

# MND NEWS

January/February

# 2019

The newsletter of the  
Motor Neurone Disease  
Association of Victoria

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



FEATURE! GO BEHIND  
THE SCENES WITH OUR  
EQUIPMENT SERVICE

COPPER-ATSM UPDATE INSIDE >>

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# 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-Crane

# 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                      Lauryn 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

# FROM THE CEO



**As many of you will be aware, I am retiring as CEO of MND Victoria and finishing employment on 12 April 2019. This may be my last communication with you as CEO of this wonderful organisation.**

Recruitment to fill the CEO role has commenced, and State Council is looking forward to completing that process and having the new CEO on deck.

Twenty five years is a long time in this role, and I acknowledge the ongoing efforts of State Council to keep me challenged and contributing. Their investment in me to engage with MND locally, nationally and internationally has continually presented challenges, learning, and opportunity to contribute to the fight against MND, and to improve support for people with MND in Australia and particularly Victoria.

What has driven me, and continues to drive me, are the people I have met over the years. There are far too many to identify personally, but I have been filled with wonder by the strength, resilience, bravery, optimism and hope of people diagnosed with MND and their families. Trying to live up to their expectations, to develop and deliver the services they need and want, and to maintain my hope, positive attitude and optimism for the future have been my greatest challenges.

I have been supported by a fantastic team of staff members who have been and are my colleagues and friends. They do the hard yards, delivering support and

services. My role has been to ensure that they have the resources to do the job, and to support them to maintain their own well-being, while they work to support others.

State government bureaucrats, especially those in Health, Disability and Palliative Care, have opened doors and taken on the challenge that is MND. In particular, we now have a palliative care system that actively works with MND Victoria and people with MND.

With the support of colleagues from other States, we have been able to drive a path through the NDIS to ensure that people with MND under 65, when diagnosed, have access to one of the best social support systems in the world, and it is getting better. And we have maintained our pressure to achieve the same for those 65 and over – not yet achieved but still working on it.

I have met and made friends with people around the world who share my passion to fight MND, and they have been models for me in my everyday work. My predecessors and successors as Chairs and members of the Board of the International Alliance of ALS/MND Associations have been models of compassion and commitment as we have grown recognition of ALS/MND as a global problem and a common fight of all countries. Their friendship and mentoring has always provided somewhere to turn to for ideas and help, and to offer the same in return - ongoing affirmation of where we are at in providing support, and maintaining aspirations as to where we could and should be.

Above all, I have relied on the support and love of Pam and our personal friends. Pam has ensured that my feet always remain on the ground, my head held high, and focussed on people with MND, while maintaining balance and peace in everyday life.

I will not be leaving MND. I intend to continue in a different role, offering to volunteer with MND Victoria and the Alliance. I will be at the Walk to D'feet, and other events, maintaining my knowledge and experience of MND, and contributing what I can to assist.

Thank you for your support. Until there is a cure, there is care. And we must never give up!

**Rod Harris**  
**CEO**



# BEHIND THE SCENES - MND VICTORIA STAFF VISIT OUR EQUIPMENT WAREHOUSE

*By Heidi Bryce and Carly McClen, Supporter Development Team*

**The Supporter Development team started the new year with a visit to the warehouse facility where most of MND Victoria's equipment is managed. It is a critical part of our services and makes an enormous difference to the lives of people with MND across the State.**

We met Josh Farmer, Account Manager – Assistive Technologies, along with his team at the equipment warehouse. They gave us an in depth, hands on experience of their role in the management of MND Victoria's assistive equipment. The facility also manages equipment for other organisations.

We were immediately struck by the sheer size of the warehouse and the breadth of essential equipment available to our clients as they need it. There is rapid turnaround of the equipment managed at the

warehouse—it can be requested at any time by an Allied Health Professional via MND Victoria's website to our Equipment Service team at Head Office who then put the dispatch request into the warehouse. It is then dispatched as quickly as possible to the person with MND at no cost to the client—if we have the equipment available in the warehouse, it can take as little as a week for equipment to be received by the client after we receive a request.

Our Equipment Service enables people with MND to remain mobile for as long as possible and live safely in their home. Melissa, whose father died from MND says,

**"We were able to keep Dad home for his entire battle with the aids and equipment the organisation supplied us."**



It is a huge operation, with over 3300 items of equipment currently on loan to people with MND. At any point in time, there may be 800+ equipment items flowing through the 4,200m<sup>2</sup> facility—either recently returned from a client and being cleaned, serviced or repaired, or in stock and ready to be dispatched to new clients as requested.

Josh shared, **"MND Vic have certainly bulked up and diversified their equipment fleet in recent times, and this has correlated with elevated demand to get the new assets out to clients throughout the State. We have seen a 19% increase in asset growth in 2018 compared to last year. Equipment delivery and collection requests have also increased by 22% this year."**

He said the warehouse team is, **"Proud to support all of those in need ... it is extremely rewarding for our team who will often go above and beyond to overcome the ever-changing circumstances that arise every day."**

Those affected by motor neurone disease may require multiple assistive technology items across eight categories: Bathroom, Bedroom, Communication, Daily aids, Furniture, Mobility, Transfer and Pressure care.

Josh explained that the Equipment Service at MND Victoria has direct access to the location and status of all tracked assets (both in-stock at the warehouse and those on location with clients). When an equipment request is logged through the system, the information is automatically loaded into a 'job' and the warehouse team is notified to ensure swift action.

For a delivery or re-issue request, a 'picking list' is generated digitally so the warehouse team can select

the exact items requested by the client's Allied Health Professional. Each item is inspected prior to dispatch, and the client or their carer is contacted to arrange a convenient delivery time and phoned again just prior to delivery to confirm.

The number and type of equipment items needed by our clients varies greatly, depending on disease length, type and progression. One client currently using our Equipment Service has 18 individual pieces of equipment. The cost to purchase this equipment, if MND Victoria's critical services were not available, would be in excess of \$35,000. A past MND carer wrote,

**"We could not have managed that ghastly disease on our own—physically, emotionally or financially."**

As people with MND often require multiple equipment items at any point in time and often urgently, equipment needs to be delivered in as short a time frame as possible. If a client was to order, and pay for a new piece of equipment themselves, the wait time would sometimes be very long. This is why our equipment is readily available and a reasonable amount of stock is kept in the warehouse so that we can efficiently process over 1300 requests from Allied Health Professionals for the 2000+ items of equipment we dispatch each year.

As Jo Whitehouse, Manager Support Services explains, **"Nearly 60% of requests for equipment we receive are urgent."**

It is due to the generosity of our donors and the dedication of our supporters that we have been able to build up our Equipment Service to the high standard it is today with enough assets to provide a responsive service to people with MND, a service which saves our clients thousands of dollars each year.



# SUPPORT SERVICES



**Happy new year to all! 2019 is already looking to be a busy one. We have hit the ground running with lots of plans for the year ahead including facilitating a Health Professional Forum in Tasmania on 1st March and looking at collaborating with MND NSW to develop an online learning platform—watch this space!**

Support Services is comprised of several programme areas:

- **Information and Resourcing**
- **MND Advisor and Support Coordination**
- **Equipment**
- **Volunteers**

Many of you know of and engage with our services however, in 2019, we thought we would showcase the different areas of our Support Services to highlight how we help and support people impacted by MND. In this edition the spotlight is on all things EQUIPMENT!

## Our Equipment Service

MND Victoria has a large range of disability aids and equipment, also called Assistive Technology (AT), available to help keep people living with MND safe and mobile—at last count, we had over 90 different equipment types consisting of 4040 pieces of equipment. The equipment ranges from daily aids to manual and powered wheelchairs, to hoists, ramps and electric recliner arm chairs.

The State-wide service we provide operates on a “re-issue model”. Clients must be registered with MND Victoria and be a Victorian resident living at home.

We also provide some equipment to people living in Residential Aged Care (RAC). RAC facilities are responsible for providing the majority of equipment to their residents, but there are some pieces of equipment such as powered wheelchairs that MND Victoria may be able to provide to RAC residents.

The equipment that we purchase is done with the guidance of allied health professionals and is selected to meet the requirements of the majority of our clients—we find that it meets over 90% of the needs of the people to whom we provide equipment. The equipment is generally standard in size but, where possible, has the option for flexibility, e.g. adjustable height.

We cannot provide “bespoke” pieces of equipment that are specifically tailored to an individual, but if there is an assessed need for this, we can often provide equipment that will suit a person’s needs whilst they are waiting for their therapist to source the individualised equipment required from alternative sources.

Requests for provision of equipment must be made by a qualified allied health professional e.g. an occupational therapist, physiotherapist or speech therapist.

### The Team

We have three fabulous staff and several wonderful volunteers who very capably run our Equipment Service:

- David Harkin, Coordinator Equipment Service
- Kathy Walker and Sandra Nicholls, Equipment Service Officers
- John McMillan and Margaret Smith, Equipment Service Volunteers.





MND Victoria has three external providers who manage most of our equipment; they deliver and collect the equipment, maintain, repair and refurbish it if it is economically viable to do so, and store it when it is not in use.

### The Cost:

Equipment is provided at no cost to the person with MND. MND Victoria does get some government funding to assist with the provision of our Equipment Service, however it is not sufficient to run the level of service that we provide, so it is heavily subsidised from fundraising dollars raised by the MND community.

### Some Interesting Statistics!

In December 2018:

- 98 separate requests for equipment were received
- 133 pieces of equipment were issued and
- 159 pieces of equipment were collected.

And December was a short month with Christmas sneaking in!

In the last 6 months of 2018:

- On average, 384 people had one or more pieces of equipment at any time
- Nearly 60% of requests for equipment we received were considered urgent
- 171 items of “non-retrievable” equipment were given to people living with MND, including shower chairs, over toilet frames, wedge ramps,

bedsticks and walking sticks. This is equipment that is low cost to purchase, and that would not, in most circumstances, be cost effective to collect, clean and re-issue.

- 124 repair and preventative maintenance jobs were completed. These are issues that have arisen other than during the normal collection and re-issue process.

REMINDER—MND Victoria has a number of iPad tablets available which can be provided to people with speech difficulties, or to those who live remotely within Victoria to assist in enabling communication with key people who are supporting them—family, friends and health professionals. Speak to your health professional or your MND Advisor if you are interested.

For further information about the Equipment Service, please contact the team on (03) 9830 2122 or 1800 806 632 or email: [equipment@mnd.asn.au](mailto:equipment@mnd.asn.au)

## Other Support Service snippets!

**NDIS—the final push:** Outer Gippsland, the Mallee and Goulbourn are the final areas in Victoria to phase into the scheme. In Tasmania, people aged 50 to 64 will also commence phasing in from 1st January 2019.

**Information packs:** We give out Information packs called “Everything Within” (remember the blue zippy folder?!) to all new people with MND who register with us. We are reviewing what is included in this pack and would welcome your feedback. Sarah Wilkie from our information team will be conducting a mini survey over coming weeks.

## New staff - Tasmania



We haven't had any new staff in Support Services for a little while now! **Jacqui Holland** is a new MND Advisor

and Support Coordinator who will be commencing in the role on the 14th February. Prior to relocating to Hobart with her family, Jacqui worked in Melbourne as a Speech Pathologist. She will be based in Hobart and will be working 2 days a week.

As always, we welcome your feedback! Please don't hesitate to email or call me.

### Jo Whitehouse, Manager Support Services

Email: [jwhitehouse@mnd.asn.au](mailto:jwhitehouse@mnd.asn.au) or phone: 0402 183 140

## INTRODUCING CARLY, OUR NEW MARKETING & MEDIA OFFICER



We are excited to introduce our new Marketing and Media officer Carly McClen. Carly brings an extensive successful career in marketing and communications. Carly shared, **"I am very excited to join this premier organisation that ensures quality care for all patients and dedication to advancing the science."**

On Carly's first day with us, she visited our equipment warehouse to get a behind the scenes experience of both the breadth of equipment available to our clients and the high quality operations required to meet the (2,890) equipment requests we receive each year.

## MND SPOKESPERSON

**At times, the media contact us to identify a person with MND to provide comment on an issue. Usually that will be about research, as it was recently with the announcement of the Cu(atSm) phase 1 trial.**

But it might be other things! It could be there is an issue for people over 65 accessing services. Or could be anything else.

We are looking to have available a list of people diagnosed with MND who are willing, at relatively short notice, to be a spokesperson for people with MND. The media are sick of the CEO and staff members telling a story—they want to hear from real people affected by MND.

If you would like to be a "spokesperson", we need you to:

- Have an email address—so that we can contact you and provide background material for you and comments you may wish to make
- Have a mobile phone so that we can text message you when something is very urgent, and is a backup to email
- Indicate if you communicate with speech, speech synthesiser or by text
- Tell us how available you are.

We will maintain a list and contact people as appropriate when required. We will also check with you regularly and make sure we understand your circumstances. We will keep that list confidential with MND Victoria, and we will seek your permission before providing any details. If you prefer, we will give you the contact details of the media and you can call or email them.

We will make sure that you have background information on the issue at hand as far as we can.

If you would like to be a spokesperson, please email me at [rharris@mnd.asn.au](mailto:rharris@mnd.asn.au) and I will send you a short form to be completed and returned to me.

It would be fantastic if we could have five or six people ready, willing and able to be our MND spokesperson! And to be able to put the human face of MND in the media!

## INFORMATION SESSIONS

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

**7pm on Tuesday, 5 March at MND Victoria,  
265 Canterbury Road, Canterbury.**

Please RSVP by 5pm, Monday, 4 March 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 Wednesday,  
17 April at 7pm in Canterbury.

# HONOUR FOR MND CRUSADE



By Olivia Reed, reprinted with permission from the Geelong Advertiser, Picture: MARK STEWART

CHRIS Hall's perseverance and determination to fight motor neurone disease by raising more than \$25,000 for MND Victoria has earned him a prestigious national award. The Leopold resident was last month awarded a Pride of Australia Medal for his volunteer work and fundraising over the past four years.

The awards, now in their 14th year, celebrate the extraordinary achievements of Australians to the benefit of their community. Mr Hall started raising money for MND research in 2015 after his work friend, Jenny, at Barwon Health passed away from the disease.

"Every year, when flu vaccinations came around Jenny would always have a good chat with me and see how I was doing, but Jenny unfortunately passed away after a 14-month battle with this horrible disease," he said. "After I found out that Jenny had MND, I thought to myself 'What is MND?'"

So I did some research and I was horrified to learn there was no treatment or no cure. I then said to myself 'What can I do to try and help find a cure?'"

Mr Hall said he was "completely honoured and shocked" to receive the Pride of Australia, which recognised eight extraordinary Victorians, this year. His award stated he was "recognised for living a life full of passion and commitment to causes, and prevailing through physical adversity".

Mr Hall, who has scoliosis and is confined to a wheelchair, has been wheeling 50km around Geelong each month since 2016 to raise money for MND research.

Last month the dedicated volunteer added another fundraiser to his list when he hosted a Music Marathon for Wheel 4 MND at Black Hatt Geelong. People can donate to Mr Hall's fundraiser for MND research at <https://chuffed.org/project/wheel4mnd> or follow his fundraising journey on Facebook at Wheel 4 MND.



## MND HEALTH PROFESSIONAL FORUM

Learn from the MND experts in Tassie on **Friday 1 March 2019** at the **Launceston Conference Centre**. The theme of the forum is 'Navigating MND: Charting a course for health professionals'.

**Keynote speaker is Dr Helen Castley, Staff Specialist in Neurology at Royal Hobart Hospital. Presentations by MND experts from Calvary Health Care Bethlehem in Melbourne.**

Please book your tickets, \$120 at: [www.trybooking.com/BAABU](http://www.trybooking.com/BAABU)  
Further information, or any questions, please contact MND Victoria: 03 9830 2122 or email: [info@mnd.asn.au](mailto:info@mnd.asn.au)

**Please share widely throughout your networks.**

# 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>

**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/340781642962036/](http://www.facebook.com/groups/340781642962036/)

## 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)

## ACCESSIBLE TELECOMS

### A new nation-wide disability telecommunications information service goes live

In December, Australian Communications Consumer Action Network (ACCAN) launched Australia's first independent information resource for telecommunications products suitable for people with disability.

Known as the Accessible Telecoms project, the interactive website and call centre will be the much needed one-stop shop for information about the accessibility features of both mainstream and assistive telecommunications equipment suitable for people with disability. It is made possible thanks to a National Readiness grant from the National Disability Insurance Agency (NDIA).

Telecommunications are now a vital part of our everyday lives, from accessing government services, to keeping in touch with family and friends. This is no less true for the more than 4 Million Australians who identify as having a disability. It is essential that every one of us is able to connect and communicate using telecommunications.

Accessible Telecoms will provide information about the accessibility features of telephone handsets (fixed, mobile and teletypewriters) as well as the accessories which make them usable for people with disability.

The service will also provide information about available set-up, training and on-going support that can provide people with disability with the skills and confidence to maximise the benefits of telecommunications access. Over time the information available will expand to include accessible tablets, mobile apps and software that can enable people with disability to connect with the telecommunications networks.

"I am excited about the new service from ACCAN. The community needs better information about accessible telecommunications suitable for people with disability, and the ACCAN referral service has the potential to provide this," said Alastair McEwin, Disability Discrimination Commissioner. "It is so important that we facilitate connectedness and participation across our communities, and creating accessible communications is essential to that."

Accessible Telecoms is available at [www.IDEAS.org.au](http://www.IDEAS.org.au) or by phoning IDEAS on 1800 029 904.

For more information read the Accessible Telecoms Information Sheet or contact Wayne Hawkins at [accessible.telecoms@accan.org.au](mailto:accessible.telecoms@accan.org.au)

# VOLUNTEER NEWS!



**Welcome to 2019. I hope you were able to have a break and I am looking forward to working you in 2019.**

We were delighted to share a day with a number of our volunteers in the lead up to Christmas and to be able to acknowledge Ann who has volunteered with MND Victoria for 10 years. Thank you Ann, for your ongoing support and commitment to our work and to supporting our clients.

Our volunteers work both with people with MND and across our entire organisation. Did you know that we have two equipment volunteers who help our Equipment team supporting people to access the equipment they require? We are very grateful to John and Margaret for their dedication to helping people with MND.

**John writes ...** "I am a Friday volunteer in the equipment department at MND Canterbury. I do data entry, help update client orders and the collection and dispatch of equipment. I have volunteered for many



years at various MND events and upon retirement took on a more regular role. I have always found that all the staff and other volunteers are very friendly and inclusive and would highly recommend to anybody with some time to spare to see what roles are available.

I see what a difference any volunteering makes to the overall running of the Association and its ability to give more care to the people living with MND."

**Margaret says ...** "I have been an MND volunteer for six years and it was always my intention that, after I retired from my position as a Personal Assistant to a Hedge Funds investor, I would volunteer at MND. My father lived with MND and passed away in 1980, aged 63, and at that time our family didn't realise, and we weren't given any information about MND, and of the horrific consequences of the disease. At that time there was no MND Association, so no support and no advice.



I am in the Canterbury office every Monday for five hours and, as well as reception and administration duties, I assist David, Kathy and Sandra in Equipment Service. Every week they arrange for around 40-45 pieces of equipment to be delivered to MND clients. My role is to ring or email each client to confirm the equipment has been received and also ensure that there are no problems or concerns. Depending on the amount of equipment distributed, this can take up to two hours. I enjoy my interaction with the clients and also the Equipment Service team.

After I finish contacting the clients I enter receipt of the equipment into the iCase database and this task can take up to two hours. This means that I am assisting Equipment Service for around four hours each week and this enables them to concentrate on getting the equipment out and dealing with other tasks and any other issues that may arise. During this time I am sitting

on Reception, answering the switchboard, franking and then posting the daily letters and dealing with any administration tasks as they arise. My role as an MND volunteer is very rewarding and fulfilling and I enjoy working alongside the MND staff who are very dedicated and caring. I am sure Dad would have benefited from and enjoyed the many valuable services that MND Victoria is currently providing to our clients."

***Would you like to volunteer with us in 2019? Here are some opportunities:***

**Campaign Champions**—our project to seek change for people living with MND has commenced and we are building the team of Campaign Champions around the state. If you would like to be involved in meeting with Local, State and Federal MPS and community groups to raise awareness around some of the issues faced by people living with MND this may be a role for you! It's perfect for people who seek a volunteer role

which is flexible and dynamic. If you have a couple of hours a week to make a difference, this role could be for you. Full training and ongoing support is offered. Contact **[volunteer@mnd.asn.au](mailto:volunteer@mnd.asn.au)** or **[mndaction@mndaustalia.org.au](mailto:mndaction@mndaustalia.org.au)** to learn more or read the Role Description on the MND Action website.

**Reception Volunteers**—we have a regular Friday afternoon position available on Reception at Canterbury Office, and are also looking for Relief Reception volunteers to join our team. Our volunteer receptionists are the frontline contact point at the MND office in Canterbury. Reception shifts are 3.5 hours morning or afternoon. These roles would suit people who are interested in learning lots about MND Victoria.

If you or someone you know would be interested, please contact me by calling 9830 2122 or email **[volunteer@mnd.asn.au](mailto:volunteer@mnd.asn.au)**

**Deb Olive, Coordinator Volunteers**

## GIVING THANKS TO MND VICTORIA

Hello my name is June. I am 86 years old and up until June 2018, I was a reasonably healthy person who led an active life and loved communicating/ socialising with family and friends. I still live at home independently in a rural property in the Outer Eastern suburbs of Melbourne, luckily I'm also still able to drive!

Unfortunately, soon after being diagnosed with Motor Neurone Disease (Bulbar Onset), I have already experienced significant changes in my speech and my swallowing. I have found these changes extremely frustrating/distressing, given I am such a proud and independent person.

My family registered me with MND Victoria and shortly after I received a visit from my MND Advisor (Rachel). She has supported my family and myself to access the supports I need to understand what services are out there and she has assisted us in accessing them.

At no cost to myself, MND Victoria has sent me a nebuliser, a boogie board, a personal alarm and an iPad. All of these items have helped me enormously and I know I can access further equipment as I need it.

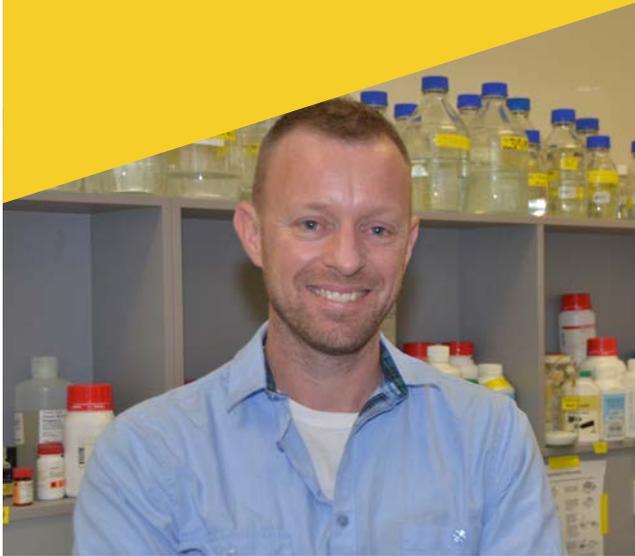
**I decided that the only way I could say thanks and show my appreciation to MND Victoria for all their caring support, was to hold an afternoon tea to raise awareness and some money in the way of donations.**

So, on November 25th, I prepared a lovely afternoon tea in my garden. Family and friends came, gave generously, had a lovely time and best of all we raised \$2100! I'm sure this money will be used to help others who have been diagnosed with MND.

The people who work and volunteer at MND VIC are amazing people. Thank you all!



# RESEARCH UPDATE



## COPPER-ATSM UPDATE

*By Dr Peter Crouch, University of Melbourne*

Clinical outcomes for copper-ATSM as a treatment for MND have very recently been reported in the media, with some of the reports describing exciting results for efficacy.

We all desperately hope for the day when any person diagnosed with MND can be prescribed a drug that will stop the disease in its tracks. Copper-ATSM may one day prove to be that drug, but we're not there yet. Here, we provide a brief update on copper-ATSM.

The development of copper-ATSM as a treatment option for MND started around 15 years ago when it and related compounds were tested in animal models of neurodegenerative disease. Over the years, the laboratory-based evidences supportive of copper-ATSM being an effective treatment accumulated to the extent where clinical testing in MND patients became a legitimate possibility. It was given to MND patients as a therapeutic for the first time in 2016 when the phase 1 testing commenced. In December 2018, outcomes from the phase 1 trial were announced at the International ALS/MND Symposium in Glasgow, and in January 2019 the same information was circulated as a press release from the company supporting the clinical testing, Collaborative Medicinal Development.

First and foremost, the phase 1 trial was a success. The primary objective, as per any phase 1 trial, was to assess safety and tolerability of the drug and, if possible, identify a dose that could be taken to the next round of testing. By assessing the drug at a number of different doses the trial successfully identified a safe and recommended dose for phase 2 testing. Many potential drugs that show promise in the research laboratory ultimately fail to get through phase 1 testing, so for copper-ATSM to get past this important milestone is an excellent achievement.

In addition to confirming that the drug is safe, reporting on the phase 1 trial also included descriptions of efficacy, such as improved respiratory function and a slowing of disease progression as assessed by the ALSFRS-R scoring system. These are very exciting indications that copper-ATSM may prove to be an effective drug for MND. However, the number of patients included in phase 1 testing (for any drug) is kept small by necessity, and phase 1 trials are not designed to demonstrate efficacy. For example, all patients in the phase 1 trial knowingly receive the drug and there is no placebo control group for direct comparison. So, while the phase 1 results for copper-ATSM are very encouraging and are good cause for excitement, there is still a considerable amount of work to do before it can be confirmed that copper-ATSM is an effective treatment for MND.

It is therefore very welcome news to hear that planning for copper-ATSM to enter phase 2 testing is already underway. Phase 2 trials are specifically designed to assess efficacy. It is reported that the phase 2 testing will start in the second half of 2019 and that the trial will include 80 MND patients. Details of the phase 2 trial, including the participating clinics and the patient recruitment criteria, are yet to be announced.

Upon completion of the phase 2 testing we all hope that the promising indications from the phase 1 trial are confirmed as a reality.

Further discussion of the phase 1 trial for copper-ATSM can be found here: [www.mndresearch.blog/2019/01/15/whats-the-story-with-cuatsm](https://www.mndresearch.blog/2019/01/15/whats-the-story-with-cuatsm)

Further information is on the MND Australia website at: [www.mndaust.asn.au/News-and-media/MND-in-the-news](http://www.mndaust.asn.au/News-and-media/MND-in-the-news)

# THE LARGEST MEDICAL & SCIENTIFIC CONFERENCE ON MND IN WORLD

– exclusive report by our CEO



**In December 2018, I attended meetings of the International Alliance of ALS/MND Associations, the Allied Professionals Forum and the International Symposium on ALS/MND.**

At the Alliance meeting, we heard about the work done over the past year by the Alliance, growth in membership, new staffing, grants for members to attend the meeting, elected new Board members and a new Chair. It has been a successful year, with increased funding from sponsorship reducing the cost of the Alliance operations.

Presentations were made on a range of topics, including advocacy, support for people with MND, partnership activities, stakeholder engagement and organisational development. A strategic planning exercise provided excellent information, and suggestions for the coming year, and a new strategic plan will be developed.

Dr David Taylor (ALS Canada) gave an entertaining and comprehensive presentation regarding the state of research, especially focussing on genetics and drug trials. He highlighted that we know more genes and have more targets for ALS treatments than ever before, and more drugs in phase 1 trials. David's slides are at <https://bit.ly/2sk8FSs> and his presentation is at <https://bit.ly/2RIKM5k>

MND Australia presented an invitation to attend the next meeting in Perth, WA in 2019.

The Alliance Meeting program and abstracts of presentations can be found at <https://bit.ly/2GVovNy>. Presentations can be viewed at <https://bit.ly/2H6g6aj>

The 'Ask the Experts' was an excellent presentation, largely mirroring the presentations at MND Connect and our own 'Ask the Experts' sessions. The big learning experience for Perth was the use of live streaming of the session via Facebook. I watched from my hotel room!

The Allied Professionals Forum was again a highlight. Sixteen excellent presentations covering a wide range of topics aimed to give take-home tools and ideas for allied health professionals to trial and implement. Topics included information provision, respiratory support, children's services and NIV. Bereavement support presented a series of challenges, including who should take responsibility for this much needed support.

Sexuality and intimacy finally made the stage, with a very sensitive presentation regarding discussion during MND. Music and Art therapy were discussed as rehabilitation in both group and individual modes. And the use of cannabis extract was presented, highlighting some of the early benefits found in ALS/MND.

A newly created award, recognising a person who had made a significant contribution locally, nationally and internationally to allied health and people with ALS/MND was awarded to Dr Sara Feldman, ALS Hope Foundation.

The program book, including CVs and Abstracts, can be downloaded online at: <https://bit.ly/2RuSAYs> The presentations are at: <https://bit.ly/2VEV9Gn>

The International Symposium on ALS/MND is presented in two streams, science and clinical, with research focussed presentations across a range of themes.

The role of environmental factors, metabolism, and physical fitness continue to be areas of interest in identifying who is at risk of developing ALS/MND.

It is also known that significant numbers of people, even without a family history, may carry detectable genetic variants which may cause or contribute to their diagnosis and condition. Presentations looked at how we can support people in making informed choices about genetic testing where specific therapies are beginning to emerge and be developed.

The role of different neuronal compartments, axons and synapses in ALS/MND continue to be examined to understand disease onset and progression. Advances in single cell biology show promise to raise knowledge to new levels where precise events which trigger ALS/MND can be seen.

Disease progression, including cognitive change and its impact on quality of life was discussed as critical to care planning and individual autonomy, and informing clinical trial design. (adapted from the Symposium Programme Forward, by Kevin Talbot)

We learned also about improvements in care of the disease. The one care improvement I found most interesting was in respiratory care. If we exercise the breathing muscles for expiration (breathing out), we can improve strength which leads to improved volume of speech and ability to cough up secretions. We also learned about our microbiome. This is the bacteria in our gut that may set up an inflammatory cascade and influence the development of neurodegenerative diseases like ALS/MND.

Some of the most exciting developments are the recently initiated and soon to be started trials in genetic forms of the disease. This is exciting because, for the first time, we are applying specific treatments for the type of ALS someone has. In the case of SOD1 based ALS and C9ORF72 based disease; the strategies will block abnormal protein from being produced.

We also heard about new and ongoing trials for ALS that are not related to the genetic variants specifically. We have treatments that are directed at respiratory muscle strength (reldesemtiv and levosimendan), anti-inflammatory medications (Acthar, Tocilizumab), drugs that modify excitability of neurones (Retigabine), and drugs that modify oxidative stress by altering SOD activity (CuASTM) among others.

Please note that these trials may not be available in Australia. (adapted from the ALS Hope newsletter, Dr Terry Heiman-Patterson)

My most important take home messages are that great steps are being made in identification of cause, development of treatments, and progress towards finding interventions. The meetings highlighted the importance of the global fight against ALS/MND, and the parts that many players have in this work. Attendance reaffirmed the quality and effectiveness of the services we provide to support people living with MND. It also underscored that **until there is a cure, there is care!**

## 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.

The TRAIN-ALS project has received Ethics Approval and the recruitment phase started in April 2018. The project aims to recruit 24 patients with MND—more patients are still required. Patients will participate in an exercise training program supervised by an exercise physiologist, 3 times/week for 12 weeks, at the new Victoria University Clinical Exercise and Rehabilitation Clinic (VUCER), Footscray. This is the first study with a large sample of patients to define if exercise could be

used as personalised medicine to improve the lives of those with MND.

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 on The Florey's website: [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)



## WRITE YOUR MND STORY

We'd love you to share your MND story, poetry, or tips and tricks for making life with MND a little easier. Please email your text and a photo to: [info@mnd.asn.au](mailto:info@mnd.asn.au) by 6 March for our next edition.

1 January 2019 saw the **NDIS roll out commence completion** across this entire region.



LAURYN MND ADVISOR +  
SUPPORT COORDINATOR

The **Daylesford Dunking Derby** organised by the Walsh family raised \$22,725 last year - thank you!!



# REGIONAL FOCUS

North West,  
Grampians  
+ Central  
highlands

35 PEOPLE WITH MND  
CURRENTLY LIVE  
IN THIS REGION

18 LOCAL  
GOVERNMENT  
AREAS

45% of clients in this area access the NDIS, however 55% 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)

LAURYN TRAVELS  
26,000+  
KMS EACH YEAR



The **Ballarat Support Group** is a group of carers and volunteers with 21 members. They meet on the last Friday each month from 1pm for general friendship and to support those with MND. They also fundraise locally.

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

The **Ballarat Wood Workers Guild** raised \$806 by donating pieces of their craft to be sold at the Annual Ballarat Wood Show Heritage Weekend

The new **Melton Support Group** meets monthly on Fridays at the Melton Country Club. Contact MND Victoria: 1800 806 632 or email [info@mnd.asn.au](mailto:info@mnd.asn.au) for more information.

\*\*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 \*\*

# FUNDRAISING



**Change is inevitable, change will always happen, but you have to apply direction to change, and that's when it's progress. Doug Baldwin, US Athlete, 1988 -**

The start of a new year is a great time to review and refresh how we can enhance our supporter's experience with us. We realise that people who dedicate their time and resources to raise funds for MND Victoria do so because they have been impacted by the disease. They are committed to the cause—they want to help people living with MND today, as well as help fund research into cause, treatment and cure. We want all our supporters to feel they are part of our team and that we want to be with them every step of their journey—from the first time they contact us.

I am therefore pleased to let you know that as a result of our review, we have appointed Carly McClen as our Marketing & Media Officer. Carly joins our team so that we can expand the resources available to assist you in your awareness and fundraising efforts. Carly has several year's experience assisting community organisations identify new opportunities to enhance their supporter experience, expand their markets, and increase their fundraising. She thrives in creating relevant and engaging social and online content, and managing digital implementation aligned to supporter events and campaigns.

As a member of our Supporter Development Team, Carly joins Heidi and Daniel and I as we continue our

efforts to raise the \$3 million plus that is needed each and every year to help underwrite MND Victoria's service delivery. This is a huge challenge and we will only be successful if you are successful.

Please check out our 2019 Events Schedule and make a point of participating in at least one event. If a "challenge" event is not for you, there are lots of other ways you can fundraise, such as a BBQ, Drink Tea for MND, Trivia Night or bowling. The list is endless and limited only by your imagination. Or perhaps you'd prefer to donate to our Appeals or Donor Updates, become a regular monthly donor or nominate MND Victoria as a gift recipient in your Will? Phone: 03 9830 2122 for more information.

We can only continue to deliver services to the 400 plus Victorians living with MND every day thanks to the continued financial support of our generous donors.

Whether your support is through participating in Challenge events, one of the various Walk to D'feet MND events, responding to our Appeals or Donor Updates, being a regular monthly donor or nominating MND Victoria as a gift recipient in your Will—each of you are a vital part of the MND Community.

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

**Kathy Nightingale, Manager Supporter Development**

# LARAPINTA TREK 2019!

**Our annual major challenge event is less than eight months away! This year we are heading to Outback Australia to take on the Larapinta Trail!**

The response has been remarkable, selling out our first trip in record time. We've been fortunate to secure a second trip, at the same time with all the same details! There are 12 spots left and we'd love to have YOU!



We've had some amazing stories from our participants:

Kellie writes, *"I want to make a difference in memory of my courageous and beautiful Mum who lost her battle in 2014. In 2019, Len and I will be walking along the Larapinta Trail in the NT, covering over 60km in five days and camping out under the stars. It's something that I feel would be a wonderful way to remember my mum and raise much needed funds for Motor Neurone Disease (MND) to continue their assistance for people living with MND"*

*"To see our beautiful friend and her family having to live with this shitty disease is truly heartbreaking. Myself (Beck), having taken part in the Kokoda trek in 2018, have got my hubby (Scott) on board and we will be trekking Larapinta in 2019! We want to help make a difference."* Beck and Scott wrote.

Greg and Sally are excited to join the trek, *"We love a challenge, but we are also inspired by how our friends with Motor Neurone Disease, and their families and community, are responding to a greater challenge than we have ever run into. We are very proud to be once again supporting MND Victoria and continuing to raise much needed funds and creating awareness."*

Sarah is also joining us, *"After losing my Dad to MND 3 years ago, I promised myself I would do anything I can to help provide support and care to others whose lives have been touched by this hideous disease. MND is relentless both physically and mentally, and it takes people like you and me to help provide the Support and Care to those suffering from MND and ULTIMATELY find a cure for this Disease!"*

Please contact Daniel: [dwoodrow@mnd.asn.au](mailto:dwoodrow@mnd.asn.au) or 03 9830 2122 for more information or to join the trek!

## MND HOODIES GO GLOBAL OVER SUMMER!

Our Hoodies had a white Christmas in both England and Canada ... and our Walk to D'feet MND Tshirt and wristband made it all the way to Mauritius. Grab all your MND gear online at: [www.mnd.asn.au/gear](http://www.mnd.asn.au/gear) ... perfect for raising awareness wherever you travel!



# ROCK OFF MND 2019!

Rock Off MND will be held from 5pm on Saturday, 23 March 2019 at Deakin Waterfront Geelong. Tickets \$65 at: [www.rockoffmnd.com.au](http://www.rockoffmnd.com.au)

Rock Off MND is a live music event that raises much-needed funds and awareness of Motor Neurone Disease (MND).

Rock Off MND was inspired by Jenny Simko. All net proceeds from the event are donated to MND Victoria to support vital MND research.

Rock Off MND is thrilled to have the legendary Russell Morris and band as the headline act for this year's event, with great support from the very talented Jack the Fox. The night will then party on with the brilliant Groove Star.

# ROCK OFF



Photograph: [www.patrickcallow.com](http://www.patrickcallow.com)

Grab your Rock Off MND tickets: [www.rockoffmnd.com.au](http://www.rockoffmnd.com.au)

## WALK TO D'FEET MND IN BENALLA OR GEELONG!

Join us in Benalla at **8.30am, Sunday 24 February 2019** at Benalla Lake Foreshore. You can choose to walk, cycle, relay or run to D'feet MND! Sign up at: [www.act2dfeetmnd.com](http://www.act2dfeetmnd.com)

Our Geelong Walk is on at **10.30am, Sunday 24 March 2019** at Barwon Valley Fun Park, Barrabool Road, Belmont. Show your support for people with motor neurone disease by walking with us, register online at: [www.mnd.asn.au/walk](http://www.mnd.asn.au/walk)

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



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



# AN INCREDIBLE \$250,000 RAISED

## FROM OUR ROSEBUD, MELBOURNE, BENDIGO AND ECHUCA WALKS!



**In an amazing result, the funds raised from our Walk to D'feet MND for the 2018 Walks in Rosebud, Melbourne, Bendigo and Echuca has surpassed \$250,000—an outstanding result!**

A huge thank you to everyone who attended and fundraised and thanks to all our amazing volunteers who helped organise all these events and volunteered on the day, we couldn't have made this result without you.

The prize winners for the Walks held so far are as follows:

**MELBOURNE:** Largest Team—Team Rob Loomes with over 70 participants followed closely behind by Team Jo and Leanne's Awesome Walkers

Most Funds raised by a team: Fabian's Family & Friends

Most Funds raised by an individual: Victoria Conners

**BENDIGO:** Largest Team—Barry Baker's Team with over 22 participants followed closely by Lawrence Thewma Fundraiser

Most Funds raised by a team: Team Heathcote followed closely by Family Fernandes

Most Funds raised by an individual: Benji Featherstone

**ECHUCA:** Largest Team—tie between Team Kev and Team Woopy

Most Funds raised by a team: TBA

Most Funds raised by an individual: TBA

**See you soon at our Benalla and Geelong Walks!**

# DONATIONS WERE RECEIVED ... THANK YOU!

## In memory of

Adrian Bonde  
Bernice Everton  
Brendan Coustley  
Brita Daly  
Carol Eden  
Christopher Ross  
Cliff Smart  
David Williams  
Dorothy Dickson  
Florence Williams  
Geoff Blake  
Glenn Peters  
Graeme Furphy  
Graham Henry  
Ian Scott  
Irene McInermey  
Jane McKendrick  
John Ryan  
John Smith  
Ken Brentwood  
Lawrence Thewma  
Les Hodge  
Lindsay Graham  
Madeline Phillips  
Malcolm Duff  
Maree Jones  
Maris Agius  
Martin Williams  
Max Sartori

Nicola Baldo  
Peter Kantzo  
Richard Edwards  
Richard Morgan  
Robert Kramer  
Sera Trantino  
Stephen Nicholls  
Susan Meredith  
Susie Harris  
Lionel Trudgen  
Sebastian Ravi

## Trusts

The William Angliss Charitable Fund

## Organisations

Lorraine Lea Linen  
Eastern Volunteers  
BizyBodies Health & Fitness  
The Village Glen  
The Pheonix Hotel  
Middy's Electrical Benalla  
Espresso Mobile Café- Wheelers Hill  
Jolt Fitness

## Clubs

Chrysler Restorers Club of Australia-  
Victoria Incorporated  
Australian Hellenic Golf Federation  
Lions Club of Boroonda Central  
Highvale Retirement Village Social  
Club

Mitcham Scottish Society  
Western Heights Tuesday Morning  
Badminton Club  
Pines Cricket Club

## Schools

Plenty Parklands Primary School  
Yinnar Primary School  
Our Lady's Primary School—  
Craigieburn  
Eltham Secondary College  
Sandringham Primary School  
Whittlesea Secondary College  
Whitehorse Primary School  
St Joseph's College  
Methodist Ladies' College

## Corporate

Express Insurance Brokers  
Qenos Pty Ltd.  
Bendigo Law Association  
Costanzo Harris Pty Ltd  
Handy Steel Stock Pty Ltd.  
Ritchies IGA  
Rens Nominees Pty Ltd  
Associated Concepts

*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 6 March for the next edition, to be mailed on 2 April 2019.

# GET INVOLVED IN AN EVENT NEAR YOU!

Date	Event	Contact
Sunday, 24 February 2019	Benalla Act to D'feet MND	www.act2dfeetmnd.com
Friday, 1 March 2019	Tasmanian Health Professional Forum	Email: info@mnd.asn.au
Tuesday, 5 March 2019	MND Information Session	Email: info@mnd.asn.au
Saturday, 23 March 2019	Rock Off MND 2019	www.rockoffmnd.com.au
Sunday, 24 March 2019	Geelong Walk to D'feet MND	Email: fundraising@mnd.asn.au
Wednesday, 17 April 2019	MND Information Session	Email: info@mnd.asn.au
<b>5–11 May 2019</b>	<b>*** MND WEEK 2019 ***</b>	Email: fundraising@mnd.asn.au
Sunday, 5 May 2019	Service of Hope and Remembrance	Email: info@mnd.asn.au
Tuesday, 7 May 2019	Ask the Experts - MND Research Forum	Email: info@mnd.asn.au
Friday, 10 May 2019	Blue Cornflower Day	Email: fundraising@mnd.asn.au
20–26 May 2019	National Volunteer Week	Email: volunteer@mnd.asn.au
Friday, 21 June 2019	Global MND Awareness Day	Email: fundraising@mnd.asn.au
Sunday, 30 June 2019	Stadium Stomp at the MCG	Email: fundraising@mnd.asn.au
16–22 September 2019	Larapinta Trek - Challenge event	Email: fundraising@mnd.asn.au

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](http://www.instagram.com/MND_Vic) | [www.facebook.com/MNDVic](http://www.facebook.com/MNDVic) | [www.twitter.com/MNDVic](http://www.twitter.com/MNDVic)