



FORUM

MND Central Coast Support Group Carers Luncheon

To celebrate Carers Week 2010 the Central Coast Support Group organised a luncheon during October at the Caroline Bay Brasserie, Gosford Regional Gallery, for their member carers. Carers work tirelessly to support their loved ones and Carers Week is about celebrating their valuable contribution, whilst giving the carers an opportunity to take a break.

Official guests at the lunch included Graham Opie, CEO MND NSW; Vicki Scott, Councillor Gosford City Council; Kuba McCormack, Community Outreach Team, Northern Sydney and Central Coast Area Health Service; Kathy Lee, Home Hospice; and Jo Fowler, Regional Advisor, MND NSW.

Ageing, Disability and Home Care, Department of Human Services NSW, once again funded Carers NSW to help carer support groups put on an event or activity for Carers Week. We would like to say thank you for their support in making a memorable day for our carers.

Joining your local support group can be of great benefit to all people living with MND, carers and members alike. Sharing and learning helps reduce anxiety, improving quality of life. Making new friends, having a chat and laugh over a cup of tea can brighten the day.

Audree Dash

Central Coast Support Group



*Audree Dash, Ila Barlow and Kathy Lee
and below, the beautiful gardens.*



Stepping Forward with a touch of Blue

Connie Lopresti, who lives with motor neurone disease asked a friend to help her organise a dinner to raise money for MND research. Nine weeks later, on 5 November 2010, 640 people attended a night of fun, filled with food, entertainment and dance, an amazing raffle, silent auction and live auction prizes. Michael Tama, Maria Tama, Pina Valente and Maryanne Laggis worked tirelessly to make this a night to remember. The local community came on board with an unbelievable response; friends, family and strangers came together to help make a difference – Stepping Forward with a touch of Blue. Over \$170,000 was raised for MND NSW. Connie is wishing that through the money raised, a cure is discovered. Many thanks to the generous people in our community who helped make this evening so very special - it couldn't have happened without you.

Michael Tama

Event Coordinator

Stepping Forward with a touch of Blue



MND NSW will be closed from 12pm Friday 24 December 2010 until 9am Tuesday 4 January 2011.
If help is needed during the Christmas break, please consult your doctor.



Motor neurone disease is known as amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease in some countries. The Blue Cornflower has been adopted in most countries as the symbol of hope for people living with motor neurone disease.

Members Christmas Party 2010

The members Christmas Party at Ryde Eastwood Leagues Club on 20 November gave us all a wonderful opportunity to begin to celebrate the Festive Season.....



↑Graham Opie kicked off the day, by officially welcoming everyone and introducing the MND NSW Board and staff. Kate Maguire took on the role of MC and also drew the raffle tickets.



↑Petra Sammut and Margaret Orr sold the tickets for the fabulous array of raffle prizes that so many had the good fortune of winning on the day. Thanks to all who generously donated these prizes.



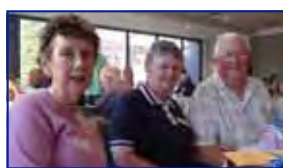
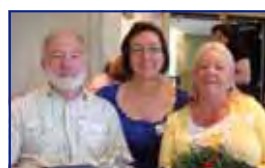
↑Staff were magnificently decorated in an array of antlers and festive head gear. This is David Wallace, Information Line Advisor, chatting with Janet Monaghan.



↓We were entertained by Bernie Segedin singing, accompanied by his guitar. The finger food was enjoyed by all.



↑Santa visited, bearing gifts for the children and delighting both young and old with his hearty wit and warmth.



↑The spacious light filled room enabled everyone to socialise and mingle with ease. In so many ways it was a day filled with gifts...the gifts of valued friends and family celebrated, and remembered; along with the gifts of new friendships forged.

Introducing...

Gail Ferguson

Regional Advisor



I am originally from Sydney, moving to the Central Coast and then relocating as a family to the ACT. Although I am based in the MND NSW Canberra office, I live with my husband and a few farm

animals on our hobby farm across the border in NSW.

I have worked and studied in the disability sector for ten years, originally supporting children, and during the past four years I worked as a case manager.

I am enjoying being part of the Family Support team and meeting the challenge of assisting families through their journey with MND.

Tom Giardina

Equipment Assistant



Where do I start? Born and bred in Gladesville I am currently living out of the area, but hopefully in the next year or so will be moving back into the suburb.

During the last 28 years I worked in the petroleum industry and I have a minor mechanical background.

My interests include rugby league, after my years in the sport; and golf – where my clubs are my handicap.

I have enjoyed my first six weeks here and I am looking forward to meeting more members and their families.



We are looking forward to welcoming the worldwide ALS/ MND community to Sydney in November 2011

A Message from the CEO

Our Annual General Meeting was held on Tuesday 26 October at the MND NSW Centre, Gladesville. Retiring from the Board are Bob Templeman and Gary Jacobson, both long serving members. Their contributions will be missed.

The MND NSW Board for 2010-11 is:

President - Phil Bower
Vice President - Roger Henshaw
Secretary - Janice Scheinecker
Treasurer - Bob Howe
Members - Phil Brady, Alex Green, Jon Masters, Michael Perry and Ralph Warren.

A copy of the Association's Annual Review is available at www.mndnsw.asn.au. Alternatively, if you would like a hard copy of the 2009-10 Financial Report or Annual Review please contact us on ph. 8877 0999 or email Petra Sammut at admin@mndnsw.asn.au.

Newly elected to the Board are Jon Masters and Michael Perry; welcome. At the Annual General Meeting the Board conferred Life Membership on Bob Templeman and Phil Bower. A brief overview of their work at MND NSW can be found on page 9 of this edition of *Forum*.

It has been a busy couple of months with many fundraising and family support events. Overviews of these activities can be found throughout *Forum*. Thank you to those involved, we appreciate your efforts.

One of these recent activities was our Sydney Walk to d'Feet MND. It was held on Sunday 7 November with a record turnout of over 500 people. Our online fundraising page at Everyday Hero was a hit with many people very successfully seeking support and sponsorship from friends and family.

During the past few months we farewelled two members of the staff, Matthew Fowler and Iva Plessnitzer. Joining us are Gail Ferguson, Regional Advisor, ACT, and Tom Giardina, Equipment Assistant.

We wish you a peaceful and safe Christmas and New Year. Thank you to all our donors for their support in 2010. Our office will be closed from 12pm Friday 24 December and will reopen on Tuesday 4 January. If help is needed during the Christmas break, please consult your doctor.

To all those who have lost loved ones and friends to MND I extend, on behalf of the Board and staff, our deepest sympathy.

Graham Opie
Chief Executive Officer

MonSTaR Cup
Friday 18 March 2011
 Pennant Hills Golf Club
www.monstarfoundation.com.au

Motor Neurone Disease Association of New South Wales

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Ayse Dalkic

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David Dubin

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Gina Svolos

Regional Advisors

Chris Carroll, Gail Ferguson, Jo Fowler, Caroline Gleig, Jenny Judd, Eileen O'Loughlen, Robyn Petersen, Noelle Smith

Information Line Advisor

David Wallace

Education and Carer Support Coordinators

Kristina Dodds, Kate Maguire

Equipment Service Coordinator

Maree Hibbert

Equipment Assistants

Tom Giardina, Michael Walker

Information Resources Coordinator

Penny Waterson



And.....many valued volunteers including the Forum packers for the September 2010 edition.

If you would like to receive Forum by email contact Petra Sammut by emailing your name, address and email address to admin@mndnsw.asn.au

Family Support Team

It's hard to believe that we are almost at the end of another year. Christmas is a time of coming together with family and friends and, for many, enjoying each others company. It can also be a time of mixed emotions as we reflect on the past year; sharing our happy memories, achievements and our hopes, as well as remembering our losses and times of sadness. We hope this Christmas is a time of peace and happiness for you and your loved ones.

In 2009 I was writing about how we had been developing more education programs in regional NSW and that it would continue into 2010. We have done this and plan to continue with more programs in 2011.

As you would be aware, educating the professionals who care for people with MND is a really important aspect of our work. The mission of the Association is to provide and promote the best possible support for people living with MND. Promoting the needs of people with MND, to professionals, hopefully results in people having the best possible care.

During 2010 we conducted more regional education sessions for health and community professionals than in previous years and we thought that perhaps not so many health professionals would attend our annual workshop in Sydney. What has been really surprising is that we had a huge response to our Special Interest Group (SIG) workshop held in Sydney during October. The number attending almost doubled previous year's attendances and we had to turn away some health and community care professionals who were interested in registering because we reached the capacity for the venue.

There were 174 people attending the SIG workshop this year from around NSW. It's great to know that so many professionals are keen and interested in increasing their knowledge of MND, so that they can make a difference to people with MND. Our heartfelt thanks to all those health and community care professionals who presented at the SIG workshop and at other events hosted by MND NSW. These people do this on top of their usual workloads and we appreciate the enormous effort they put into sharing their knowledge with others working with MND.

We were also able to offer some financial assistance with the cost of travel for regional professionals to attend the SIG workshop through funding provided by Ageing Disability and Home Care, Department of Human Services. Professionals from all over NSW attended including several from Ballina, Cootamundra, Forbes, Albury and Tamworth.

November is a busy time for our programs and 'Link and Learn' was held in Berry, 'Learn Now, Live Well' in Sydney and we also conducted training for eight more massage volunteers. There is more information on our recent activities below.

We are currently planning the Family Support events program for 2011 so please see the calendar enclosed in this newsletter or visit www.mndnsw.asn.au for up-to-date information.

Next year, the International ALS/MND Symposium will be held in Sydney from 29 November to 2 December 2011. This Symposium will attract researchers and clinicians working with MND from around the world and there will also be a day for people living with MND and their families. Keep an eye out for more information about these exciting events.

Gina Svolos

Manager, Family Support

Learn Now Live Well - November 2010

The Learn Now, Live Well program, ran over two consecutive Mondays at the MND NSW Centre at Gladesville. Eighteen members and family carers participated, with some travelling from as far away as the Central Coast and ACT to be there.

Over the two weeks the group had the opportunity to hear how to live well and maintain independence. Our speakers, who all have expertise in supporting people living with MND, included Caryn Kneale (dietitian), Christie Allen (speech pathologist), Jimmy Chien (respiratory physician), Jim Preece (physiotherapist), Kuba McCormack (occupational therapist) and Gavin Griffiths (massage therapist). We are exceptionally grateful to them all for giving so generously of both their time and experience.

It was clear from the positive feedback received from the participants that they appreciated the opportunity to gain new knowledge and to have their questions answered within a small group setting. Many also expressed how the program provided a valuable and enjoyable opportunity to connect with others with personal experience of living with MND.

If you think you might be interested in attending Learn Now, Live Well in 2011, let your regional advisor know.

Kate Maguire

Education and Carer Support Coordinator

Visit www.mndnsw.asn.au for more information about events planned for 2011

*You are welcome to provide us with feedback about our services at any time.
Ph. 8877 0999.*

Family Support Team (cont'd)

Link and Learn Workshop Berry

November 2010

MND carers from the ACT and Southern NSW were invited to attend 'Link and Learn', an MND NSW residential educational workshop held over two days and one night, in the beautiful town of Berry.

The invitation was accepted by five men and eight women, with eleven of those attending caring for

a spouse or partner with MND and the remaining two caring for a parent. Three of those attending had very young children. The workshop was free of charge to carers through a funding grant from Ageing, Disability and Home Care, Department of Human Services NSW.

The aim of the two days was to link carers with each other to share ideas, information and, as one participant said, "...to take off my mask I put on with my family and friends, (because I am) with others who are in the same position as me and know what I'm going through".

The carers learnt from their local health care professionals how to assist the person they are caring for to live well with MND. They also took some much needed 'time out' for themselves.

Some of the feedback from the evaluations included: 'it's OK not to be able to cope', 'don't blame yourself', 'accept help', 'plan early' and 'I am not alone'. In summing up the program, the carers said: 'great two days meeting new friends who understand', 'it was better than my expectations' and, 'this program enabled me to meet the people in the same situation as me. It taught me the tools to go forward. I no longer feel as scared about the future'.

Thanks to all those who participated and opened their hearts and shared their experiences. We look forward to keeping in contact.

Kristina Dodds - Education and Carer Support Coordinator

Robyn Petersen - Regional Advisor

Gail Ferguson - Regional Advisor



(L-R) Robyn Petersen, Regional Advisor, with Joy Van Heythuysen (above) and Kristina Dodds, Education and Carer Support Coordinator, with Rosanna Wallis (below) at Link and Learn



Special Interest Groups (SIG) Workshop Sydney

October 2010

Over 170 community and health care professionals came together at the Ryde-Eastwood Leagues Club for our annual SIG workshop. This was quite an unexpected turn out, nearly more than double the number we had anticipated registering for the event.

Why was it so popular? There are many reasons.

Firstly, the reputation MND NSW has in providing quality education about MND for community and health care professionals. The workshop had been a long time in the planning, with an advisory group to recommend topics and speakers. Secondly, the work of the MND NSW regional advisors and staff. All eight regional advisors are committed to raising the profile of care for people with MND and their families. Not only do they visit families in their homes, they also provide in-services and education to a range of health and community professionals. They were the ones who spread the word and encouraged people to attend and hear from the experts in the field.

The workshop provided a much needed opportunity for practitioners to meet with each other and network. One of the aims of the workshop was to get people from rural and regional NSW to attend, to decrease their geographical isolation and the isolation that comes



(L-R) Janelle Harvey, Narilan Grant, Lilliane Barone, Shellie Mason (above) and Jessica MacKenzie and Mary-Ellen Tarrant (below) at the SIG Workshop



from rural and regional areas to attend. We were also surprised by the number of people who attended from Victoria and Queensland. We were thrilled with number of case managers from community options programs who attended.

from caring for people with an uncommon but progressive life-limiting illness. Thanks to some funding from Ageing, Disability and Home Care, Department of Human Services NSW, we were able to offer financial assistance for professionals

(Continued on page 6)

Thinking about attending a Family Support workshop in 2011? Speak with your regional advisor for more information

Family Support Team (cont'd)

(Continued from page 5)

The 15 speakers presented in plenary and workshop style presentations, where interaction and demonstration was a highlight. From the feedback on the day, participants would have liked the workshops to be presented twice so that they could have attended more than one.

Sandra Erjavec, the Coordinator for the multi-disciplinary MND Service at Macquarie Neurology at the new Macquarie University Hospital spoke first about 'Understanding MND'. Sandra was a wealth of knowledge and gave many examples from her own practice. Dr Patricia Lillo, a researcher from the Frontotemporal Dementia Research Group led by Professor John Hodges, spoke of her research project on cognitive impairment and behavioural changes in MND.

Janet Monaghan, an MND NSW member who has had MND for 15 years, was a highlight of the day. She spoke of her experience of having MND and made us all think about what it would be like to have MND and how we would like to be treated – she gave those present some very useful strategies outlining some do's and don'ts.

Another highlight that emerged from the evaluations was Dr Frank Brennan's session on 'A Palliative Approach to MND'. He gave us a bit of a history lesson on Lou Gehrig, the famous American baseballer, and gave us insights into the journey of caring through the words of the Australian poet Bruce Dawe and his poem titled 'White Water Rafting'. Participants also valued his knowledge on symptom management.

Thanks to all the other speakers who gave their time to present. A particular thank you to Ross Black and Nina Brodaty from the Prince of Wales Hospital, and Alana Bain and Adam Lyn from the Spastic Centre for presenting twice. It was also great to have Vivian, the Executive Officer of NSW Community Options explain about the packages that are now available for people with MND that provide needs based assistance, relieving the caring and financial pressures often felt when living with MND at home.

We look forward to the next SIG workshop in 2012. During 2011, Sydney will be hosting the ALS/MND Symposium and we will be encouraging health and community care professionals to mark this important event in their calendar.

Kristina Dodds

Education and Carer Support Coordinator

Equipment

I would like to welcome the newest member of the MND NSW team, Tom Giardina. Tom works two days a week assisting in the maintenance and shipping of equipment and introduces himself on page 2 of this edition of *Forum*.

Christmas holidays are nearly upon us. Couriers have increased demand on their services during this time of year and delays can happen. Where possible, our equipment staff will give a time-frame for a delivery of an item but this may be changed by the courier due to circumstances in the delivery area. I ask that everyone be patient but if there are any problems to contact MND NSW and we will assist in solving the problem if possible.

MND NSW offices will close from 12pm Friday 24 December 2010 until 9am Tuesday 4 January 2011, for the short period between Christmas and New Year. If you have any urgent breakdown issues with your loaned equipment during this period please contact your occupational therapist or speech pathologist to assist you in arranging a repair. If your local occupational therapist is not available then contact your local hospital.

This year has been very busy with over 1348 loans of equipment made throughout NSW and ACT to over 285 of our members. Electric medical beds, alternating air mattress overlays, manual wheelchairs and specialised computer access devices have been a main focus on equipment demand and purchase this year.

As a reminder, if you are using a wheelchair and planning to book holiday accommodation it is important before you book to check the wheelchair access to the room and within the room; especially to the bathroom. Some accommodation is well set up and has equipment that can assist with your needs but it is always best to plan ahead as most venues can accommodate most requests if they are notified in advance.

Michael, Tom and I would like to wish everyone a safe and happy holiday season.

Maree Hibbert

Equipment Services Coordinator



Participants at the very successful Special Interest Group Workshop 2010

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close from
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until 9am
Tuesday 4
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Christmas and
New Year.**

Support Groups

Central West

In September, 36 people gathered at the tranquil Anula Healing premises in the Lake Canobolas area to remember family members and friends from the central west of NSW who had died from MND.



Reflections on bereavement were followed by a candle lighting ceremony during which we remembered all the courageous and inspirational people whose lives have been lost to MND. Local families, friends, carers, volunteers and health workers were all acknowledged as a community linked by the MND journey.

It was indeed a moving ceremony. We hope it strengthened those who attended through honouring and acknowledging their dedication and devotion

Jenny Judd, Regional Advisor

Northern Sydney (Hornsby)

We meet together every two months to enjoy a light luncheon and friendship. Looking back it has been a productive and informative year. Our guest speakers have included case managers, the MND DNA Bank manager, a massage therapist and speech pathologists.

Next year we will be continuing to meet on the second Thursday of every second month starting in February. I'm looking forward to seeing you all there.

Jo Fowler, Regional Advisor

Central Coast

Our successful application for a Carers Week grant made it possible for us to hold a luncheon at Caroline Brasserie during Carers Week for our wonderful carers, some members and special guests (see page 1). We were able to take the opportunity to use this event for press and radio promotion to extend the message to others of the advantage of joining their support group.

Also, we are presently involved with Rotary Community Raffle for the twelfth year, which we will finalise at our January meeting.

We meet bi-monthly at Gosford Senior Citizens Centre and, in 2011, our meetings will be on Thursdays at 1.30pm. This is a better time-slot for guest speakers and for Jo Fowler, MND NSW Regional Advisor, because it can fit in with her planned weekday visits to the Coast. Our first meeting will be 27 January.

Audree Dash, Coordinator

Northern Beaches

Our support group has continued meeting every second month despite a drop in attendance in the latter part of the year. We were sorry to learn about the loss of a number of our regular attendees. We send our deepest sympathy and love to their carers and families.

Our morning tea meetings commence at 11.30am and finish at 1.30pm. A 'cuppa' and light refreshments are served in the Palliative Care Cottage at Mona Vale Hospital. Parking is available nearby and a free parking voucher can be obtained from Sue Clains at the Cottage reception desk. If you would like more information about the group, please phone 8877 0999.

Jo Fowler, Regional Advisor

Visit
www.mndnsw.asn.au to view
upcoming
support group
meeting dates.

Support Groups

METROPOLITAN Ph: MND NSW 1800 777 175

Campbelltown - Robyn Petersen | robypn@mndnsw.asn.au

Gladesville - Caroline Gleig | carolineg@mndnsw.asn.au

Northern Beaches (Mona Vale) and Northern Sydney (Hornsby) - Jo Fowler | josephinef@mndnsw.asn.au

Western Sydney - Jenny Judd | jennyj@mndnsw.asn.au

REGIONAL AND RURAL

ACT and Southern NSW - Gail Ferguson | 6286 9900 | gailf@mndnsw.asn.au

Broken Hill - Jamie Mitchell | 08 8088 7093 (bh) or 08 8088 1333 (ah)

Central Coast - Audree Dash | 4384 2907 or Jo Fowler | 1800 777 175 | josephinef@mndnsw.asn.au

Central West - Jenny Judd | 1800 777 175 | jennyj@mndnsw.asn.au

Illawarra - Robyn Petersen | 1800 777 175 | robypn@mndnsw.asn.au

Newcastle and Hunter - Noelle Smith | 4921 4157 | noelles@mndnsw.asn.au or
Eileen O'Loughlen | eileeno@mndnsw.asn.au

North West (Tamworth) - Noelle Smith | 4921 4157 | noelles@mndnsw.asn.au

Our Volunteers

Massage Volunteer Program

Eight people attended our two day massage training early in November, taking the total number of volunteers trained since April to 21. For our November training, we were once again fortunate to have Wilma Davidson, a massage therapist from Canberra, as trainer for our enthusiastic group of new volunteers. Over the two days, the new group of volunteers learnt about motor neurone disease and how to provide our members with a simple hand and foot massage.

This means we can offer this valuable service to even more members in the Sydney region. Indeed the feedback that we have had from members over the last six months has been very positive. Members have reported that the hand and foot massages are not only very relaxing and enjoyable but that massage helps with stimulating circulation and provides relief for some discomfort and swelling. If you are interested in receiving a hand and foot massage, please contact your regional advisor.

David Wallace

Information Line Advisor



(l-r) Maria Johnson, Patricia Cummings, Wilma Davidson (top) and Mandy Hollins, Larissa Stanley, Maxi Davidson and Sue Spencer (above) at the Massage Volunteer Training

Melrose Health donated sample bottles of their H2Oil for our Massage Volunteer Training. Thank you Melrose Health.



Corporate Volunteers – Johnson & Johnson Pacific

A buzz of 13 Johnson & Johnson Pacific staff arrived at the MND NSW Centre at Gladesville on Friday 22 October. They had gardening tools in hand and sleeves rolled up. By lunchtime they had gardened, organised T-shirts for Walk to d'Feet MND, cleaned out the archive room, prepared publications for posting, compiled over 150 welcome packs for the Special Interest Group workshop, packed kits for massage volunteer recruits, stained two teak benches and counted and bagged Christmas cards ready for orders.

Johnson & Johnson Pacific have a social responsibility strategy and we thank them for choosing MND NSW as a recipient organisation and for allowing their staff to volunteer their energies and gain a greater appreciation of the services the Association provides.

I encourage other socially responsible organisations to contact me to discuss how MND NSW can work with them to foster a community partnership with our Association..

Ayse Dalkic

Fundraising Assistant



MND Volunteers Thank You Luncheon

On Thursday 14 October, our volunteers took time out from their busy schedules to come together for the annual MND Volunteers Thank You Luncheon. MND Volunteers are an amazing group of generous people from a variety of backgrounds and all have a special reason for connecting with the Association. Some of the volunteers come in to the MND NSW Centre at Gladesville on a regular basis to assist with administrative tasks, others massage the hands and feet of members living with MND and yet more sell MND merchandise to raise funds and awareness.

At the lunch, the volunteers sat outside and enjoyed the views of Parramatta River while Graham Opie, our CEO, cooked the sausages and kebabs. We were fortunate that the rain held off and we had a warm spring day. There was lots of chat about the activities the volunteers undertake as well as entertainment from Roseanna Gallo, a volunteer local entertainer who sang beautifully. There was even some dancing!

The volunteers were presented with an MND bookmark, pen and small native pot plant, as a token of appreciation for all the hours volunteered in providing real support and commitment to people living with MND through their volunteer work with the Association.

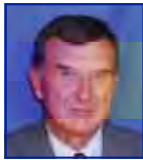
Ayse Dalkic

Fundraising Assistant



Everyone made a blue hand-print onto a white table cloth. We have Marjorie Harrap's hand print in the centre, symbolising her as a founding volunteer of the Association. We aim to get as many volunteer handprints as possible.

Congratulations to our new Life Members



Phil Bower, Life Member

Phil Bower has represented members of MND NSW for more than 15 years.

When his wife contracted MND he used all his knowledge as a scientist and his organisation skills from his business as well as his extensive work with International Lions to see if he could find a way of assisting his wife and others with MND.

As a practical man he realised he could provide a wealth of experience to the Board and he joined the Board of MND NSW in 1995. He represented NSW at the national level with MND Australia for a number of years and he has spent the last two years as President of the NSW Association.

Phil travels huge distances from his home in northern NSW to attend our meetings and his wry sense of humour and intelligent and personal insights to the plight of people with MND have always helped us keep on track and on message. He is a major link for the Board to the history of MND in NSW.



Bob Templeman, Life Member

Bob joined the Board of MND NSW in 1998, following a friend's diagnosis with MND.

Bob had been a senior financial controller in a previous life and had run a number of businesses. He felt that MND NSW could benefit from a stronger business approach and improved financial reporting and transparency.

As the Association's Treasurer for the past ten years, he has seen the organisation become financially sustainable. He has been an active participant in the strategic and financial planning processes and, for a while, assumed the role of the day to day accountant during a difficult period for the Association.

Bob's attitude to his role as a Board member and as Treasurer has shown his dedication and commitment to the cause. He is a great team member who is prepared to listen. He has always been very decisive where financial matters are concerned and he has been a champion of financial transparency and keeping administrative costs to a minimum.

Thank you Phil and Bob for your significant contributions to MND NSW and to helping those with MND.

Noticeboard



Disability Support Pension claimants fast-tracked

From 1 July 2010, Disability Support Pension assessments have been simplified to fast-track more claimants who are clearly or manifestly eligible due to a catastrophic, severe congenital disability or cancer, so they can receive financial support more quickly.

To be eligible you must have lived in Australia for a total of ten years as an Australian resident, or your disability occurred while you were an Australian resident. This payment is income and assets tested.

Under the new arrangements, Centrelink will check the claimant's medical report to see whether the person can be granted on the basis of diagnosis alone. People diagnosed with the amyotrophic lateral sclerosis (ALS) form of MND are eligible for the disability support pension on the basis of diagnosis alone (letter from doctor that includes the diagnosis of ALS). People with the primary lateral sclerosis (PLS) form of MND may be granted the disability support pension without need for job capacity assessment (letter from doctor that includes the diagnosis of PLS). For people where the prognosis is unclear, Centrelink will contact the claimant's treating doctor and/or the new Centrelink Health Professional Advice Unit to discuss the person's condition, treatment regime and likely prognosis. See www.centrelink.gov.au for more information.



Australian Disability Parking Scheme

The Federal, State and Territory governments introduced the Australian Disability Parking Permit in 2010, a first step in the harmonisation of all state and territory disability parking programs.

From 20 September 2010 all disability parking permits issued in NSW have consisted of a Mobility Parking Scheme (MPS) permit and an Australian Disability Parking Permit.

If you already hold a current MPS permit, it is not affected and will remain valid until its expiry date, unless it is revoked earlier. You do not need to apply separately for the Australian Disability Parking Permit. A new Australian Disability Parking Permit was sent to you in the post during October and November 2010. You should display the new Australian Disability Parking Permit along with your NSW MPS permit as soon as you receive it.

See www.rta.nsw.gov.au/rulesregulations/mobilityparking/index.html for more information.

You can write to the Editor, Forum, MND NSW, Locked Bag 5005, Gladesville NSW 1675

Community Events



Rita Madsen, the birthday rapper

Rapping on at 60

The theme for my 60th birthday party was anything 'R'. I went as Rita the Rapper. We had royals, Red Riding Hood, red necks, reverends, reporters, The Riddler, rock and rollers, road workers, Romans, race goers in their finery, a robin red breast, a rocket and many others! Over 70 people attended and everyone got into the theme. Donations were made to MND NSW in lieu of presents and I think the general consensus was that a good time was had by all. Rita Madsen.

Thank you to the Lismore community

Jenny Patch-Delaney has asked us to pass on her thanks to the Lismore Community for the wonderful support she received on the passing of her husband Bob Delaney. Bob was an English and History teacher at Trinity Catholic College and then St John's College Woodlawn. Hundreds of students lined the streets of Lismore to honour this much loved teacher. Jenny had asked that in lieu of flowers money would be donated to MND NSW.



Ayse Dalkic from MND NSW (left) with other grateful charity recipients of Bankstown/ Auburn Freemasons donations

Bankstown/Auburn Freemasons

The Bankstown/ Auburn Freemasons recently held a funds distribution evening at Bankstown Sport Club. It was a lovely evening where the chosen charities were able to chat with the Freemasons

to find out more about their work and share an enjoyable night with the other charity recipients. MND NSW would like to thank the Bankstown/ Auburn Freemasons for their generous support.

Thanks Alice

Alice, daughter of MND NSW member Zora Razmilic-Fisher, organised a fundraising event at her school, Ascham at Edgecliff. Thanks Alice, a great effort.



Caroline Gleig, MND NSW Regional Advisor, (right) receiving the cheque from Zora Razmilic-Fisher.

Thanks Video Ezy for the hire vouchers donated as prizes for the Members Christmas Party.

Everyday Hero: MND NSW Community Fundraising - Windows Internet Explorer

www.everydayhero.com.au

Everyday Hero: MND NSW Community Fundraising

Make your own fundraising page

Our everyday hero Community fundraising page has proved popular in the last few months with support from Suzi Heaton competing in the Sydney Marathon in September, Raymonda, Yasmin and Zakhia Aun all competing in the 2010 Rebel Sport Run 4 Fun and Jen and Tara who took on the huge task of walking the Six Foot Track. Congratulations to all and a very big thank you for the support and funds raised through your sponsorship pages.

Remember if you're participating in an event and would like to create a fundraising page it's easy.

Step 1. Visit www.everydayhero.com.au/event/MNDNSW_Community_fundraising

Step 2. Choose to:

- add details of your event and add your own pictures. Your friends and supporters can leave comments or,
- participate in one of the events currently being held where you can create your own fundraising page for MND NSW. Check out our events calendar at www.mndnsw.asn.au for events or,
- if you're not feeling quite so energetic why not pledge support for an event on an existing fundraising page?

Community Events (cont'd)

Six Foot Track

Tara and Jen walked the Six Foot Track, a 45 km walk between Katoomba and Jenolan Caves, in NSW during November 2010. They were raising money for MND



Training with our girls

because Tara's Mum, Allison, died in May 2007, just under two years after she was diagnosed with the disease.

Tara said, "The MND Association played a major role in supporting Allie and those around her. They helped her access the equipment which became so vital as the disease progressed. They provided much needed emotional support to those who were caring for Allie. We undertook this three day hike in memory of Mum." And here is Jen's story of their walk:

"Well that was tough!!

The first day was the most beautiful part of the walk. the terrain changed constantly and we enjoyed ourselves tremendously. We only had one small 'chat' about which direction to go :) We also got caught in the most horrendous torrential rain that my rain gear could not withstand. Tara had a bit more luck with her gear. We arrived wet, tired but in great spirits after the first day.

The second day we had dried up and the start of the day was amazing. The terrain was stunning and we jumped several creeks. Then.... the hill started. 3km uphill, and steep it was too! We struggled up the hill. When we finally made it to the top we still had 10kms to do, so we agreed to play games to pass the time, to avoid getting miserable. Nevertheless, we arrived with our tongues out and collapsed at the camp ground. The third day we were mainly propelled forwards by the thought of seeing our girls again. Our bodies and feet hurt and stopping for a rest no longer did us any favours. We shed some much needed tears when we were greeted by our wonderful girls at the end.

We are very proud of ourselves and the 'items' that helped us get to the end were our walking poles, our gatorade powder and our perfectly disgusting protein bars :)"

Greta-Branxton Colts

At a recent dinner for the Greta-Branxton Colts Rugby League Football Club,



Eileen O'Loughlen, Regional Advisor, MND NSW, was presented with a cheque for over \$20,000. The money was raised at an over 35's Rugby League Gala Day and Auction night held in late September. Congratulations and thank you to the Colts for organising such a fabulous event.

Gary Hodges, Artist

Member Gary Hodges recently held an exhibition of 19 of his works, all acrylic on canvas, in the John Hunter Hospital Arts for Health Galleries, Newcastle.



Gary has drawn and painted throughout his life but now, coinciding with his diagnosis of motor neurone disease, his painting has taken on new meaning and purpose.

In preparing for the exhibition, Gary thought about the messages he wanted to convey along with the sheer beauty of his work. Gary wrote a statement that hung alongside his work that informed the public about MND and the work of the Association. He also asked his MND NSW regional advisor, Noelle Smith, to open the exhibition which was a great opportunity to raise awareness.

He shared the benefits he reaps from painting in the statement, "When I paint I experience a feeling of well being. I doubt that there is any pill or medicine that would give me the same effect. I think it is called a natural high. Also when people enjoy my art it is very gratifying for me."

We congratulate Gary on the success of his exhibition and thank him for using his talent to inform the public about MND and for encouraging others to use their creativity to support their health and wellbeing.

Country talent for MND

Shirley and Stephen Peters held another very successful concert in Cessnock on 6 November at East Cessnock Bowling Club to aid MND. The concert is held annually in remembrance of Shirley's brother, Ron, who lost his battle with MND three years ago. This year the show featured Dianne Lindsay, who is the daughter of Heather McKean and the late Reg Lindsay, and Wayne Horsburgh. Wayne went to the USA for 25 years but now he is home for good. He is a very versatile entertainer and yodeller and the crowd just love his kind of county music.



Dianne Lindsay and Peter Simpson



Wayne Horsburgh

About 150 people enjoyed the night of entertainment and raised much-needed funds for MND. Special thanks to David Munn for giving his time to take photos at the event.

Are you thinking about organising a community fundraising event for MND? Speak with Kym Nielsen ph. 8877 0912 about your plans.



Walk to d'Feet MND

- Sydney -

7 November 2010



After heavy rain all week it was a relief to see the sun shining brightly on the morning of our Walk to d'Feet MND, at Blaxland Riverside Park, Homebush. Although the area was still a little water-logged following the rain, it certainly didn't dampen the high spirits and wonderful atmosphere of friendship and camaraderie shown by all participants.

By ten o'clock there was a sea of purple t-shirts and everyone was eager to get started. Over 500 participants, our largest walk yet! Around the course they ran, strode, walked and bounded for MND. After the Walk everyone was able to enjoy a cold drink and barbeque provided by Carlingford Rotary.

Our venue had changed to Blaxland Riverside Park this year, a change made necessary because of the banning of our four-legged friends from site used in previous years. However, the new site provided the added bonus of extra shelters and gas barbeques.

Thank you to the many wonderful family groups and friends who participated and made this such a successful day for MND. A special thank you to our top fundraising teams: 'Susie's Team', 'Johnny keeps us Walking' and 'Derek Ruddock'. They, along with many other teams, helped raise over \$44,000 this year. A big thank you also to Carlingford Rotary for their team who worked so hard to cook a great barbeque. It was greatly appreciated by all.

Kym Nielsen, Fundraising Manager

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DISCLAIMER All care has been taken in the preparation of this newsletter. The MND Association of New South Wales disclaims any liability for its content. The information contained within is of a general nature. For medical advice, consult your doctor.

Editor: Penny Waterson

The lucky Walk to d'Feet winner of the Johnson & Johnson product hamper, donated by Johnson & Johnson Pacific, was Mr P. Taggart.