



### **In this edition**

Trek Together for MND 2017 update... NDIS roll-out to more areas of NSW... Wrapping up MND Week 2017... the drug Radicava (edaravone) approved to treat ALS/MND in the USA... Walk to d'Feet MND... and more

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

At the beginning of MND Week in May the drug Radicava (edaravone), shown to slow MND progression in some people, was approved to treat ALS/MND in the USA. Read about what this means for people with MND in Australia on pages 2 and 17-19 in this edition of *e-news*.

The MND NSW supporters who trekked the Inca Trail are back safe and sound. You can read about their adventures and funds raised on page 20. We also have included in this edition an update on the NDIS. From 1 July the Scheme commences for people aged under 65 years in Northern NSW, Mid North Coast, Sydney, South Eastern Sydney, Illawarra Shoalhaven, Murrumbidgee, Western NSW and Far West NSW.

Thank you for your support of our recent Walks to d'Feet MND at Forbes and Tweed Heads. On 25 June we will be holding Walk to d'Feet MND Canberra and we are pleased to announce the inaugural Walk to d'Feet MND Batemans Bay to be held on Sunday 20 August at the lovely Corrigan's Beach Reserve. See inside this *e-news* edition for more details.

*Graham Opie*

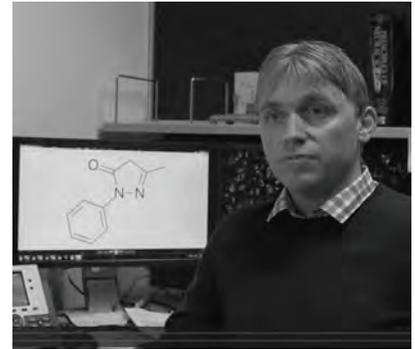


## The drug Radicava (edaravone) approved for ALS/MND in the USA

In May 2017, the U.S. Food and Drug Administration (FDA) approved the drug Radicava (edaravone) to treat ALS/MND in the USA. Shown to slow progression in some people, it is the first drug to be approved for ALS in over 20 years (it is anticipated Radicava will be available in the USA by August 2017). In 2015, edaravone was approved for use as an ALS treatment in Japan (as Radicut) and South Korea. Radicava is administered through an intravenous infusion and not yet approved for use in Australia under our country's regulatory approval process for drugs.

### [Interview with Dr Brad Turner about edaravone](#)

You can [view the recording](#) of MND Victoria CEO, Rod Harris, speaking with Dr Brad Turner, The Florey Institute of Neuroscience and Mental Health Victoria, about the US announcement of edaravone as a treatment for ALS and what this means for Australians. Great questions and informative answers.



### [MND Australia Fact Sheet about edaravone](#)

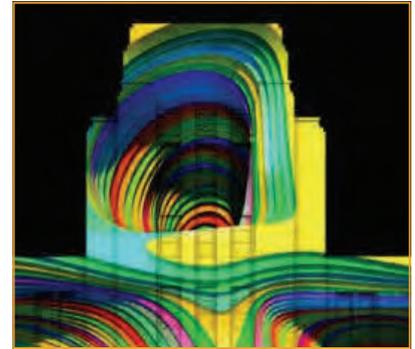
MND Australia has prepared a fact sheet to explain what this approval means for people living with MND in Australia reproduced on pages 17 to 19 in this edition of *e-news*.

## Science in the Cinema 2 June 2017

The Australian Society for Medical Research is presenting The incredible life of Stephen Hawking: The Theory of Everything on Friday 2 June, during Medical Research Week 1–9 June 2017, at Science in the Cinema, Palace Cinemas, Leichhardt. Tickets \$15+booking fee. This year's event is not only an insight into the great mind of Professor Hawking, but also an opportunity to raise awareness of the impact of this devastating disease on the 2,000 Australians currently living with MND. Professor Matthew Kiernan from the University of Sydney will talk about MND followed by a short Q&A session. More information [here](#).

## Wheelchair accessible Vivid Sydney light installations 2017

Over 23 nights between 26 May to 17 June, Vivid Light illuminates Sydney and precincts with mesmerising colour. More than 65 lighting installations will transform the city from 6pm to 11pm each night. [View the list all light installations that are wheelchair accessible.](#)



## A Fantastic Night of Trivia

A Trivia Night was held on Cornflower Blue Day during MND Week in Canberra. Fiona Heathcote who organised the event said of the night, "The 2017 HPRG Social Club Trivia Night saw an exciting night of facts, fundraising and frivolity at the 'Heroes and Villains' themed event held on Friday 12 May. A total of \$2,618 was raised for MND NSW. Congratulations go to the graduate team of 'We Are Groot' who came away with the coveted golden microscope after some fierce trivia competition. A huge thank you goes out to everyone who attended and gave so generously, as well as the Social Club and others who volunteered their time and efforts to make the night such an outstanding success." A big thank you to Fiona and everyone who attended for their support.



## March MNDay

Thank you to Peter Glattback from Taffy's coffee shop in Woolgoolga for raising \$500 in support of MND NSW during March. Peter donated \$1 from every coffee sold on each Monday during March. A raffle was also held to raise funds. A big thank you to everyone who donated prizes, made a donation, and bought raffle tickets and coffee!





### Walk to d'Feet MND Forbes ...

30 April, Lions Park



The lovely people of Forbes always make us feel welcome and Walk to d'Feet MND Forbes 2017 was no exception. Thank you to everyone who supported our Walk in Forbes.



Thanks also to the Lions Club for the yummy sausages, Duncan Stockcrates for their ongoing support and, of course, to local Walk Coordinator, Pat Duncan, and her family, who once again organised a great Walk.



### Walk to d'Feet MND Tweed Heads ...

21 May, Chris Cunningham Park



What a gorgeous day Tweed Heads turned on for us for our Walk to d'Feet MND. It had been three years since our last Walk to d'Feet MND in Tweed Heads and people travelled far and wide to attend. Our Walks have a great atmosphere of camaraderie and support and this was certainly evident on the day.



A big thank you to our local Walk Coordinator, Kim Gussy, and her very talented son, Joss, who kept the crowd entertained before and after the Walk with some great acoustic guitar. Thanks



also to our local sponsors Get Hooked and Kate Nutt Photography.

**KATE NUTT**  
p h o t o g r a p h y

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

## Save the date

It is not too late to join us at a 2017 Walk to d'Feet MND in Canberra, 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.

25  
June

### Walk to d'Feet MND Canberra

Patrick White Lawns  
Parkes, ACT

Register now

20  
Aug

### Walk to d'Feet MND Batemans Bay

Corrigans Beach Reserve  
Batemans Bay

Register now

17  
Sep

### Walk to d'Feet MND Port Macquarie

Westport Park, Port Macquarie *Supported by*



22  
Oct

### Walk to d'Feet MND Wagga Wagga

Apex Park, Wagga Wagga *Supported by*



5  
Nov

### Walk to d'Feet MND Sydney *Supported by*

Blaxland Riverside Park, Olympic Park, Homebush



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

## Wrapping up MND Week 2017

7 to 13 May

A huge thank you to our army of volunteers who turn up every year to raise funds and awareness for MND Week. In the Sydney area we had over 100 volunteers representing MND NSW at eight train stations, the Circular Quay foreshore and Martin Place raising over \$18,000 by 10am on Cornflower Blue Day Friday 12 May.

In other areas of NSW and ACT an amazing 35 volunteers, at 13 regional shopping centres, raised MND awareness in their local communities and an additional \$15,000.

Thank you to all of our MND Week volunteers and also to our supporters who contributed by selling merchandise to work colleagues, family and friends, and the many people who organised fundraising events during MND Week.



## 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. Find out more [here](#) or speak with your MND Advisor.

## Introducing... Sarah Bouch

Hello. I am excited to have recently joined the team at MND NSW as Volunteer Coordinator. Without volunteers, the Association couldn't raise the funds it needs to support people living with MND. I look forward to working with and getting to know the MND team as we strive to raise community awareness and support our members.



## Research into understanding and acceptance of PEG tubes and non-invasive ventilation

Researchers from the School of Behavioural, Cognitive and Social Sciences at the University of New England are investigating the role of psychological flexibility on understanding and acceptance of PEG tubes and non-invasive ventilation (using a BiPAP machine) in people with Motor Neurone Disease (MND/ALS). If you are aged 18 years or over and have been diagnosed with MND/ALS (regardless of whether you have opted for one of these interventions), you are invited to participate in this study.



Participation involves completing an online survey (smart phone and tablet friendly) that takes about 15-20 minutes. Click this link to go directly to the participation page. If you would like further information, contact James Pearlman at [jpearlm2@myune.edu.au](mailto:jpearlm2@myune.edu.au). This project has been approved by the Human Research Ethics Committee of the University of New England (Approval No. HE17-069, Valid to 03/05/2018).

## Our new travel mugs have arrived



Our new MND NSW travel mugs are a larger mug at 450ml and just right for that winter coffee, tea or hot chocolate. \$10 plus shipping at <https://www.online.mndnsw.asn.au>

## Living Well with MND Information Day

Newcastle, West Ryde and Wollongong in 2017

*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. During 2017 you can attend *Living Well with MND* at the following locations:

21 June - Newcastle

12 September - West Ryde

17 October - Wollongong

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>.

## Wesley Mission Carer Well-being workshops - Broadmeadow

Wesley Mission is conducting free carer wellbeing workshops in the Hunter at Broadmeadow in June. Carers attend two days from 9.30am to 2.30pm on Monday 19 June and Tuesday 20 June OR on Monday 26 June and Tuesday 27 June.

Workshops are free. Morning tea and lunch provided. Spaces are limited. Registrations are essential. To register by phone, or for more information, contact Wesley Mission Carer Support Services Officer - Christina Sullivan [Christina.Sullivan@wesleymission.org.au](mailto:Christina.Sullivan@wesleymission.org.au) or ph. 0419 448 562. To register online:

Workshop 1: <https://www.eventbrite.com.au/e/carers-well-being-workshops-tickets-34127192351>

Workshop 2: <https://www.eventbrite.com.au/e/carers-well-being-workshops-tickets-34127557443>



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## Upcoming Support Service events

Click to find out more.

8  
Jun

**Supporting NDIS participants Living with MND -  
Western Sydney/Blue Mountains**  
for allied health professionals and care workers  
Springwood

13  
Jun

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

21  
Jun

**Living Well with MND**  
Newcastle

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

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See <http://www.mndnsw.asn.au/all-events.html> for all 2017 events.

## MND in the news in the Illawarra on 11 May

Paul Watson from the Illawarra, Dr Justin Yerbury and Isabella Lambert-Smith from Illawarra Health and Medical Research Institute, University of Wollongong featured in this interview that aired on 9News Illawarra on 11 May. Thanks Paul, Justin, Isabella and reporter Rebecca Davis for getting MND talked about. You can watch the report [here](#).



## What is a bedside commode?

A bedside commode is a dual purpose chair that can be used for sitting or toileting. The chair is not attached to running water and is height adjustable. It can be positioned next to a bed if the user has difficulty with walking. It has a padded seat that flips back to reveal a toileting seat with bowl/pan underneath. The bowl/pan can be easily removed for cleaning after the commode has been used.



FlexEquip stocks two styles of bedside commodes. For more information speak with your occupational therapist, visit [flexequip.com.au](http://flexequip.com.au) or contact the MND Info Line ph. 1800 777 175.

## Sweat for MND

Thank you to Stephen Johnson of Eternally Fit who held the second Sweat for MND event during April. The weather was kind and participants took part in a 30 minute outdoor group exercise class. Our thanks also to everyone who turned out to support MND at this great event.



*Do you have a great idea for an event or activity that will raise funds for motor neurone disease care, support and research? Read here about how to get involved*

<http://www.mndnsw.asn.au/get-involved/fundraise.html>

Upcoming community fundraising events

Click to find out more.

16  
Jun

**Sportsmans Lunch Charity Fundraiser**

Lorn Park Bowling Club, Lorn

17  
Jun

**Henty NC Ladies Day**

Henty Showgrounds, Henty

17  
Jun

**University of Canberra Grizzlies Trivia Night**

Raiders Club, Belconnen

21  
Jun

**Fund Raiser**

Woy Woy Leagues Club

22  
Jun

**Fashion Parade**

Northbridge, Mosman and Macquarie Centre

blue illusion

12  
Aug

**The Cavalcade of History and Fashion**

Albert Hall, Canberra

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



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

## Boost for MND research

Big boost for MND research out of Victoria and the Victorian government is also providing \$3 million towards a research project at the Florey Institute that uses stem cell technology and a drug screening platform to help identify potential drug breakthroughs 160 times faster. Read more [here](#).

## Dale's Day

This was the second Dale's Day event organised by Joanne Moroney to raise funds for MND NSW. Although the cricket match was rained out this year the afternoon was still enjoyed with great food, family, friends and some backyard games. A fantastic \$2,312 was raised. Thank you to Joanne (pictured centre) for the continued support!



## ANXA11 – another gene closer to understanding MND

Researchers from King's College London screened genetic data of an unusually high number of people of European origin finding that specific mutations in the ANXA11 gene are associated with around 1% of all familial ALS/MND and 1.7% of all sporadic ALS/MND.

While this may seem like a small percentage, findings like this tell us more about the mechanisms of MND. See [here](#) for more information.

## Congratulations to Dr Thanuja Dharmadasa

Dr Thanuja Dharmadasa from the Brain and Mind Centre, University of Sydney, has been awarded the Susie Harris Travel Fellowship 2017. Thanuja will visit the University of Oxford, UK, and attend the 28th International Symposium on ALS/MND in Boston to present the findings of her PhD 'Motor Neurone Disease: site of origin and patterns of disease spread'.



## MND Day of Hope and Remembrance

Saturday 6 May 2017

It was lovely to see so many people, including family groups, babies and children, in attendance at our MND Day of Hope and Remembrance held at the beginning of MND Week 2017.



This year we were honoured to have researcher and neurologist Dr Nimeshan Geevasinga as our inspirational guest speaker. The ceremonial aspect of the day was very touching, especially the candle-lighting ceremony with dedications authored by those representing the MND community.

Thank you to our volunteers and to our musicians, Megan and Alex Cronin. Special thanks to the Soka Gakkai Centre at Sydney Olympic Park, for generously allowing us to hold the MND Day of Hope and Remembrance at their beautiful venue each year.

## MND March of Faces Banners 18 and 19 now online

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 18](#) and [Banner 19](#) were displayed for the first time during MND Week 2017.



If you have MND and would like to be part of Australia's MND March of Faces you need to provide a photograph of yourself and complete a consent form. You are welcome to include family in the photo if you wish. Family members are also able to submit a photograph in remembrance of a person who has died from MND. There is no charge to participate in this project and you can find out more information [here](#).

## NDIS Update

The National Disability Insurance Scheme (NDIS) has already rolled out for people living in the Hunter New England, Southern New South Wales, Central Coast, Northern Sydney, South Western Sydney, Western Sydney, Nepean Blue Mountains and the ACT areas.



From July 2017 the NDIS will start rolling out for people under 65 years of age in Northern New South Wales, Mid North Coast, Sydney, South Eastern Sydney, Illawarra Shoalhaven, Murrumbidgee, Western New South Wales and Far West New South Wales areas. If you are aged under 65 and the NDIS is starting in your area it is most likely you will be eligible to access the NDIS for funded services and supports.

The NDIS is a new way for the government to provide you with individualised support. It involves the development of a 'individualised plan' that includes funding for supports that you require now or may require in the future, such as personal care, occupational therapy, speech pathology, equipment and help in the home.

MND NSW has had nearly three years of experience with the NDIS and we are able to offer advice and insight for people with MND getting started with or already registered with the NDIS. Generally, we have found the NDIS has offered greater choice and higher levels of support and services for people with MND than have been available in the past.

However we have also found that, because the system is new, our members have benefited from speaking with their MND Advisor, before their NDIS Plan is developed. Your MND Advisor can talk to you about the best way to prepare for a planning meeting. We have also developed a MND Pre-planning package to assist you.

When your plan is developed, some services you currently receive or would like to receive must be included for you to receive those services. These include:

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- **Assistive Technology (Aids and Equipment)** - equipment you currently have, or will require in the future, from MND NSW's FlexEquip Service
- **Coordinator of Support** - to assist you with coordinating the services and supports in your plan.

The NDIS roll-out is gradual and, once the NDIS is rolled out to your area, people currently receiving supports through the NSW Government specialist disability services program will be moving to the NDIS first. If you have been contacted by the NDIS (or if you are worried about not being contacted by the NDIS) we encourage you to speak with your MND Advisor about services and supports you may need now or in the future before your planning meeting. We can provide you with advice and the MND NSW NDIS Pre-Planning Resource, which will assist you identify the areas of your life the NDIS will need to consider when developing your NDIS Plan. It also includes information on NDIS processes and timelines for new participants, and a glossary.

For your copy of the MND NSW NDIS Pre-Planning Resource or further information please contact your MND Advisor or contact the MND Info Line ph. 02 8877 0999 or 1800 777 175 or [infoline@mndnsw.asn.au](mailto:infoline@mndnsw.asn.au).

### Government NDIS information sessions for participants

Run by the Australian Government, NDIS information sessions are designed to help people with a disability, as well as their families and carers, learn about the National Disability Insurance Scheme.

Upcoming Community Information Sessions, Plan Implementation Workshops and drop-in sessions for NSW, the ACT and NT during May and June include:

- *New South Wales:* Yass: Plan implementation workshop - 30 May; Randwick: Community Information Session - 7 June; Bexley: Community Information Session - 13 June; Circular Quay: Community Information Session - 26 June.

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- *ACT*: Drop in sessions for one-on-one help with implementing your plan: Tuggeranong - Tuesdays; Braddon - Wednesdays; Woden - Thursdays.
- *Northern Territory*: Alice Springs: What is the NDIS and Participant Pathways - 31 May; Darwin: What is the NDIS and Participant Pathway - 19 June.

For more information on any session see the [NDIS events page](#).

### Out and about in May

MND NSW Education and Carer Support Coordinators Kristina Dodds and Kate Maguire had a busy May commencing with our *MND Day of Hope and Remembrance* on Saturday 6 May, which is coordinated by Kate. Kate also coordinates the MND NSW four-week *Care for Carers* program, for a family member or friend supporting the care of a person with MND, which started on 16 May and continues until Tuesday 6 June.

Kristina started the month in Bossley Park where, together with our Coordinator of Support South-West Sydney, Alexandra Matouk, she presented *Supporting NDIS participants with MND* for health and community care providers.

On 18 May Kristina was in Forbes with Susan Riggs, MND Advisor for Greater Western Sydney and the Central West, where they presented the *Living Well with MND* day for 25 participants who were people living with MND, their family and friends. This program featured presentations from local health care providers and they were excellent. Thank you to Nicole Avery, Speech Pathologist; Alex Aveyard, Occupational Therapist, Catherine Forbes, Dietitian; and Ann Bunyan and Bernadette Orange, from the Palliative care team.



And finally on 22 May Kristina was off to Tamworth to present the *MND Aware* one day training for health and community care professionals Tamworth, Armidale and Uralla. Thank you to all of our participants.

## MND Australia Fact Sheet about edaravone

MND Australia has prepared an information sheet to explain what the FDA approval of the drug Radicava (edaravone) to treat ALS/MND in the USA means for people living with MND in Australia. This information is reproduced below.

### MND Australia Edaravone Information Sheet

On 5 May, the US Food and Drugs

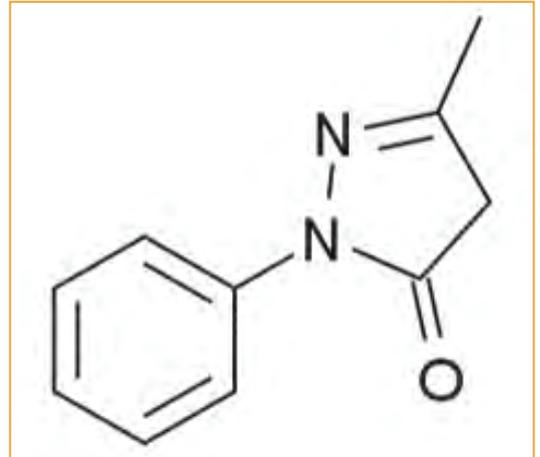
Administration (FDA) approved the drug edaravone (which will be marketed as Radicava™) for the treatment of amyotrophic lateral sclerosis (ALS) or motor neurone disease (MND) in the United States (US). It is the second MND treatment to be approved by the FDA; the first being riluzole that was approved in 1995.

We are currently liaising with our international colleagues and will keep the Australian MND community informed about further developments in the US and what they mean to people living with MND in Australia. This is what we know so far:

### Background

The drug edaravone was developed by Mitsubishi Tanabe (MT) Pharma Corporation in Japan. Edaravone was originally marketed for use in stroke patients. Later, the company decided to test edaravone in people with ALS/MND. After a series of Phase 3 trials in Japan in 2015, regulatory bodies approved edaravone to treat people with ALS/MND in Japan and South Korea. Edaravone is marketed under the brand name Radicut® in Japan and South Korea.

In June 2016, MT Pharma America submitted an application to the FDA for regulatory approval in the US. This application was approved by the FDA on 5 May 2017. Edaravone will be marketed as Radicava™ in the US and will be distributed commercially by MT Pharma America.



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### **What is edaravone?**

Edaravone is a drug with antioxidant properties. It protects nerve cells by mopping up damaging “free radicals” in the body.

Clinical trials have shown edaravone slows the progression of MND, potentially helping people preserve function longer. It appears to work in a subset of people and is most beneficial as an early treatment. The complete results of the final study have not yet been published in a scientific journal.

Edaravone is administered at a hospital or clinic by a doctor via an intravenous infusion. It should be administered in 28-day cycles. For the initial cycle, the treatment is infused for 14 consecutive days, followed by a two-week drug-free period. All cycles after that are infused for 10 days within a 14-day period, followed by a two-week drug-free period. It takes 60 minutes to receive each 60 mg dose.

Some adverse reactions of edaravone have been reported and include bruising, walking difficulties, headache, inflammation, eczema and dermatitis.

### **Access to edaravone**

At this time, edaravone is only approved for use in Japan, South Korea and the United States. Based on current information, it is anticipated edaravone will be available in the US from August 2017.

The Therapeutic Goods Administration (TGA) is yet to approve edaravone to treat MND in Australia.

MND Australia’s position statement on the [Development and approval of drugs to treat MND](#) outlines ways that patients can gain access to drugs that have not been approved for use in Australia and includes the Special Access Scheme. It should be noted this process can be challenging and expensive for the person living with MND and their family. The estimated annual cost of edaravone in the United States is US\$146,000 and in Japan \$US26,000.

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People with ALS/MND have attempted to access edaravone in Japan. A representative of the [Japan ALS Association](#) has [provided a FAQ document](#) that explains how international patients may access Radicut® in Japan. This process can be challenging and expensive. It also requires the cooperation of a local medical professional to administer the drug.

### **More Reading**

[Comment: Lancet 15 May 2017: Edaravone a new treatment for ALS on the horizon?](#)

### **News from Members of the International Alliance of ALS/MND Associations**

[The ALS Association: Press Release](#)

[The ALS Association: FAQ About Radicava](#)

[ALS Therapy Development Institute](#)

[ALS Hope Foundation](#)

[Les Turner ALS Foundation](#)

[MND Association of England, Wales and Northern Island](#)

### **Other Resources**

[Official FDA Announcement](#)

[Official MT Pharma America Press Release](#)

[Reuters News Story](#)

[For more information](#)

For more information follow the links above or speak with your neurologist. We will also update the [MND NSW website](#) with additional information as it becomes available.

You can access the MND Australia Edaravone Information Sheet online [here](#).



## Peru Trek

In May 2017 Holly Gooda, Sheena Kearsey, Hannah Martin, Cindy McGhie, Kasey McKenzie and Julie Ridley participated in the Inca Trail Trek Together for MND 2017. With little more than their commitment to supporting people living with MND in common, our intrepid supporters raised over \$35,000. These funds will contribute towards services we provide at no charge to people with MND in NSW and the ACT including the maintenance and purchase of MND NSW assistive technology equipment items and support services for families living with MND, and MND research.

Pictured above: Holly Gooda, Sheena Kearsey, Hannah Martin, Cindy McGhie, Kasey McKenzie and Julie Ridley together with Graham Opie, MND NSW CEO, Rosemary Booker and Tim Sanders, Inspired Adventures.

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### Peru Trek - Day 1

Today was a very big day of travel - almost 24 hours after departing Australia's biggest city, we finally landed in Lima, Peru's biggest city, home to almost 10 million people, or one third of the country's entire population!

Transferred to our hotel, we joined for a quick supper together before going on a bit of a group stroll around the streets. After three flights, one of them around 11 hours long, we were all itching for a bit of exercise!



Weary heads hitting the pillow tonight, but excited for our one (and only, also much shorter!) flight early tomorrow morning, and to be fully immersed in Peruvian culture.

### Peru Trek - Day 2

After a fairly early rise for breakfast and transit back to the airport to make the last of our flights into Cusco, we could do nothing but laugh when we got to the airport to find that our flight had just been delayed some two and a half hours! Many hours later, finally arriving at Cusco Airport, we were quite dazzled by the



surrounding mountains; so large and yet seemingly so close!

Transferred to our hotel with our local guide, Jaime, he managed to make seven very weary travellers laugh and smile all the drive long!

Post hotel check-in and freshen up, a lovely walking tour was guided by Jaime, introducing us to local history, both modern and ancient, to the culture of the people in Cusco and to the local way of life, before we enjoyed a street performance on our way back to the hotel. As we had travelled from Australia in two groups, tonight was our first official meal as team MND NSW, and what a night it was. Tears flowed, hugs were shared and hands held, as each member of the group introduced

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themselves, their story and their reasons for taking on this challenge. Although it was a very emotional night for all of the team, it was a very positive and an exceptionally devoted team who walked out of the restaurant together, not only ready to take on the Inca Trail, but also ready to support each other every single step of the way too!

### Peru Trek - Day 3

Today we really got immersed into Inca heritage, starting with a visit to Awana Kanchu, 'the weaving place'. Not only did we learn about the importance of alpacas and llamas to Peruvian people historically and today, but we also got to meet and feed them! Some laughs were certainly had! We were given a demonstration as to how the wool is dyed, then moved on to some examples of traditional vegetable based foods... Over 200 types of potato in Peru!



Nothing could really prepare us for the sights we were to see on our drive to and entering into The Sacred Valley and Pisac. The awe of just trying to comprehend how the Incas built and achieved what they did in this exceptionally steep, rugged and unforgiving countryside! Though we have been in Cusco since yesterday, at an altitude of over 3000m to acclimatise, our walk at Pisac starting at an altitude of 3446 metres was a challenge for us all, and a reminder of what we are all attempting as of tomorrow; The Inca Trail itself! With rain falling lightly this afternoon, we're all wondering what Mother Nature might throw at us over the next few days and nights! Tonight we must all make decisions of what is most important to us for the next three nights, as we are each allowed a maximum of only 7kg worth of luggage! Excited and anxious to bed tonight, tomorrow it's bye bye all creature comforts, hello hiking boots, Mother Nature and The Inca Trail!

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### Peru Trek - Day 4

This morning we left Cusco city early, and the comfort of our hotel, flushing toilets and civilisation! After a windy, hilly drive, we stopped at a stunning lookout, looking down into the Sacred Valley from a very different direction than that of yesterday. The first thing we all noticed was the significant drop in temperature, with snow capped mountains in the distance, wondering just what we'd signed ourselves up for! Our next stop was one we were not anticipating on the morning we were to commence The Inca Trail, for the next stop was at a pub!



It was a traditional Peruvian pub, where we learned the ways of a very traditional game. We broke into two teams, and whilst we were nowhere near as good as our guides, Jaime and Jose, it certainly was a laugh! Following this, we learned the ways of and sampled a locally brewed and traditional corn beer! Beer, made from corn! Unusual, but delicious! Next was off to the Inca Living City, which has been world heritage listed by UNESCO since 1983... the entire city! Just to get to visit was a privilege, and the walk we did with our guides Jaime and Jose amongst the ruins left us rather speechless, again. Onto a fantastic lunch, and a last opportunity to check over our luggage, refill water bottles, layer up and layer down our clothing before we were off... the start of The Inca Trail! Today was our shortest distance day, also the 'flattest' day, but certainly had all our heartbeats rising! Upon arriving into our campsite, just on dusk, set in a breathtaking location, surrounded by mountains and by a running river, we took the time to introduce ourselves and be introduced to our team of porters and chefs. Many more laughs were had before another amazing dinner, a reflection of the day we've enjoyed together, topped off by some stargazing before we all crawled into our tents. An even earlier start tomorrow, for a longer, steeper day ahead!

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### Peru Trek - Day 5

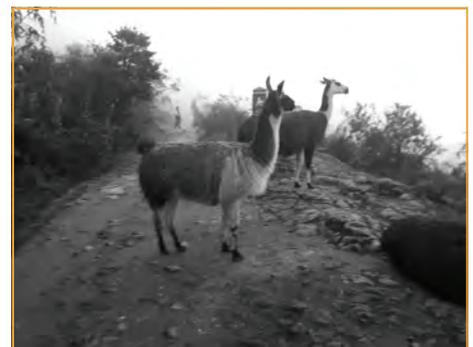
Today started with a cow, randomly running through our campsite; always gotta be on your toes around here! Once we were on the track and ready to trek, it was goodbye to The Sacred Valley, and hello to the Happiness Bridge Valley! For the first part, our legs felt just that; happy! But soon enough the continuous incline/decline started, and well, happiness was probably no longer the 'go to' word from our legs' perspective!

By the end of the day, we had trekked 12 kilometres, and elevated a huge 1200m since we began walking at 7:30am this morning! What an effort from the team! Arriving into our beautiful campsite, a light drizzle just taunting us on and off, we had a little free time (aka 'nap' time!). The temperature had certainly dropped, and it was on with all the winter woollies we could find! Meeting in our communal dinner tent, a few competitive rounds of 'Uno' card games had us belly laughing and certainly much warmer in no time! And now, at 3800m, ice covering the outside of the tent, and knowing that we have to be up at 4:30am tomorrow, it's lights out.

### Peru Trek - Day 6

Rising at 4:30am, pitch black, the outside of our tents covered in a thin layer of ice... and knowing that today was to be the longest, the steepest, the hardest of all days! Just crawling out of the warmth of our sleeping bags was challenge enough!

After a hearty breakfast to fuel ourselves (boy we knew we'd need it!), we started off, to be met by a mob of llamas! After marvelling at them and their beauty in this incredibly rugged and scenic landscape, we could find... no more excuses to put off what was ahead of us!



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The first part of our day really was straight into it... Up, up, UP! A few hours later, after a real hard slog from everybody, and lots of encouragement and support being shared around, we had made it to the highest point on The Inca Trail... We were standing 4215 metres above sea level! It was an absolute momentous and proud occasion for all involved. Standing not only in but also above the cloud line, it was a truly surreal moment for us all.

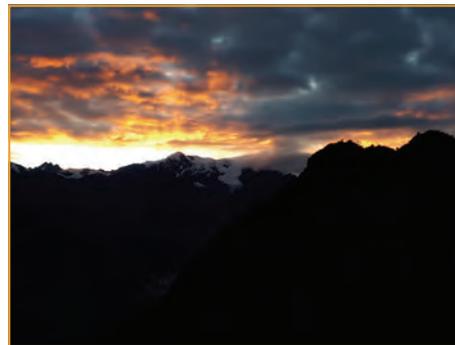
However, the hard work was not over, far from in fact! From there, we had an exceptionally steep decline, for over two kilometres! The total we were attempting for today was 16 kilometres; the immense distance was one thing, add to that the elevation, the incline/decline and fact that 'flat' just does not exist on The Inca Trail, and we were very happy to learn that our guides had organised for us an extra meal break for today! It was with ravenous stomachs and open arms that we accepted a most delicious soup, a short break, before hitting the trail again. More up, steep, more down, steep again! Add to all this the fact that the heavens chose to open up on us too! All waterproof equipment was out, covering ourselves and our packs as best we could! Things cleared for a while, and come mid-afternoon it was finally lunchtime. With the rain having slowed us down (you really need to concentrate at all times whilst on The Inca Trail, but add rain to the equation and it's even something else!), we powered through lunch and got back to the track; still a few more k's before we reached our campsite! With darkness drawing near, our head torches at the ready, we managed to pull into our campsite with just a few minutes before sundown. Camped amongst the clouds, we were rewarded for our day's efforts with a cloud clearing that left just the peak of the mountains popping above the cloud, silhouetted against the clouds behind them. Absolute magic! Very weary heads hitting the pillows (or should I say jackets scrunched up as pillows?!) tonight. But, a sleep in tomorrow... We don't have to be up until 5am!

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### Peru Trek - Day 7

Rising at 5am at Phuyupatamarca, our campsite, we walked a short distance to watch the sun rise and colour the clouds above the mountains surrounding us in every direction. Oh, and did I mention Machu Picchu was right in front of us! Not only did the clouds glow pink and orange, but the reflection on the snow-capped mountains above and around us did too... What a morning!



Today was the final day our porters and support crew would be with us, and they put on a most beautiful farewell ceremony for us, performing both traditional dances and songs! What an absolute privilege for us. After goodbyes we set off for our goal for the day, the official end of The Inca Trail! Starting the day at some 3650m, it was again an exceptionally challenging day, as we declined 1000m over 11 kilometres. Of particular adversity was the infamous '50 steps', which are more like a ladder than steps, they're that steep! Late afternoon, we finally made it, there right in front of us was the remaining ruins of THE Machu Picchu Inca Site! No magazine photos nor any words can really describe our feeling of having made it, nor the empowerment and awe one is in, standing at one of the Seven Wonders Of The World! Some 45 long, steep, inconsistent, rainy, slippery and rough kilometres after we first commenced, we had made it... What an achievement by team MND NSW!

### Peru Trek - Day 8

After our first night back in civilisation, it was a bit confusing to wake up in a bed, rather than a tent, and to use an ordinary toilet again! Another early start, up at 5am, ready to face and accept the challenge for the day by 6am. Before we could start our walking back at Machu Picchu, we first had to take the bus trip, this time in reverse of what we did yesterday afternoon.

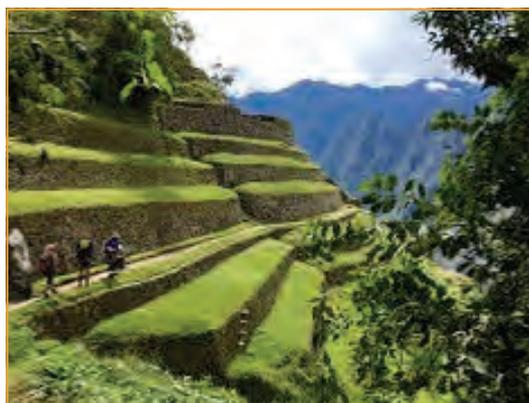
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From Aguas Calientes, the town at Machu Picchu, our bus ride took about 25 minutes to deliver us to the top... 25 minutes incorporating a 400m climb and 14 zig zag turns, each one more than a 180 degree pivot! The bus trip alone was enough to get your heart racing! We spent a few hours exploring the Machu Picchu Inca Site, learning about the history and way of life of The Incas back in the 1400 and 1500s. The stories and things we learnt were just as fascinating and captivating as the remaining ruins and how they were ever built in the first place! With 10am approaching, our excitement (and nerves) were rising, as we



prepared ourselves for our final challenge; ascending Huayna Picchu! Approximately a four kilometre round trip, ascending and then descending 300m, with some of the steepest climbing any of us had ever done! In some parts, the track was so steep we had to use cables to help haul ourselves up, some parts we were feet AND hands, not to mention the dark cave tunnel that had us bending and crouching! A really hard slog for our final physical challenge together, but fantastic comradery and inspiration being shared by the group, complimented by amazing 360 degree views from the top, and the feeling that... WE DID IT!





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