MND NEWS

November/December

2020

The newsletter of the Motor Neurone Disease Association of Victoria

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

BARWON SUPPORT GROUP

CELEBRATING 30 YEARS SUPPORTING PEOPLE WITH MND

mnd Victoria

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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 Special Projects: Kathy Nightingale

Manager Supporter Development & Communications: Daniel Woodrow

Communications & Fundraising Officer: Steph Cross

Manager Support Services: Jo Whitehouse

Team Leader MND Advisor/Support Coordinators:

Elizabeth Crask, Eric Kelly

MND Advisors/Support Coordinators:

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

Coordinator Operations: Eric Kuncoro

Coordinator Equipment Service: David Harkin

Equipment Officers: Kathy Walker, Sandra Nicholls

Coordinator Volunteer Programs: Deb Olive

Education and Client Support Coordinator: Janette McDonald

Education and Client Support Team Leader: Olivia Verschuur

Education and Client Support Administration Officer: Ruby Nunan-Jackson

Keeping Connected Advisor: Janet Cowling

FROM THE CEO

Welcome to summer and (at the time of writing) a slightly more "COVID-normal" Victoria. I can't believe how quickly 2020 has passed and that it's nearly Christmas already.

Many thanks to those who participated in our virtual Walk to D'Feet: Tour of Victoria. We were very pleased with the success of this event, and hope those who participated enjoyed walking virtually across our state.

MND Victoria held our AGM on 26 October via video link. It was a great meeting, with all motions passed and our State Council membership unchanged. Our guest speaker, Creighton Parker, speaking both in person and via pre-recorded video, captivated the audience with his positive approach to living with motor neurone disease.

I am constantly in awe of the people I meet who are impacted by MND, and their ability to remain positive and to see the silver lining in living with this dreadful disease.

An important part of our role at MND Victoria is to ensure that all people impacted by MND – those diagnosed with MND, their families, friends and the professionals and others providing care and support to them – have access to easy-to-find, current and accurate information, education and resources to help them to live as well as possible throughout the MND journey.

As you will read further on in this edition of MND News, we have done some reorganisation to create our new Education and Client Support team who will have a stronger focus on meeting the information, education and resource needs of the MND Community.

In addition, we have a new website www.mnd.org.au that has easy to find resources, information, personal stories and much more, to support people impacted by MND. Do check it out and let us know what you think.

Many of our staff will participate, either as speakers or attendees, at this year's International ALS/MND Alliance Allied Health Professionals Forum and Research Symposium. The event this year is to be live-streamed via video, enabling more of us to participate. If you are interested in seeing the program, you can learn more at www.alsmndalliance.org under the Events menu.

As the year draws to a close – from all of us at MND Victoria to all of you who are part of the MND Community – have a safe and happy Christmas and New Year. Many thanks for your support throughout 2020.

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

Kate

SUPPORT SERVICES

Jo Whitehouse

What's new in our Support Services Team!

MND Victoria's Education and Client Support Team

TEAM

Olivia Verschuur and Ruby Nunan-Jackson have joined the organisation in recent months and, together with Janette McDonald, who moved across from our Advisor team, complete the awesome threesome making up this newly formed team.

Pictured above (Left to Right): Olivia Verschuur, Ruby Nunan-Jackson and Janette McDonald

Olivia is the Team Leader - she is an Occupational Therapist and has extensive experience working with people with progressive neurological conditions, having moved to MND Victoria from Multiple Sclerosis Limited. Ruby is our new Administrative Officer. She has experience in Health Promotion and has joined us from the Cancer Council. Janette, our Education and Client Support Coordinator (also an Occupational Therapist!) has been with the organisation for over 20 years.

FOCUS

The team's focus for the next 12 months is on building our support and education programs and resources for people with MND, their carers and the Allied Health Professionals who support them. We do all of this currently, but want to expand the programs and resources that we offer!

This team is generally the Association's first point of contact for anyone in Victoria and Tasmania who has been recently diagnosed – they will continue to be the friendly voice at the end of the phone or email and provide information in advance of an MND Advisor being in touch.

SURVEY

The team has coordinated the Annual Client survey which was sent out in October. We hope there may be suggestions that arise from the survey on additional program areas that may benefit people impacted by MND. Thanks to all of you who have participated in the survey – like the American election, we have had a record number of respondents! In 2019, we had a 20.9% response rate, this year it's 42%. I will provide a summary of the survey outcomes in the next edition!

Keeping Connected Program

MND Victoria's successful application for additional Government funding has enabled us to expand our Keeping Connected Program. As a result, we have increased Advisor support from 1 day a fortnight to 3 days a week.

Our **Keeping Connected Program** works with people in Victoria and Tasmania with Motor Neurone Disease or Kennedy's Disease who are over 65 years of age, and who either have a slower disease progression or have a stable support network and environment. These people still benefit from regular contact from a qualified MND Advisor (Keeping Connected Advisor) to provide them with information and link them into appropriate services as and when their needs may change.

The Keeping Connected Advisor works collaboratively with the broader MND Advisor team, and service users may move between teams as their needs change and if more intensive support is required.

Janet Cowling has joined the team as our new Keeping Connected Advisor. Janet is an Occupational Therapist who has significant experience and skill in working with people with progressive neurological conditions.

Isabelle Lloyd, who has been the face of the program over recent years, still works for the Association but in a different capacity.

HELP NEEDED!

Equipment Reference Group

We have set up a reference group with Allied Health professionals who specialise in supporting people with MND, to review the type of equipment we have in our equipment library and to make sure we keep as current as possible.

Expression of Interest: If you are interested in joining the reference group, please email or call me for further information and tell me why you are interested in joining the group. Meetings will be held over Zoom, so you can live anywhere in the state (as long as you have an internet connection!). Initially, meetings will be held at six-weekly intervals, eventually transitioning to quarterly.

Client e-Newsletter

We will be commencing a monthly client e-newsletter with more detailed and up to date information about supports and services in 2021. To ensure you receive these important e-newsletters, please make sure your email address that we have on record is up to date.

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

Jo Whitehouse,
Manager Support Services

jwhitehouse@mnd.asn.au
0402 183 140

Olivia Verschuur

It has been a great start to my role as Education and Client Support Team Leader. In the first few months, I have been fortunate to meet with so many people in the MND community, albeit mostly via Zoom.

Everyone I have come across has been so knowledgeable and passionate about supporting people living with MND. Their energy is infectious, and I am looking forward to the year ahead!

Recently, the Education and Client Support Team has been working on MND Victoria's calendar for 2021. There are so many great things in the works for 2021, including MND Victoria's 40th anniversary. Our team's focus will be on reviewing and consolidating the brilliant service offerings we already have in place, as well as finding new ways to support people living with MND, their carers and health professionals in the community. This will include:

- Adapting our registration process alongside our new website and new customer relationship management (CRM) system to ensure the registration process and access to services is straightforward and as easy as possible for people who are newly diagnosed.
- Hosting Information Sessions for people living with MND, their families and friends, which will now run every five weeks with a mixture of times available over Zoom and (hopefully) at our Canterbury office.
- Reviewing the group programs offered, including "Living Well" which has been a great success in 2020. We look forward to updating the resources and finding additional ways to support carers in 2021.
- Connecting with our health professionals' network and providing opportunities for professional development for those working in this field. This includes a bi-monthly newsletter and recommencing our Allied Health professionals' forums in Victoria and Tasmania.
- Coordinating a brimming week of events for MND Week in May which will be here before we know it!

I am also happy to be a part of the group of staff and board members who will be developing a Reconciliation Action Plan (RAP) for MND Victoria over the coming months. I encourage anyone in our community with a particular interest or knowledge in this area to please touch base with me as we would like to draw upon the skills of others to ensure our RAP is as fitting as possible.

Janette (Education and Client Support Coordinator), Ruby (Education and Client Support Administration Officer) and I look forward to the year ahead and welcoming people living with MND, their families and friends, as well as others in the MND community, to touch base with any questions they may have. We hope to continue providing an efficient and informative service for those who are newly diagnosed and everyone seeking education and support throughout the MND journey.

Olivia Verschuur
Education and Client Support Team Leader

overschuur@mnd.asn.au

0423 304 617

NATURE'S IMPACT ON WELLBEING

Khairul, Robert and their partners participated in the 'Photovoice' Communication group through Calvary Health Care Bethlehem Hospital (CHCB).

The group has been developed for families living with MND, with a recent joint research project between CHCB and La Trobe University demonstrating that this group intervention does positively impact communication and social connection. Sharing photos is a great form of self-expression and a powerful tool to promote awareness about what helps families with MND 'live well'. The photos that the current group shared had a common theme of how they use nature to improve their wellbeing.

Research has shown that connecting with nature is health promoting and has a positive impact on well-being, which can assist people in managing chronic diseases. Whether you decide to look at nature photos, watch a sunset, or go on a stroll through a local park, each of these activities has the power to positively contribute to your sense of wellbeing.

To find some beautiful nature spaces where you live, visit the Parks Victoria's website. They have a list of parks, nature spaces and activities across Victoria that have accessible spaces: https://www.parks.vic.gov.au/get-into-nature/all-abilities-access

"The window in my house connects me with the beautiful world outside. This second photo is from Hanging Rock. I love camping and exploring nature and look forward to spending more time in nature with my friends as restrictions ease."
Khairul

"Looking at this top photo makes me feel calm and joyous. This is Robert and our daughter Leanne walking through Burke Street Park in Warragul. Without the help of MND Victoria, days like this would not be possible."
Tina (Robert's wife)

BARWON SUPPORT GROUP – CELEBRATING 30 YEARS SERVICE

In December 1990, a group of friends got together to discuss motor neurone disease as each of them had lost a friend or relative to the disease. Brenda Ryan, who worked at MND Victoria, and Mavis Gallienne, who was one of the people who started MND Victoria in 1981, met with the group in Geelong.

It was Brenda who suggested the idea of forming the Barwon Support Group so that those impacted by MND could find strength in sharing their experiences, helping those who were currently living with MND, and raising awareness in their local community.

One of the group, the Rev. Ian Parton, was appointed President, the role he still holds today some thirty years later. Many dedicated individuals have been actively involved in serving on the committee of the Barwon Support Group, ensuring that people with MND living in the area are supported as their disease progresses.

One of the immediate concerns of the group was to raise funds for a group member who needed a page-turning device for reading. This was before the establishment of the MND Victoria Equipment Service, so a Trash/Treasure stall was held at the Belmont Market. Over the years, the Barwon Support Group has supported many organisations and individuals, too numerous to list here, who chose to raise funds for MND Victoria. Each year the group organises the Geelong Walk to D'Feet MND event which usually takes place in March. While the 2020 event was cancelled, it is hoped the event will take place again in 2021 – watch this space!

MND Victoria is very grateful for the on-going commitment of past and present members of the Barwon Support Group. It is hard to quantify the incredible impact this group has had since its inception, in supporting members of their community living with MND, and in raising awareness and funds.

CHAMPION ALS STUDY

The CHAMPION ALS Study is a Phase III, double-blind, randomised, placebo-controlled, parallel-group, multi-centre study with an open-label extension period, to evaluate the efficacy and safety of ravulizumab in adult patients with amyotrophic lateral sclerosis (ALS). Ravulizumab is an investigational medication not currently approved for use in patients with ALS in any country worldwide.

More information about the study can be found on clinicaltrials.gov at the following link:

https://clinicaltrials.gov/ct2/show/NCT04248465.

The trial will be run at Monash Health, Victoria as well as other locations around the country.

The trial is currently open for recruitment at Westmead Hospital. The other sites will be open for recruitment between now and the end of 2021.

As with all trials, there is quite specific criteria for patients to be considered, so please discuss eligibility with your doctor. If they are not aware of the trial, then please direct them to:

https://clinicaltrials.gov/ct2/show/NCT04248465

The study is sponsored by Alexion Pharmaceuticals.

Any questions from clinicians can be directed to Alexion's Medical Information Department on 1800 788 189 or medicalinformation.australasia@alexion.com.

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 at: 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

FUNDRAISING

Daniel Woodrow

**"Out of adversity comes opportunity" –
Benjamin Franklin**

Say what you want about 2020, the one thing it has been is a year of opportunity. We've all had to learn new ways of living and, in our case, we've had to learn very quickly how to continue raising funds and awareness of MND, maintain MND Victoria's services and how we can move to keep engaging with the MND community whilst we can't come together in person.

The digital space has been our best friend and it's been a thrill to continuously learn and adapt to achieve so many successful outcomes. The one thing that hasn't changed is the dedication, passion and generosity of our amazing supporters. Ultimately, MND Victoria couldn't provide the services we do if it wasn't for the generosity of our fundraisers, donors, volunteers and those who want to tell their story to raise awareness of the disease and the work MND Victoria does.

The biggest change of all this year has been the adjustment of our flagship Walk to D'Feet MND from a 2000+ person event at Princes Park in Carlton to a virtual event, where participants were encouraged to walk around their own neighbourhood over a two-week period in their Walk to D'Feet MND t-shirts and facemasks. The 16th year of this event has been very different from usual. We needed to think differently, work differently and be even more creative. We are thrilled that everything came together and 2020 was still able to deliver a very successful and inspiring event! Our communications whiz, Steph, worked tirelessly to put together engaging content across countless emails, website pages and social media posts to encourage people to sign up and start their fundraising campaigns. A huge emphasis was put on the fabulous and invaluable work our MND Advisors do in the 14 different regions across the state. We were also overwhelmed by how many of our Walking Warriors shared their MND stories and reasons for participating with us. Sharing them all online has been imperative and something that has been a major highlight, and that has brought the MND community together throughout this campaign. Nothing will replace the joy in seeing thousands of people walking in one place for the same reason, however, this virtual event has been just as heart-warming given all that we have been faced with in 2020.

We embraced the challenge, took an opportunity, and believed in the MND community and the vital work MND Victoria undertakes. This recipe allowed us to raise over $270,000! To say our small team is proud is an understatement. There are so many heroes out there and we can't thank them all enough! We can't wait to gather in person once again, and hopefully our Geelong and South East Melbourne Walk to D'Feet MND events can go ahead in person in March and May next year, along with all of our other fantastic fundraising events throughout 2021.

People living with MND and their loved ones are the reason I do what I do. It's the reason all of us at MND Victoria do what we do. No matter our role and no matter the challenges we face, we want to ensure the best possible support and care is available to enable the best possible quality of life for all Victorians living with MND. I am proud to lead the Supporter Development and Communications team and to be entrusted with raising the funds needed to underwrite the critical services the Association provides for all 440 Victorians living with MND now, and for those who will be diagnosed in the future.

**"Hard times don't create heroes. It is during the hard times when the 'hero' within us is revealed" –
Bob Riley**

**Daniel Woodrow
Manager – Supporter Development and Communications**

WALK STORIES...

Penny Williams and Marie-Josee Finniss

During my Mother's illness and battle with MND, I was powerless to fight the dreaded disease and now I have the opportunity to fight. This challenge allows me to do something and focus all of my grief and hurt into a positive exercise along with many others, who have lost their loved ones from MND.

This is my fight against MND.

Karr's Clan

This will be our third year participating in the Walk to D'Feet MND. While this year's Walk is different in many ways, most notable for us is it's the first year we are participating without our Aunty Karr's (Karen).

In 2018 we walked for our Uncle Jack who lost his battle with MND in January of 2018. A few months past and she too was diagnosed with MND. After her brave battle, she passed away with family by her side in January 2020.

Sharyn Harrison

My name is Sharyn. My husband Brett was diagnosed with MND in March 2020. Being a Nurse for 27 years, I am used to nursing people back to health.

It was hard for me to accept that with Brett's diagnosis that "I cannot fix this" and I cannot nurse him back to health.

MND Vic have given our family ongoing support, equipment and guidance at no cost to us, to ensure Brett's quality of life, for as long as possible.

Wendy and Bruno Kaeser

Since my diagnosis about one year ago, the team at MND Victoria have provided caring and compassionate support to myself and my husband, Bruno. Importantly they have facilitated contact with fellow MND sufferers. We found it comforting to be part of a group in a relaxed atmosphere where experiences and information could be shared.

Lynny's Legends

Hi I'm Betsy and writing this as my friend of almost 60 years, Lynny, has been diagnosed with this rotten illness Motor Neurone Disease. For such a caring, funny, full of life person, who lights up every room she walks into, it seems even more unfair. She is however tackling this in her usual brave and smiling way and is appreciating the support from MND Victoria.

Christine and her family

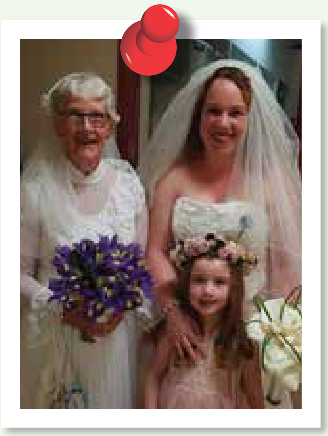
Christine joined MND Victoria as a volunteer in 2019 as a result of her niece being diagnosed with MND. Christine and the family (right) took part in this year's Walk as a way to thank the Association for its support of her niece.

WALK STORIES CONTINUED...

Team Kev

Why do we do the Walk to D'Feet MND as Team Kev? We walk to give back to an organisation that supported my dad through 2 years of living with MND. My dad, Kevin, was diagnosed with MND in April of 2017 at the age of 64 and sadly he lost his battle in June 2019.

We knew the battle was going to be tough after losing a family friend years before from MND, but little did we know how tough it'd actually be. Without the help and support of MND Victoria, Dad wouldn't have been able to stay at home for as long as he did. Not only was equipment supplied but the support given to not only Dad but to my Mum and I by his MND Advisor, Eric Kelly, was incredible.



Alison Farley

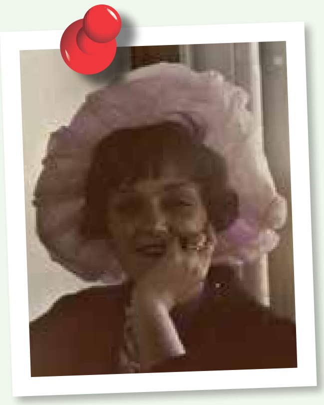
This year I will be participating in Walk to D'Feet MND in loving memory of my beautiful mother who sadly lost her battle with MND on 4 November 2020. As heartbreaking as it has been especially in her final days, I know she will be walking right beside me all the way.

We were extremely grateful and thankful for the loan hire of equipment from MND Victoria throughout this journey to be able to support mum at home.

We are all in this together and can only pray for a cure.

This photo was taken in October last year when the health service I work for had a 'Brides Revisited' event to help raise money for MND. It is a cherished day that myself, mum and my daughter, Asha could be apart of.

Macca's Team



We have been a family who knows what MND is. My Mother's younger brother, Leslie Taylor, passed away 5 years ago with MND in Ireland. This brought awareness to us all as a wider family connected by blood. We got onboard with MND in Ireland.

Mam was diagnosed in June 2020 in the advance and late stages amyotrophic lateral sclerosis and frontotemporal dementia - it has been a health benefit for Derek and myself to participate in the Walk to D'Feet MND and to raise awareness of the great work MND Vic do for people with MND and families caring for someone with MND.

The Steele Trucking team

The Steele Trucking team from Cummins Laverton are taking part in the Walk to D'Feet MND: Tour of Victoria. We're doing this to help raise much needed funds to support the 450 individuals currently living with MND in Victoria just now.

Sadly, our colleague and close friend Dave Steele was diagnosed with MND in November 2019.

Walking For Margie Parsons

Each year I set up a fundraising team, called Walking For Margie Parsons and try and participate every year. I have completed this walk most years since 2012. Margie Parsons was a Maternal and Child Health Nurse who worked at Nillumbik.

Margie (left) developed MND in 2009, and passed away in early September 2012 aged 58 years.

Margie was a beautiful person who could always make you smile. She was an inspiration to us all.

20 21

THREE PEAKS CHALLENGE

MND VICTORIA

INSPIRED ADVENTURES

mnd Victoria

CHALLENGE YOURSELF TO TAKE NOT ONE, NOT TWO, BUT THREE MOUNTAIN PEAKS ON THE MND VICTORIA THREE PEAKS CHALLENGE 2021!

On this exhilarating adventure through the Alpine region, you'll raise funds towards MND Victoria's mission of providing the best possible care and support to Victorians living with MND.

Over 3 days, you'll tackle Mt Stirling, Mt Feathertop and Mt Bogong, each view from the top as impressive as the last. Stand in awe of the majestic forests of Mt. Stirling, visit iconic Craig's Hut and discover an incredible ridgeline connecting two of Victoria's highest peaks- Mt Feathertop and Mt Hotham.

The best part? Through this challenge you'll show your support for those living with motor neurone disease and help make a positive difference to their lives.

7-9 MARCH 2021

Quite challenging (4/5)

Fundraising target:	$2,000
Travel package: *Excludes flights and subject to change*	$1,799
Registration fee: *Non-refundable*	$190

Twin-share accommodation 3-4-star

For more information contact Steph: **scross@mnd.asn.au**

Register online: **inspiredadventures.com.au/events/mndvic-3peaks-2021/**

REGIONAL FOCUS

Michelle Sharples

MND Advisor & Support Coordinator

Michelle has been an MND Advisor and Support Coordinator with MND Victoria for 1 year.

SUPPORTS:

APPROXIMATELY

27

MEMBERS ARE SUPPORTED UNDER THE COMMONWEALTH HOME SUPPORT PROGRAMME (CHSP)

15

MEMBERS ACCESS NDIS

HOURS:

IN THE LAST 12 MONTHS, MICHELLE HAS PROVIDED

1,382

HOURS OF SUPPORT FOR PEOPLE WITH MND

'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

MND Victoria volunteers are active in Michelle's area and they are available to support people living with MND with services including **Life Stories and Hand and Foot Massage.**

Volunteers also travel from this area to participate in fundraising and other events, to assist with **Reception** and roles at head office including sending out **MND News**.

We look forward to getting together with our volunteers when we are able.

Michelle works with members in Melbourne's north, including Yarra, Darebin, Banyule, Whittlesea, Nillumbik

Since the introduction of COVID-19 restrictions, Michelle like all our Victorian MND Advisors/Supporter Coordinators, has been using Zoom, phone calls and emails to deliver support services.

Most people with motor neurone disease in this region (other than those living in Yarra) attend the Progressive Neurological Disease Clinic at Northern Health/Bundoora. Most also access the associated allied health team at Northern Health.

People living in Yarra and others who choose to, access the Statewide Progressive Neurological Disease Service at Calvary Healthcare Bethlehem and local allied health services.

Many also access the services of Melbourne City Mission and Banksia palliative care services.

People with MND also access the Victorian Respiratory Support Service which is located at Austin Health in Heidelberg.

!

QUIRKY FACT ABOUT MICHELLE:

Michelle volunteers with Seeing Eye Dogs Australia and has a beautiful black Labrador called India. Michelle says “India has plenty of quirks for the both of us.”

VOLUNTEERS NEWS!

Deb Olive

As we approach the end of 2020, MND Victoria says a huge thank you to each of our volunteers who have played their part during this year.

With our primary concern being for the safety of our clients and their families, volunteers, staff and members of the community, our volunteer programs have adapted in 2020. In accordance with state government directives and health advice, many of our volunteer roles were placed on hold for much of the year. Other roles changed to "online" ways of working. And in some cases, volunteers stepped up to new roles and projects. Throughout this time, our volunteers have also been actively involved in ongoing education and development sessions.

The enthusiasm of our volunteers to recommence their significant roles is inspiring. We will continue to consult with our volunteers to ensure planning takes into account issues they identify as important to them. We are currently planning for the return of volunteer roles where, and when, it is safe to do so.

MND Victoria currently has five active Support Groups across the state. These groups provide regular opportunities for people living with MND and their families to meet and connect – sharing information, experiences and support. The friendship and connections developed through these groups is one of their strengths.

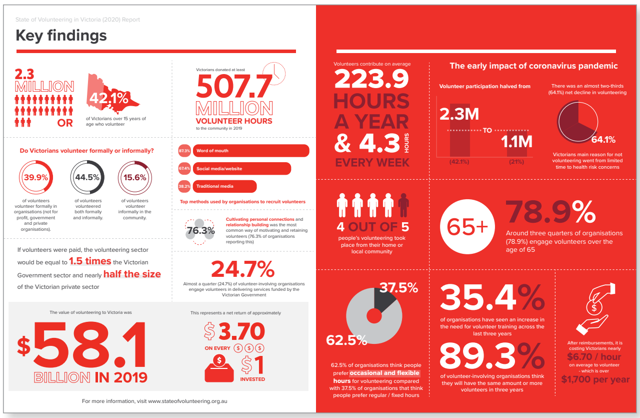
The longest-running Support Group is our Barwon/Geelong Support Group which first met on 3rd December 1990. This year the Barwon/Geelong Support Group celebrates 30 years of active involvement – raising awareness of MND in the local community, raising funds to support the work of MND Victoria and building local community commitment. To all the members of the Barwon/Geelong Support Group – "thank you" and congratulations for all you have achieved.

Throughout the 30 years of the Barwon/Geelong Support Group, Rev. Ian Parton has been the Chairman of the group. Soon after he moved to the area Ian became aware of a friend of a friend who had been diagnosed with MND. Ian stepped in to provide some emotional support and the rest, as they say, is history! Thank you, Ian, for your ongoing commitment.

This year we also acknowledge John and Betty Barling who have also supported the work of MND Victoria for 30 years since 1990. John and Betty's work has been recognised internationally when they were nominated by Jacqui, their daughter, as "Carers of the Year" through the ALS Association. Thank you, John and Betty.

Incredibly, this year MND Victoria has another volunteer who has been active within the organisation for 30 years. Thank you to Nancy who became involved with the organisation following a period when she was caring for a gentleman with MND. Since then, Nancy has been active in a range of roles. Currently, Nancy is looking forward to when she can return to Hand and Foot Massage and social contact with people living with MND. Thank you, Nancy.

Recently, Volunteering Victoria released the Victorian State of Volunteering Report. Researched over the period 2019 to 2020, it revealed 42.1% (2.3 million) Victorians over the age of 15 volunteer – contributing, on average, 4.3 hours every week. That's a total of 507.7 million hours contributed by volunteers to their community. It is calculated the value of volunteering to the state is $58.1 billion. The volunteering sector is over one and a half times larger than the Victorian Government sector and nearly half the size of the private sector.



State of Volunteering in Victoria (2020) Report

Key findings

2.3 MILLION OR 42.1% of Victorians over 15 years of age who volunteer

Victorians donated at least 507.7 MILLION VOLUNTEER HOURS to the community in 2019

Do Victorians volunteer formally or informally?

39.9% of volunteers volunteer formally in organisations (not for profit, government and private organisations).

44.5% of volunteers volunteered both formally and informally.

15.6% of volunteers volunteer informally in the community.

87.3% Word of mouth

67.4% Social media/website

38.2% Traditional media

Top methods used by organisations to recruit volunteers

76.3% Cultivating personal connections and relationship building was the most common way of motivating and retaining volunteers (76.3% of organisations reporting this)

If volunteers were paid, the volunteering sector would be equal to 1.5 times the Victorian Government sector and nearly half the size of the Victorian private sector

24.7% Almost a quarter (24.7%) of volunteer-involving organisations engage volunteers in delivering services funded by the Victorian Government

The value of volunteering to Victoria was $58.1 BILLION IN 2019

This represents a net return of approximately $3.70 ON EVERY $1 INVESTED

For more information, visit www.stateofvolunteering.org.au

Volunteers contribute on average 223.9 HOURS A YEAR & 4.3 HOURS EVERY WEEK

The early impact of coronavirus pandemic

Volunteer participation halved from 2.3M (42.1%) TO 1.1M (21%)

There was an almost two-thirds (64.1%) net decline in volunteering

64.1%

Victorians main reason for not volunteering went from limited time to health risk concerns

4 OUT OF 5 people's volunteering took place from their home or local community

65+ 78.9% Around three quarters of organisations (78.9%) engage volunteers over the age of 65

37.5% 62.5%

62.5% of organisations think people prefer **occasional and flexible hours** for volunteering compared with 37.5% of organisations that think people prefer regular / fixed hours

35.4% of organisations have seen an increase in the need for volunteer training across the last three years

89.3% of volunteer-involving organisations think they will have the same amount or more volunteers in three years

After reimbursements, it is costing Victorians nearly $6.70 / hour on average to volunteer - which is over $1,700 per year

Source: https://stateofvolunteering.org.au

"Together We Can Through Volunteering"

To all our MND Victoria Volunteers - and to all who volunteer – happy International Volunteer Day on Saturday 5th December.

GROUP PROGRAMS

We have been able to transition many of our group sessions online this year. Thank you to the wonderful MND team members who have supported this and made it possible. Also, thank you to the MND community for your patience with us making these changes to the program. There were two Living Well groups that ran successfully in 2020. This enabled more than twenty people (either those living with MND or their carer) to connect and discuss a variety of topics and experiences on the MND journey.

A group member from the most recent Living Well cohort mentioned *"you can read all the literature but being able to talk really helps"*.

We will be reviewing the Living Well program and look forward to offering this in 2021.

There have been eight Information Sessions for people who are newly diagnosed, their family and friends. Since May during Victoria's lockdown these have been offered online via Zoom. By running these sessions via Zoom families from all different regions across Australia have been able to obtain information, ask questions and gain support from the MND community. We have also continued to offer Information Sessions to health professionals and service providers so those working in this space can provide the best possible care for people living with MND.

We look forward to reviewing and expanding the group programs. The feedback provided so far will be very helpful in ensuring we can adapt our services and meet people's needs. We will be meeting with MND New Zealand in the coming weeks as they too are reviewing their services and looking at ways of helping people connect with others with experience of living with and managing MND. This collaboration is perfect timing for us and will hopefully add to our ideas about the group program in 2021.

Please touch base if you have any recommendations, requests or ideas.

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. Contact info@mnd.asn.au

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: 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: 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 phone (02) 8877 0902

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.org.au

CHANGE FOR CHANGE

MY CHARITY CHANGE
Change for Change

MND Victoria is always exploring ways in which we can raise more awareness and funds to underwrite the vital services we deliver to people living with MND and we're pleased to introduce a new, innovate way in which our supporters can easily give to the Association.

Introducing My Charity Change – a mobile app which allows you to round up your spare change whenever you choose to use your bank card. It's as simple as downloading the app, linking a bank card (credit or debit) and donating the extra change from your day-to-day purchases. So that all state MND organisations can benefit from this app, we have partnered with MND Australia and all funds donated to MND Australia via the app will be distributed to the respective state MND organisation.

You can be a part of this initiative by simply downloading the app from the Apple iTunes or Google Play stores and selecting MND Australia from the list.

Remember – every time you use your card, your change will be supporting Australians living with MND.

MND VICTORIA CARES ... AND WITH YOUR HELP WE ALWAYS WILL

Making a Will is important as it allows us to say how our life savings should be spent. A Will allows you to acknowledge the important people in your life.

Family and friends who have provided love and support can be named as beneficiaries of your estate. It also gives you the opportunity to leave a Gift to your favourite charities; charities who may have supported you or your loved ones during your lifetime.

From time to time the Association is fortunate to receive bequests and these are invested so that the earnings can provide care and support for people living with MND and be invested in research.

If you are considering writing or updating your Will, or would just like more information on leaving a Gift in your Will, please contact fundraising@mnd.asn.au and we will be happy to discuss this with you and provide more information.

DONATIONS RECEIVED ... THANK YOU!

In Memory

Christine Stafford
Philip Jago
Peter Lowe
Jim Mantovani
Robert Howden
Robert Eastgate
Martin Williams
Shantha Abeysundara
Keith Majoos
Doris Little
John Heriot
Jenny Steinicke
Robert Kelly
Les Hazel
Geoffrey Stone
Glen Roach
Christine Eaton
Richard Edwards
Graeme Ross
Ann Nicol
Annie Melican
Gary Jones
Thelma Henson

In memory for equipment

Richard Edwards
Jack Featherston

Corporations

Express Insurance Brokers
Specsavers Pty Ltd.
Ritchies Supermarkets and Liquor Stores

Organisations

Eyecare Plus Cranbourne
Terry White Chemart Narrandera
Vitality Brands Worldwide

Clubs

Portsea Golf Club
Jerilderie Golf & Bowls Club

Trusts

Australia Post Workforce Grant

Bequests

The Estate of Shirley McCosh

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 31 January 2021.

GET INVOLVED IN AN EVENT VIA INTERNET!

Date:	Event:	Find out more:
1 February 2021	**Information Session (Zoom)**	E: info@mnd.asn.au
7-9 March 2021	**Three Peaks Challenge**	E: scross@mnd.asn.au
16 March 2021	**Information Session (Zoom)**	E: info@mnd.asn.au
21 March 2021	**Geelong Walk to D'Feet MND**	E: fundraising@mnd.asn.au
15 April 2021	**Information Session (Zoom)**	E: info@mnd.asn.au
2 May 2021	**S-E Melbourne Walk to D'Feet MND**	E: fundraising@mnd.asn.au
2 May 2021	**Service of Hope & Remembrance**	E: info@mnd.asn.au
4 May 2021	**Ask the Experts**	E: info@mnd.asn.au
7 May 2021	**Blue Cornflower Day**	E: fundraising@mnd.asn.au
6-14 May 2021	**National Kokoda Challenge 2021**	E: fundraising@mnd.asn.au

We are still providing vital support and care for 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.org.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 COVID-19 gathering restrictions have been lifted.

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

www.instagram.com/MND_Vic | www.facebook.com/MNDVic
www.twitter.com/MNDVic | www.linkedin.com/company/mndvic