

motor neurone disease association of nsw



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.

# 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.

# patron

Her Excellency Professor Marie Bashir AC Governor of New South Wales

### Vice Patrons

Melinda Gainsford Taylor Kevin Langdon OAM The Hon Mr Justice Peter W. Young Dr Paul Brock AO

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## medical advisors

### Dr Helen Herz

Calvary Health Care, Sydney

### Associate Professor Matthew Kiernan

Prince of Wales Medical Research Institute and Prince of Wales Clinical School, University of New South Wales

### Professor Garth Nicholson

ANZAC Research Institute Concord Hospital & University of Sydney

### Associate Professor Roger Pamphlett

Department of Pathology & Stacey MND Laboratory University of Sydney

### **Professor Dominic Rowe**

Department of Neurology Royal North Shore Hospital

# board members

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Gary Jacobson Member

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# THE BOARD AGREED TO PROVIDE AN EXTRA \$100,000 FOR THE PROVISION OF EQUIPMENT, DRAMATICALLY DECREASING WAITING LISTS

# executive report

An increase in government support; a strong consortium approach; an increase in membership; and an international flavour to end the year.

After a slow start in the operation our FlexiRest program – a consortium approach to respite between Muscular Dystrophy, Multiple Sclerosis and Motor Neurone Disease Associations – has proved to be extremely successful. In its initial year 32 people with MND, their families and carers have taken advantage of this innovative, family centred program.

The NSW Department of Ageing, Disability and Home Care have been actively involved with the Association working to decrease assessment time and making available more High Needs Pool and Attendant Care Packages to people with rapidly degenerative neurological disorders. In late 2007 DADHC provided one off grants to assist with our equipment pool and to help fill identified gaps in service provision. This money will be expended over the next 2 – 3 years.

The NSW Department of Health have again supported MND NSW providing 20% of our ongoing funding. We are working with the DoH, investigating ways of increasing support to MND Clinics, an invaluable service for people with MND.

MND Week proved a huge success with print media monitored across Australia for the first time. This was extremely successful with between 2 and 3 articles published each day through May. The theme - Living Better for Longer was supported by a DVD featuring Stephen Hawking, produced by ALS Israel.

The board increased MND NSW's level of funding to research to \$120,000 in 2008 and agreed to provide an extra \$100,000 for the provision of equipment, dramatically decreasing waiting lists.

Staff leaving the organisation in 2007/2008 included Judy Ford, Karen Kemp, Fern Linden and Trevor Rakuraku. New Staff are Kym Nielsen (Fundraising Manager), Eileen O'Loughlen (Regional Advisor Newcastle), Robyn Peterson (Regional Advisor), Iva Plessnitzer (Regional Advisor ACT & Southern NSW) and Michael Walker (Equipment Assistant).

Our Vice Patron Dr Paul Brock AO has again been extremely active advocating for people with motor neurone disease. In July the NSW Government announced scholarships for PhD research in the area of induced pluripotent stem cells to... "be known as the Dr Paul Brock Scholarships in honour of the tireless efforts of Dr Brock in promoting research into serious disease, in particular motor neurone disease."

During the year we have taken steps to increase services to rural and remote NSW. This includes investigating video conferencing for in-services, a full-time info line operator to allow regional advisors more time with clients, a streamlined database – less time at the computer and a provision to partner with Multiple Sclerosis Association NSW/ACT/VIC on our Volunteer Visitor program.

During 2007/2008 the Hunter Newcastle Support Group and MND ACT decided that they would de-register as Associations. This has come about as the onus of operating a small association often falls on a few individuals. For over 25 years individuals within these Associations have worked tirelessly to support people with MND and their families and we thank them. I would particularly like to thank Helen Christiansen in the ACT, Paul Kentwell, Christine and Allistair Fyfe, Barry Harrison, Linda Bower and Norm Minton in the Hunter Newcastle area and other volunteers too numerous to mention. MND NSW has and always will provide equipment and services to these areas and across NSW. Support has increased in the Hunter with two regional advisors based at the John Hunter Hospital and in the ACT where our Regional Advisor is now based at Pearce.

This year saw a growth in the cooperative approach of MND Associations from across Australia. The national work of the Executive Management Group, CEOs and managers from state MND associations and MND Australia was exemplified in our national theme for MND Week Living Better for Longer and our increased service delivery to people living in regional and remote areas. MND NSW partnered with MND Australia to broaden our reach to the Northern Territory.

This year we have been overwhelmed by the support provided by individuals and community groups. With over 80% of our recurrent funding provided through donations, bequests and fundraising activities the year saw a surge in these community based activities. A full list of donors appears in the back of this report and we thank you for your outstanding efforts.

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# 93% OF RESPONDENTS WOULD DEFINITELY RECOMMEND OUR SERVICES TO OTHERS LIVING WITH MND

# family support

The family support service provides information and support to people affected by MND. This includes regional advisors, information, equipment, and support 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.

In 2007 a Member Satisfaction Survey was conducted to provide MND NSW with information about members experiences of our services. Overall satisfaction was high and it was good to see that 93% of respondents would definitely recommend our services to others living with MND and another 6% would probably recommend MND NSW. Our highest ranked activities were the Equipment Loan Service, Carers Kit, information provided when contacting the Association, such as the Info Line, and the Forum newsletter.

While our members valued our services, with over 87% rating services good or better, the survey highlights the need for comprehensive services for rural NSW. This has been considered in our planning throughout the year and MND NSW has made a commitment to improving access to our regional services.

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 people living with MND. This helps to ensure a seamless service for people with MND and their carer and minimises duplication of service.

This year the 4th National Annual MND Conference was hosted by MND Victoria with 275 delegates from around Australia and New Zealand. This was an increase of 100 delegates from the previous year's conference held in WA. The day before the conference family support staff from across Australia met to discuss the issues they face in addressing the needs of people living with MND.

Jane Barrett, Family Support Coordinator, presented a paper at this conference entitled 'FlexiRest, a new respite initiative for people living with motor neurone disease, muscular dystrophy and multiple sclerosis'. Presenting at conferences such as these promotes recognition of MND and the needs of people living with this 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.

Following the Melbourne conference MND NSW was fortunate to host a visit to Sydney by Dr David Oliver who was a keynote speaker in Melbourne. Dr Oliver is a consultant physician in Palliative Medicine from Wisdom Hospice in Rochester, UK who has worked closely with people with MND and has spoken and written widely on their care and the control of their symptoms. His visit to our Gladesville office provided a great opportunity for family support staff to consult with him and he generously shared his knowledge and experience with us. Dr Oliver did a talk to health professionals hosted by the Sacred Heart Palliative Care Service entitled Palliative Care & MND - the Challenges. More than 60 health professionals attended this talk.

### **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. The regional advisors aim to ensure that no person living with MND has a high level of unmet need. This usually means that people whose needs are high and changing rapidly have regular contact from their regional advisor. Others who are relatively stable and linked in to appropriate services, have less frequent contact.

During the year 170 people were newly diagnosed with MND and became members of the Association. The Association was advised of 157 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 2008, services were being provided to 346 people living with MND, their families and carers in NSW and the ACT. While this number was slightly less than in 2006/07 for the first three months of 2007 numbers were as high as 360 which increased the workload for family support staff significantly.

### **Regional Advisors**

	2006/7	2007/8
New members	164	170
Number of deaths	146	157
Home/hospital/office Visits	472	424
Regional advisors phone calls	1624	2115

An increase in regular phone contact with people is very important particularly in regional NSW.

In early 2008 the MND ACT association ceased its incorporation. As part of our continued commitment to providing support to people in the ACT and southern NSW we now have our regional advisor located in the office previously occupied by the ACT Association. In May 2008 the number of regional advisor hours was also increased so that support services to this area could be enhanced.

This brings the total number of hours for regional advisors to 158 hours per week. Six regional advisors support people living outside the Sydney metropolitan region. Three of these are based regionally ensuring a more responsive service. The other regional advisors support rural and regional people through field trips, telephone calls and emails to ensure the best possible care wherever people are living.

PART OF OUR
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Regional advisors continue to forge links with service providers who provide care and support for people living with MND in their regions. 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. It is these people who deliver the essential services needed.

Advocacy at the grassroots and government planning level continues to be a focus for the family support team in order to ensure that the needs of people living with MND are promoted. Service providers are increasingly aware of the rapidly progressive nature of MND and the need to respond accordingly. Recurrent funding from NSW Health and project funding from the Department of Ageing, Disability and Home Care (DADHC) continues and is greatly appreciated.

During 2007/08 two new services for people with MND have been funded. Firstly, DADHC funded the NSW Community Options Program to provide MNDPacks. These provide funding for case management and direct service

provision for up to six weeks so that a rapid service response can be provided to assist people to remain at home. This program has resulted in our regional advisors working more closely with case managers to provide services for people with MND. This program will continue through 2008/09 with funds provided from DADHC

Secondly, FlexiRest commenced in 2007. This flexible respite program was funded by DADHC following representation from a consortium of MND NSW, MS Society of NSW/Vic and the Muscular Dystrophy Association of NSW. As at June 2008, 32 people with MND and their carers had received assistance through this funding.

### 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, to have information 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 organisations from around the world. 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, 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 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 MND NSW office on either (02) 8877 0999 or the freecall number 1800 777 175. Information distribution and dissemination has continued to be a focus of our work and calls to and from the "info line" continue to demonstrate the importance of this vital service.

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# SUPPORT GROUPS CONTINUE TO THRIVE THROUGHOUT NSW AND ARE THE "FACE" OF THE ASSOCIATION IN LOCAL COMMUNITIES, RAISING AWARENESS ABOUT THE DISEASE AND SUPPORTING PEOPLE WITH MND.

	2006/7	2007/8
"Info Line" calls	3260	3017
Literature provision	850	1303
Information sessions	100	95
Newsletters	4/1400	4/1700
Special Interest Group E-Bulletins	6/200	6/243

Membership of the special interest groups continues to be active with 243 health professionals now receiving the bi-monthly bulletins and invitations to annual workshops.

The provision of information and education to service providers is a high priority for regional advisors. During the year the family support team conducted 56 information/education sessions for service providers and community groups with an audience of 339.

The website at www.mndnsw.asn.au provides accessible information about MND and a means of communication with the Association for Internet users. During 2007 we were assisted to develop a new website through the generosity of an individual who had a personal experience with MND. The new website will be completed late 2008.

### 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. 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.

This year we have focused on purchasing larger items of equipment including electric beds, electric wheelchairs and lightwriters. These are large cost items that are essential to people who have MND. Thanks to the continuing support of donors and DADHC.

Equipment loans:	2006/7	2007/8
Number of equipment items	1246	1370
New items acquired	233	124
No. of items	1048	975

### **Group Programs**

Support groups continue to thrive throughout NSW and are the "face" of the Association in local communities, raising awareness about the disease and supporting people with MND. Regional advisors coordinate some groups and attend many of the others regularly to support and recognise their valuable work.

There are now 10 active support groups throughout NSW which meet monthly or bi-monthly. A new support group facilitated by our regional advisors commenced in the Newcastle during this year

People who have been recently diagnosed, their families and friends have specific information needs. Information evenings are held regularly at the MND office in Gladesville. These have been very well attended over the last 12 months providing an opportunity to gain first hand information and 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 2007 and was attended by 24 people with MND and their carers.

Carers of people living with MND have specific needs. The four week Care for Carers program was held twice in Sydney over the year and these will continue in 2008/09, demonstrating the need for carers to gain much needed mutual support and information.

Three 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.

## research

Jennica Winhammar



For my Bill Gole Fellowship, I am determining whether a novel neuroprotective medication can slow down the rate of motor neurone disease progression, by undertaking a double-blind, randomized controlled clinical trial.

The trial is being directed through the Prince of Wales Medical Research Institute and consists of a lead-in phase whereby patients are observed at 4-weekly intervals over 12 weeks which establishes the patients rate of disease progression. After a successful lead-in phase the patient is randomized to receive trial medication or placebo. Both the investigators and patients are blinded to treatment allocation. From this point onwards the patient returns every two months for monitoring of disease progression using a variety of tests such as peripheral nerve excitablity, transcranial magnetic stimulation for motor cortex excitability, grip strength and walking test for physical strength, respiratory function tests for respiratory monitoring and the ALS functional rating scale recised (ALS FRS-r) and the Short Form 36. During the treatment phase, patients are also contracted by telephone to check for adverse events and scoring of the ALS FRS-r. After eight of the two monthly visits the patient has completed the clinical trial.

Recruitment has commenced and there are currently 25 patients enrolled in the trial. No major adverse effects have been reported to date, and the trial medication has been well tolerated. It is anticipated that by the end of the year there will be 50 patients in the trial, half of the patients needed to complete the study. I would like to thank my colleagues involved in the trial, particularly Ben Cheah, Steve Vucic and Matthew Kiernan, and the Motor Neurone Disease Research Institute of Australia for grant funding.

IN 2008
MND NSW
PROVIDED OVER
\$120,000 FOR
RESEARCH

# WHAT A FABULOUS YEAR IT HAS BEEN FOR FUNDRAISING WITH SO MANY GENEROUS PEOPLE DONATING THEIR TIME AND MONEY TO SUPPORT MND NSW

# fundraising

What a fabulous year it has been for fundraising with so many generous people donating their time and money to support MND NSW. We established a new direct mail campaign the "Circle of Courage" and what a wonderful response we have had. Thank you to everyone who has joined this very special club of supporters. Our fundraising covers many different areas including direct mail, merchandising, support from clubs and corporate and of course the great events held throughout the year by caring individuals and groups. These events not only raise vital funds for our association but help raise awareness of MND and those living with this dreadful disease. The diversity of the events this year and the fabulous outcomes are a tribute to our loyal supporters.

## Peter Hammerman's 60th Birthday Celebration

Peter Hammerman and his wife Kitty decided that instead of Peter receiving lots of lovely gifts for the special occasion of his 60th Birthday that they would invite their guests to make a donation to MND NSW. We thank Peter and Kitty very much for thinking of MND NSW and their guests for supporting their wishes.

### Singleton Lawn Bowls Charity Day

Greg Cleary, whose wife Sandra has MND organised a Lawn Bowls Day on 23 September 2007. Greg organised this event single handedly to raise money as a way of 'giving back' to the Association as he knows that this helps to keep loved ones with MND as comfortable as possible through the facilities of the Equipment Loan Pool. It was a great day with 68 people attending. Greg said that he was overwhelmed with the support he received.

### White Christmas

On the 21st of December, Isaac Greenall and Vanessa Juresic organised a Motor Neurone Disease charity event. They planned the event around the Christmas period and had it themed for their annual event at the Hunters Hill Club - "The Hunters Hill White Christmas Party".

On the entertainment list there were caricaturists, DJ's and barefoot bowls, fabulous raffles and silent auctions. Despite the horrific weather of the night, the event was a huge success raising money to be directly donated to research. The Association is most appreciative of Vanessa and Isaac's fundraising efforts for research and thanks them for their contribution.

### "Hit It for MND" Golf Day in Batemans Bay

Where would we be without people like Melissa Love who decided to hold a charity golf day on Friday 7 March supporting Motor Neurone Disease after hearing about the disease at a 'Women in Business' presentation?



Melissa worked very hard to put the day together and was well supported by her employer WIN Television. The Association is extremely grateful to both Melissa and WIN for their support and to the Catalina Country Club for providing such a lovely venue.

By all accounts it was a most enjoyable day and we thank Melissa most sincerely for organising this event; what a great way to spend a Friday!

We are also most appreciative to all of the individuals and companies who supported the day by way of playing golf, making a donation, contributing a raffle or auction prize and volunteering to assist in any way possible.

### MonStar Cup is a Monster effort again!

On Tuesday 18 March a very successful MonStar Cup golf day was held at the Pennant Hills Golf Club. Organisers Hamish Pearce, Mark Golding and Greg Hargreaves planned this fabulous day for the second consecutive year to assist two charities – The STaR Association and MND NSW.

Starting at 6.30 am the enthusiastic golfers registered and set out for a beautiful morning of golf, Melinda Gainsford-Taylor our Vice Patron played the morning round which was great. All the golfers had a thoroughly enjoyable day. The evening buffet was extremely well attended and again there was dancing to Jelly Bean Jam. The live auction, silent auction and raffle prizes were simply amazing and the generosity of those who donated them was much appreciated. John Morris from Wests Tigers joined us and held up a Tigers jersey for auction which needless to say sold well. We would also like to extend our thanks to the Pennant Hills Golf Club for their support on the day, it was a long day for all concerned and nothing was too much trouble. Our thanks must also go to the family and friends of Mark, Hamish and Greg who gave such wonderful support to this event.

The financial outcome of the day was again an incredible result and divided equally between the two charities.

# THE DIVERSITY OF THE EVENTS THIS YEAR AND THE FABULOUS OUTCOMES ARE A TRIBUTE TO OUR LOYAL SUPPORTERS.

### MLC Advice Solutions Ambrose Golf Tournament, Hyatt Coolum

On Sunday 9 March, the PGA course at the stunning Hyatt Coolum on the Sunshine Coast hosted a charity golf tournament for MND NSW.

Hamish Pearce, is a Financial Adviser with Goldram Financial Planning, who is licensed through Apogee Financial Planning, an MLC business. Hamish's boss, David Clark nominated MND NSW as the recipient of MLC's inaugural Risk Specialist Network Charity Golf Tournament due to Hamish's personal experiences with MND and the Association.

Thousands of dollars was raised on the day through competitions, fines and additional donations. In a fitting end to the tournament, David Clark was a part of the winning Ambrose team.

Our thanks to MLC Advice Solutions, Lena Ridley from MLC and David Clark for nominating MND NSW and of course to all those who participated in the golf tournament making this a great fundraiser.

### Fundraiser at Curl Curl Netball Courts

One of our wonderful members who is a great netball fan and player held a fundraiser on Saturday 10 May to sell merchandise which was a great end to MND Week. Laraine sold everything she took along on the day which was a fabulous effort: 100 cornflowers, 170 pairs of socks and 600 wristbands! Thank you to all the girls who volunteered to assist Laraine by selling merchandise and to everyone who made a purchase and of course a big thank you to Laraine for organising the event.

### Blue Week at ANZ Bank Springwood

Each year the ANZ Bank Springwood has a Blue Week where the staff nominates a charity and raise funds during the week within the bank; MND NSW was fortunate enough to be the chosen charity this year. A competition to guess the number of 'blue' jelly beans in the jar was a great fundraiser. To end the week a sausage sizzle and raffle were held outside the bank. With the assistance of wonderful volunteers a successful day was had. Our sincere thanks go to Margaret, Des, Lyn, Aris, Dane, Beck and especially Karen who initiated the event.

### The Lindsay Butler & Shaza Leigh Show

A country music concert was held at Cessnock Ex-Services Club on Saturday 5 April. This event was run by Shirley & Stephen Peters to honour Shirley's brother Ron who lost his battle to MND in 2007.

The artists included Lindsay Butler on guitar and Shaza Leigh on vocals; there were also two guest artists, Greg Bain and 'The Last of the Travelling Showmen', Brian Young.

The 150 attendees were treated to a great night including a raffle with 35 prizes! Stephen also showed some auctioneering expertise and held a live auction.

Wonderful support was received from businesses in the local and surrounding districts and we would like to extend our sincere thanks to all of those who supported this fun evening of entertainment.

Congratulations and thanks go to Shirley and Stephen who are planning a bigger and better event for next year so stay tuned!

### **Wests Tigers Players Dinner**

Wests Tigers Rugby League Club donated part of the proceeds from a Players Dinner to the Motor Neurone Disease Association.

The sold out players' dinner was held at Balmain Leagues Club on Friday, 9 May, and was attended by several of the Wests Tigers players.

Wests Tigers half-back John Morris has been a great supporter of MND after losing his father to the disease in 2002. Team-mate Bryce Gibbs also lost an uncle to MND, so it is an organisation very close to the hearts of the Wests Tigers players.

We thank Wests Tigers most sincerely for their ongoing support.



MND NSW Board Member Alex Green with Wests John Morris

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# VOLUNTEERS WERE A VITAL PART OF THE FOUNDING OF OUR ASSOCIATION AND ARE JUST AS IMPORTANT TODAY. WE HAVE VOLUNTEERS FROM ALL WALKS OF LIFE WHO ASSIST US IN MANY WAYS.

### **Newcastle Basketball Exhibition Match**

On Saturday 10 May, the Basketball Association of Newcastle held a fundraising event by way of an exhibition match of basketball between the Newcastle Hunters ABA Women and the Australian Gems Under 19 Women.

The entry fee was donated to MND NSW and a raffle was also held to raise funds. The event came about because of a special young man, Elliott Jay who lost his fight with motor neurone disease at the tender age of 19 in April.

It was a very exciting match with a crowd of over 400 people which created a great atmosphere for the game. There was excellent play by the girls and the final score was Gems 68 to 65.

### **MND WEEK 2008**

I would like to thank each and every one of our wonderful volunteers for their support during this important week in the MND calendar: starting with the volunteers who come into the office and pack the merchandise orders to be sent far and wide throughout Sydney and the state of NSW; to those who each year volunteer at a railway station, a shopping centre, a street stall, the Qantas terminal, their place of work, at hospitals etc.

The week started with "Let's Launch MND Week together" at the Waterview Convention Centre in the grounds of Bicentennial Park for the third consecutive year. We were very fortunate to have Her Excellency Professor Marie Bashir AC CVO, Governor of NSW officially launch MND Week who spoke with warmth and wisdom about motor neurone disease. Our guest speaker Professor Garth

Nicholson, The ANZAC Research Institute, Concord Repatriation General Hospital & University of Sydney spoke about the latest research which was most interesting and informative for all concerned. Carol Birks, National Executive Director gave a national and international perspective of MND which gave everyone a feel about MND Associations on a global level. Ben Fordham, Channel 9 presenter did a wonderful job as MC and brought us all together for a time of reflection. For the first time, we invited Her Excellency to light a candle of Hope and Rememberance and to say a few words of acknowledgement for people whose lives have been touched by motor neurone disease: those living and those who have lost their battle; their families, friends, carers and health professionals; this was followed by a minutes silence. 25th June was the ladies of RydeX Phoenix



Her Excellency Professor Marie Bashir AC Governor of NSW and John Morris from Wests

Women's Bowling Club fundraising bowls day to raise awareness and funds for MND NSW. One of their members Janice Berg has been struck down with this insidious disease and with visiting bowlers from Gladesville Bowling and Ryde City Bowling Club plus

some generous donations; the special day raised an impressive \$1500. Well done to all involved.

Helen Kelmsley and a group of dedicated friends organised a fundraising movie night in Bowral in memory of Helens husband James who passed away with MND in Dec 07. James was a gifted artist, and was responsible for the drawing of Ginger Meggs cartoons. The evening was a great success and raised over \$2000 for MND NSW.

Thank you to everyone who held an event for us this year. Your support is greatly appreciated.

### **Volunteers**

Volunteers were a vital part of the founding of our association and are just as important today. We have volunteers from all walks of life who assist us in many ways. Volunteers help us in administration of our offices at Gladesville, in the preparation of mailings for Forum, appeals and merchandies. Many of our volunteers sell merchandise for us and hold fundraising events. They are always ready to lend a hand when needed.



Volunteers prepare Forum for mailing

# circle of courage honour roll

Family of Late Kim Nga Le

Mr Simon Tame

John & Anne Haydon in memory of Kenneth Lawrence Haydon

Catherine Tuckwell

Doreen Delmas

Pat & Jack Davies

Mrs Marie Casey

Anthony Charles Simpson

Jim Mathews

Mr and Mrs Frank and Karen Marczan

Maryann Powney

Mary Lenehan

Lizzie & Tony Blake

Dr Stuart George Adams

Robert & Jean Martin

Patricia D Adams

Lena Leishman

John Fortey

Jan Bender

Jo Thomson

Christobelle Stolz

**Daniel Lewis** 

Colin Filmer

Lindsay Alchin

Beverley Taylor

Imelda Roche AO

Iva Davies

Gregory Corr

Joan Gray

Alan Gerald Budd

Marcella Robertson

Marie K L Aspinall

Dr Con Reed

**Buckley Family** 

Lois E Marshall

Leonie Cambourn

# WE **ARE MOST GRATEFUL FOR** THE CONTINUING SUPPORT WHICH WE RECEIVE FROM THE COMMUNITY

# honour roll

### In Memoriam

Mr Desmond (Des) Smith

Mr Eric Stano

Mr Peter Stearne

Mrs Beryl Stephens

Eddie Symonds

Mr John Taggart Ms Mary Jane Taylor

Mr Robert Thorne

Kathleen Thurgood

Mrs Audrey Troke

Mr Albertus van Miltenburg

Maria

Mrs Mary Vassiliou

Mrs Margot Verdegaal

Mrs Jean Walsh

Mr David Widdrington

Mr Norm Wilkinson Mrs Jennifer Williams

Mr Ted Wilson

Ms Lola Wilson

Ms Margaret Dawn Wilson

Mr Kenneth Winter

### Clubs

Batemans Bay Womens Bowling Club

Bathurst RSL Club Ltd

Campsie R S L Sub-Branch Club Ltd.

Cessnock Ex Services Club

Coffs Harbour Apex Club

Coffs Harbour Catholic Club

Coffs Harbour Ex-Services Club And Woolgoolga

Bowling Club

Cooma Ex-Services Club

Cronulla R S L Memorial Club

Eastwood Croquet Club Inc. Five Dock Park Women's Bowling Club

Gladesville Women's Bowling Club

Goulburn Art Club Incorporated

Lennox Head Bowls & Sports Club Lioness Club Of Camden

Lions Club of Condobolin

Lions Club Of Jervis Bay Inc

Lions Club of Parramatta

Lions Club Of Singleton Inc

Lions Club of Tamworth Peel Valley Inc.

Lodge Theo Grey

Mollymook Golf Club

Mt Beulah Chapter No 5

Murrumbidgee Country Quilters Inc.

Northbridge Cammeray Masonic Hall Co. Pty Ltd

Park Beach Bowling Club

Probus Club Of Seaforth Computer Group

Railway Tennis Club Rockdale RSL Club

Roselands V I P Club

Rotaract Club Of Lismore

Rotary Club Of Liverpool West Inc

Rotary Club Of Carlingford Inc

Rotary Club Of Concord Inc.

Rotary Club of Strathfield

Russell Vale Golf & Social Club

Sawtell RSL Club

South Sydney District Junior Rugby Football League

St Vincent De Paul Craft Group

The Model 'A' Ford Club Of Nsw Inc

Toukley Womens Bowling Club

Wednesday Morning Weigh Inn

Windsor Country Golf Club

Woolgoolga RSL Club

Yackandandah Riding Club

### **Schools**

Berkelev West Public School Blue Mountains Grammar School Bulli Public School Dapto High School Dapto Public School Epping North Public School Living Waters Christian College Mary Mackillop Primary School

MLC School St Andrews Public School St John's Primary School

St Mary's Star Of The Sea Primary School

Dapto

### Individuals and Families

Mr Mario Alfaro Ms Tracy Anders Ms Janice Barber Mr Charles Barone Mrs Mary Barone Mrs Olga Barwick Mr BHG Baynham Ms Heather Beasley Mr David Beavan Mr Alan Bennett Mr & Mrs John And Nigel Berlyn Ms Joy Bernasconi

Ms Elaine Bladen Mr S J Bora Mr Karl Bowen Ms Sarah Bower Mr & Mrs JL & WE Bradshaw Mrs Ann Breakey

Mr G Brown Mr Steve Brydon Mr P K Burrell Ms Leslev Calvert Mr Colin Capp Mrs Janet Chalker Ms Eileen Chaloner Ms Inez Chambers Mrs B Champion Mr Ngaire Clark Ms Helen Connell Mr Michael Cuberiwa

Ms Penelope Dalton Mr & Mrs Pam And Cliff Daly Mr Ross Davies Mr & Mrs Bl & Km Day

Mr & Mrs KM & RP Dellow Mr Jim Demries Mr D Donaldson Mr David Down

Mr & Mrs SM and JW Dwyer Mr Gilbert Fliott Ms Marjorie Elliott

Mr & Mrs F And M Fllis Mr & Mrs WR And RL Fairbairn

Mr Alec Fitzsimons Mr & Mrs AT and ME Ford

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Mr Ralph Garland Mrs Gina Georgiou Mrs E Gillespie and Family Ms Margaret Goodwin Mr Gilbert Halcrow And Mrs Belinda Halcrow-Clarke

Mrs V Hanlon Mr Mathew Hart Ms Anne Healy Mr J L Hemery

A V Holton Mrs R Hurst Mr Richard Im Mr Nick James Mr Stuart James Mr M Johnston

Mr & Mrs NJ And NP Jones W.R. Jones Dr. David Kershaw Ms Lisa Knowlson Mr H Kulhanek Ms Barbara Law Ms Rebecca Laws Mr M D Lee Ms Mary Lee

Mr Dwight Levinge Dr. David Liebing Mr & Mrs NC And SC Locke Ms Elizabeth Moffatt Lyall

Mr & Mrs C And Gw Legge

(Estate of the Late) Mr Lymberis Mr Jason Maclachlan Ms Tania Magoci Ms Sheela Maji Mrs Janne Marwood R J Mercer

Boguslaw Mikunda Mr Mirtsos Ms Pamela Mitchell Moira, Carrol & Mel Mr Geoffrey D Morgan

Mr Robert Morgan Mr & Mrs Tony and Mary Morrisson Mr Gary Moss

Mr & Mrs John and Marlene

Mr Paul Mura Mrs Jane Naudi Mr Alan Nicolle Mr W L Nielson Mr P OBrien Ms Ruth Okrutay Mr & Mrs C And M Omeros Mr Chris OSullivan

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**Pambris** Mr Con Parris Mr Ian Penningworth Mrs Margaret Pennycook N And A Petsalis Mr Terence Philpott Mrs Kaye Radovan Mr N Rae Ms Elba Rae Ms Nicola Ranson Mr B Raptis Mr R Richards

Dr. John Riley Mr P S B Rose Ms Joanne Rosenzweig Ms Eva Roslan Mr Tony Rowlands Mr Greg Rudkowsky J W Sadler Mr & Mrs Scott Mr Robert W Scott Ms Nell Sharpe Ms Susan Shaw Mr Kevin William Smith

Mrs Helen Spanos Mrs Kathleen Spry Mr A Sriganeshan Mr Ted Stanley Mr George Staples

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Mr Tom Wodzinski A Young Ms Daria Zahorodny

Mr Bradley Grimshaw Mr Ludwig Schmid Mr A Gow-Gates

The Hon. Justice Peter Young Lady WG Stephen

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Mr John Short Mrs M Smith Ms Carey Tan

Ms Sally Till

Ms Julie Tornet Ms Danielle White Mrs C Wilson Ms Gwen Fowler Ms M Hunt Ms Trang Nguyen Mrs D Cox Mr G Salthouse Mrs E Hipwell Mrs May Bott Mrs Pam Tate Ms Julie Becke Mrs E Campbell

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McCallum Mr Kenneth Plant Mrs M Wilson Mr & Mrs John And Beverley

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Mr & Mrs P Casey Mr & Mrs G & A Steele

Mrs F Shaw Mr A Grundy Mrs Nancy Mead Mrs Peg Jameson Mrs T Beckhaus Mr & Mrs K Hall Mrs M Sarah Mr & Mrs M F Gatto

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Mr G Thomson Mrs Lynette Thomson Mr N Rumsey

Mr & Mrs A and R Dobson

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Mrs P Dornan Mr & Mrs Peter And Irene Kardasis Mr Paul Kardasis Mrs Katon Ms Michelle Cullen Mr & Mrs Roger And Marilyn

Knowles Mrs L Charles

Mr & Mrs Warren And Elizabeth Ryan Ms Kaye Healey Mrs J Laver

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Ms Marilyn Cornish
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Ms Josephine Ziedan
Mrs Elini Dennis
Mr Roger Fletcher
Mrs Lyn Hughes
Miss Anita Jelusic
Mr Chris Lamb
Ms Pauline Clark
Mr Blago Milicevic
Ms R Boros

Mrs Anita Jeiusic
Mr Chris Lamb
Ms Pauline Clark
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Mr Philip Snelson

Ms Alex Snelson

Miss Camilla Tiernev

Mr Dragisa Zlatevski

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Mr Martin Watts

Ms S Sepaniak

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