



**MOTOR NEURONE
DISEASE
ASSOCIATION
OF NSW**

**ANNUAL
REVIEW
2007**







Mission Statement

To provide and promote the best possible support for people living with motor neurone disease, their families and carers, to advance research and to raise awareness.

Motor Neurone Disease (MND) is the name given to a group of progressive neuromuscular diseases in which the nerve cells (neurones) controlling the muscles that enable people to move around, speak, swallow and breathe fail to work normally.

With no nerves to activate them, muscles gradually weaken and waste and paralysis ensues.

The patterns of weakness vary from person to person. Some muscles can fail in a few months, while the decline of others may take years. Intellect remains unaffected for most people with MND so an active mind is trapped in an inactive body.

The most common form of MND is amyotrophic lateral sclerosis (ALS).

MND can strike anyone - most commonly people in their 50s and 60s.

The cause of MND is not known, except in about ten percent of cases when it is hereditary.

Average survival time after diagnosis is two to three years.

In New South Wales, at any point in time, up to 400 people have been diagnosed as having MND, with approximately 140 new cases diagnosed annually.

It is estimated that for every person diagnosed with the disease another fourteen, including their carers, families and close friends, will live with it forever.

In Australia, more than one person dies every day from from MND.



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Executive Report

Achievements in advocacy seemed to be the recurrent theme for MNDA NSW in 2006/2007.

The year kicked off with a \$500,000 one off grant from the Department of Ageing, Disability and Home Care (DADHC). The grant, provided for equipment, is to be spread over a three year period. This grant has allowed us to increase our equipment pool and helped us keep pace with the dramatic increase in membership and requests.

MNDA NSW became heavily involved in the human embryonic stem cell debate both at a federal level in late 2006 and at a state level in May and June 2007 when mirror legislation was passed. Working collaboratively with all state and territory MND Associations, MND Australia and organisations such as Spinal Cure and the Juvenile Diabetes Foundation through the Coalition for the Advancement of Medical Research Australia (CAMRA), MNDA NSW made a submission to and appeared before a Senate Inquiry, spoke to media releases and lobbied state and federal Senators, Members of Parliament and both houses of the state legislature.

Of particular note was the tireless work carried out by Dr Paul Brock AO an MNDA NSW board member since 2001 who resigned from his position on the board in December 2006. Paul travelled to and from Canberra briefing politicians, their advisers and senior bureaucrats only to have to repeat this mammoth task for the NSW Parliament, whilst juggling a family, work, media and motor neurone disease. Paul was unanimously conferred the position of Vice Patron of MNDA NSW by the Board and awarded the honour at the launch of MND Week 2007.

Working with Community Options who were awarded a \$200,000 grant by DADHC to look at a continuum of care model proposed by MNDA NSW, senior DADHC staff and palliative care, MNDA NSW formed part of the Motor Neurone Disease Advisory Group reporting directly to the Minister for Disability Services. The role of the Advisory Group has expanded to incorporate the Department of Health in looking at MND holistically rather than in silos. The report is due to go to the Ministers in August 2007.

MNDA NSW approached Multiple Sclerosis NSW/VIC and Muscular Dystrophy NSW to form a consortium to look at common advocacy issues. An immediate outcome has been the awarding of

\$1 million to the Consortium to initiate a flexible respite care program for our members. The program will not duplicate respite care packages readily available to members but will enhance respite care for people with MND, their family and carers.

MND Week 2007 was dominated by a national push by MND Australia and all state and territory MND Associations to forward the stalled Commonwealth State Territory Disability Agreement and for both state and federal politicians to understand the huge unmet need and inequity in disability services across Australia. Members of MND Associations across Australia were asked to write to their local federal members and all senators asking them to address this issue. We thank all members for taking part and helping to drive the MND agenda.

Once again we have to thank the Department of Health for their ongoing financial support of the Association and for supplying office space at John Hunter Hospital. DADHC's ongoing commitment to people with MND has grown stronger throughout 2006 and 2007. We would particularly like to thank the Minister and senior staff for their willingness to learn and understanding of the issues surrounding MND.

As the number of members of MNDA NSW increased so too have our numbers of Regional Advisers(RAs). 2006 saw the familiar faces of Carol Birks, Anita Richer, Christina Jason and Ruth Quaken move on, but not too far. Carol has accepted the position as National Executive Director of MND Australia while Anita is working part time on the Talking to Young People project. Ruth has joined another organisation but frequently attends MNDA NSW celebrations. New faces include Gina Svolos (Family Support Manager), Noelle Smith and Karen Kemp (RAs based in Newcastle) and Jane Barrett (Family Support Coordinator).

As well as Paul Brock, Katrina Horman left the Board in 2006. New board members are Alex Green, Nick McLoughlin; Gary Jacobson has rejoined after a brief hiatus.

MNDA NSW would like to thank all our supporters. Without you the direct services provided to people with MND, their families and carers would not be possible.



Family Support

The MND NSW family support includes regional advisors, information, equipment, volunteers and groups. Family support aims to provide and promote the best possible care and support for people living with MND, their families and carers and to promote research.

Family support continues to work closely with the MND Clinics and MND services in NSW and ACT. Over the last 12 months there continues to be local multidisciplinary teams meeting regularly with the regional advisor and other health professionals involved to discuss the care and management of the people living with MND they are caring for. This helps to ensure a seamless service for people with MND and their carer and minimises duplication of service.

The 2006 International MND/ALS Symposium was held in Yokohama in December and the family support team was very proud to be represented by Anita Richter. Anita presented a paper co-authored with Carol Birks entitled 'Building a Spectrum of Care for Carers of People with MND'.

This year the 3rd National Annual MND Conference was hosted by the WA Association with 175 delegates from around Australia and New Zealand. The day before the Conference family support staff from Australia and New Zealand met to discuss the issues they face in addressing the needs of people living with MND.

Three of our family support staff presented papers at this conference. Maree Hibbert, Equipment Services Coordinator presented 'Evolving Equipment Trends'; Allison Pearson, Regional Advisor presented 'The Link and Learn Programme' and Jo Fowler, Regional Advisor presented on 'Team Approach to Care of Patients with MND'. Presenting at conferences such as these promotes recognition of MND and the needs of people living with the disease. It also helps to develop partnerships to address the unmet needs of the people with MND and their families and demonstrates and enhances the breadth and depth of knowledge of family support staff.



Support staff enjoying a meeting

Regional Advisors

Regional advisors are professionals with specific knowledge and experience of MND and are at the forefront in supporting people living with MND. Their objective is that all people living with MND and their families are well supported throughout their journey with MND and have access to relevant information to help guide their decision making. Regional advisors aim to ensure that no person living with MND has a high level of unmet needs. This usually means that people whose needs are high and changing rapidly receive frequent contacts from their regional advisor. Others who are relatively stable and linked in to appropriate services, have less frequent contact.

During the year 164 people were diagnosed with MND and became members of the Association. During this period the Association was advised of 146 people who lost their fight against MND. Bereavement is the final loss in a series of losses experienced by carers, family and friends and our thoughts are with them.

At 30 June 2007, family support services were being provided to 348 people living with MND registered as members plus their families and carers in NSW and the ACT.

	2005/6	2006/7
New members	173	164
Number of deaths	128	146
Home/hospital/ office Visits	387	472
MND Clinic contacts	313	323
Regional advisors phone calls	1182	1624

The number of contacts we have with our members has continued to increase as the number of regional advisors grows. As part of our commitment to regional NSW a new office was established in Newcastle at the John Hunter Hospital. In late 2006 a new regional advisor position was created located in Newcastle to support people living with MND in Hunter, Lake Macquarie and New England. This new position has ensured that the number of people with MND allocated to each regional advisor remains manageable. Regional advisor hours have increased by 16 hours per week to a total of 154 hours per week. Six regional advisors support people living outside the Sydney metropolitan region and three of these are based regionally ensuring a more responsive service. Other regional advisors support rural and regional people through regular field trips, telephone and emails to ensure the best possible care wherever people are living.

Regional advisors continue to forge links with local service providers who provide care and support for people living with MND. Regional

advisor knowledge of the services available locally helps to prevent people living with MND falling through the gaps of service provision. A wide variety of health and community care providers may be involved in the care and support of people with MND and their families throughout their journey with MND. It is these people who deliver the essential services they need.

Advocacy continues to be a focus for the family support team in order to ensure that the needs of people living with MND are promoted at the grassroots and government planning level. Service providers are increasingly aware of the rapidly progressive nature of MND and the need to respond accordingly. Support from NSW Health and DADHC continues through recurrent funding and funding for special projects.

Information

Good quality information is essential for people to self manage the progression of MND. It is also important for health and community care providers, many of whom may not have had experience of MND before, to assist them to provide best practice care and support.

A wide range of quality information is constantly researched, developed and disseminated covering a wide variety of relevant topics. Information is sourced from people working in relevant areas, peer reviewed literature, conferences, other MND



Sarah Fox, Sybil Lord and Dr Ruth Powys from Northern Beaches Support Group



Lucy and Matthius Lee from Hornsby Support Group



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organisations globally around the world and the Internet. Gathering and reviewing the information and making this available to people living with MND helps empower them to seek information as and when the need arises.

For many people recently diagnosed with MND and their families and friends, the first contact with the Association is by phone. At this stage the provision of accurate information and support is vital. The phone is also a convenient and quick way for people living with MND, family members, friends and service providers involved in caring for a person with MND to obtain ongoing information.

The family support 'info line' is available five days a week from 9am to 4.30pm and can be accessed by ringing the MNDA office on either 8877 0999 or the freecall number 1800 777 175. The number of calls to and from the 'info line' have continued to demonstrate the importance of this vital service.

Information	2005/6	2006/7
"Info Line" calls	3490	3260
Information provision	902	850
Information sessions	92	100
Newsletters	4/1400	4/1400
Special Interest Group E-Bulletins	6/202	6/200

The provision of information and education to service providers is a high priority for regional advisors. During the year Family Support conducted 49 information/education sessions for service providers and community groups with an audience of 530.

Membership of the three discipline specific special interest groups:

- Communication, swallowing and nutrition
- Psychosocial and supportive care
- Independent living

continues to be active with 200 health professionals who receive the bi-monthly bulletins and invitations to annual workshops.

A wide range of printed information including:

The Carers Kit – revised and updated in early 2007

Information Packs for new members

– these were reviewed and further developed early 2007

Information Packs for Service Providers

G.P Booklets – revised and updated in mid 2007

Recipe Books

Special Interest Group Starter Packs

The website at www.mndnsw.asn.au regularly reviewed and updated and continues to provide accessible information about MND and a means of communication with the Association for internet users.

Equipment

The equipment service is essential for people living with MND to maintain their independence and communication for as long as possible and enhance their comfort and quality of life. More than 50% of the calls to and from the 'info line' were related to equipment enquiries. This service encompasses sourcing and purchasing new equipment, liaison with therapists prescribing the equipment, loans, arranging equipment hire, seeking further funding, delivery and pick up, developing relationships with equipment hire companies and couriers, maintenance and cleaning. There is no charge for this service to people living with MND.

Equipment Pool	2005/6	2006/7
Equipment items	1177	1246
New items acquired	159	233
No. of items loaned	938	1048

Volunteers

Support groups continue to thrive throughout NSW. They are the face of the Association in local communities raising awareness about the disease and supporting people with MND

in their community. Volunteers coordinate the majority of the groups and their contribution is highly valued. Family support staff coordinate some groups and attend many of the others regularly to support them and recognise their valuable work. There are now 13 active support groups throughout NSW and in the ACT which meet monthly or bi-monthly.

Group Programs

People who have been recently diagnosed, their families and friends have specific information needs and information evenings have been held regularly at the MND office in Gladesville. These have been very well attended over the last 12 months providing information and an opportunity to meet others in a similar situation.

The annual two day Learn Now/Live Well program continues to assist people living with MND and their families to prepare for the future and to live as well as possible with MND. This program was conducted at Gladesville in November 2006 and was attended by 25 people with MND and their carers.

Carers of people living with MND have specific needs related to caring for their loved one and the support they need. The annual four week Care for Carers Program was held in

Sydney in September 2006 and continues to demonstrate its relevance for carers to learn about MND and gain much needed mutual support.

Four meetings for past carers were held during the year at the MND office offering an opportunity for carers to interact with others who understand their experiences of loss.

Round three of the Link and Learn project funded through the NSW Health Carers Grants commenced in March 2007. The two day residential program was held in the Hunter and was aimed at carers living in the Newcastle and Hunter regions. This was followed by six weekly tele-link sessions which was highly valued by the participants. While this three year grant has now been completed MND NSW has decided to continue to conduct this program in regional areas and will continue to look for funding for this valuable program. The program will be held on the Far North Coast in 2008.

In April ***Sailors with Disabilities*** again took some of our members and their families on a sail around Sydney Harbour. The day was described as sensational by one of our members and we thank ***Sailors with Disabilities*** for their generosity.



Hannah, Jim and Di Nicholls and Peter Ellwood

Research

In 2006/2007 MND NSW again directed over \$100,000 to research. Money has been set aside by the MND Research Institute to fund the Bill Gole Fellowship. **Julia Morohan** is the current recipient of this award.

“As part of my Bill Gole Fellowship, I am investigating whether genetic abnormalities underlie sporadic ALS.

It has recently been recognised that gene mutations can be found only in certain tissues. In ALS, these mutations would only occur in the brain tissue of patients and not in other unaffected tissues such as blood. I have therefore been comparing genetic changes in brain and blood DNA in ALS patients and normal individuals.

We have extracted DNA from the blood and brain of individuals who donated to the Australian MND DNA Bank. By using whole genome scanning methods that permit genetic testing across all genes, I am able to test genetic regions that have previously been suspected to underlie sporadic or familial ALS (such as the superoxide dismutase 1 gene or the vascular endothelial growth factor gene) as well as previously unidentified regions.

The genetic testing can identify regions where DNA is simply changed, or duplicated or deleted. Copy number changes refer to gene regions that are duplicated or deleted. Some regions have shown possible copy number differences in patients compared with controls in our study.

Regions that we think look particularly interesting, we are now confirming using new experimental techniques that allow us to quantify the number of gene copies present in a sample. These types of mutations have not previously been studied in ALS and may represent a new mechanism for this disease.”



Research

Professor Kate White from the Faculty of Nursing and Midwifery, Sydney University is conducting a research project that seeks to formally evaluate the impact of a disease-specific, individualised future care plan for MND, as one component of a larger program of research aimed at improving end-of-life care for this population.

Future Care Planning for MND

A "Letter on Future Care" was developed by the Calvary MND Service to assist people with MND and their key support people in planning their future care. The process of drafting the Letter on Future Care has been refined over time but it has always been a disease-specific, event specific and patient-specific letter. To date it has not been formally evaluated from the perspective of patients, carers or health professionals. Given the pivotal role of care planning for the MND population, it is critical to develop effective approaches to support the individual and to provide guidance to the treating health team regarding the individual's wishes. Overall this project will aim to:

- To determine whether the disease-specific individualised future care plan helps in planning and preparing for death.
- To determine whether the disease-specific individualised future care plan assists the carer during the bereavement phase.
- To develop guidelines for MND practitioners in implementing an MND-specific individualised future care plan.

The project is exploring both carers and key health professionals perspective of this approach to care planning, as well as identifying approaches to improve this important area of MND care.



Ten Years on...

Written and presented by Carol Birks, Previous Family Support Manager and now executive Director of MND Australia at a celebratory function

"I would like to welcome you all here this evening and thank you for coming along to celebrate and reflect on the 10 years of dedicated service that Janet Nash and Anita Richter have given to the MND Association of NSW. And of course to acknowledge the enormous contribution that Alan and Ian have also made!!

I will start with Janet who joined the Association in July 1995, apologies for being a year late with your 10 year anniversary Janet; we were rather busy last year!! Janet joined Hari and many hard working volunteers such as Marjorie and Kevin as the Patient Care Coordinator. Janet was the first professionally employed person providing information and assistance to people with MND. Facilities were so paltry at the time that Janet didn't even have a desk to sit at, let alone a computer, so she picked up her desk from her office with Garth Nicholson around the corner and moved into that little run down room at Concord Hospital.

Janet started as she meant to go on – working many hours more than she was paid for – identifying gaps and filling them. She turned her practical and hardworking nature to addressing the equipment needs of people with MND running the service single handedly for many years with very little room and resources. The way she developed the service was instrumental to the support we have received in recent years to grow and maintain the service.

The provision of good quality up to date and user friendly information is essential for people with MND and this was always one of Janet's major roles. Her knowledge, perception and unique skills have ensured that high quality information has been developed for people living with MND their families and friends. The Newsletter Forum became a professional publication as Janet took on the role of editor. Her research background and scientific skills ensured that MND NSW could be confident that information given had a sound basis and of course she was always able to answer those tricky questions we have all had over the years!.

Janet helped grow the equipment service, the information service, Forum, research, and computer skills and knowledge. Then last year finally the move to this wonderful location at



Anita Richter, Carol Birks and Janet Nash

Gladesville became a reality and it was Janet, and Alan, her partner, who were instrumental in making a dream a reality – being involved in the plans for the renovations every step of the way. Getting down and dirty putting up shelves, shower rails, cleaning, assembling chairs – I could go on.

Her contribution to the growth of the MND Association has been immense and it is only fitting that Janet is now using all her valuable skills to grow the MND Research Institute of Australia and is still working tirelessly towards hope for a future without MND

For over a year Janet was the only paid person providing support for people all around NSW, in other words the only regional advisor, equipment and information officer! Then in October 1996 along came Anita.

Anita Richter was employed in October 1996 to conduct a needs survey of people with MND and their carers. The results of this survey formed the framework of a fledgling family support service.

Anita had very different skills, personality and attributes to Janet but they shared a common vision and a very small office. Over the next two years Regional Advisors and admin staff were employed, regular newly diagnosed evenings commenced, the annual conference and rural and regional seminars for health providers were established, there were field trips using the royal flying doctor service, and the first MND model of care in NSW was established at Neringah and Hornsby Hospitals – looking back it is absolutely incredible that so much was achieved in those couple of years with so few resources and a skeleton staff.

It was Anita's passion, skill and absolute commitment to people living with MND and their carers that drove these programs and the continuing development of family support. She persistently strove to meet those needs identified by people with MND and their Carers – working above and beyond the call of duty and paid hours. In January 2000 Caroline and

I (Carol Birks) joined Hari, Janet, Anita, Carole Leone, Petra, an RA for Western Sydney and one for Northern NSW and of course Marjorie and Kevin in that little office.

Janet and Anita had established a professional family support service that was beginning to really meet the equipment, support, education and information needs of people living with MND their families and health professionals involved in their care. This led to more funding opportunities and the continued growth of MND NSW.

As each new member of staff joined the team we knew very little about MND but under Janet and Anita's guidance we learnt very quickly. Over the last few years Anita has been instrumental in driving the objectives of a very ambitious strategic plan – Establishing and developing the Care for Carers program, the Carers Kit and a spectrum of care, education and support for MND carers.

She has been my right hand man and constant supporter as we worked together with the family support team on developing projects, advocacy, MND models of care and promoting best practice care.

The Annual Conference she started in NSW is now a national conference, there are five MND specific clinics or models of care in NSW, 180 health professionals have joined the special interest groups and there is no longer any need to hold seminars entitled towards multidisciplinary care. We are still a long way off a cure for MND but we have come a long way in providing optimal care and support.

Anita cares passionately for people with MND, their carers and MND NSW and she will be sadly missed when she retires – both Anita and Janet should be proud of their contribution to this Association. I know that all the staff, volunteers, board members, patrons, people with MND, carers past and present have truly appreciated their hard work, commitment and passion and most importantly have enjoyed their friendship.

Thank you Anita, Janet, Alan and Ian."



Fundraising and Volunteering

Raising funds for any cause let alone motor neurone disease is difficult these days when there is so much competition for the dollar but we are very fortunate in that we have many loyal supporters. Donations for MND NSW come in a variety of types. People respond to a direct ask by mail, spend money at functions, organise events, buy merchandise and, sadly, send donations in memory of loved ones. Other funds come from government grants, distribution of earnings from clubs and councils, donations from service clubs like Rotary and Lions, gifts from foundations and trusts and money or goods left to us in Wills. Whatever the origin of a gift, we are very appreciative to receive it and can assure the giver that it is used in such a way as to promote the well being of people living with MND.

Events

The first event this year was a BBQ at Thornleigh Bunnings organised by member **Pat Ball** and her husband **Warren**. Bunnings very kindly provided the BBQ and gas and the Balls donated the sausages and onions. MND provided the rest including staff members Roslyn Adams, Caroline Gleig and Judy Ford. Judy's husband **Peter** also assisted and, teamed with Warren, made very good cooks!

It's not everyone who relishes the thought of getting to the top of Heart Break Hill in the August City to Surf but for member **Mark Gooley** in a wheel chair it was daunting. However he had his three very supportive

children **Melinda, Ben and Marcia** to push him to the finish line. Wearing MND t-shirts, his family and friends running with him represented the Association well and through sponsorship and donations collected \$5,000 for MND. **Margaret Mappas**, who lost her father to MND also participated in the run and raised close to \$7,000 through donations and selling chocolates.

The beautiful garden of **Suzanne and Bob Ballinger** was again open to the public one weekend in September. Unlike the year before the weather was kind on both days and visitors were plentiful. The garden was open to the public through the Open Garden Scheme with proceeds from the day going to MND NSW.

Bob Delaney, who is living with motor neurone disease, challenged the elements to ride 100km to support the Northern Rivers Support Group of the MND NSW. He and three friends, **Kim Evans, Debbie Melino and Zelinda Brown** headed off from Trinity College, where Bob is a teacher, on 12th September. The ride took them from Lismore to Jiggi, the Channon, back to Lismore, then on to Woodlawn, Numulgi and home. They rode 103km and raised over \$3,000.

Fundraising manager, Judy Ford was invited to attend the 6th Annual Bar Awards Gala Dinner at the Hilton Hotel in September. Why? The manager **David Spanton of Spanton Media Group**, whose uncle has MND, donated \$10 from every ticket sold to MND NSW resulting in a donation of \$7,000.



Bunnings BBQ



Entrance to the Ballinger's beautiful garden

In October marketing staff at **American Express** had a wonderful night living it up in the 70s style and at the same time raising money for MND NSW. The party 'Disco Inferno' was held at Darling Harbour and guests, clothed in fancy dress danced to a DJ, and had fun with a silent auction. Thank you to **Lesley Longley** who organised the whole event.

Hugo's Bar in the heart of Kings Cross was a most suitable venue for MND NSW's Cocktail Party and Art Auction in November. Seventeen different and interesting original paintings were displayed ready for a fun silent auction. Organiser and volunteer **Debra Larizza**, assisted by Roslyn Adams, said she was delighted with the evening. "It was lovely to see so many new faces and watch as people participated in the auction." **Justine Mossman**, whose partner died twelve months ago from MND, organised the complimentary venue and food. This was a special night in more ways than one because it was the inaugural joint effort of MND NSW and MND Australia.

Thursday 7 December 2006 was **ICAP's** 14th global annual Charity Day and this time they chose MND NSW as one of the nine charities to benefit from the day in Sydney. ICAP is the world's largest voice and electronic interdealer broker with a daily average transaction volume in excess of \$1 trillion, 50% of which is electronic. Each year the various branches across the world have a day on which all revenues and commissions are given away to just a few charities, which means each receive

a large amount of money which will really make a difference to their operations. When the cheque arrived in the mail a few days later we discovered we had been blessed with an amazing total of \$74,000.

A pre-Christmas showing of the movie 'Happy Feet' gave residents of Tamworth an opportunity to see a great film and contribute towards finding a cure for MND. It was organised by **Colin and Helen Pearce**, whose daughter-in-law lived with MND, and raised thousands of dollars for research into this terrible disease. Although there is little to smile about MND the movie certainly brought many smiles to faces.

Once again the **Oliver Family and parents, Sue and Bob Dunn** put together a spectacular Christmas Light display for the lucky people in Cowra. Still hurting from the drought and the closing down of the abattoir, the community managed to put their hands in their pockets and donated a large sum of money to buy much needed equipment for people living with MND. The Oliver children handed out lollies and lots of Christmas Cheer to the visitors. We really do appreciate this great effort and support from the Dunns, Olivers and people of Cowra.

Sharon and Steve Buckley, whose lives have also been touched by MND, held a dance night at the Coffs Harbour Ex-Services Club on Saturday 17 March. CEO Graham Opie attended the evening. Money was raised to support research and was passed on to the Australian Rotary Health Research Fund



Roslyn Adams and Debra Larizza



David Spanton and Judy Ford

where every dollar is matched with another dollar.

On Tuesday 20th March a most successful golf day was held at the Pennant Hills Golf Club. Organisers **Hamish Pearce and Mark Golding** planned this wonderful day to help two charities – StaR Association and MND NSW. Some amazing prizes had been collected for the auction and raffle. Many thanks to **Joy Pogson and Liz Sandwith** who helped sell merchandise during the day and **Bob and Suzanne Ballinger** who took over for the evening shift. Once again our volunteers were there when we needed them. The financial outcome of the day was dazzling and divided equally between the two charities.

In March Armidale came out in force to support a Benefit Night for MND NSW in conjunction with The Australian Wool Fashion Awards (TAWFA) held at the New England Girls' School (NEGS) Equestrian Centre. Organised by a committee of Armidale families whose lives have been touched by MND included **Dianne and Bruce Sewell, Steve Sewell, Sally and Chris O'Shea and Kerrie Pearson. Liz Foster**, Managing Director TAWFA was instrumental in providing the inspiration for the event as the fundraiser followed on from the gala TAWFA parade on the previous Saturday and the luncheon on the Tuesday. Invest Blue Armidale through

the AMP Foundation's Community Fundraising Program which supports the community work of Financial Planners matched donations up to \$10,000.

Nicholas Merry lost his father to MND and his mother to Cancer. In memory of his parents, Nicholas trekked Kilimanjaro in June 2007 to raise funds for MND NSW and the CANCEL Council.

Also in June we were the beneficiary of the Roseville Memorial Club's Annual Charity Dinner which raised a record amount for their seventh event of \$24,000 for MND NSW. Congratulations to the directors and staff of the club who organised the event and club members and the community for their support of the event not only by attending but by way of donations of raffle and auction items.

MND Week 2007

Lots of volunteers, beautiful weather, new merchandise and determination were the ingredients of this year's MND Week and in particular Cornflower Blue Day.

The week started with the annual launch, again at our new venue, the Waterview Convention Centre in the grounds of Bicentennial Park. We were fortunate to have **Associate Professor Roger Pamphlett** give us a very comprehensive overview of current



Scenes from ICAP's Global day



Carol Birks, Roger Pamphlett, Janet Nash and (in front) Paul Brock at the launch of MND Week

research across the world and especially the good work done by our own scientists in Australia. Although he could not tell us of any break through or cure on the way, he did give us hope that his work, in particular, was progressing well towards identifying some of the causes of Motor Neurone Disease. This year there was no March of Faces but we did have our banners on display at the Launch.

Once again we had an army of volunteers out on the streets, at stations and in shopping centres selling merchandise and spreading the word about MND and the Association. Sitting or standing for hours trying to catch the eye of people passing by is not the most exciting thing to do so we really do value you giving up your time and helping us in this way.

Thank you to the people who held events during or around the time of MND Week. In particular, **Lorraine Walker** at Binalong for her "Out of the Blue" dinner auction and **Gemma Cooney** at Penrith for her Irish Night.

Volunteers

MND NSW was able to thank its volunteers on two occasions in May. At the launch of MND Week 2007 medallions were presented to eight volunteers, who, over a number of years have given up their free time to assist the Association in a variety of ways.

When extra help has been needed these wonderful people were only too happy to help with some of the, sometimes, tedious and monotonous tasks like stuffing envelopes, packing merchandise, counting cornflowers and photocopying Family Support manuals. They have been our receptionist, entered masses of data, or turned a chaotic merchandise storeroom into a sparkling showroom. Some have utilised special talents and skills such as helping acquire gifts for auctions and prizes, organising large events and holding special massage clinics for our members.

Medallions were presented to **Debra Larizza, Margaret Orr, Joy Pogson and Judith Saladine**. Unfortunately not all were able to be present on the day. Our thanks have been passed on to **Libby Gole, Pamela Hennessy, Gregory Morrison and Christine Williams**.

The next day the Fundraising Institute of Australia held a special presentation and luncheon for volunteers during Charity Awareness Week at Parliament House. **Debra Larizza** received the certificate from Michael Foggo, Commissioner, Department of Gaming & Racing, on behalf of all our volunteers. This was followed by lunch in the Strangers' Dining Room where she joined Fundraising Manager Judy Ford and two other long serving volunteers, **Bob and Suzanne Ballinger**.



Volunteers at the Binalong MND Week event



Joy Pogson, Margaret Orr, Debra Larizza and Judith Saladine with their awards

In Memoriam

We receive many donations in memory of a loved one who has lived with MND. This year we remembered:

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Ackroyd, Miss Betty	Cormick, Ms Evelyn	Hasapis, Mr Jim	Montgomery, Mr
Armstrong, Mr	Cornish, Mr Clarence	Haydon, Mr Kenneth	Maurie
Raymond	Cripps, Kerrie	Haylock, Mr Peter	Moylan, Mr John
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Peter	De Silva, Dr. Gitanjali	Heath, Philip	Newman, Garry
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Bell, Mrs Gwen	Driscoll, Mr Terry	Hutton, Mr John	Pateman, Mr Leslie
Bell, Mr Keith	Dunham, Richard	Ikin, Mr Adrian	Pearce, Mrs Fiona
Bevk, Mr Charles	Eichler, Mrs Marianne	Jansen, Joe	Peattie, Mr Alan
Black, Mr David	Fairlie, Mr Ian	Jarvis, Wendy	Sidney
Blackburn, Mr Bill	Falkingham, Joyce	Joannou, Mr	Pfennings, Mrs Anne
Blackburn, Mr Keith	(Corrie)	Demetrios	Phoenix, Mrs Jenny
Blackwell, Mr Alan	Farmilo, Mrs Ella	Klose, Mr	Pickup, Mrs Kay
Bolton, Mr Brian	Faul, Mrs Mary	Koenig, Mrs Susan	Poulsen, Mrs Joan
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Bourke, Mr Clint	Jenny	Layia, Mrs Mary	Ranzenbacher, Mrs
Bowden, Miss Isobel	Fischl, Mr Heinz	Longhurst, Mr Gary	Anna
Bradley, Mr William	Fitzgerald, Mr Brian	Lumsden, Mrs	Riley, Dr. John
Brooke, Mrs Patricia	Foley, Arthur	Noreen	Sandwith, Mr Nigel
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Bulgin, Mr Peter	Fowler, Mr Les	Manley, Mrs Mary	Simpson, Mrs Leone
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Burgin, Mrs Betty	Gale, Mr Bryan	Matthews, Mrs Marie	Symonds, Eddie
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Burst, Mr Rudolf	Garside, Mrs Joan	Pamela	Phillippe
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Chain, Mrs Rose	Gould, Mrs Evelyn	David &	Wilson, Mr Michael
Cheah, Mrs Kim	May	Montagnese, Mr	Zito, Joyce
Christopher, Mr Bill	Gregory, Mr Edward	Francis	

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The Community Sponsorship Programme
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