

Summer 2021/22

MNDnews

The newsletter of the Motor Neurone Disease Association of Victoria



**YOUR
SILENCE
WAS
HEARD**



Until there's a cure, there's care

MESSAGE FROM THE CEO



Welcome to our final newsletter for 2021. I was looking back at the 2020 Summer newsletter and my commentary about the time being a little more “COVID-normal”. I never thought then that 2021 would pan out to be another year of lockdowns and restrictions – but here we are again, restrictions easing and life becoming a bit more normal. At MND Victoria, we have continued to strive for excellence in our work and in ensuring that we provide and promote the highest quality care and support for people living with MND. We have had many successes and improvements across 2021.

We recently received notice of a large bequest which has led us to create the Ella Whaley MND Victoria Research Project fund. This will be an internal fund that will allow us to conduct or commission research that furthers our purpose of providing and promoting the best possible care and support for people living with MND. Projects funded through this program will aim to:

- * Pilot a new form of service or support;
- * Evaluate and/or improve a current program;
- * Commission research or a project from, or in partnership with, another agency, that will directly benefit the clients of MND Victoria; or
- * Evaluate the impact of MND on Victorians living with the disease (this includes those diagnosed, their carers, family members, colleagues and those providing professional support).

We are grateful for this new opportunity to improve services and supports for people living with MND.

We were also pleased to receive funding from FightMND to purchase a significant number of new pieces of equipment to add to, and update, our equipment library. We aim to maintain a library of high quality, contemporary equipment that is available to people living with MND as they require it; and we therefore need to regularly replace and update equipment in our library to meet this aim.

In October, we received notification from the Victorian Department of Families, Fairness and Housing that our application for Support for Carers funds was successful. Between November 2021 and June 2022, we will have funds available to support carers of people with MND to access respite either in the home or through carer retreats. This is an exciting new opportunity for us to provide support for those who care for people living with MND.

Our Shut Up! For MND fundraising and awareness campaign was a great success and generated lots of conversation about the challenges of both not being able to speak and not being heard. Whilst the funds raised are vitally important in assisting us to continue our work, the awareness raised through stories and conversations has proved equally as important.

Many of our plans to acknowledge our 40th anniversary were put on hold due to restrictions – but we look forward to being able to come together with the MND community to properly acknowledge this milestone next year.

As the year draws to a close and we look forward to a much less restricted and much more “normal” year in 2022 – from all of us at MND Victoria to all of you, your families and loved ones – thank you for your support across the year. Have a lovely Christmas and a safe and happy new year.

Until there’s a cure, there’s care.

Kate Johnson
CEO, MND Victoria

MND VICTORIA SAYS THANK YOU

Shut Up! For MND

Recently, we ran a fundraising and awareness campaign called the Shut Up! For MND Challenge.

The Shut Up! For MND Challenge was a unique opportunity to highlight what many people living with MND may face on a daily basis. Each MND journey is different, but as well as losing their voice, many people will also lose the ability to use their arms and legs. This makes the ability to communicate almost impossible without the use of modern (and expensive) assistive technologies. That's why the MND Victoria Equipment Service exists - to help alleviate the financial burden motor neurone disease can place on families.

Participants were challenged to go 6 or 12 hours without speaking on Thursday 28th October (or another date that suited) and instead use alternative methods to communicate. 220 legends took on The Challenge and we are thrilled to announce that to date, \$112,689 has been raised! These funds will be utilised to provide care, support, information and vital assistive equipment (like iPads and Etran Boards to aid communication) for people living with MND.

We received quite a bit of feedback from the MND Community, but this reflection from one of our participants - Shannon Thompson, who is the General Manager at Calvary Health Care Bethlehem - is quite fitting:

"So today was the day, and I'm in the final stretch (I officially finish at 8pm). This was really challenging and I am so glad to have been involved. I found myself feeling very isolated, frustrated and often felt it was easier to stay away from others; and even though I found lots of other ways to communicate, I found varying levels of patience from those around me.

Being so fortunate as to lead the amazing, compassionate, dedicated and highly skilled team at Calvary Health Care Bethlehem, I was also met with a great deal of empathy and support. As I've said previously, I am so very aware of the fact that I've experienced this for 12 hours, I had full use of my arms, my hands, the rest of my body, and could adapt without much assistance - this is not the case for so many who live with MND.

One of my team said that they missed my voice, and I was struck quite deeply by the grief that not only those who lose their voice experience, but by their family and friends around them. By far one of the best experiences I had today was when our Nurse Unit Manager greeted me openly, waited patiently as I clumsily used the text to speech app



to converse with her, and as she anticipated some of what I was expressing and wishing to say. My simple gestures spoke a volume to her and, in turn, she was able to make me feel heard."

Thank you to everyone who has supported this campaign. We can't wait to bring it back bigger and better next year!



Three Peaks Challenge Trek

Our Three Peaks Challenge Event participants have been hard at work. These 23 champions are training hard for the trek in mid-December and are raising some fantastic funds. So far, over \$75,000 has been raised! Thank you to all these legends - we can't wait to see you all conquer Mt Stirling, Mt Feathertop and Mt Bogong.



Café Brontos

Mohan and the team at Café Brontos in Boronia ran a unique fundraiser on Saturday 6th November. They opened up their whole menu (food and drinks) to everyone in exchange for a donation to MND Victoria. In the end, the team raised \$3,648.60! Mohan lost a very dear friend to MND and has been an incredible supporter of MND Victoria ever since. We are very grateful for his generosity. If you are ever in Boronia, make sure you go and say hello.



National Fleece and Wool Show

The National Fleece and Wool Show is one of Regional Australia's largest events. It has been a torrid time for event organisers after the 2020 version in Bendigo was cancelled entirely due to COVID-19, and the 2021 event was cancelled at the very last second. Each year the event has a charity recipient that is the benefactor from donated fleeces. MND Victoria was very fortunate to be nominated as this year's benefactor by a local family who have been impacted by MND.

Following many disruptions, Kate and Daniel hit the highway to Bendigo in November to accept a cheque to the value of \$11,655. This was also a great opportunity to talk to many Bendigo locals about the services MND Victoria provide and how these vital funds will be utilised. This donation was incredible given the difficulties the event has faced. We are very thankful to everyone who helped make this a reality.



Lions Club of Geelong Breakfast

The Lions Club of Geelong Breakfast Inc have been a long-time supporter of MND Victoria. Despite COVID-19 restrictions, they have been able to fundraise for the Association in between lockdowns! Here are club members Ed Farnsworth, Dot Warburton and Lynn McManus working hard at a recent fundraising BBQ. Thank you all for your continued support.

Marian Lowe – 30 Years of Volunteering

We would love to acknowledge the enormous contribution Marian Lowe has made to MND Victoria over the last 30 years. Marian first became a volunteer in 1990 and has helped to raise awareness and funds in a number of creative ways ever since. From shaking tins to founding the Melbourne Walk to D'Feet MND, Marian has done it all, to help those with MND live better for longer. Thank you, Marian – we are very lucky to have such a superstar volunteer like you.



LIVING BETTER

Physical Activity and MND

Finding ways to enjoy physical activity with MND can help, even as it gets harder to keep your body moving.

Why does physical activity help with MND?

Generally, activities like walking, gardening, yoga, stretches and others that involve physical movement can help support your physical abilities by strengthening healthy muscles whose nerves have not yet been affected by MND. Physical activity can also help maintain joint range of movement, reduce stiffness and pain, and support overall wellbeing and enjoyment of daily life.

Many people living with MND feel that it's important to enjoy physical activity. Recent research finds that personal enjoyment of general physical activity is more motivating for some people living with MND than a more formal exercise program. So you may want to think about the activities you enjoy doing, and how your healthcare team can best support you to do them.

What you need to do first

It's best to talk to your neurologist, GP, physiotherapist and others in your healthcare team about physical activity and how to manage:

- * fatigue
- * getting plenty of rest
- * pain and stiffness
- * aerobic, strength and endurance exercises, if they're suitable
- * assistive technology for maintaining independence, mobility and comfort, if suitable.



Fatigue is an issue

It's important not to push yourself to exhaustion while exercising and to get plenty of rest after physical activity to reduce fatigue. Even daily tasks like washing and dressing can drain energy, and you may need to rest and take time to recover. Physiotherapist and occupational therapist assessments and regular reviews can help to guide you.

What can I try?

- * Walking outside the home, housework, gardening
- * Yoga, stretching limbs with a physiotherapist, hydrotherapy (activities in a pool of water)
- * Exploring best ways with a physiotherapist to do physical activities while sitting in a bed or chair
- * Talking with your health professionals regarding medications that may help with discomfort
- * Stable and supportive shoes, walkers, braces, orthotics
- * If active movement is no longer possible, active-assisted physical activity may help, such as active-assisted arm or leg cycling, or various team sports with your local electric wheelchair/powerchair sports association.

Being active for wellbeing

Physical activity may help you to focus on things that you enjoy. You can have a break from other worries, build your confidence and sense of control, and spend time with others and feel supported by them.

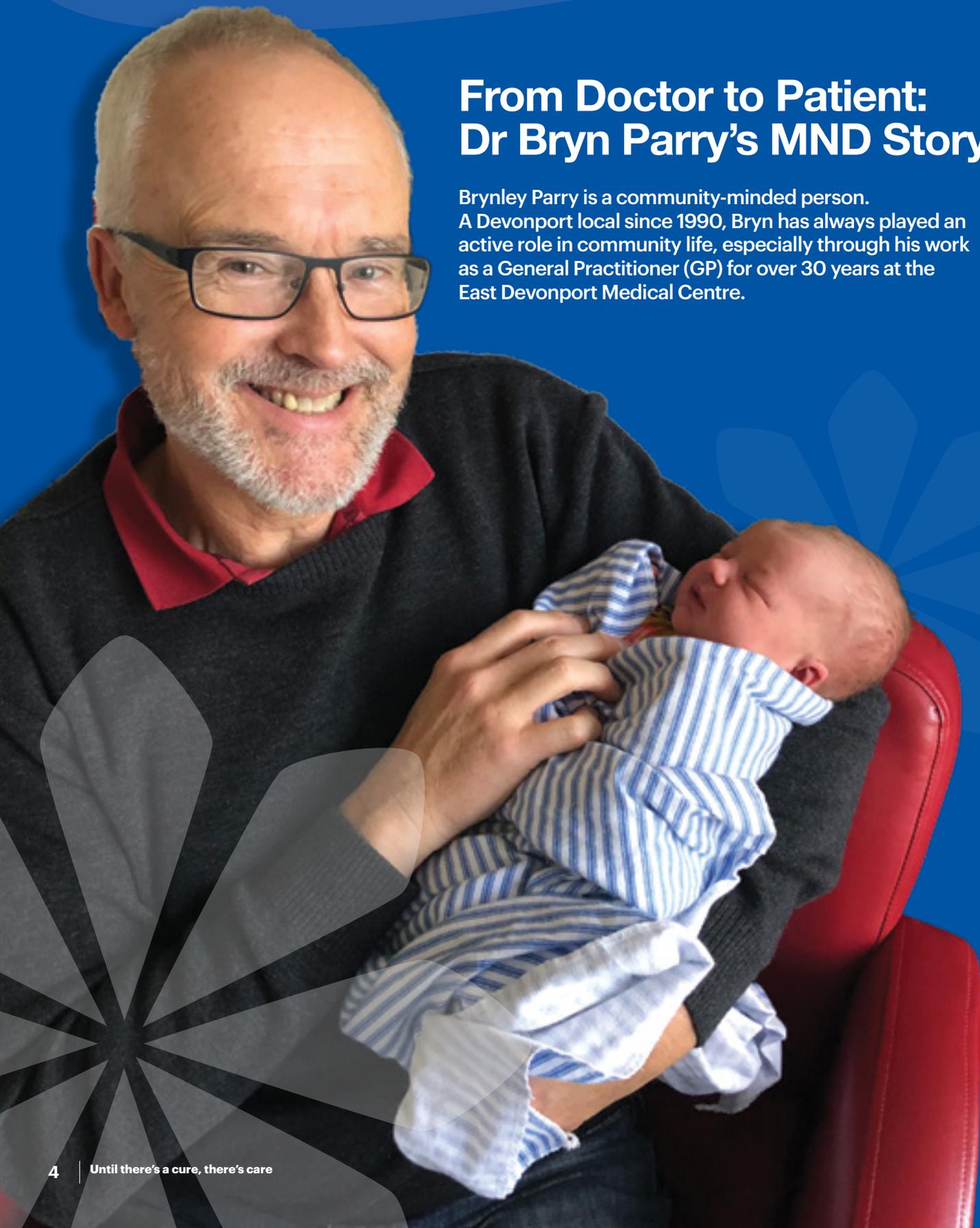
This article has been adapted from the MND Australia factsheet 'Physical Activity and MND'. For more information, visit <https://www.mndaustralia.org.au/mnd-connect/information-resources/physical-activity-and-mnd> (or scan the QR code on the right), contact your local MND State Association or call the MND Info Line on 1800 777 175.



PERSONAL STORY

From Doctor to Patient: Dr Bryn Parry's MND Story

Brynley Parry is a community-minded person. A Devonport local since 1990, Bryn has always played an active role in community life, especially through his work as a General Practitioner (GP) for over 30 years at the East Devonport Medical Centre.



Like all other Australians living with MND, Bryn receives services from his local MND Association. Please contact your local State Association for more details on the services they provide.



Bryn and his wife, Clare, had not planned to settle in Devonport, but the longer they stayed, the more they felt it was a great place to bring up children and raise a family. Dedicated to his community as well, Bryn signed on as a Partner at the East Devonport Medical Centre in 1992. This was the same day their first son, Lucas, was born. Their next son, David, soon followed and then sixteen years later, their daughter, Myf, was born, completing their family.

During his career, Bryn had only encountered one patient with motor neurone disease (MND). In early 2020, he first started to notice his right foot was dragging when he jogged, but MND was not something that had really crossed his mind. By April, this slight drag was enough to get caught on uneven surfaces, and Bryn fell over a traffic hump when running down to the pool with Myf. It was then that he realised this developing foot drop was not going away and decided to investigate what was going on.

It can often take a long time to get a confirmed diagnosis of MND. For Bryn, it was no different and the impacts of COVID-19 only prolonged the process. His doctor referred him for a nerve conduction study, which was where the delay started. "There is a lack of availability of nerve conduction studies as Tassie, at least in the North, has been reliant on fly-in neurologists to perform nerve conduction studies."

By June, diagnostic progress was still at a halt and his right leg was continually weakening. Being a proactive GP, Bryn referred himself to see a Sports Medicine Physician who specialises in feet and a Neurosurgeon in Hobart. They then referred him for a number of tests to investigate the cause of his symptoms. Although Bryn was not in pain, the results indicated that it was nerve related. He was encouraged to start advocating for himself and push to get the nerve conduction study done.

"It's funny because I was used to advocating for my patients, but it hadn't occurred to me that I should jump up and down on my own behalf. It was interesting as a doctor, having the experience from the opposite side."

Bryn eventually had his nerve conduction study done through the Launceston General Hospital in July, which was then followed by a lumbar puncture. "By the time I had the lumbar puncture and all the results, it was another seven weeks before the formal diagnosis. The diagnosis didn't happen until late September."

He does not see the date he was officially told he had MND as anything in particular. "It was almost just like another day. I think I had virtually accepted that that was going to be the

diagnosis by then. We'd eliminated everything else. Perhaps that was one of the advantages of such a drawn-out process."

One of the hardest things for Bryn was learning of the prognosis of the disease. Typically, the average person lives with MND for 27 months, and that news left him dismayed.

"My son Lucas is actually a GP, so he's well aware of what MND is. When I told my second son [David], I watered it down a bit. I didn't want to shock him. He and his wife were living in Melbourne at the time and within 24 hours he'd phoned to say they were moving back to Tassie. It was a real shock and surprise, but I realised that Lucas has been in his ear telling him about the prognosis of MND."

Myf was only 12 years old when Bryn was diagnosed, so he and Clare gave her the "PG version" of his diagnosis. "We didn't really want to confront Myf with that information, but it was inevitable that she must now have had some idea about it. Our main emphasis has been to try and keep things as smooth, even and normal for her for as long as we can."

Bryn is very thankful for the care and support he has received from MND Tasmania. His MND Advisor and Support Coordinator, Emma Forsyth, has been very helpful every step of the way, personalising everything for Bryn to ensure that all of his needs are being met.

"When you're battling with this illness and coming to terms with a life-limiting prognosis, you don't want to be spending the time you have left in some sort of bureaucratic maze. The service that MND Tasmania offer really converts what could be a terribly difficult, stressful, miserable time into something that is more like it should be – a positive, helpful step. I can't imagine how much more difficult it would have been without them."

Bryn is not letting his diagnosis get in the way of giving back to his community - he is currently a Board Member of the Mersey Colts Cricket Club and part of the Pastoral Leadership Group at the Lifeway Baptist Church. This is his way of supporting the "good people doing good things in the community."

"While it can be difficult on a day-to-day basis to stay positive, one of the big things to remember is that the mind is still able to function. I'm just working on maintaining the right attitude and approach to dealing with the ongoing challenge of MND."

MND RESEARCH



To learn more, visit www.mndaustralia.org.au/research or scan the QR code above.

MND Research Australia (MNDRA) supports high-quality MND research to discover the causes, improve care, and find treatments and ultimately a cure for MND. They have recently revamped their website to make it even easier to keep up to date with the latest research information in MND.

How to get involved with research

There are a number of **clinical trials** and **non-clinical research** currently happening all across Australia, and people living with MND may be eligible to take part in them.

A **clinical trial** tests new treatments and interventions in people to find out if they are safe and/or effective – you will need to speak to your neurologist first to assess your eligibility. **Non-clinical research** looks at other, non-medicinal factors – these are sometimes open to family members of those who have been affected by MND.

A full list of current clinical trials and non-clinical research opportunities can be found on MNDRA's website (see details above).

Research news and updates

MNDRA are frequently uploading publications, updates and webinars on the latest advances in MND research in Australia and internationally to their website. These updates include:

- * Advance – a biannual research newsletter, detailing the latest on MND research in Australia.
- * State of Play Webinars. Developed in 2020 and set to return in 2022, these webinars are open to the whole MND community and are designed to provide an introduction to the advancements of the research community in Australia.
- * International Research Update – produced quarterly.
- * Updates from the International Alliance Scientific Advisory Council (SAC) - a centralised resource to review and provide a global perspective on scientific and biomedical announcements, information and opportunities relating to ALS/MND.

MNDRA's research

Since 1987, MND Research Australia has funded over \$46 million in research grants. A number of these grants are funded by the State MND Associations through the generosity of their supporters and donors. A full list of the current recipients of Research Fellowships, Innovator Grants, MNDRA PhD Scholarship Top-up Grants and currently funded multiyear grants from previous years can be found on MNDRA's website (see details above).

GLOBAL MND NEWS! A truly monumental day for MND research

The UK Government have announced that they will commit £50 million (AUD\$92.5 million) over five years into targeted motor neurone disease research.

The **United to End MND** campaign started two years ago, with a group of five people living with MND who were determined to accelerate research in the cause, treatments and ultimately a cure for MND. They joined forces with MND Scotland, MND Association, and My Name's Robbie Foundation, as well as leading researchers, neurologists and others living with MND, to call on the Government to fund a virtual centre of excellence for MND research, providing the infrastructure needed for accelerating treatments for MND.

Research into the cause, treatments and ultimately a cure for MND is a joint effort from the brightest minds right across the globe. This investment will accelerate the fantastic work already underway.





Join MND Victoria's Larapinta Trek to help provide and promote the best possible care and support for people living with MND.

Over seven days, you'll discover the rich history of Australia's First Peoples, exploring scenic landscapes along well-worn, red dirt tracks. At night, you'll camp under a blanket of stars and fall asleep to the nocturnal sounds of the desert.

Best of all, with every step you take, you'll raise vital funds to support the 470 Victorians living with MND and those who will be diagnosed in the future.

Highlights

- ◆ Discover the Australian Outback on one of the world's premier walking treks
- ◆ Immerse yourself in the rich history of Australia's First Peoples, following red dirt tracks across the West MacDonnell Ranges
- ◆ Camp under star-studded skies and fall asleep to the nocturnal sounds of the desert
- ◆ Raise vital funds to provide care and support to people living with MND

 15-20 August 2022

 Moderately challenging (3/5)

 Fundraising target: \$3,000

Travel package: \$2,999
Land only and subject to change

Registration fee: \$390
Non-refundable

 Twin-share in 4-star hotel and at comfortable campsites

For more information, contact Steph at scross@mnd.org.au

EARLY BIRD SAVINGS: Register before 4 January 2022 and get \$100 off your registration fee

Register now:

 www.inspiredadventures.com.au/events/mndvic-larapinta-2022



UPCOMING EVENTS



Annual Quality Survey

We would like to say a huge thank you to those who gifted us with their thoughts and feedback in the MND Victoria Annual Quality Survey this year. The information you provided helps us know if we are on track and if there are opportunities for our services to develop and improve. The 2021 Annual Quality Survey was completed by 141 people affected by an MND diagnosis (97 respondents were people living with MND or Kennedy’s disease).

The following statistics were of note:

- * 94% of people are happy with the MND Advisor/Support Coordination service they receive
- * 91% of people would recommend the Equipment Service to others
- * More than half of the respondents have adapted to using technology during COVID-19 lockdowns
- * 95% of people would recommend MND Victoria services to others should the need arise

Areas we have identified for some focus in the coming year:

- * Increasing awareness and access to our volunteer programs (Life Story, Hand & Foot Massage, Social Support visits and phone calls, Support Groups)
- * Increasing awareness and participation in the Living With MND group
- * Facilitating options for people to connect with others in the MND community

- * Continuing to advocate for parity of services for those accessing the NDIS and the Aged Care system
- * Sharing information and updates on research
- * Collaborating with health professionals and service providers to ensure people living with MND have access to the best possible care and support

An extra special thanks to the volunteers who called people to ask if they wanted the survey posted out or the option to complete the survey over the phone. Over 85 calls were made to people in our community which helped immensely in gathering all of this valuable information.

If you have any questions about the 2021 Annual Quality Survey, or you have some feedback to share with us, please call us on 1800 777 175 or email info@mnd.org.au.

Education and Information Sessions

We are very passionate about providing information and expert knowledge about MND. Our Education Team runs various education and information sessions throughout the year which are targeted at the general public, people impacted by/living with MND, and Health Professionals.

These are the types of sessions which we currently run:

Information Sessions: Information sessions are held regularly to provide information about MND to people who have been diagnosed with MND, their family and friends, in an informal setting. Discussion includes symptoms and progression of MND, interventions, support services provided by MND

Victoria, and an opportunity to connect with others who have been recently diagnosed.

Health Professionals Webinar Series: The MND Victoria Health Professionals Webinar Series provides an overview of a variety of topics relevant for those health professionals working with people living with MND. It is also suitable for those wanting to increase their knowledge of MND.

‘Living with MND’ Group: The ‘Living with MND’ group sessions are for anyone living with MND, and their carers, who are interested in meeting with others who are early on in the MND journey. They are an opportunity for people to share experiences, strategies and feel connected with others.

If you are interested in learning more about our education and information sessions, please call us on 1800 77 175 or email info@mnd.org.au. Our current upcoming events can be found on our website – www.mnd.org.au/events or scan the QR code on below.



GIVING



Christmas Appeal 2021

This year, our Christmas Appeal is a bit different... All proceeds raised through this Appeal will fund a wish for someone living with MND through our new BUCKET LIST WISH PROGRAM.

Living with motor neurone disease is incredibly hard for those diagnosed, and for their loved ones. This new initiative and pool of funds will be able to provide experiences, gifts or services to help make a wish come true and give families a chance to create memories they can cherish together during an incredibly difficult time.

This is where we need YOUR help. The more we raise through our 2021 Christmas Appeal, the more wishes we can grant.

MND Victoria and MND Tasmania have focused on care and support programs to improve the lives of thousands of Victorian and Tasmanian families impacted by MND for the last 40 years. We are the only not-for-profit organisations which are providing direct care for all Victorians and

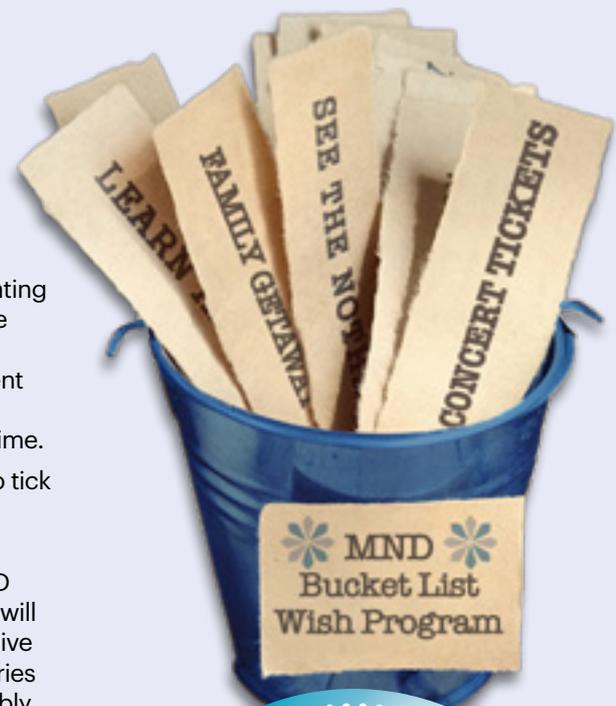
Tasmanians living with the devastating disease, at no cost to them. We are proud of the vital care, support, information and assistive equipment we have provided to thousands of people living with MND over that time.

But there is one thing we are yet to tick off our list...

We kindly ask you to consider a donation to MND Victoria and MND Tasmania this Christmas. Your gift will help make a wish come true and give families a chance to create memories they can cherish during an incredibly difficult time.

Help us to add another layer of support to the services which we have been providing since 1981.

Visit www.mnd.org.au/christmaswish or scan the QR code above, top right.



We often hear "I wish I could..."

"I wish I could go skydiving." David

"I wish I could watch my footy team play in luxury." Peter

"I wish I could have a night to remember at Hamer Hall." Catherine

MND Victoria and MND Tasmania's Bucket List Wish Program will be able to provide experiences, gifts or services that will put a smile on faces and allow some solace from the daily burden of MND.

Proceeds raised through this Christmas Appeal will fund a wish for someone living with MND

40 YEARS OF CARE AND SUPPORT



2021 will be a memorable year for so many people but, for us at MND Victoria, it has been a very important year.

2021 is the year that we have acknowledged 40 years of having a significant impact on the lives of thousands of Victorians affected by motor neurone disease. Since we were founded (originally as the Motor Neurone Society) in 1981, it has been our mission to provide and promote the best possible care and support for people living with MND.

In each newsletter this year, we have been looking back on a decade in our history to reflect on the journey that has led us to where we are today.

Below are our milestones from 2011 – until today.

*** 2011** The discovery of mutations in the C9ORF72 gene was announced. Since then, this mutation has been found in about 40% of all families with familial MND.

*** 2012** Four determined women banded together to walk the 265km from Melbourne to Wangaratta to raise awareness of MND and raise vital funds for MND Victoria. In the end, they raised over \$11,000.

The inaugural Geelong Walk to D'Feet MND was held.

*** 2013** The Deb Bailey MND Research Centre officially opened. This was the first research unit in Australia dedicated to MND.

The Biography Service (now the Life Story Program) began. This service assists people to write their stories, reflect on their lives, and produce beautiful documents to treasure and share.

*** 2014** Over 60,000 supporters donated more than AUD\$3 million to MND Australia and the MND State Associations through the Ice Bucket Challenge.

*** 2015** Rock Off MND made its debut. All funds raised go toward the Jenny Simko MND Research Grants. The incredible team at Rock Off MND have raised over half a million dollars so far to fund research and raise awareness.

*** 2016** The NDIS rollout commenced across Victoria. It took another three years until it was fully implemented across all of VIC (2019).

*** 2017** We hosted our first challenge event. A group of 12 legends took on The Great Wall of China, raising over \$110,000.

Sallie Jones and Gippsland Jersey organised the Big Milk Freeze in Warragul. Frozen milk was poured over all who participated, and in the two years that the Big Milk Freeze ran, approximately \$10,000 was raised.

*** 2018** We celebrated the 15th year of the Walk to D'Feet events - we had events in Geelong, Rosebud, Melbourne, Bendigo and Echuca, raising over \$250,000 in total.

We embarked on our second challenge event - the Kokoda Trail. 8 legends took on the challenge and raised over \$58,000.

*** 2019** After 25 years, Rod Harris stepped down as CEO and we welcomed Kate Johnson.

*** 2020** COVID-19 arrived and changed the way we operated. Our very own Daniel Woodrow started our infamous "Zooming with Dan" series, where he facilitated casual but informative chats with various people from the MND community.

Our traditional Walk to D'Feet MND was changed to the Tour of Victoria, a fundraising and educational campaign. This event broke all records, raising a whopping \$282,561.

*** 2021 & Beyond** Our mission is 'To provide and promote the best possible care and support for people living with MND'. We are driven to ensure that 'best possible' can be even better than it is today, and we know that, with the support of the MND community, we will achieve that. We look forward to the day when we are no longer required. But as we say ... until there's a cure, there's care.



MND VICTORIA

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