



In this edition

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A Message from the CEO

The end of the financial year has passed and we're heading towards Christmas. We'd like to thank all of our supporters in 2017/2018, large and small. We could not have provided the services, support and research funding we do without your generous support. For over 35 years MND NSW has supported people with MND, their families and carers. MND NSW remains the only organisation supporting all people with MND across NSW and the ACT.

We would also like to acknowledge the ongoing support from NSW Health, NSW FACS, Gundaroo Music Festival, Run MND, Riddla Golf Day and the Newcastle Film Festival. Thank you also to each and every community fundraiser who has generously given their time to raise funds for MND NSW and awareness about MND.

It is not too late to show your support at Walk to d'Feet MND Port Macquarie, Wagga Wagga and Sydney. Find out more on page 5.

Graham Opie



Past Carers Lunch

Twice a year MND NSW holds a lunch at our centre in Gladesville, for those who have cared for someone with MND and experienced bereavement during the past 12 months. Those who have previously attended one of these luncheons tell us that they found it beneficial to meet with others who understand MND. The next lunch will be held on 17 September. [Learn more and reserve your place.](#)



Living Well with MND Information Day

Tuesday 25 September, West Ryde

Living Well with MND is an informative day for people living with motor neurone disease, their family 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 cost to attend the program but you need to reserve your place. More information here <http://www.mndnsw.asn.au/all-events/living-with-mnd.html>.



Ask the Experts

Monday 5 November, West Ryde

Do you want to hear from the experts about the latest emerging MND research and have your questions answered by MND experts? Then save the date for the *Ask the Experts Forum* at West Ryde! Find out more and reserve your place [here](#).



Manly Warringah Netball Gala Day

Thank you to the Manly Warringah Netball Association (MWNA) for your continued support from the MWNA Charity Gala Day. It was a wonderful winter's day to play some great netball with 118 teams participating, and \$7,218 raised for MND NSW. The MND puppies were especially popular (see photo page 1).



City 2 Surf

Thank you to the participants in the 2018 City 2 Surf held in Sydney on Sunday, 12 August who nominated MND NSW as their charity of choice. What a huge effort with over \$18,000 raised to support people living with MND in NSW and the ACT - Until there is a cure, there is care! Are you planning to participate in 2019? Don't forget to nominate MND NSW as your charity of choice and make a real difference to the lives of people living with MND.

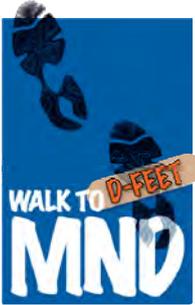


Stem cell therapy: the good, the bad and the ugly

20 September 2018

Sydney Ideas is the University of Sydney's public events program. At their next event, to be held 6-7.30pm Thursday 20 September at the Charles Perkins Centre Auditorium (D17), an expert panel will unravel the good, bad and ugly dimensions of stem cell research to inform and empower health consumers, examining the evidence of stem cell breakthroughs. Speakers include Professor John Rasko AO, clinical hematologist, pathologist and scientist; Dr Wendy Lipworth, bioethicist and health social scientist; and Professor Ian Kerridge bioethicist. Cost is free and the event is open to all but you must register to attend. Only very limited parking is available. For more information and to register contact the University of Sydney <https://sydney.edu.au/news-opinion/sydney-ideas/2018/stem-cell-therapy-the-good-the-bad-and-the-ugly.html>

Wrapping up Walk to d'Feet MND Batemans Bay Sunday 26 August at Corrigans Beach Reserve, Batehaven



Thank you to everyone who supported our Batemans Bay Walk on Sunday 26 August. Although there was a bit of rain overnight, the morning sun shone brightly.

Many wonderful families and friends gathered to show their support for people with motor neurone disease. Thank you to the local Lions Club for their yummy sausage sizzle and the many stall holders who supported the Walk.

A special thank you to the large contingent who made the trek across from Young and to the Go Go Girls who raised over \$4500. It was a great day with over \$11,500 raised.

Supported by

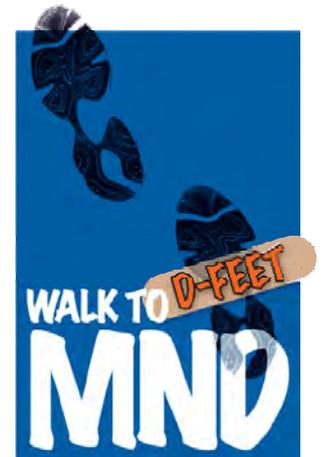


Together, let's take steps to d'Feet MND

Join us at a 2018 Walk to d'Feet MND.

Teams made up of family, friends, colleagues and individuals, regardless of age or fitness levels, walk to raise funds and awareness for research and support for people living with motor neurone disease.

Why not join in the fun at a 2018 Walk to d'Feet MND?



Sun 16
Sep

Walk to d'Feet MND Port Macquarie *Supported by*
Westport Park, Port Macquarie

Register now

Laing+Simmons
Port Macquarie

helloworld
TRAVEL
THE TRAVEL PROFESSIONALS
SETTLEMENT CITY

essential
energy



Sat 13
Oct

Walk to d'Feet MND Wagga Wagga *Supported by*
Apex Park, Wagga Wagga

Register now



Les Gray Plumbing



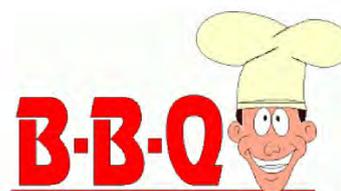
Sun 4
Nov

Walk to d'Feet MND Sydney *Supported by*
Blaxland Riverside Park, Olympic Park

Register now



**NEWS
FLASH**



**Join us Saturday evening 13 October
for our first Twilight Walk
Lake Albert Wagga Wagga**

Register today & include your sausage sizzle & salads dinner to enjoy after the Walk
<http://www.mndnsw.asn.au/all-events.html>

Education and training

On 2nd August we had over 20 health and community care providers attend the full day MND Aware face-to-face training at Gladesville.

Participants from across Sydney came to learn more about MND, how people living with MND can live better for longer, the benefits of multidisciplinary care, understanding the impact of MND and models of funding. There was much discussion in the group around a series of real life scenarios with health and community professionals brainstorming ideas to keep 'one step ahead'.



In the middle of the month we took education to regional NSW and conducted the Living well with MND Information Day for people with MND, their family and friends in the ACT. Sue Donaldson, MND Advisor, and I were the MCs for the day, and the allied health professionals from the ACT spoke about their roles and how they can assist people stay well and independent. We had an incredible 50 people attend the day, with some travelling to attend from Ulladulla and even Parkes.



Sue and I continue to be impressed with the commitment and care from the ACT MND clinic and we thank the staff from the clinic for making the day such a success.

Susan Wakil, School of Nursing and Midwifery at the University of Sydney invites MND NSW each year to present an hour long lecture on MND to over 100 final year nursing students. The students attending in 2018 were a very interested group and we look forward to our ongoing involvement in this program.

At the end of August the 9th National MND Conference is on in Adelaide. We have a range of speakers from NSW presenting including:

(Continued on page 7)

(Continued from page 6)

- Anna Fulford, physiotherapist from Port Kembla and Paul Watson, who was diagnosed with MND, are the driving force behind the MND NSW 15 page online reference guide I have MND. Now What?. Anna will speak at the conference about the collaborative development of this resource. It is practical and person-centred with the goal to enable early intervention, utilise available services, access multidisciplinary care and assist with future life planning accessibility.
- Alicia Gibb and Manasi Thornley, occupational therapists from Liverpool Hospital and the Liverpool MND Clinic, will speak on 'The Impact of Assistive Technology on Quality of Life (QOL)'. They will provide an overview on how multiple forms of assistive technology were recommended and implemented successfully. One of their take home points is that "advances in technology now mean that as a client with MND deteriorates their level of independence does not always reduce as in many instances, assistive technology bridges this gap."
- MND NSW will present on 'Supporting NDIS participants living with MND – an integrated approach'. Over the past five years we have incorporated ongoing learning with ongoing service development to develop an integrated organisational approach to enhancing outcomes for people with MND who are NDIS participants. We will be sharing our experiences and what we have learnt.



We are very committed to providing quality education in NSW/ACT, both in city and regional areas, and formal sessions are only one small part of the education provided by MND NSW. Our MND Advisors run support groups, provide in-service education to service providers and speak one-on-one with health and community care workers by phone or at the member's home, with the aim of improving outcomes for people living with this disease.

Kristina Dodds
Education and Carer Support Coordinator

Tumut Blues Rugby League Club

Thank you to the boys from Tumut Blues Rugby League Club who recently raised \$6,200 for MND NSW. What a great effort!



Australian Bee Congress

Raffles and the sale of some lovely auction items at the 3rd Australian Bee Congress held recently on the Gold Coast from 27 to 30 June. A big thank you to Therese Kershaw, Australian Honey Bee Industry Council and the delegates and industry representatives for their support, with over \$17,500 raised for MND NSW.



Goulburn Toyota GUNDAROO MUSIC FESTIVAL Saturday 13 October, 2018

People like Marg (pictured right) benefit greatly from the funds raised every year at the Gundaroo Music Festival and it's what keeps the organisers going. The Goulburn Toyota Gundaroo Music Festival on 13 October 2018 is the vision of a very talented local musician Scott Windsor who died from MND in April 2015. The Festival continues as Scott's legacy. The aim of this entertaining day of music and family activities is to raise awareness of MND, and to raise funds for equipment for those who have been diagnosed with MND.



It is a celebration of music, with over 12 hours of non-stop entertainment from 10am to 10pm, and a fireworks display for all to enjoy at 8.30pm.



See www.gundaroomusicfestival.com for the full line up and tickets.

Introducing new staff...

Steve Miholic | Equipment Assistant

Hi. I recently joined the MND NSW team as FlexEquip Equipment Assistant. I have felt very welcomed by the other staff and hope my contribution will make the FlexEquip service we provide to members even better. My background is medical manufacturing management, service and customer support, specifically for anaesthesia and respiratory related products. I am looking forward to learning more about and working with the FlexEquip aids and items of equipment.



Upcoming community fundraising events

- 2
Sep

Bowls Day

Tuggeranong ACT
- 5
Oct

Giving MND the Chop
- 7
Oct

Bunnings Sausage Sizzle

Eastgardens
- 13
Oct

Gundaroo Music Festival 2018

Gundaroo Park


- 9
Nov

Newcastle Italian Film Festival

Tower Cinemas Newcastle


- 29
Nov

Dave Matthews Seniors Tennis Tournament

Nelson Bay

Do you have an idea for an event to raise funds for MND care, support and research? [Find out more here.](#)

Our members need your ongoing support in the future

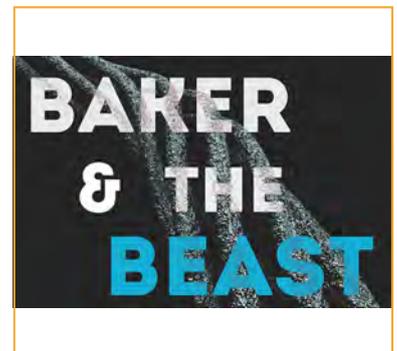
Over half of our members have developed motor neurone disease after they turn 65 years of age, making them ineligible for the National Disability Insurance Scheme (NDIS). Due to this lack of NDIS assistance, MND NSW provides equipment and services free of charge as Aged Care Packages are inadequate for a persons needs.

A gift in your Will enables MND NSW to provide its members, whether they are under or over 65 years, with the quality of service they deserve. A gift in your Will can assist MND NSW to provide aids and equipment for our members so they can live comfortably at home for as long as possible.

If you would like more information about helping our members through a gift in your Will please contact Yvonne Hamilton, Supporter Liaison Officer, ph. 02 8877 0927 or by email at yvonneh@mndnsw.asn.au

'Baker and the Beast'

We all want more people to be talking about motor neurone disease. 'Baker and the Beast' is an ABC Radio Life Matters 5 part series that first aired during August 2018. It is a no holds barred account of how one family and a community of friends are responding to a disease that has no cure. Mother of three, Cath Baker knows the beast



that is motor neurone disease (MND). As a critical care nurse she'd seen what this disease did to her friend Angie Cunningham. Then, in the cruellest of coincidences, Cath too was diagnosed. [You can read more or listen to/download the series here.](#)

Australian Clinical Trials Register

Find out more and register for updates about clinical trials in Australia at AustralianClinicalTrials.gov.au - a joint initiative between the National Health and Medical Research Council and the Department of Industry, Innovation and Science to provide information and resources to consumers, health care providers, researchers and industry about clinical trials.

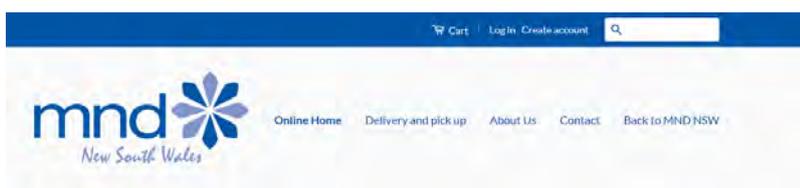
'The Village' - ABC TV

On 21 August ABC TV aired 'The Village' featuring former Foreign Correspondent reporter Sean Dorney who has MND, as he visited his beloved Papua New Guinea. You can catch up on this episode on [ABC iView](#) and read the backstory from Cameraman, Craig Berkman, [here](#). Many families living with MND will be able to find a lot



in common, "Sean and Pauline take a fairly practical and good-humoured approach to dealing with this increasingly frustrating condition, so you might wonder where the emotion comes from for the rest of us since we're not the ones dealing with it... As a team we learned early that we could all do little things to make day-to-day life easier, such as finding a drinking straw so cups and glasses didn't need to be lifted, or cutting up food to eliminate the need for Sean to grapple with a knife and fork, or being aware that a simple step-up might need a bit of physical intervention". Read Craig's full backstory [here](#).

Keyring Torches and Dog Bandannas now available



We have some great new keyring torches. They are aluminium with a 3-LED flashlight, on a keyring with batteries included. Only \$5, order yours today before they are all gone.



And while you are online help raise awareness about MND. Order your puppy one of our trendy dog bandannas at \$6.



Both available now through our [online shop at http://www.online.mndnsw.asn.au](http://www.online.mndnsw.asn.au)

Upcoming Support Service events

Click to find out more.

17 Sep **Past carers lunch**
Gladesville

25 Sep **Living Well with MND**
West Ryde

16 Oct **Information Evening for people recently diagnosed with MND**
Gladesville

17 Oct **Celebrating National Carers week morning tea**
Gladesville

5 Nov **Ask the Experts Forum**
West Ryde

1 Dec **Members' Christmas Party**
West Ryde

4 Dec **Information Evening for people recently diagnosed with MND**
Gladesville

MND support groups and coffee mornings



MND support groups and coffee mornings are held in city, regional and rural areas of NSW, in the ACT and on the Gold Coast, Queensland. Find out more [here](#) or speak with your MND Advisor.

What have *you* learnt that has made living with MND a little easier?

Kelly Carr or Kate Maguire at the MND NSW Info Line

infoline@mndnsw.asn.au would love to hear your tips and tricks, so we can share them with others.

Motor Neurone Disease Association of NSW

Christmas Orders 2018 - Support our fundraising efforts - stocks are limited.

Click the item to view online and place your order



Christmas Pudding
1kg Pudding Made by
Pudding Lane



Presents

"Best Wishes for a Merry
Christmas and a Happy
New Year"



Aussie Animals and Santa
"Season's Greetings and Best
Wishes for the new Year"



Three Wise Men
"May Peace Joy and
Happiness be yours this
Christmas"



Circle Stars

"Warmest Greetings of
the Season and every
good wish for the
Coming Year"



Bottle Brush

"To wish you Peace, Joy and
Happiness for Christmas and
the New Year"



Keyring Torch



Shopping Bag



Socks

Ladies - Purple
Mens - Navy



Plush Puppies

Black & White, Tan & White, Cream, Black



Dog Bandana



Motor Neurone Disease Association of New South Wales

Building 4 Gladesville Hospital, Gladesville NSW 2111
(Locked Bag 5005, Gladesville NSW 1675)

Ph 02 8877 0999 Freecall 1800 777 175 Fax 02 9816 2077

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...and many valued volunteers