

### In this edition

MND Ask the Experts 2018 video recordings now on Youtube... Great support for Walk to d'Feet MND Sydney... MND in the media... Don't miss out on your Christmas Pudding by Pudding Lane... Recipients of MND Australia 2019 MND Research Grants announced... We appreciate your support... and more.

### A Message from the CEO

We recently conducted our AGM where our end of year financial statements were approved. Three of the current Board members stood down but under the Constitution were allowed to, and did, re-nominate. Board members for 2018/2019 are Lara Kirchner – President, Roger Henshaw – Vice President, Amy Critchley - Vice President, Anita Richter – Secretary, Nick Shaw – Treasurer and Kirsten Harley, Ann Tout, Ralph Warren, Elizabeth Rayment. You can download a copy of the Annual Review [here](#).

Our Christmas Appeal is in full swing and contributions can be made [online](#) or by simply calling our office ph. 8877 0999. Your generosity supports our vital work.

Please be aware our holiday closing will be from 12pm Monday 24 December 2018 until 9am Wednesday 2 January 2019. On behalf of the Board and staff of MND NSW I'd like to wish everyone a happy and safe Christmas and new year.

*Graham Opie*



So many wonderful teams of families and friends



Walk to d'Feet MND Sydney  
 Sunday 4 November Olympic Park

Supported by



While watching the hundreds of walkers at the start of the Sydney Walk to d'Feet MND, I was reminded of a line from a beautiful poem shared with us from MND UK. "Because of you, there is HOPE, a harbour of love, courage determination, defiance, generosity.....walking shoes purpose and drive."

I think this is the epitome of the amazing spirit and atmosphere that we have seen at all our Walks throughout 2018, and the Sydney Walk was no exception. So many wonderful teams of families and friends there to show people living with motor neurone disease that they are not alone. Over \$76,000 has been raised to date for the Sydney Walk, a fantastic result and one that will help us to continue to provide information, education, equipment and support for members and their families.

It's very true - "Together we can move mountains, alone we can't move at all". Thank you for your support during 2018 and we look forward to

seeing you at a Walk to d'Feet MND in 2019.

Just remember, "Keep Walking we are not there yet".

*Kym Nielsen  
 Fundraising  
 Manager*





## Support Service Update

In the short time I have been in this role it is easy to see that 2018 has been a busy and productive year for the Support Service team with much achieved, but also that there is so much more waiting to be done. I am particularly mindful, not only of our staff but of the many volunteers who work quietly and generously alongside us to help us deliver our services to our MND community. Most especially, I am grateful for the many people who fundraise on our behalf, who attend our MND Walks and other events and whose contributions enable us to keep doing what we do.



Next year will see us launch our new online education platform. This has been in the planning for some time and we are all very excited at the possibilities it will bring, especially for those living in rural or remote communities. We will continue to add programs and courses to this platform as it evolves particularly in relation to supporting allied and community health professionals deliver services to people living with MND.

Alongside our education platform we will be continuing to roll out video calling to enable our Coordinators of Support and MND Advisors to enhance their service to our members. We think this is especially important for people living in regional areas and believe it will improve both response times as well as understanding of real needs.

As the festive season draws near, with all its celebrations and busyness, we are reminded that this time also brings us opportunity to just enjoy some of the simpler things such as a catch up with friends, a beautiful view or a favourite television show. No matter how you intend to spend this Christmas, we hope that you have the chance to make some beautifully simple moments of your own and do so knowing you are a very much valued member of our community.

Wishing you all a peaceful Christmas and a happy New Year!

*Karen Martin*  
*Manager*

## FlexEquip equipment

FlexEquip is the equipment service provided by the Motor Neurone Disease Association of NSW. FlexEquip provides equipment to adults diagnosed with MND, who are over 65 years old and to adults diagnosed with MND who are NDIS participants living in NSW or ACT.



## Equipment in the past 12 months

Since November last year FlexEquip has purchased 179 items of equipment for the equipment library at a cost of \$167,175. Some of the items purchased include 16 electric raiser recliner armchairs, 11 Homecare beds, 4 powered wheelchairs and 24 bathroom aids including shower commodes, over toilet aids and shower chairs. During the same period 1882 items of equipment were shipped to 352 members throughout NSW and the ACT.

## Equipment trial

FlexEquip provides health professionals with a two week trial of an iPad, preloaded with a number of communication apps, to use as an assessment tool with members or participants. FlexEquip does not offer or provide trial of any other equipment items.

## Christmas New Year close

Over the Christmas and New Year period FlexEquip will be closed from 3pm Friday 21 December 2018 and will reopen at 9am Wednesday 2 January 2019.

## What if your equipment breaks down during the Christmas break?

With all breakdowns of equipment **if there is a risk to your health please go to your nearest hospital**. Repair companies only provide very limited services over the holiday period and limitations as to what can be done apply. If there is an **emergency breakdown** of FlexEquip equipment during the Christmas close period and it cannot wait until FlexEquip reopens please contact your occupational therapist or speech pathologist to assist you in arranging a repair or if they are not available please contact your local hospital.

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Please remember to let FlexEquip know as well so we can follow up when we reopen. FlexEquip can be contacted on ph. 02 8877 0999 or email [flexequip@mndnsw.asn.au](mailto:flexequip@mndnsw.asn.au)

### Battery charging

Remember, battery operated equipment that is used every day, for example a power wheelchair, hoist or communication device, needs to be charged overnight for it to be ready for use the next day.

The FlexEquip team wish everyone a very safe and very happy holiday.

*Maree Hibbert*

*FlexEquip Coordinator*

### The education just keeps on rolling out

On Thursday 25 October 17 allied health professionals from the Illawarra attended our MND Aware training at the Novotel Northbeach. Some had been working with people with MND for over 10 years, while others had just started in the area, including a very experienced physiotherapist who has her own private practice in Vincentia.

The aim of the MND Aware training is for participants to develop:

- an increased awareness of MND, the nature of its progression as well as some of the common experiences that people with MND, their family and carers may encounter
- empathy and compassion for people with MND, their family and carers
- an understanding of the importance of care coordination and multidisciplinary care
- an appreciation of the importance of quality of life for someone facing a life limiting illness and how service providers can make a difference
- support strategies for those who provide services for people with MND to encourage self-care
- strategies to further knowledge and skills

We thank the participants for their interest in MND and in responding to the needs of people living with this disease.

## Information Evening

If you or someone close to you has been recently diagnosed with MND, our Information Evenings provide an opportunity to have some of your questions answered in an informal setting. Our next Information Evening will be held on 4 December at the MND NSW Gladesville Centre. There is no charge for you to attend but you will need to reserve your place. [Find out more here.](#)



## Christmas Puddings by Pudding Lane

Our wonderful Pudding Lane puddings are back. We have limited stock so don't miss out. Orders can be placed by contacting the MND NSW Centre at Gladesville ph 02 8877 0999 or online [here.](#)



## MND in the media

On 5 November 2018 [Australian Story](#) caught up with MND researcher Dr Justin Yerbury. Justin, who has MND, featured on the same program in March 2018. Follow the links in the stories to watch both programs on ABC iView. You can also read an article by Justin on MND and the National Disability Insurance Scheme on [The Conversation.](#)



## Have you let your MP know?

People diagnosed with MND when aged 65 or over are not getting the care and support they need. Join the campaign and help us end this inequity. Let your MP know that we need to Make Aged Care Fair for people living with MND by using our online e-action to email your federal MP to raise awareness of the issues people with MND are facing and call on Government for changes to Aged Care. [Take action now and ask your MP to Make Aged Care Fair for people living with MND.](#)



## Thank you to DUAL Australia

A big thank you to DUAL Australia who selected MND NSW during 2018 as their 12 month charity partner raising \$11,000. Special thanks go to Emma Morgan, from DUAL Australia, who coordinated the fundraising. Emma said of the support, "Some of our colleagues have unfortunately seen first hand the effects of MND and what it can do. They have lost friends and family and we want to help raise funds and awareness to support others suffering the same way."



## Does perceived stigma influence psychological distress in individuals with MND?

An international research study aims to find out if there is a relationship between levels of stigma and levels of psychological distress experienced by individuals with a diagnosis of MND.

Researcher Natalie Leigh, Clinical Psychology, Lancaster University, United Kingdom, is seeking participants for her research. Anyone aged 18 or over who has a diagnosis of MND is invited to complete an online survey. [Click here to take part or for more information](#)



This study has Ethics Approval from Lancaster University Faculty of Health and Medicine Research Ethics Committee (FHMREC) Reference: FHMREC17027

## Together we can

Leaving a gift in your will to MND NSW will help us to provide support as needed for people living with Motor Neurone Disease. Until there is a cure we need to make provision for the support and care required by our members and their families. For more information about making a gift for the future please contact our Supporter Liaison Offer, Yvonne Hamilton ph. 02 8877 0927 or [YvonneH@mndnsw.asn.au](mailto:YvonneH@mndnsw.asn.au).

## 2018 Christmas Wrapping Stall at Deepwater Plaza Woy Woy



Show your support at the Deepwater Plaza 2018 Christmas wrapping and MND NSW merchandise stall from 10am to 5pm on Thursdays and Fridays - **6 and 7 December, 13 and 14 December, 20 and 21 December**. Gold coin donation for wrapping Christmas gifts.

## Community Calendar 2018-2019

Click to find out more.

**2 Dec** **MND Fundraising Garage Sale**  
Berry Chiropractic Clinic

**4 Dec** **The Lap of Honour 2018 - Raffle**  
Lakehaven Shopping Centre

**4 Jan** **Bunnings Tuggeranong Sausage Sizzle**  
Tuggeranong

**23 Feb** **5th MND Charity Concert**  
Grace Evangelical Church Auditorium - Glendale

**5-11 May** **MND Week 2019**  
Various across NSW and ACT

**26 May** **Run MND - Sutherland Shire**  
Sutherland

**26 May** **Run MND - Central Coast**  
Long Jetty Reserve

**27 May** **Hike for Health - Great Wall of China**  
Raise vital funds for MND NSW.

**18 June** **Riddla MND Golf Fundraiser 2019**  
NSW Golf Club, La Perouse

## MND Australia 2019 MND Research Grants announced

MND Australia's research arm – the MND Research Institute of Australia (MNDRIA) - has awarded almost \$4 million for new research projects commencing in 2019.



Following a review of grant applications by the MNDRIA Research Committee, 28 new research projects across all Australian States will be supported in 2019 in addition to funds previously committed to support an innovative, national NHMRC partnership grant (2019–2023).

The Betty Laidlaw Prize was awarded to Dr Marco Morsch, Macquarie University, for his project targeting the nucleo-cytoplasmic transport machinery in sporadic and familial ALS.

The Bill Gole MND Postdoctoral Fellowship (2019-2021) was awarded to Dr Rosemary Clarke, University of Tasmania, and the Beryl Bayley MND Postdoctoral Fellowship (2019–2021) was awarded to Dr James Hilton, University of Melbourne.

Twenty five Innovator Grants were awarded. The Charcot Grant, for the highest ranking application, was awarded to Professor Julian Gold (The Albion Centre, Sydney) for a phase 3 clinical trial of Triumeq.

Associate Professor Justin Yerbury, Illawarra Health and Medical Research Institute, was awarded the Dr Paul Brock MND NSW Research Grant for investigation into the overexpression of Ubiquitin-like modifier activating enzyme 1 (UBA1).

MNDRIA funds only the best research and researchers from across Australia. If more funds were available, grants could be awarded by the expert MNDRIA Research Committee to a greater proportion of the many excellent applications that are received each year.

If you would like to contribute to funding MND research please [donate here](#).

## Grill'd Local Matters Program

MND NSW was selected for the Local Matters program at Grill'd Macquarie Centre in Sydney for the month of July. Every month this program provides support to groups, organisations and causes to generate extra support and increase awareness. We were thrilled to receive strong support from the community through this program.



Pictured are the MND NSW fundraising team receiving the winning cheque of \$300 from Grill'd Macquarie Centre staff. Thank you Grill'd!

## Are you, or is a person in your family, an MND Genie?

MND Genies is a closed unlisted Facebook group for people, living in Australia or New Zealand, who have a motor neurone disease related genetic mutation, but do not have MND.



About 10% of people diagnosed with MND have a familial form of the disease. Of these, about one in five have a mutation on the SOD1 gene and about two in five have a mutation on the C9ORF72 gene. These mutated genes can be passed down through families and children can inherit the mutated gene.

The aim of MND Genies is to provide a space where people can connect and share their experience of having an MND related genetic mutation. MND NSW does not endorse comments or posts made by group participants.

To join MND Genies or for more information about the group contact Kate Maguire MND NSW at [mndgenies@mndnsw.asn.au](mailto:mndgenies@mndnsw.asn.au) or ph. 02 8877 0902.

*Note* - People diagnosed with MND who are not eligible to join or continue to participate in the group will be offered support through other MND NSW services and programs.



### We appreciate your support

2018 has seen many community events held across NSW and ACT. 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 to the following supporters:

- Drag Me Down Productions who donated \$2,610 from their bingo nights, this is their second year of support.
- Ron and Leonie Sheriff who held their final Christmas Lights display in 2017, donating \$1,550 from the event.
- The Windsor Wolves Rugby League Club for their donation of \$1,750 from the 'Gary Longhurst Memorial Golf Day'.
- \$500 was donated from the 'Glenn Sargood MND Fundraiser', in their sixth year of support.
- Power Yoga Canberra for their donation of \$200.
- The skills of three AFL girls teams were on display at the St Ives AFC Girls Footy Fights MND event which raised \$1,000.
- Karalee Baker who has supported MND NSW over many years. This year Karalee organised a 'Bowls Day' donating \$245.
- St Matthews Catholic School who made a donation of \$1,600 on behalf of their 2018 Year 12 graduating students.
- Celia Walker who raised \$900 from her 'Give MND the Chop' event.
- RGH Consulting Group who held a 'Party For No Reason' and donated \$2,100 from the night.

## MND NSW Support Service events for 2019

Are you newly diagnosed with motor neurone disease? Caring for someone with MND? Would you like to ask an expert panel your questions about MND?

MND NSW conducts regular education and information sessions for people living with motor neurone disease, family members, carers and friends. MND education and information sessions are held throughout the year in Sydney and other areas of NSW and the ACT.

There is usually no charge to attend an MND NSW education or information session if you are a person living with motor neurone disease, a family member, carer or friend. However, bookings are essential. Keep an eye on [mndnsw.asn.au](http://mndnsw.asn.au) and future *enews* and *news* editions for 2019 dates and locations.

## Submissions open for 2019 MND March of Faces Banner

Australia's March of Faces Banners are a photographic display of people with MND. Our 22nd banner in the MND March of Faces series will be displayed during MND Week 2019.

If you have MND and would like to be included in the new banner, you need to complete a permission form and submit a photograph of yourself. Family members are also able to make a submission in remembrance of a person who has died from MND. More info at [mndnsw.asn.au](http://mndnsw.asn.au).



## 2018 - A year of steps, leaps and bounds

Throughout 2018 and across NSW and the ACT, sports charity days, school fundraisers, ice bucket challenges, cake bakes, craft fairs, galas, dinners and dances were organised to raise funds for MND NSW.

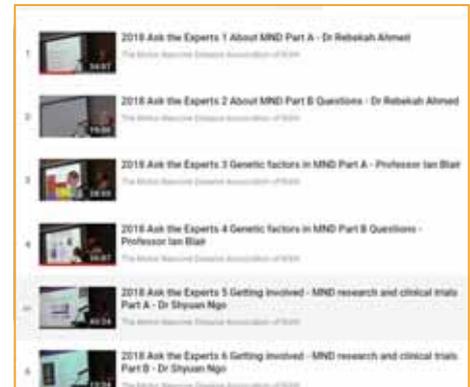
Read more in the [MND NSW Annual Review 2018](#).



## MND Ask the Experts 2018 video recordings now on Youtube

The calibre of the researchers who presented at MND NSW Ask the Experts Monday 5 November 2018, was excellent.

Dr Rebekah Ahmed, Consultant Neurologist, Senior Lecturer and Director of the Memory and Cognition Clinic at Royal Prince Alfred Hospital and the University of Sydney, provided a very interesting overview of MND.



Professor Ian Blair, Director of the Macquarie University Centre for Motor Neuron Disease Research, explored genetic factors and MND and Dr Shyuan Ngo, Scott Sullivan MND Research Fellow at the University of Queensland, explained about getting involved in MND research and clinical trials.

There were many thoughtful questions from the participants. Watch the [full playlist](#) or select individual videos below.

### Dr Rebekah Ahmed

#### [1 About MND Part A - Dr Rebekah Ahmed](#)

Part A of the About MND session recorded at MND NSW 2018 Ask the Experts, for people living with motor neurone disease, their family and friends. (Continued in Part B).



#### [2 About MND Part B Questions - Dr Rebekah Ahmed](#)

Part B (Questions) of the About MND session recorded at MND NSW 2018 Ask the Experts, for people living with motor neurone disease, their family and friends.



## Professor Ian Blair

### [3 Genetic factors in MND Part A - Professor Ian Blair](#)

Part A of the Genetic factors in MND session recorded at MND NSW 2018 Ask the Experts, for people living with motor neurone disease, their family and friends. (Continued in Part B).



### [4 Genetic factors in MND Part B Questions - Professor Ian Blair](#)

Part B (Questions) of the Genetic factors in MND session recorded at MND NSW 2018 Ask the Experts, for people living with motor neurone disease, their family and friends.



## Dr Shyuan Ngo

### [5 Getting involved - MND research and clinical trials Part A - Dr Shyuan Ngo](#)

Part A of the Getting involved - MND research and clinical trials session recorded at MND NSW 2018 Ask the Experts, for people living with motor neurone disease, their family and friends.



### [6 Getting involved - MND research and clinical trials Part B - Dr Shyuan Ngo](#)

Part B (Questions) of the Getting involved - MND research and clinical trials session recorded at MND NSW 2018 Ask the Experts, for people living with motor neurone disease, their family and friends.



Feedback from the day included “Lots of information and a greater understanding”, “More insight into the research into MND and the clinical trials”, “Greater optimism” and “Very encouraged by the huge amount of research being done”.



# Motor Neurone Disease Association of New South Wales

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Brenda Smith

...and many valued volunteers