



# FORUM

## Seize the day

Despite the weather forecast of morning showers, a fun group of people arrived at the Cruising Yacht Club at Rushcutters Bay on Sunday 18 October ready for adventure. The sun came out, the wind settled down and Jason, our wonderful skipper from Sailors With a DisAbility (SWD), took MND NSW members and carers past the Opera House, under the Harbour Bridge and around Darling Harbour. There we saw the buildings of Sydney from a new perspective.

We debated the pros and cons of the development around the Barangaroo area and saw the queue for the ferry for the inaugural Comedy Festival on Cockatoo Island. All agreed seeing the city from the water, especially around Darling Harbour and the King St Wharf, was a great experience in itself, and Lillian told us how much the city had changed from her day.

Back under the Harbour Bridge again and we were hoping for a train to go over – Jason had told us a SWD legend that if a train goes over the bridge when the boat goes under it, the skipper at the time has to buy all the crew and guests a drink at the bar. Thirteen year old Dean was at the helm but he was underage so everyone else agreed that his parents would be responsible for the 'shout'. Alas, there was no train when we went under the Bridge, so Cathy and Philip saved their money that day!

It was time to put the headsail up and that made a great sight. Jo and Caroline, MND NSW regional advisors, handed around the essential sustenance - coloured snakes, jellies and fruit cake. Most of the guests had a go at steering the boat but it was a special joy for Philip who had a keen interest in sailing.

Zora just revelled in the feeling of being on the water. Lillian used her white board and pen to tell us all about her family and their interests, and to give her comments about the day. Sandra and Paul kept saying it was "soooo good to get out for the day". Carol and Anton were in a similar position, with grown-up children, so they had all day to enjoy their time together.

So with thanks all round to the wonderful SWD crew and with many photos and memories we said our goodbyes. It's incredible how close people can get to each other in just a few hours. A bond is formed by the feeling of freedom that is unique to sailing. On the water your mind is free to enjoy the sights and feel the powerful ocean underneath you. With such a glorious day and such amazing people it doesn't get much better than the day we had on the harbour.

**Melinda Lyons**

*Sailors With a DisAbility member*



*Carol and Anton Obereigner*



*Cathy Josling and Philip Hearnshaw*



*Ian and Lillian Palmer*



*Paul and Sandra Tosolini (above)*



*Phillip Hearnshaw at the helm*



*Thumbs up after a great day*



*Zora Razimilic Fisher with Sailors With a DisAbility crew member, Bill Watkins*



MND NSW will be closed from 12pm Thursday 24 December to 9am Monday 4 January. 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.*

## Santa, lizards, members... Oh my!



(clockwise from right) Brett White and Frances Miceli with Lillian and Ian Palmer; Phil and Trish Brady, Warren Ball, Anne Shepherd and Anthony with the tawny frogmouth; Diana Stewart with Carline Welfare; Phil Lancaster and Joan Rodwell with Janet Monaghan.



Maree Hibbert (above) and Margaret Lee and Michael Lee (below), all not too sure about the crocodile



(l-r) Greg Corr and John Perryman



Santa with his helper, Ozlem Dalkic

What happens when you put Santa, several lizards, a crocodile, a frog, a fruit bat, a tawny frogmouth, a snake and MND NSW members, families, carers, volunteers, board members and staff all in one room with Roger on the guitar? That's right, the 2009 Members' Christmas Party.

Held in late November at the MND NSW Centre at Gladesville, the afternoon provided a great opportunity for people to meet others for the first time or to catch up with those they had already met at a support group, Ask the Experts or other MND NSW event. The room was a bit cramped but having someone in very close proximity did make it easier to chat and get to know them.

The proceedings kicked off with a Christmas sing-a-long, led by our musician board member, Roger Henshaw. As we all sang Jingle Bells, Santa and his helper arrived to draw the lucky door and raffle tickets. There were many winners and thanks must go to the individuals and companies who donated the prizes.

After the raffle draw, Anthony from Australian Wildlife Displays captivated everyone as he introduced the various Australian creatures he had brought along for the afternoon, sharing his love and knowledge of each as they were revealed. For many people it was the closest they had ever been (or would ever want to be) to a metre-long saltwater crocodile, fruit bat, frog or python.

The afternoon was over all too quickly. Thank you to Ryde City Council for their sponsorship of the wildlife demonstration. Thanks also to Roger Henshaw's son Grady, who looked after the audio equipment, Ayse Dalkic's daughter Ozlem, who provided great assistance to Santa, and Jane Barrett's partner John Coomber who assisted with the drinks. And of course, thanks to you too Santa!

See flyer enclosed with Forum for Dates for your diary or visit [www.mndnsw.asn.au](http://www.mndnsw.asn.au)

## Introducing...



### Chris Carroll

*Regional Advisor for the Far North Coast.*

I grew up in Geelong, Victoria, where I trained as a registered nurse. While raising my family I

completed my community nursing studies and since then I've worked in hospitals, aged care and in the community.

As a family we travelled around Australia on a working holiday and eventually relocated to a small farm close to Murwillumbah in northern New South Wales. We love the area, are very settled and have been here for eight years. I have learnt a lot about cows.

It's a pleasure to be part of the MND NSW team and I look forward to meeting families in the Far North Coast region and the Gold Coast area.



### David Wallace

*Information Line Advisor*

I have previously worked in the community health sector in a variety of client service roles, with the Department of

Corrective Services working in their Statewide Disability Service and, most recently, as a Rehabilitation Consultant with CRS Australia supporting people with disabilities, work injuries and other health issues return to the workforce.

I am looking forward to being part of the Family Support Team, providing information and support over the phone to members, their families, carers and health care providers and contributing overall to the fantastic work of MND NSW.

## A Message from the CEO

Our Annual General Meeting was held on Tuesday 27 October at the MND NSW Centre, Gladesville. The MND NSW Board for 2009-10 is:

President	Phil Bower
Vice President	Janice Scheinecker
Vice President	Roger Henshaw
Secretary	Bob Howe
Treasurer	Robert Templeman
Members	Phil Brady, Alex Green, Gary Jacobson, Ralph Warren

A copy of the MND NSW Annual Review is available on our website. Alternatively, if you would like a hard copy of the 2008-09 Financial Report or Review please contact us on ph. 8877 0999 or email [admin@mndnsw.asn.au](mailto:admin@mndnsw.asn.au).

Newly elected to the Board is Phil Brady. Phil has been a member of the Association since 1996 and has spoken to local, state and federal politicians on behalf of MND NSW and MND Australia. Phil is also an active member of his caravan club and you can read more about how Phil and his wife Trish caravan with MND on page 7 of this edition of Forum.

Our Walk to d'Feet MND was held on 8 November at Homebush Bay with an amazing roll-up of over 360 people. If you would like to hold a Walk to d'Feet MND in your community, Kym Nielsen, MND NSW Fundraising Manager, can supply you with more information and a start-up kit. You can contact Kym by email at [kymn@mndnsw.asn.au](mailto:kymn@mndnsw.asn.au) or ph. 8877 0912.

During November we welcomed several new staff to the MND NSW team. David Wallace, based at the MND NSW Centre at Gladesville, is our new Information Line Advisor. Chris Carroll, based in Murwillumbah, is our new Regional Advisor for the Far North Coast. In this role Chris will also work closely with MND Queensland to make contact with people living with MND on the Gold Coast. David and Chris introduce themselves on page 2.

We wish you a peaceful and safe Christmas and New Year. Thank you to all our donors for their support in 2009. Our office will be closed from 12pm Thursday 24 December and will reopen on Monday 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

*MND NSW will be closed from 12pm Thursday 24 December and will reopen on Monday 4 January.*

**Vale**

**Nick McLoughlin**

*MND NSW Board Member*

Nick died on 9 September 2009.

A board member since 2006  
and tireless advocate for people  
living with motor neurone disease.

## MND NSW

Building 4 Old Gladesville Hospital  
Gladesville NSW 2111  
(Locked Bag 5005  
Gladesville NSW 1675)

Phone: 02 8877 0999  
or 1800 777 175  
Fax: 02 9816 2077  
Email: [admin@mndnsw.asn.au](mailto:admin@mndnsw.asn.au)  
[www.mndnsw.asn.au](http://www.mndnsw.asn.au)  
ABN 12 387 503 221

**PATRON**  
*Her Excellency Professor Marie Bashir AC  
Governor of New South Wales*

**VICE PATRONS**  
*Paul Brock AM  
Melinda Gainsford Taylor  
Kevin Langdon OAM  
The Hon. Mr. Justice Peter W. Young*

**Auditor**  
*C.M. Pitt & Co.*

**Solicitors**  
*Mallesons Stephen Jaques*

**MND NSW BOARD**

**President**  
*Phil Bower*

**Vice Presidents**  
*Roger Henshaw and Janice Scheinecker*

**Secretary**  
*Bob Howe*

**Treasurer**  
*Robert Templeman*

**Board Members**  
*Phil Brady, Alex Green, Gary Jacobson,  
Ralph Warren*

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*Graham Opie*

**Office Coordinator**  
*Petra Sammut*

**Administrative Assistant**  
*Anne Jones*

**Accountant**  
*David Radford*

**Fundraising Manager**  
*Kym Nielsen*

**Fundraising Assistant**  
*Ayse Dalkic*

**Family Support Manager**  
*Gina Svolos*

**Family Support Coordinator**  
*Jane Barrett*

**Regional Advisors**  
*Chris Carroll, Jo Fowler, Caroline Gleig,  
Jenny Judd, Eileen O'Loughlin, Robyn  
Petersen, Iva Plessnitzer, Noelle Smith*

**Information Line Advisor**  
*David Wallace*

**Equipment Service Coordinator**  
*Maree Hibbert*

**Equipment Assistants**  
*Matthew Fowler  
Michael Walker*

**Information Resources Coordinator**  
*Penny Waterson*

**Regional Education Project Officer**  
*Anita Richter*

*And..... many valued volunteers*



## Family Support Team

### Merry Christmas

At Christmas time we reflect on memories of the past year: shared happiness - shared sadness - loss, love, achievement, joy, hope. Christmas is a time of mixed emotions, particularly when motor neurone disease is involved. We hope this Christmas will be a time of peace and happiness for you and your loved ones.

### Family Support Regional Developments

Our focus for this year has been on providing educational programs in regional locations of New South Wales. This was identified as a priority for the Association following our 2007 member satisfaction survey. Programs have been conducted in Newcastle, Ballina and Orange, with the final program for the year to be run in Port Macquarie in early December.

As well as providing information about motor neurone disease to our members and their families, we have also focused on providing motor neurone disease educational workshops in regional areas for health and community care professionals. These workshops have been highly successful with an attendance of 75 at our one-day workshop in Orange during October. As I write this we are finalising the arrangements for a one-day workshop in Port Macquarie which already has 45 health and community care professionals registered to attend. This interest by professionals is very encouraging because it improves the quality of care our members receive. We plan to hold further information and education days next year and have appreciated the funding from Ageing, Disability and Home Care, Department of Human Services NSW that has made these days possible.

Another development has been the opening of our new office on the Far North Coast and the employment of a new regional advisor to provide information, support and advocacy for our members living in the area. Christine Carroll has now commenced in this new role, which also covers the Gold Coast, ensuring people with motor neurone disease in the area have a local point of contact at the MND Association. Her office will be near Murwillumbah in a house owned by the Tweed Palliative Service.

### Satisfaction Survey

To assist us in planning our priorities for the next few years we have sent out a member satisfaction survey that you should have received by now. We appreciate your honest feedback about the services you receive from us and any suggestions you may have as to how we can develop our services further. If you haven't returned your survey yet please post it back by 16 December.

### New Fact Sheets



A series of evidence based fact sheets have been developed by MND Australia to provide up-to-date information to people with motor neurone disease. Topics include an overview of motor neurone disease evidence-based interventions, multidisciplinary care, breathing, riluzole and gastrostomy (PEG and RIG). You can download the factsheets from [www.mndnsw.asn.au](http://www.mndnsw.asn.au) or contact your regional advisor to obtain printed copies.

### New Database

We are about to start using a new administrative database at MND NSW. Much planning has gone into its development and we hope it will help to reduce some of the duplication involved in our current systems. We ask that you be extra patient with us during the implementation phase, between January and March 2010, while all staff learn to use a brand new system. We have planned for and hope for minimal impact to our members. If there are times we are not able to respond immediately to your concerns please be assured we will be endeavouring to respond as soon as it is possible.

### 20th International Symposium on ALS/MND and Allied Professionals' Forum, Berlin 8 to 10 December

This year Jo Fowler, Regional Advisor for Northern Sydney and Central Coast, will be attending this international conference about motor neurone disease. Jo is presenting a poster about the MND NSW partnership with the community mentoring program, HomeHospice.

We look forward to hearing more about developments in care and research in motor neurone disease that are discussed at the International Symposium in the next edition of Forum.

**Gina Svolos**

*Manager, Family Support*

*If you haven't returned your member survey yet please post it back by 16 December.*

## Equipment

As the year is winding down it is good to look back and review what has happened in the MND NSW Equipment Loan Service. Once again it has been another busy year with 1,034 items of equipment loaned to 222 members from all over NSW and the ACT. These loans have included 58 raiser recliner armchairs, 50 electric hospital beds, 94 cushions, 45 powered wheelchairs, 34 hoists and 49 Lightwriters. Equipment returns have also kept us busy with transport organised for the retrieval of 950 items.

This year over \$180,000 has been spent on new equipment for loan and MND NSW fundraising is an integral part of keeping the equipment pool operating. Very recently, eight new powered wheelchairs were purchased to help meet demand. Within a week of us taking delivery, all had been shipped for loan. Our equipment pool purchases cannot be made without everyone's continuing support. Thank you.

Christmas holidays are nearly upon us and the MND NSW Centre at Gladesville will close for the short period between Christmas and New Year, from 12pm Thursday 24 December 2009 to 9am Monday 4 January 2010. Deliveries during late December and early January can often be delayed due to the increased demand on courier services and the post office.

If an equipment breakdown does happen during the time the Association is closed, DO NOT PANIC. Please contact your health professional, for example your occupational therapist, or if they are not available contact your local hospital. They can assist with arranging repairs during this time.

Michael, Matthew and I would like to wish everyone a very safe, memorable and happy holiday season. Remember to smile, enjoy and take lots of photos.

Merry Christmas

**Maree Hibbert**

*Equipment Services Coordinator*

*Information Evenings for those newly diagnosed with MND are held regularly at the MND NSW Centre at Gladesville. Contact our Info Line on 1800 777 175.*

## On the road with a regional advisor

I think it's fair to say that home visits are the best part of a regional advisor's job. It is always special to meet a member and their family in the comfort of their own home. We get to share a little of your life and see how resourceful and clever you are when living with motor neurone disease.

On a recent home visit on the picturesque Central Coast I was blown away by a very beautiful bathroom. I was inspired and I thought one or two other readers of *Forum* might be too. Lee and Jeff combined their knowledge and skills to design and build this bathroom. Lee worked as a nurse for most of her working life and Jeff is very handy, and just happens to be a tiler.

Bali, a much loved destination of the couple, is the theme that runs through their semi-rural haven. When you enter the bathroom you can imagine being in an exclusive Asian resort as the huge windows fill the room with light and offer views of nothing but greenery, wildlife and an odd horse wandering by.

The fully accessible bathroom features a raised toilet, rails and a huge double shower and a lazy bath, which Lee and Jeff's five year old son, Jay, gets the most use out of these days.

**Noelle Smith**

*Regional Advisor - Hunter and New England*



Get your diary out and start thinking about a taking a break in 2010.

There are just a few criteria that have to be met to get FlexiRest funding, however, you must live in New South Wales.

**Do talk to your regional advisor about the program.**

You can find further information about FlexiRest at [www.mndnsw.asn.au](http://www.mndnsw.asn.au) - just follow the link on the left Our services > Carer support > FlexiRest.

## Caring for someone and caring for yourself go hand-in hand

**You can choose to take a break (respite)**

**You can choose when to do this**

**You can choose who you go with**

**You can choose the break that best suits your situation**

**You can discuss your ideas with your regional advisor**

**You can apply for FlexiRest funding**

**Making time for you**

## Noticeboard

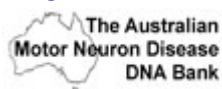
### DADHC now to be known as ADHC



**Human Services**  
Ageing, Disability & Home Care

The NSW Department of Ageing, Disability and Home Care (DADHC) oversees the Home Care Service of NSW, Attendant Care Program, High Needs Pool, Domestic Assistance, Seniors Card, Companion Card and some respite programs. On 1 July DADHC was renamed to Ageing, Disability and Home Care, Department of Human Services NSW (ADHC). Services provided remain unchanged and the ADHC website can still be accessed at [www.dadhc.nsw.gov.au](http://www.dadhc.nsw.gov.au). For more information contact ADHC ph. 8270 2000.

### Progress with DNA collection



The Australian MND DNA Bank has been set up to look for genetic and

environmental susceptibility to motor neurone disease. Lorel Adams, Manager, reports that the Bank now has over 2500 samples and progressing well towards the target of 1000 samples from people with MND, and control samples to match these, by early 2011.

During 2010 the Bank needs to collect blood samples and questionnaires from:

- o 200 people with MND
- o identical twins of people with MND
- o both parents of people with sporadic MND
- o all family members of people with familial MND
- o 90 men over 50 years of age with no family history of MND
- o 30 women over 75 years of age with no family history of MND

If you have previously donated blood to the MND DNA Bank, you do not need to donate again.

For more information contact Lorel Adams at the MND DNA Bank, ph. 9036 5456 or [dnamnd@med.usyd.edu.au](mailto:dnamnd@med.usyd.edu.au). Lorel can arrange for a questionnaire to be sent to you and for blood samples to be taken locally, in your home if needed. There is no cost to you.

### Library News

The MND NSW library is a work in progress. We are taking stock of what we have, cataloguing our resources and hopefully will have the library up and running ready for the next edition of *Forum*.

Have you read, seen or heard of anything inspiring/funny/insightful/useful/enjoyable that would be suitable for our library, something you would recommend to others who use our service? It can be a book, DVD or CD. Some of our categories include personal stories, hobbies, fun, travel, self care and relaxation, carers, nutrition, recipes. I'm sure there are lots more but we need your suggestions. Just pass them onto Jane Barrett, Family Services Coordinator, ph. 8877 0999 or email [janeb@mndnsw.asn.au](mailto:janeb@mndnsw.asn.au). Also, if you have any books, DVDs or videos currently on loan, please also let Jane know.

*Did you know MND NSW support group meeting dates, venues and times are listed on the MND NSW website at [www.mndnsw.asn.au](http://www.mndnsw.asn.au)?*

*Just follow the link on the left Our services > Support groups.*

### An update on MND clinics and services in NSW

There are several specialised services in New South Wales that provide an integrated approach to the management and clinical care of a person affected by motor neurone disease. MND NSW provides funding that contributes towards the cost of employing an MND coordinator at some of these services. This health professional coordinates your care and links you to appropriate services in your local area.

Regional advisors from MND NSW work closely with these services, attending clinics and meetings. They also work closely with MND coordinators to promote the best possible care for people with MND.

If you wish to find out more about these services please contact the MND coordinator or your regional advisor.

*Note: Fees may apply for some services provided by specialised MND clinics and services however the Medicare rebate does apply. Please check with the service provider.*

- o **Prince of Wales Hospital MND Clinic**, Randwick  
Professor Matthew Kiernan leads this team. Margie Zoing is the MND Coordinator, ph. 9382 2449.
- o **Macquarie Neurology MND Service**, Wahroonga  
Professor Dominic Rowe, previously located at Royal North Shore Hospital, currently provides a specialised clinic at his rooms and plans to establish a service at the new Macquarie Hospital in 2010. Sandra Erjavec is the MND Coordinator, ph. 9489 0111.
- o **Sydney West MND Clinic**, St Joseph's Hospital, Auburn  
Dr Steve Vucic is the neurologist who attends this clinic and Julie Labra is the MND Coordinator, ph 9749 0329.
- o **Calvary Health Care MND Service**, Kogarah  
This service is attended by both palliative care and rehabilitation specialists. Margie Zoing is the MND Coordinator, ph. 9553 3111.

*We are currently auditing the books in our MND library. If you have any books on loan could you please return these as soon as possible.*

## Mailbag

I am a writer based in London, UK and I am emailing in the hope you may be able to help me with a book project. My father died of motor neurone disease last year and I have written about MND for both the Times ([www.timesonline.co.uk/tol/life\\_and\\_style/health/article4487470.ece](http://www.timesonline.co.uk/tol/life_and_style/health/article4487470.ece)) and Guardian ([www.guardian.co.uk/lifeandstyle/2009/aug/28/motor-neurone-disease](http://www.guardian.co.uk/lifeandstyle/2009/aug/28/motor-neurone-disease)) newspapers. I am now compiling a book on the subject and need to speak to as many people as possible who have MND or have experience of it through being a relative, carer, doctor, researcher etc. I have spoken with many people in the UK, USA and Canada but I'd really like to cast the net wider.

Many thanks

**Susan Greenwood**

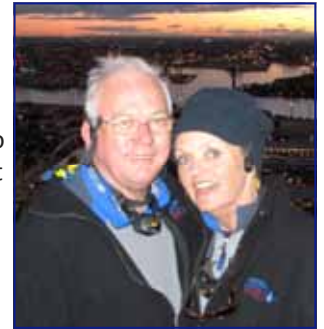
[susan.greenwood@guardian.co.uk](mailto:susan.greenwood@guardian.co.uk)

*If you have suggestions for books for our library please let us know. Contact Jane Barrett, Family Support Coordinator, ph. 1800 777 175.*

We did it! I recently did BridgeClimb with my husband Craig - a gift to us from our children for his 60<sup>th</sup> birthday. It was an awesome experience and such an achievement to stand at the top of the Harbour Bridge alongside the two (huge) Aussie flags. We were also lucky to see a beautiful sunset on the way back down. It was truly a very worthwhile experience!

Best wishes

**Sue Quinn**



*Craig and Sue atop the Sydney Harbour Bridge*

*MND NSW member, Phil Brady recently featured in Issue 135 of Caravan & Motorhome magazine.*

*Phil explains...*

My wife Trish and I always planned that after I retired that we would join the 'grey nomads' and tour the country. However my being diagnosed with motor neurone disease has made a bit of a dent in these plans. But we still went ahead and purchased a caravan and joined a caravan club - the Sydney - Central Coast 'A' Van Group Inc. Since then we have actively participated in club activities and gatherings, toured most of Queensland and New South Wales, and in 2006 did the big trip round Australia.

As my disease has progressed, the more I have become a spectator, but 'luckily' I have a slowly progressive type of MND, so I can still enjoy our travels and adventures. As time goes on Trish has taken on more responsibilities but she has readily and skillfully accepted these tasks. However most importantly, we get a lot of support from our caravan club members. They willingly help me get to the amenities and assist us to join in club activities. One day it will be just too difficult for us to continue on caravanning but in the meantime the support of club members encourages us to carry on. We very much appreciate this support.

*John Brown, President, Sydney – Central Coast A Van Group Inc says...*

You might say that Phil and Trish Brady are 'Special Members' of our caravan group but this would be an understatement. They are themselves an inspiration to us all. Despite Phil's condition they have managed to attend many of our gatherings over the past years. As Phil's condition has deteriorated over time this has placed an increased burden on Trish. Realising this situation the members of our caravan group have quietly and without any fuss unofficially resolved to provide every support we can to ensure that they can continue their retirement dream to travel this great country of ours.

Trish now has the responsibility to pack the van and do all the driving and she provides all that loving support for Phil. We as members of our caravan group can only do so much, but when Phil and Trish pull into a caravan park the word soon spreads the 'Brady's' have arrived. Even before the car stops at their allocated site our members are there ready to assist with the positioning of the van and uncoupling from the car, connection of power and water, levelling and stabilising the van, unloading Phil's scooter etc. Inevitably there is also a group of members there to help them with the packing up when they leave. I know that all our members will be there for Phil and Trish for as long as they feel able to participate in our activities. We wish them all the best for the future.



*Phil 'towing' a van*

Photo courtesy of Kylie Dapiran  
Caravan & Motorhome magazine



*The Central Coast A Van Group*

Photo courtesy of Kylie Dapiran  
Caravan & Motorhome magazine



## Support Groups

### ACT and Southern NSW

Hello everyone! During August we visited the ACT Independent Living Centre for a tour guided by an occupational therapist. We saw a variety of specialised equipment as well as lots of small gadgets that can help, particularly kitchen gadgets. In October, Bernie Bissett, Senior Respiratory Physiotherapist, spoke about keeping the respiratory system as healthy as possible.

Our last meeting for the year will be our Christmas meeting on 14 December where we can all relax with food and fellowship. Come along, meet others, relax from the Christmas rush and enjoy the air-conditioning! Please feel free to bring a small plate to share.

**Iva Plessnitzer**  
Regional Advisor

### Central West

The Information Day held for people living with MND and their families in Orange during October was well attended and very well received. After an overview of motor neurone disease there were sessions on equipment, accessing services, breathing difficulties and an interactive massage session. People came from far and wide, even as far away as Broken Hill.

The next day we held an education day, Directions in Care, for over 75 health and community care professionals including some who travelled from distant parts to attend. It is a testament to those working in the region that there is so much interest and dedication to meeting the needs of people living with motor neurone disease. It was a rewarding day for all concerned and I would like to acknowledge all the speakers, attendees and the Orange Ex-Services Club for their skill, commitment and professionalism in ensuring the day ran smoothly and met the needs of all concerned.

And finally, our support group which has been held at the Orange Ex-Servicemen's Club will not be continuing regular bi-monthly meetings for the time being. The demographics in the area have changed and a support group is not practicable for our members with motor neurone disease at the moment. However, while the support group is not meeting, I will still be travelling to visit individuals and families in the Central West.

**Jenny Judd**  
Regional Advisor

### Campbelltown

A support group for people living with motor neurone disease, including family members and carers, is now up and running in the Campbelltown area. Our first meeting took place in October.

You are very welcome to join us at this support group. Discussions are informal and educative and talking with others living with motor neurone disease often provides people with new information and support. Future meetings of the group will be held at Community Options, 16 Warby Street, Campbelltown. Disabled access parking is available at the side of the building and other parking is available on the street, but if transport is difficult for you please contact me and we may be able to offer assistance.

However, our next meeting is a luncheon on 15 December at Campbelltown Catholic Club. If you are interested in coming along contact Janell Mahoney, Macarthur Community Options, ph. 4620 1400 or Robyn Petersen, MND NSW, ph. 1800 777 175.

**Robyn Petersen**  
Regional Advisor

*Do you have a new general practitioner or neurologist? Let your regional advisor know, so that we can update your member information.*

## Support Group Contacts

### METROPOLITAN

Ph: MND NSW 1800 777 175

#### Campbelltown

Robyn Petersen - [robypn@mndnsw.asn.au](mailto:robypn@mndnsw.asn.au)

#### Gladesville

Caroline Gleig - [carolineg@mndnsw.asn.au](mailto:carolineg@mndnsw.asn.au)

#### Northern Beaches (Mona Vale) and Northern Sydney (Hornsby)

Jo Fowler - [josephinef@mndnsw.asn.au](mailto:josephinef@mndnsw.asn.au)

#### Western Sydney

Jenny Judd - [jennyj@mndnsw.asn.au](mailto:jennyj@mndnsw.asn.au)

### REGIONAL AND RURAL

#### ACT and Southern NSW

Iva Plessnitzer ph. 6286 9900  
[ivap@mndnsw.asn.au](mailto:ivap@mndnsw.asn.au)

#### Broken Hill

Jamie Mitchell ph. 08 8088 7093 (bh)  
or 08 8088 1333 (ah)

#### Central Coast

Audree Dash ph. 4384 2907  
Jo Fowler ph. 1800 777 175

#### Central West

Jenny Judd ph. 1800 777 175  
[jennyj@mndnsw.asn.au](mailto:jennyj@mndnsw.asn.au)

#### Illawarra

Robyn Petersen ph. 1800 777 175  
[robypn@mndnsw.asn.au](mailto:robypn@mndnsw.asn.au)

#### Newcastle and Hunter

Noelle Smith or Eileen O'Loughlen ph. 4921 4157  
[noelles@mndnsw.asn.au](mailto:noelles@mndnsw.asn.au)  
[eileeno@mndnsw.asn.au](mailto:eileeno@mndnsw.asn.au)

#### Northern Rivers

MND NSW ph. 1800 777 175



## Focus on.... MND NSW volunteers

### Joy's story

*By Joy Pogson*

*MND NSW Volunteer*

I began volunteering for MND in 2004, a year after I retired. During that year I had been associated with the caring of a Rotary colleague, Jim Gordon, and became aware of the devastation of motor neurone disease.

I began around MND Week and so my initial tasks involved merchandise. I became quite the master of the postal packages, from the sticky tape and brown paper parcels, to the selection of boxes to match the size of the order. Merchandising also involved a lot of counting. I did appreciate all the fundraisers who returned their goods in neat counted packages with a reconciliation sheet! We have quite perfected the system now and have accurate tracking records of all orders.

After a while I learned more about the systems in the office and became more helpful with other tasks. Although I can assist with merchandising when needed I now mostly concentrate on administrative tasks for the Family Support Team. There are new files to set up, records to archive and publications to package. With my teaching background I am a bit of a 'red pen' checker and so I am also often asked to review printed materials before they are published. I have information technology/librarianship training and have also contributed to discussions about how information systems are set up for Association use.

I have also been able to increase my skills. I work on several of the databases at the office. Recently, I acquired new skills while using the events registration database processing health and community care worker registration forms for the National MND Conference.

I regularly attend the MND NSW Centre at Gladesville weekly on a Friday. I have specific responsibilities which involve photocopying, collation and packaging of the printed information and educational material distributed by the Association. This involves using a database to extract research and other needed articles and assembling special interest group packs, new member packs, recipe books, Aspects of Care books and our popular Carer's Kit.

I look forward to Fridays. As a volunteer at MND NSW I have been able to use my own skills and learn new ones.

Of course all this is imbedded with the friendliness and friendship that the Association staff offer. And I should also add how much I enjoy the friendships I have with other volunteers too! MND volunteering is the highlight of my week.

*If an equipment breakdown does happen when the MND NSW office is closed at Christmas please contact a health professional, such as your occupational therapist, or your local hospital.*

### Have you ever wondered how *Forum* is packaged ready for posting?

MND NSW volunteers generously contribute their time every three months to get *Forum*, the newsletter of MND NSW labelled, packaged and ready for posting.



*Volunteers who helped with packaging the September 2009 edition (l-r) Debra, Jaya, Nadheera, Gail, Greg, Annette, Marcia and Shohreh.*

### A treat for MND volunteers

*by Brian McErlane*

*MND NSW Volunteer*

More than 20 volunteers, who regularly give up their time to help the MND NSW with administrative tasks, fundraising events and selling merchandise, recently enjoyed a BBQ held in their honour, plus an enlightening presentation by the Australian Wildlife Displays kindly sponsored by Ryde City Council.

The whole afternoon was an amazing success, kicking off with the BBQ cooked by Graham Opie, CEO. The BBQ was kindly supplied by Ed Strong of the Rotary Club of Carlingford. Ayse Dalkic, Fundraising Assistant, thanked the volunteers, saying how pleasant it was to be in the company of such generously spirited people. Volunteers play an important role in the work of the Association and this was a chance to say thank you for their tireless efforts.

Volunteers and staff were able to see and touch Blossom the ringtail possum, Joanna the goanna, Bubblegum the bluetongue and other interesting native animals presented by Australian Wildlife Displays topping off a glorious afternoon at the MND NSW Centre at Gladesville.



*Michelle Paton and Jennifer Foster at the Volunteers' lunch*

### Community Events

A number of community events have been held in the past few months to help raise awareness about motor neurone disease and funds for research and services. **The Men of League, Illawarra**, held a wonderful luncheon at the Steelers Club in Wollongong. Graeme Murray was the master of ceremonies with football greats like Trent Barrett, Rod Wishaw and Craig Fitzgibbons lending their support to the great fundraiser **in memory of Mark Gooley**.

Early October saw an event of a different kind held around the streets of Brisbane. **Belinda McElroy** organised a car rally **in memory of her dad**. Thank you to the wonderful teams, supporters and organisers who made this a great day.

Once again we have had some great support in regional areas with a very successful **Open Garden** being held by **Helen and Colin Pearce** in Tamworth. Helen tells me that the weather wasn't very kind to the supporters but the plants loved it.

**Kerrie Skeffington and friends** organised a wonderful **dinner and dutch auction** at the Raymond Terrace Hotel. The night was a great success with a huge turn up and lots of fun had by all.

The annual **Ray McDougall and Margaret Burge memorial weekend** was held in South West Rocks during late October. Wonderful support from the local community resulted in a very successful sporting memorabilia auction at the Seabreeze Hotel. On the following day a golf tournament at South West Rocks Country Club was wrapped up with a BBQ and raffle back at the Seabreeze.

Also during late October, the St Mary's Rugby League Club hosted the **Lions Pride Car Show** in their carpark. A big thank you to the organisers for their hard work to put together this show.

**Kym Nielsen**  
Fundraising Manager

### Battle of the sexes



After Melinda and Marcia Gooley's dad died, their soccer mates decided the best way to show their support was to raise money for the debilitating disease that took his life.

Recently the Burragorang Soccer Club hosted a battle of the sexes soccer match to raise funds and awareness for motor neurone disease. Marcia Murphy (nee Gooley) said it was a great day with fabulous support from local businesses and the community.

The main event was on the soccer pitch, where the Burragorang division 5 women's team went head to head with their husbands and partners. While the men may have won the best dressed players' prize for their pink soccer singlets, it was the women who walked away as match winners, beating their male counterparts 4 to 2.

### Entertainment Books



Once again the Entertainment Books have been a great fundraiser for our Association. A very big thank you to Entertainment Publications for donating five books as prizes for our Members' Christmas Party.

### New CD - 'A Time for Us'



'A Time for Us' is a collection of inspirational and reflective music recorded on an Orla Organ by Margaret Lawrence as a tribute to her late husband, Bob.

Robert (Bob) and Margaret moved from Melbourne to retire in beautiful Yamba on the north coast of New South Wales in 1998. In July 2000 Bob was diagnosed with motor neurone disease and Margaret cared for him at home for seven years until he died in April 2007.

Margaret says they had wonderful support from MND NSW and from their local community services. Music was a common interest, which provided a stimulating activity which they could pursue in a home environment. During those years Margaret started learning to play the organ and Michele Saunders, Margaret's music teacher, involved Bob in selecting the music she was to learn.

Margaret has now put together this collection in memory of Bob.

For just \$20 you can purchase this CD and help support programs and research into MND.

Available from MND NSW Freecall 1800 777 175 or Margaret Lawrence ph. 6646 9002 or email marglaw1@tpg.com.au

### Electric Wheelchair Appeal



We recently held a very special appeal to raise funds to help purchase a new electric wheelchair for the MND NSW Equipment Loan Pool.

Over \$8500 was raised online towards the purchase. A sincere thank you to everyone who donated.

*Are you thinking about organising an event for MND during 2010? Talk with Kym Nielsen, MND NSW Fundraising Manager ph. 8877 0912*

## Kokoda Challenge for MND

After months of fundraisers and training we departed for Port Moresby on 8 August 2009, as prepared as one can be to trek the Kokoda Track. While we had made email contact with others on the Kokoda Challenge for MND, it wasn't until we all arrived in Papua New Guinea that the eleven of us met as a group.

Each of us had been touched by motor neurone disease in one way or another. For me, it was the loss of my 19 year old brother, Elliot in April 2008. I considered this opportunity as one that would allow me to test myself and to remember and honour Eli and all other people lost to motor neurone disease. I also hoped it would be an opportunity to gain insight into the battles for control of the Track, which claimed the lives of too many others too young to die. It was so much more than I had imagined, in that I gained a sense of clarity in my life. The natural environment and the history buried within it allowed me to be in touch with myself. The terrain, the wet, the cold and the history of the Track are well documented, maybe less so the respite and welcome offered by the villages and villagers along the way. My brief encounters with the locals reinforced a valuable lesson, that nothing is more important than this moment. For each hurdle I overcame, I was filled with an indescribable feeling and was reminded of the overwhelming power of the mind.

They said it would be tough and it was. The Kokoda Track is uncompromising, it is relentless because you have to take it step by step, and stay focussed and above all not let the mind wander, particularly in the early days. Thoughts like, "How many more steps are there?" ... "How far is camp?" ... or "How many days of this do we have?" have to be quickly dismissed. But if it wasn't so testing it wouldn't be a 'challenge' and the eleven people who completed the trek to raise funds for MND NSW, met it head on and as a group revelled in it and agreed, as one, that it was a unique, rewarding and self-fulfilling experience.

I really enjoyed the friendliness and support of the porters, so too the comradeship, humour and warmth of the ten other trekkers, brought together by a common cause and shared dream. It all came together wonderfully, completed without incident or injury with Laurie, our guide, saying it was one of the two best treks he had led. Quite a compliment, given he had taken 52 of them! A great character, Laurie is a Vietnam veteran from Western Australia who, as he kick-started each day with a double-dose of coffee and cigarettes, gave us our morning 'briefing' about what lay ahead of us and the events of 1942. Stories of strategy, bravery and sacrifice; inspiring and overwhelmingly sad at the same time. It was truly amazing.

**Emily Jay**  
Aged 17 years



*Me with my dad, Geoff Jay. Water intake is crucial and it is thirsty work, camel packs are a godsend....*

*..and with several children from the village...one very inquisitive about the visitor.*



*We love this photo...it also hangs at Maitland Toyota, our major sponsor. We were Eli's crew (for Elliot of course).*

*And the track would go down and up...often...and narrow and lush...and most of the time head down to watch your step.*



*It was wet for the first few days...plenty of rain and a river or two to cross.*

*The beauty of the butterfly, which lives for such a short time, with the MND wristband message, 'never give up'.*



*Made it!! The eleven of us at the Kokoda District Office, the 'finish' line. This is where the troops used to assemble.*

*Pencil it in  
your diary -  
Friday  
19 March  
2010  
MonSTAR  
Cup 2010*





A dull and drizzly November day was not going to dampen the spirits of the 360 participants who lined up for this year's Walk to d'Feet MND at the Newington Armory site in Sydney Olympic Park.

They came with wheelchairs, prams and pooches to help raise awareness and much needed funds for research into motor neurone disease. What a sight it was to see the sea of walkers in their blue Walk to d'Feet MND T-shirts pounding the pavement for MND.

A very special thank you to the many teams who not only participated on the day but also raised \$29,800 through team sponsorships and registration. A huge thank you also to Jackie Mears who worked so tirelessly to raise awareness for this event through radio and newspaper networks.



(above) The Sam the Man Group

(below right) Dereck Chubukoff demonstrating that if you wear the right T-shirt you can almost walk anywhere and (below left) Ian Bond and family.



#### ACKNOWLEDGEMENT

We wish to thank Snap Printing, North Ryde for their generous support.

**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

#### A delicious donation



Newman's Own Foundation has selected MND NSW as one of the 23 Australian

recipients of their annual philanthropic campaign. Profits from Australian sales of Newman's Own dressings, mayonnaise and pasta sauces are given to worthwhile causes nationally.

MND NSW has allocated the grant to the purchase of much needed equipment for the Equipment Loan Pool. For more information about Newman's Own Foundation see [www.paulnewmansown.com.au](http://www.paulnewmansown.com.au)

#### Thank you State Street and United Way

MND NSW was recently awarded a grant from the American philanthropic foundation, State Street. The funds will be used to purchase equipment for the MND Equipment Loan Pool.

The support from State Street was facilitated by United Way Sydney, a long-time supporter of MND NSW. State Street Foundation addresses local needs by working with 35 individual contribution committees in 21 countries.

You can view or download your MND merchandise order form from our website at [www.mndnsw.asn.au](http://www.mndnsw.asn.au)



#### Are you looking for a last-minute Christmas gift idea?

MND NSW silver-plated Christmas photo frame (height 7cm) only \$10 plus postage.



Great little aluminium flashlight, handy size to carry in your handbag or pocket. Uses one AAA battery. Only \$5.



MND puppies are back. This time the litter has a gorgeous tan coat. Take one home for just \$5.



**Contact MND NSW today to place your order for pre-Christmas shipping.**  
**Phone 8877 0999.**

