MND NEWS

January/February

2020

The newsletter of the
Motor Neurone Disease
Association of Victoria

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

mnd Victoria

NEW YEAR NEW OPPORTUNITY

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ABN 44-113-484-160

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SUPPORT GROUPS

MND Victoria Support Groups provide opportunities for people living with MND, their carers and interested members of the public to come together on a regular basis. For information about Support Groups contact MND Victoria, 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

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Administration Assistants: Isabelle Lloyd, Rebecca Moussa

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Elizabeth Crask, Eric Kelly

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Sam Mitchell
Julie Wilson
David Cox
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Jenny Fuller (Hobart)
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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

As we head into 2020, we take this opportunity to acknowledge the difficult start to the year that those in bushfire affected parts of our State, and indeed our country, are currently experiencing. At MND Victoria, we have endeavored to stay in close contact with our clients and families who are in these areas or are otherwise impacted by fires and poor air quality and offer any support that we are able. We encourage affected clients to make contact with our Information and Resourcing team or with their advisor should they require information or advice. Our thoughts are with all those affected by these events.

December saw researchers, allied health professionals, support staff, fundraisers and leaders of MND/ALS support organisations from across the world, come together in Perth for the International Allied Health Professionals Forum and the 30th International Symposium on ALS/MND.

As a first time attendee at this annual International meeting, I was so fortunate to meet many CEOs and leaders from MND/ALS organisations from many other countries and hear about the work they are doing to raise awareness, raise funds and provide support to people living with MND. I made a number of very valuable contacts and look forward to having ongoing communication with these dedicated people.

MND Victoria supported 43 researchers and allied health professionals to attend the Allied Health Professionals Forum and/or International Symposium through our annual Nina Buscombe awards.

Some of the feedback from those we supported to attend included:

"A fantastic opportunity to hear about the range of programs that are running across the world to support carers & those with a diagnosis of MND."

"I was thrilled to have the opportunity to attend the Allied Health Professionals Forum this year and felt very privileged to be one of the presenters that day, which allowed us to come together and share knowledge around the supports, comfort and improvements we can make to the quality of life for people and their loved ones living with MND."

"The poster sessions afforded me the opportunity to discuss my work with other MND geneticists who provided great insight into future avenues for my research as well as some interesting interpretations of my results."

As part of this International event, the first ever Global Walk to D'Feet MND was held, with more than 400 participants joining together for a 5km walk to raise awareness of MND/ALS. This was a moving and inspiring event with attendees wearing t-shirts from ALS/MND organisations across the world.

"I was also fortunate enough to participate in the first Global Walk to D'Feet MND. With over 400 walkers it was touching to see the support for MND research and patient care. Though it was a hot afternoon walk, it was truly a miniscule effort compared to that put in by MND patients and their carers each and every day. Hopefully this one small act has made a difference and improved MND awareness in the general community."

Our Walks to D'Feet MND are such important events, not only to raise the funds that are needed for MND Victoria to continue to provide the services that support people living with MND, but also in raising awareness of the impact that MND has on those living with it, including their families, carers, friends and communities. We have a number of Walks coming up in 2020 –please join us if you can, form a team to walk and share these events on social media to maximise the impact of our Walks.

Finally, wishing you and your families a Happy New Year. I hope 2020 brings you love and laughter.

Until there's a Cure, there's Care.

Kate

SUPPORT SERVICES

HAPPY NEW YEAR TO ALL!

Thinking of everyone who has been impacted by the terrible fires that have been blazing over the Christmas period, including any clients, their friends and families, staff and volunteers. I hope everyone has kept safe and will continue to stay safe from any threat of bushfires. Please contact us if there is anything we can do to assist. A reminder that our staff will not travel to attend home visits on days declared as Code Red (Catastrophic), but we will be in touch in the event that we need to change any appointments.

In December the majority of the support services team attended the Allied Health Professionals Forum and the International Symposium in Perth. It was a fabulous opportunity to meet colleagues from around the world and hear about the latest clinical perspectives and research being undertaken. Please see Alison Jones, our Information Coordinator's article for more details.

2020 is already looking to be a busy year. We have hit the ground running with lots of plans for the year ahead including:

- Facilitating a Health Professional Forum in Tasmania on the 27th March.
- Reinvigorating our Living Well Program which provides support to people diagnosed with MND and their carers – this will initially be run from the Canterbury Road office, but we hope to expand it to regional areas in the future.
- Developing our online information provision e.g. running webinars or using other online tools to try and reach more people.

Staff updates

The team continues to GROW!

We have a new MND Advisor position that has been created in the Southern metro area of Melbourne because the caseloads of staff covering this area have been very high. Sarah Wilkie, who has been working for MND Victoria as an Information Officer, has been appointed to the position and will transition to the role at the end of January. She has developed a huge amount of expertise about MND in the 2 years she has been working for the Association.

We are recruiting for the vacant position in the Metro Outer East area. Elizabeth Crask, MND Advisor Team Leader, continues to support this area in the meantime.

OTHER SUPPORT SERVICE SNIPPETS!

Equipment Reference Group

We are looking to set up a reference group this year in conjunction with our allied health professional colleagues from the MND Clinics to help us with new equipment choices and to review some of the guidelines regarding equipment use.

NDIS

We continue to collaborate with our state MND colleagues to influence the provision of supports for people with MND by the NDIS. The NDIS has asked us to provide some de-identified case studies to enable them to look at why allocation of supports can be so widely different in different regions. We hope this will improve consistency!

Audit

Up until now, we have been audited by the Department of Health and Human Services. Due to the recent disability sector changes and the completion of the rollout of the NDIS, we are now required to be audited by the NDIS Quality and Safeguards Commission. We successfully competed stage one of this audit in November and are scheduled to undertake stage 2 of this audit in February. In the second stage, the auditors need to talk to service users about their experiences. I will be communicating directly with all NDIS clients prior to the audit about the process.

As always, please don't hesitate to contact me if you have any feedback about any of our Support Services.

Jo Whitehouse, Manager Support Services

Email: jwhitehouse@mnd.asn.au

Mobile: 0402 183 140

HEALTH PROFESSIONAL FORUM

Our next MND Health Professional Forum will be held in Hobart on Friday, 27 March 2020 - please save the date!

If you would like to attend the forum, please book online via the link **www.bit.ly/2s9qfMw**

If there is information or topics you would like covered at this forum, please email: **info@mnd.asn.au**

If you would like to join our mailing list to hear about future events and conferences for Health Professionals, please email: **info@mnd.asn.au**

MND INFORMATION SESSION

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

7pm on Wednesday, 19 February at MND Victoria, 265 Canterbury Road, Canterbury.

Please RSVP by 5pm, Monday, 17 February 2020.
Phone: (03) 9830 2122, 1800 806 632 or
Email: info@mnd.asn.au The following session is on Thursday, 2 April at 7pm.

ALS / MND Symposium

Introduction

A warm welcome awaited delegates at the 30th International Symposium on ALS / MND in Perth which was held from 4-6 December 2019. Visitors from colder parts of the world needed to acclimatise quickly in order to cope with Perth's hottest first week of summer on record!

This annual event, held in a different country each year, attracts over a thousand delegates and is the largest medical and scientific conference specific to ALS / MND. It is the main event on the research calendar and provides opportunities for learning about the latest advances in research and clinical management. It was hosted by MND Australia in partnership with MND WA.

The three day symposium was preceded by the 17th Annual Allied Professionals Forum and an 'Ask the Experts' session, both held earlier the same week. A large team from MND Victoria attended the first two days with a smaller group staying on for the symposium. Networking with colleagues from other MND Associations and organisations from within Australia and overseas was encouraged and there were social opportunities included in the program including a Global Walk to D'Feet MND.

'Ask the Experts'

Key researchers in the field including Prof Matthew Kiernan from Australia, Prof Ammar Al-Chalabi from the UK and Prof Leonard van den Berg from the Netherlands provided an easy to understand overview of current developments in the MND space and explained how the research community's understanding of the disease is evolving. Genes and environment both play a part in the development of MND which appears to be a multistep process. Clinical trials were also discussed including the lengthy, complex and expensive process required to take a drug from a phase 1 trial through to it being approved for use and made available on the market.

Allied Professionals Forum

A full day's program for allied professionals featured a number of speakers from Calvary Health Care Bethlehem in Victoria as well as other experts from around the world. This was a very practical session which covered a diverse range of topics including adapting and adjusting to rapidly changing function, managing neck weakness, improving recruitment to clinical trials, cough and secretion management, intimacy issues for people with MND, assistive technology and voice banking.

International Symposium

The MND research community is a very collaborative one and it was exciting to hear from the many brilliant minds from around the world who are engaged in research to find causes, effective treatments and ultimately a cure for the disease.

The symposium was structured into two streams: (i) biomedical research and (ii) clinical research and management, and delegates were able to swap from one stream to the other in order to attend sessions that were of most interest and relevance to their work.

Researchers who participated in the biomedical research stream presented on various topics including genetics and genomics, biology and pathology, and disease models, and those who participated in the clinical research and management stream presented on respiratory and nutritional management, cognitive change, carer and family support, person-centred care, assistive technology and more.

The research community was delighted that Prof Justin Yerbury from the University of Wollongong was able to attend and present at the symposium. Justin is a molecular biologist who was diagnosed with MND in 2016 after losing a number of family members to the disease. Considerable planning and preparation were required to enable him to travel safely to Perth including a custom-made hoist for transferring him in and out of the plane as well as removal of seats on the aircraft to accommodate all his medical equipment. Justin has already contributed significantly to research in the MND field and is keen to continue his work with his colleagues for as long as possible.

A very engaging presentation was delivered by US researcher and social worker Assoc Prof Melinda Kavanaugh who had been investigating support for young caregivers in families with MND. She discovered that young people aged 6-20 years, in some instances, had significant carer responsibilities that were impacting on their school attendance and performance, as well as social opportunities and mental health. Many were assisting with a range of their loved one's personal care tasks including dressing, feeding, bathing and toileting and were experiencing interrupted sleep, social isolation from their peers, caregiver stress and burnout. In some cases, the young people were using equipment such as hoists and ventilators that they had not been trained how to use safely, and as a result, they felt anxious about potentially causing harm to their loved one. Often they had no one to talk to who understood their situation and could provide emotional support, and schools were generally unaware of the carer burden that these young people were carrying. Peer support groups and education programs were trialled with promising results. This may be relevant to young carers in Australia too and would be worthy of further research.

Two fascinating presentations were delivered by Prof Samar Aoun from Australia. The first focused on the palliative approach to care and key issues for patients, including quality of life, quality of care and quality of death. It was recommended that conversations about palliative care be initiated as soon as possible after diagnosis. Carers of people with MND were identified as needing support in many areas including knowing what to expect in the future, who to contact if concerned, and how to deal with their feelings and concerns. The second presentation looked at the gap between standards and practice in delivering a diagnosis of MND. If communicated poorly and without empathy, this can have a devastating impact on individuals and their families and many examples of this were cited. However there were also many instances where neurologists had handled this process well by providing an extended, uninterrupted consultation where individuals and their families could ask questions and receive emotional and psychological support. Future planning, goal setting and follow up were also identified as important factors in this process, as was education of neurologists.

On behalf of all staff who attended, thank you to MND Victoria for the opportunity to participate in these inspiring international events.

Alison Jones

Coordinator Information & Resourcing

YOUR STORY

By Creighton Parker (member at MND Victoria)

My diagnosis was in March 2017. I must have presented with classic MND symptoms, as on my first visit to the neurologist and within 30 minutes, I was given the sad news. I didn't know much about MND but I have learned a lot since then.

The first thing I learned was that on average from diagnosis to death was 28 months, that of course was a shock and very confronting. Even at 66 years old I felt indestructible, especially as I had been very fit and healthy for my entire life.

Nearly 3 years on and I am still going ok. Eating normally, sleeping ok but now unable to walk and the feeling loss of the use of my fingers and my hands along with reduced lung capacity. I am fortunate to have some strength in my arms and shoulders. What you learn as you gain more knowledge of your MND is that no two people travel the same road. The disease can manifest in different parts of the body, at variable rates of decline, and there seems to be no real way of understanding how your symptoms might unfold into the future. It speeds up, then plateaus for no apparent reason.

It goes without saying that having the support of family and friends is critical to your well being, comfort and mental health. I am extremely fortunate to have such support and every day I am very appreciative of the people around me, especially my wife, Judy who is my 24 hour carer. I also get personal care for an hour each morning through my Aged Care Package.

As time progresses it is also important to be aware of, and understand, the support you can receive from external organisations. MND Victoria have provided me with equipment to meet my changing needs. From day one, MND Victoria have been a phone call away to provide a helping hand. I also get support from Eastern Palliative Care which helped facilitate and drive my application for an Aged Care Package which we now fully utilise, along with some "non medical" financial support. The medical profession at all levels has been wonderful.

Making early application for Government support is really important as these processes are usually complex and can take considerable time. Reasonable levels of "on line" skills can be handy to help you undertake these tasks. Advocating for your self and your situation is also important. For those under 65 the NDIS is the place to start, if over 65 the My Aged Care is for you.

MND is a difficult prognosis to deal with especially if you are relatively young. To give encouragement to others, I have tried to think of the positive opportunities and outcomes I have discovered whilst under this dark cloud. Being as positive as possible has helped me to cope with my situation. I definitely appreciate how modern equipment contributes to making life easier. Motorised wheelchairs*, shower chairs*, a hospital type bed for more comfortable sleeping. I have a B-pap machine to assist my breathing whilst lying down and sleeping. Modern technology has been so necessary and helpful.

We had a ceiling hoist installed to allow me to be lifted and transferred from bed to chair etc. It has been a great investment and has made caring for me so much easier. My ability to stay at home for as long as possible has been considerably enhanced because of the quality and functionality of the modern equipment I have access to. My advice to others is to plan in advance and, if you are able, get these aides in place before you really need them. Of course your Occupational Therapist and medical advisors would need to be there to guide you in this regard.

*Equipment from MND Victoria

Another positive I draw upon is access to TV, Foxtel, Netflix and other online sources of entertainment. I enjoy classical music and discovered, much to my delight, terrific music on YouTube. An online subscription to a daily newspaper, online books, email, casting from my android tablet to the TV, so many forms of entertainment that keep me stimulated and are accessible from my wheelchair. If needed, find a tech guru to help you with these things.

I enjoy regular visits from family and friends and the affection shown to me by so many has constantly lifted my spirits. Of course there are days that are hard, but they are few and far between. Of course every individual is different and will have different ways of coping with their disease.

There is no right or wrong about how you should feel. MND is a dreadful disease, incurable and difficult to accept. If I were to give some advice, then that is to remember that those who are caring for you are doing their best, and might be just as stressed and worried as you.

All the best to those reading this article. I hope the road you travel is as kind as it can possibly be.

GROUP PROGRAMS

Our next **Living Well Group Program** for people with MND and their carers will be running over 6 weeks commencing on Friday, 14 February 2020. Participants will have the opportunity to share knowledge and discuss topics relevant to living with MND. They will also provide support for each other and will be able to share ideas and solutions of their own.

Please contact MND Victoria to register your interest in our group programs for people with MND and their carers. Phone: (03) 9830 2122 or 1800 806 632 or email: **info@mnd.asn.au** to register your interest.

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.

MND Victoria has a client, a woman who lives in the Maroondah area who is very keen to link up with other local people with a diagnosis of MND. Please contact the MND Victoria Information Team or Elizabeth Crask: 03 9830 2122 or **info@mnd.asn.au** to be linked in.

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/3407816ß42962036/

Support services for carers of people with MND

Carers Victoria— 1800 242 636

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

VOLUNTEER NEWS!

The welcome of 2020 has been overshadowed by the emergency fire situations impacting much of Australia. Our thoughts are with all those affected by the fires and also with the volunteers who have worked to protect, support and start to rebuild communities struggling with fire and its aftermath.

It seems very appropriate that in 2020 the theme for National Volunteer Week is "Volunteering – Changing Communities; Changing Lives". It reminds us of the impacts of volunteer involvement for communities and for individuals – volunteering really can be life changing.

MND Victoria grew out of the work of a small and dedicated group of volunteers. Today much of the work of the association is underpinned by the commitment, skills, hours of work and the compassion of our volunteers. Our volunteers help to change the life experiences of people living with MND. Our volunteers also report the experience of volunteering can in itself be life changing for them.

In the last MND News we featured **Cynthia Vincent** one of our long standing volunteers who was recognised with a **Premier's Volunteer Champions Service Award** early in December 2019. Here Cynthia provides an insight into what volunteering with MND Victoria means for her.

Photo of Cynthia with her family at the Premier's Volunteer Champion Award presentation.

Letter from Cynthia Vincent

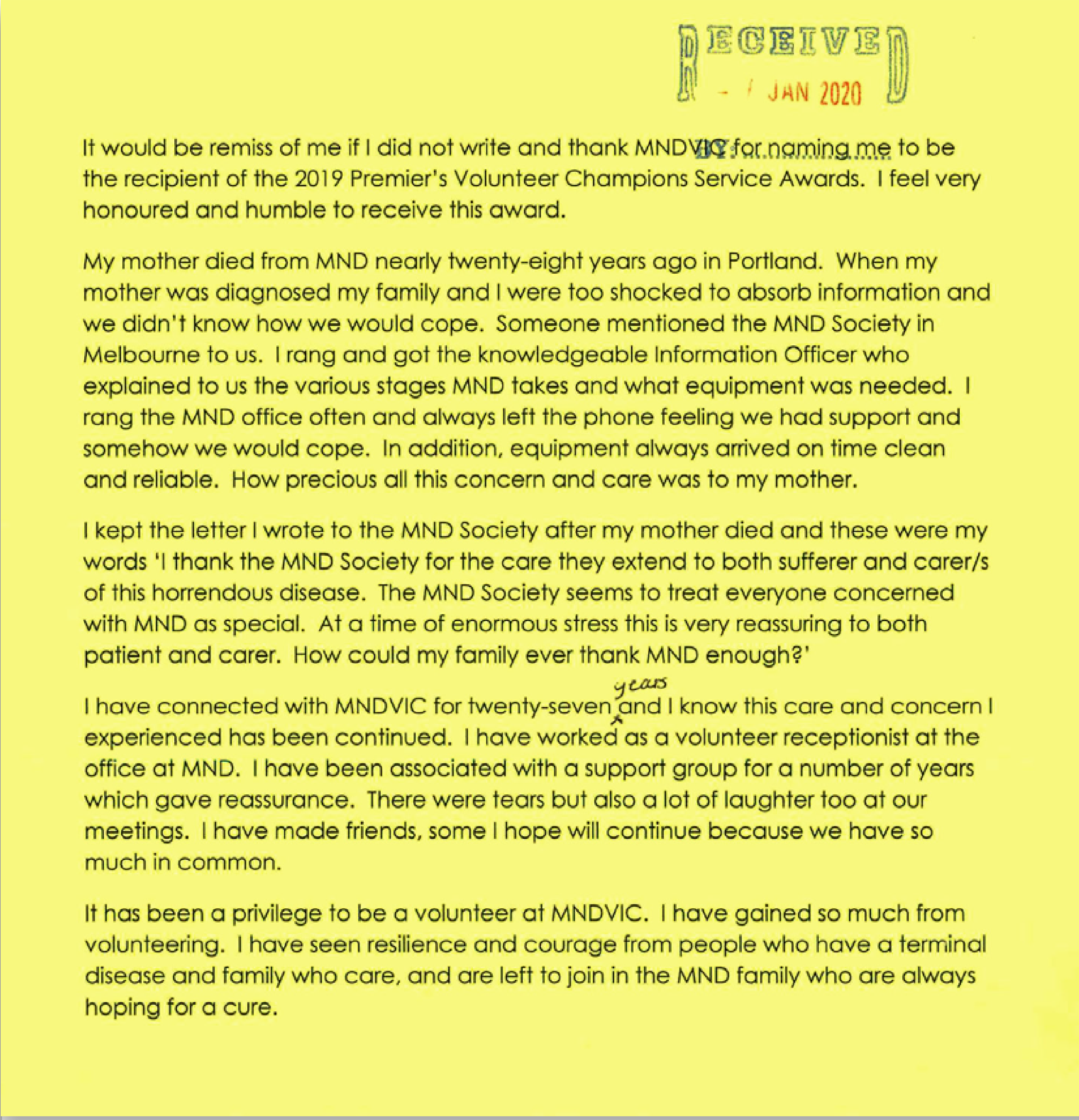
We look forward to working with our current volunteers in 2020 and to welcoming new volunteers to our team.

If you would you like to volunteer with us in 2020 here are some opportunities:

Volunteer Hairdressers

We regularly are asked whether we have a volunteer hairdresser to visit clients at home. The simple act of being able to have a haircut can make a real difference for someone living with MND who has reduced mobility and who is finding it difficult to go out to an appointment.

We have a need for Volunteer Hairdressers across Metropolitan Melbourne. In this role you could expect a couple of appointments in your local area each month. If you are an experienced hairdresser who



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BY:

It would be remiss of me if I did not write and thank MNDVIC for naming me to be the recipient of the 2019 Premier's Volunteer Champions Service Awards. I feel very honoured and humble to receive this award.

My mother died from MND nearly twenty-eight years ago in Portland. When my mother was diagnosed my family and I were too shocked to absorb information and we didn't know how we would cope. Someone mentioned the MND Society in Melbourne to us. I rang and got the knowledgeable Information Officer who explained to us the various stages MND takes and what equipment was needed. I rang the MND office often and always left the phone feeling we had support and somehow we would cope. In addition, equipment always arrived on time clean and reliable. How precious all this concern and care was to my mother.

I kept the letter I wrote to the MND Society after my mother died and these were my words 'I thank the MND Society for the care they extend to both sufferer and carer/s of this horrendous disease. The MND Society seems to treat everyone concerned with MND as special. At a time of enormous stress this is very reassuring to both patient and carer. How could my family ever thank MND enough?'

I have connected with MNDVIC for twenty-seven years and I know this care and concern I experienced has been continued. I have worked as a volunteer receptionist at the office at MND. I have been associated with a support group for a number of years which gave reassurance. There were tears but also a lot of laughter too at our meetings. I have made friends, some I hope will continue because we have so much in common.

It has been a privilege to be a volunteer at MNDVIC. I have gained so much from volunteering. I have seen resilience and courage from people who have a terminal disease and family who care, and are left to join in the MND family who are always hoping for a cure.

would be prepared to volunteer with clients in their own home we would love to hear from you.

Home Visitors

We are seeking volunteers who are able to make regular visits to a client - helping them to stay socially involved and connected with the things that interest them. This role would suit someone who has a couple of hours available each fortnight. Volunteers are provided with training and support to prepare them for this role and are matched to someone living with MND in their local area. We currently have Home Visitor roles available across Victoria.

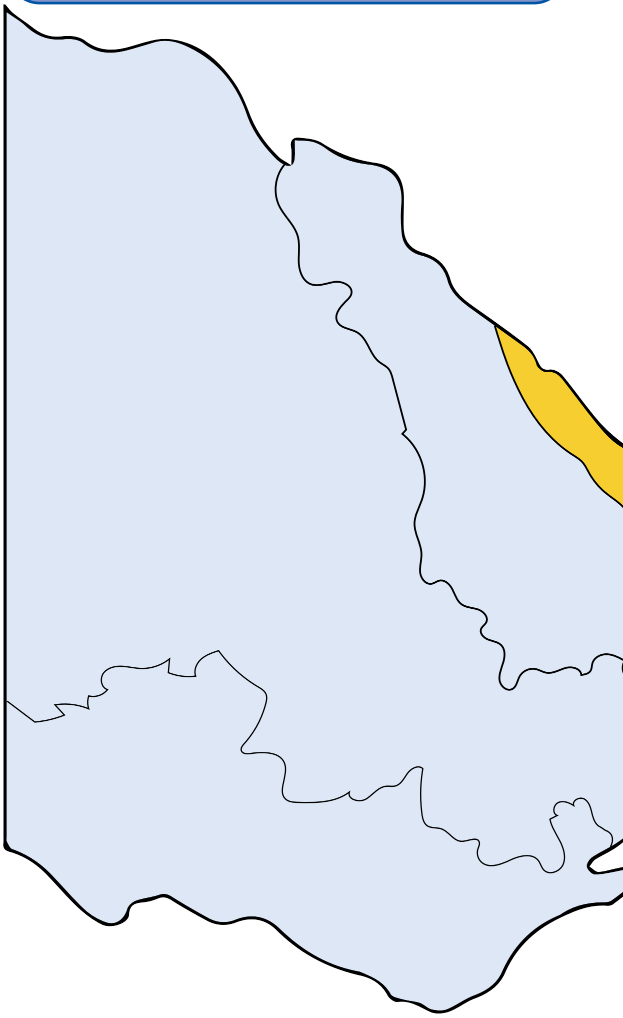
If you or someone you know would be interested in one of these volunteer roles please contact MND Victoria by calling **9830 2122** or email **volunteer@mnd.asn.au** .

The FIRST ever Echuca Walk to D'feet MND was held in late 2018 and organised by the Pagram Waters family.

The furthest town to which Sam currently drives to visit clients is **212 kms** away.

11 Local Government areas make up this broad demographic region.

In the last 6 months, Sam has presented 7 Health Professional Information Sessions to 78 attendees at Aged Care Facilities across this region.



Sam Has Been An MND Advisor Support Coordinator With MND Victoria For The Past 7 Months. She Also Worked With People With MND In Her Previous Role And Presented At The National MND Support Services Conference In 2018.

In the Last 6 months, Sam Provided

480 Hours

Of Support To People with MND.

SOME Clients in this region attend the Statewide Progressive Neurological Disease Service at Calvary Health Care Bethlehem. Clients also attend the Victorian Respiratory Support Service at Austin Health AS WELL AS USING MANY LOCAL ALLIED HEALTH SERVICES.

In April last year, MND Victoria 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 created and were carried in each race by the number one horse. To see our 2 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!

We have **two amazing volunteers** in this region who provide hand and foot massage to people with MND. If you are interested in volunteering in this region we would love to hear from you: **volunteer@mnd.asn.au**

**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 **

Sam - MND Advisor
+ Support Coordinator

32 People With MND Currently Live In This Region

10 clients in this area access the NDIS, however 22 clients are stuck with the 'My Aged Care' system which fails to meet the needs of people with MND. Please join the campaign to Make Aged Care Fair: **www.mndaction.org.au**

The 300km **Great Never Give Up Ride** From Hoppers Crossing To Tocumwal Was Held Over 3 Days In October 2019 Raising An Incredible $25,000 For MND Care, Support + Equipment!

Hume, parts of Loddon, and clients living in NSW close to the Victorian border.

37 vintage tractors participated in the 'Ian Sneddon's 2 Rivers Run' Tractor Trek to raise funds for MND care and research in honour of local identity Ian Sneddon. As a result $5,000 was donated to MND Vic to underwrite service delivery.

If you live in this area (or anywhere in Victoria!) and would like to hold a fundraiser at your local sporting club, school, workplace, or with your friends and family, please contact our fundraising team for support and to get started: **fundraising@mnd.asn.au**

The **Benalla Act to D'feet MND** has been raising valuable community awareness and funds for MND research for over 10 years now! Participants can choose to cycle, walk, relay and/or run on the day.

The Benalla Act to D'feet MND is held in memory of local Mick Rodger who died from MND, and all proceeds from the event fund the Mick Rodger Benalla MND Research Grant.

This year will be held on19 April.

Full details at: **www.act2dfeetmnd.com**

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 a supervised exercise training program in Footscray three times a week for 12 weeks. For further information about this project, please contact: Dr. Alessandra Ferri, Ph: 03 9919 4756 or email: **alessandra.ferri@vu.edu.au**

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**

EXPLORTECH PROJECT

You are invited to take part in the EXPLORTECH 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!

YOUR STORY

By Corey Rich (The Grandson of Janet Rich, Volunteer at MND Victoria)

On October 19, Will and I took on the 'toughest mudder' in aid of MND Victoria. MND is a cause close to our hearts, having lost my Grandpa to the condition before I was born.

The event is an ultra-endurance obstacle race beginning at 8pm and finishing at 8am the following morning. The goal is to complete as many 8km loops including obstacles in the twelve hours, with merely a head torch to guide the way.

Mother Nature served up gruelling conditions, sub-zero temperatures and rain, adding to the already difficult task. However, at the back of our minds, was the inferiority of our struggle compared to those directly affected by MND.

Despite having to complete the majority of one lap barefoot and another without a working head torch, Will and I managed to complete 112km as a team.

More importantly, we raised over $2000 for MND Victoria. A huge thank you must go to everyone who donated. Each and every little bit counts.

ROCK OFF MND 2020!

Rock Off MND will be held from 5pm on Saturday, 14 March 2020 at Deakin Waterfront Geelong. Tickets $70 at: www.rockoffmnd.com.au

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

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

Rock Off MND is thrilled to have the legendary Dragon as the headline act for this year's event. The night will then party on with the brilliant MDRN LOVE and Stereo Stars.

Photograph: Rock Off MND Facebook

Photograph: www.rockoffmnd.com.au

Grab your Rock Off MND tickets: www.rockoffmnd.com.au

WALK TO D'FEET MND IN BALLARAT & GEELONG!

Join us in Ballarat at **9.00am, Sunday 1st March 2020** at Pleasant Street Primary School, Lake Wendouree, Ballarat. You can choose to walk or cycle to D'feet MND! Sign up at: **www.mndwalk.org.au/events/7/ballarat**

Our Geelong Walk is on at **10.30am, Sunday 22 March 2020** at Barwon Valley Fun Park, Barrabool Road, Belmont. Show your support for people with motor neurone disease by walking with us, register online at: **www.mnd.asn.au/walk**

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

FUNDRAISING

"Every day is a new beginning. Treat it that way. Stay away from what might have been, and look at what can be." – Marsha Petrie Sue, Author, 1946-

January – the New Year! Time to focus on new ideas, new opportunities, new ways to make something special about every day. What a privilege it is to be able to do that at MND Victoria.

This January really is a new beginning for the Supporter Development Team. Although, before we can celebrate the new beginnings, we must first acknowledge the incredible contribution made by Heidi Bryce in her five plus years with the Association. Heidi's experience, creativity and commitment to the MND Community raised our social media presence and digital fundraising to new levels. She will be missed by us all and we wish her well in her future endeavours.

Heidi's departure gave us the opportunity to re-evaluate how we can best assist our supporters. As a result, we have added two new members to the Supporter Development Team. I think you will agree from their bios later in this newsletter that both ladies will contribute immensely to our team.

The next six months promise to be very busy and very exciting! Daniel has detailed several activities which will strengthen our relationships with many of our dedicated supporters. The opportunities to raise awareness and funds are diverse and we believe there's something for all ages and abilities.

MND has a huge financial impact on those living with the disease. This is especially true for anyone aged over 65 when diagnosed, as they cannot access NDIS funding. It is therefore vital that we raise funds so that we can continue delivering care and support to all people with MND regardless of their age or where they live. Thank you for your support.

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

Kathy Nightingale

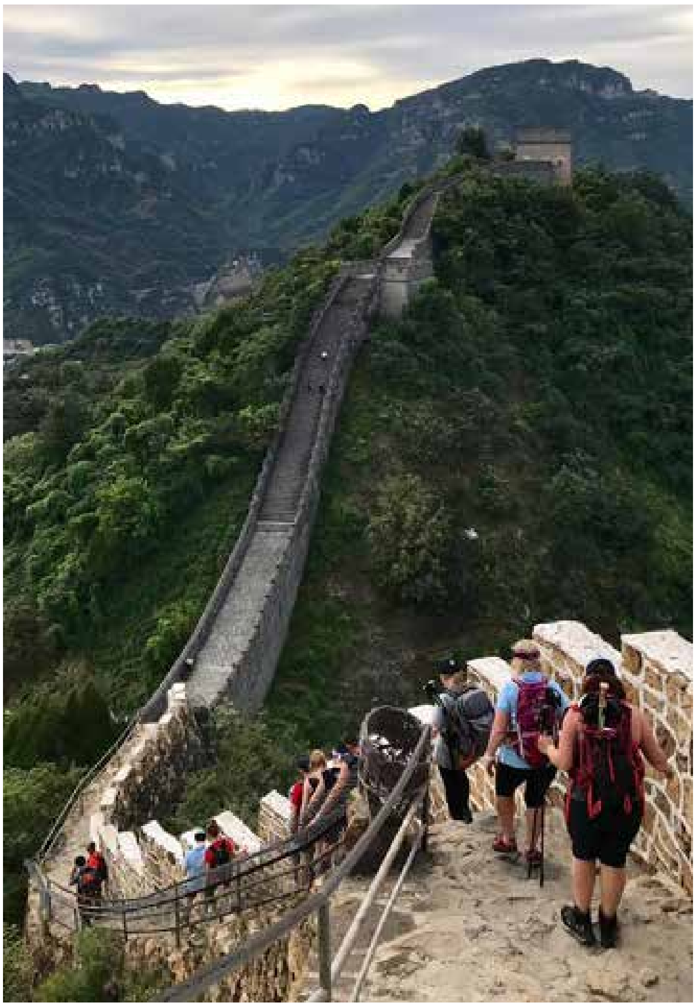
Manager Supporter Development

INTRODUCING OUR TWO NEW SUPPORTER DEVELOPMENT TEAM MEMBERS!

We have been very fortunate to recruit two new members to our team.

Beryl Chen has taken on the role of Communications Officer and Steph Cross has taken on the new position of Supporter Development Officer – Digital. Both ladies have been involved with the Association previously. Beryl has been a volunteer with the Association for two years and produced the "Make Aged Care Fair" video that was launched for the 2019 MND Awareness Week. In the USA, Beryl used her creative skills to help produce commercials for Google, Microsoft, Facebook, Amazon, Coca-cola, Samsung, and award-winning music videos, we're thrilled that she is now going to use this experience to increase awareness of the work of MND Victoria and take our digital fundraising to new heights. Beryl's mother, who lives overseas, has been diagnosed with MND so this is a cause that is close to her heart.

Steph is currently one of our Global Charity TV Ambassadors and over the past twelve months has raised almost $16,000 for the Association. Steph has been a creative fundraiser since high school but it was in 2018 that MND came into her life when a close family friend was diagnosed with the disease. Steph recently graduated with a Bachelor of Communications (Professional Communications) degree from RMIT and is keen to put into practise the communications and media training she has gained. As both ladies have personal experience of MND they are very passionate about raising awareness of the positive impact of MND Victoria's services on the lives of people with MND and the need for on-going fund raising to support this service delivery.



LOOKING FOR CHALLENGES?

Do you wonder how you can make a difference to the lives of others?

Do you need a new goal to work towards?

Do you want to experience the joys that raising funds for an organisation that is close to you brings?

In 2020 there are endless ways to raise funds for MND Victoria, funds that allow the organisation to continue providing the best possible care, support and vital assistive equipment for all Victorian living with MND.

Challenge events are a popular way of doing something amazing whilst raising funds. This year we are taking a group to hike on The Great Wall of China and more locally, recruiting a team of Champion Runners for Run Melbourne.

MND Victoria's Great Wall Challenge

A group of 11 passionate individuals took on this challenge back in 2017, they raised $111,000 and became great mates in the process. The experience was so good that we just needed to go back again!

We are currently recruiting for those who are up for this amazing challenge. You will spend 5 days hiking on the famous wall with phenomenal views everywhere you look. It truly is breathtaking. You will also get to experience some of the local culture whilst in Beijing. Visiting Tiananmen Square, making dumplings and taking part in morning Tai Chi are just some of the highlights!

You will spend the lead up raising funds with your own personalised fundraising page and the expert guidance of our team. There will be many group catch ups and training hikes throughout the year so you can meet the group and keep your fitness on track!

Fast Facts:

Dates: 12-20 September 2020

Difficulty: Moderately Challenging (3/5)

Fundraising Target: $3500 / Person

Travel Package: $2990

Registration Fee: $770 (Non-refundable)

Run Melbourne

Run Melbourne isn't your average run. Over the last 12 years it has grown into a movement that has changed the culture of what it means to run through the city streets.

We are absolutely thrilled to be one of ten Champion Charities in this year's event. We have an allocation of places into the event of your choice. Whether you are up for a half marathon, 10km run or 5km jog, your participation will help MND Victoria immensely. If you commit to raising a minimum of $1000, your entry into the event is covered and you will receive many other VIP privileges.

It's been a few years since the streets of Melbourne were flooded with legends running for MND Victoria and raising funds for the care, support and equipment for all Victorian living with MND. On July 26 this year, we can't wait to see MND Victoria well represented amongst the tens of thousands of runners taking part in the city's most popular running event!

To find out more or register your interest, please contact Daniel on **03 9830 2122** or at **dwoodrow@mnd.asn.au**

Not keen on a challenge but still want to help?

You may not be a hiker or a runner but you can still do amazing things to help our cause. Our team are here to help get your ideas off the ground and make them reality. There are many traditional and common ways to raise funds and there are endless new and creative ways. We will help you in every way possible to maximise your efforts and make the experience enjoyable and rewarding.

MND Victoria can only continue providing its vital services because of all the dedicated donors and supporters that are so generous and continually amaze us all. Whether you have an amazing idea or no idea but a desire to do something to help, get in touch with us and we will get right to work!

WALK TO D'FEET MND HAS RAISED $200,000

Rosebud
Melbourne
Bendigo

Our first Walk for the season was held on 3 November in Rosebud and was greatly supported by members of The Village Glen Retirement Village. This year 135 people participated and over $12,000 was raised. We would like to acknowledge the great support of Gwen Phillips who has organised the Rosebud Walk since its inception. Gwen will be retiring this year but her successor, Sue, has already started to organise the 2020 Walk so we look forward to continuing to raise awareness in the Rosebud area.

On 17 November our biggest Walk to D'Feet MND event took place in Princes Park, Carlton. Around 1,900 people turned out at Princes Park to show their support for all those impacted by MND. To see such a large number of participants of all ages and abilities, including our four-legged friends, decked out in their Walk to D'Feet MND T-shirts is an amazing sight. At one point it seemed that we had encircled Princes Park – we were definitely hard to miss.

A week later we had an amazing turn out in Bendigo also with around 340 participants, a significant increase on 2018. This year we were joined by members of the Dragon Boats who rowed up and down Lake Weeroona as one of their crew was recently diagnosed with MND.

As always we would like to thank not just those who participated in the walks but also those who supported us – our amazing volunteers and sponsors. Without you these Walks could not take place

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

MELBOURNE: Largest Team—Jacks Crew

Most Funds raised by a team: Papargiris Family

Most Funds raised by an individual: Ciara Timmons

BENDIGO: Largest Team—Gid's Flanny Angels

Most Funds raised by a team: Team Heathcote

Most Funds raised by an individual: Kathleen Johnson

MINDFULMND

at Calvary Health Care Bethlehem

My initial reason for doing it [the mindfulness program] was that I'm one of those people who has always juggled multiple balls at one time. In this space, that is not helpful and can be quite unsafe … I'm now getting better at not getting distracted, which is really good, and I'm a more relaxed person these days. (Jenny, person with MND, 2019)

With a diagnosis of Motor Neurone Disease, people suddenly find themselves on a path they hadn't planned for, with progressively deteriorating health and multiple stresses. Although incurable, important aspects of MND are treatable, and the team at Calvary Health Care Bethlehem work with people to help reshape their lives to meet their core priorities. An important and critical part of that work is exploring new therapies to enhance their quality of life.

What does research say about the benefits of mindfulness?

Mindfulness is emerging as a powerful new tool which has been described as a 'game-changer' for helping people to cope with both mental and physical suffering. Mindfulness has been shown to reduce stress, depression, and anxiety, and to promote a positive quality of life. People can develop more helpful ways of responding to real life challenges, while keeping the focus on what really matters to them.

A recent Italian study has shown the value of mindfulness in improving quality of life and reducing distress for people living with MND and their families. At Bethlehem, we are examining the efficacy of mindfulness here in Australia, and in so doing are offering our MND families an opportunity to learn skills to help move closer to the important aspects of their lives, even while living with MND. We recently presented some initial findings at the MND Symposium in Perth, which showed positive changes to quality of life, resilience and mood.

What do the mindfulness groups involve?

The aim of our MindfulMND groups is to empower MND families to find ways of living well. The course teaches practical mindfulness skills that can be used by anyone, including:

- How to take time out from the overwhelming focus on the illness
- How to practice different awareness exercises, including learning to better focus on the present moment
- How to work with stress and other strong emotions and reactions
- How to enrich daily life experience and relationships

In the MindfulMND program, people with MND and their families also have an opportunity to meet with others and share their experiences. The groups are taught by psychologists who are experienced in working with MND families. Each mindfulness group involves a 2 hour meeting on a Thursday morning, with four sessions run fortnightly over eight weeks. We will be running a number of MindfulMND groups through 2020.

If you are interested in learning more, please contact **Dr Sarah Velissaris** (Clinical Psychologist): **sarah.velissaris@calvarycare.org.au**

GRAB YOUR SUMMER MND GEAR!

Stubby Holders

$12

Onesies

$32

Active Singlet

$31

Active Wear

3/4 or long Leggings

$55

Grey Singlet

$31

MND Caps

$19

Order yours online today at:

www.mndwalk.org.au/store

or phone:

03 9830 2122

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

DONATIONS RECEIVED ... THANK YOU!

Corporations

Ritchies IGA

Specsavers Pty Ltd

Express Insurance Brokers Pty Ltd

Marubeni-Itochu Steel Oceania Pty Ltd (MISO)

Trevor P Weichmann and Associates Pty Ltd

Clubs

Werribee Bushwalking and Outdooor Club

Lions Club of Macarthur and District

Western HeightsTuesday Morning Badminton Club

The Village Glen Golf Club

Portsea Golf Club

Belmont Rotary

Mitcham Scottish Society

Lions Club of Boroondara Central

Rochester Golf Club

The Village Glen Quilters

The Village Glen Bowls Club

The Village Glen Fidelity Club

The Village Glen Croquet Club

The Community Villages Association

Bendigo BMX Club

Bequests

The Estate Dorothy Jean Mahler

The Estate of Agnes Florence Wilkinson

Support Groups

Barwon Support Group

Trusts

The Wanless Family Fund

The William Angliss Charitable Fund

The Lord Mayor's Charitable Fund

The Collier Charitable Fund

In Memory

Gemma Carnevale

Margaret Stone

Flora Jessie Vale

Sofia Sakkas

Peter Lowe

Andrea Camier

Phillip McDonald

Lynette Pow

Robbie Caliste

Florence Williams

Robert Hudson

Lynettte Lewis

Johanne Yianni

Jillian Meade

Judith Boyle

Marlena Stanway

Herve Babet

Malcolm Duff

Martin Williams

Aldo, Peter & Maria Petrilli

John Ryan

Geoff Blake

Richard Edwards

BJ Chatham

Tracey Paspali

Heather McLean

Margaret Langley

Kerry Glide and Ron Biffin

Yvonne Worrad

Terry Lewis

Jean Jackson

James Eastwood

Ron McCann

Michael Larcombe

Dimitrios Karlaftis

Ian Aitken

Organisations

Loraine Lea Linen

Salvation Army Wodonga Branch

Kew Skin Therapy

Mini Max Camberwell

Schools

Ballarat Specialist School

Yarra Hills Secondary College

Plenty Parklands Primary School

Methodist Ladies College

Koonung Secondary College

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 4 March for the next edition, to be mailed on 7 April 2020.

GET INVOLVED IN AN EVENT NEAR YOU!

Date:	Event:	Find out more:
Wednesday,19 February 2020	MND Information Session	Email: info@mnd.asn.au
Sunday, 1 March 2020	Walk to D'feet MND, Ballarat	www.mycause.com.au/events/robsride
Saturday, 14 March 2020	Rock Off MND, Geelong	www.rockoffmnd.com.au
Sunday, 22 March 2020	Walk to D'feet MND, Geelong	www.mndwalk.org.au
23-24 March, 2020	Wandin Park Equestrian Event	Email: yarralynne@bigpond.com
Friday, 27 March 2020	MND Health Professional Forum, Hobart	Email: info@mnd.asn.au
Thursday, 2 April 2020	MND Information Session	Email: info@mnd.asn.au
Sunday, 19 April 2020	Walk to D'feet MND, Benalla	Email: fundraising@mnd.asn.au
Sunday, 26 April 2020	Shepparton Harness Racing	Email: fundraising@mnd.asn.au
3-8 May, 2020	MND Week 2020	Email: fundraising@mnd.asn.au
Sunday, 3 May 2020	Day of Hope and Remembrance	Email: info@mnd.asn.au
Sunday, 3 May 2020	Walk to D'feet MND, South East Melbourne	www.mndwalk.org.au
Tuesday, 5 May 2020	Ask the Experts - Research Event	Email: info@mnd.asn.au
Sunday, 21 June 2020	Global MND Awareness Day 2020	Email: fundraising@mnd.asn.au
Sunday, 26 July 2020	Run Melbourne	Email: fundraising@mnd.asn.au
Saturday, 8 August 2020	MND Charity Ball - Superball XIII	Email: fundraising@mnd.asn.au
12-20 September 2020	Great Wall of China Trek	Email: dwoodrow@mnd.asn.au
Sunday, 4 October 2020	Melbourne Marathon	Email: fundraising@mnd.asn.au
Sunday, 1 November 2020	Walk to D'Feet MND, Village Glen Rosebud	Email: fundraising@mnd.asn.au
Sunday, 15 November 2020	Walk to D'Feet MND, Princes Park, Carlton	Email: fundraising@mnd.asn.au
Sunday, 22 November 2020	Walk to D'Feet MND, Bendigo	Email: fundraising@mnd.asn.au

For further information and the latest events list, please visit our website at: **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** We can also provide you with our Event Flyer template to use for your event!

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