

# MND NEWS

May/June  
**2019**

The newsletter of the  
Motor Neurone Disease  
Association of Victoria

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



28 AMAZING  
YEARS AS AN  
MND VICTORIA  
VOLUNTEER!



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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 from 11.30am to 3pm.  
Coordinator – Carolyn Hutchinson-Kane

# STAFF

**Chief Executive Officer:** Kate Johnson

**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

**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
Sam Mitchell	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



**I am excited to be contributing to our newsletter for the first time since I commenced at MND Victoria as CEO on the 23rd April. I am grateful to have been made to feel very welcome by the State Council, staff, volunteers and clients of MND Victoria and am looking forward to getting to know more of our clients and supporters as my time continues.**

I would like to acknowledge Rod Harris for the incredible contribution he has made to MND services and support, research, advocacy and awareness in Victoria, Australia and globally across the 25 years he has been CEO. Rod's dedication, knowledge and passion are second to none – and his are very big shoes to fill. We will still see Rod around as he continues as a volunteer and advocate for people affected by MND.

**MND Week** is coming to a close as I write this article. Our Melbourne **Day of Hope and Remembrance** at the Town Hall was a moving and wonderful event attended by about 50 people on Sunday 5th May. We heard an incredible story of hope from Haley Chartres, who carries the MND gene, and has used IVF and pre-implantation genetic screening to ensure her currently 6 month old baby Frank, does not carry the gene. Those gathered had the opportunity to share their stories with one another and come together in hope for a world without MND.



Our **Ask the Experts** Day at the Florey Institute was attended by over 70 people and provided attendees with fascinating presentations about current research and drug trials in progress addressing MND. Attendees also had the opportunity to tour the MND laboratories at the Florey Institute – giving incredible insight into the detailed work being undertaken. Our thanks to our speakers **Associate Professor Brad Turner** from the Florey Institute, **Associate Professor Peter Crouch** from the University of Melbourne and **Dr Tristan Iselli** from Neuroscience Trials Australia.



Given the impending Federal Election, the MND Associations have stepped up our **'Make Aged Care Fair'** campaign. There are 243 people with MND in Victoria who are stuck with an aged care system that doesn't meet their needs – and we are calling on the government to support people over 65 living with MND by providing funding for more high level home care packages, fast tracking access to level 3 & 4 packages and provide additional assistive technology funding.

You might have seen our **"243 for MND"** campaign on social media and in our various communications. To raise awareness of the need to Make Aged Care Fair, our goal is to have 243 people raise \$243 each to help fund



support and to raise awareness of the need to improve our aged care system for people affected by MND who are over 65: [www.mnd.asn.au/243](http://www.mnd.asn.au/243)

To add your support to our campaign – you can go to [www.mndaction.org.au](http://www.mndaction.org.au) to take action by contacting your State and Federal politicians to tell them you want to Make Aged Care Fair for people with MND, or you could jump on board our 243 for MND campaign.

Once again, I thank the MND Victoria community for so warmly welcoming me to the role of CEO and I am looking forward to taking the organisation into the future to continue to support people affected by MND to receive the care and support they need to live as independently as possible for as long as possible.

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

Regards, Kate

## MND WEEK - A DAY OF HOPE AND REMEMBRANCE

*MND Week occurs in the first full week of May each year and in 2019, MND Victoria organised two special events to mark the occasion.*

The **Melbourne 'Day of Hope'** was held on Sunday 5 May 2019 in the Supper Room at the Melbourne Town Hall. MND Victoria's new **CEO, Kate Johnson**, led the event and spoke about carers and the important role they play in the lives of loved ones with conditions such as MND. **Haley Chartres** shared a moving reading about the way in which MND has touched her family and how pre-implantation genetic screening can be used successfully in families with a history of MND.

**Konnie Ambatzidis** sang and her beautiful rendition of Amazing Grace added to the reflective ambience.



A candle lighting ceremony also took place which acknowledged the many different people whose lives are touched by MND including people living with the disease, families and friends, those who have passed away, supporters and friends of MND Victoria, health professionals, MND Victoria support groups, MND Victoria volunteers, MND Victoria State Council and staff,

researchers working to find a cure for MND and others involved with the global fight against MND. Many of the people who attended took the opportunity to light a candle for someone in their life touched by MND.

The service was followed by morning tea which gave people the opportunity to chat with one another and share stories and experiences.

On Sunday 5th May the **Barwon Region "Hope and Remembrance"** event was once again held at St Luke's Church Highton. The 2pm service was attended by family and community members who took time to light a candle in remembrance of their loved ones.

Deb Olive Coordinator Volunteer Programs with MND Victoria and based at the Canterbury Office was guest speaker sharing a history of volunteer involvement with MND Victoria.



*Read about our Day at the Florey - Ask the Experts in the Research section.*

# SUPPORT SERVICES



The first year in any job is a “round of firsts”, and May marked my first MND week. The Melbourne Day of Hope and Remembrance at the Town Hall was a very special event and a wonderful way to remember all those who are no longer with us, and also to acknowledge those who are living with, and are impacted by, the disease. Each event that I attend or am involved in reminds me of how passionate and supportive the MND community is.

## Support Services Staff Update

**MND Advisor position in the Hume Region - Welcome to Sam!**



Samantha (Sam) Mitchell commenced in the role at the end of April. She has been working at Goulburn Valley Health for 9 years as a speech pathologist and has worked with many people who have been diagnosed with MND during this time, so comes to us with great experience in the field. She will be a great addition to the team. Sam also presented at the MND National

Conference in Adelaide in 2018 about MND support in the regional setting.

We now have twelve MND Advisors and Support Coordinators in the team in Victoria and Tasmania.

### **MND Advisor and Support Coordinator in Launceston, Tasmania**

We are in the process of recruiting another part time Advisor to work in the north of the state. Interviews are planned for 24th May, so I hope to be able to introduce the new team member in the next newsletter edition!

The new team member will work collaboratively with our MND Advisor and Support Coordinator based in Hobart.

### **Coordinator of Operations**

Farewell to **Georgina Diacos**, our Coordinator of Operations.

Every organisation has behind the scenes staff who are essential to the efficient and effective running of the service.

Georgina has been with us for 18 months and has been integral to the development of our CRM database and played a critical role in managing the quality management system for us. Georgina will be leaving in June to travel overseas with her partner and will be greatly missed. We are in the process of recruiting to the role.

## Annual Quality Survey

Thank you to everyone who has responded to our annual survey about the services we provide. We will be collating the feedback in June and will report the findings in the next newsletter.

## NDIS

Full rollout of the scheme in Victoria is fast approaching, however it is clear that not everyone will be “in” by the 30 June 2019, which was the planned date for full scheme transition. It is anticipated that some people will still be transitioning in the latter part of 2019. We will continue to be strongly advocating for people with MND to be prioritised.

We have regular meetings with the NDIA to advocate for people with MND. Recent meetings have focused

on the timeliness of provision of home modifications and equipment (where the MND Victoria equipment bundle does not fully meet an individual's needs). We will continue to advocate in this space. Our MND Advisors are aware of many of the issues that NDIS participants face, but please get in touch if you have any specific feedback.

## Aged Care

People over 65 unfortunately do not have access to the same level of supports and services as those who are under 65. We think this is unfair.

If you haven't done so already, **please join MND Australia's Make Aged Care Fair Campaign** to advocate about this issue and to 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 on the MND Action website: **[www.mndaction.org.au](http://www.mndaction.org.au)**

As always, if you have feedback please don't hesitate to email or call me.

Jo Whitehouse, Manager Support Services

**[jwhitehouse@mnd.asn.au](mailto:jwhitehouse@mnd.asn.au)** | 0402 183 140



# 28 YEARS MAKING A WORLD OF DIFFERENCE!

Thank you Marian Lowe for your hard work and dedication over 28 years as a MND Victoria Volunteer

**Marian writes, "From Cakes to Kokoda ... Fundraising—it's the 'f' word that is a constant in the vocabulary of organisations such as ours.**

As I step back from my role as a volunteer in the fundraising area, I've been thinking of all the past efforts that have helped make the Association so successful.

In 1990 when I first became involved with the MN Society as it was then, the need for funds was critical. Volunteers stood at strategic places during MND week shaking cans and answering the common question – "What is MND? Can you get it from driving a car?" Support groups would hold stalls, raffles and trivia nights, the Gippsland group was famous for its Soup

and Sandwich day, and a member of the Outer Eastern Group ran a 'tattslo' every month for years using the supplementary numbers. There was a sock drive, open gardens, lunches and dinners, and one of my favourites – a no effort fundraiser where people were asked to donate a sum of money in lieu of baking a cake, manning a stall etc.

Then of course there were Christmas card sales which brought in 1000's of dollars in the early days, as did the annual fete where you had to get in early for the homemade apricot jam and lemon butter! We selected wines that were bottled with a MND label and took orders from around the State.

One enterprising member started collecting corks, this soon ballooned out into the "Equipment, it's a Corker!" programme. At its height there was a team





of volunteers who regularly sorted out the wires, caps and occasionally money, which came with the bags of corks. It was also a great way of promoting the Association. Local Rotary and other community groups got involved, I think the idea of buying a wheelchair from sales of corks appealed to people. We even had corks sent over from a winery in South Australia. Sadly it came to an end when the firm who bought the corks for recycling decided it was easier and cheaper for them to purchase overseas.

Hundreds of boxes of cornflowers were made up for MND week and distributed to support groups and members. My own group would distribute around 200 boxes in Knox City shopping centre the week before and collect them the week after. This finally came to an end when shops changed to having miniscule counters.



With Judith Durham's influence, we collected donations in buckets at the end of Seekers concerts. Judith would talk about MND and the Association before the last song, and the generosity of the audience as they left was overwhelming. The ice bucket challenge caught the imagination of the public and ricocheted around the world.

The bequest programme was set up in the 1990's along with the MND Care Foundation to provide financial security for the Association. Walk to D'feet MND started in Melbourne, but quickly took off in different regions of Victoria and interstate. Not only do the Walks raise significant funds, but bring together the MND community in relaxed and friendly atmospheres.

It is always a challenge to think up something new and recently extreme events have answered that. Walking on the Great Wall of China, battling the Kokoda Track and now trekking the Larapinta, appeal to the young and the fit who must raise significant sponsorship money as one of the conditions of registration.

There are many other ways, too many to mention here, that members and supporters have employed to bring in funds. But from 'cakes to Kokoda' every cent is a valued contribution to the care of people living with MND and to the research that will one day find a cure.

## INFORMATION SESSIONS

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

**7pm on Monday, 22 July at MND Victoria,  
265 Canterbury Road, Canterbury.**

Please RSVP by 5pm, Friday, 19 July 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 Tuesday,  
27 August at 7pm in Canterbury.

# YOUR STORIES ...



**Mark Lehane | 26.2.1959 – 2.1.2019**

**By Camilla Hullick**

Dearest Mark, I'm sitting here on my veranda after a distracting day at work, reminiscing about you, as I often do.

It's been three months since you left and I still cannot believe that I will never see you again in this lifetime. It's just so surreal and heart wrenching. In my mind, I see you as clear as day, and I hear your familiar voice just as always. I guess that's why I'm having such difficulty accepting your passing. Spontaneous triggers constantly happen, and I find myself engrossed in wonderful, now precious, memories. I laugh at flashbacks which come to mind. I laugh, then I cry, remembering you're gone.

I still vividly remember meeting you for the first time. Anthony and I had dropped into the Tarwin pub for a quick drink. The year was around 2009. I remember you were tall, slender, clean shaven and quiet. You seemed to be on your own in the corner, as you leaned against the bar with a drink in hand. There weren't many patrons in the hotel and I recall Anthony and I were talking with bar staff. You joined in on the conversation and I couldn't help but think how polite, decent and interesting you were.

I didn't meet you again until the desalination plant project was in full swing. Many tradesmen had moved into our little community. You were one of those. In those days I still frequented the pub and that's where our friendship blossomed. You hilariously began calling me 'Stunner', which stuck. You continued to

call me "Stunner" throughout our friendship and I miss hearing your voice speak the word. A while later, you bought your impressive beach house in Venus Bay, as you'd decided you loved the area. Early mornings I would often leave home-made treats at your house and then text you, to check outside your front door. I loved leaving you little surprises, even if sometimes my baking skills weren't up to scratch.

In the early days of our friendship we would often bump trolleys while shopping in Safeway, and we would swap 'specials' information. That was amusing and always a nice surprise, and as I'm an op-shop queen, you asked me to keep an eye out for warm knits because you struggled with the cold during the harsh South Gippsland winters.

We shared so much over the years, Mark. You drove me to Traralgon to see your beautiful house. When your mother passed away, I attended her funeral to show respect and offer you my support during that sad time. One of my happiest memories is our amazing bike ride. For years I had been asking if you would take me for a ride on your motorbike and the only answer you'd ever give me was 'one day'. Because you were fearful something might happen and thought Anthony would never forgive you, that "one day" didn't come ... until Anzac Day weekend, 2011.

Mike, Lindy, Theresa, Nick, you and I were having dinner at the pub one night. After a few drinks, I asked you again if a ride might be out of the question. I guess because you were half smashed, you agreed, and I was to come over the next morning at 8 a.m. which I promptly, and excitedly, did. I found you on the couch nursing a painful hangover. You weren't a good sight, however you did finally rise to the occasion and, after a shower and a coffee, you were fit to go, although feeling a little seedy. It was a fantastic day! I absolutely loved it. It was sensational weather and we rode all morning around beautiful South Gippsland, stopping wherever we wanted. We ate a delicious lunch at an old country pub we discovered along the way, before heading home. It really was a magical day.

Then my wedding day neared and I asked if you would do me the honour of escorting me on the back of your bike to meet Anthony and the wedding celebrant at Venus Bay's Beach No.1. You accepted. The celebratory event arrived. I had rented a holiday house



in the vicinity of Beach No.1 to spend the pre-wedding afternoon with my gorgeous friend, Conny, who had flown over from Germany to be my bridesmaid. You and Conny had a mutual admiration for each other. During her stay, you went out of your way to make her feel at home, and I was grateful to you for that.

After Conny had been picked up from the beach house to leave for the ceremony, you arrived on your bike. Finally, we received the call that all guests had arrived and it was time for us to make our way to the beach setting. I remember us sitting there on your bike, ready to go. It was a beautiful summer's night with a lovely warm temperature. The sunset was perfect and would be magnificent for the photos. It was a special, memorable moment and I was so thankful that you were a significant part of my wedding. Writing all of these wonderful memories down, I'm right back there again, reliving every moment. You were such a unique, extraordinary friend. God, I just can't believe you're gone!

Distressingly, over the last couple of years, you began to feel unwell. Not only did you experience unpleasant physical symptoms, you were also emotionally drained and frustrated as you sought answers that no professional was able to provide. Eventually, you underwent a complicated operation in the hope that you would once again regain your health. I remember you telling me that, while spending time in rehab, you had motivating thoughts of purchasing a camper van and taking off travelling around Australia, stopping wherever your heart desired. It sounded fantastic and I was happy for you. But you didn't get well! Instead you were diagnosed with the despicable, unforgiving Motor Neurone Disease: the aggressive type.

I was devastated for you, Mark. It took a little while to digest the news and have it sink in. All that kept rotating around in my head was, what could I do to help you and how can I fix this? There wasn't much I could think of besides attempting to emotionally support you as best I could, and to donate regularly to MND in the hope that a cure would be found sooner rather than later.

You know, the last few months of your journey seem like a complete blur to me now. I can no longer pinpoint everything that eventuated time wise. However, I do know for a good four months, I texted you each every



morning and evening, whether I was overseas or not. I would try and send you different uplifting words. Initially, you always replied however, after a couple of months, you responded less frequently. I knew you were struggling and I was struggling to find appropriate words to continue to comfort and motivate you. I felt so useless.

Your brother Steve and his wife Carol graciously and unconditionally took you in when you were physically no longer able to look after yourself; such amazing people. You were so frustrated and kept saying it shouldn't be this way. Steve was your older brother and you should have been there for him when he needed you, not the other way around!

As you now lived a couple of hours' drive away, I came to see you less often. On each visit, I noticed how your health was declining, although your quick, witty sense of humour stayed sharp. I had shared with you my spiritual beliefs that when we leave this world, our souls venture 'home' to be joyfully reunited with all of our loved ones who have passed before us, and we return to complete health, feeling light and free. Initially, you thought it was a load of crap, but I was so pleased to hear you talk of going 'home' as your passing drew near.

The very last time I saw you, I visited you in hospital on my way home from the airport. I entered the four bed hospital room and initially couldn't spot you. I nearly wandered back to the nurse's desk until I saw you were sitting in a chair with your back to me. It took all my might not to cry as I knelt to surprise you. You looked so frail and were struggling to breathe. It was horrific and heartbreaking. You asked me if I thought you were a good person, as you believed good people don't get

dished out this sort of hell. I remember reassuring you that you were the most amazing, witty, smart, selfless, caring, lovable, protective gentleman I'd ever had the pleasure of knowing. Were you a good person? Yes Mark, you were one of the best!

I didn't stay too long that day. You were tired and I was mindful of your energy levels. It took all of your strength and concentration to keep breathing. I don't remember our parting words. I was numb as I left you and drove the two hours home to South Gippsland in a daze. Six days later I woke to Steve's message advising everyone that you had peacefully slipped away during the night. My heart sank. The struggle was over and you had gone – just like that. On the morning of your funeral, the news headline that day read 'Major breakthrough for MND patients!' Sadly, too little, too late, for you dear Mark.

Your funeral was monumental. They came from everywhere to respectfully bid you goodbye. You've left such a hole in our community, impossible to replace. Magnificent photos of you hang proudly on The Cavity and Tarwin Hotel walls now, so you will continue to remain fresh in peoples' minds, while new patrons will curiously ask who that guy is, which we will proudly answer.

I miss you so much, Mark. I miss our bear hugs that spoke a million words. I miss your cheeky face trying to gain my attention through the PBE real estate window when you walked past on your way to The Cavity, and I miss our regular texts. I stare at your beautiful house now looking so forlorn, and I imagine you sitting on the couch in front of the television, being warmed by your cosy fire.

I desperately need to upgrade my mobile phone, but I still have precious texts from you which I'm not able to let go of just yet. Since you've passed away, I still pick up my phone to text you morning and night – until I remember the awful reality.

I could go on. I'm not even sure why I'm writing you this letter! Maybe it's for my own healing, or maybe it's to keep our memories alive. I guess, quite simply, I feel close to you when reminiscing and reliving our story. If my love for you could have saved you, you would have lived forever.

Be happy, be free, my dear friend, until we meet again.

Always in my heart,

Your Stunner xoxoxox

## 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!



## National Volunteer Week 2019

Each year during National Volunteer Week, the contributions of volunteers across Australia are recognised and celebrated. This year National Volunteer Week was celebrated from 20-26 May 2019.

With an estimate of more than one billion people volunteering across the world and more than 932 million hours contributed by volunteers in Australia each year, it really is true that volunteers are "Making a world of difference."



**NATIONAL VOLUNTEER WEEK**  
*Making a world of difference*

MND Victoria formally acknowledged our volunteers this year with a tour of the State Library of Victoria followed by high tea at a local café. It was once again a wonderful opportunity for a significant number of our 127 active volunteers to come together to share time and to celebrate the bonds which being a volunteer with MND Victoria create.

Kate Johnson, our new CEO, welcomed forty of our volunteers to the event and was pleased to present service awards to volunteers who have given twenty-five, ten and five years of service to MND Victoria.

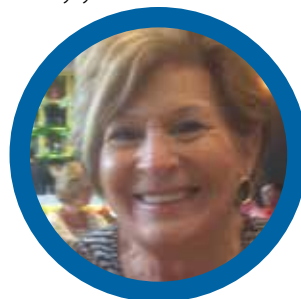
**Cynthia** joined MND Victoria as a volunteer in 1994. Her contributions since that time have included Reception, Secretary of the Outer Eastern Support Group, assisting with the Walk to D'feet MND and MND News mailout.

Always one to offer to help and to challenge herself, Cynthia joined our Bereavement Caller volunteer team in 2018.



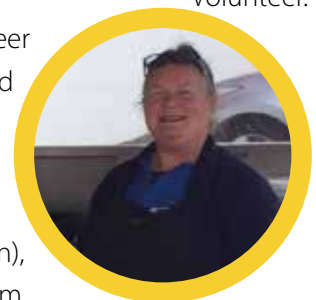
Four of our volunteers were recognised with Ten Year Service Awards. **Lorraine** has actively supported the work of MND Victoria in Bendigo and continues as a Massage Volunteer.

**Fay** is an active member of the Barwon Region Support group and was the coordinator of the very successful Geelong Walk to D'Feet MND for many years.



Janet volunteers with the Massage team and has previously been active in Bereavement Support. Elizabeth (photo below) is also active as a Massage Volunteer.

Awards for 5 Years of Volunteer Service were also announced for - **Pat** (Newsletter and Events), **Alanah** (Massage), **Ross** (Community Visitor), **Jayne** (Events and Reception), **Helen** (Massage), **Jo** (Program Support – Fundraising and Events), **Simone** (Events), **Renee** (Massage and Life Stories), **Eileen** (Bendigo Support Group and Events) **Jan** (Life Stories) **Kathleen** and **Jenny** (Massage).



A huge thank you to every one of our volunteers!

MND Victoria staff always appreciate the contributions of our volunteers. Recently, Isabelle from our Finance and Administration team wrote this note: "One of the

many great things about working at MND Victoria is that no two days at the office are ever the same. The volunteers contribute to this diversity immensely. We have such a vast array of beautiful faces and personalities who come into the office, or work remotely, to assist the organisation. All have their own unique set of skills.

Here in the office alone we receive so much assistance. We have volunteers who assist us on the reception desk, send out merchandise, collate data, compile information kits, pack and mail out the newsletter you're reading right now! This is only a very short list of jobs I get to see the volunteers perform, but we have others who collect money at fundraisers, offer home visits; give hand and foot massage to clients; call clients' families and loved ones. The list goes on and on.

Not only do they lighten our ever growing work load by contributing multiple hours across the admin, equipment, information, and fundraising departments, but they always provide us with endless laughs and smiles. Our volunteers are some of the most dedicated individuals and will always go above and beyond to help us in any way, and for that we are forever grateful. Keep up the good work volunteers."

## MND Volunteers have many talents

Recently one of our very talented volunteers, Beryl, was integral to filming and editing the video developed to illustrate our Make Aged Care Fair campaign – featuring Graham and Nancy and launched during MND Week.

Beryl was able to share her professional skills in videography, compositing and animation design to complement the skills of MND Victoria staff to film

and edit the video and to capture the story of what the current Aged Care system means for older people living with MND. Thank you Beryl, Graham and Nancy for your involvement. Watch Graham and Nancy's story at: [www.mndaction.org.au/Make-Aged-Care-Fair](http://www.mndaction.org.au/Make-Aged-Care-Fair)

## VOLUNTEER OPPORTUNITIES

### Massage Volunteers

We are looking for volunteers to join our team of Massage Volunteers. Massage Volunteers provide hand and foot massage helping with comfort and relaxation for people living with MND. We currently need more Massage Volunteers in locations across the state. We are planning a training session in the coming months - 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.

For more information please call 1800 806 632 or email [volunteer@mnd.asn.au](mailto:volunteer@mnd.asn.au)

### Visitors for Social Support

Social Support Visitors are volunteers who meet with a person living with MND in their local area. Volunteers may meet for a coffee or a walk and 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 will be provided. For more information please call 1800 806 632 or email [volunteer@mnd.asn.au](mailto:volunteer@mnd.asn.au)



# RESEARCH UPDATE



## A DAY AT THE FLOREY

**By Alison Jones, Coordinator Information & Resourcing**

'Ask the Experts' was held on Tuesday 7 May 2019 at the Florey Institute of Neuroscience & Mental Health in Parkville and consisted of three presentations by researchers, followed by tours of the laboratory facilities.

**Associate Professor Brad Turner** gave an update on local and international MND research. He explained that 10% of MND cases are inherited and 90% are sporadic (scattered or isolated) cases. Possible risk factors for developing MND include smoking, playing sport at an elite level, retroviruses, blue-green algal blooms and military deployment in the Gulf War. He spoke about genetics, advising that 70% of MND-related genes have now been found and that they point to various disease pathways and potential treatments. It is hoped that the remaining 30% of genes will be identified over the next 5 years.

Brad talked about how MND is a complex disease with many phenotypes (clinical presentations) and that current medical practice tends to adopt a 'one size fits all' approach. However precision medicine, where the focus is on identifying which approaches will be effective for which patients based on genetic, environmental and lifestyle factors, is likely to be the way of the future.

Brad also spoke about the Florey's high-throughput Drug Screening Program which aims to find potential new treatments for MND. The effects of thousands of drugs on motor neurones derived from the skin cells of people with MND will be tested. Lab tour participants were given the opportunity to see the multi-million dollar state-of-the-art drug screening equipment in action. Five groups of participants were rotated through various lab stations including cell culture, mice, molecular, microscope and stem cells where staff spoke about their current MND research and answered participants' questions.

**Associate Professor Peter Crouch** from the University of Melbourne reported on the Copper-ATSM clinical trial that has been the subject of recent media attention. Peter explained that copper is found in all body tissues and plays a role in various processes such as energy production. The drug Copper-ATSM has been in existence for many years and has been recognised as having the potential to treat neurodegenerative diseases such as MND. The phase 1 trial started with a small group of MND patients in 2016 and it is hoped that the phase 2 trial, which will involve a larger number of patients, will commence in late 2019, however details are yet to be announced. Peter added that a complex disease like MND is likely to require complex treatments involving a combination of potential therapies.

**Dr Tristan Iseli** from Neuroscience Trials Australia was the final speaker and provided an overview of clinical trials and MND. He explained that clinical trials are performed for safety and tolerability, to find a dose that works and establish who it works for. Clinical trials must always be conducted ethically and the risks and benefits weighed up carefully. In addition, the rights, safety and wellbeing of the participants are of utmost importance.

The clinical trial process is both long and expensive, with the development of a new drug costing on average more than \$US800 million from discovery to approval. It is a complicated process that typically spans 10-15 years which can be frustrating for people with MND and their families who hope for effective new treatments to be available sooner rather than later.



The knowledge that Brad, Peter and their labs collaborate with the best and brightest researchers internationally to find effective treatments for MND is a source of hope for those whose lives are touched by MND. Feedback from one MND Victoria client summed up how the event was received:

‘Thank you for the opportunity given to hear and see what is being done at the Florey Institute...it showed me that marvellous things are being done through the hard work of so many of you.’

## 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. 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)

# OVER 465

items of equipment were delivered to people with MND in this region in the past year.

JENNY TRAVELS APPROX  
**25,000**  
KMS EACH YEAR

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

The furthest town to which Jenny drives to visit clients is **338 kms**.



The first **South East Melbourne Walk to D'feet MND** was held on 4 May 2019. Over 250 people attended and they raised nearly \$25,000!



A **Life Story Volunteer** from the Gippsland area has just been trained and is ready to start working with people with MND to record and print their stories. If you are interested in recording your life story, please contact your MND Advisor.

**8** VIC LOCAL GOVERNMENT AREAS

JENNY HAS PROVIDED  
**700 HOURS OF SUPPORT**  
FOR PEOPLE WITH MND IN  
THE LAST YEAR.

The **NDIS roll out completion date for this region is from January–June 2019.**

42.5% of clients in this area access the NDIS, however 57.5% 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



The last two years, Sallie Jones and Gippsland Jersey have held the Big Milk Freeze in Warragul. In 2018, icy milk was poured from a tractor loader onto the brave participants. The event is held in honour of Wendy Gillam who died of MND last year.

**\*\*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 \*\***



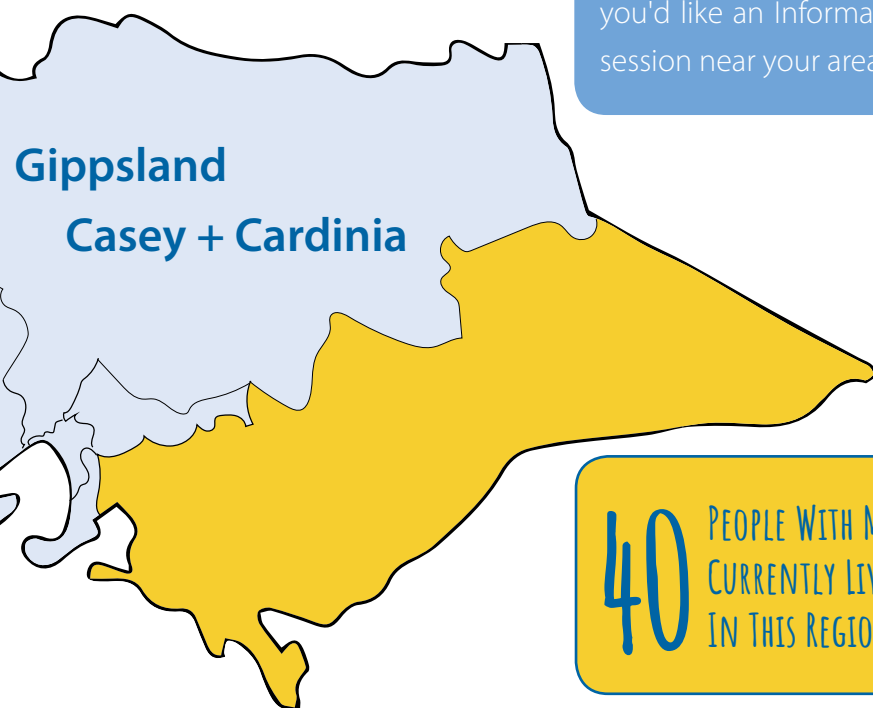
JENNY - MND ADVISOR  
+ SUPPORT COORDINATOR

JENNY HAS BEEN AN MND  
ADVISOR AT MND VIC FOR  
**12 YEARS**

An **MND Information Session** was held in this region during 2018 for 18 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.



In July 2018, **Warragul's Annual Snow Fest** was held. All funds raised through their Dunk for Gold Challenge was donated to MND Victoria. We can support you to run a fundraising event in your area, please email: [fundraising@mnd.asn.au](mailto:fundraising@mnd.asn.au)



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



The **Cox's Bridge to Cox's Place** ride has been on the calendar for many years now. It is a 64km (approx) bike ride from Cox's Bridge in Sale to Cox's Place in Loch Sport. It is held in memory of Bruce Cox who died from MND in 2016.



The **Lakes Entrance Walk to D'feet MND** is held every second year! Danielle Milito and team organise the Walk and family fun day in honour of their Pa, Terry Leadbeater. Close to \$12,000 raised in 2017. Danielle received the Australia Day Community Award for her efforts in organising and running the Lakes Entrance Walk.



# NBN & MEDICAL ALARMS

The following information is for any members or clients who use medical alarms:

Many medical alarms rely on the existing landline phone network. As the nbn (national broadband network) gets rolled out, the old landline technology is being replaced. This may affect how medical alarms connect and provide services. It is therefore important that all medical alarm users check the compatibility of their existing alarms with the new network. This can be done by contacting the medical alarm provider and/or the nbn.

We recommend that all medical alarm users register their medical alarm with the nbn. This will mean that the nbn can provide medical alarm users with additional information and support when they move across to the nbn network. This will also help to minimise any break in service. Registration is free, and can be done online or by calling 1800 687 626.

Further information about medical alarms and the nbn is available at **[www.nbn.com.au/medicalalarms](http://www.nbn.com.au/medicalalarms)** or by calling 1800 003 095.

## RILUZOLE UPDATE

The following information is from the revised MND Australia Riluzole fact sheet:

Riluzole is manufactured under the names Rilutek™ and APO-Riluzole. In Australia, riluzole is available for eligible people at a subsidised price on the

Pharmaceutical Benefits Scheme (PBS) under an authority prescription. To get your first authority prescription for riluzole, you must be diagnosed with the ALS form (including PBP) of MND by a neurologist, have had the disease for five years or less, and meet several other criteria.

Your doctor needs to provide your date of diagnosis and information about your forced vital capacity (respiratory function test) with the first application.

Subsequent prescriptions may be issued by your general practitioner.

Teglutik® (riluzole) a liquid formulation of riluzole (for ease of swallowing or use via PEG tube), distributed by Seqirus (Australia) Pty Ltd, will be listed on the PBS from 1 April 2019 under the same prescribing conditions as Rilutek™ and APO-Riluzole.

## LATEST TECHNOLOGY

A company called Control Bionics has launched new assistive technology, NeuroNode Trilogy, for people with MND and other neurological conditions. The NeuroNode is a wireless, wearable AAC device that non-invasively captures the body's own electrical signals. These signals, generated by minute muscle movements, can be detected even when there is no visible muscle movement, allowing a locked-in user to control a computer with incredible accuracy, and to speak, email, socialize, be entertained, and to control their environment.

The technology is priced at under \$20,000 and may be available to people with MND through NDIS funding. Find out more: **[www.controlbionics.com](http://www.controlbionics.com)**

## THANK YOU JEANWORKS!

A HUGE thank you to Jeanworks for their support in providing our last order of baseball caps free of charge.

This means the entire cost of any baseball caps ordered will provide support for people with MND!

Order yours at: [www.mnd.asn.au/gear](http://www.mnd.asn.au/gear)



# FUNDRAISING



**"People who ask confidently get more than those who are hesitant and uncertain. When you've figured out what you want to ask for, do it with certainty, boldness and confidence."**  
**Jack Canfield, Author, 1944-**

I can hardly believe that it is now close to the end of this financial year. Time to put extra effort into our fundraising so we can ensure that we raise sufficient funds to underwrite our service delivery. This is critically important for those aged 65 years or older who cannot access NDIS and who have to rely on the Aged Care system for funding. The equipment we provide for these people, at no cost to them, is vital to keep them, and their carers, safe and able to participate in family and community activities.

This year MND Victoria has been well supported by individuals, families and groups throughout Victoria putting on fundraising events on our behalf (check out Daniel's write up on the latest events). We're also working closely with a group of supporters who are participating in the Larapinta Walk to D'Feet MND in September; three very fit people participating in the New York City Marathon and a group who are each committed to raising \$10,000 this year and taking part in a mystery activity in March next year which will be filmed and shown on pay TV.

We know that not everyone is able to run events or participate in challenges, which is why we also send out a Tax Appeal at this time of year.



This year, our Tax Appeal highlights the story of Ian and his family. You may have already read their story and donated. If you haven't, please check it out and share with your family and friends at: [www.mnd.asn/tax](http://www.mnd.asn/tax) Your donation will make a difference to people living with MND.

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

Kathy Nightingale, Manager Supporter Development

## EVENTS WRAP UP!

### **Portland Summer Ball**

The Portland community got together once again for an MNDVictoria fundraising event. A terrific group from the Gorae Portland Cricket Club decided to put on a Summer Ball to help raise funds for all the Victorians living with MND. MND has hit Portland hard over the years so it's great to see the community rally together. The event was very well attended and enjoyed by all. The total amount raised was \$3553.77. Thanks to Rebecca, her team and everyone who supported the event!

### **Lilydale Cricket Club**



For the second year in a row, Lilydale Cricket Club hosted the Lilydale Little Chill MND Ladies Day. This is in recognition of a club legend who lost his battle with MND last year. We thank Mel and the whole crew for bringing this event to life and making it a regular

fixture for all the ladies of Lilydale Cricket Club. Thank you for all the awareness you bring and for raising \$2435 this year!

## Knoxfield Knights Cricket Club

The Knoxfield Knights Cricket Club hosts an annual Past Players function each year. In recent times it has been in honour of a club favourite who passed away from MND a couple of years ago. Elaine, who is a volunteer with MND Victoria, continues to make sure the event is a successful fundraiser as she wants to keep supporting the organisation that supports those living with the disease. We thank Elaine and all involved at Knoxfield Cricket Club for raising another \$2000 this year!

## Rock Off MND



Another year, another incredible Rock Off MND event. The concept behind 'Rock Off MND' was originally conceived by Jen Simko back in 2014 after she was diagnosed with MND. Sadly, Jen passed away a year later but the event lives on through her husband, Peter and their 3 kids. The 2019 edition at Geelong's Waterfront Deakin Campus played host to hundreds of music lovers who enjoyed acts from Russell Morris, Jack the Fox and party band, Groove Star. We thank the Simko family for putting on another memorable event that raised over \$90,000 for MND research.

## Leanne Oliver Book Launch

Leanne's mother, Rose is currently living with MND. Leanne is a Self-Awareness Educator and Author. Leanne was inspired to write a book called 'The Uncommon Sense' which she dedicated to her mother. Leanne is grateful for all the assistance she is receiving from MND Victoria so she wanted to do something to give back. Leanne turned Event Manager and created a wonderful Book Launch at Rippon Lea Estate. This doubled as a fundraiser and MND awareness session where our Information Officer, Sarah, presented to the crowd.



Leanne's event managed to raise over \$3500 for MND Victoria and helped sell many books! We thank Leanne for all she is doing to promote MND awareness!

## The Patti sisters

Sarina and Patrina are superstars! We first met the twins back in 2017. They came to us because they wanted to do something to help, as their brother was battling MND. They started by contacting their local shopping centre, Ivanhoe Plaza, and arranged to set up tables to sell our merchandise. They were given an area to set up and managed to sell over \$1000 worth of merchandise. They did an incredible job educating the community as they explained about MND and MND Victoria. Over the next 2 years, they have turned this into a regular thing at various shopping centres around the Northern Suburbs. Sadly, they lost their brother late last year, but are still passionate about raising funds and awareness for MND Victoria through the sale of merchandise and talking to everyone they meet about the importance of raising funds for the organisation that provides support, care and vital assistive equipment to people like their brother.

## Last Resort Concert

An 80's band, known as Last Resort, who hadn't played together in almost 30 years, were shocked by the diagnosis, and then the loss, of some great mates from MND. It didn't take much convincing for them to reunite for a fundraiser for MND Victoria. They wanted to raise funds and awareness for the organisation that provided so much support, care and equipment to their mates. Through the generosity and help of so many local organisations and individuals, the event was a tremendous success. The band was incredible and it was as if they had never stopped performing together. Through ticket sales, raffles and silent auctions the event managed to raise over \$10,000! We want to say a huge thank you to Kerrie who was the driving force behind the event. She put in hours and hours of hard work to make it the success it was.



## Geelong Walk



A stunning autumn day greeted the huge crowd which gathered for the annual Geelong Walk to D'feet MND in late March. The Barwon Valley Fun Park in Belmont was a sea of white MND t-shirts and doggie bandanas on the huge number of dogs that were in attendance. A team of new volunteers took over organising the event this year. They did an incredible job putting on another fine edition of the Geelong Walk for locals who have been impacted by MND to get together and walk as one strong community.

## South East Melbourne Walk



The inaugural South East Melbourne Walk to D'Feet MND was launched in Pakenham to kick off MND Week this year. The turnout was spectacular with well over 250 people walking as one huge group in memory of loved ones who have passed from motor neurone disease or in support of those currently living with the disease. The large group was led off for a lap around the lake by the police bagpipers. A little drizzle of rain right at the beginning certainly didn't dampen the mood! We thank all the amazing organisers and volunteers who have made the event a huge success!

## Shepparton Trots

On April 26th, MND Vic partnered with the HRV Hero program, Shepparton Harness Racing Club and the wider



trots community to put on an incredible night to raise funds and awareness. Our very own silks were carried in each race by the number one horse. To see our two main messages 'until there's a cure, there's care' and 'never give up' race around the Shepparton track and on live TV was very special! Funds were raised by selling two-seater sulky rides between races. There was also a gold coin donation entry and raffle on the night. Smudge Bromac was the star horse of the night. He was owned by John Brain who sadly passed away from MND a few years ago and was the reason this event came to life. Smudge had a fantastic racing career but is now enjoying retirement as one of HRV Hero's ambassadors. Smudge worked tirelessly on the night as one of the horses which gave fans an experience of a lifetime through his sulky rides.

## Wandin Park Equestrian Event

Wandin Park has been a terrific supporter of MND Victoria over a number of years. In March this year, they hosted the Australian Eventing Championships where hundreds of Australia's finest Equestrian athletes came together for one of the largest competitions in the country. Our amazing team of volunteers was manning the entrance before the sun came up both days, braving all sorts of weather conditions to take donations from spectators and competitors alike. A total of \$4357.75 was collected!

## 33 Variations

Throughout March, MND Victoria was fortunate enough to partner with the producers of the acclaimed play '33 Variations'. In the play, Oscar winning actor, Ellen Burstyn, was a musicologist suffering from MND. The play showcased her obsession with Beethoven whilst facing her MND battle. The supporting crew included Lisa McCune, William McInnes and Helen Morse. Our team of volunteers had the opportunity to collect donations at intermission at most shows over the fortnight it was on at the Melbourne Comedy Theatre. They managed to collect \$1,650 in donations from the generous public!

# ALL NEW MND GEAR!

Check out our all new  
MND winter gear at:  
[www.mnd.asn.au/gear](http://www.mnd.asn.au/gear)

We have reversible  
unisex vests and cozy  
scarves available.

All proceeds provide VITAL care  
+ support for people with MND  
and fund research.



Grab your ALL NEW MND gear at: [www.mnd.asn.au/gear](http://www.mnd.asn.au/gear)

## GLOBAL MND AWARENESS DAY - FRIDAY 21 JUNE!

Get involved! Can you host a fundraiser  
on Global Day in your school, workplace  
or community venue?

Contact our fundraising team to get  
started: [fundraising@mnd.asn.au](mailto:fundraising@mnd.asn.au)

Or challenge yourself to raise \$243  
to support people with MND at:  
[www.mnd.asn.au/243](http://www.mnd.asn.au/243)

**Your fundraising is VITAL for us to  
provide care + support for people  
with MND and fund research.**





# DONATIONS WERE RECEIVED ... THANK YOU!

## In memory of

Allan Godbold  
Arnold Stewart  
Bernie Crockford  
Beverley Klopogge  
Brian Lovell  
Cassandra Bench  
Cassie Secombe  
Coral Cass  
Dorothy Dickson  
Gayle Higgins  
Ian Sneddon  
Jarrod Hunt  
Jean Worrall  
Jeff Bibby  
Johanne Yianni  
Joy Allen  
Kathleen Chandler  
Kevin Webster  
Kirsty Gough  
Lella Jenkins  
Malcolm Duff  
Marlene Stanway  
Michael Leach  
Michael McCartney-Lees  
Patrick Bourke  
Peter Munday  
Philip Jack  
Po Yin Kan Yu

Madelun Farrugia  
John Mayger  
Sonia Rowstron  
Teresa Valdea  
Jenny Simko  
R.W Ball  
Peter Clymo  
Bonnie Dickson  
Robyn Glover  
Paul Ludekens  
Ashlee Verma  
Peter Brazier

## Research in memory

John Smith

## Organisations

Ruby Red Dancer  
Trevor P Wichmann & Associates  
Garth Lisle Property Consultants  
Loch Sport Business & Tourism  
Association  
Clifton Waters Village  
Creative Wholesale Blinds  
The Phoenix Hotel  
Mornington Mazda

## Clubs

Midlands Golf Bowls Club  
Knoxfield Cricket Sporting Club

The Heidelberg Over 50s Dance  
Group  
Pines Cricket Club  
The Goraw Portland Cricket Club  
White Hills Bowls Club  
Central Wendouree Bowling Club  
Ivanhoe Bowling Club

## Trusts

Mona Georgina Harris Perpetual  
Charitable Trust  
The Lord Mayor's Charitable Trust

## Corporate

Express Insurance Brokers  
Ritchies IGA  
Waterman AHW Pty Ltd  
Specsavers Pty Ltd.

## Bequests

The Estate of the late Crockett Cooke



*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 3 July for the next edition, to be mailed on 6 August 2019.



# GET INVOLVED IN AN EVENT NEAR YOU!

Date	Event	Contact
Saturday, 15 June 2019	Superball "XII" MND Charity Ball	Email: russellhigginsconsulting@gmail.com
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
Monday, 22 July 2019	MND Information Session	Email: info@mnd.asn.au
Sunday, 28 July 2019	Run Melbourne	Email: fundraising@mnd.asn.au
Tuesday, 27 August 2019	MND Information Session	Email: info@mnd.asn.au
16–22 September 2019	Larapinta Trek - Challenge event	Email: fundraising@mnd.asn.au
Wednesday, 9 October 2019	MND Information Session	Email: info@mnd.asn.au
Sunday 13 October, 2019	Melbourne Marathon	Email: fundraising@mnd.asn.au
Monday 28 October, 2019	MND Victoria Annual General Meeting	Email: info@mnd.asn.au
Sunday, 17 November 2019	Melbourne Walk to D'feet MND	Email: fundraising@mnd.asn.au
Thursday, 21 November 2019	MND Information Session	Email: info@mnd.asn.au
Sunday, 24 November 2019	Bendigo Walk to D'feet MND	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:**

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