



FORUM

#icebucketchallenge - Thanks for your support!

The Ice Bucket Challenge for ALS/MND is a social media campaign initiated by Pete Frates, a former Boston College captain who is living with motor neurone disease (MND) in the US. Since Peter Frates posted his challenge online, the Ice Bucket Challenge quickly went viral and is now spreading across Australia's MND, sporting and entertainment communities.

ALS (amyotrophic lateral sclerosis) is known as MND (motor neurone disease) in Australia. In August the Ice Bucket Challenge reached Australian shores. Since then we have been able to create much-needed awareness about MND. Also, Ice Bucket Challenge donations to MND NSW (amounting to about \$30,000 to date) will help us to continue to provide our family support service (including the MND Info Line, regional advisor service, equipment, educational events and information) for our members, their family and friends. Funds have also been dedicated for research into MND and MND Australia will be announcing new research grants for Australian research into MND in the very near future.

Ask your friends and family to support the Ice Bucket Challenge. Get them to

1. Fill a bucket (or larger container) with water and ice
2. Tip it over their head
3. Challenge three other people to take the Ice Bucket Challenge within 48 hours
4. If nominees don't take the Ice Bucket Challenge within 48 hours they make a donation to an MND charity. Of course people can take the challenge AND make a donation and ask the people they nominate to do the same!

We are asking people living in NSW, ACT and the NT make their Ice Bucket Challenge donations to MND NSW at www.mndnsw.asn.au



MND NSW CEO, Graham Opie, and several brave staff (above) and Blue Mountains Musical Society (below) taking the challenge



City 2 Surf 2014

Well the City 2 Surf snuck up on us this year, but not on our wonderful supporters. We had some very colourful participants raising funds and awareness for MND NSW. Thank you to everyone who participated, and their supporters, who helped raise over \$18,300.



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.

You, your family and friends are invited to
MND NSW Family Support Members' Christmas Party
2.30pm to 4.30pm
Saturday 22 November 2014

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 regional advisor
 - Please let us know if you have any special dietary requirements
- For catering purposes, let us know if you are coming by 8 November by email to reg@mndnsw.asn.au or ph. 02 88770999 or Freecall 1800 777 175

We look forward to seeing you there!



Find out more
about the
Ice Bucket
Challenge at
www.mndnsw.asn.au

Living well with MND - Orange - *A day for people living with MND, their families and friends*

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.

When: 10.30am to 3pm Wednesday 22 October

Where: Orange Ex-Serviceman's Club

There is no charge for you to attend this program but you need to reserve your place by 15 October. 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 Kristina Dodds Ph 8877 0999 or Freecall 1800 777 175.

Carers catching up

During July, family carers from our 4-day Care for Carers Workshop in May/June 2014 self-organised a reunion lunch at the MND NSW Centre at Gladesville. A lovely time was had catching up!. Here they are pictured together with Kate Maguire, Education and Carer Support Coordinator (left) and Jo Fowler, Regional Advisor (right).



Introducing...

Madeleine Bowman - Regional Advisor Sydney East and South

I am originally from the United Kingdom and moved to Australia in 2008 with my husband and daughter after living for almost two years in New Zealand. My background is in social work – mainly with children and families – and I have worked in this field in three countries, including two years in Malta – my husband's home country. Since moving to Australia, I have worked in a State Government Department involved in decision-making for adults with disabilities. I have a lot to learn and I am enjoying getting to know everyone and meeting members out and about in the community. I hope to bring my skills, experience and compassion to the role.



A Message from the CEO

The winter solstice has passed, as has MND Global Day in June and now in August ... the Ice Bucket Challenge is upon us, literally. I'm no user of social media but this viral media event has even taken social media savvy people by surprise. Thank you to our supporters for their involvement and for their donations in support of MND NSW.

During July we were incredibly busy undergoing external review for national quality standards accreditation. MND NSW is required to meet both health quality standards and disability quality standards. We passed our review and I'd like to thank the members and volunteers who took part.

At the moment there is a huge amount of change within the health and disability sector. The NDIS has commenced in the Hunter and the ACT; there has been a change in the State government's approach to ageing, disability and home care

in anticipation of the NDIS state-wide role out; and, from NSW Health, the Grant Management Improvement Program is undergoing change. NSW Health provide the bulk of our recurrent funding, around 18% and all non-government organisation grants expired in July 2014. These have been rolled over until July 2015 as contracts and will be 'awarded' on a 'contract basis'. Unfortunately we have not been told when contracting will take place. We'll keep you informed.

There have been some fantastic events over the past three months and you can find more information on page 10. We have three more Walks to d'Feet MND before the end of the year and it's your chance to get together some family and friends to show your support. Our next walk is at Port Macquarie on Sunday 14 September. I hope to see you there.

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

Graham Opie
Chief Executive Officer



MND NSW member, Dr Malcolm Buck speaking with The Maitland Mercury on 29 August, and board member, Kirsten Harley, on Channel 9 on 31 August.



14 September
Port Macquarie
26 October
Wagga Wagga
9 November
Sydney

Motor Neurone Disease Association of New South Wales

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MND NSW

Building 4 Gladesville Hospital
Gladesville NSW 2111
(Locked Bag 5005
Gladesville NSW 1675)
Phone: 02 8877 0999
or 1800 777 175
Fax: 02 9816 2077
Email: admin@mndnsw.asn.au
www.mndnsw.asn.au
ABN 12 387 503 221

Chief Executive Officer
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FlexEquip Coordinator
Maree Hibbert

FlexEquip Assistants
Tom Giardina, Michael Walker

FlexEquip Support Officer
Julie Becke

Information Resources Coordinator
Penny Waterson

*And...many valued volunteers
including Dawn Meldrum,
our newest administration volunteer
assisting every Thursday MND NSW Centre at Gladesville.*



Family Support Team

Ask the Experts

It was great to see so many attend the Ask the Experts Forum on 21 July. We have included a summary of the speakers' talks on page 8. It is unfortunate that events such as these are not able to be conducted in the regions as most of the experts in MND in NSW are based in Sydney. However, with the permission of the speakers, we can now video events and share them on our website for wider viewing. So videos of the day are also now available on our website. If you can't access them let us know and we will send you a DVD.

Talk-Link Program

MND NSW is proud to partner with Carers NSW and their National Carer Counselling Program, to offer our carers the opportunity to participate in a Talk-Link telephone support program.

Each Talk-Link program runs for an hour for six consecutive weeks. There is no charge to participate. The Carer Wellbeing Talk-Link will commence on 23 September and will focus on the needs of those currently caring for someone with MND. We will announce dates soon for the Grief and Loss Talk-Link. If you would like to find out more or express your interest in participating in either program ph. 02 8877 0999, Freecall 1800 777 175 or email reg@mndnsw.asn.au

Learn Now Live Well

We are busy planning our Learn Now Live Well program that will be held at the MND NSW Centre at Gladesville on 20 and 27 October. This is a great opportunity to hear more about living well with MND from a range of allied health professionals including an occupational therapist, physiotherapist, speech pathologist and dietitian. It's also a good opportunity to meet with others and share experiences. See page 9 for further details.

Christmas Party planning

And it's hard to believe it's that time of year already but we have started planning the annual Christmas Party to be held on Saturday 22 November. So put this date in your calendar and we hope to see you there. See page 2 for further details.

If you have difficulty getting to any of these events please contact your regional advisor to see if there are suitable transport options that we can assist you with.

And finally, thank you to all who completed the member satisfaction survey earlier this year. We have now compiled the results and have provided a summary on page 5.

Gina Svolos

Manager, Family Support

FlexEquip

Loan and referral update

During the past two months there have been 389 referrals made to FlexEquip, the MND NSW equipment service, for 129 of our members. FlexEquip has been able to package and ship 300 items of equipment during this time. The highest demand has been for power wheelchairs, cushions and communication devices. Although FlexEquip has been able to provide 19 power wheelchairs and 31 pressure cushions, waitlists continue for these items.



FlexEquip switch adapted door chimes

A battery operated door chime is a low tech device often used by people living with MND so they can get the attention of someone else in their home. The door chime set comes in two parts; a button part to activate the chime, and the chime part. The button



switch adapted door chime

part stays with the user while the chime part can be taken by the other person around the home and outside. Using a door chime for contact can provide the user and the carer with a small degree of independence and confidence in contact between each other while at home, especially if the user has a soft voice and decreased mobility. Before relying on the door chime, the distance the chime part can be used away from the button part should be tested because homes are constructed from various materials and this affects the range of the chime.

The FlexEquip range includes switch adapted door chimes which can be used with a specialised switch that connects into the button part of the set. Using one of these door chimes with a switch enables a person with limited hand function and decreased mobility to operate the button part of the door chime. There are a large range of switches available and the FlexEquip range includes those most useful for people living with MND. These switches can be activated by a movable part of the body including feet, chin, knee and even eye movement. When set up properly, with the switch in the correct place, the user can contact another person within the home if required. The set up and assessment for the most appropriate switch type is done by an occupational therapist or speech pathologist.

Maree Hibbert

FlexEquip Coordinator

*Carer Wellbeing
Talk-Link
telephone
support program
Starts 23 Sept for
6 weeks, 1 hour
per week.
Contact MND
Info Line ph.
1800 777 175
for more
information*

Member Satisfaction Survey Results

This year we had a lower than usual response rate with only 22.5% (n=111) of members returning the questionnaire. Two years ago 46% (n=208) of members returned the questionnaire and we will be looking more closely at why the response rate was lower this year. However, although the number of responses was lower, those who did respond are a representative sample when compared with our overall membership for location (metropolitan = 59.6% and regional/rural = 33.7%), duration of membership and time since diagnosis.

Some results

- 96% of respondents felt that the quality of the information and support they receive when they telephone/email MND NSW was very good (85%) or good (14%)
- 97% of respondents thought the content of the MND NSW newsletter *Forum* was either very good (78%) or good (19%)
- 95% of respondents rated the ability of their regional advisor to offer support and information as needed as very good (72%) or good (23%)
- 94% of respondents rated the support and information from MND NSW for their carer as either very good (76%) or good (18%)

It was encouraging to see that when asked would you recommend MND NSW to other people living with MND, 98% said yes. Some positive comments included:

- I cannot speak highly enough of this service and the staff - very supportive and always helpful
- The service and response is without a doubt exceptional
- All written information has been very helpful and informative
- Appreciate Forum newsletter because of variety of articles
- Equipment pool is fantastic
- Regional Advisor is lovely to speak with, informative, positive approach and tries to get things done

We also appreciate constructive feedback and suggestions. Some of these comments related to:

- Not being aware of a support group being available and that location and time of meeting or education programs created barriers to attending
- Limited range of equipment provided
- Turnover of regional advisor in an area

We will be looking at how we can address some of these issues and recognise it was unfortunate that we had some difficulty recruiting to one of our regional advisor positions last year. Our range of equipment is limited by the amount of funds we have and, as we don't have any recurrent funding

from the government for equipment, we are limited in what we can provide. However our fundraising efforts and some one-off funding from NSW Government has really helped to keep this much valued service going. Suggestions for items to include in the FlexEquip range are always appreciated by us.

Some very specific suggestions related to other aspects of the MND NSW Family Support Service were also appreciated and we will consider these in our future planning. One great suggestion was to create a YouTube video library of resources that would help with things such as manual handling and other practical information. Thanks for the great idea.

This survey assists us in the future planning of services. We really do appreciate your feedback, not just when we send the survey, but at any time that you would like to contact us to provide feedback. You can do this by contacting your regional advisor or Gina Svolos, Manager, Family Support Service, by phone or email. You can also request a copy of our brochure *Member rights, responsibilities and feedback*. Thank you all for your time and comments.

Gina Svolos

Manager, Family Support

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

Learn Now, Live Well

20 and 27 October 2014

10am to 3pm

MND NSW Centre, Gladesville

A two day educational program to assist people to live well with MND.

For people living with MND, their family and friends.

Learn Now, Live Well provides a range of strategies to live well with MND and to maintain independence. It also provides the opportunity for you to have your questions answered by a range of health professionals with expertise in MND, and to meet others who understand what it is like to live with MND.

This venue is wheelchair accessible with parking available on site. Lunch and refreshments will be provided each day (let us know if you have dietary requirements). There is no charge to attend this event.

To book your place or for financial assistance with travel arrangements contact Kate Maguire Ph. 8877 0999, Freecall 1800 777 175, or reg@mndnsw.asn.au

Around the support groups

Central Coast

Our group meets on the first Thursday afternoon of every second month at Narara. In the past few months we have been very fortunate to have some wonderful guest speakers share their knowledge with the group. At our April meeting, Robyn Curtois filled us in on the range of services available from Coast Community Connections, especially the valuable support offered by case managers. In June we all learnt so much more about our bladders than we ever thought possible, thanks to Jacqui Swindells from Erina Community Health Centre.

Many members of the group enjoyed a fabulous sunny day at our first 'Walk to d'Feet' on the Central Coast on 23 March. Over \$7,500 was raised at this one event, with more from a string of stalls organised at local shopping centres in support of MND Week in May. Many thanks to the organisers and volunteers, including those who have generously donated items for our raffles.

Great news also that our group has been successful in gaining a grant of \$1,500 from Carers NSW under their 'Together' program. Our carers will be busy planning how to best use these funds over the coming year. One of the most useful and beneficial aspects of our group, however, continues to be the practical sharing of information, tips and tricks which sometimes only those living with MND and their carers know about.

Meetings for the rest of this year will be on 2 October and 4 December from 1pm-3pm at Gosford/Narara Neighbourhood Centre. Our group is fun, relaxed and with a strong sense of local community. We hope to see you there.

Deb Ward, Regional Advisor
and **Audree Dash**, Volunteer

Northern Beaches

Our friendly round table has been full of new attendees at the last couple of support group meetings. You may have noticed that the building we meet in has changed its name and is now known as the Cora Adcock Centre for Palliative Care. We are so fortunate to be able to meet in this newly renovated building with its lovely sea views. So if you are looking for a 'sea change' and a chance to learn from others about how to live well with MND come and join us for morning tea. We meet every second month on a Monday. Don't forget to pick up a parking voucher from Sue at the front desk when you arrive. For more details, contact Jo Fowler, Regional Advisor, ph. 0408 803 789 or the MND InfoLine ph. 1800 777 175.

Jo Fowler, Regional Advisor

Western Sydney

We have welcomed some new members to the group in the last few months and encourage everyone in the area to come along and meet others living with MND in Western Sydney. Our recent guest speakers have included Nicole Jordan, case manager from Anglicare, and Jody O'Connor from the ANZAC Research Institute. Nicole spoke about the role of a case manager and the types of services available to assist members and Jody explained about a research project involving genetics and MND that people with MND and their family members can contribute blood samples to. For more information about the research and eligibility criteria contact the research group via Jody ph. 02 9767 7016 or jody.oconnor@sydney.edu.au.

Our support group venue at Kingswood Neighbourhood Centre is accessible and there is plenty of parking. As the weather warms up we look forward to sitting outside under the verandah, so come along and enjoy good company and the chance to share your ideas and experiences of living with MND. If you have any questions about the group, or if you are having difficulty with transport please contact Melanie Oxenham, Regional Advisor, ph. 02 4731 6168.

Melanie Oxenham, Regional Advisor

Northern Sydney

Do you know about the types of augmentative and alternate communication (AAC) aids used to enhance or replace speech? Do you know about safe ways to get up off the floor after a fall? Are you aware of the assistive and adaptive devices that can help you manage your daily life activities and make your home situation a safer place?

If you are a regular attender at the Northern Sydney Support Group you will most likely know about all of these things! We meet together over a light luncheon to learn from each other and from highly experienced allied health professionals who share their knowledge. Thanks to our great guest speakers over the past few months.

The group meets every second month at the Thornleigh Community Centre on a Thursday. We would love to see you there. For more details, contact Jo Fowler, Regional Advisor, ph. 0408 803 789 or the MND InfoLine ph. 1800 777 175.

Jo Fowler, Regional Advisor

My Aged Care

My Aged Care is a national phone contact centre and website. It can provide you with information on aged care, whether for yourself, a family member, friend or someone you are caring for. Ph. 1800 200 422 or www.myagedcare.gov.au

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

Around the regions

Living Well with MND in the Hunter

On 25 June, 84 people with MND, their family and friends attended the MND NSW 'Living well with MND' day at Charlestown in Newcastle. Although MND affects an individual, it also impacts the lives of family members and friends of the person living with the disease. So it was great to see many family and friend groups attending the day - learning more about the disease, how to live well with MND, meeting others in their local area and just being there in support of the person in their family or their friend with MND.

It was a jam packed program. All of the speakers were from the Hunter region and MND NSW thanks the presenters for their time and interest in the needs of people living with MND.

Professor David Williams, Director of Neurology, John Hunter Hospital, gave an excellent opening presentation about MND that answered these questions:

- Why are there so few historical descriptions of MND?
- What's age got to do with it?
- Why has it been so hard to find a cause of MND?
- Why don't they just fix it with stem cells?

Nick Yates, Clinical Nurse Specialist, Respiratory and Sleep Medicine, John Hunter Hospital, explained about breathing and MND. Alex Tait, Speech Pathologist, Rankin Park Rehabilitation Centre, covered maintaining communication and managing saliva and swallowing difficulties. Kellie Strong, Occupational Therapist, Port Stephens Community Rehabilitation Team, spoke about preparing your home, aids and equipment. Kathryn Jones and Liz Bosworth, Carer Support Officers, HNE Carer Education and Support Program, provided practical information about entitlements, benefits, accessing respite care, advance care planning and local services and resources. Eileen O'Loughlen and Kim Sinclair, MND NSW Regional Advisors based in the MND NSW Hunter regional office, gave tips on managing fatigue and living well.

Some of the feedback included:

- "It gave me more of an insight with what to expect and how to deal with it, gives me an incentive to continue"
- "The information provided has been excellent, knowing which services to contact and how"

We have two more 'Living well with MND' days planned:

- **Wednesday 22 October 2014 in Orange** (*see page 2 for more information*)
- **Thursday 19 February 2015 in Canberra**

If you would like more information, or would like to register ph. 1800 777 175 or reg@mndnsw.asn.au

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

Support Groups

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 ph. 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 ph. 4731 6168 | melanieo@mndnsw.asn.au

Griffith and Region - 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) - Kim Sinclair | 4985 5022 | kims@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

Ask the Experts 2014

Just under 100 people attended our 2014 Ask the Experts Forum at West Ryde in July. People with MND, their family and friends came together to be updated with the latest directions in MND research and to quiz the experts. Our three experts this year were Associate Professor Steve Vucic, Dr Ken Rodgers and Professor Roger Chung. We are grateful to each of them for sharing their knowledge and insights on MND. If you were unable to attend Ask the Experts this year, or if you would like the opportunity to hear these experts speak again, videos of some of the presentations are now available by following the link at www.mndnsw.asn.au. We also have several copies on DVD available for free loan to members and their families through the MND Info Line ph. 1800 777 175 or 02 8877 0999 or admin@mndnsw.asn.au

About MND – an overview

Steve Vucic - Associate Professor Neurology, Sydney Medical School Westmead, University of Sydney and Neuroscience Research Australia

View this presentation online at www.mndnsw.asn.au

Steve explained that MND has moved on from being considered a neuromuscular disorder to a full neurological disorder that may include frontal lobe degeneration that can lead to cognitive change and, for some, frontal temporal dementia. He also said there is emerging evidence of a genetic predisposition, even in people diagnosed with a sporadic form of MND. However having the gene doesn't necessarily mean that a person will develop the disease or, if the disease does develop, when this will occur.

Steve told us about the role of glutamate excitotoxicity in MND. Something goes wrong in the motor cortex, bombarding the motor neurone with glutamate and eventually causing it to die. This hyper-excitability may be a precursor to developing MND before it is clinically evident. Cortical hyper-excitability is a unique signature of MND and seems common across different mutations. This may explain why riluzole works and also why an earlier start to riluzole improves effectiveness and prognosis. Therefore, having an earlier diagnosis is very important in MND.

However, Steve highlighted that MND is difficult to diagnose, with diagnosis taking, on average, around 14 months. This is because numerous conditions can mimic MND and it is important these are not missed. Magnetic resonance imaging (MRI) is often used to exclude several other conditions. Steve is currently heading a consortium that is investigating whether nerve conduction tests can be enhanced to be more used as a more accurate diagnosis tool. However, split hand wasting, where there is noticeable physical change on the hand between the base of the thumb and the first finger is almost exclusive to MND and driven by pathology in the cortex.

An area of current interest in MND research is the role of T-cells which are overexpressed in the early stage of MND. T-cells dampen the autoimmune system. In contrast regulatory T-cells are greater in people with a slower disease progression.

Phototherapy may increase regulatory T-cells and a trial is being planned at Westmead to find out if band UVB light stimulates these cells, thereby slowing the progression of MND.

Steve emphasised the importance of being treated by a multidisciplinary team or MND clinic. Studies show that people treated by professionals working together live better for longer. To conclude Steve said we have increased our understanding of the underlying processes of MND in the past few years, but more work was needed to understand the triggers and how MND progresses.

There were a number of questions asked on stem cell therapy. Steve noted that treatments offered in India, China and Russia had no independent verification and he considers them 'risky'.

Could blue-green algae cause MND?

Dr Ken Rodgers - Research Scientist, School of Medical and Molecular Biosciences, University of Technology, Sydney

View this presentation online at www.mndnsw.asn.au

Ken spoke about environmental factors implicated in MND and how blue-green algae, which is not algae but a cyanobacteria, could be linked to MND-like illnesses. Some cyanobacteria make a neurotoxic amino acid called β -methylamino-L-alanine (BMAA). Past studies have shown that cyanobacteria living in the roots of cycad palms on Guam released BMAA into the palm tree; and consumption of flour made from cycad palm seeds was implicated in the high incidence of neurological disease on the island. Fruit bats, which were a local delicacy, also fed on the seeds and concentrated the BMAA further. This could still be a problem today since BMAA has recently been found to bio-accumulate in fish in the Baltic sea and in pink shrimps in Washington USA. There are theories that cyanobacteria are present in fertilisers used on sports fields and this may explain a higher incidence of MND in elite sportspeople. BMAA has been found in brain tissue of people who have died from MND and questions need to be answered such as, "did BMAA cause the disease, or was the disease there anyway?"

You can view event videos online at www.mndnsw.asn.au

(Continued on page 9)

(Continued from page 8)

Ken's recent research at UTS has shown that BMAA mimics one of the body's building blocks for cell proteins and this can cause proteins to form large aggregates in nerve cells and could explain why the disease could develop gradually over many years. Current studies include examining the neurotoxicity of BMAA in zebrafish with Dr Nicholas Cole at Macquarie University and examining the toxicity of BMAA to human neurones with Dr Rachael Dunlop and Brendan Main at UTS.

What's new in MND research?

Roger Chung - Professor of Neurobiology and Neurochemistry, Australian School of Advanced Medicine, Macquarie University

What do IKEA boxes and MND research have in common? Roger explained that a box is like a cell, we can see the outside, but not the inside. There is an Allen key in an IKEA box to assemble the contents and with MND research we are trying to understand what is in the cell and how we might unlock information so that we can find some answers – but there is no manual to follow. Current MND research is looking at 'garbage' in cells – why is protein getting stuck in the cell and what does this do to the cell?

Roger told us that Macquarie University has gathered a team of over 30 researchers, the biggest MND research team in Australia, to answer such questions and work collaboratively across a range of disciplines. They have a biobank, studies

of cell biology, pre-clinical and clinical trials. Roger outlined what we know about MND; that several causative genes have been identified; and that MND proteins stick together in cells. Researchers have been growing motor neurones in dishes to overcome the difficulty of being able to observe cell behaviour in people with the disease.

The team at Macquarie are examining mutant genes and comparing them to normal genes and that they are using zebrafish to do this. Zebrafish are fast growing, breed quickly, are transparent when young and can be genetically modified relatively quickly. The team can get good microscopic images of motor neurones in the fish which means they can see good images of mutant gene expression. They are looking for the initial process that triggers the disease and what causes it to spread.

Roger was asked whether there will be a cure for MND. In response he explained that it will be a couple of years to get the fish going and then they can start testing the mutant cells in the fish with drugs. Hundreds of drugs a year could be tested, whereas with mice they can only test one drug every two years due to research costs. Roger explained that Australia is 'hitting above its weight' in terms of research. At Macquarie University they are looking to link laboratory research to clinical practice, which they can do with so many clinical disciplines under one roof.



Register now for Learn Now, Live Well 20 and 27 October 2014 MND NSW Centre, Gladesville (see page 5)

Noticeboard

Need some advice about Centrelink?

The Welfare Rights Centre community legal services program offers one-off advice and information over the phone about most Centrelink problems. If your matter is the kind that Welfare Rights Centre can give you more help with, they will work with you to try to resolve your Centrelink problem. This could mean being at appointments with you, making submissions on your behalf to Centrelink or a Tribunal, or going to a Tribunal hearing with you. All advice and any representation is free. For more information ph. 02 9211 5300 or 1800 226 028 (outside of Sydney).

Magic Mania

CareFlight's annual Magic Mania show will be on 20 December 2014 at Homebush. Each year CareFlight offers free tickets to families living with MND who would like to attend. If your family would like a free ticket contact the MND InfoLine ph. 1800 777 175 or email your details to admin@mndnsw.asn.au

Family Support Calendar

| | |
|---------------|--|
| 14 Oct | Information Evening for people recently diagnosed with MND, family and friends Gladesville |
| 20 and 27 Oct | Learn Now Live Well Gladesville |
| 22 Oct | Living Well with MND for people living with MND, family and friends Orange |
| 22 Nov | Christmas Party for family support members, their family and friends West Ryde |
| 9 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. 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.

MND NSW Ambassadors

In the last three months, our Ambassadors have represented MND NSW at various venues including:

- cheque presentation from Masonic Lodge at Castle Hill Bunnings
- View Club Australia
- Rotary Club of North Rocks
- Club Turramurra
- Crookwell Rotary Club
- MND Information Day at Charlestown Bowling Club
- Newcastle Group Knitters' Guild of NSW at Mayfield

It is important that we all continue to be proactive in raising awareness of MND so if you or any of your family members belong to a sporting/social club or if you know of a club in your local area that may be interested in inviting one of our Ambassadors as a guest speaker, please let us know so we can contact the Club.

We currently have nine ambassadors in the following areas: Sydney, Tumut, Nowra, Illawarra, Newcastle, ACT and Goulburn. If you live in another area and are interested in becoming an MND NSW Ambassador and would like more information about becoming an Ambassador and raising awareness of MND in your locality, contact our Supporter Liaison Officer, Anne Jones Ph. 02 8877 0999, freecall 1800 777 175 or email annej@mndnsw.asn.au



MND NSW Ambassadors, Don McMurray (above), accepting a cheque from Newcastle Group Knitters' Guild of NSW and Dee Doughty (below), accepting a cheque from Masonic Lodge at a BBQ at Bunnings in Castle Hill



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

Annual Derby Day, Wakehurst Soccer Club

During June, the Wakehurst Soccer Club again held their Annual Derby Day in support of MND, raising \$876 from donations and a raffle. Bryan Floyd, who died from MND in 2011, was a life member of the club. Thank you to Marissa Floyd and all those who assisted on the day.

Junior Netball Gala Day

The Manly Warringah Netball Association held their annual Charity Netball Junior Gala Day which this year supported MND. A fantastic day of netball was held in perfect weather during July with 136 teams participating. A very big thank you to Jeanie Ashley and all those who assisted, raising \$10,506!

Fundraiser for MND research

A big thank you to Brett Swain who organised a great night at the Bellingen Golf Course in July with a fashion show and raffles. The event raised a fantastic \$4,381 and lots of awareness of MND.

Charity Golf Day Port Macquarie

On 10 August Bev Smith organised the first MND NSW Charity Golf Day at the beautiful Emerald Downs Golf Course Port Macquarie. It was a great day with 112 players turning out to support MND NSW, including Mayor Peter Besseling, who had a team entered. Leslie Williams MP, Member for Port Macquarie, dropped by in the afternoon to show her support. Thank you to all the wonderful volunteers who made this day the success it was. Thanks also to the management and staff at Emerald Downs Golf course for their amazing support.

Walk to d'Feet MND in the Central West



Our first Walk to d'Feet MND in the Central West was held on Sunday 15 June. It was a bitterly cold day in Dubbo but a small band of determined walkers turned up to show their support. Thank you to Sharon Doick, the local co-ordinator, and to the Dubbo RSL for their assistance with the marquees and BBQ.

D'Arcy and Dennis for MND

A fantastic week of fundraising was held during May by Trinity Catholic College Lismore. A big thank you to Emily Green and Allison Bing who organised the week. Allison said, "Trinity Catholic College Lismore has been affected greatly by MND in recent years. Our close connection to this disease motivated both D'Arcy and Dennis houses to join forces and fundraise so one day nobody will have to feel the loss of MND. Fundraisers, including a cupcake sale and a Mother's Day raffle as well as various donation tins around the school, allowed us to raise over \$2,000. We would like to thank our sponsors Trevan Auto Group, Mrs. Julie Gilmore, Chandler's Betta Electrical Home Living, Little Polli & The Blackbird, Diamond Sands Resort, Gaia Retreat & Spa, Northern Rivers Pilates & Remedial Massage, Summit Massage & Beauty, Gold Coast Adrenalin Park, Sanity and Independent Sports who made our Mother's Day raffle and cupcake sales possible. We also express our gratitude towards Andy Ridd and his wife, Cathy Ridd, for attending our assembly to give an inspirational speech to our college community. Trinity Lismore keeps all those living with MND in our thoughts and prayers."

Community events (cont'd)



**Glen Sargood
MND Fundraiser**

This is the third very successful year that Yerrinbool Bargo Soccer Club has

hosted a football fundraising event to raise funds and awareness of MND. Close to \$10,000 was raised and we thank Sheree Cosgrove and all those who assisted for their continued support of our Association. The event was held in May in honour of one of their members who has MND. Pictured is Fundraising Manager, Kym Nielsen, accepting a cheque for funds raised at the event.



**Lovely afternoon in the
sunshine with friends**

Thank you to Michelle Wyatt who held an afternoon tea in May raising \$440. Michelle said of the event, "In

honour of my mum, Sue Quinn, I decided to organise a High Tea for MND. I had lots of fun baking treats and decorating the table and enjoyed a lovely afternoon in the sunshine with friends. They were keen to support such a worthy cause, especially after a glass of bubbles!"



Warming up in Canberra

Many thanks to Stephanie Reilly who organised a lovely High Tea for MND in Canberra during May. Stephanie said, "Around fifty people gathered on an unseasonably cold, wet, grey day in Canberra for a High

Tea for MND! Guests, from a two month old baby to several ninety year olds, some living the MND story, gathered at a local nursing home to hear the tales of eighty-two year old guest of honour, Deirdre Jeeves. Deirdre spoke of her more than ten year journey living with primary lateral sclerosis (PLS), a slowly progressive form of MND. Hard-working volunteers (many were staff of the nursing home volunteering on their day off) served home-cooked delicacies to a chattering crowd. Guests from all walks of life left that afternoon as advocates, knowing that they had raised around \$2,000 for MND research with a further \$340 raised for MND NSW."

**Stroud and Hawks Nest
drinking tea for MND**

In May Jane Burrage-Swift, Senior Leader of the Southern Ageing Services for Great Lakes Council, held two morning tea fundraising events for MND raising \$1,374. The first was held in Stroud where volunteers and members from the community and residential care units enjoyed singing, dancing and laughs. The second morning tea held in Hawks Nest was hugely successful with around 100 people attending. There were lots of wonderful cakes, two tables full of raffle prizes and lots of laughs. Pictured are some of the wonderful volunteers who assisted.



Golden Oldies

The annual Golden Oldies A-Grade reunion event organised by the Como-Jannali JRLFC, was a great success, raising around \$5,000. One of the organisers, Hayden Garn, said, "The day has been a tradition for Club's Como-Jannali and Sutherland United since the late 80's where past A-Grade players over 35 years old get together for a beer, BBQ and a game of touch/tackle footy and raise monies for our respective charities. MND has been Como's chosen charity because we have past players and friends who have battled or are now battling with MND."



**Raising funds in the
Northern Territory**

A small but dedicated group of supporters in Darwin have been raising awareness and funds for MND with market stalls, raffles and merchandise sales already reaching over \$6,300. A big congratulations to the 'Darwin mob' and thank you for all of your hard work.



Cooma Market Stall

A market stall held in Centennial Park, Cooma, in July was a great success raising \$600 for MND. Jodie Swain, who organised the stall, said, "It was great to raise awareness and get people asking about the cause of MND". Pictured from left are Jodie, her sister-in-law Laine and mum Cherilyn.



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

Leaving a Gift in your Will

Leaving MND NSW a gift in your Will (a bequest) is a tremendous and thoughtful way of supporting the work our Association does.

For further information, contact our Supporter Liaison Officer, Anne Jones ph. 02 8877 0999, Freecall 1800 777 175, annej@mndnsw.asn.au or visit www.mndnsw.asn.au for more information.

Community events (cont'd)



Kerrie Cripps Memorial Golf Day

Cronulla Golf Club held The Kerrie Cripps Memorial Golf Day on 9 July. This day is held each year in memory of their much loved member Kerrie Cripps who died from MND 11 years ago. The lady members raise funds on this day for MND Research, and this year \$953 was raised from selling merchandise and a cake stall. The winner was Ruth Watson and she is pictured above at the Trophy presentation with Michael Cripps.



Afternoon Tea Fundraiser

Many thanks to Linda Smith for organising an afternoon tea fundraiser in June raising \$500. Linda said of the event, "We had a wonderful time, the enthusiasm shown by everyone there made it more memorable. So many wonderful donations were given to me, which made the door prizes and raffle very interesting." Pictured are 'The Rock-a-Hula-Babes' - Linda, Rhonda and Sarah.



MND Trivia Night

A fun night of trivia, games and raffles was held in August at the Muswellbrook RSL Club. Organised by Rachel Gageler, the event raised around \$12,000. Those who attended were invited to dress up as something starting with either M, N or D. Thank you to Rachel for your continued support of our Association.



Federal Parliamentary Press Gallery Midwinter Ball

The Federal Parliamentary Press Gallery Midwinter Ball celebrated its 15th anniversary this year with MND NSW chosen as one of the supported charities. Held in the third week of June, the Midwinter Ball brings together the journalistic, political and corporate chiefs of Australia for a memorable night of entertainment and networking – and the big winner is charity. Kym Nielsen, MND NSW Fundraising Manager, received a cheque for \$30,000 from David Speers President, Federal Parliamentary Press Gallery.

Kogarah City Council Annual Mayoral Ball

On 19 July Kogarah City Council hosted its Annual Mayoral Ball at the Museum of Contemporary Art in the Rocks Sydney. This year Mayor Stephen Agius chose to support MND NSW and what a glittering event it was, with music from Chris Sebastian, a major auction, raffles and balloon auctions. The evening raised over \$21,000 for MND NSW. A big thank you to the Mayor and his team for this wonderful support.



Riddla Golf Day

The 3rd annual Riddla Golf Day was held on 16 May, again at the lovely Twin Creeks course at Luddenham. Over 80 players enjoyed some great sunshine and a wonderful day with golf, lunch, raffles and some spectacular silent auction items. Daniel Geale - The Real Deal - is pictured with Nathan Ridd (R) above. Thanks again to Ann Ridd who does an amazing job in organising this annual event.

**Community events
Dates for the Diary 2014**

| | |
|-----------|--|
| 14 Sep |  Walk to d'Feet MND Port Macquarie |
| 21 Sep | MND Charity Day Shellharbour Bowling Club Shellharbour |
| 11 Oct | Gundaroo Music Festival Gundaroo |
| 12 Oct | Halloween Fundraiser Bexley |
| 26 Oct |  Walk to d'Feet MND Wagga Wagga |
| 26 Oct | Burgh2Beach Fun Run |
| 1 Nov | Greg Redgrove Memorial Fundraiser Kitchener Pub Kitchener via Cessnock |
| 9 Nov |  Walk to d'Feet MND Sydney |
| 21-23 Nov | Newcastle Italian Film Festival Newcastle |

*For more information see
www.mndnsw.asn.au or contact MND NSW
ph. 02 8877 0999*

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DISCLAIMER

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Editor: Penny Waterson

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