



# FORUM

## Volunteers are the lifeblood of our Association

Thank you to the many volunteers who continue to provide vital support to MND NSW. In the last three months our:

- corporate volunteers from Optus have continued their ongoing support and packed 10,000 Christmas cards in readiness for our Christmas merchandise sales
- graphic artist, copywriter and website volunteers have assisted with content development, promotional flyers, publications and an appeal letter
- event volunteers have assisted at the Kogarah Mayoral Ball, Ask the Experts Forum, the Volunteer Expo at University of NSW and at our information evenings for people recently diagnosed with MND. Volunteers also assist at Walks to d'Feet MND and many other events.
- merchandise volunteers packaged our yummy Pudding Lane puddings into posting boxes
- administration and IT volunteers have provided regular and much needed photocopying, proof-reading, data entry, packaging large mail outs and other office support at the MND NSW Centre at Gladesville
- community fundraising volunteers have organised successful fundraising and awareness raising events in their local areas
- ambassador volunteers have represented and promoted MND NSW at service and other club events and various cheque presentations
- massage volunteers have provided hand and foot massages for members with MND in their local area

If you would like some information about our Volunteer Program, contact our Supporter Liaison Officer, Anne Jones ph. 02 8877 0999 or Freecall 1800 777 175 or [annej@mndnsw.asn.au](mailto:annej@mndnsw.asn.au)



*Our Forum packaging volunteers preparing the June 2014 edition for mail.*

## Show your support

We would like to thank all of our wonderful supporters for the many community fundraising events held throughout 2014. These events have not only raised vital funds but also raised much-needed community awareness about MND.



Spare a thought for Matt Tosolini who will be having a rather 'warm' Christmas. Matt married in September and, on the same day, committed to not shaving and growing a beard in support of MND NSW. Matt writes, "A few years ago one of my best mates, Adam, lost his close Uncle John; and my stepmother, Liz, and her two children Emma and Alex, lost her then husband and their father, Nigel, to MND. I will be sustaining this beard until 31 January 2015 (with minimal trimming) in memory of two very special people who touched the lives of some of the people closest to my heart, and to raise much needed funds for MND NSW. While the hype of the Ice Bucket Challenge may

have come and gone, MND is still very real for people living with the disease - GROW FOR A CURE! If you would like to show your support for Matt visit <https://give.everydayhero.com/au/grow-for-a-cure>.

On 16 January eight of Lake Macquarie's professional beach lifeguards are setting out to challenge themselves on a 130km board paddle from their own Blacksmiths Beach to Sydney's Bondi Beach. The eight lifeguards paddling are Lucas Samways, Danny Napper, Rory Chapman, Lucas Chapman, Rory Tanner, Sam Earp, Jake Ingle, and Troy Ham. For more information about the paddle and to show your support see <https://give.everydayhero.com/au/paddle4mnd>



**MND NSW will be closed from 12pm Wednesday 24 December 2014 until 9am Monday 5 January 2015.**

**If help is needed during the Christmas break, please consult your doctor.**



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.*



A big thank you to all of the participants and supporters of our Walks to d'feet MND in 2014, with special thanks to those who created an 'Everyday Hero' page and encouraged their family and friends to support their Walk with a donation. Over \$96,000 has been raised this year through these donations alone.

#### Walk to d'Feet MND Port Macquarie - 14 September

Port Macquarie turned on another beautiful day for this year's Walk. We were joined by the Mayor of Port Macquarie, Cr Peter Besselings, who walked with the many families and supporters. And what a great turn out it was. A huge thank you to Bev Smith, our local Walk to d'Feet MND coordinator, who worked so hard throughout the year to make this a successful day. Thank you also to Stewart and his team from Port Macquarie High School who provided the great music after the Walk and to the Lions Club for their yummy sausage sizzle.

#### Walk to d'Feet MND Wagga Wagga - 26 October

This is the second Walk to be held in Wagga Wagga and the event has already grown considerably with lots of local support. Over 250 participants walked the track around beautiful Lake Albert. It was a very warm morning in Wagga but that didn't deter the many walkers who walked with family and friends to support this day. Thank you to the local member for the Riverina, Michael McCormack, and Wagga Mayor, Cr Rod Kendall, for their promotion of the Walk and their participation on the day. Local Walk to d'Feet MND coordinator, Pat O'Hara, did a wonderful job organising the event with lots of help from local volunteers, including South Wagga Rotary on the sausage sizzle and students from the Riverina Anglican College.

#### Walk to d'Feet MND Sydney – Sunday 3 November

After a cold and wet Walk last year in Sydney we were delighted with a summer morning this year. Hundreds of families, friends and their puppies turned up to show their support for people living with MND. It was a great atmosphere - everywhere you looked you were surrounded by happy faces, excited people and a sea of blue MND t-shirts and of course happy dogs and pups sporting their blue MND bandannas. This was our largest Sydney Walk yet with 571 people and 52 dogs registered. A huge thank you to Margie Abbott who took time out of her busy schedule to join us for the Walk. Thanks also to Carlingford Rotary for the sausage sizzle. Over \$45,000 has been raised from this year's event so far and donations are still being received through supporter 'Everyday Hero' pages.



Watch the video  
from Walk to  
d'Feet MND  
Sydney at  
[www.youtube.com/mndnsw](http://www.youtube.com/mndnsw)

### Family Support Members' Christmas Party Photo Album

Saturday  
22 November  
2014



Ho  
Ho  
Ho

## A Message from the CEO

The 2014 Ice Bucket Challenge, which hit Australia several months ago, raised huge awareness about MND (known as amyotrophic lateral sclerosis, or ALS, in the USA). The Challenge also provided a world-wide boost to MND research funding and an overview of recently funded projects is included on page 9 in this edition of *Forum*. We have put together a video that explains MND and the Ice Bucket Challenge and you can find that on the MND NSW YouTube channel at [www.youtube.com/mndnsw](http://www.youtube.com/mndnsw). The video highlights that although donations are needed for MND research, donations are also needed for services for people living with the disease now.

MND NSW is governed by a Board and at the 2014 annual general meeting in late October there were no changes to the current Board members (see list below) and we thank the Board members for their continued service to the Association.

Over the past 33 years many very committed people have contributed their time, energy and expertise as Board members. During these decades the Association has demonstrably improved services for people living with MND throughout NSW and the ACT. MND NSW has done this directly for people living with MND through our regional advisor, information, equipment and education services; and indirectly through education programs for service providers,

advocacy and community awareness activities.

With what now seems like constant change and the threat to our NSW Health recurrent funding, we are looking at ways of diversifying our income to help maintain our regional advisor, information, equipment and education services at no direct cost to people with MND, their families and carers. We welcome suggestions and the involvement of all our members and you can view the MND NSW Strategic Plan 2014-2015 at [www.mndnsw.asn.au](http://www.mndnsw.asn.au).

Our final Walk to d'Feet MND for the year was held at Homebush in early November. A record Sydney crowd of over 570 people and almost as many dogs turned up to show their support. Not to be outdone, the first Walk to d'Feet MND for 2015, in the Hunter on 15 February, is looking to encourage as many as 800 people to attend, and registrations will open early in the new year.

It's Christmas!!!! Almost. Don't forget to look out for our Christmas Appeal coming to a letterbox near you.

From all at MND NSW we wish you and your families a happy and safe Christmas and new year.

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

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

## Motor Neurone Disease Association of New South Wales

### PATRON

*His Excellency General The Honourable David Hurley AC DSC (Ret'd)  
Governor 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](mailto:admin@mndnsw.asn.au)  
[www.mndnsw.asn.au](http://www.mndnsw.asn.au)  
ABN 12 387 503 221*

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### Fundraising Assistant

*Ellen Hibbert*

### Family Support Manager

*Gina Svolos*

### Regional Advisors

*Madeleine Bowman, Chris Carroll, Dianne Epstein, Jo Fowler, Ann McCutcheon, Eileen O'Loughlen, Melanie Oxenham, Kim Sinclair and Deb Ward*

### Information Line Advisor

*David Wallace*

### Education and Carer Support Coordinators

*Kristina Dodds, Kate Maguire*

### 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 Donnamaree Gasparrini, MND NSW Ambassador, who is currently organising the 28 January Stephen Hawking movie night at Shellharbour.*





## Family Support Team

It has been a busy time leading up to the end of the year. In October we held our **Learn Now Live Well** program at the MND NSW Centre at Gladesville and a **Living Well with MND Day** in Orange (see page 5 for more). We are now busy planning programs and groups for 2015. A **Living Well with MND Day** for members and families will be held in the ACT in February and a two-day residential program for carers, **Link and Learn**, in Berry in March. These programs, together with the programs at the MND NSW Centre, are designed to assist you live your life well with MND and we hope you will be able to attend. See page 5 for more information.

It was good to see so many of our members enjoy the Christmas party on 22 November with their family and it was great to be able to catch up with those who attended. Santa was thrilled to see so many children in attendance and he was honoured to be able to pick the winning tickets for our raffle and the lucky door prizes. He loved being in your photos! Thank you Santa.

### Talk-Link program for carers

As mentioned in the September edition of Forum we have partnered with Carers NSW to offer our carers the opportunity to participate in a six-week **Talk-Link** telephone support program. The first program was conducted in September and October and was evaluated very positively by our carers. We will have more of these programs in 2015, with the first starting on 16 February for one hour per week over six weeks. If you would like to find out more or express your interest in participating contact the MND Infoline ph. 02 8877 0999, Freecall 1800 777 175 or email [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au).

### Retirement of Michael Walker, Equipment Assistant

Many of you will know Michael Walker from his phone calls to you about FlexEquip equipment. Michael has been working with MND NSW for nearly seven years and will be retiring in December. During his time at the Association, Michael has provided valued phone assistance to many people organising equipment deliveries, pickups and helping with any issues with equipment.

We thank him for his hard work and commitment to the position and wish him well in his retirement. Michael's last day at work will be 19 December.

### Christmas wishes

The Christmas season is upon us and for many it can be a time to reflect on the past year and share memories including happy times, sad times, achievements, hopes and wishes. We hope this Christmas will be a time of peace and happiness for you and your loved ones.

**Gina Svolos**

Manager, Family Support

## FlexEquip

### Return of unused equipment and waitlists

If you have been provided with an item of equipment from FlexEquip that you are no longer using please contact us and we will make arrangements for its return (especially if you are not using a FlexEquip power wheelchair or FlexEquip iPad - there has been high demand for these items in particular, resulting in waitlists for members).

### New equipment

In the past three months, to help relieve our waitlists, we have spent \$34,000 purchasing an additional 63 items of equipment. Items purchased include hoists, iPads, raiser armchairs, hands-free computer mice, manual wheelchairs, shower commodes and voice amplifiers. This has assisted us in providing over 440 items to our members during this period. During the year we have provided more than 1800 items.

Thank you to our supporters for their fundraising efforts that enable us to provide equipment for members and cover the costs of couriers and repairs. All the effort goes a long way and thank you everyone for your continued support.

### Christmas close

Pre-Christmas is the busiest time of the year for FlexEquip with the rush to get equipment to members before our short close from 12pm on 24 December to 9am on 5 January. The couriers we use will become increasingly busier and, although we try to organise delivery times with courier companies, delivery times can sometimes be out of our control. Therefore I would like to ask everyone to be patient during this time but please do not hesitate to contact us if there is a problem.

### Christmas break equipment breakdown

Just in case the unexpected happens and there is an urgent equipment breakdown during the Christmas close, please contact your occupational therapist or speech pathologist to assist you in arranging a repair. If they are not available then contact your local hospital. Please let FlexEquip know as well so we can follow up when we reopen. Remember if you are using a battery operated item of equipment every day, such as a power wheelchair, hoist or communication device, then the battery needs to be charged overnight.

The FlexEquip team - Julie, Michael, Tom and I - wish everyone a very safe and very, very, happy and memorable holiday.

**Maree Hibbert**

FlexEquip Coordinator



*MND NSW will  
be closed from  
12pm  
Wednesday  
24 December  
2014 until 9am  
Monday  
5 January  
2015.*

## Around the regions

### Up north

A huge thank you to the families from Grafton to the Gold Coast who have welcomed me into their home. Our bi-monthly carer support group on the Gold Coast continues to provide a pleasant, informative and supportive few hours for carers who can be there. In October Cheryl Miller, CEO of MND Queensland (MNDQ) met the group members and introduced Amanda Pavey, the new MNDQ Regional Advisor for the Brisbane area. We also had a visit from Ruby and Isabelle from Carers QLD who updated us about what's new in Carers QLD.

We are going to try something new on the far north coast in 2015 with a 'roaming' support group, over morning tea or lunch, for people with MND and their family carer. We will post the upcoming dates on the MND NSW website at [www.mndnsw.asn.au](http://www.mndnsw.asn.au) when these become available.

The MND clinic at Murwillumbah Hospital Outpatient Rehab is now well established. It is really pleasing to see supports developing for the families in this region.

**Chris Carroll**, Regional Advisor

### Heading west

*"Thank you for coming up to the country, it was appreciated."* (Participant)

During October MND NSW held a **Living Well with MND** information day in Orange for people living with MND, their family and friends. People travelled from over the Central West to attend, including Forbes, Mudgee and Gilgandra.

Professor Simon Hawke, a neurologist from Orange, opened the day with an excellent overview of MND and MND research. Hilary Britton, occupational therapist, provided information and tips for getting the home organised, aids and equipment; and Danielle Leahey, speech pathologist, spoke about maintaining communication, managing saliva and managing swallowing. Other speakers included James Daley, palliative care clinical nurse consultant, and Helen Nott, case manager. Many in the audience didn't know about the role of palliative care and case management and how they can make a real difference to people living at home with MND.

Our next **Living Well with MND** information day is in Canberra on 19 February 2015 (see below).

**Kristina Dodds**, Education and Carer Support Coordinator

## Living well with MND - Canberra - 19 February

*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 Thursday 19 February Where: Calvary Retirement Community, Bruce, ACT**

There is no charge for you to attend this program but you need to reserve your place by 12 February. Lunch and refreshments will be provided (let us know if you have any special dietary requirements). To register email [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au) or contact Kristina Dodds Ph 8877 0999 or Freecall 1800 777 175.

## Are you a family member, relative or friend caring for someone with MND on the South Coast of NSW? - Link and Learn - 26 and 27 March

If you are keen to gain some extra information and support and you would like some time out for yourself, our **Link and Learn** program may be ideal for you. It is suitable for those new to the caring role and also those who have been caring for some time. You will have the opportunity to hear from a range of health professionals and MND NSW staff, who will answer your questions in a relaxed and informal setting. You will learn how to prepare your home, manage symptoms such as difficulties with swallowing, communication and breathing and also how to access services and equipment.

Those who have attended **Link and Learn** tell us that they especially valued the opportunity to take time out for themselves and to share their ideas and experiences with others in similar situations.

**This program is residential and will run over two days and a night in Berry on 26 and 27 March 2015.**

Participation in the program, including meals and accommodation, is free of charge for people caring for someone with MND, but we do ask that you commit to attending the two days. If you might be interested in attending contact the MND Info Line ph. 1800 777 175 or speak to your regional advisor.

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

## Around the support groups

### Campbelltown

The Campbelltown support group wound up a busy year with our Christmas get together at Wests Leagues Club 18 November. It was a great opportunity to kick back and reflect over the past year and have some fun together.

Recently our guest speakers have included Kathy Schofield, Clinical Nurse Consultant, Macarthur Community Palliative Care. Kathy spoke about the role of palliative care in terms of symptom management and as a holistic approach in maintaining quality of life. She stressed the importance of linking in early to gain maximum benefit from the service. At another meeting, Maureen from Tender Loving Cuisine told us about their service, how to order meals and provided us with samples for the group to try. As many of the members and their carers could not get to **Ask the Experts** in Sydney in July, we brought the presentation to them in October via the online video of the day, watching a session as a group. The presentation created great discussion and outlined the types of research that is currently happening around MND.

I would like to take this opportunity to thank Janelle and Jessie from the Community Options Team at Campbelltown for their input and commitment and great humour they bring to this group. The group meets monthly on a Tuesday 10am-12pm at Eaglevale. The venue is fully accessible and has plenty of parking.

**Ann McCutcheon**, Regional Advisor

### Central Coast

The Central Coast support group is very active and, as well as meeting regularly, is involved in many MND awareness-raising activities in the local community. We were sad to hear that Patricia Powell, who has worked as a volunteer with our group for many years, died in September. Audree Dash, who coordinates many of the group's community activities writes, "Pat joined the support group about 20 years ago when her daughter was diagnosed with MND. This diagnosis was later found to be incorrect and Pat was so grateful, she stayed and supported the group, becoming our official 'tea lady' for about 18 years until recent poor health prevented her attending. Pat also worked hard on our many street stalls. We will miss her beautiful smile and special gifts".

**Deb Ward**, Regional Advisor

### Member library

*Don't forget that members and carers have the opportunity to borrow MND-related books and DVDs for up to a month at a time, at no cost, from our member library.*

*Built up over several years, our library contains many personal stories of living with MND as well as books for carers and books for young children.*

*Contact the MND Info Line ph. 02 8877 0999 or 1800 777 175 or email [info@mnidnsn.asn.au](mailto:info@mnidnsn.asn.au) for details about how to access the library and the books and DVDs available for loan.*

*Support group meeting dates are at [www.mnidnsn.asn.au](http://www.mnidnsn.asn.au) or contact the MND Info Line 1800 777 175*

## Support Groups

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

Campbelltown - Ann McCutcheon | [annm@mnidnsn.asn.au](mailto:annm@mnidnsn.asn.au)

Liverpool - Ann McCutcheon | [annm@mnidnsn.asn.au](mailto:annm@mnidnsn.asn.au)

Northern Beaches (Mona Vale) - Jo Fowler | [josephinef@mnidnsn.asn.au](mailto:josephinef@mnidnsn.asn.au)

Northern Sydney (Hornsby) - Jo Fowler | [josephinef@mnidnsn.asn.au](mailto:josephinef@mnidnsn.asn.au)

Western Sydney - Melanie Oxenham ph. 4731 6168 | [melanieo@mnidnsn.asn.au](mailto:melanieo@mnidnsn.asn.au)

### REGIONAL AND RURAL

ACT and Southern NSW - Dianne Epstein | 6286 9900 | [dianne@mnidnsn.asn.au](mailto:dianne@mnidnsn.asn.au)

Central Coast - Deb Ward | 1800 777 175 | [debw@mnidnsn.asn.au](mailto:debw@mnidnsn.asn.au)

Central West - Melanie Oxenham ph. 4731 6168 | [melanieo@mnidnsn.asn.au](mailto:melanieo@mnidnsn.asn.au)

Griffith and Region - Dianne Epstein | 6286 9900 | [dianne@mnidnsn.asn.au](mailto:dianne@mnidnsn.asn.au)

Illawarra - Ann McCutcheon | 1800 777 175 | [annm@mnidnsn.asn.au](mailto:annm@mnidnsn.asn.au)

Muswellbrook (Upper Hunter) - Kim Sinclair | 4985 5022 | [kims@mnidnsn.asn.au](mailto:kims@mnidnsn.asn.au)

Newcastle and Hunter - Eileen O'Loughlen | 4921 4157 | [eileeno@mnidnsn.asn.au](mailto:eileeno@mnidnsn.asn.au) or Kim Sinclair | 4985 5022 | [kims@mnidnsn.asn.au](mailto:kims@mnidnsn.asn.au)

North West (Tamworth) - Kim Sinclair | 4985 5022 | [kims@mnidnsn.asn.au](mailto:kims@mnidnsn.asn.au)

Port Macquarie - Eileen O'Loughlen | 4921 4157 | [eileeno@mnidnsn.asn.au](mailto:eileeno@mnidnsn.asn.au)

Gold Coast Carers - Chris Carroll | 0421 252 455 | [chrisc@mnidnsn.asn.au](mailto:chrisc@mnidnsn.asn.au)

## Mailbag

Beautiful words written for Glen and Rachael Sargood by their friend, Caitlin von Berky

*The morning sun, is getting in  
And he wakes up and sings  
He's got a lot, not everything  
He knows there's something missing  
He knows the ground he's walking on  
Has been through pain and fear  
But there's a joy abiding deep inside  
That no one can try and steal*

*And her love, her love has covered everything  
The good the bad and the frightening things  
They all fade to nothing in her arms*

*He's got a heart that's beating strong  
Her smile is all he needs, he says  
"My dear don't cry, you're good to me  
I know there's something missing"*

*And at the door, they're waiting for  
The time when it is opened wide  
And he will wait there for his darling girl  
To be right by his side*

*And her love, her love has covered everything  
The good the bad the frightening things  
They all fade to nothing in her arms*

*Do you see, the sun rises in the morning  
But when it sets at night  
We don't sleep in the light  
But we know when it's dawning  
Do you see, when I go don't worry  
I'll be in your arms In the morning sun  
And it'll all be new, do you feel it to?*

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

## Family Support Calendar

15 Feb	<b>Sailors with disabilities</b>   Carers only (to be confirmed)
16 Feb	<b>Talk-Link. Carer wellbeing, week 1</b>   by phone (see page 4)
17 Feb	<b>Information Evening for people recently diagnosed with MND, family and friends</b>   Gladesville
19 Feb	<b>Living Well with MND for people living with MND, family and friends</b>   Bruce, ACT
9 Mar	<b>Lunch for bereaved carers</b>   Gladesville
26 and 27 Mar	<b>Link and Learn</b>   Berry   (see page 5)
21 Apr	<b>Talk-Link. Grief and loss, week 1</b>   by phone
28 Apr	<b>Information Evening for people recently diagnosed with MND, family and friends</b>   Gladesville
2 May	<b>Day of Hope and Remembrance</b>   Sydney Olympic Park
May/Jun	<b>Care for Carers</b>   To enable you to care for a person with motor neurone disease at home, while still taking care of yourself

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 March of Faces Banners

Australia's MND March of Faces Banners are a photographic display of people with motor neurone disease.

The MND NSW March of Faces banners are displayed at various MND awareness raising and remembrance events throughout the year. Our 14th banner in the MND March of Faces series was displayed for the first time during MND Week 2014 and you can now view it on the MND NSW website at [www.mndnsw.asn.au](http://www.mndnsw.asn.au).

If you have MND and want to be included in the new banner, you need to complete a permission form and submit a photograph of yourself. You are welcome to include family in the photo if you wish. Family members are also able to submit a photograph in remembrance of a person who has died from MND. For more information ph. 8877 0999 or email Penny Waterson [info@mndnsw.asn.au](mailto:info@mndnsw.asn.au)





## MND Australia Research Meeting 2014

by Dr Justin Yerbury, Illawarra Health and Medical Research Institute, Wollongong.

The annual MND Australia Research Meeting for 2014 was held at The Florey Institute, University of Melbourne on 27 October. There was an air of excitement at the meeting due to the recent world wide phenomenon that was ice bucket challenge, which has not only raised vital funds to allow much needed research in to the causes of MND but has also significantly raised the profile of MND in the Australian community. Fittingly, on this particular Monday morning Melbourne decided to open its skies and hold its own version of the ice bucket challenge with huge thunderstorms crashing across the city resulting in train and tram line failure and more than a few meeting attendees arriving soaking wet.

The meeting was bigger and better than ever with 21 platform presentations, 27 posters and over 100 people registered to attend. Prof Phil Beart, head of neurodegeneration at the Florey Institute gave the opening address and kicked the day off by speaking about protein misfolding and aggregation and the need to "take out the trash" using protein degradation machinery. His insights into neuron specific processes set the tone. On the subject of protein misfolding Prof Ken Rodgers, University Technology Sydney provided evidence that the blue green algae toxin BMAA can be misincorporated in to growing polypeptides which may cause protein misfolding and aggregation. It was proposed that non-proteinogenic amino acids such as BMAA may accumulate in misfolded proteins throughout life and result in MND. One way of degrading such misfolded proteins is autophagy and Dr Brad Turner of the Flory Institute, University of Melbourne, presented his work outlining small molecule activation of autophagy and its consequences on accumulation of misfolded and aggregated proteins. It seems the effectiveness will depend on which specific autophagy pathway is targeted.

While there have been many recent discoveries outlining genetic causes of MND there is still a significant amount of inherited forms of MND in which a genetic defect is not identified. As a result, genetics of MND is still a hot topic and Prof. Ian Blair, and Dr Kelly Williams from Macquarie University spoke on the use of next generation sequencing and epigenetics in the study of MND respectively. In addition, Beben Benyamin from the University of Queensland spoke about his work on genomic and epigenetic changes in the Chinese population. Studying specific populations seems important due to the differences in inheritance such as the lower age of onset in the Chinese population compared to the European population

and the lower frequency of c9orf72 expansions. It appears that as we move forward with genetic studies we may have to move towards studying polygenic analysis of common SNPs. Importantly, we were reminded that the discoveries made in the genetics arena feed in to the study of molecular and cellular biology and provide more pieces to the puzzle. This lead directly to the construction of model systems to study these genetic discoveries such as the zebra fish presented by Dr Nick Cole, Macquarie University, and the iPSC derived motor neurons generated in the laboratory of Dr Lezanne Ooi, University of Wollongong. Importantly, Dr Ooi's models were generated with mRNA so as not to change the DNA of the patient cells and the models recapitulated major MND phenotypes such as increases in phosphorylated TDP-43.

Prof Peter Noakes, University of Queensland, advocated for the use of human tissue in the study of MND and showed some breathtaking images of neuromuscular junctions from human muscle biopsy. ALS NMJs were significantly fragmented, withdrawn, and showed terminal sprouting. Dr Catherine Blizzard, University of Tasmania, presented work to suggest that TDP-43 plays an important role in the maintenance of the synapse through delivery of vital mRNA. While the cytoskeleton, was shown to be important to trafficking of TDP-43 in to axons by the work of Dr Anna King also of the University of Tasmania.

Cellular signaling also was a prominent theme in the presentations with Dr Marie Mangelsdorf, University of Queensland, presenting her work on the EphA4 protein, its splice variants and its role in speed of disease progression. Further, Dr Jeff Liddell presented work to show that the copper containing drug used in his laboratory at the University of Melbourne activated the Nrf2 pathway possibly leading to beneficial effects. Lastly, Dr Aaron Russell, Deakin University, presented his work showing that mitochondrial health and thus motor neuron survival may be promoted by suppressing specific micro RNA that control mitochondrial gene expression.

The poster session followed and was a hive of activity, with many discussions around the interesting work being presented. By then the clouds had parted and we could all make our way home and reflect on how fast the field is growing, what the year 2014 has delivered and what major challenges lie ahead.

Extract from ALS/MND Research and Care Community Blog <http://reccob.wordpress.com/2014/11/13/mnd-australia-research-meeting-for-2014/>

*If you are caring for someone living with MND on the South Coast, why not join us for Link and Learn at Berry on 26 and 27 March. (See page 5)*



## Ice Bucket Challenge donations a watershed for research

### Australia

\$1.05 million will be provided by the MND Research Institute of Australia (MNDRIA) to support a major grant to a team of Australia's researchers for a novel three-year research project that aims to understand the causes of sporadic MND in humans and seeks to find a treatment for the disease. This grant will be called the MND Australia Ice Bucket Grant. Applications for this project opened on 21 November with the announcement of the successful team to be made in 2015.

On 4 November, the MND Australia Research Committee awarded \$2,573,184 in new MND research grants commencing in 2015. This vital source of funding is only possible thanks to the generous support of state MND associations, donors and bequestors. Included within these grants is a \$100,000 MND Ice Bucket Challenge Grant-in-aid awarded to Associate Professor Ian Blair from the Australian School of Advanced Medicine at Macquarie University as start-up funding for Australia's participation in the largest international collaborative genetic study of sporadic MND ever conducted, Project MinE (see below).

### USA

In October, the ALS Association announced \$21.7 million in funding from Ice Bucket Challenge donations to support six programs and initiatives. Additionally, \$12.5 million in matching donations brings the total commitment to \$34.2 million. Four of these projects involve global research cooperative alliances that would not have moved forward without this significant funding from the Association, made possible through the generosity of donors worldwide.

The bulk of the Association's \$21.7 million commitment (\$18.5 million) will advance four new cooperative alliances for the next one to three years involving research identified as critical to finding new treatments for ALS and these projects would not have been possible without Ice Bucket Challenge donations:

#### ALS Accelerated Therapeutics (ALS ACT)

ALS ACT is a novel academic-industry partnership to accelerate treatments for people living with ALS, which is able to proceed with a \$10 million commitment from the ALS Association and matching gift of \$10 million from the ALS Finding a Cure Foundation. ALS ACT will enact a multi-pronged approach to expediting clinical trials in ALS. Efforts will include (1) developing neuroimaging tools as potential biomarkers for ALS progression, a key unmet need in trials; (2) development of therapeutic approaches to decrease production of misfolded proteins within motor neurons and reverse neuroinflammation; (3) a challenge grant program to overcome key roadblocks in the search for therapies; (4) support for phase IIA pilot clinical trials using biomarkers.

#### New York Genome Center (NYGC)

The ALS Association and its Greater New York Chapter will match a \$2.5 million gift from The Tow Foundation in support of a new project at the NYGC, which will bring together for the first time a world-class scientific team to further understand the genetic basis of ALS. Recent

discoveries have indicated that genes may contribute to a much larger percentage of ALS cases than previously thought. Finding these genes and understanding how they work will allow development of new therapeutic approaches. The NYGC will spearhead a cooperative and multidisciplinary effort to provide open-source "big data" to benefit the entire ALS research community.

#### Neuro Collaborative

The Neuro Collaborative will combine the efforts of three world renowned California labs focused on ALS: Cedars-Sinai in Los Angeles, the University of California San Diego and the Gladstone Institutes, an affiliate of the University of California San Francisco, to develop and expedite therapeutic approaches for ALS. The collaborative, which now has funding to proceed with \$5 million in Ice Bucket Challenge funding from the ALS Association, will focus on: (1) development of antisense therapy for the C9orf72 gene, the most common genetic cause of ALS, in partnership with Biogen-Idec and ISIS Pharmaceuticals; (2) gene therapy to down regulate SOD1, the second-most common ALS gene; (3) establishment of a Stem Cell and Motor Neuron Core Facility to create clinical-grade induced pluripotent stem (iPS) cell lines, which will be openly shared with the ALS research community. iPS cells have emerged as a key research tool and potential source of therapeutic cells in ALS. 4) Using a novel screening tool, identify new targets for drug development and in partnership with the industry these leads will be developed further with the potential of new treatment options in the clinic.

#### Project MinE

Project MinE is a global collaboration with the goal to sequence the genomes of at least 15,000 people with ALS in an effort to discover new genes that affect ALS, either increasing the risk for the disease or protecting against it. The ALS Association's funding commitment of \$1 million will enable Project MinE to expand to the United States. It has become clear that risk for ALS is likely influenced by variants in multiple genes, each of which is relatively rare. The development of advanced sequencing technologies has dramatically reduced the cost of screening large numbers of individuals for these rare variants. Discovering these variants, and understanding how they contribute to disease, or protect against it, is likely to lead to novel approaches to ALS therapies. International partners include the Netherlands, United Kingdom, Ireland, Spain, Portugal and Belgium.

### England

The MND Association in England reported donations totalling £7 million from Ice Bucket Challenge. In October seven new research grants were announced, totalling over £1 million. These will go to UK research teams and studies aimed at understanding the causes of MND, the processes that lead to motor neurone degeneration and the development of new approaches to treating the disease. Many of these grants will run for up to three years. Additionally, six new PhD studentship projects were announced, totalling over £500k. The projects range from learning more about the form of dementia associated with MND, to using stem cells to understand the electrical activity of motor neurones.

Register now  
for  
Living Well  
with MND

19 February

at

Bruce, ACT  
(see page 5)

## Ice Bucket Supporters

*John Nicholson passed onto us a copy of the speech made by his grandson, Corey Muscat, aged 9 years, when he represented his school in a public speaking competition.*

Cold, Icy Water being poured all over me.  
Brrrrrr.

Now I'm all cold and wet.

I've just done the Ice Bucket Challenge and made a donation to Motor Neurone. Hopefully I've made a difference.

Well it's going viral, everyone knows about it and everyone is talking about it.

So what is the Ice Bucket Challenge? What is motor neurone disease? And how will doing the challenge help?

In my speech today I'd like to answer these questions. And tell you why I'm so interested in this challenge.

Well if you don't know already the Ice Bucket Challenge is where someone nominates you to pour a bucket of ice water all over yourself and make a donation to Motor Neurone.

Everyone is doing it because it is a crazy fun thing to do. People upload their video to social media then nominate other people to do it. They have 48 hours to do it. And make a donation.

There have been some interesting people doing the Challenge. Russell Crowe, Lady Gaga, Guy Sebastian and Fitty. Even Kermit the Frog.

So what is motor neurone disease? Well, it is where the nerve cells that control muscles in our body start to break down and die.



*From Corey Muscat*

When this happens it becomes harder and harder to move, speak, swallow and breathe.

The horrible thing is that 2 people die and 2 people are told they have the disease every day in Australia.

It is very sad because once you get told you may only have two years to live.

There is no cure or treatment for this disease. It really is not a very nice disease.

So how will doing this Challenge help? It will help by making people aware of the disease. It gets everyone talking and wanting to know more. By making a donation it raises money for a good cause.

The money raised can be used by scientists to help figure out a cure. The money can also be used to help people with the disease.

My nanny has a very rare type of motor neurone disease. And this is why I have a special interest in the Ice Bucket Challenge.

She is very unlucky to have it but luckily for her it is a very slow type of MND.

So far it has only affected her movement, she is almost unable to walk, she has a lot of trouble with her hands and arms.

So if you have not been nominated yet, then I nominate you to take the Challenge.

Pour a bucket of Icy water all over you and donate to Motor Neurone. Or just donate because if we can make a difference then it will all be worth it.

### Thank you to the following groups for their support with Ice Bucket Challenge events

- Binya Public School
- Boree Creek Public School
- Bunnings, Kirrawee
- Campbelltown Catholic Club
- Cranbrook Junior School
- Elmore Vale Public School, Wallsend
- Fitness First, Deakin
- Girl Guides Association (Alpine Trefoil Guild), Strawberry Hills
- Koorlingal High School, Wagga Wagga
- Lake Munmorah Public School
- Lismore Workers Club
- Narooma Rotary Markets
- New England Mutual, Armidale
- Ryde Public School

- San Souci Leisure Centre
- St Pats Football Club
- Stanwell Park Public School
- Toowoomba State High School
- United Realty Carnes Hill
- Woden Community Services

If we have missed your group please let us know.

...and a very special thank you to Declan from WA for doing the Ice Bucket Challenge for MND. Declan is 7 years old and is the grandson of Ian and Suzanne Boniface.



*Would you like to receive Forum by email? You can save MND NSW postage costs. Let us know at [admin@mndnsw.asn.au](mailto:admin@mndnsw.asn.au)*

## Community events (cont'd)



### Quiz Night

A very big thank you to Jenny Armour from the Northern Territory who continues to raise funds for the Association, organising a quiz night in

September. It was a great success and enjoyed by all who attended with \$1,855 raised. A very big thank you to the Darwin Fundraising Support Team who have raised in excess of \$10,000 this year.



### Quilt Raffle

A raffle in September was organised by Helen Cole raising \$300. First prize was a beautiful patchwork quilt (pictured). Thank you Helen!



### Ratcliffe Charity Surf Day

The Ratcliffe Charity Surf Day for MND was held in October at Kianga Beach. The event was organised by Anna Rogerson, who is just 11 years old, in

support of family friend Matt Ratcliffe. It was a fantastic day with almost \$3,000 raised. Pictured is Anna (standing on the left) and Matt Ratcliffe's youngest daughter Grace (sitting on the left). Thank you Anna for your fabulous work!

### Halloween Fundraiser

A Halloween Fundraiser was held during October dedicated to Mr Doug Bradshaw who died from MND in June of this year. Many thanks to Eve Barboza, who was the organiser of the day, and all those who assisted. A great day was had, with lots of scary costumes and more than \$2,000 raised.

### Super Saturday

It was Super Saturday in October at ReKreate Ladies Fitness where Kate Ridd organised a fun-filled workout event with refreshments, a raffle and a pop-up clothing store afterwards. Kate was really pleased with how the morning went with just over \$1,400 raised. Thank you Kate for all your hard work.

### Drink Tea for MND

Lots of delicious food was baked by staff from Southern Cross Austereo and Southern Cross Ten in Newcastle for a Drink Tea for MND event in October. Danielle Richards organised this lovely event with \$140 raised towards the 2015 Hunter Walk to d'Feet MND of which Danielle is the coordinator. Thanks again for your ongoing support.

### Spit Roast Dinner

Thank you to Norma Daley who organised an enjoyable and successful fundraising evening in Urunga during October. The night included a Spit Roast Dinner and a raffle raising around \$2,000.

### Charity Morning Tea

Jan McGeorge of the Glenreagh Creative Group organised a charity morning tea for MND in November with invitations to attend sent to other



surrounding craft groups. The morning was a great success and enjoyed by all with over \$600 raised. Pictured is the President of the Glenreagh CWA presenting a donation to the President of the Glenreagh Creative Group. Many thanks to Jan for organising this morning tea event.

### Coffee Van

Lareen Dunstone is raising awareness and funds in memory of her mum who died from MND. Lareen owns a coffee van in Forster on which she displays MND posters and takes donations. Lareen has said it has been wonderful to see peoples interest in the poster and giving their change in support. Thank you Lareen.



### Wool Muster

The Kurrajong Handspun Crafts group raised \$3,000 for MND NSW from their fundraising event, Dyed in the Wool, held in August. Many thanks to Barbara Scanes and all those who assisted with the event.

### High Tea for MND

Thank you to Libby Dickeson and Belinda Pratley who organised a High Tea for MND during July in Newcastle in memory of local theatre identity Barbara Delaney. It was an intimate afternoon yet they managed to raise over \$900 and hope to make it an annual event.

### MND Charity Day

A fantastic day of barefoot bowls was held in September at the Shellharbour Bowling Club raising \$3,315. A big thank you to the organiser of the day, Donnamaree Gasparrini, for her continued support.



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



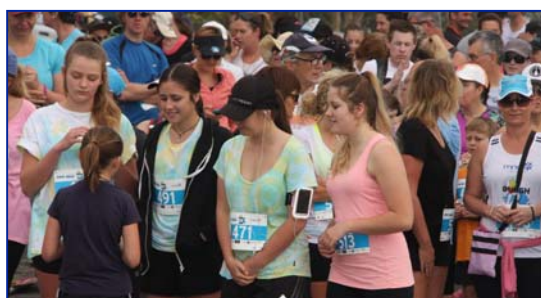
## Community events (cont'd)

### Gundaroo Music Festival

Held annually during October, the Gundaroo Music Festival is truly an event for the whole family with something for everyone - young and old. The 2014 Festival had food stalls, vintage cars, jumping castles, a great 4-wheel drive track, a kids zone, fireworks and, of course, fantastic musicians including The Borders, Blue Zoo Groove, Nova Scotia, The Corbys and Daryl Braithwaite and his band. A big thank you to Scott Harding and his team who put this wonderful event together, the major sponsor, Goulburn Toyota, and all of the supporting sponsors who made this event possible. Lock in Saturday 10 October for next year's Gundaroo Music Festival, it's a great day of music and fun not to be missed, just 30 minutes from Canberra and under an hour south from Goulburn.







### Burgh 2 Beach

This is the third year this event has been run and on 26 October close to 400 participants pounded the pavement from Helensburgh to Stanwell Park Beach. Walkers were off at 7.30am and runners at 8am, travelling along the picturesque 8km trip down to Bald Hill and finishing the last 500 metres on sand. Very cruel. James Turnbridge was the first male home and Erin Hargrave took the title for the women. A lot of work goes into the organisation of this event, a huge thank you to Nathan Johnston, Nathan Shoemark and the members of their hard working committee who make this such a well-run and enjoyable event for all. Over \$15,000 was raised for MND NSW.



At Gundaroo (clockwise from top left) Fireworks, Daryl Braithwaite, Blue 200 Groove and the Ice Bucket Challenge

## Community events Dates for the Diary 2015

16 Jan	<b>Paddle4MND</b>   Blacksmiths to Bondi
28 Jan	<b>Movie Night – The Theory of Everything</b>   Shellharbour
15 Feb	 <b>Walk to d'Feet MND</b>   Hunter
29 Mar	 <b>Walk to d'Feet MND</b>   Illawarra
19 Apr	 <b>Walk to d'Feet MND</b>   Forbes
3 May	 <b>Walk to d'Feet MND</b>   Tweed
3-9 May	<b>MND Week</b>
21 Jun	 <b>Walk to d'Feet MND</b>   Canberra
25-26 Jul	<b>34th Liverpool Doll Fair</b>   Liverpool
9 Aug	 <b>Walk to d'Feet MND</b>   Central Coast
13 Sep	 <b>Walk to d'Feet MND</b>   Port Macquarie
25 Oct	 <b>Walk to d'Feet MND</b>   Wagga Wagga
8 Nov	 <b>Walk to d'Feet MND</b>   Sydney
For more information see <a href="http://www.mndnsw.asn.au">www.mndnsw.asn.au</a> or contact MND NSW ph. 02 8877 0999	

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Editor: Penny Waterson

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