



In this edition

Goulburn Toyota Gundaroo Music Festival tickets on sale now... Volunteer... Great support for Canberra Walk to d'Feet MND... International Research Update June 2018... MND Australia research strategy... and more.

A Message from the CEO

If you open this edition of e-news within a day of receiving it you're not too late to [donate](#) to our winter appeal and claim a tax deduction for 2017/2018. Our winter appeal is one of our most important fundraising efforts and helps us provide support for people with MND and their families and helps fund research. All donations over \$2 are tax deductible.

A fresh -4°C didn't deter a record crowd at our most recent Walk to d'Feet MND in Canberra (Shaz's Squad is pictured above). There are still five Walks to be held across NSW this year. Make sure you are part of the movement.

I'd like to remind everyone of our Make My Aged Care Fair campaign. The only way to help change a system is to participate. You can find out more [here](#) and add your voice.

Every day at MND NSW we are made aware of many, many more people fighting this cruel diagnosis. Our work supporting people living with MND and, ultimately, working towards a cure, drives the Association and all staff. Please support us to support others.

Graham Opie



Introducing new staff...

Cathy Amatya | Coordinator of Support - Sydney

I am looking forward to getting to know our members and families and assisting them navigate the NDIS. It's wonderful to be part of a team who share a passion for the work they do and the people they support. I have 10 years' experience in the community sector and love the opportunity this work provides to support and interact with very inspiring people.



Kelly Carr | Info Line Advisor

As the new Information Line Advisor for the Association, I am happy to have joined such a supportive and compassionate community for people whose lives are touched by MND. Having worked within a hospital environment previously and having been a carer myself, I can see how invaluable our services are and I'm proud to become part of such a dedicated team. I recently moved to Australia from the UK and am looking forward to my first sunny summer in Sydney and maybe even catching some waves!



MND Information Line

The MND Information Line can be contacted ph. 1800 777 175 or 02 8877 0999 Monday to Friday during business hours or email info@mnidnsn.asn.au. We receive over 3,500 calls and emails to this Info Line each year from people seeking information or advice about MND. The Info Line is often the first point of contact for people who are newly diagnosed with MND.

VALE

Sheila Holmes

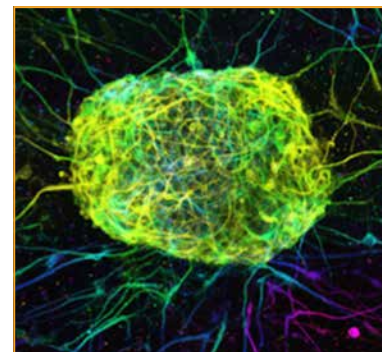
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MND NSW Life Member

Advance June 2018

Magnified: A science art exhibition

The Illawarra Health and Medical Research Institute (IHMRI), in association with the School of Arts, English and Media at the University of Wollongong (UOW), are presenting *Magnified: A science art exhibition*. This fundraising exhibition features 52 stunning images of the work of researchers and students at IHMRI, UOW and the Illawarra Shoalhaven Local Health District. Images will be on sale to the general public, with all proceeds going towards MND research at IHMRI, in honour of Associate Professor Justin Yerbury. Open Monday to Saturday, 6–20 July at TAEM Gallery, UOW. Find out more [here](#).



MND Australia International Research Update June 2018

The June 2018 *International Research Update*, produced by MND Australia is now available.

Topics include proteins, inflammation, aggregates and MND and much more. Read the latest international MND research news free online [here](#).



Advance June 2018

Find out about new projects and the progress of research funded by the research arm of MND Australia, the MND Research Institute of Australia (MNDRIA), in the June 2018 edition of *Advance*. Also in this edition is the new released MND Australia research strategy 2018–2021:

Investing in Innovation, Partnering for progress.

The vision is, of course, to find effective treatments and ultimately a cure for MND. There will be an increased focus on strategic partnerships while continuing MND Australia's commitment to innovation and developing the MND research workforce. Read online [here](#).



Wrapping up Walk to d'Feet MND Canberra Sunday 24 June at Peace Park, Parkes, ACT



Congratulations Canberra - you have certainly set the bar high with 600 participants at our Walk to d'Feet MND on Sunday 24 June raising in excess of \$59,000. An awesome effort. What a fantastic morning and the atmosphere was just wonderful with supporters of all ages showing their support.

A huge thank you to everyone who supported the Walk. Thanks also to our wonderful guitarist Matt Dent, supplied by Funnell Entertainment who represent the best in Canberra's music entertainment scene. The support from our friends at the Goulburn Toyota Gundaroo Music Festival and McGrath Real Estate was invaluable. A special thank you to our wonderful volunteers, we couldn't organise events like this without your help.

Let's see what you can do Penrith. Penrith Walk to d'Feet MND will be held at the Regatta Centre on Sunday 15 July.



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 15
Jul

Walk to d'Feet MND Penrith

International Regatta Centre, Castlereagh

[Register now](#)

Supported by



Sun 26
Aug

Walk to d'Feet MND Batemans Bay

Corrigans Beach Reserve, Batehaven

[Register now](#)

Supported by



Sun 16
Sep

Walk to d'Feet MND Port Macquarie

Westport Park, Port Macquarie

[Register now](#)

Supported by



Sat 13
Oct

Walk to d'Feet MND Wagga Wagga

Apex Park, Wagga Wagga

[Register now](#)

Supported by



Les Gray Plumbing



Sun 4
Nov

Walk to d'Feet MND Sydney

Blaxland Riverside Park, Olympic Park

[Register now](#)

Supported by



Big Morning Tea

Thank you to Frances Earl and the wonderful community of Coastal Waters Singles who held a Big Morning Tea in support of MND NSW. The morning included great company, lots of delicious treats and a raffle, raising \$1,000. Our thanks to everyone for their generosity.



A gift in your Will can make a world of difference to people with MND.

Making a gift in your Will to MND NSW is very easy and will ensure that our members have the assistance they need from our Association in the future.

After you have provided for your family and loved ones, a gift in your Will to MND NSW, no matter how large or small, means that we can give the necessary care and equipment to our members as well as provide funds for research for many years into the future. There is no better way to show your care and concern for people with MND.

For further information contact Yvonne Hamilton ph 02 8877 0927 or email yvonneh@mndnsw.asn.au.

Caring for carers

The MND NSW *Care for Carers* program was held for four weeks during May and was a great success, with some participants already letting us know they have had opportunities to put what they learnt into action. The support and friendship formed within the group was also greatly valued by all.

If you are a carer or person with MND and keen to learn more about what can be done to live as well as possible with MND, you may like to attend *Living Well with MND*, an information day for people with MND, their family and friends in Woden, ACT on 15 August or at West Ryde on 25 September. More info [here](#).

MND NSW volunteers

Volunteers provide many extra services that supplement the functions of our staff and are the life-blood of our Association. We couldn't do all we do without our volunteers.

What do our volunteers do?

- **Administration Volunteers** - packing the *news* print edition, packing merchandise, stocktaking merchandise, general admin (photocopying, mailouts, compiling info packs) and gardening.
- **Event and Merchandise Sales Volunteers** - assisting with set up and pack up of events such as our Walks to d'Feet MND, selling merchandise/raffle tickets at an event, assisting with traffic flow of people and vehicles, serving food and drinks and so much more.
- **Support Group Volunteers** - assisting with the set up and pack up of the room for these meetings, preparing and serving food and drinks to those attending (each support group requires different assistance from their support group volunteer).
- **Ambassadors** - our Ambassadors speak to groups of people at fundraising and other events, sharing their experience and informing the groups what MND is and what we at MND NSW do to assist our members - people living with MND. They explain why we need to fundraise and how donations really do make a difference.

We are all working towards the same cause – advocacy, information, support, a better quality of life for those with MND and ultimately, a cure. However, without a cure, there is care. Be part of the team that cares, Volunteer - support MND NSW so we can support our members and support researchers so they can find a cure.

We are currently looking for volunteers in all areas, especially Canberra, Port Macquarie, Wagga Wagga and rural areas of NSW. Volunteering with MND NSW is great fun! I've met some amazing people who volunteer at MND NSW and you can too. If you would like to join our volunteer team, contact sarahb@mndnsw.asn.au.

Sarah Bouch

Volunteer Coordinator

Upcoming Support Service events

Click to find out more.

14
Aug

Information Evening for people recently diagnosed with MND

15
Aug

Living Well with MND
Woden, ACT

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.

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 experts in MND? Then save the date for the *Ask the Experts Forum* at West Ryde! Find out more and reserve your place [here](#).



Living Well with MND Information Day

15 August at Woden, ACT
25 September at West Ryde

Living Well with MND is an informative day for people living with motor neurone disease, 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 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>.



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. Contact the MND Info Line ph. 02 8877 0999 or email [info@mndnsw.asn.au](mailto:info@info@mndnsw.asn.au) for details.

Are you doubling up?

The MND NSW e-news is issued every month or so and compiled into a condensed print version every quarter as MND NSW News (formerly *Forum*). Let us know if we can remove you from the print News list.

Baking a Difference sets a record

Congratulations to Anjelica Karagiannis and her team of helpers who set a new fundraising record at Bunnings Kingsgrove with their second bake sale supporting MND NSW. The team raised over \$1,400 with lots of lovely homemade and decorated cupcakes, cakes and cookies. Thank you also to Campsie Woolworths who provided their support to the bake sale for a second time.



Anjelica shared the following with us, "My team and I have different backgrounds, experience, skills and ages. We are a combination of friends and family. What we have in common is our dedication in helping others." Anjelica said of the day, "We met many people and families affected by MND. It was truly inspirational and amazing to have had them share their personal stories and to be able to support them emotionally and in raising funds. Our team is of the belief it is equally important to connect with, offer support, give hope and raise awareness - not just sell yummy cakes!"

Upcoming community fundraising events

29
Jul

Manly Warringah Netball Charity Gala Day
Curl Curl



7
Oct

Bunnings Sausage Sizzle
Eastgardens

13
Oct

Gundaroo Music Festival 2018
Gundaroo Park



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

Goulburn Toyota GUNDAROO MUSIC FESTIVAL Saturday 13 October, 2018



The classic **Moving Pictures** line up of Alex Smith, Andy Thompson, Charlie Cole, Ian Lees, Mark Meyer and Garry Frost are back together again and coming to the Gundaroo Music Festival on 13 October 2018 for one big spring show.

The Goulburn Toyota Gundaroo Music Festival 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.

In 2018, more than thirty years after the release of their hugely successful debut album, 'Days of Innocence', which spawned the mega hit 'What About Me', Moving Pictures will be taking to the stage to show their fans, both old and new, why they were known as one of the best live bands to grace the stages of Australian clubs and pubs throughout the eighties.

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



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 <http://fb.me/mndnsw> ABN 12 387 503 221

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Governor of New South Wales

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Coordination of Support

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Matouk

Team Cathy Amatya,

Jasminka Gojkovic,

Lauren Lovegrove,

Samantha Potter, Marnie

Roelink, Kim Sinclair, Kristie

Stamford

Admin Assistant NDIS

Brenda Smith

...and many valued
volunteers