



FORUM

The week that was MND Week 2015

There are few amongst us who can resist the pull of a puppy. Blessed with deep, trusting eyes and inquisitive natures, they are as troublesome as they are playful. But during MND Week, held this year between 3 and 9 May, puppies could only be described as ferocious, targeted weapons of fundraising and awareness as they were deployed in Sydney's train stations and shopping centres. On Cornflower Blue Day, Friday 8 May, more than 80 volunteers were at Sydney city and metropolitan stations selling branded merchandise including pens, keyrings, silk cornflowers and yes, puppies (four varieties still available online). More volunteers were at temporary stalls they had established in metropolitan and regional shopping centres. Additionally, individual supporters and HCF and Harvey Norman stores sold selected MND NSW merchandise. During the week more than \$40,000 was raised. Thank you to our lovely and generous volunteers.

Susan Duric

(Volunteer) MND Week Volunteer Coordinator

MND Awareness Week is a huge event on our fundraising calendar. This year, we were lucky to have the assistance of Susan Duric who coordinated the necessary permissions for venues and organised merchandise, donation buckets, volunteer t-shirts and identification badges for our volunteers at the designated railway stations, shopping centres and event venues in NSW, ACT and Darwin. Apart from coordinating our regular event volunteers, Susan also recruited an army of new volunteers from various social media sources making it possible for us to be more visible in the Sydney CBD area. Thank you to Susan who worked tirelessly with an optimistic outlook. A big thank you also to our MND Week volunteers for their time, enthusiasm and ongoing support..

Kym Nielsen

Fundraising Manager



Queanbeyan



Chatswood



Circular Quay



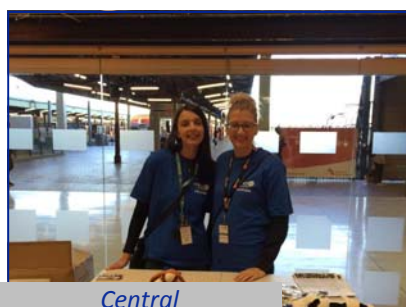
Shellharbour Square



Woy Woy



Erina Fair



Central



Penrith



Junee



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.

Our [Day of Hope and Remembrance](#) held at the beginning of MND Week 2015 was attended by approximately 140 people. It was an occasion to reflect on hope and also to remember those whose lives are affected by MND. It was so special to have everyone there, all people involved in the Association; whether as a member, family member, friend, supporter, volunteer, health professional, researcher, staff or board member. Associate Professor Roger Pamphlett shared his insights on hope for MND saying that there is a lot of hope that some answers will be found through research. He has been involved in research into MND for over 30 years and is more hopeful now than ever before. We thank Roger for sharing his thoughts with us and also thank the participants who read dedications and lit candles.



Walk to d'Feet
MND
See page 12

MND NSW Ask the Experts Forum

Monday 20 July 10.30am to 2.30pm
Ryde Eastwood Leagues Club, West Ryde

This is an opportunity for people living with MND, their family, carers and friends to hear from and ask questions to experts in the fields of neurology and research. Our expert speakers include:

- Professor Matthew Kiernan - *Bushell Chair of Neurology, Brain & Mind Research Institute, The University of Sydney, speaking about motor neurone disease*
- Dr Justin Yerbury - *University of Wollongong Centre for Medical and Molecular Bioscience, Illawarra Health and Medical Research Institute, speaking about what is new in motor neurone disease research*
- Associate Professor Megan Munsie - *Head of the Education, Ethics, Law & Community Awareness Unit, Stem Cells Australia, speaking about the future of stem cell research*

There is no charge to attend but registration is essential and includes lunch and afternoon tea. This venue is wheelchair accessible with parking available on site. RSVP by 15 July to reg@mndnsw.asn.au or ph. 02 8877 0999 or Freecall 1800 777 175.

Introducing...

Youvanna Chantharasy - FlexEquip Equipment Assistant



Since starting at MND NSW I get asked, 'How're you feeling, Youvanna?' I am constantly amazed that people remember my name! In the three months since joining the FlexEquip team, I have nothing but praise for the way things are run at the Association. I feel fortunate and privileged to be in an environment where the common threads we share are care, a common cause and compassion. I hope that I may contribute with my insight as a past carer and my technical knowledge.

A Message from the CEO

It has been another fantastic MND Week and we thank all those involved in collection, stalls and events across NSW, the ACT and in Darwin. Our 2015 Day of Hope and Remembrance, held at the beginning of MND week, attracted a record turnout. We have included some of the photos and updates from MND Week activities in this edition of Forum and also on the MND NSW Facebook page at www.facebook.com/mndnsw

You may have seen the *EndMND* campaign advertisements on television and at Harvey Norman stores during May. This MND Australia campaign (paid for by Harvey Norman) ran throughout Australia to raise MND awareness and funds. It has had a positive response to date.

On 1 July 2015 the Australian Government will release more reforms to aged care to give older people more choice, more control and better access to a wider range of aged care services. Most people living with MND have complex and individual care needs that rapidly snowball as the disease progresses. The crucial issue is whether people with MND who are aged 65 years and over will have access to adequate supports to meet their individual needs in the new aged care system. Our Call to Action *Let's make the system fair for all people with MND* started in May and we thank members and families who have already

taken part. It's not too late to write to your state and federal member. We only have a limited amount of time before the reforms are in place. So, if you haven't done so already, now's the time to make a noise! Ask the Government to end the inequity now. See www.mndnsw.asn.au for more.

We have had great community involvement in our recent Walks to d'Feet MND in the Illawarra and Forbes. The Lismore Walk to d'Feet MND was planned for the same weekend some unplanned major storms hit the north coast of NSW. Although the Walk was cancelled, it had terrific support from the local community who are already thinking about next year's event. Join your local community and Walk to d'Feet MND during 2015 in Canberra on 21 June, Central Coast on 9 August, Port Macquarie on 20 September, Wagga Wagga on 25 October or in Sydney on 8 November. Funds raised at events such as these enable us to keep providing information, equipment, workshops, programs, regional advisors, coffee mornings and support groups and further research into MND.

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

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FlexEquip Coordinator

Maree Hibbert

FlexEquip Assistants

Youvanna Chantharasy

Nicole Smith

FlexEquip Support Officer

Julie Becke

Information Resources Coordinator

Penny Waterson

And...many valued volunteers including

Jackie Mears who has provided ongoing event volunteer support for the last nine years. Jackie and her brother Doug are the coordinators of Cornflower Blue Day at Wynyard Station.



FlexEquip



New Equipment Assistant – Youvanna Chantharasy

In March this year Youvanna Chantharasy joined the MND

NSW FlexEquip team working two days a week, Tuesday and Thursday, in the equipment store area. Youvanna assists in ensuring equipment is ready for reissue and makes minor repairs to items. You can read more about Youvanna on page 2 of this edition of *Forum*. Youvanna has taken over from Tom Giardina, who resigned in early February this year, after four years working with FlexEquip. We wish Tom all the best with his new endeavours.

Referrals and equipment provision

In the past two months FlexEquip has received 328 equipment referrals for 101 of our members. We have provided 304 items during this time including 38 bathroom aids, 33 cushions, 21 power wheelchairs, 21 armchairs and 72 communication devices. Additionally we provided 11 trial iPad communications sets for health professionals. Each of these sets include an iPad preloaded with communication apps, a switch interface and a switch. The trial sets are used by the health professional for two weeks to assess whether an iPad and a particular communication app is suitable for a member to use.

Equipment batteries

Batteries are used in power wheelchairs, hoists and communication devices provided by FlexEquip.

The rule of thumb for charging batteries for equipment use is that if you are using the item frequently, every day, then the batteries should be charged overnight. If the item is only being used infrequently or every other day then the item should be charged overnight every three days. Batteries are expensive to replace and if they are looked after the inconvenience and expense of replacing them can be minimised.

Wrapping up Link and Learn Program, Berry - March 2015: “Live each day at a time”, “It’s OK to feel cranky and upset”, “I’m not alone”, “Care for yourself too”. These were some of the comments made by the 24 participants in the *Link and Learn* program that was held for those caring for someone with MND at home. Each year, MND NSW runs a two-day residential workshop in regional NSW for family carers to give them a bit of time out, to link with each other and learn about caring for a person with MND. This year the program was held on the 26 and 27 March in Berry and carers came from as far away as Canberra, Bega, the Southern Highlands, Young, Nowra and more. We were very fortunate to have so many health professionals share their expertise and give their time freely. Special thanks also to Rosanna Wallis who gave insight on the caring journey and how to try to make every moment count; her husband Keith having died from MND just over a year ago.

Wrapping up Living Well with MND, Canberra - February 2015: On 19 February, over 50 people living with MND, their family and friends attended the *Living Well with MND* day held in Canberra, a great turn out. The team from the ACT MND clinic and Dianne Epstein, MND NSW Regional Advisor, spoke about what to expect and how the team can work together to enable people with MND to live better for longer.

What is a transfer or walking belt?



A transfer belt (also known as a walking belt) is used by a carer when they are assisting a person, who is unsteady or weak on their feet, walk from one position to another.

The transfer belt (two types are pictured above) looks like a very wide waist belt and is made from soft material with non-slip material on the underside. This helps prevent slipping when in use. It is adjustable with either clips or Velcro fastenings. The belt also has a handle on each side for the carer to hold when assisting with the transfer.

It is recommended that a health professional, usually a physiotherapist or occupational therapist, shows you the correct and safe use of the transfer belt before you use it, to minimise the risk of any falls or injury to the person or their carer.

If you think a transfer belt would assist you please contact your health professional for more information.

Links to video information on transfer belts transfer belt can be found at:

- <https://youtu.be/ZDXgnTv5-4s> and
- <https://youtu.be/2Pxxm58OLq4>

Maree Hibbert

FlexEquip Coordinator

*Let's make the
system fair for
all people
living with
motor neurone
disease
(see page 3)*

MND NSW March of Faces Banners

The MND NSW March of Faces banners assist in raising community awareness about motor neurone disease and are a visible reminder of the urgent need for support for families and research into the causes, more effective treatments and a cure for MND. The banners are displayed annually during MND Week at the Day of Hope and Remembrance.

This year our display included two new banners, numbered 15 and 16, pictured right.

Thank you very much to the individuals, families and friends who submitted photos. You can view these banners and banners from previous years in detail on our website at www.mndnsw.asn.au.

To contribute a photo for a future banner see the information about submitting a photo on the MND NSW website or contact the MND Info Line ph 1800 777 175 or info@mndnsw.asn.au for more information.



MOTOR NEURONE DISEASE

Australia's March of MND Faces



Motor Neurone Disease Association of New South Wales
Phone: 1800 777 175

MOTOR NEURONE DISEASE

Australia's March of MND Faces



Motor Neurone Disease Association of New South Wales
Phone: 1800 777 175

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

Support Groups and Coffee Mornings

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

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

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

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

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

Western Sydney - Melanie Oxenham 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/Wagga Wagga - Dianne Epstein | 6286 9900 | diannee@mndnsw.asn.au

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

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

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

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

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

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

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

Noticeboard

Vale - Lloyd Affleck

Lloyd Affleck was a Life Member and past board member of MND NSW.

Prior to joining the Association in January 1991, Lloyd was instrumental in the formation of the MND Newcastle Support Group.

In 1991 members from this group joined the Association. Lloyd served on the MND NSW Board from 1992 to 1994 and was a great advocate for people living with MND. Lloyd died on 22 December 2014.

ALS Quest now open to all people, including those with any form of MND and those who do not have MND

You are invited to participate in a new research project that is looking for risk factors that might precipitate MND. An online anonymous questionnaire asks a series of questions about you that may give clues as to what factors trigger MND.

People with any form of MND as well as people without MND are eligible to complete the questionnaire. This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney Local Health District.

The questionnaire, designed by Associate Professor Roger Pamphlett of the University of Sydney, and instructions on how to complete it, can be found at alsquest.org

ILC Assistive Technology on Tour

The Independent Living Centre NSW (ILCNSW) is a non-profit organisation providing independent assistive technology / equipment information and advice. They are not a supplier. In June, ILCNSW is visiting Coffs Harbour and Armidale as part of 'Assistive Technology on Tour'. At this free event you can get information on:

- What do I need to consider when choosing assistive technology (equipment)?
- How can I find out what is available?
- Where can I get advice?

The session is FREE and is suited for people with disabilities, carers and family members.

There will also be a hands-on display of equipment and aids for daily living. The ILCNSW occupational therapists will be available at the event to answer your questions regarding assistive technology equipment and home modification options. There will be focus talks on mobility, self care, communication and vision options.

For more information, including dates, other locations and to register see www.ilcnsw.asn.au/home/what_we_do/at_workshops.html or contact Odelle at the ILCNSW on 9912 5806 or events@ilcnsw.asn.au

Your views about getting MND specialist multidisciplinary clinic advice via telehealth

The St Joseph's Auburn Multidisciplinary MND Clinic is inviting people living in NSW/ACT with MND and people who care for people living with MND to participate in a study. They want to find out your views about getting specialist multidisciplinary MND clinic advice at home via telehealth.

This project will involve participating in an interview. The interview can be done face-to-face, by phone, email or using video-teleconferencing, such as Skype. You will also be asked to complete questionnaires about your MND or your caring role, and previous computer and technology experience. If you would like to participate or get more information about the research project contact: Natalie Mohr, St Joseph's Clinic, ph. 9749 0329 or natalie.mohr@svha.org.au. This project has been approved by the St Vincent's Health Network Human Research Ethics Committee Executive.

Family Support Calendar

16 Jun	Information Evening for people recently diagnosed with MND, family and friends Gladesville
24 Jun	Lunch for bereaved carers Newcastle
20 Jul	Ask the Experts West Ryde
18 Aug	Information Evening for people recently diagnosed with MND, family and friends Gladesville
14 Sep	Lunch for bereaved carers Gladesville
17 Sep	Living Well with MND Illawarra
13 Oct	Information Evening for people recently diagnosed with MND, family and friends Gladesville
20 and 27 Oct	Learn Now, Live Well Ryde
21 Nov	Christmas Party for family support members, their family and friends West Ryde
8 Dec	Information Evening for people recently diagnosed with MND, family and friends Gladesville

For more information contact the
MND NSW Info Line ph. 1800 777 175. or
info@ilcnsw.asn.au

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.

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

MND Australia Ice Bucket Challenge Grant Awarded

The search for new risk genes and therapies to treat MND is set to accelerate with the announcement of the \$1.05 million MND Australia Ice Bucket Challenge Grant that will bring together clinicians and researchers from Australia's leading MND centres.

Funding and grant review

All funds for the grant came from over 30,000 Australians who donated to MND Australia's research arm, the MND Research Institute of Australia (MNDRIA) during last year's MND Ice Bucket Challenge. This has enabled the largest grant ever awarded by MNDRIA. It will provide \$350,000 per year over three years.

Seven grant applications were reviewed and scored by four eminent international MND research experts:

- Dr Brian Dickie, Director of Research Development, MND Association UK
- Professor Emeritus Andrew Eisen, Neurology UBC, Vancouver
- Professor Orla Hardiman, Neurology, Trinity College, Dublin
- Professor Emeritus Michael Swash, Neurology, London UK

When scores were tallied, the Sporadic ALS Australian Systems Genomics Consortium ranked highest.

Project overview

This is the largest collaborative MND project to be undertaken in Australia. It will be led by Professor Naomi Wray of the University of Queensland's (UQ) Queensland Brain Institute and Associate Professor Ian Blair of Macquarie University.

The Sporadic ALS Australian Systems Genomics Consortium (SALSA-SGC) comprises sixteen researchers from nine MND centres across Australia who will work together to build an integrated infrastructure for the collection and analyses of biological samples and clinical data. This pooled expertise will lead to a better understanding of the causes of sporadic MND.

According to Professor Wray the biology of MND is complex and poorly understood, but there have been dramatic advances in MND research in the past five years.

"These advances have been driven, almost entirely, by gene discoveries from the small number of families with more than one affected individual," she said.

For the vast majority (90% of all cases) of those with MND the diagnosis is sporadic, meaning they have an isolated case with no family history of the disease.

Recent developments in technology have revealed that people with sporadic MND may have genetic changes that could be risk factors for MND. SALSA-SGC aims to collectively identify new risk genes through whole genome analysis.

This initiative will generate a research resource that will underpin future research and enable people living with MND to benefit from advances made through genomic medicine.

About the new Sporadic ALS Australian Systems Genomics Consortium (SALSA-SGC)

"The biological basis of MND (also known as ALS) is complex and poorly understood. Nevertheless, there have been dramatic advances in MND research in the past five years that have been driven, almost entirely, by gene discoveries from families with more than one affected individual (familial MND). These have opened new chapters in MND research. Recent advances in technology mean that sporadic cases (90% of all cases of MND) can also contribute to gene discovery, but DNA from those affected is needed. We estimate that less than half of those with MND in Australia are currently recruited into genetic studies.

Here, we propose to build an integrated infrastructure for collection of biological samples and clinical data. Our proposal brings together clinicians from the major MND clinics across Australia. This new initiative will generate a research resource that will underpin future research and position future MND patients to benefit from advances made through genomic medicine.

In this proposal we will build upon the growing MND/ALS genomics resource and contribute to the international genomics initiatives. The sixteen investigators of our proposal bring expertise in MND genetics and genomic analysis integrated with clinical interpretation. The interpretation of analyses of genetics data will be assisted by three international associate investigators. The outcome of our project will be identification of new risk genes for MND and a nationwide strategy for genomic research through the new Sporadic ALS Australian Systems Genomics Consortium.

Identification of new risk genes will build a more complete picture of the underlying mechanisms and pathways for disease. Each new molecule offers a unique opportunity to discover mechanisms leading to neurodegeneration. Any new MND molecule is potentially a new therapeutic target."

If you are caring for someone living with MND in the Illawarra, why not join us for Living with MND on 17 September (see page 4)

MND Australia Ice Bucket Challenge Grant Awarded (cont'd)

SALSA-SGC researchers

Chief Investigators

Prof. Naomi Wray – Queensland Brain Institute, The University of Queensland, Brisbane, QLD

A/Prof Ian Blair – Macquarie University, Sydney, NSW

Dr Beben Benyamin – Queensland Brain Institute, The University of Queensland, Brisbane, QLD

Dr Robert Henderson – Royal Brisbane & Women's Hospital, Brisbane, QLD

Prof Matthew Kiernan – RPA Hospital/Brain & Mind Institute/Prince of Wales Hospital, Sydney, NSW

Prof Nigel Laing – University of WA, Perth, WA

Dr Susan Mathers – Bethlehem Hospital, Melbourne Victoria

Prof Pamela McCombe – Royal Brisbane and Women's Hospital & University of Queensland Centre for Clinical Research, Brisbane, QLD

Prof Garth Nicholson – Concord Hospital, Sydney, NSW

A/Prof Roger Pamphlett – University of Sydney, NSW

Prof Dominic Rowe – Macquarie University Hospital, Sydney, NSW

Dr David Schultz – Flinders Medical Centre, Adelaide, SA

Prof Peter Visscher – Queensland Brain Institute, The University of Queensland, Brisbane, QLD, 10%

Professor Steve Vucic – Westmead Hospital, Sydney, NSW

Dr Kelly Williams – Macquarie University, Sydney, NSW

Dr Qiongyi Zhao – Queensland Brain Institute, The University of Queensland, Brisbane, QLD

Associate Investigators

Prof Ammar Al-Chalabi – Professor of Neurology and Complex Disease Genetics King's College, London, UK

Prof Jan Veldink – Professor of Neurology and Neurogenetics, University Medical Centre, Utrecht, Netherlands

Prof Leonard van den Berg – Professor of Neurology, Director of ALS Center, University Medical Centre, Utrecht, Netherlands

Ms Anjali Henders – Queensland Brain Institute, The University of Queensland, Brisbane, QLD

If you would like more information about flexible respite funding speak with your MND NSW regional advisor.

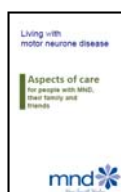
New MND NSW publications for members

Living with MND is a set of four in-depth publications especially written for people living with motor neurone disease, their family and friends.

The publications are available free online at the MND NSW website at www.mndnsw.asn.au >

Information resources > Managing MND. MND NSW members can request a print copy at no charge by contacting the MND Info Line info@mnidnsw.asn.au or ph. 1800 777 175.

Thank you to those involved in the development of these publications with particular thanks to past carers Julie Berents and Debra Jurss and for their review and comments on draft versions.



Living with motor neurone disease: aspects of care

48 page A4 book providing an overview of motor neurone disease and strategies for symptom management.



Living with motor neurone disease: day-to-day

72 page A4 book providing strategies for living at home with MND, more in-depth information and day-to-day tips.



Living with motor neurone disease: services and resources

72 page A4 book providing contact details for more than 200 services and resources that may be of interest to people living with MND in NSW, the ACT and NT.

The fourth publication in the series **Living with motor neurone disease: for carers** is currently under development.

We are always very happy to receive comments, feedback and suggestions for any MND NSW publication. For example, you may know of a service or resource that could be helpful but is not listed or find a mistake in a publication or in one of the listings. Please let us know by contacting the MND Info Line ph. 1800 777 175 or info@mnidnsw.asn.au

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@mnidnsw.asn.au for more information.

Seeking volunteer MND NSW Ambassadors

Thank you to Rotary Club of Dee Why Warringah for welcoming our Ambassador Ben Gooley to address their meeting on 17 March 2015 at Dee Why RSL Club. Ben presented a talk to 20 of their members raising awareness of MND.



Glenn Booth, President Rotary Club of Dee Why, with Ben Gooley, MND NSW Ambassador (r).

If you would like to make enquiries about our Volunteer Ambassador Program, whether you are considering becoming an Ambassador yourself or you would like one of our Ambassadors to speak to your Club members, contact Anne Jones ph. 02 8877 0999 or email annej@mnidnsw.asn.au

Get your team together for 2015 City2Surf



And speak with
Kym Nielsen
ph. 8877 0912
about supporting
MND NSW

Bequests

Leaving a Gift in your Will

Making a Will is an important way to secure the future of your loved ones and to make known your wishes to those you leave behind. Leaving MND NSW a gift in your Will (a bequest) is a tremendous and thoughtful way of supporting the work that we do. For a confidential discussion, contact our Supporter Liaison Officer, Anne Jones ph. 02 8877 0999 or annej@mnidnsw.asn.au

Community events

Anzac Day Two Up Charity Day

Thank you once again to Lesley and Lindsay Maher from Putney Tennyson Bowling Club for their ongoing support. This year \$675 was donated taking the total donations from this event to \$5,308 over the past seven years.

Arnie's Table Tennis Club

Terry Memory continues to fundraise with his weekly Table Tennis Club in the Laurieton area on the Mid North Coast. Thank you to Terry for the recent donation of \$1,500.

Movie Night

Thank you to Donnamaree Gasparrini who organised a movie night for a screening of The Theory of Everything. The night was held in Shellharbour at the end of January and raised \$2,850.

Fashion Styling Event

A lovely afternoon was held at the Blue Illusion Northbridge Boutique in February. Guests enjoyed light refreshments and a fashion parade, with \$114 raised. Thank you to Mary Edwards, Store Manager, who organised this event.

Fundraising for MND

Thank you to Kate Solomon and the Australian Bureau of Statistics Social Club NSW for their fundraising activities held during the month of March. Over \$1,500 was raised from cake sales, donations, a raffle and a social event in their Sydney Office.

In addition, the VIC and NT state offices ran cake sales to support the fundraising activities. Kate said, "This fundraising exercise was done in memory of a colleague of ours, Anne Bartlett, who sadly passed away late last year of MND. She was a loved and respected part of our organisation and will be missed by many people."

Trivia Night at Frenchs Forest Lions Club

Many thanks to the Lions Club of Frenchs Forest who held a very successful trivia night during March raising \$2,230. Thank you also to Susan Falkingham who was the coordinator for the event as well as MND NSW Ambassador Suzanne Ballinger for attending on the night.

Dale's Day

Joanne Moroney organised this picnic style afternoon in the Newcastle area during March which included a BBQ and a cricket game to celebrate the life of her son Dale, who died of MND. The relaxed and enjoyable afternoon was attended by around 60 people and raised just over \$1,400. Thank you Joanne and all those who attended.

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

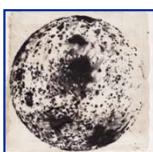
Community events

Manly Lawn Tennis Tribute to Brad Drewett

A big thank you to Tanya Lee, Founder of The CorriLee Foundation, who organised this wonderful event held in April raising \$11,372. Tanya said of the event "The Magic Guy in the sky was on our side and gave us a very rare rain free day and thankfully The CorriLee Foundation was able to hold the MND NSW Tennis charity day". The fundraiser was in honour of Northern Beaches tennis player and former CEO of the ATP tour Brad Drewett who died of MND two years ago. Friends, family, former pro tennis players (Ken Rosewall, Sandon Stolle, Kerry Pratt, Lesley Bowrey, Judy Dalton, Kim Warwick, Mark Edmondson, John Marks) and work colleagues all gathered to remember Brad. Everyone enjoyed the social tennis, the gourmet barbeque and the wonderful hospitality of Manly Lawn Tennis Centre. John Alexander MP was the MC and auctioneer. Speeches were made by Wally Masur, Brad's school mate Phil Gardner, Brad's business partner John Curtis and ATP's Alison Lee. Special thanks to John Newell Mazda for sponsoring the event and thank you to the MND NSW volunteers who assisted at the event.



Pictured above, Josef Drewett, Sandon Stolle, Brian Levine and Kim Warwick



Art Exhibition by Vanja Zaric

An exhibition of Artwork by Vanja Zaric was held during January in Canberra. A wonderful evening was enjoyed by those who attended with \$380 donated from the sale of artworks. Thank you to Vanja for your support.

ReJoyce High Tea

Lynda Leith organised a High Tea Fundraiser at Café Pirouette in Robertson during MND Week raising around \$1,500. The day was a great success with funds raised from donations, merchandise sales, and the sale of Lynda's Joyous Jam. Lynda's mum, Joyce Whatman, died of MND earlier this year. A big thank you to Lynda for her ongoing support.



Director's Meat Raffle, Canada Bay Club

The Canada Bay Club in Five Dock selected MND NSW as their chosen charity



for the Director's Meat Raffle during February with \$2,425 raised! Our Supporter Liaison Officer, Anne Jones, recently attended the club for the cheque presentation ceremony (above). We would like to thank Jacqueline Collins and the Canada Bay Club for their continued support.

Lifeguard 130km MND Awareness Board Paddle

What a great effort! Eight Lake Macquarie Professional Beach Lifeguards



completed a 130km board paddle from Bondi Beach to their own Blacksmiths Beach at the end of March. The sole purpose was to raise money and awareness for MND. A staggering \$14,000 has already been raised. Thank you to the Lifeguards that took part, Lucas Samways, Danny Napper, Rory Chapman, Lucas Chapman, Rory Tanner, Sam Earp, Jake Ingle, and Troy Ham.

150km Paddle for MND

Juliana Bahr-Thomson also embarked on a marathon paddle raising \$3,500. Juliana completed an unassisted 150km board paddle from Mereweather to Bondi at the end of February. After three days of staring down sharks, constant bluebottle stings and strong headwinds, Juliana completed her journey to a massive ovation at Bondi Beach. Thank you Juliana for your wonderful support.



Newcastle Half Marathon



Thank you to Chris Garland who ran the Newcastle Half Marathon on 19 April in support of MND NSW. Chris was moved by the courage of friends who lived with MND and ran with those friends in mind as well as all who live with MND. Chris raised funds by way of sponsorship for his fabulous effort!

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



Walk to d'Feet MND

Support for our Walks to d'Feet MND continue to amaze us with the fantastic support and wonderful atmosphere of camaraderie at each event. The Illawarra Walk this year was no exception with the largest participation yet, with over 400 supporters walking along the path from Bulli Surf Club (pictured right). A big thank you to Shelly-Anne Demirov our local co-ordinator, Keith Caldwell from Bulli Surf Club, Justin Anderson who provided some great after-Walk music and the Woonona Lions Club for their yummy barbeque. Of course we couldn't hold these Walks without support from our local sponsors I.98FM, Bulli Surf Club, DragonFit and Snap Printing. Thanks to everyone involved for another great day in the Illawarra.



A cold and windy day greeted us for the inaugural Walk to d'Feet MND Forbes in April, but the locals were made of stronger stuff, ignoring the wind and light rain. Some 179 locals showed up to show us what Forbes was made of, with a brisk walk around Lake Forbes. Congratulations to Pat Duncan who worked so hard to organise this Walk with support from Duncan Stockcrates and the local Lions Club. The sausage sandwiches were certainly appreciated in the cold weather and an amazing total of \$23,391 was raised by participants.

Terrible weather conditions in early May saw the cancelling of our inaugural Walk to d'Feet MND in Lismore. The local committee, led by Katrina Jeffries, had put in an amazing effort to organise the Walk. It was a very difficult, but necessary, decision to cancel the Walk, that was made in consultation with the local committee and on the advice of the local NSW State Emergency Service. The people of Lismore are to be congratulated with an amazing total of \$9,558 raised. Thank you also to the local sponsors Cruise & Travel, Bennett & La Baracca. Your support is greatly appreciated. Can't wait for next year.

Newcastle Italian Film Festival

Nick Moretti and Dino Cesta, who has MND, are the organisers of an Italian Film Festival held in Newcastle every year in which the profits are donated to charity. MND NSW was chosen as the benefactor from last year's festival held at the end of November. The festival comprised seven films screened over three days. Blue cornflowers, the symbol of MND, were given to women who attended the event. An amazing \$11,000 was donated to MND NSW from the event. We thank Nick and Dino for their fantastic support. Picture below is Kim Sinclair (front left), Regional Advisor, accepting the cheque from the organisers.



ACKNOWLEDGEMENT

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

Editor: Penny Waterson

Community events Dates for the Diary 2015

21 Jun	Walk to d'Feet MND Canberra
27 Jun	Charity Dinner and Quiz Night Under the Stars Darwin
25-26 Jul	34th Liverpool Doll Fair Liverpool
19 July	Wardy's Bowls Day Taren Point
9 Aug	Walk to d'Feet MND Central Coast
20 Sep	Walk to d'Feet MND Port Macquarie
10 Oct	Gundaroo Music Festival Gundaroo gundaroomusicfestival.com
10 Oct	Concert to Support MND NSW Glendale
25 Oct	Walk to d'Feet MND Wagga Wagga
8 Nov	Walk to d'Feet MND Sydney
For more information see mndnsw.asn.au or contact MND NSW ph. 02 8877 0999	

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