



In this edition

Winter warmer package... Making an Advance Care Directive... Thanks to our community fundraisers... Are you an adult sibling of someone with a disability?... Research update... Walk to d'Feet MND... and more

A Message from the CEO

MND Global Day, held on 21 June every year, is a day of recognition of ALS/MND. Raising awareness about MND is important because it reminds others about the needs of people currently living with the disease.

On Global Day 2017, the Prime Minister Malcolm Turnbull and the Australian Parliament showed their support of people with MND by wearing blue cornflowers. Also in June, Bob Montgomery completed his mammoth 4500km ride from Darwin to Perth, his third long distance ride in five years, raising awareness and funds for MND NSW. The same month, our Walk to d'Feet MND was held in Canberra with a record crowd rugged up for the event.

In this edition of *e-news* we include Richard Sleeman's story that shows, with determination and support, barriers can be hurdled and life can be lived, even with MND. Richard is pictured above 'taking tea in Calgary'. Let his story inspire you to raise awareness about MND and/or take on a challenge as small or big as you desire.

Graham Opie



Winter Warmer Package

Our Winter Warmer Package includes a MND beanie, a large MND travel mug and either MND ladies or mens socks.

- Ladies socks are purple for sizes 2-8.
- Mens socks are navy for sizes 7-11

Travel mug has a lid with seal plug, 450ml size and is BPA free. \$25 + shipping at <http://www.online.mndnsw.asn.au>



Run MND

A big thank you to Sophy Townsend who, for the second year, has organised Run MND in support of individuals and families living with MND, and for research.



A group of 86 runners and walkers took part following the Sutherland 2 Surf route ending at Dunningham Park in Cronulla. The event raised \$10,000 to support families with much needed equipment and services, as well as \$10,000 for research. Thank you to everyone who participated and donated to this wonderful event!

Riddla Golf Day

Congratulations to the wonderful Ann Ridd who organised another great Riddla Golf Day at the lovely Twin Creeks Golf Course at Luddenham. This was the sixth year for this event and it continues to get bigger and better every year.



Darwin2Perth4MND&HD

Congratulations to Bob Montgomery on another amazing ride. In June, Bob completed a mammoth ride from Darwin to Perth raising over \$44,000 for MND and Huntington's disease.

At 73 years of age Bob is such an inspiring supporter. This is Bob's third epic ride for MND and what a challenging ride it was for Bob and his team.

Bob is pictured right (top) on Day 32 and at the finish of the ride on Day 38 at The Niche in the grounds of QE11 Hospital in Perth. Catch up with Bob's day-to-day posts from the ride on our Facebook page <http://fb.me/mndnsw>.



New *Making an Advance Care Directive* information booklet

NSW Health has released a new information booklet to help people understand and complete an Advance Care Directive in NSW. The booklet outlines some key questions that people face when discussing Advance Care Directives, including:

- what is an Advance Care Directive?
- why an Advance Care Directive is important?
- how to prepare for making an Advance Care Directive
- how to make an Advance Care Directive
- when it applies and when is it valid.



In this package you will find an Advance Care Directive form to complete and an information booklet to help you complete your Advance Care Directive. More information here <http://www.health.nsw.gov.au/patients/acp/Pages/acd-form-info-book.aspx>



Walk to d'Feet MND Canberra ...

25 June, Patrick White Lawns, Parkes, ACT



What a wonderful roll up we had in Canberra for our Walk to d'Feet MND. Over 450 people turned out on a chilly but sunny Canberra morning to show their support for people living with MND. This year we were able to do the Walk around Lake Burley Griffin and what a great atmosphere we had as families and friends headed off around the Lake. It's always a stunning sight watching that 'sea of blue with a purpose' as the walkers head off. It was great to see WIN TV there helping us to get our important message out.



A big thank you to Nigel Ah Wong from the ACT Brumbies. Nigel not only participated, but also helped promote the Walk in the lead up to the day.



Thank you to everyone who created an Everyday Hero page - with over \$26,000 raised. Thank you also to the ladies from Black Magic Coffee for your support and wonderful coffee.



You can view more pictures from the day on the MND NSW Facebook page. <http://fb.me/mndnsw>

We are off to Bateman's Bay next. Don't miss this lovely Walk on the South Coast.

Save the date

Get involved. Join us at a 2017 Walk to d'Feet MND in Batemans Bay, Port Macquarie, Wagga Wagga or Sydney Olympic Park at Homebush.

The name of this event reflects the hope and inspiration these special days provide for the MND Community. 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 MND. You can create your own online fundraising page to raise funds in an individual name or a team name.

20
Aug

Walk to d'Feet MND Batemans Bay

Corrigans Beach Reserve

Register now

17
Sep

Walk to d'Feet MND Port Macquarie

Westport Park

Register now

Supported by



15
Oct

Walk to d'Feet MND Wagga Wagga

Apex Park

Register now

Supported by



5
Nov

Walk to d'Feet MND Sydney

Blaxland Riverside Park, Olympic Park, Homebush

Register now

Supported by



For more information see <http://www.mndnsw.asn.au/get-involved/walk-to-dfeet-mnd.html>.

Can you help? We are looking for some volunteers to help out at the Port Macquarie Walk to d'Feet MND on Sunday 17 September. Please contact our Fundraising Manager Kym Nielsen email kymn@mndnsw.asn.au if you can assist.

Introducing our new staff...

Jasminka Gojkovic | Coordinator of Support - South Western Sydney

I am very excited to be working at MND NSW and feel privileged as this role will allow me to be a part of the life of members and their families. I bring to MND NSW over 20 years of experience working in the disability and aged sectors across a number of programs, as well as my passion for improving quality of life of people with disability and their carers. I am looking forward to meeting the members of MND NSW and to contributing to the MND NSW community by being a compassionate advocate for our members and their families.



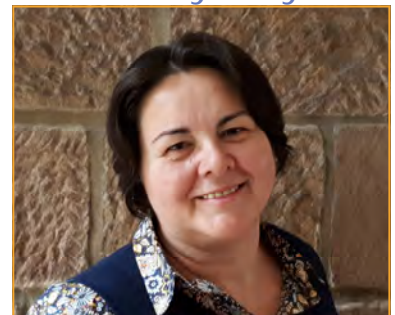
Michelle Malouf | MND Advisor

I am delighted to form part of the dedicated and passionate team at MND NSW as an MND Advisor. I have worked in disability and community services, the Deaf community and communication sector for the past decade and I'm enjoying working and visiting people living with MND once again. Being from the UK and marrying an Aussie we have two boys which creates considerable sporting rivalry in our house, which I'm always happy to contribute to!



Sonja Mitrikeska | Coordinator of Support - South Eastern Sydney

For the past seven years I have worked in the disability sector and my background is in counselling. I love the location of MND NSW Gladesville Centre on the banks of Parramatta River and appreciate the friendliness of staff members and management. I am really looking forward to assisting members with their NDIS supports coordination.



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Samantha Potter | Coordinator of Support - Illawarra

I've lived in the Illawarra my whole life and wouldn't want to live anywhere else, it is such a beautiful place. I am mum to three beautiful children and have worked in the disability sector for over ten years. My experience is varied and includes complex case management and support service coordination. I love being busy and getting involved, and I am passionate about helping and empowering other people. I am proud to be working for an organisation with values in line with my own and I look forward to meeting and working with our members.



High Tea for MND

A big thank you to Quakers Hill Veterinary Hospital who have held their second High Tea in support of MND.



Here is what they said about the day, "We are thrilled to announce that our High Tea for MND has raised just over \$5000! Thank you to all of our lovely clients for your continued support especially over the last few months. This cause is very close to all of our hearts. Your kindness and generosity means the world to us. We hope those that could make it enjoyed the homemade sweet treats and drinks. It's safe to say our vets and nurses are clever in the kitchen. Thanks again everyone."

Inspired Adventures, Adventurer of the Month - Sheena

Sheena Kearsey was named Adventurer of the Month by Inspired Adventures in May for her participation in the Trek Together for MND 2017 in Peru. Well done Sheena!



Are you an adult sibling of someone with a disability?

Carers NSW invites you to complete a short online survey on your experience of being the sibling of a person with a disability, including your knowledge of existing supports, identifying any supports or information you would like to access, and what you would like service providers to know about your sibling experience. Click here <https://www.surveymonkey.com/r/adultsiblingssurvey> to access the survey or if you have any questions, contact Lorraine Villaret, Carers NSW Project Officer on lorrainev@carersnsw.org.au

Contenance seminar for people with neurological conditions in the ACT

If you're living with a neurological condition and are experiencing bladder problems, you're not alone – these issues are common among people living with conditions such as multiple sclerosis, Parkinson's disease, MND and muscular dystrophy. MS are hosting this workshop on 21 July in the ACT which will be presented by urologist Prof Richard Millard, physiotherapist Irmina Nahon and MS continence nurse Katherine Smith. For more information see <http://www.mndnsw.asn.au/all-events/events-other-organisations/314-neurological-contenance-seminar.html> or contact MS Connect ph. 1800 042 138 or email education@ms.org.au

MND NSW Puppies in Singapore

A huge thank you to Charlotte for her wonderful fundraising in memory of her Poppy. Charlotte attends the Australian International School in Singapore and contacted us to say she wanted to raise funds for MND NSW. Charlotte, with a little help from her friends, conducted a very successful puppy sale and also received donations raising \$1,065. What a fantastic effort! A big thank you also to the AIS Singapore for allowing Charlotte to have this sale at school.



Upcoming Support Service events

Click to find out more.

25
Jul

MND Aware

for health and community care professionals
Wagga Wagga

15
Aug

Information Evening for people recently diagnosed with MND

Gladesville

24
Aug

MND Special Interest Group (SIG) Workshop

for clinicians, allied health and community care professionals
West Ryde

12
Sep

Living Well with MND

West Ryde

18
Sep

Past Carers Lunch

Gladesville

10
Oct

Information Evening for people recently diagnosed with MND

Gladesville

17
Oct

Living Well with MND

Wollongong

2
Nov

Link and Learn

A residential educational workshop held over two days and one night for carers
Cowra

11
Nov

MND Connect 2017

Community, researchers and clinicians in an interactive forum to discuss MND research.
University of Sydney

5
Dec

Information Evening for people recently diagnosed with MND

Gladesville

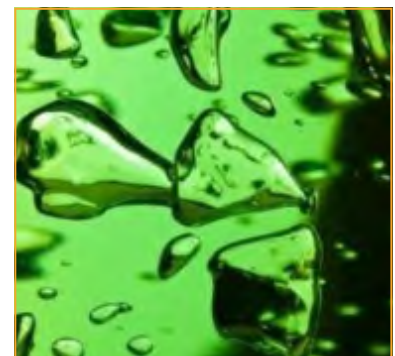
Advance June 2017

Advance is the newsletter of the MND Research Institute of Australia - the research arm of MND Australia. Click the link below to read the June 2017 edition. <http://www.mndnsw.asn.au/blog/204-june-2017/1079-advance-june-2017.html>



MND Australia Research Update June 2017

This research update is produced by the MND Research Institute of Australia - the research arm of MND Australia. Read the latest MND research news. <http://www.mndnsw.asn.au/blog/204-june-2017/1078-mnd-australia-research-update-june-2017.html>



Applications now open for MND Research Grants for 2018

Applications are now open for the MND Research Institute of Australia 2017 funding round for new research grants commencing in 2018, closing 6 pm 25 August 2017. Funding decisions are made by the MNDRIA Research Committee on 9 November 2017. A list of all grants available and detailed application guidelines are available online <http://www.mndresearch.org.au/>.



Crestwood Public School - MND Fundraiser

Students and teachers at Crestwood Public School held a great fundraising day for MND NSW with the whole school enjoying a walk around Crestwood Reserve in a sea of blue! Thank you to the school community for their generosity having raised \$1,087 from the day.



Upcoming community fundraising events

Click to find out more.

29
Jul

Binalong Brahmans RLFC Charity Day
Binalong Recreation Oval, Binalong



12
Aug

The Cavalcade of History and Fashion
Albert Hall, Canberra

19
Aug

Giving For Life Trivia Night for Charity
Panthers, North Richmond



23
Sep

10th Annual Spring Art for Charity
City Walk, Canberra



23
Sep

Navratri Garba 2017
Bernie Millane Sports Complex, Kellyville

7
Oct

MND Awareness Trivia Night
Cooma Ex-Services Club, Cooma

14
Oct

Gundaroo Music Festival
Gundaroo Park



12
Nov

The Illawarra Chilli, Spice and All Things Nice Festival
Jamberoo Resort, Jamberoo



17
Nov

Maria's Open Garden
Wanniassa, ACT

25
Nov

Craft Market Greystanes
Greystanes

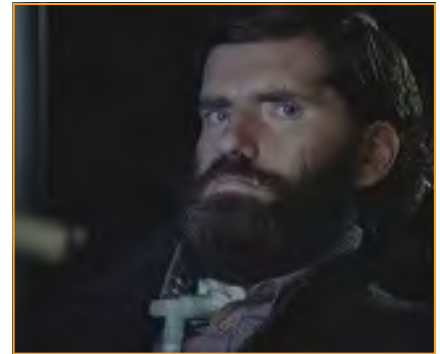


BINGO with BALLS - 7.30pm every Tuesday night at STONEWALL
175 Oxford Street, Darlinghurst. Charity donation to MND NSW.

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

Sydney Film Festival - It's Not Yet Dark

This year's Sydney Film Festival featured the wonderful film, *It's Not Yet Dark*. This passionate story, narrated by Colin Farrell, is of a young Irish filmmaker Simon Fitzmaurice who is diagnosed with motor neurone disease (ALS) but fiercely determined to continue his career. Simon also directed the Screenability film *My Name is Emily*. More info at <https://www.facebook.com/ItsNotYetDark/>



MND NSW Education and Carer Support Programs

Despite the winter solstice and the cold weather people still flocked to the education sessions held by MND NSW over June.

Nineteen family carers of people living with MND attended our *Care for Carers* program that ran over four Tuesdays in June at Gladesville. This program provides carers with information and tools to increase confidence in caring for a family member or friend with MND at home. Six guest speakers, all experts in their field, gave freely of their time to speak and answer questions about respiratory care, physical management of MND, preparing your home, maintaining communication, swallowing, nutrition, the emotional aspects of caring and more. Our participants said:

"The talks were so informative and relevant to my own situation."

"I am enjoying these sessions very much as I find meeting other carers who are going through much the same as I am."

"Attending each week has provided a routine when nothing else in life is. Many thanks to you all."

Care for Carers is held each year in Sydney. *Link and Learn* is also an MND NSW program for carers but it is held in a regional location each year. This year *Link and Learn* is being held in Cowra on 2 and 3 November.

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On 8 June, 25 allied health professionals braved the cold temperatures and attended our *Supporting NDIS participants living with MND* session held in Springwood. I am always amazed at how many allied health professionals are truly interested in MND and want to find out how they can more effectively work within a multidisciplinary framework.



Henry and Adele Pozywio (top), and Kathy Leech and Angie Gibson (below) at Living Well with MND Newcastle on 21 June

On 21 June, 43 people living with MND, their family and friends attended our *Living Well with MND* day in Newcastle. Thank you to our speakers - Dr David Williams, Sarah Bell, Susan Harrison, Alicia Harris, Nick Yates, Lynette Campbell and Dr Nina Vogel. Eileen O'Loughlen, MND Advisor, also presented and facilitated the day.



Our next *Living Well with MND* day will be held at West Ryde on 12 September and then in Wollongong on 17 October.

Kristina Dodds - Education and Carer Support Program Coordinator

MND support groups and coffee mornings

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. Often, a guest speaker is invited to the meeting. Guest speakers include health workers who know about motor neurone disease or a person with expertise in a topic that may be of interest to the members of the group.

Support groups and coffee mornings are located in city, regional and rural areas of NSW, in the ACT and on the Gold Coast Queensland.

CANADIAN ROCKIES

By Richard Sleeman*

It seemed an impossible dream.

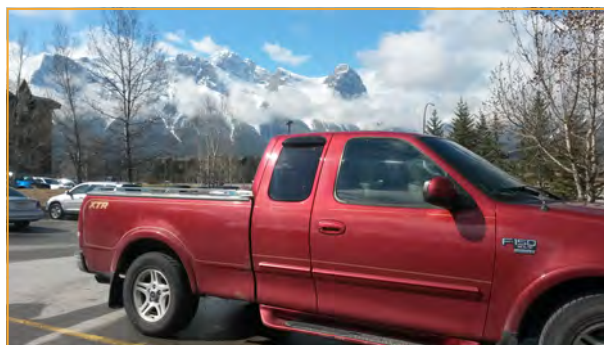
Three years after being diagnosed with MND, wheelchair bound and well into my 60s, I saw a TV ad one evening showing spectacular views of the Canadian Rocky Mountains.

I'm going, I declared, to no-one there. The next day I ran the dumb notion past a few more sensible people than me and the answer was almost invariably the same. It can't be done.

How would I survive a 15-hour flight from Sydney to Vancouver, a layover of some hours and then another flight to Calgary without being able to get up from an economy seat or airport wheelchair? That's some 24 hours on my bum. On my own!

And even if I did arrive in one piece, I had no wheelchair there, no walking frame, no bathroom or bedroom aids. My dear friend Travis had an apartment in Calgary but with a shower over a bath and

nowhere to sit or sleep I could safely get up from. And how was I to get around? It was a year or more since I'd been in a vehicle other than a wheelchair taxi. If we were to drive through the snow and mountains for days, I'd need to get up and down from Travis' big red truck.



Travis' truck

I'm a stubborn bugger though. I knew the negatives. I went looking for positives. Nurse Margie at Sydney's Forefront clinic in Camperdown was adamant. "Go, and go now", she said.

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**Richard Sleeman is a journalist, author and broadcaster based in Sydney. He was diagnosed with MND in 2014.*

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I bought a return ticket the next day. Committed now – no refund on the ticket. I took a calculated risk and travelled uninsured. Calls to a number of agents proved additional travel insurance for me to be either unavailable or cost prohibitive, so I set about making it safely possible.

Madeleine Bowman from MND NSW was at my doorstep the next day, God bless her, having tracked down a contact, Jeremy, responsible for equipment loan at ALS Alberta, in Calgary. Fill out the paperwork, Jeremy said, and of course it can be done.

We requested a manual wheelchair, a four wheel walker, a bed pole, a toilet surround, and raised toilet seat, a bath bench and a shower chair. Even, and this was a bit cheeky, a recliner lift lounge chair. No problem, said Jeremy, we'll deliver all that to your Calgary address the day before you arrive and pick it up the day after you leave. How much will it cost, I asked? Not a dime, he said. You only need ask and fill out the form and have it verified by MND NSW. And deliver all that they did.

So at least I could live comfortably and safely in Canada. I just had to get there. Nurse Margie devised a wee system for the plane, a bag strapped to my leg and an exterior catheter. Seemed like a good idea at the time. It wasn't. There just isn't enough leg room. I ditched it before boarding and used a spill proof container and a towel more or less discreetly placed over my lap. No one was any the wiser. I don't think.

For those who, like me, have never flown immobile, the procedure is surprisingly safe and simple. Change from your wheelchair to theirs at check in, a staffer pushes you round to the boarding gate, transfer to a much smaller aisle chair at the aircraft door, and shift or be shoved onto the aircraft seat. There are burly staffers to assist in safe transfers. A transfer belt helps them get a grip. I wore one at all times

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while getting on and off flights. Getting on, you are first in. Getting off, the last out. On the advice of an occupational therapist, I took the Roho cushion from my wheelchair onto the plane with me and put it on the aircraft seat. That's one secret for a pain free and pressure free long haul. The other is to drink and eat lightly. And above all, shift about in the seat and move arms and legs as much and as often as physical and space limitations allow. Keep moving.

Handicapped facilities in Canada are an eye opener. Every building, every store, every restaurant, has a separate push button wheelchair entrance. Taking the train in and around Calgary was as simple as pushing a button on the outside of the carriage, waiting for a ramp to descend and watching it retract



Taking tea in Calgary

once you were inside. Reverse the process on exit. Footpaths and public parks were a dream to negotiate. We have so much to learn. In my inner west suburb in Sydney, the footpaths are often cracked and unmanageable, my local public park devoid of wheelchair toilets, and about one in every four or five shops and restaurants accessible.

Life on the road in Alberta, Canada, even in bitter cold and heavy snow, wasn't difficult. The road through the Rockies from Banff to Jasper is said by *National Geographic* to be the most spectacular on the planet. Hard to argue. Around every bend, a view even more jaw-droppingly stunning than the last. Six hours of sheer driving bliss.

I was lucky to have my friend Travis manhandle me in and out of his truck. At times, it was more an exercise in ballistics – whether I'd shoot out the open window on the other side. Not terribly dignified but who cares. We phoned ahead to book accommodation with wheelchair friendly rooms. Lots of availability though it wasn't the high season.

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The sights of Banff and Canmore and Lake Louise and even some of the remote forest and lakeside tracks were readily accessible. So too, the amazing dinosaur museum in Drumheller. Some icy or snowbound paths provided a problem at times but there's always a way around. And when you can sit by an isolated mountain lake, surrounded by snow-capped peaks and having seen deer and moose and caribou and mountain goats and squirrels and snow bunnies along the way, any hard road is worth it.

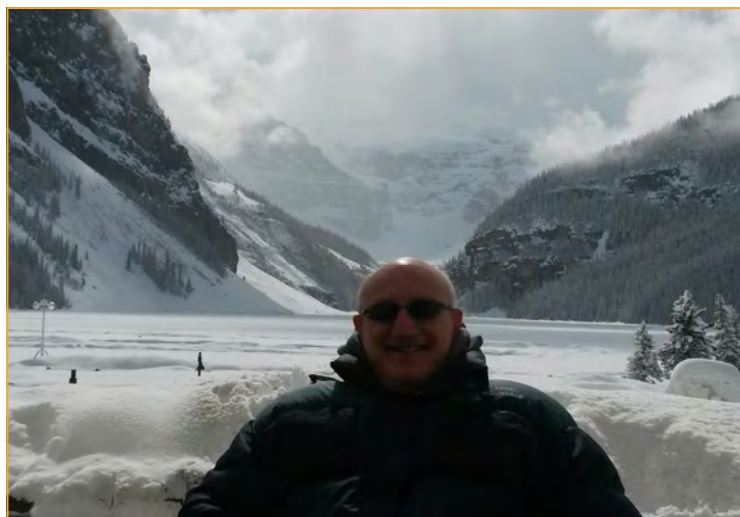
Back home now, and I feel empowered as I battle this rotten, evil condition. What a fabulous trip! If the thought crosses your mind, that you might want to travel, I would say without hesitation, do it. Prepare well. And go. I hope you might be inspired to do so. Let me know if and where you go.

Richard

rsleeman6@gmail.com



Fishing for trout in the Bow River at Canmore



The author at Lake Louise



Motor Neurone Disease Association of New South Wales

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...and many valued
volunteers