was held for the first time during MND Week. It was attended by over 130 people from the MND community who joined together to celebrate hope while also remembering those who have died from motor neurone disease. The day also provided a great opportunity to acknowledge several of our volunteers with life membership awards. It was very successful and will now be held annually.

