



### **In this edition**

ALS Untangled - more than 50 completed investigations... MND education events in Sydney, Berry, Ballina and the Hunter... Videos from Ask the Experts 2019 now online... Christmas Orders 2019 - support our fundraising efforts... MND Chat and Connect 18 September... Open source gaze control software... Don't miss out on Walk to d'Feet MND 2019... and more.

### **A Message from the CEO**

If you're in Taree on 8 September why not come along to our Walk to d'Feet MND. Details of this Walk and our Forbes and Sydney Walks can be found on page 8. I'll see you there.

Thanks to all those who have responded to our call out on peoples experiences with the My Aged Care (MAC) system. We are working with the Ministers from the NSW Government to help push their Commonwealth counterparts to Make Aged Care Fair. So please keep sharing your experiences with us. I also encourage you to speak with your state or federal member on the MAC issue. If you'd like any information why not email me or phone me.

If you missed Ask the Experts you can catch up on our three great presenters and the questions they answered on our YouTube channel. An overview of the day and details of the videos can be found on page 11.

*Graham Opie*



## Support Service update

While a lot of our work seems to have been around the NDIS and My Aged Care space I thought it would be good to let you know that we are also working closely with groups such as the Consumers Health Forum of Australia (CHF) and Genetic Alliance Australia to more broadly achieve better access to health services as well. To that end, we are now part of a special interest group for regional and remote health consumers through CHF. This group is currently gathering information about the health service challenges people living in rural and remote areas are experiencing. I would be very interested in hearing your stories and sharing them with this group to strengthen the voice of people living with MND in the discussions CHF are having with policy and decision makers. Please email me at [karenm@mndnsw.asn.au](mailto:karenm@mndnsw.asn.au) if you would like to contribute.

We have had a great response to my recent 'call out' to our members about their experiences with the My Aged Care system. We really appreciate your responses and it has been interesting to see the common themes emerging. As expected there are some long waiting times for packages being reported, although some members have secured a package at the level they needed within three to six months of their application. Sadly though, there are still a lot of people waiting for two years or more, so the fight will continue to get this system working the way our members need it to.

A very big thank you to our 'online education' member testers who volunteered their time to help us test our new online education system. With their help we have now been able to iron out some issues and to better understand the information participants need from us so they can access the platform with ease. Our first online Chat and Connect sessions will be held on Wednesday 18 September 2019. For more information see page 4 of this edition of *e-news*.

Don't forget that you can call the MND Information Line 9am-4.30pm Monday to Friday Freecall ph. 1800 777 175 or 02 8877 0999 if you need to ask a question outside our education events. Leave a message if you phone outside these hours and we will call you back.

Until next time.

*Karen Martin | Manager, Support Service*

## ALS Untangled - more than 50 completed investigations

ALS Untangled is an international network of physicians and researchers investigating alternative and off-label treatments for ALS/MND. People with motor neurone disease (known as amyotrophic lateral sclerosis or ALS in some parts of the world) often consider alternative treatments, based on information gleaned from the internet. These can be expensive and some are potentially harmful.

Moreover, the evidence presented for the efficacy and safety of these treatments is often sketchy and frequently inaccurate.

ALS Untangled investigates these alternative treatments. Goals for each investigation are to clarify exactly what is on offer, how much it costs, the scientific and ethical basis of the treatment, and the potential benefits and risks. More than 50 investigations have now been completed. ALS Untangled reports provide timely, accurate and scientifically valid analysis of alternative treatments. They are prepared by clinical scientists who are members of the World Federation of Neurology Research Group on MND or the International ALS Research Group. To view ALS Untangled reports about specific alternative and off-label treatments for ALS/MND see <http://www.alsuntangled.com>. Some of these reviews are now available as podcasts by following the link on the ALS Untangled home page. The ALS Untangled video - 'How to use ALS Untangled' can be viewed on YouTube [https://youtu.be/NKQSa\\_DaBHg](https://youtu.be/NKQSa_DaBHg).



## Living Well with MND Information Day

24 September at Berry

22 October at West Ryde

*Living Well with MND* is an informative day for people living with MND, 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. [Find out more](#).



## Upcoming online Chat and Connect sessions

We have scheduled two online Chat and Connect sessions to be held on Wednesday 18 September 2019. This is an exciting development for us as we look forward to being able to connect with our MND Community right across NSW and ACT through our online platform.



Our team will be online to answer questions and provide information to members, their family and friends. This session will be particularly helpful to people who are newly diagnosed with MND.

If you have internet access via a smart phone, tablet, pc or laptop you will be able to access the session. A microphone and camera can be used but are not essential as you can easily listen along and type responses and questions into the chat box.

To register for this free event email [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au) or contact the MND Info Line ph 1800 777 175 and let us know whether you would like to book in for the morning session which will run between 10am and 11am or the evening session which will run between 5.30pm and 6.30pm. [Find out more here.](#)

## East Hills Charity Car Show

The 5th annual East Hills Charity Car Show was held at Kelso Oval, Panania on Saturday 28 July. The show included a great field of classic cars with all makes and models present from the 1920s through to the 2000s. MND NSW was chosen as this year's charity by the East Hills Charity Car Show 2019 Committee, with \$11,000 donated from the day.



Thank you to the Committee and to everyone who so generously supported this event. Our thanks also to MND NSW volunteers Ben, Cynthia, Rhiannon and Bridget who attended and raised a further \$503 from MND NSW merchandise sales and donations. The Committee said of the day, "The weather was fantastic and it was a great community day for a truly great cause". Pictured above, MND NSW CEO, Graham Opie (at left) with event Committee members.



## Introducing new staff...

Jessica Orman | MND Advisor - Newcastle, Hunter, New England and Mid North Coast

I am excited to be taking on this new challenge in an organisation which provides amazing support for people living with MND. I previously worked for 11 years as a dietitian with NSW Health, so I have a good understanding of the public health system which many of our members are navigating. I grew up in Newcastle, however I have worked in Tamworth, Armidale, Taree, Muswellbrook and all across the Hunter. I am really looking forward to meeting members and their families, either in person or over the phone, to provide any support I can.



## MND Connect - International Ask the Experts 2 December - Perth or live stream

Leading international ALS/MND researchers are providing the MND community with the opportunity to ask questions about the latest research advances at the 2019 MND Connect - International Ask the Experts on 2 December in Perth. If you can't attend, register for the live stream. Speakers include Professor Matthew Kiernan AM - (Australia), Professor Ammar Al Chalabi (UK) and Professor Merit Cudkowicz (USA). The aim of this free session is to connect people living with ALS/MND, their family and friends with leading international researchers. [Find out more.](#)



## Past Carers Lunch

17 September at MND NSW Centre Gladesville

This is a lunch and get together for people who have experienced bereavement during the last year. This occasion provides an opportunity for past carers to reconnect with old friends from MND NSW as well as meet others who have cared for someone with MND. After lunch there will be a talk and discussion about some of the experiences of bereavement and possible ways to manage these. There is no cost to attend the program but you need to reserve your place. [Find out more.](#)



## New listings on [find.mndhub.org.au](http://find.mndhub.org.au)

The online directory at [find.mndhub.org.au](http://find.mndhub.org.au) provides information about services and resources that may be of interest to people living with MND. Recent new and updated listings include the following:

- Boosted is a web and device App that provides a platform for people to connect to services that match their needs.
- Gathered Here an Australia-wide website to compare funeral directors, prices and reviews.

## International ALS/MND meetings in Perth in December 2019

MND Australia, in partnership with MND WA, is proud to host the International ALS/MND meetings in Perth in 2019. This will be an opportunity for the Australian MND community to come together with their peers and leading international researchers from around the world to present and debate key innovations in their respective fields. All meetings will be held at the Perth Convention and Exhibition Centre.



On Sunday 1 December members of the International Alliance of ALS/MND Associations will gather for the AGM and annual meeting. This meeting is an opportunity for ALS/MND support and advocacy organisations from around the world to share best practice and ideas for better supporting people living with ALS/MND in their communities. Observers are welcome to register to attend this meeting.

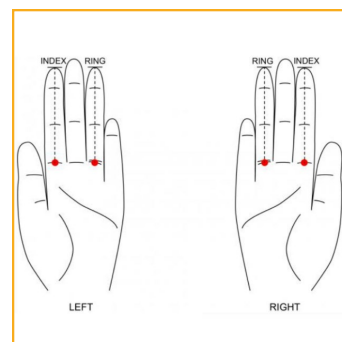
The Allied Professional Forum is a full day meeting on Tuesday 3 December where health and community care professionals from around the world present on evidence based and best practice models of care and support for people living with MND, their family and carers. All are welcome to register to attend.

The 30th International Symposium on ALS/MND will run from Wednesday 4 to Friday 6 December. Concurrent platform and poster sessions will focus on scientific and clinical advances. We expect to see many MNDRIA funded researchers presenting their findings this year. All are welcome to register to attend.

For more information on all these meetings and links to registration pages visit the [MND Australia website](http://MND Australia website).

## ALS Quest - get involved and complete the questionnaire

You are invited to participate in an ongoing research project that is looking for risk factors that might contribute to the development of motor neurone disease (MND). An online anonymous questionnaire asks a series of questions that may provide clues as to what factors trigger MND in some people. Anyone is welcome to complete the questionnaire - people with a sporadic or familial form of MND, their relatives and also people without MND in order to compare lifestyle factors. This questionnaire can be completed regardless of geographical location, so please share with any friends or family who may live overseas who would be happy to contribute.



The questionnaire, designed by Dr Roger Pamphlett at the University of Sydney, and instructions for how to complete it can be found at [www.alsquest.org](http://www.alsquest.org). This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney Local Health District. Please note, if you have previously submitted a response to the ALS Quest questionnaire, there is no need to complete it again. If you have any queries or concerns regarding the survey then you can contact the researchers directly via email [als.quest@sydney.edu.au](mailto:als.quest@sydney.edu.au)

## Free tickets for Careflight's Annual Magic Mania

MND NSW members and their families are invited to attend this year's Careflight Magic Mania extravaganza. This annual event is a fun and family-filled afternoon of music, bright lights, dancing, clowns, magicians, illusionists and acrobats. This is a unique day, primarily aimed at children's enjoyment, with guests attending from a range of organisations that support families through illness, disability and financial hardship.



This is a free show and a great day out for the family at the Quaycentre (formerly the State Sports Centre) in Sydney Olympic Park. Save the date - Saturday 14 December 2019 and, because we anticipate that these free shows will fill quickly, MND NSW members and families can let us know of their interest in attending by emailing [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au) with the number of free tickets you would like, or by contacting the MND Info Line ph 02 8877 0999 or 1800 777 175.

## Together We Can 2019 Walk to d'Feet MND

Register today at [walktodfeet.org.au](http://walktodfeet.org.au) and raise funds when you participate.

Show your support for people living with MND.

It is not too late for you to get involved. Register today at <https://walktodfeet.org.au>. Together We Can.



8  
Sep

**Walk to d'Feet MND Taree**  
Endeavour Place Reserve  
Taree

*Supported by*



20  
Oct

**Walk to d'Feet MND Young**  
Arboretum Park  
Young

*Supported by*



3  
Nov

**Walk to d'Feet MND Sydney**  
Sydney Park  
Alexandria

*Supported by*



## JOIN OUR VOLUNTEER TEAM TODAY

Volunteers are vital to MND NSW. Volunteers allow us to continue to:

- Support our members with information, resources and equipment
- Support our member's family and friends
- Educate carers and health professionals

**As a Registered Volunteer you can:**

- Assist at events
- Provide administration support
- Become an Ambassador, speak at events, raise awareness of MND and MND NSW



For more information  
phone Sarah on 02 8877 0999  
or email [Sarahb@mndnsw.asn.au](mailto:Sarahb@mndnsw.asn.au)



## Sydney Hawks Charity Day

A big thank you to the Sydney Hawks Supporter Group who supported MND NSW for a second year with a Charity Day raising \$1,500. The Camelia Grove Hotel was the location for the event with game day TV viewing, competitions, raffles, an auction, and cupcake and merchandise sales to keep everyone entertained.



Special thanks to Ruth Langdon who coordinated the event. Ruth said of the Charity Day, "We are all so grateful for the opportunity to make a contribution to such a wonderful cause." Ruth and David Langdon visited the MND NSW Centre in Gladesville to present the donation cheque to CEO, Graham Opie.

## Community Calendar

Click the event for more information.

7  
Sep

**Kilimanjaro For Derek**

7  
Sep

**High Tea at Ashdon B&B for MND**  
Arakoon

7  
Sep

**Spring Has Sprung Musical Showcase**  
Mount Colah

8  
Sep

**Market Town Show & Shine**  
Wetherill Park

26  
Oct

**Gundaroo Music Festival 2019**  
Gundaroo

27  
Oct

**Colour Me for MND**  
Coniston Public School, Coniston

*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>

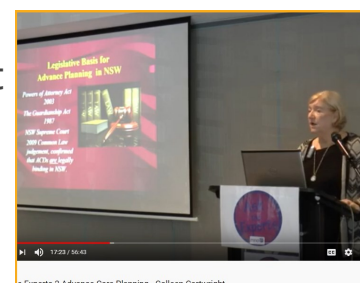
## Wrapping up Ask the Experts 2019

Our Ask the Experts Forum in August was a great success, with an impressive line-up of three experts in their fields.

Associate Professor Roger Pamphlett of the Brain and Mind Centre has spent thirty years dedicated to MND research. He provided a most interesting overview of MND. Roger also spoke about the results to date from the ALS Quest research exploring genetics, epigenetics, lifestyle and environmental triggers, toxins, life events and aging.



Professor Colleen Cartwright is Emeritus Professor and Chair of the Human Research Ethics Committee of Southern Cross University and Principal Director of Cartwright Consulting Australia. Colleen provided an engaging and thought-provoking talk about the ways that a person can maintain control and peace of mind about their future health care by completing an Advanced Care Directive. We learnt about the practical and legal benefits of appointing substitute decision makers to make future financial, personal, medical or lifestyle decisions on behalf of another who has lost capacity to do this for themselves.



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. As a trained developmental biologist, Megan's talk drew upon her scientific expertise along with her deep understanding of the ethical and regulatory considerations required to facilitate responsible research in stem cell science. She spoke about the importance of clinical trials and maintaining hope, whilst also challenging the hype of social media marketing of unproven and often risky therapies. It was encouraging to learn that Australia is a leader in stem cell research.



*(Continued on page 11)*

*(Continued from page 10)*

Those who were able to attend the event provided very positive feedback including, "All three presenters provided excellent, new and thought-provoking messages", "Each time I leave an MND event I feel as though I have won the lucky door prize, as I leave with the gift of knowledge and reassurance!", "A warm welcoming feel to the whole forum. MND staff are fabulous!" and "I shall be completing my Advanced Care Directive".

You can view videos of the event at the [MND NSW YouTube channel on the 2019 Ask the Experts playlist](#).

## Ballina

We are off to Ballina in November. For more information on the events listed below and to RSVP contact [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au) or ph. 8877 0999 or Freecall 1800 777 175. Please let us know if you have any special mobility or dietary needs.

There is no charge for you to attend but you will need to reserve your place.

### MND Hope and Remembrance - Ballina 12pm-3pm, 11 November

We welcome you, your family and friends to join us in a gathering to honour and celebrate those who have lost their lives to MND. Following a brief ceremony there will be a light luncheon and opportunity to chat and connect with others. [Find out more.](#)

### Information Evening for people diagnosed with MND - Ballina 6pm-8pm, 11 November

If you or someone close to you has been diagnosed with MND, this evening will provide an opportunity to have some of your questions answered in an informal setting. You will also be able to meet others who also understand the impact of living with MND. [Find out more.](#)



### MND Carers Morning Tea - Ballina 10.30am-12.30pm, 12 November

Are you caring for someone who has MND? Join us for a complimentary morning tea which offers an opportunity for you to meet others caring for someone with MND. [Find out more.](#)



## Link and Learn

7-8 November in the Hunter Valley

Are you a family member, relative or friend caring for someone with MND? If you are keen to gain some extra information and support, this program may be ideal for you. It is suitable for those new to the caring role and also those who have been caring for some time.



The program, called 'Link and Learn', is residential and runs over two days and a night in the beautiful Hunter Valley on Thursday 7 and Friday 8 November 2019.

You will have the opportunity to hear from a range of health professionals and MND NSW staff with expertise in MND, who will answer your questions and facilitate discussion in a relaxed and informal setting.

The aim of 'Link and Learn' is to support you to give the best possible care at home for the person with MND by:

- reducing the sense of isolation associated with becoming a carer through meeting other carers and sharing ideas and experiences
- providing you with information so that you can be prepared and able to plan ahead for the changes that may occur. This will help you, and the person you are caring for, to maintain a sense of control over these changes
- letting you know how to find support services and how to care for yourself so that you can carry on caring.

Those who have attended this program previously tell us that they especially valued the opportunity to take time out for themselves and to share their ideas and experiences with others in similar situations. As one person said, "this program is a very valuable insight for anyone in a carers role with plenty of learning, laughter and knowledge gained".

Participation in the program, including meals and accommodation, is free of charge for people caring for someone with MND, but we do ask that you commit to attending the two days. If you have any questions, would like to RSVP or need support in arranging care for your family member while you are attending contact the MND Info Line ph 1800 777 175, speak to your MND Advisor or email [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au) by 31 October 2019.



## Upcoming Support Service Events

Click the event for more information or contact [reg@mndnsw.asn.au](mailto:reg@mndnsw.asn.au) or the MND Info Line ph. 8877 0999 or Freecall 1800 777 175.

**17 Sep** **Past carers lunch**  
Gladesville

**18 Sep** **MND Chat and Connect**  
Online

**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

**11 Nov** **Information Evening for people diagnosed with MND**  
Ballina

**11 Nov** **MND Hope and Remembrance**  
Ballina

**12 Nov** **MND Carers Morning Tea**  
Ballina

**2 Dec** **International Ask the Experts - ALS/MND Connect 2019**  
Perth (in person or live stream)

## Dying to Know Day

Dying to Know Day (D2KDay) is an annual day of action dedicated to bringing to life conversations and community actions around death, dying and bereavement. D2KDay was launched in 2013, by the Groundswell Project and has been embraced across NSW. In 2019, Dying to Know Day was on 8 August.



The Northern Beaches Hospital, in partnership with the Sydney North Primary Health Network and HammondCare hosted an Advance Care Planning (ACP) forum to mark D2KDay this year. Our Education and Carer support coordinators were invited to attend and set up an information table about MND NSW with fact sheets, booklets and a few puppies in tow. It was a full house with over 150 attendees.

Dr Peter Saul, Senior Specialist in Intensive Care at John Hunter Hospital spoke about how advance care directives have not only legal authority, but also provide a framework for discussion and a way of documenting preferences when substitute decision makers may be unsure or disagree. GP Stephen Ginsborg spoke of his work in Compassionate Communities, an international movement that aims to build community capacity to support people approaching the end of their lives. Colleen Carter, from the NSW Ambulance service who shared the [NSW Ambulance Authorised Adult Palliative Care Plan \(APCP\)](#) that enables paramedics to provide individualised care to a patient with life limiting illness.

*Kristina Dodds and Kate Maguire | Education and Carer Support Coordinators*

## Open source gaze control software

Academics and students at Otago Polytechnic in New Zealand have been working on their open source Windows Gaze Control project for the past three years and report the GazeToolbar has now reached sufficient maturity to be used by real users. The GazeToolbar allows users to control a computer hands-free using only their gaze, together with a low-cost eyetracker. [Find out more here.](#)



## Motor Neurone Disease Association of NSW

Christmas Orders 2019 - Support our fundraising efforts - stocks are limited.

**Click the item to view online and place your order**



### Presents

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



Australian Baubles  
"Wishing you all the Best for the New Year"



### Decorative Star

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



### Peace, Joy and Happiness

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



### Aussie Animals and Santa

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



Christmas Pudding  
1kg Pudding Made by Pudding Lane



### Keyring Torch



### Shopping Bag



### Socks

Ladies - Purple  
Mens - Navy

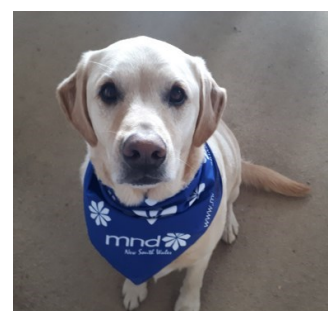


### Photo Frame

Brushed Aluminium.  
Engraved with MND NSW logo  
205mmH x 153mmW  
(to suit 4"x 6" photo)



Plush Puppies  
Black & White, Tan & White, Cream, Black



### Dog Bandana



# Motor Neurone Disease Association of New South Wales

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(Locked Bag 5005, Gladesville NSW 1675)

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[admin@mndnsw.asn.au](mailto:admin@mndnsw.asn.au) <http://www.mndnsw.asn.au>

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

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

**VICE PATRONS** Melinda Gainsford Taylor, Kevin Langdon OAM, The Hon. Mr. Justice Peter W. Young OA

**AUDITOR** Walker Wayland NSW

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**Administration and Finance Manager** Brenda Smith

**Accountant** David Radford

**Receptionist** Arja Aladjadjian

**Administrative Assistant** Freya Herschel

**And  
many  
valued  
volunteers**