



FORUM

Celebrating our carers!

Earlier in the year, the Campbelltown support group decided that they would like to host a pampering day for people with MND and their carers. On Tuesday, 16 June, they brought together two hairdressers and a massage therapist who gave neck massages, foot rubs and hand massages to the group.

It was a great day, full of chat and laughter. The group enjoyed themselves immensely. You could see tensions disappearing as members enjoyed a massage or had their hair done and they went home feeling relaxed and glamorous. There were big smiles on many faces.

Caring for someone with MND can be very challenging. Having a break and something to look forward to is vital for the wellbeing of the carer and for their ability to continue in this important role.

We thank Carers NSW via The Australian Foundation for Disability for funding the massage therapist and Stefanie Breyley and Emma Tarlington from Red 1 in Campbelltown for donating their time and their amazing skills with mobile haircare. This day provided a break from MND for all involved and also acknowledged the amazing role carers play in looking after their family members.

Ann McCutcheon
MND Advisor



Carers Week 2015 is from 11 to 17 October

MND NSW would like to take this opportunity to thank and congratulate MND carers. For a special message from one carer to all others, see *A Carer's Story* on page 3 of this edition of *Forum*.

Living Well with MND
Wollongong Golf Club, Wollongong
Thursday 22 October
10am to 3.30pm

*One day programs for people living with MND,
their families and friends.*

Living Well with MND
Royal Rehab, Ryde
Tuesday 27 October
10am to 3.30pm

You will be provided with a range of strategies to live well with MND and to maintain independence.

You will also have the opportunity to have your questions answered by health professionals with expertise in MND, and to meet others who understand what it is like to live with MND.

There is no charge for you to attend either of these programs but you need to reserve your place. Lunch and refreshments will be provided. Let us know if you have any special dietary requirements. To register email reg@mndnsw.asn.au or contact MND NSW ph. 02 8877 0999 or Freecall 1800 777 175.



A long-time supporter of MND NSW, **Snap Printing North Ryde** is offering to donate 10% from all print jobs when MND NSW is mentioned. For total printing referrals over \$20,000 annually Snap will donate 15%. Simply mention the Motor Neurone Disease Association of NSW when placing your order. All money received will help enhance our equipment, regional advisor services and research.

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.



Walk to d'Feet MND

Canberra

On 21 June, a beautiful winter morning greeted walkers for the annual Walk to d'Feet MND in Canberra. And what a wonderful roll up we had, with many family teams and friends participating to raise awareness and funds for MND. This is the second year that we have been at Peace Park on the edge of Lake Burley Griffin and it is a terrific venue. A big thank you to singer Megan Longhurst, who had appeared on The Voice, for speaking to the walkers before the start about her journey with MND with her dad, Gary Longhurst; and for entertaining the crowd after the Walk, with her new single and other songs. Thank you also to the Gungahlin Rotary who provided the yummy sausage sizzle. This was the biggest roll up we've had yet for a Walk in Canberra, with 240 supporters raising \$20,651, and we hope to see the numbers continue to increase. If you would like to get involved in helping us grow this Walk, contact Kym Nielsen at kymn@mndnsw.asn.au



Central Coast

It was the Central Coast's turn to shine on Sunday 9 August at their second Walk in Woy Woy. One hundred and fifty participants raised \$7,565. Many thanks to the organising committee lead by Wendy Whitmore and Bill Haire, our many event volunteers who helped ensure the smooth running of the event and Brett King who was the highest fundraiser, raising \$1,217 for MND NSW on Everyday Hero. A big thank you also to the Lake family for their contribution to the event.



20 September
Port Macquarie

25 October
Wagga Wagga

8 November
Sydney

Riddla Golf Day

Congratulations to Ann Ridd for organising another great Riddla Golf Day on 15 May at the beautiful Twin Creeks Golf Club at Luddenham.

One hundred and fifty golfers had an enjoyable day playing a 4-ball Ambrose on this lovely course, followed by some great food and auctions in the clubhouse. More than \$10,000 was raised at this great annual event.



City2Surf

What a fantastic fundraising effort from our participants in this year's City2Surf! Over \$60,000 was raised to support people living with MND and to further research in pursuit of a cure. Thank you to everyone who pounded the pavement and faced the challenge of Heartbreak Hill.

A special mention for Team Rejoyce which raised over \$27,000, and to Carl Austin who individually raised more than \$4,500. Russell Fox ran again this year in his spectacular blue morphsuit and received some great coverage from the media, including from the Sunrise program and ABC. Thanks, Russell, for your ongoing commitment to raising funds and awareness of MND.

To each and every runner, we appreciate your support!



A Message from the CEO

The end of winter is on the horizon and things should, hopefully, be warming up.

As usual, winter brought with it our annual Ask The Experts Forum, MND Information evenings for people recently diagnosed with MND; and many support groups in regional areas. We also conducted our MND Special Interest Group (SIG) workshop for health and community care professionals and CommSPOT, a new workshop dedicated to speech pathologists and occupational therapists, that focussed on communication devices and assistive technology; A full report on these events, and details of upcoming events can be found on the pages following.

Australian Government aged care reforms came into effect on 1 July and we are already starting to see problems arising due to 'finite' packages of funding for individuals and the inability of the NSW Government's equipment/assistive technology service, EnableNSW, to provide for people on such packages. This is due to current State legislation and, as far as we can see, does not occur in other states.

We are working with service providers and advocating for change to both NSW and Australian Governments and hopefully this absurd situation will be rectified soon.

August has seen the relaunch of the Ice Bucket Challenge (IBC) with the tag line 'Every August Until a Cure'. It will be difficult to replicate last year's IBC, but we hope that making this an annual challenge will keep MND front of mind in Australia and internationally.

Events leading up to Christmas include several Walks to d'Feet MND, our members' Christmas party, support groups, and MND Aware training sessions. Information on these can be found in this edition of *Forum* and on our website and Facebook page. We have also enhanced our Living with MND publication series with the development of an online services and resources directory for people living with MND which can be found at mnd.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

STOP PRESS: Photoneuron MND trial at Westmead seeking participants closing 15 September see page 10 of this edition of Forum for details

Would you like to make a compliment or a complaint about our service? Ph. 02 8877 0999 or 1800 777 175.

Motor Neurone Disease Association of New South Wales

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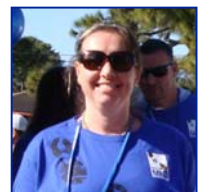
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And...many valued volunteers including Wendy Whitmore who worked tirelessly to help coordinate and promote the Central Coast Walk to d'Feet MND



A carer's story

*Having cared for her partner with MND, **Marian Lowe** knows how dangerous stress and burnout can be for committed carers.*

The Shorter Oxford English Dictionary defines care as "To feel concern or interest, to provide for, look after, take care of, to be inclined or disposed, to be agreeable or willing to".

So as a carer, the inference is that we do all these things for other people, and of course it is always our primary aim. However, I would like to suggest to you that one of the most important aspects of being a carer is in fact, to care for yourself.

Carers are notoriously poor self carers, and having been in that position, I know how easy it is to let oneself slip into ill-health both mentally and physically. Whoever we care for and whatever the circumstances or length of time, we are bound to experience different levels of stress. The better we look after ourselves reflects on how we cope, and as carers we all want to do the very best we can. I think it helps to reflect on a few points from time to time.

Firstly recognise that you are working in an area where there is a high risk of exhaustion. Be aware of your emotional involvement and try to understand your own feelings and acknowledge them.

Those of us who care for a spouse or close family member cannot avoid being touched by their pain, their anger, their frustrations.

Realise your limitations. We are not superhuman, although at times it may seem so. But there are always things that are beyond our control and it's a good idea not to waste our precious energy on trying to change the unchangeable.

As carers we go through a vast range of feelings, sadness and depression, anger and resentment, frustration, anxiety, we become tired through lack of sleep and physical hard work, we couldn't care less how we look, and if we do get around to doing something for ourselves, we feel guilty! We feel trapped!

So, what steps can we take to minimise the effects that caring has on us?

I think it is important to recognise that we do have a choice in many instances. Most of us who care for our spouses or close family do so for several reasons which vary according to the individual. We all do the best we can within our capacities. No one person is better or worse than another.

The caring experience can be a very isolating one, but it is important to know that we are not alone unless it is our choice. Other carers feel as we feel, struggle with the same dilemmas, indeed if we look around we may even feel that we are luckier than some.

As a carer I found it enormously difficult to ask for help. To admit that I couldn't cope, was an admission of failure.

How wrong, stubborn and stupid I was! I drove myself until I was in a state of nervous and physical exhaustion, and only the threats of our wise and concerned GP saved the day and enabled me to complete the task I had chosen to do.

So what can we do to reduce and prevent what is known as "burnout"?

Firstly we need to be able to recognise the symptoms . . . Are we sleeping? Are we eating balanced regular meals? Do we feel out of control? Do we have recurring headaches, indigestion or allergies?

There is a simple test that you can have a look at that might help you evaluate where you stand on the burnout scale. Once you have identified this, you are in a better position to take positive action.

Try to build into your routine time that is solely yours - you may wish to go out, meet friends, play tennis, or stay home and read, or merely find somewhere quiet and go to sleep! Whatever your choice is, allow yourself to relax without any feelings of guilt know that this time is essential for you to refuel and will enable you to keep on with your job as a carer.

Talk to yourself; are your expectations of yourself so high that it would take ten people to fulfil them? Do you feel you are incompetent and therefore a failure? Or is it that the real reason for feeling beaten is because the situation is unwinnable?

Talk to others tell them how you feel, try to build up a support network and accept help that is offered.

Talk to the person for whom you are caring. Explosive situations can often be diffused by voicing one's feelings at an early stage. Allow them to discuss their fears and concerns. Keeping the lid on it all will inevitably lead to an eruption of the volcano, and this tends to exacerbate all those negative feelings that I mentioned earlier.

Remember that you do not have to be a saint!

I'd like to leave you with a couple of quotations, the first from Shakespeare's Macbeth:

"Give sorrow words; the grief that does not speak whispers to the over fraught heart, and bids it break."

The second is from an unknown source, but I think it is one that every carer should take to heart:

"Asking for help does not mean that we are weak or incompetent. It usually indicates an advanced level of honesty and intelligence."

Reprinted, with permission, from MND News, the newsletter of MND Victoria, Mar-Apr 2015.

If you would like more information about flexible respite funding speak with your MND Advisor

Support Service Team

Changes to services in the community

As you may be aware there are many changes occurring, at all levels of government, to the way community support services are delivered to people with disabilities. And every day we are learning something new. What we know so far...

If you are under 65, the National Disability Insurance Scheme (NDIS) will become the single access point for community services. For our members the NDIS is currently only available in the Hunter in NSW, the ACT and the Barkly region of NT. We do not know when or how the NDIS will rollout to other areas, even though it is scheduled to commence from July 2016-18. The Nepean NDIS office is currently being established but is currently only providing services to people under 18.

We hope to know more about the NDIS rollout in coming months and, when we do, we will let you know. For further information about the NDIS in your area see ndis.gov.au or Ph. 1800 800 110.

If you are 65 years and over, My Aged Care is the access point for community services through myagedcare.gov.au or Ph. 1800 200 422.

For people with MND who have complex needs, you will be able to access a Home Care Package to assist you to live independently at home. This package is to provide for all your support needs **including** your equipment needs. However, once you are on a Home Care Package, you will not be able to apply to EnableNSW for equipment as it is now expected that you will have sufficient funds in your Package to purchase the equipment needed. This is a big change. Until now our equipment service, FlexEquip, has provided equipment to people in the short to medium term and, for those requiring equipment for longer, we have continued to provide it until it is available from EnableNSW. Although we will continue to do that, we believe it is important you apply to EnableNSW before you require a Home Care Package. So we will be encouraging your allied health professionals to apply to EnableNSW to meet your equipment needs while you are still eligible.

Otherwise, if you end up requiring equipment for longer periods of time, you will need to use the funding in your Package to purchase or rent equipment. This reduces the funding you have available for other purposes such as home and personal care.

The changes to the way people who are 65 years and over are going to be able to access community services will inevitably impact on the way we provide equipment to our members. We do not receive any recurrent funding from government to provide equipment to people with MND and we rely heavily on fundraising to keep FlexEquip going. However, we remain committed to providing our members with equipment when they need it and

encourage you to contact us if you have any questions or concerns about any aspect of these changes. If we know the answers, we will be happy to assist you...and if we don't know the answers, we will do our best to find out.

Coming events

With the release of our new publication series *Living with MND* (see *Forum*, June edition) to replace the Carers Kit, we have also redesigned some of our education programs. We are now running a series of education days called *Living Well with MND*. In October we plan to hold a day in Wollongong and another in Ryde. See page 1 for further details.

The new publication series *Living with MND* includes three booklets that provide information about living with MND at home. Thank you to everyone who has assisted us develop and edit these publications to ensure that the information is helpful to our members and their families. We are also keen to receive your feedback, as this is a first printing and we intend to keep on improving the information we provide. The publications are available free online at mndnsw.asn.au > Information resources > Managing MND. MND NSW members can also request a print copy at no charge. For more information contact the MND Info Line ph. 1800 777 175 or info@mndnsw.asn.au.

Our last event for the year will be our annual Christmas party. I do hope to see you on 21 November as it is a special time for all of us at MND NSW. We look forward to spending some time with our members and their families, and it is always a big hit with the young ones when Santa arrives.

Gina Svolos

Manager, Support Services

Support Service Calendar

13 Oct	Information Evening for people recently diagnosed with MND, family and friends Gladesville
22 Oct	Living Well with MND Wollongong
27 Oct	Living Well with MND Ryde
21 Nov	Christmas Party for support services members, their family and friends West Ryde
8 Dec	Information Evening for people recently diagnosed with MND, family and friends Gladesville

For more information contact the MND NSW Info Line ph. 1800 777 175 or info@mndnsw.asn.au
If you would like assistance with travel to attend or would like us to organise an MND information session in your region, please speak to your MND Advisor.

Write to the
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info@mndnsw.asn.au

Ask the Experts – 20 July

Our speakers at the 2015 MND NSW Ask the Experts Forum provided information 'About MND' and 'What's New in MND Research' and also explored the 'Hope, Hype, and Reality' surrounding stem cells. Thank you to Professor Matthew Kiernan, Dr. Justin Yerbury, and Associate Professor Megan Munsie.

You can watch videos of the presentations and the associated question and answer sessions on the MND NSW Youtube channel www.toutube.com/mndnsw. Here are some brief notes taken from the day.

About MND

Professor Matthew Kiernan

ForeFront Motor Neurone Disease Research Clinic,
University of Sydney

Professor Kiernan opened with a slide of an aboriginal rock painting showing human hand prints. It is the hand that separates us from other species. The hand can also be an indicator of neurological disorders, including MND.

Jean-Martin Charcot first described ALS following a study of thirteen people in the 1860s. He identified lateral sclerosis—hardening of areas of the spinal cord plus muscle wasting coming from the anterior horn. These two components are needed to make a diagnosis of MND. Very few diseases involve upper and lower motor neurones as MND does and we still don't understand why it occurs.

There was not much progress in the ensuing 130 years, until 1993 when the SOD1 gene on chromosome 21 was discovered. Glutamate was identified as being toxic to motor neurones.

Riluzole is a neuroprotective treatment which reduces the production of glutamate. Worldwide, 150-160 trials have reinforced the benefits of riluzole, particularly when therapy is started early.

Multidisciplinary care came to prominence during World War II. Good multidisciplinary care can extend life for someone with MND by 12-18 months. The RPA/University of Sydney clinic is a model of multidisciplinary care. Teams include a nurse, MND advisor, occupational therapist, speech pathologist, physiotherapist, neurologist and social worker. Respiratory physicians and gastroenterologists are critical team members.

Studies have shown chance findings of signal changes in the cortico-spinal tract under MRI. These changes can confirm diagnosis. Nerve conduction and EEG studies look at neuromuscular information. Other signs to look for include "split hand" syndrome. This can be linked directly to affected parts of the brain. Humans have a massive representation in the brain for thumb, forefinger and bulbar regions.

It is now thought that MND is a primary neuro-degenerative condition in the brain—this is known as the "dying forward" hypothesis, according to which MND lies on a spectrum with other conditions such as Parkinson's and Alzheimer's and is not a peripheral neuromuscular condition.

What's new in MND research?

Dr Justin Yerbury

University of Wollongong Centre for Medical and Molecular Bioscience, Illawarra Health and Medical Research Institute

Dr Yerbury's research team is involved in looking at actual neurones and have observed a build-up of junk proteins in the motor neurone cells. It appears that the cells develop a problem with "clearing out the trash." Their natural garbage trucks are faulty, leading to the accumulation of junk proteins. "Dying back"—the theory that the axon dies back from the muscle—is believed to be caused by an accumulation of junk proteins in the motor neurone cell. Scientists are trying to work on ways to speed up the garbage removal. However there are many other things going on in the cell.

There has been a rapid increase in gene identification since 2010, with 35 genes implicated in MND now identified. More than 60 per cent of people with familial MND now know the cause. There are overlapping genes with MND, FTD and other diseases such as Paget's disease. We are starting to cluster the genetic changes into groups that act in different ways:

- protein stability
- metabolism, RNA involvement
- axonal/cytoskeletal involvement

Studies of disease progression in mice shows that the disease needs a trigger to start. This gives us a way to stop the process. Studies of C9ORF have produced lots of different theories about why FTD occurs. It is a hot topic for research. In addition, there are new models in the lab:

- C9ORF mouse—the hope is to speed up the process of trials using the mouse model.
- dish models—it is now possible to take a skin sample from someone with MND and trick the cells into becoming stem cells, and then to change these into motor neurone cells for experimentation. This is one way of studying sporadic MND.
- zebra fish—it is possible to implement genetic changes in the zebra fish brain. The advantage is that the fish are totally transparent so changes can be seen in real time. Motor neurones can be seen to die within 10 hours.

How does this research help us to get to a therapy? There is a process of moving from genetics to lab work to models. We can use this information to see how different things affect the motor neurone and

If you live in the Illawarra, why not join us for Living Well with MND in Wollongong on 22 October (see page 1)

Ask the Experts – 20 July (cont'd)

then come up with ideas for treatment.

Trial therapies in development:

- “antigene” for the SOD1 variant—studies have shown that if you lower the SOD1 gene in mice, the mice live longer. A phase 1 clinical trial has been completed; Phase 2 should start in a few months. The promise of this therapy is mostly for genetic forms of MND. Another study of gene suppression showed an increase in survival of 50 per cent.
- delivery of copper to the motor neurones—there should be a clinical trial by the end of the year.

Currently 75 clinical trials across the world—details available at alstdi.org. These trials include studies of nerve stimulation, stem cell therapy, gene knock downs, and growth factors. The majority of these studies are taking place in the US, also some are being conducted in France and Germany.

Hope, Hype and Reality - headlines are often simplistic and misrepresent the research.

Associate Professor Megan Munsie

Head of the Education, Ethics, Law & Community Awareness Unit, Stem Cells Australia

Hope

The hope is that cellular replacement therapy using stem cells could fix dysfunctional cells by replacing them. Cellular replacement therapy works in bone marrow but is not as simple in other cells. We are a long way from making it a reality.

Reality

Blood stem cells have been used in blood diseases for many years and it is a proven treatment. There have been more novel applications recently such as creating sheets of cells for treatment of severe burns. In another instance, a team in Sydney is using contact lenses as a scaffold to build new corneas from a biopsy of the eye. These treatments are effective because they are working on a very discrete type of cell. Everything else is highly experimental.

In the US, researchers have been able to grow motor neurones in a dish—then see how the motor neurones react to certain drugs and stimuli. It may be possible to screen drugs in this way, in order to test whether they can protect neurones from MND. For example, Retigabine is now ready for a clinical trial.

The hype

Despite the lack of evidence, stem cell replacement therapy is being promoted in the community. The reality is that this is all marketing. ‘Therapy’ is happening overseas in unregulated countries and unfortunately it is also happening in Australia.

In Australia, there is a legal loophole that allows

doctors to sell cell therapy despite the lack of clinical trials for safety and efficacy.

Professor Munsie has been researching the experiences of people who have undergone stem cell treatment and notes there are serious risks. Clinics don’t talk about the complications that may occur. When stem cell treatment is used for MND, injections of ‘substances’ are often injected into the brain or spine in order to cross the blood-brain barrier. This is potentially dangerous due to the risk of infections, growths or other harms. There is also a financial burden.

Professor Munsie is keen to hear from people regarding their experiences. You can contact her at megan.munsie@unimelb.edu.au. Resources mentioned during the presentation include

- stemcellsaustralia.edu.au
- nhmrc.gov.au - National Medical Research Council Stem Cell treatment FAQs
- isscr.org - Patient handbook on Stem Cell Therapies
- alsuntangled.com
- closerlookatstemcells.org - Nine things to know about stem cells treatment

*If your MND Advisor is unavailable the MND NSW Info Line may be able to assist
ph. 1800 777 175 or email info@nmndnsw.asn.au*



You, your family and friends are invited to



MND NSW Support Services Members' Christmas Party 2.30pm to 4.30pm Saturday 21 November 2015

Ryedale Room,
Ryde Eastwood Leagues Club,
117 Ryedale Road, West Ryde
Join us for an informal gathering.
Renew old acquaintances, make new friends and meet MND NSW staff and board members.

- Finger food and refreshments will be provided
 - Santa is expected to visit the children, so please let us know the ages of yours
 - The venue is accessible with facilities to meet all members' needs
 - For assistance with travel arrangements, contact your MND Advisor
 - Please let us know if you have any special dietary requirements
- For catering purposes, let us know if you are coming by 18 November by email to reg@nmndnsw.asn.au or ph. 02 88770999 or Freecall 1800 777 175.

Around the Groups

Western Sydney (Penrith)

The Western Sydney Support Group meets at Kingswood Neighbourhood Centre every second month on a Tuesday afternoon. We are a small but friendly group who share experiences and ideas about how to live well with MND. At our meetings we have a mix of informal chat and guest speakers as chosen by the group. Earlier this year we had an occupational therapist come to give us ideas about managing daily tasks at home and we had a great hands-on demonstration of a range of useful tools and technology to help get things done.

As the weather warms up we are looking forward to moving the meeting out onto the verandah to enjoy the sunshine! Everyone is welcome to come, and to bring family members or friends. Let us know if you have any difficulty with transport or special dietary needs.

Melanie Oxenham

MND Advisor

Central Coast

Our support group meets on the first Thursday afternoon of every second month at Narara. We are very fortunate to have a great line up of guest speakers willing to share their knowledge with the group and to help with any queries. At our most recent meetings we have welcomed Sue Bonnor, Speech Pathologist, and Diana Maddrell, Social Worker, both from the CORT team, and Dr Kelly Williams, a researcher working with the Macquarie University team.

The group maintains a focus on supporting people living with MND and their carers on the Coast, so we ensure there is plenty of time to share ideas and information over a casual cuppa and afternoon tea. Meetings for the rest of this year will be on 1 October and 3 December from 1-3pm at Gosford/ Narara Neighbourhood Centre, 2 Pandala Rd, Narara. We hope to see you there.

Deb Ward

MND Advisor

Northern Beaches

A major challenge for our support group attendees throughout this year has been where to park at Mona Vale hospital because of construction next door. Many thanks to all those who have had to negotiate the stairs, barricades and oversized lorries blocking the roadway in an attempt to reach the Cora Adcock Palliative Care Unit.

Our meetings are a mixture of education about MND, learning about symptom management strategies, and an opportunity for care givers to connect with others who are sharing similar challenges. As our group has grown in size, we have been able to attract many competent speakers!

We are always on the lookout for new members to join us and encourage anyone with MND, their family members and their carers to attend our free morning tea meetings.

Jo Fowler

MND Advisor

Northern Sydney (Hornsby)

This year, we have learnt much from each other and from our guest speakers. We started by looking at ways to record our life story using techniques like journaling, genograms and timelines. We had a visit from Margaret O'Sullivan, a specialist community nurse who talked about the importance of early symptom management. Lorel Adams, the Bio Bank Coordinator from Macquarie University Hospital, spoke about some of the research being conducted there in the hope of finding a cure. Lorna Hutchinson, a senior occupational therapist, introduced us to equipment that can assist mobility and help prevent falls. She also explained some of the recent changes to services and their provision through EnableNSW and My Aged Care.


Many thanks to Malcolm, Diane and Philip, our wonderful volunteers who help set up the room, toast the wraps, serve the coffee and who look after us so well.

Our group is open to new members, so come along and gain support by connecting with others who are experiencing similar challenges. The meetings are free, a light luncheon is provided and there is plenty of parking nearby.


Jo Fowler

MND Advisor

Support group meeting dates are at mndnsw.asn.au or contact the MND Info Line 1800 777 175



MND NSW
 YouTube Channel

Walk to d'Feet MND




2014 Sydney - Walk to d'Feet MND
 by The Motor Neurone Disease Association of NSW
 9 months ago • 670 views
 Thank you to our supporters for a fantastic Walk to d'Feet MND at Homebush on Sunday 9 November 2014.

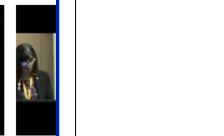
Recordings by Event



2015 Ask the Experts
 by The Motor Neurone Disease Association of NSW



2015 Special Interest Group Workshop for Health, Aged and Carers
 by The Motor Neurone Disease Association of NSW



2014 Allied Health
 by The Association of NSW

Catch up on an event you may have missed
youtube.com/mndnsw

Educating health and community care professionals

One of our aims at MND NSW is to educate health and community care professionals about MND and what they can do to improve the services and support they provide. June was a big month, with two workshops held.

The first was the MND NSW CommSPOT workshop. This workshop was designed specifically for speech pathologists and occupational therapists (SPOTs) who support people with MND regarding their communication needs. The aim of the workshop was to explore evidence-based approaches to providing assessment and support, to put theory into practice and to learn about strategies and devices that commonly meet the computer access and communication needs of people with MND. It was so popular that we reached our maximum enrolment of 60, six weeks before the event.

We have received very positive and constructive feedback with 93 per cent of participants rating the workshop overall as above average to excellent. A common theme from the participant evaluation was that a need for more time in the hands-on workstation session, 'powering up'.

The second workshop was the MND NSW Special Interest Group (SIG) workshop, which was held the following day. The SIG workshop is held every other year and is open to all health and community care professionals with an interest in MND. Many participants in their evaluation rated the SIG workshop this year as "the best ever".

Steve Vucic, Professor of Neurology at Westmead Hospital, spoke in depth on MND types, progression and prognosis.

Rod Macleod, Palliative Care Staff Specialist at HammondCare, spoke on caring for people with MND near end of life and introduced palliativecarebridge.com.au as a staff educational resource.

Shea Morrison, Rehabilitation Physician at St Joseph's Hospital, presented three mini topics on sialorrhoea, constipation and advance care planning.

There was much more, including workshopping in role-specific groups and information on how to engage in research.

Special thanks to the SIG Advisory Group members, who are leaders in MND care in their respective allied health fields. They developed the program, suggested and secured the speakers, presented and facilitated. As one of the 100 participants wrote, "all presentations were relevant and informative, my brain is sufficiently buzzing with new information that needs to be processed".

Our future health and community care education session plans include an MND Aware workshop for community and hospital based physiotherapists, to be held in the Shoalhaven region.

Kristina Dodds

Education and Carer Support Program Coordinator

If you live in the Sydney, why not join us for Living Well with MND on 27 October at Royal Rehab, Ryde (see page 1)

Support Groups and Coffee Mornings

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

Campbelltown - Ann McCutcheon | annm@mndnsw.asn.au

Liverpool - Ann McCutcheon | annm@mndnsw.asn.au

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

Northern Sydney (Hornsby) - Jo Fowler | josephinef@mndnsw.asn.au

Western Sydney - Melanie Oxenham | 4731 6168 | melanieo@mndnsw.asn.au

REGIONAL AND RURAL

ACT and Southern NSW - Dianne Epstein | 6286 9900 | diannee@mndnsw.asn.au

Central Coast - Deb Ward | 1800 777 175 | debw@mndnsw.asn.au

Central West - Melanie Oxenham | 4731 6168 | melanieo@mndnsw.asn.au

Griffith/Wagga Wagga - Dianne Epstein | 6286 9900 | diannee@mndnsw.asn.au

Illawarra - Ann McCutcheon | 1800 777 175 | annm@mndnsw.asn.au

Muswellbrook (Upper Hunter) - Kim Sinclair | 4985 5022 | kims@mndnsw.asn.au

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

North West (Tamworth) - Madeleine Bowman | 8877 0905 | madeleineb@mndnsw.asn.au

Northern Rivers - Chris Carroll | 0421 252 455 | chrisc@mndnsw.asn.au

Port Macquarie - Eileen O'Loughlen | 4921 4157 | eileeno@mndnsw.asn.au

Gold Coast Carers - Chris Carroll | 0421 252 455 | chrisc@mndnsw.asn.au

Noticeboard

Living with MND photo series

MND NSW is creating a photo series to visually describe the impact MND has on the daily life of people living with the disease, their family, and their friends. Karl Welsch, professional photographer, Welsch Photography, has kindly offered to take these photos showing people with MND going about their everyday lives. If you use MND NSW FlexEquip equipment we would like to take photographs of you using the equipment. We would also like to take photographs of members using MND NSW services, such as looking at the Association's website and reading information about MND. If you live in the Sydney metropolitan area and would like to be part of this exciting project, contact Penny Waterson, Information Resources Coordinator, MND NSW at info@mndnsw.asn.au or ph. 02 8877 0915.

Photoneuron MND trial at Westmead seeking participants

Westmead Hospital in conjunction with the Westmead Millennium Institute is conducting a Phase IIA randomised controlled study assessing the effectiveness of narrow-band UVB phototherapy in patients with MND. Preliminary research in MND patients has identified the importance of the immune system in regulating progression of MND. Narrow-band UVB phototherapy aims to modify the immune system such that it markedly slows the disease course. The trial will be conducted at Westmead and the aim is to recruit 20 patients who have been diagnosed with MND. Participant physical function needs to be not greatly affected by MND and participants also need to be willing to travel to Westmead for the study. This study is randomised which means that 50% of patients (10 patients) will receive phototherapy while 50% will receive standard care. If you are interested in finding more about this study please contact Professor Steve Vucic via email s.vucic@neura.edu.au or steve.vucic@sydney.edu.au. Recruitment closes on 15 September 2015. This project has been approved by the Western Sydney Local Health District HREC.

The conversation project

theconversationproject.org has useful information on how to talk about advance care planning. Although some of the content is USA-specific, the Starter Kit PDF, available for free download, includes questions that will help you get your thoughts together before having conversations about advance care planning with your family, friends and doctor. For specific information about advance care planning in NSW and the ACT, follow the links at advancecareplanning.org.au.

Online Living with MND Directory of Services and Resources

Find direct links to more than 200 services, programs, entitlements and resources that may be of interest to people living with MND in NSW, the ACT, and NT. You can search by listing name, state or type, or you can browse listings by category. Follow the links at mndnsw.asn.au.



ALS Quest

You are invited to participate in a new research project that is looking for risk factors that might precipitate MND. Anyone can contribute by completing the questionnaire—people with the sporadic form of MND (that is, the type that does not affect other family members), people with familial MND, relatives and others without MND. The questionnaire, designed by Dr Roger Pamphlett at the University of Sydney, and instructions for how to complete it, can be found at alsquest.org. This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney Local Health District.

For Sale

2006 Toyota Alphard; very low km. Seats 7 people (4 if wheelchair is in vehicle). \$35,000. Ph. Loretta 0419 423 356

2007 Kia Carnival EX, reg. to Aug 2016. 77000k. White. 4 seater plus wheelchair. New tyres \$45,000 ono. Ph. John 0438 239 115 or 02 4392 6752

2014 VW Caddy TDI 250 Wheelchair Access Vehicle. As new, seats 4 plus wheelchair (wheelchair also available). \$54,900 ono. Contact Wilfred Ph. 03 9888 3130.

Have you purchased your **MND NSW beanie** yet? If not, get in quick before they run out. Cost \$15 plus postage.



Purchase online at mndnsw.asn.au or ph. 02 8877 0999

Yummy **MND NSW Christmas Puddings** by "Pudding Lane" Cost \$34.95 plus postage.



Purchase online at mndnsw.asn.au or ph. 02 8877 0999

Would you like to receive Forum by email? You can save MND NSW postage costs. Let us know at admin@mndnsw.asn.au

Community events

A Winter Ball, Cooma

A big thank you to the Monaro Dance Centre in Cooma who hosted A Winter Ball.



The night was organised by principal Kayla Bogatek, with Kylie Asanovski, Shannon Salvestro and Lisa Towing assisting (Lisa is pictured with Grace Towing).



It was a great night with more than 170 people in attendance, and included raffles, merchandise sales and live music. An amazing \$10,000 was raised on the night.

Charity Dice Run to Hat Head

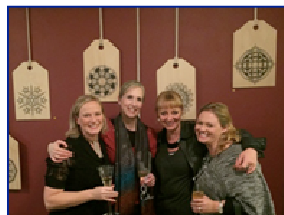
The Harley Owners Group of the Mid North Coast held a group charity ride which raised \$772. Riders started in Coffs Harbour and Port Macquarie, meeting at Hat Head Bowling Club for lunch. Thank you to Paula Skinner who coordinated this event.

Wardy's Bowls Day

A good time was had by all who attended Wardy's Bowls Day, an annual charity day held at the Taren Point Bowling Club. The day included lawn bowls, a raffle, BBQ, and a 100ft putt. Organiser of the event, Michael Hamson, chose to support MND NSW this year with \$1,582 donated. Thank you Michael!

Ply Party

A Ply Party was held to sell lovely artworks by Kristen Trollove, hand drawn on hoop plywood using pigment, pen inks, and pencil, and inspired by old vintage and costume jewellery. A fun time was had by those who attended the party, which raised \$1,230. Thank you to Kristen for supporting MND NSW.



High Tea by the Sea

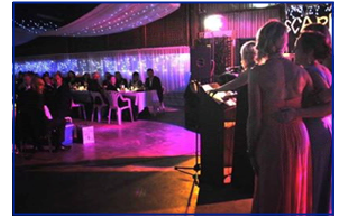
An afternoon of fun, fashion, and fundraising was held in Camden Haven. Thank you to Gayl Ellis who organised this enjoyable afternoon which raised \$1,000 for MND NSW.

Emus Rugby Club Ladies Day

A lovely afternoon High Tea fundraiser was held at the Orange Emus Rugby Union Club raising \$2,062. The afternoon included a high tea and wine tasting as well as a raffle and lucky door prize. A big thank you to Kylie Haigh who organised this event.

The Robertson MND NSW Country Charity Ball

A huge thank you to the organisers of the Robertson MND NSW Country Charity Ball: Lynda Leith, Jo Gair, Michelle Van Eimeren and Natasha Blenkinsopp (pictured right).



The ball was enjoyed by all and included lucky door prizes, a balloon raffle and a very successful auction featuring an Ice Bucket Challenge by the Mayor of the Wingecarribee Shire Council, Duncan Gair. The band, Scared Stiff, kept the crowd dancing until late!

Congratulations to Team Rejoyce for raising just over \$15,000 in memory of Lynda's mum, Joyce Whatman, who died of MND in February.

Charity Day at Tathra Beach Women's Bowling Club

Sixty-six lawn bowlers took part in a charity day to support MND NSW, hosted by the Tathra Beach Women's Bowling Club. Louise Pearson, the daughter of club member Anne Pearson, has been living with MND for eight years and was present on the day. A big thank you to Anne and everyone who helped organise this event, which raised \$1,520.



Riverwood Downs Mother's Day Lunch

A Mother's Day lunch was held at the beautiful Riverwood Downs in Monkerai in May. The afternoon included a two course lunch and live music by Sandy Bennett. A big thank you to Kathleen Turner, the Operations Manager from Riverwood Downs, who coordinated this lovely event which raised \$584.

MND Morning Tea

Thank you to Argyll Parkins and staff of Amgen Australia, Sydney Office, who held a morning tea to support MND NSW. Staff brought a plate to share and watched videos of Ice Bucket Challenges as well as the trailer for the movie The Theory of Everything. Thank you for your support and for raising \$310 for the Association.

Visit us
on Facebook
at
[facebook.com/
mndnsw](https://facebook.com/mndnsw)



Community events (con't'd)

Tullibigeal v Ungarie Football and Netball Match

A day of football and netball matches was held at the Tullibigeal Recreation Ground to raise funds and awareness for MND. Thank you to Leanne Imrie who was the coordinator for the day, which raised \$502 from donations and merchandise sales.



Campbelltown City Lions Club BBQs

Thank you to the Campbelltown City Lions Club who held BBQs at Homebase in Campbelltown earlier this year, raising \$5,000 for MND NSW. Pictured above are Allan Smith, George Semrani (President of the Lions Club), Sue Coppola and MND NSW Fundraising Manager, Kym Nielsen.



Our community events for MND would not be possible without our supporters who volunteer to organise events. Thank you for your support.

Community events Dates for the Diary 2015

20 Sep	 Walk to d'Feet MND Port Macquarie
25 Sep	MND 'Thumbs Up' Ball Orange
10 Oct	Gundaroo Music Festival Gundaroo gundaroomusicfestival.com
10 Oct	Concert to support MND NSW Glendale
18 Oct	Charity Barefoot Bowls Barrack Heights
25 Oct	 Walk to d'Feet MND Wagga Wagga
1 Nov	Charity Concert for MND Bellbird
3 Nov	Melbourne Cup Luncheon Katoomba
8 Nov	 Walk to d'Feet MND Sydney
16 Nov	Worrigeer Wattle Charity Day Worrigeer
20-22 Nov	Newcastle Italian Film Festival Tower Cinemas Newcastle
9 Dec	Metal Art Auction Newcastle
For more information see mndnsw.asn.au or contact MND NSW ph. 02 8877 0999	

Could you organise a community event for MND NSW? Have a chat to Kym Nielsen, Fundraising Manager ph. 02 8877 0999 or kymn@mndnsw.asn.au

Honour the life of someone you care about by leaving a lasting gift

However large or small, your charitable bequest will have a huge impact on the lives of people living with MND and their families.

Your generous gift will form a key part of our Association's long term income and help us to continue providing essential equipment, information, practical support, education and advice free of charge to our members.

It will also help us continue to fund research for more effective treatments and ultimately a cure for MND.



Therese Aoun, 1980-2012, and with her family at Walk to d'Feet MND in 2008

Therese was a well-known and much-loved member of the MND community and I had the privilege of meeting her and her family on numerous occasions. She was a warm, caring and inspirational young woman who was passionate about helping other people living with MND and their families.

Therese died in 2012 at the age of 32, having battled MND for six years.

Therese continues to support our Association because she left a gift in her will to MND NSW. Her legacy is helping others with MND lead a better quality of life at home with their families.

If you would also like to leave a gift in your will, please contact Anne Jones ph. 02 8877 0999 or email annej@mndnsw.asn.au.

Like Therese, you can make a huge difference in people's lives.

Anne Jones

Supporter Liaison Officer

ACKNOWLEDGEMENT

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

Editor: Penny Waterson