

Perth 2 Sydney for MND NSW

When Bob Montgomery approached us to say he wanted to do a bike ride from Perth to Sydney as a fundraiser we knew he was serious. Bob had previously ridden from Leura to Port Stephens for MND raising over \$25,000.

This time he was setting the bar higher in both kilometres and dollars. Bob left Perth on his pushbike on 14 September and rode into Leura, his final stop, on Saturday 17 October.



An amazing ride made even more amazing by the fact that Bob is 71 years old. Thank you to Bob and his support crew for the fantastic effort of raising awareness and over \$30,000 to date for MND NSW during his 4,140km ride across Australia.

Gundaroo Music Festival

This year's Gundaroo Music Festival on 10 October was a very special one, honouring Scott Windsor, the talented local musician who died from MND earlier this year.

Over the past few years Scott has inspired many friends and others to support his vision for this annual event, and this was the first year the event was held without Scott being there.

It was a wonderful tribute with some fantastic music from Mental as Anything, Angry Anderson (pictured below, centre), Roo Arcus and many more. Live music played from 10am to 10pm with fireworks displays, food stalls, 4WD displays, vintage cars and loads of activities for the kids.

Congratulations to Scott Harding (pictured right with Graham Opie, CEO, MND NSW) and his hard working team on another successful Gundaroo Music Festival. Thank you for your continued support.



MND NSW will be closed from 12pm Thursday 24 December 2015 until 9am Monday 4 January 2016.

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 Message from the CEO

I think the photo of Jeffrey Walsh (right) really does speak a thousand words. Robyn, Jeffrey's wife, said in her email that accompanied the photo:

"Here is a photo of Jeffrey out in the garden – his 'happy place'. He is still able to go into the garden thanks to the electric wheelchair on loan from MND NSW. It is greatly appreciated."

Robyn Walsh

Our goal is to be able to provide assistive technology to people with MND as and when they need it and it is through the generosity of donors that we are able to do so.

The 2014-15 financial year was an extraordinary year. The Ice Bucket Challenge kicked off the year with unprecedented awareness. Funds donated allowed us to bring forward the purchase of much needed items. The provision of equipment is a continuing focus of the Association along with the provision of support services including the MND Advisor service, the MND Info line, information, education and training.

Additionally, in the last financial year over \$300,000 was donated for research. This has contributed to the \$5.07 million allocated to the best researchers Australia-wide by MND Australia through the MND Research Institute of Australia in November 2015.

I'd like to thank the Board of MND NSW for their guidance and support in 2015. All remain in place following the AGM in October. For a copy of MND NSW's audited financial statement or our review please email or call MND NSW.

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

Graham Opie

Chief Executive Officer



Jeffrey Walsh (above) and MND NSW FlexEquip staff Julie Becke, Youvanna Chantharasy and Nicole Smith with recently purchased power wheelchairs.



Volunteers – wrapping up 2015

2015 has been an extremely productive year for our Association. This has only been possible because of the valuable contribution made by our volunteers – administration, event, walk, ambassador and massage volunteers.

On behalf of the board, staff and people living with MND and their families, I would like to thank all our volunteers for their tremendous efforts, dedication, hard work and commitment to our Association. We are extremely thankful for your support and would like to take this opportunity to wish you all a very Merry Christmas and a happy new year.

We look forward to your continued association in 2016.

Anne Jones

Supporter Liaison Officer



Mary and Kayla Sparks getting the puppies organised.



Our Forum packing volunteers packaging June 2015 edition.



See the 2016 Walk to d'Feet locations and dates on page 10

Spotlight on MND research

On 25 August the inaugural Spotlight on Motor Neurone Disease Research was held at Charles Sturt University (CSU) Wagga Wagga.

MND NSW members, families and friends attended from as far afield as Sydney, Queanbeyan, Albury and Griffith.

The morning included a welcome from MND Advisor, Dianne Epstein, and an update on current MND research, including an overview of the specific MND research plans in the School of Biomedical Sciences at CSU, presented by Dr Robyn Wallace. Dr Padraig Strappe followed with a presentation about how conversion of skin cells into functional motor neurones can advance MND research. Participants met the researchers over morning tea and the very informative event wrapped up with a tour of CSU's award-winning National Life Sciences Hub.



Dr Robyn Wallace and Dr Padraig Strappe

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

Living Well with MND

Club Marconi, Bossley Park

Monday 21 March 2016

10am to 3pm

One day program 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.

There is no charge for you to attend this program but you need to reserve your place. Lunch and refreshments will be provided. Let us know if you have any special dietary requirements.

To register email reg@mndnsw.asn.au or contact MND NSW ph. 02 8877 0999 or Freecall 1800 777 175.

Motor Neurone Disease Association of New South Wales

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*FlexEquip Support Officer
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And...many valued volunteers including Ben Gooley, MND NSW Ambassador and event volunteer. Ben has represented MND NSW on numerous occasions giving presentations to clubs as well as assisting at the Central Coast and Sydney Walks.



Support Service Team

You may have noticed changes in what we name our support service and some staff roles. Our Family Support Service is now called MND NSW Support Service. Also, our regional advisors are now called MND Advisors. This was a national decision so that MND Association services and staff had the same names around Australia and we feel it more adequately describes our support service and the advisor role.

Planning for 2016

In November we launched our new Living Well with MND one-day program by running the program in Wollongong and Ryde. Participant evaluations have been very positive and we will be holding more of these days in Sydney metropolitan and NSW regional areas throughout 2016 (see below and mndnsw.asn.au for information).

We have been planning our events for 2016 and we do encourage you to attend those that are in your area or to travel if you are up to it. We do try our best to have days in different regional areas. Look out for dates in issues of *Forum* or on mndnsw.asn.au or check with your MND Advisor. Your family and friends are also welcome to attend our events.

We find that the more information you have about MND, the more you are able to plan forward, to have better supports in place when you need them. Many people don't want to think ahead too far and, while that is ok, it sometimes results in people being in a crisis. Finding a balance between

planning ahead and living in the present isn't always easy but, by talking about it, at least you are making your wishes known. You can also discuss planning ahead with your MND Advisor or see our *Living with MND* publications that describe in more detail how you might make plans to ensure your arrangements for financial, health and lifestyle decision-making are in place. These are available at mndnsw.asn.au or through your MND Advisor or MND NSW Info line ph. 1800 777 175.

Staff Changes

Ann McCutcheon and Melanie Oxenham, MND Advisors, will both be leaving MND NSW in December. We have really appreciated the work both have done during their time at MND NSW and the contribution they have made to the lives people with MND. We will be recruiting to these positions and hope to have new staff available by the beginning of 2016. We wish both Melanie and Ann all the best with their future plans.


Christmas wishes

The Christmas season is upon us and for many it is a time to enjoy the company of family and friends and to share meals and exchange gifts. Christmas can also be a time of mixed emotions as we reflect on memories of the past year: shared sadness, love, loss, achievements, joy and hope. We hope this Christmas will be a time of peace and happiness for you and your loved ones.

Gina Svolos

Manager, Support Services

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

 Services and resources for people living with motor neurone disease <input type="text"/>	mnd.mndnsw.asn.au Find direct links to more than 200 services, programs, entitlements and resources that may be of interest to people living with MND in NSW, the ACT, and NT.
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Support Service Calendar to June 2016

16 Feb	Information Evening for people recently diagnosed with MND, family and friends Gladesville
21 Mar	Lunch for bereaved carers Gladesville
21 Mar	Living Well with MND Bossley Park
5 Apr	Information Evening for people recently diagnosed with MND, family and friends Gladesville
30 Apr	Day of Hope and Remembrance Sydney Olympic Park
17, 24, 31 May and 7 Jun	Care for Carers To enable you to care for a person with motor neurone disease at home, while still taking care of yourself
21 Jul	Living Well with MND Wyong

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

NDIS roll out in NSW announced



The types of supports the NDIS may fund for participants include:

- household assistance
- aids and equipment
- home modification
- vehicle modification
- other

The National Disability Insurance Scheme (NDIS) will roll out across New South Wales between 1 July 2016 and 30 June 2018. This scheme is for people who are under 65 years. How this roll-out affects you will depend on where you live, what supports you currently receive and your need for supports if you don't already receive any. The following information is from the NDIS website at ndis.nsw.gov.au

How does this affect people aged under 65 currently receiving supports?

The majority of people currently receiving specialist disability supports will be able to access the NDIS in the first six months of each of the two year roll out periods, using a simplified access process. This includes people who might be living in supported accommodation, accessing a community access service such as a day program or case management service.

People who access specialist disability supports from time-to-time, or for a short amount of time each week, will be able to access the NDIS throughout each of the two year roll out periods. People receiving respite services will go through a simplified access process. People receiving community care services will be supported to apply for access to the NDIS.

When will the NDIS be available?

With so many people coming into the scheme in such a short time it is important that there is a planned approach to how they access the NDIS.

People with disability living in the local government areas of Newcastle, Lake Macquarie and Maitland can already access the NDIS through the Hunter trial. From July 2014 the NDIS has been available in the ACT to those who are eligible and from 1 July 2015, the NDIS has also become available to eligible participants aged between 0-17 in the Nepean and Blue Mountains area, a full year ahead of schedule.

From 1 July 2016, people living in the Hunter New England, Southern New South Wales, Central Coast, Northern Sydney, South Western Sydney, Western Sydney and Nepean Blue Mountains districts will be able to access the NDIS.

From 1 July 2017, the NDIS will be in place across the rest of NSW, and people living in Northern New South Wales, Mid North Coast, Sydney, South Eastern Sydney, Illawarra Shoalhaven, Murrumbidgee, Western New South Wales and Far West NSW will be able to access the NDIS.

How does this affect people aged under 65 who do not currently receive supports from the New South Wales Government?

Supporting people who are in immediate need of assistance, and do not currently have support, is important during the roll out. There is some capacity during the roll out for people who have not previously received supports to access the scheme when it starts in their local area.

People wishing to access the NDIS should check that they meet the access requirements, which are available on the national NDIS website at ndis.nsw.gov.au. The website has information about the details of the NDIS roll out in NSW in both English and languages other than English. You can also contact the National Disability Insurance Agency (NDIA) on 1800 800 110.

MND NSW and NDIS

When more information becomes available from the NDIA, MND NSW will be in a position to determine what role it will play in the NDIS. Currently, in the Hunter where the NDIS trial site has been in place since July 2013, our MND Advisors have taken on the role of Support Coordination. This role is more involved than the MND Advisor role has been in the past and Kim Sinclair and Eileen O'Loughlen have been doing a great job working alongside people with MND in this location. Additionally, FlexEquip, the MND NSW Equipment Service, has been providing equipment for rental to NDIS participants and we plan to continue to provide equipment to NDIS participants as the NDIS rolls out more widely across NSW.

Although our role within the NDIS remains unclear, we will continue to provide support and information to people with MND, their carers and service providers. We will be available to help guide you through these changes and we will continue to advocate for the needs of all people with MND.

People 65 years and over are not eligible for the NDIS. They will continue to access services through My Aged Care, the access point for community services for people aged 65 years and over, at myagedcare.gov.au or ph. 1800 200 422.

Write to the
Editor of Forum
MND NSW
Locked Bag
5005
Gladesville
1675 or email
[info@mndnsw.
asn.au](mailto:info@mndnsw.asn.au)

FlexEquip

In the past 12 months FlexEquip has:

- provided over 1700 items of equipment to over 348 members throughout NSW and the ACT
- retrieved nearly 1800 items of equipment
- organised 15 new bed hires for members in regional areas or where FlexEquip beds are difficult or too costly to deliver.

We have also purchased 140 items of equipment for inclusion in the FlexEquip Library at a cost of nearly \$190,000. This includes the purchase of 11 power wheelchairs which has helped us to reduce waiting time for our members. This would not be possible without the ongoing efforts of MND NSW supporters in all of their fundraising adventures. A big, THANK YOU, to everyone who has joined in to help fundraise throughout the year.

Hot weather and equipment

With the hot weather approaching please remember to regularly check the air pressure in any air cushion, air mattress or wheelchair tyre inner tube. With hot temperatures the air inside these items expands and can increase the air pressure resulting in the item being overinflated and not appropriate to use. For wheelchair tyres, the correct tyre pressure is marked by the manufacturer on the outside rim of each tyre. For air cushions, including Roho cushions and air mattresses, please follow the inflation instructions in the user guide you received with the item.

Did you know that storage of equipment in vehicles that are parked in the sun for extended periods of time can cause heat damage? We have seen manual wheelchairs, cushions and transfer aids all damaged by long exposure to high temperatures inside a vehicle, becoming brittle, warped and no longer safe. It is best not to store equipment items in vehicles where possible.

Christmas New Year close

MND NSW, including the equipment service FlexEquip, will be closed over the Christmas and New Year period from Thursday 24 Dec 2015 until Monday 4 January 2016.

Equipment breakdown during Christmas/New Year break

If there is an **urgent** breakdown of FlexEquip equipment during the Christmas close period contact your occupational therapist or speech pathologist to assist you in arranging a repair, or if they are not available, contact your local hospital. Remember to let FlexEquip know as well so we can follow up when we reopen. FlexEquip can be contacted on 02 8877 0999.

On behalf of the FlexEquip team: Julie, Nicole and Youvanna, thank you for your support during 2015. We wish everyone a very safe and very happy, memorable holiday.

Maree Hibbert

FlexEquip Coordinator

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

Support Groups and Coffee Mornings

Campbelltown - MND NSW | 1800 777 175 | infoline@mndnsw.asn.au

Liverpool - MND NSW | 1800 777 175 | infoline@mndnsw.asn.au

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

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

Western Sydney - MND NSW | 1800 777 175 | infoline@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 - MND NSW | 1800 777 175 | infoline@mndnsw.asn.au

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

Illawarra - MND NSW | 1800 777 175 | infoline@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 | 1800 777 175 | 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

Out and about – ‘Living Well with MND’ series of education events

By the beach in Wollongong...

On Thursday 22 October MND NSW hosted a *Living Well with MND* day at the Wollongong Golf Club, overlooking the beach, for people living with MND, their family and friends. We had an incredible turn-out of 68 people. Many local members attended the event, but we also had people travel from as far away as Canberra and Bega.

A special thanks to the Port Kembla multidisciplinary team who gave of their time to share their insights, knowledge and expertise with all those attending: Dr Geoff Murray, Divisional Director, rehabilitation Medicine, Illawarra and Shoalhaven; Stephanie Taylor, Speech Pathologist, Port Kembla Hospital; Karen Davison, Dietitian, Palliative Care and MND, Port Kembla Hospital; Heather McLaughlin, Occupational Therapist, Illawarra Shoalhaven; and Vivienne Connolly, Social Worker, Illawarra Palliative Care services, Port Kembla Hospital.

Some feedback from the day included:

- *I liked putting faces to names in terms of the care team*
- *was very informative and really helped join the dots regarding MND and its treatment*
- *meeting together is always nice. Talking to others is informative and information is always welcome*
- *thankyou for providing this day in our local area*
- *Improved understanding on how I could provide the best care*
- *developed additional contacts and exposed to issues that will be important in a future stage.*

And in the city...

This day, on 27 October, was the first time *Living Well with MND* was held in Sydney and the Ryde Rehab Conference Centre was an excellent venue. We are grateful to the health professionals who so generously gave of their time to prepare and attend: Fiona Barry, Occupational Therapist, St Josephs Hospital; Elaine Chui, Physiotherapist, St Josephs Hospital; Berna Gurisik, Speech Pathologist, Ryde Hospital; Ella Murray, Dietitian, Royal North Shore Hospital; and Dr Amanda Piper, Coordinator, Home Ventilation Program, Royal Prince Alfred Hospital.

People travelled from as far afield as Tamworth and Dubbo to attend. We had great feedback from all participants and although some were newly diagnosed and others had lived with MND for some time, they all left saying how much they had gained from the day. Comments included:

- *I found it interesting and lovely how much people cared about quality of life*
- *lots of practical advice and good ideas for home!!*
- *realising there is so much help out there! I didn't realise the MND Association was so vital - glad I joined*
- *lots more questions answered.*

Living Well with MND days in 2016

We have a number of *Living Well with MND* days already confirmed for 2016, so why not consider attending? The day is relevant to people who are newly diagnosed as well as those who have been living with MND for some time, and their family and friends.

Sydney: Monday 21 March - **Bossley Park**

Central Coast: Thursday 21 July - **Wyang**

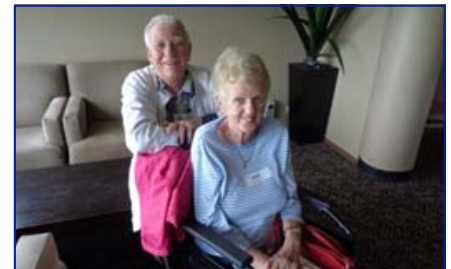
Southern NSW: Tuesday 6 September - **Wagga Wagga**

Sydney: Wednesday 2 November - **Ryde**

We will keep you posted when additional dates are scheduled.



Senga Rogan with family and friends



Bill and Anne Laudenbach



Glenn and Rachel Sargood



Helen Thurling and Joy Waldron

*Living Well
with MND*

*Club Marconi,
Bossley Park
Monday
21 March
2016*

See page 3

Noticeboard

AIDER

The AIDER program is run by the Rural Fire Service to assist you to be prepared for a bush fire. It is a once off, free service for people, living in bush fire prone areas, who have a disability or who are aged. When you contact AIDER, you will be assessed for eligibility (by phone). A member of your local Rural Fire Service team will assess your property and advise about your bush fire survival plan. If you have limited domestic support, AIDER services may also include clearing gutters, clearing up to 30m around the property and slashing of long grass etc. The timeframe from initial phone call to the work being done can be some weeks. www.rfs.nsw.gov.au/plan-and-prepare/aider

Digital Legacy

A researcher from Edge Hill University, UK is investigating the use of a 'digital legacy' with people who are affected by MND. This means people with MND creating video messages and recordings of their memories specifically to be given to children in their family to watch. The study has received approval from a research ethics committee and also has support from the UK MND Association. If you would like to take part in the study contact Olly at clabburo@edgehill.ac.uk or see www.facebook.com/mndlegacy.

For Sale

Kia Grand Carnival. Auto. Approx 26,000k. 4 seater plus wheelchair. \$60,000 ono. Contact Heike ph. 0432 098 424.

ALS Quest

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

Expert patients and family carers wanted!

People living with MND have to make many decisions about their care and treatment as the disease progresses.

Macquarie University is conducting a project to develop decision support tools to guide MND patients and their family carers through symptom management and quality of life decisions. Decisions include whether to take medication (such as riluzole), have a surgical procedure (such as a PEG), or to use assistive equipment (such as a ventilator). This study has been approved by Macquarie University Human Research Ethics Committee. If you would like to be involved, or would like more information, contact Dr Anne Hogden at anne.hogden@mq.edu.au

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

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 15th and 16th banners in the MND March of Faces series were displayed for the first time during MND Week 2015 and you can view them on the MND NSW website at 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



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 infoline@mndnsw.asn.au for details about how to access the library and the books and DVDs available for loan.

MND NSW Christmas Puddings by Pudding Lane

\$34.95 plus postage. Purchase online at mndnsw.asn.au or ph. 02 8877 0999



MND Australia Research Meeting 2015

Researchers funded through the MND Research Institute of Australia in 2015 were invited to share the outcomes of their funded research as platform presentations at the MND Australia Research Meeting on 23 November 2015 in Sydney. In a very full day, some 21 researchers presented short papers and 43 poster presentations were on display. We have included several abstracts below. You can access abstracts of all the day's papers and posters at www.mndaust.asn.au.

Next-generation sequencing in Australian MND

Kelly Williams¹, Jennifer Fijita¹, Emily McCann¹, Katharine Zhang¹, Matthew Kiernan², Roger Pamphlett², Garth Nicholson³, Dominic Rowe¹, Denis Bauer⁴, William Wilson⁴, Ian Blair¹

¹ Faculty of Medicine and Health Sciences, Macquarie University.

² Brain and Mind Research Institute, University of Sydney.

³ ANZAC Research Institute, University of Sydney and Concord Hospital.

⁴ Translational Bioinformatics, CSIRO

There have been dramatic advances in MND research over the past seven years that have been driven by gene discoveries. To date, the only proven causes of MND are gene mutations that lead to motor neuron death, typically in familial MND. There is strong evidence that sporadic MND is a multifactorial syndrome caused by combined effects and interaction of susceptibility alleles (genetic variations that confer risk to developing MND) and environmental exposure. These alleles may confer weak, modest, or strong risk for MND. The identity of most MND risk alleles, and their relative contribution to developing the disease, remain unknown. There is also strong evidence that unknown genetic factors contribute to the progression of MND, influencing the spread and speed of degeneration. Unknown genetic variation can also influence a patient's response to treatment. Collectively, these genetic components are known as the genetic architecture of MND. With recent dramatic advances in DNA-sequencing technology (next-generation sequencing, NGS), we are working to unravel the genetic architecture of MND by 1) continuing to identify familial MND genes and mutations, and 2) sequencing the whole genomes of sporadic MND patients to identify MND risk alleles, as part of the largest multinational genetic study (called "Project Mine") ever attempted in MND.

Decision support tools for motor neurone disease multidisciplinary care

Anne Hogden¹, David Greenfield¹, Xiongcai Cai², Jashelle Caga³

¹ Australian Institute of Health Innovation, Macquarie University

² School of Computer Science and Engineering, University of New South Wales

³ Brain and Mind Centre, University of Sydney

Objective: MND patients and families make numerous decisions for symptom management and quality of life as their condition deteriorates. Decisions may include: use of medication; assisted ventilation; artificial nutrition and hydration; and end-of-life care. MND challenges well-timed decision-making. Patients are often overwhelmed by their diagnosis, and take time to come to terms with their prognosis. Information needed to support their decisions is frequently confronting. Currently, there are no decision support tools available to guide MND patients through treatment and quality of life decisions. We will develop tools to help patients and families engage with health professionals to make well-timed and well-informed decisions over the course of the disease.

Methods: The project will use an iterative and consultative process to develop and validate decision support tools for MND multidisciplinary care. An expert stakeholder panel of MND patients, family members, health professionals and researchers will be formed to determine content, usefulness and feasibility of the tools. The tools will comply with International Patient Decision Aid Standards criteria, drawing on MND research, best practice and clinical guidelines.

Expected outcomes: Completed decision support tools will inform patients of the benefits and risks of each option, the consequences of 'doing nothing', and clarify patients' personal values. Tools that tailor MND information to decision-making will assist patients to make difficult decisions in a timely and informed manner, to improve patient outcomes and service delivery. The tools, and their process of development, have potentially wider clinical application for a range of degenerative neurological conditions. (See page 8 of this edition of *Forum* if you would like to be involved in this study.)

STOP PRESS: New MND Research Institute of Australia 2016 grants

On 26 November 2015 MND Australia announced the 36 successful recipients of MND research grants to commence in 2016, totalling \$5.07 million. Grants are awarded on the recommendation of the MNDRIA Research Committee. This is an expert panel whose members are approved by the National Health and Medical Research Council (NHMRC). The Research Committee comprises eminent clinicians and scientists from all over Australia. Their combined expertise covers all fields of MND research.

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Community events Dates for the Diary 2015-16

18 Dec	MND Charity Golf Day and Auction Sanctuary Point
6 Mar	Walk to d'Feet MND Illawarra
3 Apr	Walk to d'Feet MND Hunter
17 Apr	Walk to d'Feet MND Forbes
15 May	Walk to d'Feet MND Ballina
19 Jun	Walk to d'Feet MND Canberra
4 Sep	Walk to d'Feet MND Port Macquarie
16 Oct	Walk to d'Feet MND Wagga Wagga
6 Nov	Walk to d'Feet MND Sydney
For more information see mndnsw.asn.au or contact MND NSW ph. 02 8877 0999	

Not all gifts fit under the tree..

This Christmas, give a gift that doesn't fit under the Christmas tree - a gift in your will for MND NSW. Your generosity will be immensely appreciated and your gift will help to ensure that our Association can continue to provide equipment, care and services, free of charge to people with motor neurone disease and to fund research for more effective treatments and hopefully one day soon, a cure for this disease.

Show your care this Christmas by leaving a lasting legacy.

For more information about leaving a gift in your will or to request a free copy of our bequest booklet *Preparing for the Future* please contact our Supporter Liaison Officer, Anne Jones ph. 02 8877 0999 or freecall 1800 777 175, or by email giving@mndnsw.asn.au



*Celebrating Christmas in style
Michael Lee and Joanna Mawson-Lee*

Community Events

2015 has been a big year with community events held across NSW, ACT and NT. Special thanks must go to each and every organiser who gave so generously of their time to raise funds for MND NSW and awareness about MND. Thank you.

Glen Sargood MND Fundraiser

This is the fourth year that the Yerrinbool Soccer Club has organised this wonderful event to help Glen and his family and to raise funds and awareness for MND. This year the event included a soccer day and a fundraiser evening with raffles, auctions and entertainment. Close to \$8,500 was raised for MND NSW and we thank Tracy Lynch and all those who assisted for their continued support.

High Tea Afternoon

Staff at the Department of Family Services Hawkesbury held a lovely high tea afternoon including a raffle, silent auction and a lolly guessing competition raising \$1,821. The event was held in honour of a colleague's father who recently lost his battle with MND. Thank you to the staff who organised this event and for the generosity of everyone who attended.

Maroubra United Soccer Club Family Day

A fun family day was held for the end of the season at the Maroubra United Football Club. A popular sausage sizzle was held with all proceeds going to MND with a fantastic \$1,150 raised. Thank you to Katie Jones and all those who assisted on the day.

Bowls Carnival

The Taren Point Women's Bowling Club held their annual Bowls Carnival charity day which raised \$5,400 for MND. A very big thank you to Barbara Holden and to everyone at the club for their generous support. Barbara said, "Our members worked very hard to make this day a success and this resulted in a record result for the club."

Charity Golf Day

We would like to thank the generosity of members of the Lynwood Country Club who raised \$1,700 from a charity raffle for MND NSW. A member of the club has MND. The club was overwhelmed by the donations from members of prizes to raise funds via the raffle.

Charity Barefoot Bowls Day

A great day of barefoot bowls was held at the Warilla Bowls Club raising \$1,469. A big thank you to the organiser of the day, Donnamaree Gasparrini, for her continued support.

Illawarra Combined Seniors Dance Groups

Betty Davies has been organising this annual MND fundraiser since 2008 with \$1,000 donated from this year's events. Thank you Betty for your hard work and ongoing support.

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

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Community events (cont'd)

MND High Tea

Thank you to the staff at NIB Newcastle who held a High Tea in support of MND which raised \$1,727. Bridget Wilks who was an organiser of the event said "Everyone enjoyed the high tea event and way too many cupcakes were consumed, but all for a wonderful cause."



Musical Concert

Thank you to Don McMurray who has again organised a concert to support MND NSW. The afternoon included a variety of musical items provided mainly by Grace Musicians and the Sing Australia Choir. This year's concert raised \$2,333. Pictured are Don McMurray (second from left) and three friends performing as a Barbershop Quartet.



Young Saints Day for MND

A very big thank you to Ethan Silk who organised a football day fundraiser with the Young Saints AFL Football Club. Ethan said "Our MND day on the weekend went really well and we managed to raise a total of \$2,680."



Signify Thirty Exhibition

Talented artist Liesel Arden painted 30 portraits in 30 days of 30 inspiring people who have made a significant impact in their chosen fields to raise funds and awareness for people living with MND. Bids for portraits were taken online and an evening fundraiser was held at the Secret Garden in Byron Bay, raising just over \$16,000. Liesel held the fundraiser in memory of her inspiring friend Stacy Neild who passed away in 2013 from MND. Thank you Liesel for your time, talent and support.



Ice Bucket Challenge

Many thanks go to Tara McGowan and Phil Bates from the Department of the Environment in Canberra who hosted an Ice Bucket Challenge event to raise awareness and funds for MND and to support their dear friend and work colleague Scott Lisle. The day included a sausage sizzle, drinks, cupcakes, merchandise sales and a raffle. Tara said the day was very successful and went off without a hitch! Pictured from left, Phil Bates, Scott Lisle and Tara McGowan.



WaterNSW Raffle

Thank you to all of WaterNSW employees for their generosity in buying and selling tickets for a raffle to support MND NSW which raised a fantastic \$2,000. Tim Trembath who has MND and is a WaterNSW employee requested that the money be donated to our Association. Special thanks to Jodie Lawler who coordinated the raffle.



MND Thumbs Up Ball

A huge thank you to Brooke Wright, Les Wright and Donna Golding for the very successful MND Thumbs Up Ball held in Orange. Thank you also to the many local businesses who donated some fantastic prizes for the night. The ball was organised in the honour and memory of Jean Wright - wife, mother-in-law and aunt of members of the organising committee - who was diagnosed with MND in December 2010, and lost her battle in August 2013. Jean lost her speech and communicated by simple hand signals, thumbs up for yes or good, thumbs down for no or bad. Thumbs Up is what she used the most and Thumbs Up was her last message to her husband Les, before she died. Congratulations to the event organising committee for raising just over \$36,000 for MND NSW.



Drummoynes Sailing Club Juniors

Thank you to the Drummoynes Sailing Club Juniors who presented a cheque for \$1,000 to MND NSW which was raised at their Presentation Evening. The cheque was presented at their season opener on 13 September and was accepted by MND NSW Ambassador Sheona Robertson. The funds raised were in memory of Jane Nyult, the mum of one of their young sailors, who died last year from MND.



Ice Bucket Challenge in Memory of Russell Foster

An Ice Bucket Challenge was held in memory of Russell Foster who died from MND in 2014. Four generations were present, with three generations taking part. Those to undertake the challenge were Pam Foster, Erin Conlon and Jessica Blackman, with Olivia Blackman helping with the pouring of ice. Thank you for the generous donations and your support!



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Walk to d'Feet MND

They must 'breed them tough' in Port Macquarie because even though the weather was appalling on 20 September more than 150 supporters participated in **Walk 2 d'Feet MND Port Macquarie**. The mood and atmosphere the participants created was wonderful! Thank you to everyone who made it such a great day.



In contrast, on 25 October, the weather was on its best behaviour for **Walk to d'Feet MND Wagga Wagga**. As usual, Pat O'Hara and her wonderful team were very organised. The sun shone and supporters enjoyed walking around beautiful Lake Albert. It's great to see so many family groups and friends joining in our Walks.



Walk to d'Feet MND Sydney was held on Sunday 8 November and it was a record-breaking day in both attendance and fundraising. It is hard to describe the sense of community and common purpose when the 'sea of blue' walks together to let people living with MND know they are not alone. Thank you to families, friends and supporters who participated. Thanks also to those who supported the event with donations. Your support really does have an impact on the services we are able to provide people with MND and their families.



Thank you to our volunteer Walk 2 d'Feet MND local

coordinators who put so much time and energy into local promotion of the events in their towns in NSW and the ACT. During 2015 we have had great local support and participation, with attendance records broken in the Hunter and in Sydney, and a wonderful spirit and comradery at each of the Walks. More than \$236,000 and much awareness about the impact of MND has been raised.

Get those shoes, wheels and dogs ready—see page 10 for 2016 dates and locations.



Bennelong 100 - Walk for motor neurone disease

Keeping visible in local communities and raising the profile of MND is extremely important and we were thrilled when John Alexander MP, Federal Member for Bennelong advised he was planning a fundraising event on a huge scale for MND NSW. John was keen to support our Association as he recently lost a close friend to MND.

John's original plan was to walk 100km throughout the Bennelong electorate. During the course of the walk this grew to 206km. Along the way John stopped at schools, aged care centres, businesses and shops raising awareness of MND and collecting donations for MND NSW. With a hectic and gruelling schedule over 18 days, John covered a huge area - starting from his office in Epping on 24 October and finishing at Eastwood on 21 November.

Prior to the start of his walk, all households in the Bennelong electorate also received John's newsletter 'Bennelong Update' which included information about MND and the vital role that our Association plays. We thank John for his energy and tireless efforts raising money and awareness of MND and congratulate him and his team on a very successful outcome.

(From left) Students at Gladesville Public School with Principal Judi Partland and MND NSW volunteer, Frank Fullbrook selling merchandise at the school on 2 November to coincide with John's visit. John meeting Kevin Langdon OAM, Vice-Patron and Life Member MND NSW.



ACKNOWLEDGEMENT

We wish to thank Snap Printing, North Ryde for their generous support.

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