

# MND NEWS

March/April  
**2019**

The newsletter of the  
Motor Neurone Disease  
Association of Victoria

**Until there's a cure,  
there's care.**



OUR CEO, ROD, RETIRES  
AFTER 25 YEARS LEADING THE  
ORGANISATION IN DELIVERING  
SUPPORT SERVICES, CARE,  
ADVOCACY + RESEARCH FUNDING

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ABN 44-113-484-160  
Reg. Assoc. No. A7518

# SUPPORT GROUPS

MND Victoria Support Groups provide opportunities for people living with MND, their carers and interested members of the public to come together on a regular basis. For information about Support Groups contact MND Victoria on Tel: 1800 806 632 or [info@mnd.asn.au](mailto:info@mnd.asn.au)

**Western Metro:** Last Monday each month at 12.30 in Footscray.  
Coordinator – Christine Robson

**Barwon Region:** First Monday every second month at 12 noon  
Coordinator – Ian Parton

**Ballarat Region:** Last Friday of each month at 1pm  
Coordinator – Bev Phillips

**Melton Area:** Meets every 4 weeks on Fridays at 12pm  
Coordinator – Leanne Dewhurst

**Hoppers Crossing Area:** Meets every 4 weeks on Thursday at 1pm  
Coordinator – Leanne Dewhurst

**Bendigo Area:** Meets once a month on a Thursday at 1.30pm  
Coordinator – Carolyn Hutchinson-Kane

# STAFF

**Chief Executive Officer:** Rodney Harris

**Manager Finance & Administration:** Megan Crellin

**Administration Assistants:** Isabelle Lloyd, Rebecca Moussa

**Manager Supporter Development:** Kathy Nightingale

**Supporter Development Officer:** Daniel Woodrow

**Digital Communications Officer:** Heidi Bryce

**Marketing & Media Officer:** Carly McClen

**Manager Support Services:** Jo Whitehouse

**Coordinator MND Advisor Service:** Janette McDonald

**Team Leader MND Advisor/Support Coordinators:**

Elizabeth Crask, Eric Kelly

**MND Advisors/Support Coordinators:**

Ruth McEvoy                      Laurn Matheson

Jenny Waites                      Trish Duffy

Leanne Conway                      Melissa Kettle

Fran Hurst                      Rachel Ritchie

Jacqui Holland (Tasmania)

**Coordinator Operations:** Georgina Diacos

**Coordinator Equipment Service:** David Harkin

**Equipment Officers:** Kathy Walker, Sandra Nicholls

**Coordinator Volunteer Programs:** Deb Olive

**Coordinator Information & Resourcing:** Alison Jones

**Information & Resourcing Officer:** Sarah Wilkie



# FAREWELL TO OUR CEO ROD HARRIS!

By David Lamperd, President, MND Victoria State Council

**Further to my article last year in which I advised the news of Rod's decision to retire, it is time I reflect further on Rod's influence in leaving a major legacy within the MND community here in Victoria, Australia and internationally.**

Rod commenced as CEO of MND Victoria in 1993, the year that Michael Jordan retired from basketball to give baseball a try, Shane Warne delivered his "ball of the century" to Mike Gatting, Paul Keating was our PM and Jeff Kennett was Victoria's Premier, the World Wide Web became available in the public domain, and the first genetic mutation related to MND was discovered in the SOD1 gene.

Many challenges (and opportunities) have come and gone over the past quarter of a century and Rod's

vast experience has ensured that our organisation has progressed from a small, at risk, not-for-profit to one of the leading MND establishments in the world.

Influenced by Rod's creation of the MND Care Foundation, and watching this become a significant funder of MND Victoria, we have an organisation which has become financially strong, with the ability to finance the important services for those with MND and also promote research – particularly research that improves the care of people living with MND.



**Visit our website at: [www.mnd.asn.au](http://www.mnd.asn.au)**



Overseeing a very successful fundraising strategy, that has become more creative due to intense competitive pressures, Rod has provided an incredible foundation for our current financial strength.

MND Victoria is now recognised by people with MND in Victoria as the “go to” organisation for support and advocacy – with an excellent team of volunteers, supporters and donors who are all focussed on MND.



Every day Rod lives and breathes our mission - to provide and promote the best possible care and support for people living with MND. This stubborn focus and passion guided Rod throughout the years and has influenced his terrific team at MND Victoria to also think and act similarly, notwithstanding their high workloads. Great leaders inspire vision and confidence and Rod has been able to do both, including the skill to develop strong relationships with his team, so that they can competently deliver services, support, fundraising and advocacy to work towards a world without MND.

Rod’s role has meant that he has needed (and wanted) to act as the “face” of MND Victoria, requiring his attendance at numerous fundraising or publicity functions – mostly out of hours and during weekends – and often with his forever supportive partner, Pam (photo of Pam and Rod below).



Rod has proactively engaged with media and often has represented MND Victoria on television or radio appearances. Rod’s networking skills have enabled the development of strong relationships with influential government contacts and other like-minded not-for-profit organisations – many of which have proven invaluable and most beneficial to our organisation.

As I mentioned in my 2018 article, Rod received an **Order of Australia (OAM)** for his work to ensure that palliative care was available to everybody. Rod has always believed that palliative care should always be referred to as a quality of life service, not an end of life service.

Rod’s ability to lead his team through the many changes and challenges brought about by our important transition to NDIS and 'My Aged Care', together with the implementation of our new client management system, has been most impressive and highly successful.

Rod’s influence and experience extended beyond Victoria and Australia to his well-deserved appointments as a Board Member and then Chair of the International Alliance of ALS/MND Associations. This enabled Rod to influence service delivery not only in Victoria and Australia but also globally – recognising the differences demanded by culture and development.



All members of our State Council will miss Rod’s experience in all matters MND related, and his ability to answer any query clearly and insightfully. Rod has been able to generate significant trust, and therefore our strong support, over the years, because when Rod says it will get done – it does.

I could go on.

Rod will thankfully continue to offer his support to the MND community, well after his retirement date. We are all indebted to Rod’s commitment, contribution and value-added service which he has provided to MND Victoria.

# SUPPORT SERVICES



**Hello again! Autumn is here...although the weather does not seem to be very autumnal for March! There is a lot of information to share...**

## MND Health Professional Forum

On Friday March 1st we held a Health Professionals Forum in Launceston, Tasmania. We had a fantastic turn out with 50 people in attendance.

The conference presentations focused on treatment and symptom management as this is what the "pre-conference scoping" of health professionals had informed us was of interest.

The Forum was opened by Joyce Schuringa, President of MND Association of Tasmania, followed by addresses from a range of experts in the field:

Speakers at MND Health Professional Forum	Topic
<b>Charles Smith</b> – person living with MND	<i>Personal perspective</i>
<b>Dr Helen Castley</b> – Staff Specialist in Neurology at Royal Hobart Hospital	<i>Overview of MND &amp; treatment update</i>
<b>Sarah Solomon</b> - Occupational Therapist Calvary Healthcare Bethlehem	<i>OT for people with MND: Adjusting and adapting to rapidly changing function</i>
<b>Marian McCarron</b> – Speech Pathologist, Calvary Healthcare Bethlehem	<i>Secretion Management in MND &amp; Technologies for Communication and Environmental Control</i>
<b>Dennis Lo</b> - Speech Pathologist, Independent Living Centre Tasmania	<i>Assistive Technology for Communication for people with MND</i>
Dr Christine Edwards - Staff Specialist in Palliative Medicine, Tasmanian Health Service	<i>The benefits of an early referral to Palliative Care</i>

We also had **Alison Jones** and **Eric Kelly**, staff members of MND Victoria talking about our Information and Advisor services.

The feedback about the presentations was very positive. It means that Health Professionals in Tasmania will be better equipped to support people with MND (see forum report on pages 9-10).



## Support Services Staff Update

### New MND Advisor position in the Hume Region

We are in the process of recruiting a new MND Advisor and Support Coordinator to the team who will be based in the Hume region. We hope to be in a position to announce who that will be in the next newsletter – watch this space!

### MND Advisor & Support Coordinator in Tasmania

One in and one out! We welcomed Jacqui Holland, our newest recruit in the role of MND Advisor and Support Coordinator role in February. She is co-sharing an office with other disability organisations in the ABC Centre in the centre of Hobart.

Hayley Tristram, our Advisor based in Launceston sadly resigned and left the organisation in January. Jacqui has increased her days from two days a week to three in

the short term to cover some of Hayley's work. Leanne Conway and Elizabeth Crask, Advisors from MND Victoria are also supporting Tasmanian clients.

## NDIS

### Training for NDIA Planners

MND Victoria, MND NSW and MND Australia have been working with the National Disability Insurance Agency (NDIA) to develop some training for NDIA planners and other NDIA staff about specific conditions and disabilities (the NDIA call them "disability types"). A fact sheet has been developed about MND which is available to all planners on their internal online system.

To supplement the fact sheet, the NDIA asked MND Victoria to assist in the production of a short 5 minute video of a person with MND. Fabian Fitzgerald, who was diagnosed with MND in 2012, kindly agreed to share his story which was filmed in a warehouse in the back of beyond in Melbourne in February! Fabian was able to highlight some of the key symptoms and issues that MND cause, whilst emphasising that everyone's journey is different. This video will be a resource used in the training of all NDIA planners.



### NDIS rollout – so nearly there!

The final areas in Victoria of Outer Gippsland, the Mallee and Goulbourn are in the process of transitioning into the NDIS, as is the final age group in Tasmania with the 49 to 64 year old cohort of people being phased in. It was planned for full scheme rollout in Victoria and Tasmania to have been achieved by July 2019, however the NDIS has advised that there are some delays and it is anticipated that some people will still be transitioning in the latter part of 2019. We will be strongly advocating for people with MND to be prioritised.

## National Disability Services (NDS) State Conference

NDS is the peak body for disability organisations. I was lucky enough to attend the Victorian State Conference in March, titled 'From Obstacles to Opportunities'.

It certainly was a great opportunity to network with colleagues and explore issues and solutions that are shared across the sector.

The focus of the conference was on the impact and implementation of NDIS. My three main "takeaways" from the conference were:

1. NDIS continues to be the focus of the sector and while it is indeed of great importance, people with disability who are over 65 are not receiving the same equity of service. It highlighted to me that we still have a lot of work to do to ensure all people with MND have access to appropriate services, no matter what their age. MND Australia's 'Make Aged Care Fair' campaign to advocate about this issue is vitally important. If you haven't already, please join the campaign and help make sure that everyone with MND has access to the right care, in the right place, at the right time, irrespective of age. Details are on the MND Australia website.
2. MND Victoria needs to remain up to date and on top of the processes required when Victoria transitions across to the NDIS Quality and Safeguards Commission from July 2019. Lots of behind the scenes work to be done!
3. Development of a skilled and suitable workforce (from support workers, to allied health professionals) is critical to the success of the NDIS and something that the NDIS, NDS and service providers are grappling with especially in regional and remote areas.

## Annual Quality Survey

We will shortly be undertaking our annual client survey which gives all of the people who use our services the opportunity to provide feedback on what we are doing well and on areas that we could improve – please take the time to complete the survey when you receive it... and thanks in advance for your time!



By the way, if you have feedback – both good and bad, don't wait until annual survey time – please feel free to provide feedback at any time throughout the year! Please don't hesitate to email or call me.

I look forward to meeting many more of you in the coming months especially at one of the many activities that will be held during **MND Awareness Week (5 to 11 May 2019)**. I am looking forward to attending my first **'Day of Hope and Remembrance' service on**

**Sunday, 5 May** and the **'Ask the Experts' session at the Florey Institute on Tuesday, 7 May** which I've heard is a fabulous opportunity to learn about current MND research. Please see the enclosed flyers for further information about these events.

**Jo Whitehouse, Manager Support Services**  
[jwhitehouse@mnd.asn.au](mailto:jwhitehouse@mnd.asn.au) or 0402 183 140

## MEET OUR NEW CEO – KATE JOHNSON

**On behalf of the State Council, I have great pleasure in announcing that Kate Johnson has agreed to commence as CEO, MND Victoria – to fill Rod Harris's rather large shoes.**

Kate has enjoyed over 20 years' experience in leadership and the strategic development of not-for-profit organisations. Kate's current role is General Manager of St Vincent de Paul Society Victoria (Service Development) where, for the past 18 months, she has led a large team of employees and volunteers. Kate has been able to develop and coordinate a number of effective and targeted support programs by focussing on the use of partnerships, collaborating with other St Vincent de Paul Society associations in other states and through community engagement.

Kate's previous role was at Carers Victoria—as GM of Carer and Community Services where she had the overall responsibility for service delivery and improvement across all Carers Victoria's services.

Amongst many other tasks, Kate led transformational change of the organisation in order to respond to the challenges (and opportunities) presented by reforms in the Aged, Disability and Mental Health sectors.

Kate has a Bachelor of Science (majoring in Genetics and Psychology), a Post Graduate Diploma in Psychology and is moving towards the completion of her MBA/ Masters of Leadership studies.



We look forward to Kate commencing at MND Victoria on Tuesday 23rd April and are very grateful for Rod's flexibility in offering a two week overlap in order to provide Kate with the opportunity to gain a little of Rod's vast experience from his time with MND Victoria.

**David Lamperd, President**  
**MND Victoria State Council**



Charity TV participants (3 not pictured)

## CHARITY TV SHOW

Charity TV Global is an international award-winning television production company. They've developed a ground-breaking fundraising project that screens on TV! After applying to be a part of this new concept, MND Victoria were chosen as one of their charity partners!

After a casting process late last year, 12 ambassadors were chosen for an incredibly fresh and exciting concept. MND Victoria and our 12 ambassadors will be embarking on a 12 month, unique, fun and rewarding journey to raise funds and awareness for the organisation. The culmination of this journey is a trip of a lifetime in early 2020 to a surprise destination where the group will be filmed by the Charity TV Global crew, with their exciting adventure to be broadcast on national television.

## GEELONG DAY OF HOPE AND REMEMBRANCE

**The Geelong Day of Hope and Remembrance service will be held at 2pm on Sunday, 5 May at St Lukes Uniting Church, Highton.**

Please contact Fay: [fayhaywoodmnd@gmail.com](mailto:fayhaywoodmnd@gmail.com) for further details.

All of our ambassadors are well aware of MND due to personal connections. They have all lost a loved one with the disease or are currently experiencing the journey. We were privileged to have so many amazing and passionate people to choose from.

Our ambassadors need to raise a minimum of \$10,000 each prior to departing. Many are already well on the way with so many exciting events and unique fundraising avenues planned. We will be working hard to support them in their efforts and we can't wait to see them reach, or go well beyond, their target.

Over the coming months we will showcase these amazing people and detail the work they are doing for MND Victoria.

## INFORMATION SESSIONS

We warmly invite people with MND, their families and friends to an Information Session about MND.

**7pm on Wednesday, 17 April at MND Victoria, 265 Canterbury Road, Canterbury.**

Please RSVP by 5pm, Monday, 15 April 2019.

Phone: (03) 9830 2122, 1800 806 632 or

Email: [info@mnd.asn.au](mailto:info@mnd.asn.au)

The following session will be held on Thursday, 30 May at 7pm in Canterbury.



# TASMANIAN MND HEALTH PROFESSIONAL FORUM 2019

*By Joyce Schuringa, President, MND Tasmania*

**On 1 March, nearly 70 people, including speakers and staff, attended the MND Health Professional Forum in Tasmania.** A diverse group of people from Victoria and Tasmania attended and networked throughout the day – people who have MND, volunteers, neuroscientists, medical specialists and other health professionals, staff from other support and advocacy groups and from funding organisations, people working in public and private health, disability, community and other care and support services.

This was the first Forum we have held in the new funding era of **My Aged Care** and **NDIS**. In the past it has been relatively easy to know who to invite to attend as services for people with MND were linked mainly within the public and not for profit sector. We now look forward to finding and engaging with other service providers especially in the private sector and many that are new to MND.

A constant in this changing environment has been the support we have received from Palliative care services. When **Dr Paul Dunne** became the first State-wide Palliative Care Specialist in Tasmania, he changed palliative care services to include people with MND and their families. He and his team formed a relationship with MND Tasmania over 20 years ago which has been continued and further developed by his successor **Dr Christine Edwards**.

We enjoyed a day filled with excellent presentations and learning. As the first speaker, **Charles Smith** shared his every day experience of living with MND. His personal journey includes the change in his mindset from an illness such as heart disease to MND which has such a different predicted outcome than to his cardiac surgery. He spoke of the stress of meeting health professionals who had no understanding of MND and

of the obstacles in the aged care system. He wondered about the future and who will be there to help him on the way.

**Dr Helen Castley**, (photo below) Staff Neurologist at Royal Hobart Hospital, taught us Neurology at a level we could absorb and utilise to improve our understanding of MND. She provided an update on current data, medical management, medications and research and on the expanded team of Neurologists in Tasmania.



**Sarah Solomon**, Occupational therapist and Marian McCarron, Speech pathologist from Calvary Health Care Bethlehem, Victoria gave us practical guidance and information on effective assistance where there is no recipe or clinical pathway. MND is currently incurable but NOT untreatable. The role of the multidisciplinary team is vital for the person with MND, from managing 600ml of saliva per day to knowing which minimal home modifications will be required.

**Dennis Lo**, Speech pathologist, Independent Living Centre (ILC) Tasmania opened up the rapidly changing world of assistive technology (AT) and the enhancements it offers to the quality of life for people with MND and those who assist them. The MND Tasmania Communication Equipment Library hosted and managed by the ILC is a fine example of two local not for profit organisations working together to care for people with MND.

**Dr Christine Edwards**, Staff Specialist in Palliative Medicine, Tasmanian Health Service, provided the whole of journey perspective on MND and the importance of a coordinated and well managed pathway of support in order to empower the person with MND to have control and make informed choices. Palliative care is a “Quality of life service” and early referral is essential to



optimise the well-being of the person with MND and their family.

A panel of the speakers chaired by **Jo Whitehouse**, Manager Support Services, MND Victoria applied their expertise to two fictitious case studies which provided a great opportunity for general discussion, questions, answers and the sharing of ideas and emotions.

**Eric Kelly** and **Alison Jones** from MND Victoria explained the "go-to" expertise offered to everyone who has questions and needs related to MND and Kennedy's Disease. This specialised knowledge is shared by the MND associations in Australia and they described the MND Advisor and the Information and Resourcing services.

The Forum featured only a little of the breadth and depth of MND. We hope that relationships, work and practice will be changed as a result. We hope that more people now know where to turn when they have further questions that may arise about MND. We know that more Forums will be needed so look out for one next year.

Behind the scenes was the MND Victoria team who worked on this program for months and who came from Melbourne to present it to us. THANK YOU MND Victoria!



## GROUP PROGRAMS

### Living Well

'Living Well' is a group program for people with MND and their carers. Participants have the opportunity to share knowledge and discuss topics relevant to living with MND.

The format of the program varies to suit the needs of participants and may include readings, group discussion, video presentations and guest speakers. Additionally, participants provide each other with support and are able to share ideas and solutions of their own.

### Living Through

'Living Through' provides an opportunity for newly bereaved carers and family members to meet with others who share similar experiences in an informal and friendly environment.

Participants hear from a guest speaker who presents on typical grief experiences. They also have the opportunity to share advice with one another and have access to bereavement support resources.

### Living On

'Living On' is a four week program designed for former carers. It provides the opportunity for people who have been bereaved for 12 months or more to meet in a facilitated group to explore positive ways of moving forward whilst finding ways of retaining treasured memories.

### How do you get involved with the groups?

Please contact MND Victoria to register your interest for our group programs: Phone: (03) 9830 2122 or 1800 806 632 or email: [info@mnd.asn.au](mailto:info@mnd.asn.au)

## Meeting others

Are you interested in having contact with others living with MND? MND Victoria can assist people with MND, carers, family members and friends to get in contact with others in similar circumstances. This can be done through:

- MND Victoria group programs
- Ongoing support groups
- Facilitating contact either in person, by phone or by email or
- Referring to external online support groups.

If you would like to be in contact with others, but are uncertain on how to go about it, then contact us and we can talk you through your options.

Phone: (03) 9830 2122 or 1800 806 632 or email: [info@mnd.asn.au](mailto:info@mnd.asn.au)

## Facebook support groups

**MND Carers Australia:** An online support group for Australian MND carers to discuss issues they face. MND Carers Australia is independent from MND Victoria, but has asked us to promote their group. To access the group you will need a Facebook account.

A message from MND Carers Australia's administrators: MND Carers Australia's focus is to support the primary carer of someone with MND. The primary carer faces many challenges. They often feel isolated, feeling like no-one understands what they are going through. Only one family member is allowed in the group as the primary carer needs a safe place to discuss any and all issues they may face. This is a private group where you can feel supported, ask questions and vent about the difficulties you face as the primary carer of someone with MND. We hope you will be proactive in the group and gain knowledge from others, but we understand everyone will be at a different point on the MND road.

If you would like to join, go to Facebook and search for: "MND Carers Australia" or visit: <https://www.facebook.com/groups/1408400102747388>

**MND Angels Australia:** An online support group for people in Australia whose partners have died from MND. MND Angels is independent from MND Victoria, but has asked us to promote

their group. MND Angels offers participants an opportunity to share experiences and support one another. To access the group you will need a Facebook account.

If you would like to join, go to Facebook and search for: "MND Angels Australia" or visit: <https://www.facebook.com/groups/1512117609036086>

**Are you an MND Genie?** About 10% of people diagnosed with MND have a familial form of the disease. Of these, about one in five have a mutation on the SOD1 gene and about two in five have a mutation on the C9ORF72 gene. These mutated genes can be passed down through families and children can inherit the mutated gene.

The aim of MND Genies is to provide a space where people can connect and share their experience of having an MND related genetic mutation.

MND Genies is a closed and unlisted Facebook group, to join or for more information, please contact Kate Maguire MND NSW at: [mndgenies@mndnsw.asn.au](mailto:mndgenies@mndnsw.asn.au) or ph. 02 8877 0902

**Kennedy's Disease Facebook Group:** Did you know that MND Victoria also provides support for people living in Victoria with Kennedy's Disease? Kennedy's Disease (also known as Spinal and Bulbar Muscular Atrophy) is a condition that has similar symptoms to MND.

One of our members has shared a Facebook group for Australians with, or affected by, Kennedy's Disease.

The group aims to help raise awareness within our communities and to help each other out:

[www.facebook.com/groups/3407816342962036/](https://www.facebook.com/groups/3407816342962036/)

## Support services for carers of people with MND

**Carers Victoria**— 1800 242 636  
[www.carersvictoria.org.au](http://www.carersvictoria.org.au)

**Carer Gateway**—1800 422 737  
[www.carergateway.gov.au](http://www.carergateway.gov.au)

**CareSearch**— (08) 7221 8233 [www.caresearch.com.au](http://www.caresearch.com.au)

**BrainLink**—1800 677 579 [www.brainlink.org.au](http://www.brainlink.org.au)

**MND Victoria**—1800 806 632 [www.mnd.asn.au](http://www.mnd.asn.au)



# VOLUNTEER NEWS!



## Life Story Volunteers



MND Victoria welcomes our four new volunteers who have recently joined the Life Story Volunteer team. Having completed Life Story training, our volunteers are now available to meet with clients to record their stories and develop those into books and publications for them to share.

With eight Life Story Volunteers, we now have a strong and motivated team who are keen to work to support clients develop their stories. For more information, please call 1800 806632 or [volunteer@mnd.asn.au](mailto:volunteer@mnd.asn.au)

## Information Resources



Joan and Betty (photo previous column) are long term MND Victoria volunteers, having together contributed almost 34 years volunteering with the association.

In 2011, Betty and Joan took on responsibility for maintaining the large collection of resources which are available to send to clients, family members, health professionals and members of the public. Resources such as information kits which our MND Advisors take out on their first visit to meet with a new client are collated each week by Betty and Joan.

Information and resources for student assignments are copied and ready for distribution thanks to Betty and Joan. Together they help ensure people have access to the information they need. Our opportunity to provide timely information to those who need it is ensured through the support these two wonderful volunteers bring to MND Victoria.

Alison and Sarah from the Information team really appreciate the work done by Betty and Joan.

## Bendigo Support Group



The Bendigo Support Group meet on a monthly basis in central Bendigo. *(Photo above at their Christmas gathering last year)*

The group recommenced meeting approximately 18 months ago due to a need identified by people living with MND in the area. Carolyn coordinates the group and while she downplays her involvement, it is through her commitment the Support Group can provide opportunities for people living with MND and their families to come together to spend informal time with people to share experiences.

The group meet at a local café on a Thursday every four weeks. Members are able to attend at times that suit them between 11.30am and 3pm. Carolyn books tables and ensures available space is accessible



for wheelchairs and walkers. Carolyn also emails all members a week prior to confirm numbers. For more information about the Bendigo Support Group call 1800 806 632.

## **MND Volunteers supporting people living with MND in the Bendigo area**

We are very fortunate to have several volunteers in the Bendigo area who offer support to people living with MND.

Lorraine and Kathy are members of our Massage Volunteer Team and are able to provide hand and foot massage to people living with MND. Regular massage can assist people to feel more relaxed and comfortable. Massage can include either hands or feet or both depending on what the client prefers. Our volunteers are matched with clients and then visit them at their home or place of residence on a regular basis.

Anne helps clients develop and print their Life Story. This can take a number of months with Anne visiting regularly with the person living with MND to record the stories they want to share. Anne then transcribes the story and, using pictures or other mementoes provided by the client and their family, produces a printed book for them to keep.

Thank you to our volunteers for your support in providing these personalised services to people living with MND in the Bendigo area.

For more information about either our Massage Volunteers or Life Story Volunteers in the Bendigo area or other parts of the State please contact your MND Advisor or call 1800 806 632.

# **VOLUNTEER OPPORTUNITIES**

## **Massage Volunteers**

Our massage volunteers are so popular with our members that we need more!

Massage Volunteers provide hand and foot massage helping with comfort and relaxation for people living with MND.

We currently need more Massage Volunteers across the State. All training will be provided so you do not need to have experience with massage. Being available to spend time one on one with our members in their community is what makes for a successful massage volunteer.

## **Visitors for Social Support**

Some of our clients can feel isolated in their homes or place of residence. Our Social Support Visitors meet with a person living with MND on a regular basis to share interests, conversation – maybe even a crossword!

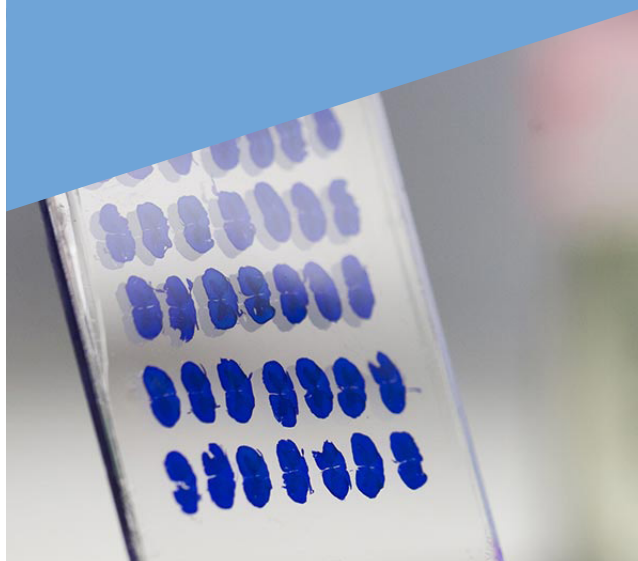
If you would be interested in helping someone with MND stay socially connected – we'd love to hear from you.

Training and ongoing support is provided for all roles.

For more information please call 1800 806632 or email [volunteer@mnd.asn.au](mailto:volunteer@mnd.asn.au)

**Deb Olive, Coordinator Volunteers**

# RESEARCH UPDATE



## COPPER-ATSM UPDATE

*By Amanda Bourne, International Alliance of ALS/  
MND Associations' Coordinator*

**As you may be aware, on January 7th, a media release was published stating that CuATSM slowed disease progression by 70% in the Phase 1 clinical trial, resulting in an international outcry for people living with ALS to access CuATSM.**

This created particularly strong interest in Australia and the UK, and also throughout the rest of the World

The Alliance was contacted by many of our member organisations for more information and so the Alliance has sought the advice of its Scientific Advisory Council for a balanced and scientifically accurate response to these claims.

After studying the data the response from the Scientific Advisory Council is as follows:

An Australian company called Collaborative Medicinal Development were funded through FightMND to run a Phase 1 clinical trial of a compound called CuATSM that ended in 2018. The trial was designed only to determine if CuATSM is safe for humans and to determine what dose (if safe) would be ideal to test in a further clinical trial (Phase 2 or 3) that would be designed to determine if it has the ability to alter ALS disease progression.

At the doses tested, using clinical grade CuATSM, it was considered safe, but a press release also stated that the company has seen a substantial slowing of disease progression. This clinical trial was not designed to make such a public statement and a number of aspects in its design require this result to be taken with as much caution as possible. Essentially, there is no substantiated scientific evidence that CuATSM has any effect on ALS in humans.

Furthermore, until there is a peer-reviewed publication of the data, it is not possible at this time to evaluate the safety beyond the claims of the release. A Phase 2 clinical trial is being set up to further test safety and to more rigorously determine if there is any effect on the course of disease.

The field remains hopeful that CuATSM will work, but the proper trials need to be done before anything can be known.

Please refer to the MND Association blog for a more detailed explanation: [www.mndresearch.blog/2019/01/15/whats-the-story-with-cuatasm/](http://www.mndresearch.blog/2019/01/15/whats-the-story-with-cuatasm/)

We hope this information is useful to our membership. Within the Scientific Advisory Council there is a significant level of knowledge regarding the pre-clinical data, key investigators, and clinical trial nuances surrounding CuATSM.

If you do have any other specific questions that are not answered by this response, they can be directed to the Scientific Advisory Council via the Alliance.

Please send these questions to [alliance@alsmnd.org](mailto:alliance@alsmnd.org)

## A DAY AT THE FLOREY!

Hear directly from **Assoc Prof Peter Crouch** at our **Day at the Florey** on **Tuesday, 7 May** where you can ask the MND experts all your research questions. The day will begin with presentations from leading MND researchers and is followed by lunch and laboratory tours in the afternoon.

**See the enclosed flyer for further information. Don't miss out! To secure your place, email: [info@mnd.asn.au](mailto:info@mnd.asn.au)**



# HOW CAN I HELP MND RESEARCH?

## Exercise and MND study

Researchers from the Institute for Health and Sport (Victoria University), in collaboration with neurologists at Western Health, want to better understand the role of personalised exercise training in patients with MND.

Their hypothesis is that moderate-intensity exercise training, tailored to the needs of each patient, will be beneficial in terms of maintaining strength and exercise tolerance. The maintenance of these functional capacities will help improve the physical independence and quality of life of patients with MND. Patients will participate in an exercise training program supervised by an exercise physiologist, 3 times/week for 12 weeks, at the Victoria University Clinical Exercise and Rehabilitation Clinic (VUCER), Footscray.

If you would like more information about this project, please contact: Dr. Alessandra Ferri, Ph: 03 9919 4756 or email: [alessandra.ferri@vu.edu.au](mailto:alessandra.ferri@vu.edu.au)

## Participate in Familial MND research

Professor Garth Nicholson and his research team based at the ANZAC Research Institute, Concord Hospital Sydney, are studying gene variations in familial motor neurone disease. Professor Nicholson and his collaborators are keen to obtain DNA samples from patients with familial motor neurone disease. To assist this research, a single blood sample is required together with your consent to take part in the research and, where necessary, your permission to obtain a copy of clinical information from your treating physician. The blood sample can be taken locally and then sent to Sydney for analysis.

If you are interested in donating, then phone (02) 9767 6796 or email [molmed@med.usyd.edu.au](mailto:molmed@med.usyd.edu.au) for further details.

## ALS Quest Survey

The ALS Quest survey is an anonymous online questionnaire looking at environmental risk factors for MND. ALS Quest is a University of Sydney project and you can take the survey online at: [www.alsquest.org](http://www.alsquest.org)

Both people with and without MND can fill in the survey—it takes approx 90 minutes to complete.

## Donate to the Tissue Bank

People with a diagnosis of MND confirmed by a neurologist are needed to donate tissue to MND research.

If you are interested in donating, or if you are just interested in finding out what tissue donation involves, please contact Fairlie Hinton, Coordinator, Victorian Brain Bank or find out more by visiting The Florey's website at: [www.florey.edu.au/vic-brain-bank](http://www.florey.edu.au/vic-brain-bank) or contact: [fairlie.hinton@florey.edu.au](mailto:fairlie.hinton@florey.edu.au) Phone: (03) 8344 1900 Mobile: 0438 530 372

## Join the Australian Motor Neurone Disease Registry

The MND Registry is an ambitious project to register and collect data from every person diagnosed with MND in Australia. It contains de-identified data from people diagnosed with MND including information about the diagnosis, symptoms, treatment and management. This information is made available to researchers studying MND.

The MND Registry provides people living with MND with an opportunity to actively contribute to research and learn more about the disease.

The participant's neurologist will fill out a case report form detailing the treatment and health situation at the time of the visit. There are no extra tests, procedures or treatments involved. People are free to decline or to withdraw from the study at any time.

If you would like any further information concerning this project please visit: [www.mndregistry.org.au](http://www.mndregistry.org.au) or contact Anna Smith by phone: 03 9595 3355 or by email: [anna.smith@calvarycare.org.au](mailto:anna.smith@calvarycare.org.au)

MND Advisors + people with MND in this region have close links with **Barwon Health**, **Calvary Healthcare** and **VRSS** for support and care.

ERIC TRAVELS APPROX  
**45,000**  
KMS EACH YEAR

**90** PEOPLE ATTENDED MND VICTORIA PRESENTATIONS FOR LOCAL HEALTH PROFESSIONAL SERVICE PROVIDERS IN THIS REGION DURING 2018

Palliative Care Shared Care workers are in **Wangaratta + Bendigo**.



The **Bendigo Walk to D'feet MND** is held in November each year. To sign up for a Walk near you, please visit: [www.mnd.asn.au/walk](http://www.mnd.asn.au/walk)



The **Bendigo Support Group** meet once a month at a cafe in Bendigo on Thursdays. The group currently has 15 members and includes partners, carers and support staff as well as the MND Advisor and partners of those who have died from MND.

Call MND Victoria to get involved or for further information about support groups: **1800 806 632** or email: [info@mnd.asn.au](mailto:info@mnd.asn.au)

**15** VIC LOCAL GOVERNMENT AREAS  
+ SOME TOWNS  
OVER THE BORDER IN  
SOUTHERN NSW

The **NDIS** rolled out across the **Mallee + the Goulburn Valley** in January 2019.

39% of clients in this area access the NDIS, however 61% are stuck with the 'My Aged Care' system which fails to meet people with MND's needs. You can help - please join our campaign to Make Aged Care Fair at: [www.mndaction.org.au](http://www.mndaction.org.au)

## REGIONAL FOCUS

SHEPPARTON HARNESS  
RACING EVENT ON  
FRIDAY 26 APRIL!



Now in its 4th year, the **Heathcote Bowls** event has become a regular feature on our events calendar every January. A huge thank you to the **Heathcote NeverGiveUp** crew for organising this fabulous fundraising day!

**\*\*All services and equipment needed by people with MND can be accessed in all rural areas of Victoria - please discuss your needs with your MND Advisor + Support Coordinator or Allied Health Professional \*\***



ERIC - MND ADVISOR +  
SUPPORT COORDINATOR

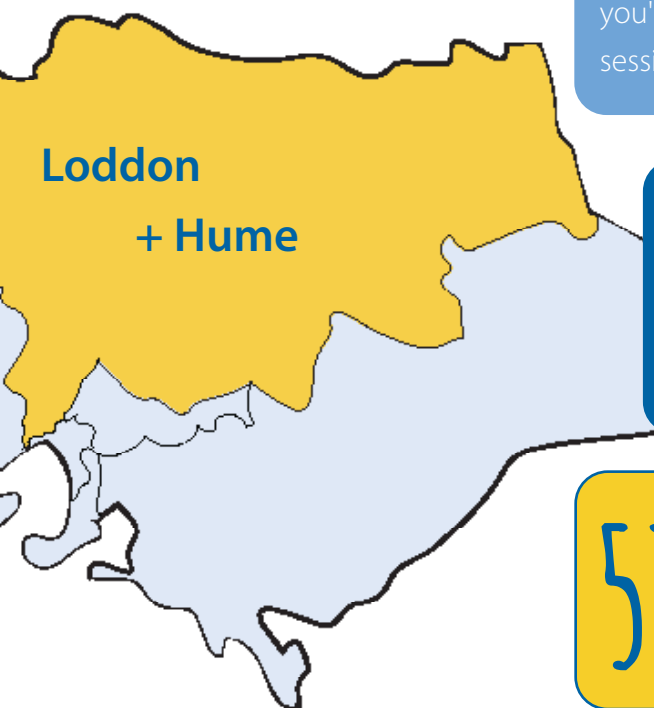
ERIC HAS BEEN AN MND  
ADVISOR AT MND VIC FOR  
**11 YEARS**

Our **MND Information Sessions** were held in **Echuca** and **Bendigo** during 2018 for people with MND, their families and friends. Contact your MND Advisor or email us at: [info@mnd.asn.au](mailto:info@mnd.asn.au) if you'd like an Information session near your area.



The first **Echuca Walk to D'feet MND** was held last year, organised by the Pagram-Waters family. They also held a Family Fun Day to raise funds for people with MND!

We can support you to start a Walk in your area, please email: [fundraising@mnd.asn.au](mailto:fundraising@mnd.asn.au)



Loddon  
+ Hume

TRACTOR TREK  
19-25 MAY IN  
JERILDERIE!

**57** PEOPLE WITH MND  
CURRENTLY LIVE  
IN THIS REGION



The **Benalla Act 2 D'feet MND** is in it's 12th year! It began after local Mick Rogers was diagnosed with MND and has raised in excess of \$600,000 for MND research since it began. This year Olympian Victoria Mitchell was one of the 500 participants in attendance!



The **MND 300** crew ran an incredible 300km last year from **Wangaratta to Melbourne** wearing Funky Trunks ... they raised over \$28,855 to support people living with motor neurone disease!



# TIPS, TRICKS + TRAVEL WITH MND

By Lyn Pow

I have MND and also have a PEG for feeding and when I go travelling or for an overnight stay I take a desktop phone holder to hold my syringe while I feed—it works well.

I went away for an overnight stay but I have used this for several days to try it out. You can save time if you put the nebulizer on the feed yourself at the same time.

I hope this will help people out there with my idea. Keep up the great work MND.

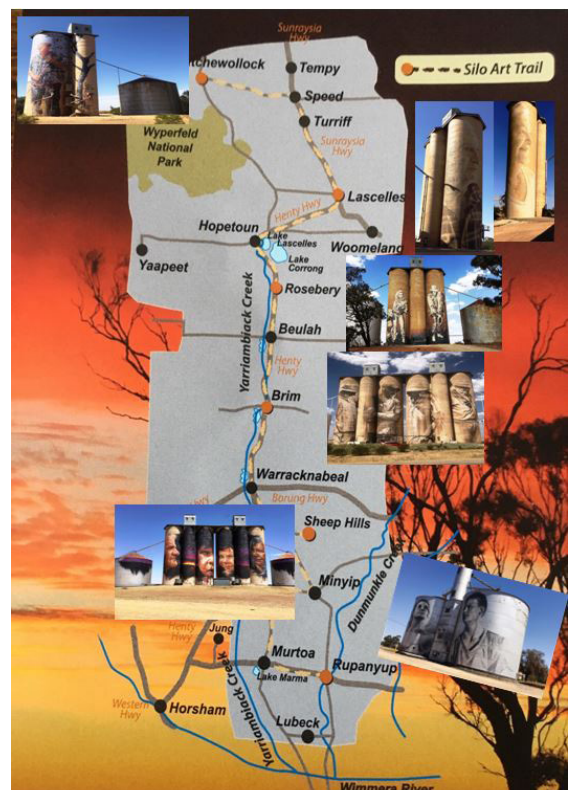
Here is a photo from just recently when I was traveling on the Silo Art Trail, in Victoria, Australia with my family, my daughter and her partner, me and my husband.



## WRITE YOUR MND STORY

We'd love you to share your MND story, poetry, travel adventures or tips and tricks for making life with MND a little easier.

Please email your text and a photo or two to: [info@mnd.asn.au](mailto:info@mnd.asn.au) by 8 May for our next edition.



# FUNDRAISING



**It's not about having the skill to do something, it's about having the will, desire and commitment to do your best.**

Every time we are contacted by someone who wants to hold an event for us as a way to show their appreciation of the services we deliver, we are reminded that the number one focus for everyone at MND Victoria is our clients. They are real people, with real lives who are now facing so many challenges each and every day. That's why we want to ensure we deliver the best possible care and support to families living with MND.

We know that, without our services, many families would struggle financially, and this is an additional burden they don't need.

There have already been a number of successful fundraising events this year – from Walks to Bowling Events and these activities have raised awareness and much needed funds. We continue to advocate for the over 65s because they are not able to access NDIS funding and, without access to our equipment service, many of them would be isolated or forced to move into an Aged Care facility away from family and loved ones. We are very grateful to everyone who continues to raise funds – you can be assured that these funds are very carefully managed to ensure that they are used wisely for the benefit of all Victorians living with MND.

Check out some of the events that have already taken place this year and don't forget to review our Events

Calendar and make your plans to join one or more of our fundraising activities this year.

## **MND Victoria Cares ... Always Has, Always Will**

Kathy Nightingale, Manager Supporter Development

## LARAPINTA TRIP!



**20 individuals have already signed up for our incredible adventure on the Larapinta Trail in Outback Australia on 16-22 September 2019. Training started a couple of months ago and a number of participants are enjoying getting to know each other on some of the best hikes around Victoria!**

The goal for all participants is to raise a minimum of \$3500 each which goes directly to the care, support and vital assistive equipment for all Victorians living with MND. So far the group have raised over \$21,000! All participants have a connection to MND in one way or another so we have no doubt that their passion to raise funds and awareness will help make this one of MND Victoria's largest fundraisers ever!

This is our third annual challenge event and we are absolutely thrilled with the crew we have on board. These adventures can be life changing or a simple break from reality. Signing up for any challenge can be daunting but knowing you are doing it to help others on top of challenging yourself is very rewarding. The fact that everyone coming to outback Australia with us this year knows how brutal MND, is and how much of an impact on family and friends it has, will make for a very powerful and special experience.

There's still time to join us: [www.mnd.asn.au/events](http://www.mnd.asn.au/events)  
Or contact Daniel: 98302122, [dwoodrow@mnd.asn.au](mailto:dwoodrow@mnd.asn.au)





## BENALLA PUTS MND RESEARCH PROJECTS ON THE MAP

**The Benalla and surrounding regions came out in good numbers to support the 12th annual Benalla Act2DfeetMND on Sunday 24 February, with over 500 people taking part in the walk.**

'Benalla, surrounding communities and the families affected by MND have been magnificent in their support of us and this event.' said Benalla Act2DfeetMND committee member Robyn Smith

This year's event saw participants come from a number of towns across the region to support the cause, many of whom have either a direct connection to someone suffering or, who have passed from MND, or they came to support friends of those affected. Participants this year came from Benalla, Cobram/Barooga, Shepparton, Finley, Kyabram, Mitchelton, Wangaratta, Tatura and Melbourne and many more towns.

The support of these communities and the local businesses has enabled the Benalla Act2DfeetMND

committee to raise in excess of \$600,000 to go towards MND research over the past 12 years.

**'Benalla has put research projects on the map and a cure is closer than ever because of the support you have shown.' Robyn Smith said.**

Olympian Victoria Mitchell was in attendance and took out the Benalla Railway Staff Queen of the Lake run as expected, slashing over 2 minutes off the race record set by Caitlin Sinclair in 2014.

We are so grateful to Benalla and surrounding communities for supporting MND research through the Act2DfeetMND over the past 12 years. A huge thank you to the organising committee, volunteers and all the local businesses who support the event every year.

To sign up for our Walks: [www.mnd.asn.au/walk](http://www.mnd.asn.au/walk)



# LAST RESORT!

80's Bayside Band LAST RESORT are having a reunion night in conjunction with MND Victoria at Chelsea RSL/Town Hall, 11th May to finish MND Week 2019.

We are raising money for the equipment needed to help people suffering motor neurone disease.

Your support would be greatly appreciated by either attending the night or donating.

**Tickets \$35.00** via Trybooking:  
[www.trybooking.com/470512](http://www.trybooking.com/470512)

Can't make it? Please donate at:  
[www.trybooking.com/BAUQAQ](http://www.trybooking.com/BAUQAQ)

*ALL proceeds go directly to MND Victoria.  
Donations are fully tax deductible.*



## LAST RESORT 80'S BAND REUNION BENEFIT CONCERT

**Grab your hoodies for winter: [www.mnd.asn.au/gear](http://www.mnd.asn.au/gear)**

## GRAB YOUR #NEVERGIVEUP HOODIES FOR WINTER!

Perfect for your winter training sesh or simply reading on the couch ... our #NeverGiveUp hoodies are super warm and deliciously comfy!

Grab yours for \$75 (includes shipping):

**[www.mnd.asn.au/gear](http://www.mnd.asn.au/gear)**

**ALL proceeds provide VITAL support for people with MND and fund research.**







# JOIN OUR ALL NEW SOUTH EAST MELBOURNE WALK

Starts MND Week - Saturday, 4 May 2019 in Pakenham: [www.mnd.asn.au/walk](http://www.mnd.asn.au/walk)



# DONATIONS WERE RECEIVED ... THANK YOU!

## In memory of

Althea Bernet  
Bernie Crockford  
Bert Jones  
Bill Dunn  
Collin Beatty  
Christopher Reeve  
David Mather  
Geoff Woodrow  
Gordon Robson  
Graeme Williamson  
John Walker  
Jarrod Hunt  
Jeff Bibby  
Kathy Chandler  
Kirsty Gough  
Lawrence Thewma  
Lesley Keene  
Leslie Alston  
Lynette Tantrum  
Madeline Phillips  
Madelyn Farrugia  
Margaret Williams  
Mark Lehane  
Mark Lundberg

Marlaine Stanway  
Martin Williams  
Michael Cuthbert  
Michael Larcombe  
Michael Taylor  
Nicola Baldo  
Nicola Di Camillo  
Nicole Hall  
Roger Stokes  
Sebastian Ravi  
Sharon Radford  
Stephen Rouse  
Stephen Wallis  
Trevor Ennals

## Organisations

The Cavity restaurant, Venus Bay  
Bennet's Butchery  
Sapphire Hairdressing  
The Australia Day Long Table Group  
Jolt Fitness  
The Brook Point Cook  
Warragul Linen Service

## Clubs

Heathcote Bowls Club  
Geelong Football Club

Croydon Bowling Club  
Telecom Fidelity Club

## Schools

Glen Iris Primary School  
St Mary's Primary School

## Corporate

Signiversal Vic Pty Ltd  
Ritchies IGA  
Specsavers Pty Ltd  
Express Insurance Brokers



*Thank you all so much for your support for the 440 Victorians with motor neurone disease!*

## MND Victoria Membership

### Have you renewed your membership for 2019?

You will have received a reminder if your membership is due for renewal. Please keep up your membership—we need you.

Please phone the office on: 03 9830 2122 or email: [info@mnd.asn.au](mailto:info@mnd.asn.au) for more information on MND Victoria membership.

## Contributions are invited!

MND Victoria members are invited to write stories, anecdotes, letters, or 'Handy Hints' for the newsletter. We cannot guarantee that all contributions will be published as this is dependent on available space, but every effort will be made to do so.

Please email your story or article with a photo to: [info@mnd.asn.au](mailto:info@mnd.asn.au) by 8 May for the next edition, to be mailed on 4 June 2019.



# GET INVOLVED IN AN EVENT NEAR YOU!

Date	Event	Contact
Sunday, 7 April 2019	Sonata Classics for Cello and Piano, Ballan	Phone: 0437 682 325
Wednesday, 17 April 2019	MND Information Session, Canterbury	Email: <a href="mailto:info@mnd.asn.au">info@mnd.asn.au</a>
Friday, 26 April 2019	Shepparton Harness Racing	Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a>
Saturday, 4 May 2019	South East Melbourne Walk to D'feet MND	<a href="http://www.mnd.asn.au/walk">www.mnd.asn.au/walk</a>
<b>5–11 May 2019</b>	<b>*** MND WEEK 2019 ***</b>	Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a>
Sunday, 5 May 2019	Service of Hope and Remembrance	Email: <a href="mailto:info@mnd.asn.au">info@mnd.asn.au</a>
Tuesday, 7 May 2019	A Day at the Florey - Ask the Experts	Email: <a href="mailto:info@mnd.asn.au">info@mnd.asn.au</a>
Friday, 10 May 2019	Blue Cornflower Day - host a fundraiser!	Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a>
Saturday, 11 May 2019	Last Resort 80's Band Reunion Concert	<a href="http://www.trybooking.com/470512">www.trybooking.com/470512</a>
19-25 May 2019	Tractor Trek, Jerilderie area	Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a>
20–26 May 2019	National Volunteer Week	Email: <a href="mailto:volunteer@mnd.asn.au">volunteer@mnd.asn.au</a>
Friday, 21 June 2019	Global MND Awareness Day	Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a>
Sunday, 30 June 2019	Stadium Stomp at the MCG	Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a>
Sunday, 28 July 2019	Run Melbourne	Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a>
16–22 September 2019	Larapinta Trek - Challenge event	Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a>

For further information and the latest events list, please visit our website at: [www.mnd.asn.au/events](http://www.mnd.asn.au/events)  
 Please email details of events you would like listed on our events calendar to Kathy Nightingale: [fundraising@mnd.asn.au](mailto:fundraising@mnd.asn.au) We can also provide you with our Event Flyer template to use for your event!



**Visit our website at: [www.mnd.asn.au](http://www.mnd.asn.au) or follow us on:**

[www.instagram.com/MND\\_Vic](https://www.instagram.com/MND_Vic) | [www.facebook.com/MNDVic](https://www.facebook.com/MNDVic) | [www.twitter.com/MNDVic](https://www.twitter.com/MNDVic)