THE NEWSLETTER OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NSW

September 2011

mnd New South Wales

FORUM

Celebrating MND Global Day 2011

Walk to d'Feet MND in the National Capital

People with MND, their loved ones, carers and supporters gathered on Sunday 19 June 2011 for the capital's third Walk to d'Feet MND, alongside Lake Burley Griffin to mark Global MND Day in Australia. The Global Day Walk to d'Feet MND organised jointly by MND NSW and MND Australia has now become a regular event providing an opportunity for people touched by MND in the ACT and Southern NSW to come together. The deep connection people feel with MND and the world-wide MND community was very evident that day. People travelled many kilometres to join in the Walk grateful for the opportunity to raise awareness in Canberra and to raise funds for vital research.

21 June is a solstice - a turning point - and each year ALS/MND communities worldwide undertake a range of activities to express their hope that this day will be another turning point in the search for cause, treatment and cure of this awful disease.

This year, although chilly, Canberra turned on the sunshine to welcome 318 people living with MND, families, MND Australia board directors, volunteers, MND association staff, and dogs of all shapes and sizes. Retiring Tasmanian Senator Guy Barnett and long time friend and supporter of MND Australia gave a rousing speech to welcome the crowd.

Many took the walk very seriously determined to be the first past the post, some even running the route twice, whilst others enjoyed a stroll and a chat and the blue Canberra skies.

Once again our Canberra based volunteers were integral to the success of this event and we sincerely thank the small team of young women, Amy Critchley, Laura King and Cindy McGhie, who worked so hard to promote the event and to engage with media near and far. Print media coverage nationally for Global Day events had a total circulation of 434,217. The Global Day Walk featured in the Canberra Times, Grenfell Record and Bland Advertiser, Muswellbrook Chronicle, Forbes Advocate and the Northside Chronicle (Canberra) and once again the Walk featured the next day on the local TV news.

Over $16,000 was raised for research through registrations, donations and online fundraising. We thank everyone who was involved in making this event such a success. It was great to catch up with all the people who joined the Walk in previous years and also those who joined us for the first time - we look forward to seeing you again in Canberra next year!

Carol Birks
MND Australia

PORT MACQUARIE

Sunday, 9 October

5.5km walk/run/bike
Westport Park to Town Beach Park and return

Register today

SYDNEY

Sunday, 6 November

5km walk/run/bike
Blaxland Riverside Park, Sydney Olympic Park, Homebush

Come along. Run, walk or wheel with your family, friends and dogs. For more information and to register your attendance visit www.mndnsw.asn.au or contact MND NSW ph. 8877 0999.

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.

The Power of Touch

Bryan first heard about the MND NSW *Hand and Foot Massage* program after his wife, Christine, attended the *Care for Carers* program at Gladesville. He requested to be matched with a massage volunteer and, after a bit of a wait for an available volunteer, was matched with Mandy in February this year.

Bryan says that before he has his weekly massage, his hands and feet are usually stiff and painful. But after Mandy has massaged them, devoting about 15 minutes to each hand and foot, they feel supple and less painful and he can usually bend his fingers more easily for the rest of that day, as well as the day after.

Bryan with MND NSW Hand and Foot Massage Volunteer, Mandy

Bryan describes the hour long massage as ‘a wonderful experience’ and really looks forward to Mandy’s weekly visits. He says he not only feels more relaxed after the massage but also enjoys chatting and catching up with Mandy each week.

For her part, Mandy also enjoys her weekly visits to see Bryan and being able to ‘give something back’ to the community. She also gets to use and develop her massage skills in the process. Mandy says she’s noticed Bryan’s hands and feet have become ‘more flexible’ over the time that she has been massaging him and that Bryan experiences ‘almost immediate relief’ especially as soon as his feet are touched. Mandy acknowledges that having a hand and foot massage is not going to effect any major or permanent physical changes with Bryan’s MND but hopes that any relief, however small, is beneficial for him.

Indeed not only is the massage experience beneficial for Bryan but he also says that Mandy’s visits give his wife Christine a chance to either relax for an hour or at least be able to do other things she needs to do at home while Mandy is there with Bryan.

Bryan accepts that a hand and foot massage may not be for everyone but he encourages people to try it because he says not only is it a fantastic service but it is ‘completely free’ too!

If you live in the Sydney area and would like more information about how to receive a simple hand and foot massage or indeed to find out about becoming a massage volunteer, contact Ayse Dalkic or David Wallace at MND NSW ph. 8877 0999. We especially need volunteers in the Western and Southern Sydney metro areas.

David Wallace

Sydney 2011
International Symposium on ALS/MND
Ask the Experts
28 November
register now
www.mndnsw.asn.au

Motor Neurone Disease Association of New South Wales

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And.....*many valued volunteers including Greg Corr who assists with Forum packaging, mailouts and fundraising during MND Week.*

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

A Message from the CEO

MND Global Awareness Day was celebrated on 21 June and our ACT Walk to d'Feet MND took place on the Sunday prior to Global Day. Now a regular event on the Canberra calendar, the Walk this year attracted over 300 people and their dogs but unfortunately no Alpaca as there was last year. A full report on the Walk can be found on page 1 of this edition of *Forum*.

Also on Global Awareness Day, three NSW Parliamentarians spoke in the Lower House about motor neurone disease as a Matter of Public Importance. Dr Andrew McDonald (Macquarie Fields), Ms Gabrielle Upton (Vaucluse) and Ms Tania Mihailuk (Bankstown) explained about the disease, the work of the Association and of the need for increased awareness of the impact MND has on individuals, families and friends.

The end of June also signalled the end of the financial year and, thanks to a massive effort by individuals and community groups across NSW and the ACT, nearly $450,000 has been raised over the year through dinners, motor cycle and bicycle runs, golf days, Walk to d'Feet MND, runs and a broad array of other innovative events. These events have not only helped raise funds to support people with motor neurone disease but have also been instrumental in raising awareness about the disease in local communities across NSW and the ACT. Thank you to our supporters for their efforts. If you need ideas on events that can be run in your local community please contact Kym Nielsen, Fundraising Manager, ph. 8877 0999.

The NSW Government, through Ageing, Disability and Home Care (ADHC), has again been of immense support with top-up funding for our equipment loan pool and a review of our communication devices. The Minister for Disability, Mr Andrew Constance visited the MND NSW Centre at Gladesville during July to get a first-hand view of the services provided, meet people with MND, carers, volunteers and staff, and to announce the funding.

This funding is particularly welcome as we have had to replace a large number of old equipment items. This has led to deficits in our budget over the past two years, due to the fact that we rely on community fundraising, bequests and donations for over 80 per cent of our recurrent funding.

Still with the NSW Government, a current and retired board member Phil Brady and Suzanne Ballinger played an integral role in helping to get a petition to government containing over 23,000 signatures calling for the restoration of funding for palliative care services in northern Sydney. This resulted in a debate in the NSW Parliament and a recognition and commitment to fund holistic treatment within our healthcare sector.

In big news, the Federal Government has released the Productivity Commission's final report into a national long term care and support scheme for Australians with a disability and their families, supporting the overhaul of the disability system and the introduction of a National Disability Insurance Scheme. You can still show your support by following the link to Every Australian Counts website at www.mndnsw.asn.au.

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

Vale

Hari Pal Singh

Hari Singh was the first employee of MND NSW when he commenced in the role of Office Manager/Chief Executive in 1993. He retired ten years later, by which time the Association was on a firm footing with 13 staff offering family support services, equipment and advocacy for people with MND in NSW.

Hari died suddenly in June 2011 and our thoughts are with his wife Tara and family.

INTERNATIONAL

Ask the Experts

Hilton Hotel, Sydney
2pm to 4.30pm
Monday 28 November 2011

This session, chaired by **Professor Dominic Rowe**, is an opportunity **for people living with MND, family and friends** to ask international experts about the latest developments in MND care and research.

There is no charge to attend this event. For further information contact MND NSW ph. 8877 0999 or 1800 777 175 or visit www.mndnsw.asn.au

Program

- *What do we now understand about MND compared to 5 to 10 years ago? How has clinical and scientific research impacted on current clinical care for people living with MND?* **Kevin Talbot, Nuffield Department of Clinical Neuroscience, University of Oxford, UK**
- *How might stem cell research lead to a cure for MND?* **Kevin Eggan, Harvard Stem Cell Institute, USA**
- *Lessons from MND genetics* **Robert Brown Jr, Harvard, NEALS, USA**
- *Clinical Trials in MND Past, Present and Future* **Orla Hardiman, Clinical Professor of Neurology, University of Dublin and Consultant Neurologist, National Neuroscience Center of Ireland**
- and **questions** from the **audience** and **people attending via the live streaming website**

Family Support Team

We have a number of events coming up in October and November. On 10 and 17 October, *Learn Now, Live Well*, a two-day education program for people with motor neurone disease and their carers, will be held at the MND NSW Centre at Gladesville (see page 6).

Our members Christmas party will be held on 12 November, which is a bit earlier than usual. Hopefully we will beat all those other invitations for Christmas celebrations by getting in early but the real reason is that the International ALS/MND Symposium will be held in Sydney in late November. We are very excited to be hosting this event with MND Australia because it provides us with a great opportunity to hear from MND researchers from around the world.

In conjunction with this event there will be an opportunity for people living with motor neurone disease, their family and friends to attend *Ask the Experts.* At this event you will be able to ask international experts about the latest developments in MND care and research. This free event will be held Monday 28 November in Sydney and we hope as many of you as possible will be able to attend. We are particularly excited that there is some financial assistance with travel or parking costs. Also if you are not able to come to Sydney, you can attend via a live stream to a dedicated website. You will be able to submit questions via live stream website and watch the event live. This has been made possible through funding obtained by MND Australia. See the insert in this edition of *Forum* for further information.

Because many of the MND NSW staff will be involved in organising or attending the Symposium and Ask the Experts, the MND NSW Centre at Gladesville, regional offices and MND Info Line will be operating for limited hours between 28 November and 2 December. If we are unavailable please leave a message and we will get back to you as soon as possible. The Symposium is an important opportunity for staff to learn the latest about motor neurone disease so they can share this information with you, so I ask for your understanding and patience during this time.

Multidisciplinary Care Update

Multidisciplinary care is an important approach to care for people with MND. Multidisciplinary care occurs when health professionals, from different disciplines, work together to address as many of your health and other needs as possible. Research has shown that the health professionals you consult can give you better care and advice when they are knowledgeable about MND and have a coordinated, multidisciplinary approach to your care.

Multidisciplinary care may be provided either through a coordinated community based team approach with health professionals meeting regularly and working together to provide coordinated care, or through an MND-specific clinic.

MND NSW conducts education programs in NSW and the ACT for health and community care providers that assist them stay up-to-date with a multidisciplinary approach to MND care. We are excited to be planning education days for these professionals in Newcastle on 15 September and the ACT on 20 October. Please let your care team know about these days and to contact MND NSW for more information.

In some areas MND Clinics have been set up to give the person with MND access to a range of health professionals who work together to provide a coordinated response to care. Multidisciplinary MND Clinics in NSW include the Prince of Wales Hospital MND Clinic at Randwick, St Joseph's Hospital Multidisciplinary MND Clinic at Auburn and as of August 2011, the Macquarie Neurology MND Clinic at Macquarie University. An MND NSW regional advisor attends each of these clinics and works as part of the multidisciplinary team.

For further information about any of these clinics contact your regional advisor or the MND Info Line ph. 8877 0999 or freecall 1800 777 175.

Gina Svolos
Manager, Family Support

This year the MND NSW Members Christmas Party *is* scheduled earlier than usual due the International Symposium on ALS/MND in late November/December.

You and your family are invited to the

MND NSW
Members Christmas Party
Saturday 12 November 2011
2.30pm to 4.30pm
Ryedale Room, Ryde Eastwood Leagues Club,
117 Ryedale Rd West Ryde

Reserve your place by calling MND NSW ph. 8877 0999 or freecall 1800 777 175 or email annej@mndnsw.asn.au

Kindly RSVP by 5 November

Back issues of Forum *are available at www.mndnsw.asn.au*

Family Support Team (cont'd)

Equipment

Currently there are 408 people diagnosed with MND who are members of MND NSW; 395 in NSW and 13 in the ACT. In the past three months there were 361 referrals for equipment loan for 125 members. Of these, 331 loans have been made to 125 members.

MND NSW Biannual Equipment Stocktake

Every two years we have an equipment stocktake. This year the stocktake will be done during 26 to 30 September 2011.

In mid-September members who have MND NSW equipment will receive a stocktake letter. You will be asked to confirm you have the listed items and to notify us of any discrepancy. A reply-paid envelope will be included to help make the process easier. During the time of the stocktake the MND NSW Equipment Loan Service will need to be closed, however urgent referrals or repair calls will be taken.

I apologise in advance for any disruption during this time. The stocktake is a necessary part of maintaining our service and I hope there are not too many disruptions.

Purchasing of equipment by members

Sometimes members or their family consider purchasing their own equipment. If you are considering this, please make sure you contact your occupational therapist, physiotherapist or speech pathologist BEFORE you go ahead with the purchase. These health professionals will give you unbiased information on the specifications of a piece of equipment most suited to your individual needs. Although it may take a little extra time to get the information required, in the long run it will ensure you have the equipment that best meets your needs and may save you money.

Maree Hibbert
Equipment Services Coordinator

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

Morning of Remembrance - Botanic Garden Wollongong

Are you someone who has previously cared for someone with MND?
You and your family are warmly invited to join us on 22 October from 11am to 1pm at the Woodland Garden Gazebo, Botanic Garden Wollongong. A gentle occasion to remember your loved one and to connect with friends old and new. Morning tea will be provided.
RSVP by phoning Kate or Robyn on 8877 0999 or 1800 777 175.

Carers

In May, our *Care for Carers Program* ran over four consecutive Mondays. Those who attended said that they found it beneficial and supportive to meet others in similar situations. It was wonderful for me to see how quickly everyone seemed to connect with each other and how much laughter and chatter filled our meeting room at times during the Program.

Each week the group had the opportunity to hear from different health professionals with expertise in MND. The relaxed setting allowed ample time to ask questions. The participants said that this really helped them to gain new understandings of ways to best support and care for their family member with MND.

At the end of the four week program, participants were asked to complete a detailed evaluation form. Here are some of the comments we received:

"Things are so much easier for me now. I feel stronger. I know what to expect and I am no longer afraid."

"Doing Care for Carers *made me realise that there is a lot of support out there for me and my partner and I have realised that I don't need to feel guilty about asking for help from friends or from health professionals."*

"I was concerned that it may be too early for me to attend a program like this, yet I am now so glad I didn't put it off! The knowledge I have gained is invaluable."

Since the completion of *Care for Carers*, some supportive new friendships have formed and the group has already enjoyed one reunion lunch at the MND NSW Centre at Gladesville, with another planned for September.

Kate Maguire
Education and Carer Support Coordinator

Sarah Darrington (right) and her mother Shireen Jones at Care for Carers

Mailbag

From Don

In memory of June McMurray

29 April 1934 to 21 January 2011

I was sitting up in bed this morning and singing a few hymns from Mum's *Christian Hymns.* A couple of them were common metre and I sang them to *Amazing Grace*.

I had recently finished the book *What's so Amazing about Grace* by Philip Yancey and my mind was much on grace as I thought about my dear June.

I also thought about the couple of one-liners in one of her books she used to communicate with home care personnel and others -

"I am poor old woman and I want to be with Jesus."

"I'll go to be with Jesus and I'd love to have him hug me."

I was prompted to write this hymn sung to *Amazing Grace*. Hopefully it fits the tune and sounds ok -

Motor neurone disease has come
At Thy sure hand, Oh LORD!
That we might see how frail we are
And Thee alone adore.

It does take hold of young and old
And none can stay it's hand.
The fears and tears that do take hold
Oh! Help us LORD to stand.

As we see the face of those nearby
And groan within and sigh;
We find no hope apart from Thee
For Thou art by my side.

My wife sees through those dying eyes
At loved ones all around
And finds her comfort in the ONE
By whom she was once found.

Jesus the Christ is HIS dear name
More precious than us all
And when she sees HIM on HIS throne
She'll praise HIM more and more.

Learn Now Live Well

For people with motor neurone disease, their family and friends

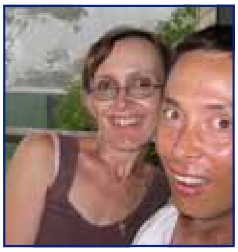
10am to 3pm **10 and 17 October**

MND NSW Centre, Gladesville

Learn Now Live Well is a two-day educational program. It covers living well with MND and the services available for people living with MND. There is no charge to attend but bookings are essential. Please RSVP by Friday 7 October. Contact Kate Maguire ph. 1800 777 175 or katem@mndnsw.asn.au

From Joanna

Bushwhacking!



Joanna and Michael

People are drawn to my boyfriend Michael, like bees to the honey; he has this happy glow which people want to be near. Unfortunately, his weekly routine consists of carers, lifting machines, food liquidisers, swimming therapy, urinal bottles, hospital beds, motorised wheelchairs, commodes, assisted computer software, nurses and massage therapists. The tell-tale signs of an MND diagnosis.

The busy week, with people constantly coming and going, did not stop us finding time for each other and falling in love, in amongst the quiet spaces. I never knew him when he was not battling MND, nor was I one of those friends who helped him in the early days when he was still fairly mobile. We fell in love when the disease had taken its toll on his body. It seems that sometimes, life just demands that you keep living it, no matter what it throws at you.

Just like other couples though, as the holiday season approached last Christmas, I wished we could go away together. It seemed like a foolish dream, as I knew the long list of equipment that we would need to take and assumed it would be too difficult.

Enter one enthusiastic, 'never say never' bushwhacking friend of ours called Chris. An expert in 'going bush', he was confident that he and his wife Cissy, could not only take Michael on holiday, but take us bushwhacking for a Summer holiday!

It took some organising, a few lists ticked off, reassurances to uneasy parents and a spacious trailer packed sky-high (with motorised wheelchair, commode, lifter, ramps etc) but early February, found us piled into a four wheel drive heading bush. Our destination? Newnes, a tiny relic of a shale mining town situated in the Wolgan Valley, just past the Blue Mountains.

If you have never heard of Newnes, you are not alone. Most people have never heard of it, and yet it is only three hours or so from Sydney. We had six nights booked at an environmentally friendly, solar energy powered, wheelchair accessible cabin! The cost for six, only $650 in total.

(cont'd over)

Write to the Editor of Forum MND NSW Locked Bag 5005 Gladesville 1675 or email info@mndnsw.asn.au

Mailbag (cont'd)

(Continued from page 6)

If you have ever wondered what life was like, thousands of years ago, when hardly any human beings walked the earth and civilisation had not stomped all over the planet, then take some time out of your busy schedule, and visit Newnes. It is a tiny ghost-town, situated in the heart of a small valley, with escarpment on all sides.

There are three cabins at Newnes, maintained by the owners of the only remaining building from the original town, the spectacularly authentic, Newnes hotel. Only one cabin is wheelchair accessible however. A ramp is needed to get into the cabin, but once inside it is extremely spacious with plenty of room in the bathroom for a commode. The cabin sleeps six, but there were only the four of us, so we had plenty of room.

The main bedroom was a bit tight on space. The lifter could not fit under the queen sized bed, because the bed base was flush with the ground, however we were able to position the walker by the bed to assist with standing at night, and a wheelchair just fitted alongside the bed.

Outside the cabin, the ground was a bit bumpy but the motorised wheelchair coped with it well, and I suggested to the owners they might smooth it over a bit.

Learn Now Live Well
For people with MND, their family and friends
10am to 3pm
10 and 17 October
MND NSW Centre, Gladesville

Some might think that our days consisted of gazing serenely on the landscape and resting etc. Well, we did do plenty of that, however Chris was also keen to do something adventurous every day.

We visited the Newnes hotel, and marvelled at the ghostly atmosphere of the building (the owner made a make-shift 'ramp' for us, which Michael bravely negotiated). On the first day, we walked along the dirt road that runs through Newnes, saw kangaroos, and wild-life, dipped our toes in a stream and familiarised ourselves with the area.

On one very hot day, Michael had a bath in the river, courtesy of a stretcher! With a lot of care and taking it slowly, we were able to lower Michael onto the stretcher (which had metal raised legs) and then carry him into the water. It sat just above the water line and Michael was able to feel the river washing over him.

Michael having a bath in the river, courtesy of a stretcher

One evening we waited until the night sky was upon us, to look at the thousands of stars that suddenly appeared! Ten times as many stars, as you would see in Sydney. We tilted Michael's wheelchair back so he could look up easily. Another day, we went four wheel driving! With someone holding onto Michael's head to stop it bouncing around, and Chris driving very slowly over the bumps. One afternoon, we had a storm, which brought blissful cooling rain after the heat.

As Chris said to me, 'where there's a will, there's a way'. We certainly proved that. If you take it slowly, think ahead and pace yourselves, MND does not always have to win the fight. If you want a fabulous holiday destination next summer, check out the Wolgan cabins at Newnes.

We had a normal holiday, just like everyone else. When I send out my holiday snaps to friends and family, it is easy to forget that there are some strange photos in there. However to me, those photos are just of me and Michael, with two good friends, having a great time. I do not see the stretcher or the wheelchair, I just see us on holiday.

Joanna

Michael in the beautiful bush with Chris and Joanna

Support Groups

Northern Sydney (Hornsby)

The group continues to flourish and is well attended. We have covered some interesting new topics this year and are grateful to the community health professionals who willingly spend time sharing their knowledge and expertise with us. The group has been able to meet face to face this year with David Dubin, Bequest Officer, and David Wallace, Information Line Advisor. Our members were surprised to learn that we now have three ‘Davids’ in our MND NSW Centre at Gladesville and that we fondly refer to them as D1, D2 and D3. Of course David Radford is the other David on our staff and he is the MND NSW Accountant.

Mary Clifton, from The Dementia Advisory Service spoke at our April meeting and brought with her an insightful presentation demonstrating how to *Mind your minds* and teaching us new techniques that challenge our thinking and improve our brainpower. It was also handy learning little tips to help us function better in our day-to-day lives. We learnt tips to help us remember where we parked our car at large venues like multi-storey shopping centres. Coincidentally that day, when we arrived for our April meeting at the Thornleigh Community Centre we were all wondering if we already had a little lapse in memory, for surprisingly we found the hall was ‘doubled-booked’. It was packed with boxes of pre-loved books and a band of keen volunteers who were getting ready for the Life Line Book Sale the following Saturday. We did manage to squeeze into a tiny corner and generously share our space with the others - it was a most ‘unforgettable’ meeting.

We also meet up with Barbara Lewis, Manager, Northern Sydney Carer Support. Barbara spoke about the many services available to assist a person with MND and their carer. She spoke about the importance of talking to your MND NSW regional advisor and the community health professionals about what would help to make the caring journey easier. Barbara also spoke about a new approach being used in the Northern Sydney Sector. It is called *Communication and Care Cues* and is designed to individualise a person’s care whilst in hospital. We all came away with an information-filled *Carer’s* folder, the bright red, handy compact *My Health* record, *Keep well Keep track* folder, a coloured de-stress ball, a clear portable medication bag and a lot more knowledge of when and how to get the support we need.

At our August meeting, our guest speaker was Sandra Erjavec, the Clinical Nurse Consultant from the New Macquarie Neurology Hospital. Sandra told of the recommencement of the specialist MND Clinic that opened there on 3 August. The MND clinic is held every second Wednesday and Professor Dominic Rowe heads a team of allied health professionals. This clinic draws people with MND not only from the Northern Sydney and Central Coast areas, but also from all over Australia. For more information contact Macquarie Neurology Reception ph. 9812 3720.

Our next support group meeting is on 13 October and I am looking forward to seeing you there. For more information about the group, please call the MND NSW Centre at Gladesville ph. 8877 0999 or freecall 1800 777 175.

***Jo Fowler**, Regional Advisor*

Western Sydney

The Western Sydney Support Group continues to be well attended and popular with members. At the last meeting an occupational therapist from the Independent Living Centre at Parramatta spoke about maintaining independence in the home. She had lots of small and large gadgets and gizmos to show us, and for us to try. The group had many questions.

At the next group, which will be held on 13 September, we will welcome the Head of the Physiotherapy Department at St Joseph’s Hospital MND Service, Liz Taylor, as our guest speaker. She will speak about mobility, falls prevention, exercise, transfers, mobility aids and anything else that might be relevant for your own circumstances relating to mobility. I am still hoping to have a luncheon outing later in the year.

These groups are a great way to connect with other people experiencing similar challenges. Afternoon tea is provided and the group is convivial, relaxed and very informal.

***Jenny Judd**, Regional Advisor*

North West (Tamworth)

On a recent field trip to the New England area it was a pleasure to attend the North West support group to recap on the regional advisor's role, and the supports and services that our Association can provide. What an inspiring and supportive group of people; it was a privilege to meet each and every one of you. Special thanks to Ruth Loseby, from Northcott Disability Services, who coordinates and facilitates the meetings. Without her dedication, this regional support group would not function as effectively as it does. The group continues to meet bi-monthly from 10am to midday at 27 Ford Street Tamworth. The next meeting is on 10 October. Morning tea is provided and the venue is wheelchair accessible and has a homely, comfortable atmosphere.

***Kim Sinclair**, Regional Advisor*

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

Support Groups (cont'd)

Central Coast

Our 100th support group meeting, on Thursday 7 April, opened with Sheila Holmes, MND NSW Life Member, reading the following report. Sheila has worked extremely hard for MND since attending the inaugural meeting of the group in Lloyd and Naomi Affleck's lounge room seventeen years ago.

"Today is our 100th meeting … This is a milestone reached. Seventeen years ago we met in Lloyd Affleck's lounge room where we decided a support group would be a good idea. Many people have passed through the group since then. They have been involved in raffles, street stalls, home visits, phone calls and in organising meetings and guest speakers. They have also provided support and information about MND to fellow group members.

Our sincere thanks to Audree who works tirelessly for the group. Thanks also to Pat, our 'tea lady' who we could not do without, and Jo, MND NSW Regional Advisor. We must not forget the people who help out at street stalls or who sell merchandise at work to friends. People who attend our meetings are so important and show the need for a support group. So please continue to come, you are so necessary. Research continues - a cure for MND will be found - and our group supports the work being done."

In August, Emma Thompson, dietitian from the Central Coast Community Outreach team, presented lots of helpful hints about good nutrition and spoke at length about gastrostomy (PEG). It was reassuring and helpful and a pleasure to have Emma with us.

Next meetings are at 1pm on 6 October and 24 November at Niagara Park Community Centre. I hope you are able to attend.

Audree Dash

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

Port Macquarie

We meet bi-monthly at the Rotary Community Hall, Hastings River Drive. The Rotary Club Board Members have kindly donated the use of the room for the purpose of the MND Support Group.

The aim of the support group is to provide an opportunity to meet other members their family and friends in a relaxed informal environment and to provide support, information and to share ideas.

Kym Nielsen, MND NSW Fundraising Manager attended our June meeting. The group showed interest and great enthusiasm in the idea of organising a fundraising event in the Port Macquarie area and as a result we are having a Port Macquarie Walk to d'Feet MND on 9 October. Thank you to Bev Smith, and all the people who have helped to make this event possible.

The meetings are facilitated by Eileen O'Loghlen Regional Advisor and volunteer Rosemary Mann. We are also joined at our support group by volunteer Janice Campbell; her assistance at the support group is much appreciated. For more information about the group contact Eileen O'Loghlen MND NSW Regional Advisor ph. 4921 4157 or mobile 0418 463 057.

For more information about joining us to Walk to d'Feet MND in Port Macquarie on 9 October visit www.mndnsw.asn.au or contact Kym Nielsen ph 8877 0999.

***Eileen O'Loghlen**, Regional Advisor*

Have you thought about FlexiRest lately?

FlexiRest funds a range of services offering respite (including holidays) that cannot be met by existing community and respite services. Ask your regional advisor for more information.

Support Groups

METROPOLITAN Contact MND NSW ph. 1800 777 175 for more information

Campbelltown - *Robyn Petersen | robynp@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*

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 | robynp@mndnsw.asn.au*

Newcastle and Hunter - *Eileen O'Loghlen | 4921 4157 | eileeno@mndnsw.asn.au or*
Kim Sinclair | 4985 5022 | kims@mndnsw.asn.au

North West (Tamworth) - *Kim Sinclair | 4985 5022 | kims@mndnsw.asn.au*

Port Macquarie | *Eileen O'Loghlen | 4921 4157 | eileeno@mndnsw.asn.au*

Noticeboard

UBQLN2

On 21 August 2011, the journal Nature posted the online publication of the following paper:

Mutations in UBQLN2 cause dominant X-linked juvenile and adult-onset ALS and ALS/dementia

Han-Xiang Deng, Wenjie Chen, Seong-Tshool Hong, Kym M. Boycott, George H. Gorrie, Nailah Siddique, Yi Yang, Faisal Fecto, Yong Shi, Hong Zhai, Hujun Jiang, Makito Hirano, Evadnie Rampersaud, Gerard H. Jansen, Sandra Donkervoort, Eileen H. Bigio, Benjamin R. Brooks, Kaouther Ajroud, Robert L. Sufit, Jonathan L. Haines, Enrico Mugnaini, Margaret A. Pericak-Vance & Teepu Siddique

The authors represent five academic institutions, with the lead investigators based at Northwestern University in Chicago.

Synopsis

The underlying causes of most forms of ALS have not been identified. This new study has confirmed a mechanism common to all forms of ALS, reinforcing the need to continue developing therapies related to that mechanism. The problem is a breakdown in the recycling system for damaged proteins in specific neurons in the spinal cord and brain that results in severely damaged cells. Problems with this mechanism also likely play a role in other neurodegenerative disorders such as Alzheimer's and Parkinson's disease.

It is a new piece of the puzzle that will help us find a treatment/cure for ALS.

Why is the study of interest?

One, it confirms that pathways and mechanisms we have been focusing on as a research community for the past 15 years are important since the protein (ubiquilin2) which they report in this paper (part of the natural intracellular mechanisms for processing and degrading) has mutations in human ALS patients. However, it is important to note that this study does not identify any brand new mechanisms or pathway.

Two, the results in human patients validate the cellular and animal experimental models of ALS which have been used for the past 15 years, as those models already led to the study of this particular intracellular mechanism.

Three, it should be noted that the presence of neuronal protein accumulations/aggregates/ inclusions in a number of adult-onset neurodegenerative disorders - such as Alzheimer's and Parkinson's as well as ALS - has already been the impetus behind the development of treatments to counteract the formation of such inclusions. This new study provides additional motivation to pursue preclinical studies and clinical trials to develop and test such therapies.

In summary

A solid and interesting new finding. Hopefully it will attract additional basic scientists to study these mechanisms in ALS, and garner support to develop and test new therapies related to those mechanisms.

There has been considerable publicity surrounding this study with coverage by major news sources.

Source: extract from ALS Society of Canada, Concerning ALS-related press releases of 21-22 August 2011 www.als.ca

If you do not have internet access and would like a print copy of articles referred to in Forum contact the MND NSW Info Line ph. 1800 777 175

Family Support Calendar

10 and 17 October	**Learn Now Live Well** | *Gladesville* | For people with MND, their family and friends. A two-day educational program held over 2 weeks on Mondays. See page 6 for more.
11 October	**Information Evening for people recently diagnosed with MND, their family and friends** | *Gladesville* | Informal information evening for people who are newly diagnosed with MND, and their families and friends
22 October	**Morning of Remembrance** | Botanic Garden | Wollongong. See page 5 for more.
12 November	**Christmas Party for family support members, their family and friends**
28 November	**International Ask the Experts** | *Hilton Hotel, Sydney* | Where you, family members, carers and friends can bring your questions about MND and have them answered. See page 3 for more.
13 December	**Information Evening for people recently diagnosed with MND, their family and friends** | *Gladesville* |

For more information contact MND NSW Info Line ph. 1800 777 175

If you would like assistance with travel to attend family support sessions or would like us to organise an MND information session in your region, please speak to your regional advisor.

Community events

Thank you to the community fundraisers who have held events for MND NSW in the past few months. Our supporters have raised funds in many different ways. Here's just a few.

***Rachel Gageler** organised the first **Muswellbrook Walk to d'Feet MND** on 25 May. The Walk commenced in Aberdeen and the participants walked for a well-earned treat to McDonalds in Muswellbrook. A great day was had by all with plenty of support from the local community.*

*Some 130 people attended the **Trivia Night for MND** at **Warilla Bowls Club**, Warilla. Organised by **Donna Maree Gasparrini**, the night was plenty of fun with great trivia questions, raffle prizes and a silent auction.*

***Belrose Bowling Club** held a **Bingo Night**. Thank you. **Sharon Penman** organised a movie night in **Bateman's Bay** with the opening night of Red Dog. **Wakehurst Football Club** held a **Gala Day** and **Gavin Turnbull** participated in the **Spring Cycle**, raising funds through his Everyday Hero page.*

***Oceanic Coal Newcastle's afternoon shift** chose to support MND NSW through their safety incentive program. Local MND NSW Regional Advisor, Eileen O'Loghlen, met the workers and received the donation cheque at a shift afternoon tea.*

*Graham Opie, CEO MND NSW and I recently attended the **Rotary Club of Narellan's 'A Night to Remember Charity Ball'** held at **Roma Function Centre** in **Liverpool.** It truly was a night to remember with 500 guests treated to a wonderful night of food and entertainment with a special appearance by stunning young tenor, **Mark Vincent**. Graham was presented with a cheque for $21,000 on the evening from the **Rotary Club of Narellan.***

***Kym Nielsen**, Fundraising Manager*

walk to d'feet MND

PORT MACQUARIE
Sunday, 9 October

SYDNEY
Sunday, 6 November

Central Coast

Several months ago we presented the results of the Central Coast MND Support Group's 13th year of involvement with the **Rotary Community Raffle**, a cheque for $880, to MND NSW. This donation will go towards equipment. More recently, the **Bateau Bay 'Wrong Bias' Bowlers** fund made a $331 donation to MND NSW.

During **Awareness Week** we accepted donations, sold merchandise and conducted a raffle. Congratulations to the winner of our beautiful patchwork quilt, P Matthews, the daughter-in-law of one of our members. These events, together with our ongoing sales of merchandise during the past year, have enabled us to send in $2,488 to MND NSW.

Audree Dash with Terrigal Trotters Leon Harradine and Kevin Andrews
Photo: Central Coast Express Advocate

One of our members, Leon, is a Life Member and founder of the **Terrigal Trotters** – an enthusiastic **Central Coast** running and walking club. The proceeds of the **Terrigal Trotters Bay to Breakers Run**, $10,000, has been donated to MND NSW to go towards the purchase of much needed equipment. We do have some beautiful people on the Coast.

Audree Dash

M7 Run

Mum was diagnosed with MND earlier this year. It was a real shock and I didn't know much about MND at the time. I went along to one of the information nights that the Association runs and personally found it very helpful. But, I also felt a bit helpless.

I have wanted to run a marathon for a long time, but have never seemed to get there. I had started training again at the end of last year and this diagnosis of Mum's became a catalyst for me to do the marathon this year. I heard about the *Everyday Hero* website from the information session and found it was the perfect way to link the marathon run with raising money for the Association. It felt really empowering - it was at least a way for me to help the Association in some kind of way, seeing as they are doing a wonderful job helping Mum and Dad.

So, on 31 July this year, I ran my first marathon, and there was Mum at the finish line. I'm thrilled at the amount of support my friends and family have showed with the fundraising effort. What a great run!

Karl

Karl with his mum at the finish

Building communities, Bridging continents

On 10 May Rotary Club of Carlingford celebrated the Rotary International theme of 'Building communities, Bridging continents'. At this inaugural volunteer dinner Heather Walsh, representing the MND NSW massage volunteers and Helen Park, MND NSW volunteer administrative assistant and musician. They were recognised by Rotary for their 'service above self' activities.

left to right - Norrie Boorman, Community Service Director, Heather Walsh, Evelyn Lasper, State Emergency Services with Pamela Lawrance, President, Carlingford Rotary

STOP PRESS

MND supporter Rod McDonald, in training for the 2011 City2Surf. He ran the 14km race barefoot and wearing a kilt. Thank you to all of our 2011 City2Surfers – more stories in the next edition of *Forum*. Image: Southern Highland News

My Nearest & Dearest
Art Exhibition

the ARThouse Hotel
275 Pitt Street, Sydney

Opening Night Event
Monday 10 October
filled with art, music special guests and a silent auction

Exhibition open from
10 October to 12 November
over 60 artists exhibiting

Enquiries
Jennifer Mattiussi
jmatt@bigpond.net.au 0417 437 900
Christine Farkas
cfarkas@bigpond.net.au 0407 867 596

MND NSW Christmas Puddings

by "*Pudding Lane*"
on sale now!
$34.95 for 1 kg pudding
(plus postage and handling)

All puddings are individually wrapped and sealed for freshness. Pudding Lane puddings are handmade using environmental friendly and traditional methods with fresh ingredients which are locally sourced. Contact Anne Jones, ph. 8877 0999.

If you would like more information about leaving a gift to MND NSW in your Will, contact David Dubin ph. 02 8877 0917 or davidd@mndnsw.asn.au

Dates for the Diary

17 September	**Girls Night pre-loved clothes and makeovers** | Farmborough Heights | Contact Rachel Yerbury ph. 0419 226 794 rachyerbury@googlemail.com
9 October	**Walk to d'Feet MND Port Macquarie** | Westport Park to Town Beach Park and return | 5.5km Fundraising Walk | Contact Kym Nielsen ph. 8877 0999 or kymn@mndnsw.asn.au
10 October - 12 November	**My Nearest and Dearest Art Exhibition** | Arthouse Hotel | Contact Jennifer Mattiussi ph. 0417 437900 or jmatt@bigpond.net.au
15-16 and 22-23 October	**Birds of a Feather Art Exhibition** | Recent paintings by Judy Brownlie and Ruth Aldrich | 85 Stahls Rd Oakville | Contact 4579 1173
6 November	**Walk to d'Feet MND Sydney** | Blaxland Park, Sydney Olympic Park, Homebush | 5km Fundraising Walk | Contact Kym Nielsen ph. 8877 0999 or kymn@mndnsw.asn.au

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Editor: *Penny Waterson*