

Together We Can

DONATE TODAY TO OUR 2019
WINTER APPEAL

In this edition

Canberra Walk to d'Feet MND a great success... New study - Environmental risk factors and MND in the Riverina... My Aged Care system failing... New Coffee Morning at Bondi Junction... UK FaTHoM meeting 2019 videos... Hike for Health Trek for MND... Ambulance Care Plans... and more

A Message from the CEO

21 June marked Global MND Awareness Day, a day where all organisations across the globe working with people with MND highlight the need to find a cause, treatment and cure.

MND NSW marked the day by celebrating our volunteers — without whose support the Association would not have been set up and would not be continuing today.

Ask the Experts (see page 3) takes place on 12 August and if you are unable to attend you can forward your questions to us. The presentations will be made available online after the event.

Our Make Aged Care Fair campaign continues (see page 12) and will only truly have an impact with your support. People aged 65 and older should have the same access to appropriate supports as those aged under 65 (and eligible for the NDIS) but the My Aged Care system is failing them. Please add your voice and encourage family and friends to do the same.

Together we can break down the barriers.

Graham Opie

MND NSW provides information, support, equipment and education services for people living with motor neurone disease, their families, friends and carers, health, community and residential care professionals in NSW, ACT, the Gold Coast and NT.



Support Service Update

Carers NSW is currently running a number of workshops around NSW about the upcoming changes to the way supports are provided to carers in Australia. We wrote about some of these changes in our last e-news.

Carers NSW are also offering carers in the Newcastle area access to some Carer Representative training and there is more information about this on page 9. We need every one of our members, carers and families to join with us in raising issues with their local member and others in the community and the training being offered by Carers NSW will certainly help to build skills and confidence in speaking up for MND.

One of the reasons why we need your support and advocacy is to help us address the inadequacies in the health and disability support services. The Commonwealth Department of Health recently released their quarterly report on their Home Care Packages program. As at 31 March 2019, there were 129,038 people over the age of 65 still waiting for a home care package. 13,278 of those waiting were waiting for services and support under a level 4 community package with wait times still reported to be 12 months plus. This is a system that is chasing its tail in terms of delivering what older Australian's actually need and want. If you are interested in reading the report you can find it here: <https://beta.health.gov.au/resources/publications/home-care-packages-program-data-reports>

We are planning a Coffee Morning and Support Group for people living in the Eastern and Southern Suburbs of Sydney. The group will hold its first meeting at Waverley Library on Tuesday 30 July 2019. We would really love to see you there, so if you are able to attend, RSVP to Michelle Malouf, MND Advisor, ph. 02 8877 0906 or michellem@mndnsw.asn.au or the MND Info Line Ph. 1800 777 175.

On page 14 of this edition of *e-news* is some important information about Ambulance Care Plans. We would really encourage everyone to plan ahead and this is a great document to help you do exactly that.

`Til next time

Karen Martin | Manager, Support Service

Register now for Ask the Experts 2019

Monday 12 August, West Ryde

Come along to the Ask the Experts Forum at Ryde Eastwood Leagues Club and have your questions answered by the experts! There is no charge to attend but you will need to RSVP by 7 August. Morning tea and lunch will be provided. To RSVP or for more information contact reg@mndnsw.asn.au or ph. 8877 0999 or Freecall 1800 777 175.



If you are unable to attend, you can email your questions to katem@mndnsw.asn.au by 5 August and we will ask the question for you. Sometime after the event, you will be able to view the presentations online. Here's a little preview of two of our speakers.

Associate Professor Roger Pamphlett at the University of Sydney is a neurologist and neuropathologist who has a longstanding interest in finding causes of MND.

The reason most people get MND remains unknown. This had led to efforts to find out what environmental risk factors could make people susceptible to the disease. An Australian initiative, called 'ALS-Quest', has been to design an online questionnaire, available in many languages, asking people both with and without MND about potential risk factors they may have been exposed to in their lives. Results arising from some of these survey questions will be presented at the Ask the Experts Forum.

Associate Professor Megan Munsie is Deputy Director of the University of Melbourne's Centre for Stem Cell Systems where she leads a research program in the ethical, legal and social implications of stem cell research. She also heads the Engagement, Ethics and Policy Unit of the Australian Government funded Stem Cells Australia initiative.

The challenge is striking a balance between maintaining community hopes in the promise of these new technologies, while acknowledging the reality of the science and the risks posed by unproven interventions. Megan will explore the complexities involved in 'managing hope' and the role of evidence in keeping hopes in check.

MND Australia Research Update June 2019

This research update is produced by MND Australia. In this edition - MicroRNAs, C9ORF72, SOD1 and other research shorts. [Read the June 2019 edition free online.](#)

Advance June 2019

Advance is the newsletter of the MND Research Institute of Australia - the research arm of MND Australia. In this edition—The MND Ice Bucket Challenge five years on, SALSA-System Genomic Consortium, Carers' Behavioural Screen for clinical care and research, brain sensors, FUS, neuroinflammation and emerging researchers. [Read the June 2019 edition free online.](#)

New study - environmental risk factors for MND

Do you live in the Riverina area in NSW? Macquarie University is looking into how environmental risk factors may play a part in causing motor neurone disease. They are recruiting research participants who either have an MND diagnosis or have lived in the same household as someone with MND in the past 10 years.



Participants must either currently live in the Riverina area or have lived there for at least 10 years in the past and are now living elsewhere. This study aims to screen for environmental risk factors and their potential association with MND in Australia, specifically in the agricultural Riverina Region. A number of groups are being sought from the region: patients with an MND diagnosis; people living in the same household as a person diagnosed with MND in the last ten years; or people who have lived in the region for at least ten years in the past, but have since moved away. All participants will be required to provide a urine sample and answer a questionnaire. For more information contact Neurodegenerative Disease Biobank Centre for MND Research Macquarie University ph. 02 9812 3741 or 02 9850 2722 or email susan.dsilva@mq.edu.au or Nd.biobank@mq.edu.au

This study has been reviewed and given ethical approval by the Macquarie University HREC (Medical Sciences) under application number 5201600387

MND support groups and coffee mornings - 2019 calendar

New - Eastern Suburbs Coffee Morning

10.30am-12.30pm

Tuesday 30 July

Bondi Junction

Join us at the Eastern Suburbs Coffee Morning on 30 July at Bondi Junction. To RSVP or for more information contact Michelle Malouf, MND Advisor, ph. 02 8877 0906 or michellem@mndnsw.asn.au or the MND Info Line Ph. 1800 777 175.



MND support groups and coffee mornings provide the opportunity for people living with motor neurone disease to meet together regularly to chat and learn from each other.

Regular meetings are also held in the ACT, Campbelltown, Central Coast, Gold Coast, Illawarra, North West NSW (Tamworth), Northern Beaches and Northern Sydney. Meetings are also held from time-to-time in the Northern Rivers and Wagga Wagga/Albury areas. See the full 2019 calendar online.

Thank you to our volunteers

During June, twenty MND NSW volunteers attended lunches in Sydney and Newcastle. This was a small token of thanks from MND NSW to those who give their time and support to our organisation.

All enjoyed themselves, chatting over some great food, connecting with and getting to know each other and relaxing for a few hours.



Volunteers are essential to our organisation, assisting with administration tasks, fundraising, merchandise sales and volunteering at events, raising awareness of MND and MND NSW. For more information contact Sarah Bouch, Volunteer Coordinator, ph. 8877 0928 or sarahb@mndnsw.asn.au.

Thank you to our supporters

Walk to d'Feet MND Canberra

16 June 2019

Peace Park, Parkes ACT

Wow Canberra! What a great morning it was at our Walk to d'Feet MND. This Walk is growing each year. Thank you to all of our amazing fundraisers, participants and volunteers. Our Walk results are in and \$50,952.57 was raised!

Thank you to our wonderful sponsors Duncan Stockcrates, Kennards Hire, SunSense and Twisted Sister.

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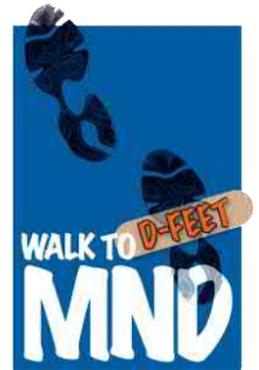
Together We Can 2019 Walk to d'Feet MND

Register today at walktodfeet.org.au and raise funds when you participate.

Show your support for people living with MND.

In 2019 we have made it even easier for you to register for a Walk to d' Feet MND and raise funds when you participate. All of our Walks and the local information for each venue can now be accessed through the one site. Register today at <https://walktodfeet.org.au>. I look forward to seeing you at a Walk in 2019. Together We Can.

Kym Nielsen | Fundraising Manager



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|-----------|--|--|
| 14
Jul | Walk to d'Feet MND Penrith <i>Supported by</i>
International Regatta Centre
Castlereagh NSW |  
   |
| 8
Sep | Walk to d'Feet MND Taree <i>Supported</i>
Endeavour Place Reserve
Taree |     |
| 20
Oct | Walk to d'Feet MND Young <i>Supported</i>
Arboretum Park
Young |    |
| 3
Nov | Walk to d'Feet MND Sydney <i>Supported by</i>
Sydney Park
Alexandria |     |



Upcoming Support Service Events

Click the event for more information.

12
Aug

Ask the Experts Forum
West Ryde

17
Sep

Past carers lunch
Gladesville

24
Sep

Living Well with MND
Berry

10
Oct

Celebrating National Carers Week morning tea
Pennant Hills

22
Oct

Living Well with MND
West Ryde

7-8
Nov

Link and Learn
Hunter

MND March of Faces Banner 21 now online

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 MND March of Faces Banner 21 was displayed for the first time during MND Week 2019.

March of Faces Banner 21 features Terry Blair, Russell Breward, John Christoforatos, Susan Ellis, Teresa Marie Gillespie, Federico Gregson, Julian 'Pont' Hercus, Vivien Hills, Gloria Karahalios, Paul Mortimer Kelly, Peter Kilgannon, Graham Mogford, Daniel O'Connell, Steven Ramaker, Louise Snelson, Diane Styles, Don Taylor and Leone Willoughby.



Are you or is someone you know a young carer?

Did you know that a young carer isn't necessarily a primary carer and they may not even share a home with the person that they care for? A young carer may be a child or a young person 25 years or under, who helps to support a family member or friend who has a disability, chronic condition, terminal illness, mental illness, drug or alcohol dependency or who is frail.



Young carers may be daughters, sons, brothers, sisters, granddaughters, grandsons, nieces, nephews, cousins and even friends, who have a role in helping to provide practical or emotional support to support someone in their life.

Carers NSW recognises the role that young carers have across NSW and can provide a variety of strategies to help with balancing school, university or work commitments. Young carers also have access to variety of free workshops and events, support with learning to drive and counselling when needed. [Find out more about the Carers NSW Young Carer Program.](#)

Newcastle Carer Representative training

Carers NSW is organising a Carer Representative training session in Newcastle in September 2019. If you are 18 years or above, and you would like to speak up on behalf of carers, you can find out more about the Carers NSW Carer Representation Program on the [Carers NSW website](#) or express your interest by calling 1800 242 636 or emailing carerrepresentatives@carersnsw.org.au or

Well done Daniel

Daniel Samuel and his father recently visited the MND NSW Centre at Gladesville to present \$2,080 raised from growing and then cutting off his Afro! Daniel was deeply touched by hearing from friends and family about MND and wanted to do



something to increase awareness and raise money for MND. Pictured is Daniel with CEO, Graham Opie. Thank you Daniel for your fantastic support!

Hike for Health

Congratulations to our team of five who completed the Hike for Health Trek in June and raised over \$23,000 for MND NSW. Here is the Day 7 journal.

Day 7: Great Wall: Juyongguan Great Wall - Sunday, 2 June 2019

After a slightly slow start, we checked out of our hotel and began the bus ride to the next and final section of the Wall. On the way, our guide Tony once again entertained us and informed us about Chinese culture and history. Today we learned about the Chinese zodiac and its importance in compatibility, especially when parents are doing the matchmaking. Apparently dragons are compatible mates with monkeys and rats, pigs are wise, and everyone wants to have a golden pig. Go figure!



Once we arrived at the Juyongguan Great Wall, we were also greeted by a wall of heat rising up from the stone. The mercury had hit 30 degrees, and once again the first part of the day was straight up. Once we had made it up, we could look down into the river valley below, to see the series of fortresses and defences that had been built to protect this important potential invasion point. We then sauntered along the Wall, taking shelter from the sun occasionally in the ancient watchtowers, much as the Chinese soldiers must have done in days gone by.

The Wall then dipped down back into the valley, and connected up to a fortress, which marked the end of the hiking part of our Great Wall adventure! Everyone was footsore and exhausted, and many were carrying minor injuries or niggles, or struggling with stomach upset, but we had done it - 5 days hiking along the Great Wall!



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Trekking the Te Araroa

Congratulations to Gary White on a fantastic achievement trekking the Te Araroa long trail in New Zealand and raising \$11,830 for MND.

Gary writes - "I have always promised myself to do a really long trek when I retire, the time is here so from the 7th December I will start trekking the Te Araroa long trail in New Zealand commencing at Cape Reinga at the top of the north island and then south bound (commonly known as SOBO).



All being well after 5 months and 3000 kms and hopefully my soon to be 66 year old body will arrive at the bottom of the south island at The Bluff.

In doing this trek I hope to raise \$10,000 for motor neurone disease as I lost one of mates that I left England with 38 years ago. Chris Sorrell was diagnosed with this awful disease in his early 50s and put on a brave front until he lost the battle 18 months later.

I will be walking with Chris in spirit as he too was a bushwalker as well as being creative, artistic, intelligent and a fun guy to have around."

Community Calendar

Click the event for more information.

28 Jul **East Hills Charity Car Show**
Kelso Oval, Panania

10 Aug **Saturday Night Italian Cinema**
Event Cinemas, Kotara

26 Oct **Gundaroo Music Festival 2019**
Gundaroo

Do you have a great idea for an event or activity that will raise funds for MND support and research? <http://www.mndnsw.asn.au/get-involved/fundraise.html>

How the My Aged Care System is failing people living with MND

Currently in Australia, we have two discrete systems of support for people with a disability. If you are under 65 years of age when you first seek support, you will be directed to the National Disability Insurance Scheme (NDIS). If you are aged 65 years or over you will find yourself traversing the quagmire that is My Aged Care, known disaffectionately as MAC.

While the NDIS is far from a perfect system, we have been able to work within it to achieve some positive outcomes for our members. On the other hand, our members aged 65 years and older who only have MAC to turn to, receive very little and what they do seem to receive comes too late and with a very expensive price tag.

Here is a quick comparison of the two:

How the My Aged Care System is failing people living with MND

	NDIS	My Aged Care (MAC)
Access	<ul style="list-style-type: none"> - Self-referral system followed by provision of paperwork and evidence. - Can take a few weeks to a few months to get initial planning meeting. - Once the meeting has taken place, the supports are approved fairly quickly and a funding amount provided 	<ul style="list-style-type: none"> - Self-referral followed by 'triage' by MAC call centre - Meeting with MAC representative reasonably quickly to determine needs - Approval letter provided in weeks that follow. - No supports automatically follow
Costs	<ul style="list-style-type: none"> - NDIS is a fully funded scheme - This system is not means tested. 	<ul style="list-style-type: none"> - Participants funding is being eroded by provider administration, brokerage and case management fees - Participants are required to make co payments - Participants are charged additional fees called Income Tested Fees which are determined through assessment of participant assets and income.

FAIL

FAIL

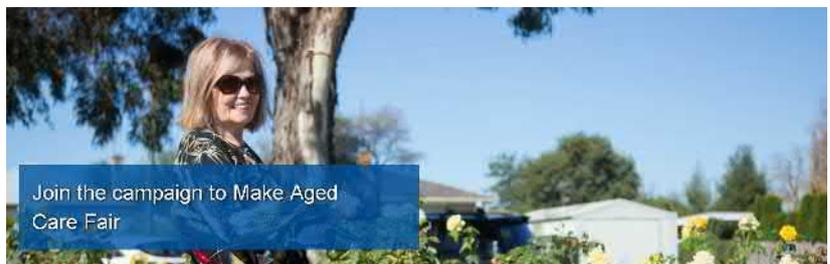
How the My Aged Care System is failing people living with MND (Cont'd)

	NDIS	My Aged Care (MAC)
Supports	<ul style="list-style-type: none"> - Choice and control of what supports are provided and when - Once the plan is approved supports are able to be put in place reasonably quickly. - Still experiencing some wait list delays but much improved over recent times. 	<ul style="list-style-type: none"> - Still locked into what providers are 'comfortable' with providing rather than having the same flexibilities that are offered under NDIS - Approval letter only tells you that you are in a queue for support - Vague time line of when you may actually be able to access support. - Average wait time for high intensity support 18 months - Average wait time for lower intensity support – it varies but generally better - Much harder to use non traditional service providers who have lower admin and hourly rates.

FAIL

Our position is that denying people aged 65 years and older access to appropriate supports and services is not only ageist but is tantamount to elder neglect.

Please don't let our members find themselves being corralled into the residential aged care system just because the My Aged Care system is failing them.



Add your voice by emailing me at karenm@mndnsw.asn.au or join MND Australia's Make Aged Care Fair campaign at <https://www.mndaction.org.au/Make-Aged-Care-Fair>

We need your story to support our advocacy work because 'together we can break down the barriers' for people aged 65 years and over who live with MND.

Do you have an 'ambulance care plan'?

The Ambulance Service of NSW has developed two types of care plans to help ambulance staff to make the best decisions in the event



of an emergency. Ambulance Care Plans authorise paramedics to provide individually tailored treatment based on the directions documented by a patient's medical practitioner. Ambulance care plans can also help you and your family prepare for potentially traumatic events before they occur.

The plan can be initiated by the individual or member of their care-team, however final approval and signing prior to submission to NSW Ambulance is the responsibility of the local family GP or palliative care team. Some palliative care teams will routinely discuss ambulance care plans with their patients and ensure an appropriate plan is completed together, but this is not always the case and you may need to instigate the plan yourself. Once authorised, ambulance care plans are kept by the patient and reviewed annually.

Points to remember

- All ambulance care plans must be completed by a medical practitioner (GP or palliative care nurse/doctor).
- All ambulance care plans must be endorsed by the NSW ambulance service.
- Keep a copy of your endorsed ambulance care plan somewhere easily accessible at home (i.e. document holder on the back of the front door, on the fridge, on a telephone table)
- Any medications that may be needed for symptom management, but are not routinely kept by ambulance staff, will need to be available for the patient in their home.

Ambulance staff do not have copies of ambulance care plans, this must be provided to them on arrival. Keeping several copies of the plan, and other appropriate documentation, in your home is advised.

There are 2 different types of Plans:

- **Authorised General Care Plans**
- **Authorised Palliative Care Plans**

Authorised General Care Plans

For people who have disabilities or have medical conditions requiring specific treatment outside the paramedic's scope of



practice or transport to specific destinations for management of their disease or illness. To view or print a copy of a blank ambulance general care plan see: [NSW AMBULANCE Authorised General Care Plan Adult \(Printable Version\)](#)

Authorised Palliative Care Plans

For people who have a diagnosis of a life-limiting illness and may wish to prescribe treatment for specific symptoms, document resuscitation plans or to guide where they should be admitted if care at home becomes difficult.



Caring for an individual with palliative care needs can be a complex undertaking and an Authorised Palliative Care Plan is an appropriate response for individuals with motor neurone disease. For a patient with palliative care needs, transfer to hospital may be avoidable if the paramedic has access to a Palliative Care Plan which includes the administration of medications and other actions to relieve and manage symptoms in the home. The Palliative Care Plan allows the paramedic responding to a Triple Zero call to respect the palliative care wishes of the patient and to follow the GP's advice.

Once you have completed and endorsed your palliative care plan, if the paramedics are called via Triple Zero they are advised that a patient at that address has an Authorised Palliative Care Plan in place. The finer details within the plan are not visible on their system. The patient/person responsible will be required to provide a copy of the endorsed plan to the paramedics when they arrive. To view or print a copy of a blank ambulance palliative care plan see: [NSW AMBULANCE Authorised Palliative Care Plan Adult \(Printable Version\)](#)

UK FaTHoM meeting 2019 videos now free online

From <https://mndresearch.blog/2019/06/20/fathom-2-uk-leading-mnd-clinicians-on-inherited-mnd/>)

Videos from the 17 April 2019 Families for the Treatment of Hereditary MND (FaTHoM) meeting organised by the University of Oxford are now available free online. Below you can find out more about what was presented on the day and links to the [videos of recorded talks](#).

[Watch Prof Martin Turner: Understanding familial MND](#)

Introducing the rationale of the meeting, Prof Martin Turner set the scene by explaining the great difficulty in understanding the disease due to its many possible causes. Being such long cells, many things can go wrong in the motor neurones and in the vast amount of their support cells. But one factor can help us understand the disease better – genes. Specifically, if we consider the ‘multistep hypothesis’ of MND which assumes that six steps have to happen in our lifetime for the disease to develop, a mistake in a specific gene may reduce the number of the necessary steps to four or even two).



[Watch Prof Anneke Lucassen: Getting genetically tested – what to be aware of?](#)

In order to receive a treatment for suspected MND, a person with a familial link to the disease first needs to know whether they carry the genetic mistake. But getting genetically tested isn't an easy decision to make as it can affect many other family members as well as wellbeing of the person being tested. This is especially true of a disease that is not fully penetrant – that is, when inheriting a faulty gene doesn't guarantee that the person will develop the disease.



A clinical geneticist, Prof Anneke Lucassen of University of Southampton, provided an overview into the ethics of genetic testing and posed questions some people might be thinking, such as ‘Will my unborn grandchildren be affected?’ or ‘Why can't children be genetically tested?’.

(Continued on page 17)

(Continued from page 16)

[Watch Prof Louise Locock: The value of online shared experiences](#)

Although not restricted to inherited MND, support is an important factor when going through any serious health condition.

Prof Louise Locock of University of Aberdeen, a social scientist who is interested in understanding the social experience and context of a disease, introduced us to her work on the healthtalkonline.org project that captures people's experiences living with various conditions, including MND.



[Watch Prof Christopher McDermott: Early genetic trials in MND](#)

Perhaps the most awaited session was on gene therapy, which was led by Prof Christopher McDermott from University of Sheffield.

During the talk, Prof McDermott introduced us to the different stages of clinical trials and what is needed to get a drug from its initial discovery all the way to approval, assuring its safety across the different phases. And although the important question of whether the drug works is monitored throughout, it only becomes the main focus once safety and correct dosage have been established.



[Watch Prof Kevin Talbot: The future of treating genetic MND](#)

In the final talk of the day, Prof Kevin Talbot built on the previous sessions by looking at the future of precision medicine, and some of the hurdles that still need to be overcome. He went on to explain how gene therapy works and how it can be delivered to cross the blood-brain barrier and reviewed the recent successes of gene therapy in Spinal Muscular Atrophy.





Motor Neurone Disease Association of New South Wales

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

Together we can break down the barriers for people living with MND

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...and many valued volunteers