

MND NEWS

May/June

2020



The newsletter of the
Motor Neurone Disease
Association of Victoria

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



FOCUS
ON
VOLUNTEERS

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Instagram: www.instagram.com/mnd_vic

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, phone: 1800 806 632 or info@mnd.asn.au Support Group Meetings:

Western Metro: Last Monday of 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

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

Bendigo Area: Meet 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

Supporter Development Officer Digital: Steph Cross

Communications Officer: Beryl Chen

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	Jenny Waites	Lauryn Matheson
Trish Duffy	Sam Mitchell	Michelle Sharples
Fran Hurst	Julie Wilson	Jenny Fuller (Hobart)
Lesley Burcher	David Cox	Emma Forsyth (Launceston)
Alex Talvy	Sarah Barratt	

Coordinator Operations: Eric Kuncoro

Coordinator Equipment Service: David Harkin

Equipment Officers: Kathy Walker, Sandra Nicholls

Coordinator Volunteer Programs: Deb Olive

Coordinator Information & Resourcing: Alison Jones

Information & Resourcing Officer: Vacant

FROM THE CEO



Welcome to our May/June edition of MND News. Life has certainly been different over the past few months, with COVID-19 requiring us all to remain physically distanced and live our lives in such a different way. I hope you have all managed with these restrictions and have still been able to connect with those who you are close to, receive the support required, and carry on as normally as possible.

I am so proud of the team at MND Victoria, who responded quickly and flexibly to the required changes – moving to work from home, continuing to provide the best support via video, phone and email, arranging equipment delivery and collection, answering phones, keeping our administration running and taking our usual face to face events online.

Our Supporter Development team has delivered two fantastic events via Facebook live during MND Awareness week – both our Day of Hope and Remembrance and our Ask the Experts sessions were really well attended and viewed by people across the State, the country and in some cases the world. Our information sessions for newly diagnosed people and their friends and family have also been delivered via video which has had the benefit of making them more accessible to all clients across Victoria and Tasmania.

We have also launched our first ever National Virtual Fundraising Campaign – Australia Moves 4 MND – www.am4mnd and we hope to see this become an annual event across the country.

There are many positives that have come from the need to work differently – and we will make sure that we carry these positives forward with us, beyond COVID-19 and isolation.

In this edition of MND News, we are celebrating our volunteers and all they do to support those living with MND. Without the support of our strong volunteer team, we would not be able to provide the level and quality of services that we do. Our 130 strong volunteer team provide direct support to people living with MND – through visiting, massage, and life story writing for example – as well as support in the office, through reception, merchandise, administration tasks, and support to our fundraising events – and much much more.

In addition, there are many more people out in the community who dedicate their time and talents to organising and running their own independent events to raise funds for MND Victoria. Every one of these events, whether small or large, means so much to us in the provision of care and support to those living with MND today, and enables us to contribute to research into the cause, effective treatment and ultimately cure for MND.

Our volunteers too have been so flexible – and have maintained their dedication throughout the current isolation requirements, and wherever possible have moved to deliver their services via phone or video to ensure that people living with MND continue to be well supported.

We are so grateful for the support of all our volunteers and the thousands of hours of support they provide in helping us to achieve our mission.

This year's National Volunteer Week theme was "Changing Communities, Changing Lives" and we certainly thank all our volunteers for the work they do in the MND community to improve the lives of people living with MND.

During National Volunteer Week we celebrated with our volunteers through a number of online events to properly thank them for all that they do.

"Thank you to all our volunteers"

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

Kate

SUPPORT SERVICES



What a difference a pandemic makes!!

MND Victoria continues to offer all of our services, but in a different way! Each week we are finding new ways to work, and technology certainly has been our friend.

Advisor and Support Coordination Service

Our 16 MND Advisors are all working from home providing support, advice and information either over the phone or by video conference. The transition from office to home working was thrust upon us very quickly and all the staff had to run with making the necessary changes to continue to work effectively to support people impacted by MND. Some days they spend hours video conferencing, attending remote NDIS planning meetings or doing introductory meetings with people who have been newly diagnosed. It certainly does not replace face to face catch ups, but for the time being it is a great alternative, and when the lockdown is over, I am sure we will continue to do some of our work via video conference in conjunction with face to face visits.

Information Service

We continue to be available to provide information and resources about MND to anyone who asks! We are in the process of making some of our information kits electronic, so we are not reliant on Australia Post!

Our six-weekly information nights have traditionally been face to face sessions for people newly diagnosed with MND and their families. We are now offering these remotely via video conferencing. This has meant that people living in rural Victoria or Tasmania are able to participate - a small silver lining to the pandemic! - we will continue to offer sessions in this way long after COVID-19 has left our shores as it has been great to open them up to a wider audience.

Our six-week Living Well program, which provides support to people diagnosed with MND and their carers, including topics such as Reaction to an MND Diagnosis, Taking Charge of your Health and Living Day to Day, has also moved to a remote format for the time being. Our next Living Well program will commence in the second half of the year. Please contact our Information line if you are interested in joining. It is a great forum for people with MND and their carers to get together and share experiences, tips and to support each other.

MND Australia was successful in being awarded a three-year Information, Linkages and Capacity Building Grant from the NDIA to develop a national approach to providing an information service for people with MND, their families, carers and service providers. We will be working collaboratively with MND Australia and the other State Associations to make this project come to life.

Volunteer Program

Volunteers are integral to all the services we provide. Our 130 active volunteers help MND Victoria, and hence people with MND, in so many ways. Like our staff, they have been fantastic at adapting to work in different ways to accommodate the social distancing requirements.

A big shout out to all of our volunteers as we celebrated volunteer week from 18 -24 May with a virtual morning tea! Different! The theme for volunteer week this year was "Changing Communities. Changing Lives." Our volunteers certainly do this in spades!

I would like to thank all of our clients, MND families and volunteers for their patience and understanding about MND Victoria needing to change how we do things in these challenging times.

As always, please do not hesitate to contact me if you have any feedback about any of our Support Services.

Equipment Service

This service also continues to operate pretty much as normal, despite the challenges. Our Equipment Service staff are also working from home, processing the assistive technology (AT) requests received from Allied Health Professionals, organising delivery, collection, maintenance, and repair of a whole variety of equipment.

Jo Whitehouse, Manager Support Services

Email: jwhitehouse@mnd.asn.au

Mobile: 0402 183 140





Gary Covington at Walk to D'feet MND

MY VOLUNTEERING HISTORY

Gary Covington

Gary Covington has been involved with MND Victoria since the 90s. He has been converting MND Victoria Newsletter into online news for worldwide audiences for 10 years. He and his wife and their families raised \$7,205 for MND Victoria during MND Week in 2014.

Some background which gives an insight into why I do what I do.

In 1976 I began my teaching career at a large outer eastern Melbourne high school (1100+ students at times) teaching maths at all levels from Year 7 to Year 12. In 1984, as computers were being introduced into schools, I was appointed Maths and Computers co-ordinator. I could already see the enormous potential for computers within the school environment and in 1985 was successful in splitting the roles and just becoming computers co-ordinator, with responsibility for introducing them right across the curriculum.

Unfortunately, the principal at that time was nearing retirement and viewed these computer jobbies as just a flash in the pan, so would not allocate any decent funding for them. I was forced to do things like run walkathons in order to raise funds, and to do all my own computer maintenance, something I still love doing on my own pc. That still left us with only being able to afford cheap "second class" computers when most schools had the real deal (Apple 2 with lots of educational software). There were a small number of mainly primary schools in the same situation, so a group of teachers from these schools used to collaborate to do the best with what we had.

By the end of 1988 I was frustrated with continually banging my head against the proverbial brick wall, so having done a bit of programming at uni and having since self taught myself a couple of other

microprocessor programming languages, I was successful with my application to join a (then) big American company in a programmer/analyst position. It was a tough decision and there were aspects of teaching I missed. For those who think teaching is a bludge with great holidays, in my almost 20 years in private industry, I never saw anybody work as hard as a dedicated teacher and for such measly pay. I never needed holidays as badly as I did when teaching.

I'd only been working in I.T. for just over four years and picked up skills in more languages, when after about a year of increasing "strange" occurrences, I was diagnosed with PLS (Primary Lateral Sclerosis), a form of MND. That was exactly 27 years ago as I write this (May 2020). PLS is a very rare form of MND which affects about 1 in every 250,000. It typically progresses much more slowly than ALS and although one can still end up very disabled it is typically described as a disease you die with, not of.

The company I worked for were absolutely fantastic!! At the time of my diagnosis we were living in Gembrook on 10 acres, which was unfortunately on a slope with steps down to and inside the house. They were proving increasingly difficult for me to safely manage and the 10 acres was too difficult for my full time working wife with two young daughters (9 and 7) to cope with, so in early 1995 we moved to Narre Warren North on a dead flat acre (couldn't cope with a normal suburban block after having our nearest neighbour 300m away).



Arrows point to Gary and his wife Jacqui at Volunteer Lunch in 2017

My work location was close to Monash Uni so in mid 1995, as my walking and speech were already being affected, the company very kindly organised a move to one of our other huge clients in Dandenong/ Doveton. By 5 years from diagnosis I was unable to take even a single unaided step without my walker/ rollator and only my family could understand what was left of my speech, but using email and chat programs, I was still able to contribute in a big way for another 9 years. However, at that point, our company lost the contract for the worldwide company we were performing all the processing for, so I was forced to retire.

I'd already been involved with MND Vic since the mid/late 90s so, at that point, offered my skills hoping they could utilise them. Initially I was involved in maintenance of the www.mnd.asn.au website, including some major upgrades of the system running behind it. **More recently I've been converting the hardcopy bi-monthly MND newsletter into online format so people anywhere in the world can read it.** For example, see the March-April one at www.mnd.asn.au/mnd-news/635-mnd-news-march-april-2020

At our Christmas volunteer lunch at the end of 2017 I was awarded my 10 year volunteer badge and aim to keep on volunteering as long as I possibly can. Fortunately, although I still legally drive with Vic Roads' blessing, most of my work can be done from home on my own pc.



Gary received 10 Year Volunteer Award

Cycling for MND

For many years I have greatly appreciated the free use of equipment such as my wheelchair from MND Vic's equipment library and, more recently, an expensive hoist so Jacqui doesn't hurt herself trying to lift me back up when I fall.

My wife, her sister and brother-in-law, all 60 years old or very close to, cycled from Adelaide to Melbourne in 11 days. I didn't cycle of course but I drove my ute as the Support And Gear person (SAG wagon).



Cycling For MND raised **\$7,205** for MND Victoria during MND Week in 2014.

Visit **Cycling For MND** www.mycause.com.au/page/68928/cycling-for-mnd

VOLUNTEER NEWS!



NATIONAL 18-24 MAY 2020
VOLUNTEER
CHANGING COMMUNITIES.
CHANGING LIVES. **WEEK**

National Volunteer Week, from 18 - 24th May in 2020, is a time each year when we make a special effort to recognise and acknowledge our volunteers.

MND Victoria developed through the efforts of a small group of volunteers nearly 40 years ago. Today, with over 130 volunteers, MND Victoria is actively aware of the significance of our volunteers to day-to-day operations and services we offer to people living with MND.

Each year MND Victoria makes time to recognise the significant contributions our volunteers make, the care they extend to people living with MND, and the support they give to staff across the organisation. Our volunteers are "Changing Communities – Changing Lives".

Since we were not able to come together to celebrate National Volunteer Week with our volunteers this year, MND Victoria created a range of activities which enabled us to reach out to our volunteers and let

them know their effort and commitment is very much needed and appreciated now and in the future.

National Volunteer Week activities included participation in an online education session – "MND and Communication" with MND Victoria staff. A small gift sent to each volunteer included messages from MND Victoria staff along with tea and coffee bags and a cookie for a shared morning tea. Our first "virtual" National Volunteer Week Morning Tea and Update enabled our volunteers to catch up with the MND Victoria Management Team and hear how current social isolation restrictions have, and will, impact MND Victoria Services.



260 Years of Volunteer Service

This year we are remarkably fortunate to recognise four volunteers who have each given 30 years of volunteer service to MND Victoria. Our great thanks and admiration go to Nancy Calderone, Betty and John Barling and Reverend Ian Parton who, in 2020, each mark 30 years volunteering with MND Victoria. Your volunteer efforts have changed lives and communities across Victoria and we thank you for that.

We also acknowledge Christine Robson and Joan Douglas who have each contributed 20 years of volunteer service with MND Victoria. Betty Eberle and Sally Edwards mark 15 years volunteering with MND Victoria this year and Karl Lapinskas has been volunteering with us for 10 years.

This year marks 5 years of volunteer involvement for Daniella La Pila, Jessica Taylor, Geoff Goulet, Amanda Elmer, John Lazzari, Louise Clayton, Jessica Tan, Lorraine McConnell, Gina Nathan, Caroline Lee, Leonie Lockwood and Kerry Bytheway

In total 260 years of volunteering by these 21 volunteers. That is remarkable. A huge “thank you” to each of you.

Usually, during National Volunteer Week, we would present Years of Service awards at our volunteer gathering. This year, when we are able to come together, we will present these volunteers with their service awards.

Services provided by MND Victoria volunteers have changed in line with the impacts of COVID-19. A number of volunteer services involving face to face contact with clients, support groups, community events and roles normally completed at the Canterbury Office have been placed on hold until it is safe to resume. A number of roles have seen volunteers change the way they work during this period, with volunteers completing project work from home, volunteers taking on new roles phoning clients and carers to reduce the impacts of social isolation, and our Life Story volunteers using webcams and the internet to continue to meet with their clients and work to record and write their stories. MND Victoria thanks every one of our volunteers for their ongoing support and confidence during this time.

Catching stories of our Volunteers

We are pleased to announce a new project recognising our volunteers.

Our new “Story Catchers” are volunteers who will talk with and record the stories of our volunteers – what brought them to volunteering with MND Victoria, what volunteering looks like and what volunteering means for them.

The aim is over time to catch up with many of our volunteers across the State and to record their stories. Two of our volunteers, Amanda and Marilyn are developing the “Story Catcher” role and are looking forward to meeting other volunteers and hearing their stories. Their first tasks were to interview each other.

Amanda’s Story:

Amanda joined MND Victoria as a volunteer following the loss of her dad to MND in 2013.

Motivated to “give back” to people with MND, Amanda initially volunteered with MND Victoria as a Bereavement Caller – calling those who had lost a loved one to MND. Amanda describes the privilege she felt when families shared stories of their loved one – showing how much they loved the person and the courage they showed.

With family and study commitments, Amanda took a break from volunteering for 18 months but stayed in contact with the organisation - particularly through MND News. She returned to help develop this new role of “Story Catcher Volunteer” this year. Having recently completed her Master’s Degree, Amanda notes this role relies on writing - a skill she knows she has, is flexible around her family and work commitments, and is possible with the increased uptake of technology many of us have been experiencing since the start of COVID-19 restrictions.

Amanda describes “I just want to be able to convey the stories of anyone who has volunteered and their part in supporting those with MND. Whether it be their connection with MND, or whether it be that they are a volunteer looking to commit their time to a cause”.

“Sharing people’s stories keeps the world ticking over and helps to embed our history for years to come”.

We look forward to sharing more stories from our volunteers in coming issues.

Contact Deb Olive to find out more

phone: (03) 9830 2122 or

email: volunteer@mnd.asn.au

Amanda and her father on her wedding day in 2007.



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

Story by Leah Rosenberg

Raymond Isadore Rosenberg

1949 - 2019

Written 4 months after his death.

Four months later

I wake looking at the sea in front of my eyes. All is still but the water runs to the west so fast. Today I shall try not to run but to be still. But then the thoughts come.

Perhaps missing is not a thought but a deep longing in my heart. Memories that can't be retrieved. I search to remember the good times, the times of joy and laughter.

I know we had those times. I look at all the photos, a chronicle of our 50 years together. The three children that we raised together, the daily happening, the holidays, the celebrations. Life changed dramatically after the diagnosis. For four and a half years we were expecting death to come. This in no way precluded times of intense connection, laughter and tears. As well as this there was fear and anxiety and for him the coldness. Always trying to insulate against the coldness.

When Ray died, I felt relief. Relief from witnessing his pain and suffering. Not that he let anyone know about this. He was afraid of the dark and the darkness ahead. Having to sleep separately. He wanted to protect us all. For me there was relief from the physical demands on my body as his carer. It was all so hard.

Grief takes many forms. No one can prepare oneself. The heavy heart, or I just want to tell him. An inexplicable longing. Or even "why can't he help me with the computer".

I will never forget that tight embrace on the day of diagnosis. His tears became my tears. Mine that became his.

If I knew that he would be one of the 6% to last 4 1/2 years perhaps this feeling of not wanting to leave his side would not have been so intense. Maybe we might have done more but we did what we could.

We discovered unknown parts of ourselves, all informed by the deepest love for each other. We were lucky. There were family friendship coffees. But most of all when the sun shone, they were the best of times.

Having lived through the best and worst of times now life continues.

GROUP PROGRAMS

MND Victoria runs a 6 week **Living Well program** for people with MND and their carers. Participants have the opportunity to share knowledge and discuss topics relevant to living with MND as well as provide ideas and support for each other.

The next program is scheduled to commence in **July**. Please contact MND Victoria either by phone or email to register your interest and you will be notified when the starting date has been confirmed. Phone: **(03)9830 2122** Email: **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 via phone, email, and video conference.

Facebook support groups

MND Carers Australia: An online support group, independent of MND Victoria, for Australian MND carers to discuss issues they face. 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. 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. 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 or ph. 02 8877 0902

Kennedy's Disease Facebook Group: Did you know that MND Victoria also provides support for people in Victoria living with Kennedy's Disease? One of our members has shared a Facebook group for Australians with, or affected by, Kennedy's Disease:

www.facebook.com/groups/3407816342962036/

Support services for carers of people with MND

Carers Victoria— 1800 514 845

www.carersvictoria.org.au

Carer Gateway—1800 422 737

www.carergateway.gov.au

CareSearch— (08) 7221 8233 www.caresearch.com.au

BrainLink—1800 677 579 www.brainlink.org.au

MND Victoria—1800 806 632 www.mnd.asn.au

EXPLORETECH PROJECT

You are invited to take part in the EXPLORETECH research project, which explores the views of participants with or without Motor Neurone Disease (MND) on the use of assistive technology.

Use of technology, such as the internet, handheld devices and computers is part of everyday life and offers ways to enhance the life of people living with disabilities. This can range from basic assistive technology, such as adapted keyboards or text to speech application, to sophisticated applications involving brain computer interface technology (BCI). In Motor Neurone Disease (MND), assistive technologies

may compensate for motor and communication impairment, facilitating social interaction. Usually this technology is developed by research and technical teams.

This research will help us to better understand what is important to end-users in their everyday life and guide the development of these technologies effectively to meet end-user needs appropriately.

This study aims to recruit up to 20 people with, and without, MND (relatives/carers). This research is initiated by Calvary Health Care Bethlehem and is funded by The University of Melbourne.

Please contact: christin.bird@unimelb.edu.au to get involved!

REGIONAL FOCUS

Ruth primarily works with clients in the Western Metro region and some in the Northern Metro region: Wyndham, Hobsons Bay, Brimbank, Maribyrnong, Moonee Valley, Whittlesea and Darebin.

IN THE LAST 6 MONTHS, RUTH PROVIDED 400 HOURS OF SUPPORT TO PEOPLE WITH MND.

Ruth has been an MND Advisor for **11** years.

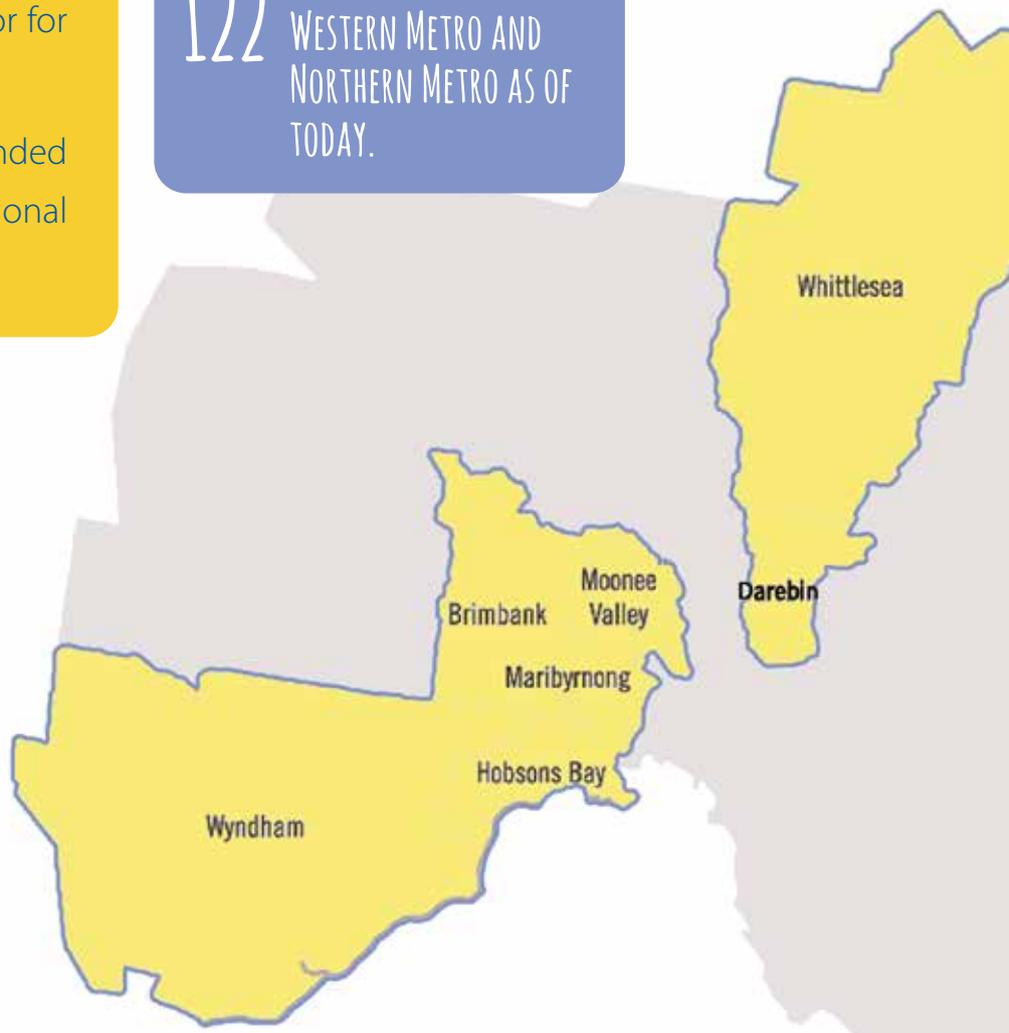
Last December, Ruth attended 2019 ALS/ MND International Symposium in Perth.

122 CLIENTS IN TOTAL IN WESTERN METRO AND NORTHERN METRO AS OF TODAY.

Ruth is also a registered nurse, health visitor and district nurse. She previously worked in Complex Care Intake and Assessment, local government and case management.

Ruth has provided 6 information sessions to residential aged care, hospital teams and MND Victoria's Information Sessions from 2017 to 2020.

Clients in this region attend the Statewide Progressive Neurological Disease Clinic at Calvary Health Care Bethlehem, Outreach Clinics at Bundoora Extended Care, and Barwon Clinic in Belmont, Geelong.



**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 **



RUTH - MND ADVISOR
+ SUPPORT COORDINATOR

Ruth shares support services with other MND Advisors. Ruth personally works with **34** people with MND in these regions (Western and Northern Metro).

19 clients in this area access the NDIS.

5 clients aged 65+ are waiting for Commonwealth funded Home Care Package (HCP).

5 people have HCPs, another **5** people are in Residential Aged Care.

'My Aged Care' system fails to meet the needs of people with MND. Please join the campaign to make Aged Care fair:
www.mndaction.org.au

An example of the furthest distance Ruth might drive one way is, from Wyndham to Epping, **70 km**.

Many of Ruth's clients are from multicultural backgrounds, including Italy, Eastern Mediterranean region, East Africa, Vietnam, Malaysia and Asia - a rich cultural mix.



"Approximately **5** MND Victoria Volunteers provide fabulous support across the Northern and Western Metro regions, with my client group. My clients are linked with volunteers who are able to offer **hand and foot massage**, support in writing their **life story** and coordination of **local MND Victoria Support Groups** in Hoppers Crossing and the Western suburbs of Melbourne. MND Victoria greatly appreciate our volunteers and would struggle without them."

Ruth has been using Zoom/video conference to deliver support services.

Please see page 18 for fundraising activities in this region.



HOW CAN I HELP MND RESEARCH

Familial MND research

Prof. Garth Nicholson and team based at the ANZAC Research Institute, Concord Hospital Sydney, are studying gene variations in familial MND. They are keen to obtain DNA samples from patients with familial MND. 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. Please phone (02) 9767 6796 or email molmed@med.usyd.edu.au for further details.

ALS Quest Survey

ALS Quest, a University of Sydney project, is an online anonymous questionnaire looking at environmental risk factors for MND: 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: fairlie.hinton@florey.edu.au Phone: (03) 8344 1900 Mobile: 0438 530 372 or visit: www.florey.edu.au/vic-brain-bank

Join the Australian MND Registry

The Motor Neurone Disease Registry is an ambitious project to register and collect data from every person in Australia diagnosed with MND. It contains de-identified data from people with MND including information about the diagnosis, symptoms, treatment and management. This information is made available to MND researchers. 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 can decline or withdraw from the study at any time.

Please contact Anna Smith: 03 9595 3355 email: anna.smith@calvarycare.org.au or visit the website: www.mndregistry.org.au

NINA BUSCOMBE AWARDS 2020



The annual Nina Buscombe awards celebrate the contribution and commitment demonstrated by Nina Buscombe to improve services, management and research for people with Motor Neurone Disease, through travel, training and conference attendance. The Awards are presented and administered by MND Victoria and are intended to fund attendance at training, conferences or seminars within Australia or overseas.

Given the current travel restrictions due to the COVID-19 pandemic – there are currently very few opportunities that would meet the eligibility criteria for the awards.

The 2020 International Symposium on ALS/MND, scheduled for December 2020 in Montreal has now been cancelled – with the International Alliance looking to create alternative opportunities to exchange latest advances in research and clinical management.

Given the current conditions, MND Victoria's State Council has taken the decision to postpone these awards until next year – when we hope there will be new opportunities for those doing such important work in the field of MND research and management to attend valuable conferences and training opportunities.

We thank all of our previous award applicants and recipients for their continued interest in working to improve the lives of people living with MND.

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

YOUR STORY

Poem By Maureen Fordyce

I went to my letterbox and what did I see
A parcel from the postie that was addressed to me.
I opened it up and inside were some things
Coffee, a blue biscuit and teabags with strings
For me to use and enjoy on National Volunteer Day
When we will all get together, just in a different way.

This year there will be no outing or meeting in a room
Just sharing time with each other and catching up via Zoom.
I can imagine the screen all filled with smiling faces
Of all the volunteers who live in different places
But wherever we come from there's one thing we all share
That we are a part of "until there's a cure there's care".

DAVE STEELE AND CUMMINS FOR MND VICTORIA

Cummins Laverton has chosen to support MND Victoria through a series of fundraising activities in 2020, as sadly our colleague and friend Dave Steele was diagnosed with this disease in November 2019. Although Covid-19 has impacted many of the planned events, fundraising has not stopped for a day with the tally climbing over \$15,000 by May thanks to so many generous donors.

Dave has a long history of employment with Cummins spanning back to 1990 when he started as an Apprentice in the Parts Department of the Mount Gambier Branch; since then he has also worked at Cummins Branches in Dandenong, Campbellfield and most lately in the Role of Parts Manager at Laverton since 2012. Dave has a great sense of humour and is often "En pointe" at our Management Team meetings; however, I'm sure his wife Kim thinks his latest attire of 'Socks, Crocs and Boardies' that he wears to walk along

to the local shops won't become Boardroom attire any time soon.

For the last 3 years, Dave has been the Cummins co-ordinator of 'The Very Special Kids' treadmill challenge and has successfully encouraged colleagues to fundraise for children with terminal illnesses. Now it's time for the colleagues who supported Dave in his efforts to fundraise for this cause to return the favour and support him in his effort to raise a minimum of \$20,000 in 2020 for MND Victoria. Dave and his family are already so thankful for the support received from his MND Advisor, Ruth, and the whole team at MND Victoria. These funds will go a long way in supporting Dave and the other 440 people currently living with MND in the State.

Dave's fundraising page can be found at -

www.mycause.com.au/page/222911/steele-trucking-for-mnd



FUNDRAISING



"I am a firm believer in the people. If given the truth, they can be depended upon to meet any national crisis. The great point is to bring them the real facts." Abraham Lincoln

Fundraising in the time of COVID-19

Since our last Newsletter we, like virtually every individual in the world, have faced many many challenges, from how we work to how we stay in contact with family and friends. It's hard to imagine that many of us had never heard of Zoom a couple of months ago and yet now we're Zooming experts!

While it's been relatively easy to find new ways to stay connected, finding ways to fundraise has been much harder. In the past three months, all community led and MND Victoria led fundraising events have either been cancelled or postponed. This has severely impacted the Association's income but we are determined it won't impact on the care and support we provide to people living with MND.

As we've heard from many sources lately, "every crisis brings a silver lining" or "when there's a crisis you need to look at different ways of doing things". Well here at MND Victoria we decided we were going to rise to the challenge and find ways to beat the negative impact of COVID-19 and fully embrace the use of technology to run "virtual" events. We want to make sure the MND community has every opportunity to actively participate with us in as many events as possible.

Our first foray into the virtual world was Zooming with

Dan. This has become a regular Thursday night event. Each week Daniel Woodrow, Supporter Development Officer, spends 30 minutes talking with one or two special guests about a topic relevant to MND. Our first event was with Eric Kelly, MND Victoria Team Leader. Eric and Dan discussed the role of MND Advisors / Support Coordinators and how they continue to support people with MND during COVID-19. You can watch these events live each Thursday between 7 – 7:30pm just by going to our Facebook page. Past interviews can also be seen there: www.facebook.com/MNDVic For information about Zooming with Dan please read Daniel's write-up on Page 21 of this newsletter.

If you have been part of the MND Association for some time you will be aware that throughout Australia the first week of May is MND Awareness Week. In Victoria, we have traditionally held a "Day of Hope and Remembrance" to start the week. Knowing how important this event is to our community we didn't want to let the week go by without acknowledging those impacted by MND either now or in the past. We did some brainstorming and decided we could present a Virtual Day of Hope which we live-streamed on Facebook on Sunday 3 May. As part of the event, we showcased a number of people lighting candles in honour of a loved one and encouraged viewers to light their candle at home while viewing the event. It was very moving to know that Day of Hope was being viewed around Australia with over 100 people watching live and many more watching at a time more convenient to them.



Over the last five years, our second event during MND Awareness Week has been "Ask the Experts", hosted by Dr Bradley Turner of The Florey Institute with guest researchers from other Melbourne research facilities. This is an opportunity for people with MND, their family and friends, to come and hear the latest advances in

MND research and then enjoy a tour of the Neurology Laboratory at The Florey Institute. Many clients look forward to this event so we were determined that somehow it would go ahead. Once again technology came to our rescue! On Tuesday 5 May, Dr Turner, Dr Nirma Perera and Dr Samantha Barton came to MND Victoria's office and gave us a summary of their MND research. The event was live-streamed on Facebook and many people from across Australia, and even New Zealand, took the opportunity to hear their presentations as well as submit their research questions. Over 100 people viewed the live event. We would like to acknowledge the invaluable support of The Producers in putting these two events together and managing the live-streams. If you missed either event they are still available on our Facebook page. www.facebook.com/MNDVic

While these three events have been a great opportunity for us to stay connected with the MND Community, they were never meant to be a way to raise funds. However, it is important that we acknowledge the significant impact COVID-19 has had on fundraising and this is why we launched "Australia Moves for MND". AM4MND is a national campaign which aims to raise \$250,000 to support the State MND Associations in their on-going delivery of care and support to people living with MND, as well as help fund research into cause, treatment and cure. For information about AM4MND and how to participate please read Daniel's write-up on Page 22 of this newsletter.

Thank you for your support and commitment to MND Victoria and to all Victorians living with MND today and in the weeks, months and years ahead.

Kathy Nightingale
Manager, Supporter Development



Zooming with Dan

The Covid-19 pandemic has been a challenging time for just about everyone. It has however opened the doors to those wishing to be innovative and do things differently because, as we all know, what we classed as 'normal' has been completely thrown out the window. Technology has allowed us to all stay together, whether it be family catch ups, trivia nights, virtual pubs or work meetings, amongst many other ways to stay connected via our phones, tablets and computers

Zooming with Dan is just like any online catch up except that we broadcast it live via Facebook so anyone can tune in. Dan, who works in our Supporter Development team loves a chat and is so passionate about working in the MND space. This seemed a natural fit to let Dan have conversations with the endless number of amazing people we come into contact with.

The MND community is full of incredible people. Whether they be our staff, health professionals, volunteers, carers, fundraisers, donors and of course, people living with MND. Zooming with Dan came about simply because we wanted to showcase all of these people. We wanted to highlight those who make a huge difference to the lives of others. It may have taken a pandemic to make this happen in an online forum but we are so glad we can bring the best and most up to date information, heartwarming stories and many smiles to those that tune in from their own homes.

Zooming with Dan is broadcast live every week. You can follow along on our Facebook page to see who Dan will be chatting to next. If you miss an episode don't worry! All episodes stay online so you can view in your own time.

Zooming with Dan is here to stay and we can't wait to see and hear from many more knowledgeable, inspiring, humorous and informative individuals.

Zooming with Dan



Tune in at 7:00 pm each Thursday for a fun and informative discussion with those in the MND community

www.facebook.com/MNDVic



AUSTRALIA MOVES FOR MND

Become a SUPERMOVER! Join this awesome FUNdraising campaign to raise funds and awareness for motor neurone disease.

AM4MND is a virtual event and runs from MND Week in May through to Global MND Day on June 21st. It's FREE to join and it's definitely not too late so why not choose your movement, get active and as creative as you wish to raise vital funds to help support the 2100 people living with MND in Australia.

Join team Victoria and the many amazing participants who have already committed to their 'movement' at www.am4mnd.org.au

Why register for AM4MND?

COVID-19 has resulted in the postponement of all scheduled Walk to D'Feet MND events across all States,

as well as hundreds of community run fundraising events for MND, resulting in significant loss of income. All State MND Associations are committed to caring for people living with MND but we can't do it without your support. People with MND have to face daily loss of physical movement, you can make sure they don't have to face financial hardship as well.

Because you want to make a difference whilst staying active, it's free to register and designed to be fun and engaging. Whilst everyone is stuck in their own home and neighbourhoods, why not commit to doing something fun, creative and healthy for you and everyone affected by MND.

What are you waiting for? Register today – start moving – take a photo or video, share it with friends, post it on your Facebook page with the tag: #AM4MND

www.am4mnd.org.au



DONATIONS RECEIVED ... THANK YOU!

In Memory

John Ryan
Stephen Nicolls
Warren Larsen
Rosie Grey
Ray Rosenberg
Barry Baker
Anne Hope
Jim Mcmillan
Jim Bugeja
Angie Navas
Warren Larsen
David Henderson
Gary Dooley
Giovanni Pozzebon
Patricia Begg
Ivana Quattricci
Zandra Fuller
Cliff Smith
Gemma Carnevale
Chester Keon-Cohen
Athanasios Nikolakopoulos
Joyce Critchley
Greg Slevison

Liliana Vanni
Robert Briggs
Thelma Henson
Doug Daines
Daphne Hollingsworth
Peter Larner
Allan Priest
Trish Borg
Van Hao Duong
Robert Tottle
Graeme Williamson

Organisations

Halit Flowers
Salavation Army-Wodonga Branch

Clubs

Pines Cricket Club
Clunes Netball Football Club
Knoxfield Cricket Sporting Club
Midland Bowls Club
White Hills Bowls Club
Portsea Golf Club
Lions Club of Bass Valley

Corporations

Express Insurance Brokers
JM Hiscock & Sons P/L
Ritchies IGA

Bequests

The Estate of Edna May Bastian
The Estate of Isobel Caroline McLaren

Trusts

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

Thank you so much for your support of our work and people with motor neurone disease!

MND Victoria Membership

Have you renewed your membership for 2020?

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 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 by 1 July for the next edition, to be mailed on 4 Aug 2020.

GET INVOLVED IN AN EVENT VIA INTERNET!

Date:	Event:	Find out more:
3 May 2020 - 21 June 2020	Australia Moves for MND	Email: info@mnd.asn.au
Sunday, 21 June 2020	Global MND Awareness Day 2020	Email: fundraising@mnd.asn.au
Wednesday, 24 June 2020	Remote MND Information Session - Video Conference	Email: info@mnd.asn.au
Thursday 6 August 2020	Remote MND Information Session - Video Conference	Email: info@mnd.asn.au

We are still providing vital support and care to all Victorians and Tasmanians living with motor neurone disease (MND). Our MND Information Sessions are presented live via Zoom, allowing access to everyone throughout Victoria and Tasmania.

For more information and the latest events updates, please visit our website www.mnd.asn.au/events

From all of us here at MND Victoria, we want to say a very BIG thank you to all of our donors, supporters, fundraisers and event organisers. We look forward to working with you all again in the near future, once all COVID19 gathering restrictions have been lifted.



Visit our website at: www.mnd.asn.au or follow us on:

www.instagram.com/MND_Vic | www.facebook.com/MNDVic

www.twitter.com/MNDVic | www.linkedin.com/company/mndvic