

MNDnews

The newsletter of the Motor Neurone Disease Association of Victoria

Walking Warriors Unite!
Over \$94,000
raised for care and support



Until there's a cure, there's care

MESSAGE FROM THE CEO



Wishing you all a happy New Year and a warm welcome to the first edition of MND News for 2023.

The International MND/ALS Alliance held their annual International Alliance Meeting and Allied Health Professionals Forum in San Diego from 27 November to 2 December 2022. I had the privilege of attending this event along with many ALS/MND Association staff, allied health professionals, and other interested people from around the globe.

Presentations at the meeting addressed technology opportunities and developments, support for young carers, examination of the impacts of COVID on people living with MND, various registries, and much more.

The Allied Health Professionals Forum saw presentations about multidisciplinary care, decision making tools, positive tiredness, various educational tools, difficult conversations, voice banking, and more. It was wonderful to see the Speech Pathologist from MND Victoria attending with the support of a Nina Buscombe Award from MND Victoria, and presenting Calvary's research into the offering and uptake of voice banking.

This is such an important event in bringing together like-minded people from around the world to share innovation, developments, and passion in providing the best possible care and support for people living with MND.

It has been wonderful to attend a range of community fundraising events held in support of MND Victoria. The annual Tee Off for MND Golf Day and Jen's Bubbles and Brunch events were held at the Clifton Springs Golf Club on Sunday 19 February. This is always a magnificent day and this year saw 96 golfers participate, with another 98 attending the Bubbles and Brunch. The combined events raised a total of \$31,220 which will be added to funds raised at the Rock Off MND Gala Dinner later this year and will generate the Jenny Simko MND Research Grant.

As I write this, another magnificent event is in progress. Grounded for MND is an exhibition of the photography of Greg Levin who lives with MND. Greg was diagnosed with MND in January 2022. A former doctor and photographer, he is no longer able to use his arms. This is his first exhibition featuring photos taken in many corners of the globe. Funds raised through the exhibition and surrounding events will be donated to MND Victoria to assist us in providing the best possible care and support for people living with MND, and their families and carers. We are so grateful for the incredible efforts of organisers of these events – Greg, Abby, and Sofia Levin for the Grounded for MND events; and Russell Lowe and Peter Simko for the Tee Off, Bubbles and Brunch, and Rock Off events. These amazing people go to great lengths to support our work, and we are so very grateful that they do!

Lastly, in February, the MND Victoria State Council expressed our gratitude to retiring State Councillor Barry Gunning. Barry has been a member of our State Council for 10 years and, through that time, has lent his expertise, knowledge and time to supporting the governance of our Association. Barry is retiring due to ill health, and we wish him well and thank him for his incredible contribution across the last decade.

Wishing you all a happy Autumn – enjoy this edition of MND News.

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

Kate Johnson
CEO, MND Victoria

MND VICTORIA SAYS THANK YOU



Walk to D'Feet MND 2022

With dances of delight, the Walk to D'Feet MND events were up and running for 2022. The spirit of the Walking Warriors was out in full force at the Latrobe Valley, Bendigo and Melbourne events. Across all Walks, our Walking Warriors commented on how marvellous it was to be gathering in groups again to honour those living with MND and those who have passed.

Every one of these Walks has, at its core, the continued dedication and enthusiasm of the volunteers who put them together year after year. We see you and we thank you.

Together, the Walk to D'Feet MND events raised over \$94,000.

Bendigo

Under sunny skies and accompanied by two Lion Dancers from the Bendigo Chinese Association, the Walking Warriors of Bendigo stepped out for the Bendigo Walk to D'Feet MND. Ably organised by Chris and Angela, the walk on Sunday 20 November was back after a 2-year hiatus. With the beautiful Lake Weeroona to stroll around, a wonderful day was had by all. Together, the Walking Warriors of Bendigo raised \$7,000.



Latrobe Valley

On Sunday 2 October, Walking Warriors met for the Latrobe Valley Walk to D'Feet MND event. Entertained by the Gippsland Country Music Club and the Traralgon Pipe Band, the Walk to D'Feeters raised a total of \$17,000. With two choices for walking, 0.4km or 1.2km, both pram and wheelchair friendly, there were walking options for everyone. Congratulations to Lorraine and the amazing volunteers who put this inaugural Walk together. We can't wait to see what you do this year!



Lorraine was nominated for the Latrobe City Council 2023 Australia Day Award for Community Event of the Year. This nomination was in recognition of her outstanding contribution to the local community through the Latrobe Valley Walk.

Melbourne

This year's Melbourne Walk to D'Feet MND was once again held at Princes Park. Over 900 people attended on Sunday 27 November. There were games and face painting for kids and adults alike to enjoy. New to this year's event was a Carer Support marquee. Knowing that carers play a crucial role in supporting those living with MND, the marquee was a place for carers to gather, informally chat, and receive information and support from

MND Victoria's Carer Programs' team. Seated massage was also available for carers.

Through the generosity of many local businesses, we were able to raffle off over \$1,000 in prizes to 5 lucky winners. The raffle itself raised \$1,300 and a total of \$70,000 was raised overall.

Heathcote Bowls

7 years ago, a group of members at Heathcote Bowling Club got together to discuss a way of honouring their great mate, Dennis, who was living with MND and experiencing the decline associated with the disease right in front of their eyes.

Dennis was able to attend the first fundraising event at the Heathcote Bowling Club where his legacy was cemented, and the ongoing concept created.

This year, The Dennis Gleeson Superchallenge was another incredibly successful day. Bowls in Heathcote and Australia Day have become

synonymous in the local area and general bowls community, so it was no surprise to see the club packed with people having a great time and remembering such a popular person.

Raising funds for the care and support of people living with MND - just like Dennis - has been at the forefront of this fundraising event. The goal this year was to crack the \$100,000 mark raised since the beginning of the event. With the support of so many, the day raised over \$13,000, which absolutely smashed through the \$100,000 overall total since the first event. We thank the entire team at Heathcote Bowls Club for their ongoing dedication. Dennis would be so proud of what has been achieved over the years!

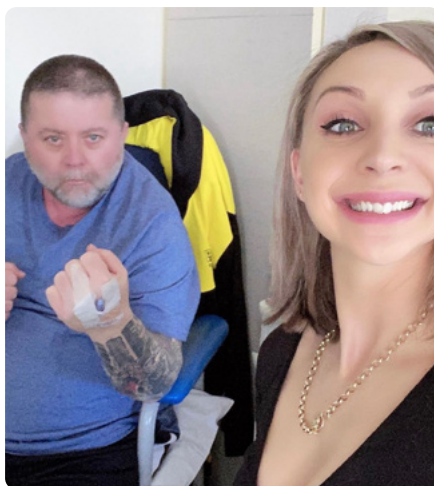


The Brow Design Co

For the past 12 months, Niki has been running her own beauty shop – The Brow Design Co – in Bentleigh East. She provides women and men with brow microblading, brow lamination, lash lifts, and lash and brow tinting.

All services have a portion donated to MND Victoria. Since she began, Niki has raised \$875 for MND Victoria in honour of her dad, Robert, who passed away with MND in June 2022.

"I wanted to create a business where everyone can afford amazing beauty treatments whilst giving back to such a brilliant organisation," says Niki. "Dad was the happiest, funniest, most supportive man in the world. He had a big heart and everything he did in his life was for his family and my Mum, the love of his life, Rosa. The support that MND Victoria gave not only for my Dad, but my entire family will never be forgotten. Whether it's MND Walks, MND fundraisers, MND donations from my shop, or bringing awareness to MND, my life mission is to keep pushing, fighting, and supporting MND until there is a cure."



Mercy Place Colac and 'The Max Factors'

In late November 2022, Mercy Place Colac ran an Ice Bucket Challenge fundraiser in honour of their resident, Max. "The Max Factors" raised \$1,300 for the care and support of people just like Max who are living with MND.

A very big thank you to Mandy who organised the event, Max and his wife May, and all the staff at Mercy Place Colac for putting on such a wonderful day.

We would also like to say thank you to Mercy Health for their support, and to local radio stations Mixx FM 106.3 and 3CS who came down and broadcast live about the event and the MND cause. *Pictures below.*



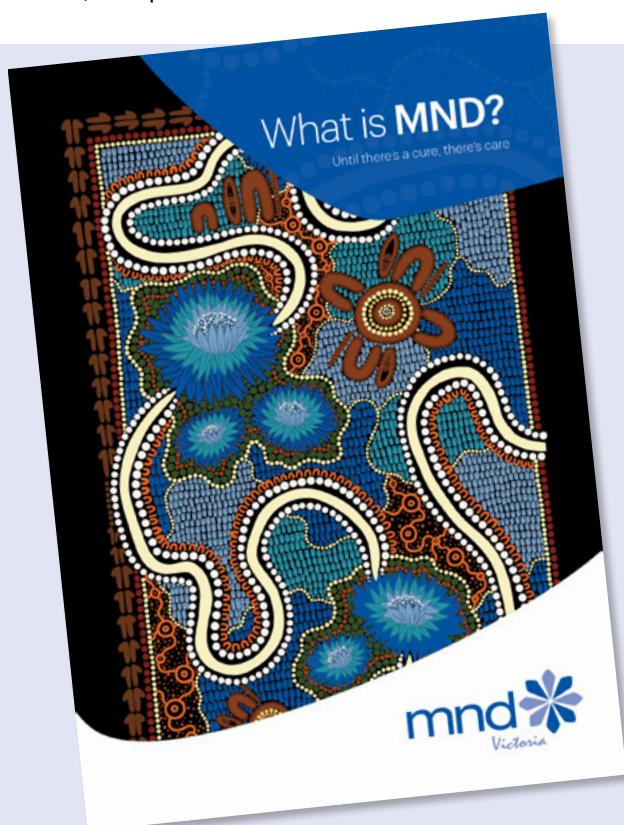


Café Brontos

Mohan and his team at Café Brontos, Boronia, have excelled themselves again. In their annual 'Pay What You Feel' fundraiser (held on 13 November 2022) they raised over \$5,500.

Along with donating the takings for the day, Café Brontos donates staff time, food, and beverages - café visitors 'pay what they feel' for their meals and drinks.

The event is held in honour and celebration of Raj, Mohan's best friend who passed away with MND in 2017. Mohan has been an incredible supporter of MND Victoria – since 2018, he has helped to raise over \$29,000. We were very excited to have Mr Jackson Taylor MP, State Labor Member for Bayswater, and our CEO, Kate Johnson, present Mohan with a commemorative plaque recognising his support and continued generosity. When you're in the Eastern Suburbs of Melbourne, a stop at Café Brontos is a must.



Australian Manufacturing Workers Union

In support of their colleague and friend, Fred Molluso, the Australian Manufacturing Workers Union held a "Dunk Tank" fundraiser in Echuca back in September.

Through a combination of donations, sponsorships, and merchandise sales, nearly \$9,000 was raised for MND Victoria.

A big part of their fundraising was the selling of a limited edition AMWU x MND Victoria t-shirt (pictured) that aims to bring awareness of both organisations and their support of people living with MND. A very big thank you to Naomi, Kelly and Fred for organising the event and helping to raise awareness and funds. *Pictured below.*



RAP Update

MND Victoria's Reconciliation Action Plan working group continues to implement the goals of our plan. Progress in the last few months has included the development of a resource for Aboriginal and Torres Strait Islander peoples titled "What is MND?", a dedicated page on our website, and a plaque acknowledging the traditional owners of the land on which our office sits, the Wurundjeri people. We have also commenced adding the name of the traditional owners on mail to our Victorian clients.

LIVING BETTER



Mindfulness for Carers

By Carmela Quimbo



Mindfulness is a mental training practice that teaches you to slow down racing thoughts, let go of negativity, calm both your body and mind, while cultivating compassion and friendliness towards yourself.

In this article, Carmela discusses the free 5-week Mindfulness for Carers Program that she is running which began at the start of March. You are more than welcome to join any of the upcoming sessions, regardless of whether or not you attended any previous sessions.

If you are unable to make any sessions but would like to learn more about mindfulness, you can view a recording of a previous session Carmela ran, which includes 3 mindfulness exercises. You can view this session at <https://vimeo.com/730195649/bdb5a1c79e> or by scanning the QR code above right.

Hello everyone.

My name's Carmela Quimbo and I am one of the Keeping Connected Advisors at MND Victoria. I'll be leading a 5-week online Mindfulness for Carers group beginning on Thursday 9 March at 2pm. The practice sessions will run for 45 minutes. They're free of charge, and you are welcome to attend one, all, or any number of the sessions.

Each Thursday for 5 weeks, we at MND Victoria would like to encourage family and friends of people who have been diagnosed with MND to come together and experience how mindfulness practices can support people by cultivating an inner state of kindness, peace and wellbeing in the midst of all of life's array of circumstances ... including the often difficult and sometimes heartbreaking challenges of caring for someone diagnosed with MND.

The practices we will do together are an invitation to explore the effects of bringing non-judgmental attention, curiosity and friendliness to all aspects of our daily lives. With practice, we begin to discover that the inner quality of mindfulness can be a reliable, loving and wise companion as we navigate the fullness of a human life.

I've heard people say that they "can't do mindfulness" because their minds are too distracted, or that they can't stop thinking, or that they can't sit still, or that they are too anxious or they don't have enough time. But the great gift of the quality and practice of mindfulness is that it can be present and attentive to all the distractions, all the discursive thoughts, all the physical sensations, all the emotions, and all the busyness of our lives.

Mindfulness practices are not aimed at changing the content and circumstances of our lives. The wonderful and powerful shift that occurs is in how we relate to our life's circumstances. We begin to see ourselves, our families, our friends, our community, our work, our

environment, our world, and all of the experiences of our bodies and minds with more clarity and spaciousness.

As I sit here typing these words, I am becoming aware of a wish to have this article finished and submitted. I am starting to feel anxious that I am not going to reach the 600 words I promised by tomorrow. So, I intentionally pause and notice there is worry right now, there is a thought that I won't be able to get this done. I'm not trying to change this experience, I'm not trying to fight it or ignore it, I'm allowing it to be there. I notice where the worry is alive in my body, a tightness in the shoulders, a clenching in the stomach, a dryness in the mouth. I allow those too. I stay with myself, the way I would stay with a beloved friend, sitting on a chair at my kitchen table, typing, breathing, thinking, worrying. And, in this staying with my present moment experience of worry, with mindfulness, kindness and curiosity, I can see it more clearly. I can see that it is not permanent and that, in fact, it is already ceasing.

So now, I can bring this article to a close with a sincere and warm invitation for carers of people who have been diagnosed with MND to join me in the practice of mindfulness. You can register your interest by emailing info@mnd.org.au or calling MND Victoria on 1800 777 175. If you have any questions, or would like to talk with me about it, please feel welcome to call me on 0479 039 402 or email on cquimbo@mnd.org.au

MND RESEARCH

Cough medicine to be trialled for MND treatment

By Professor Brad Turner

Researchers at the Florey Institute will lead a world-first clinical trial of Ambroxol as a potential treatment for MND. Ambroxol is a generic drug found in cough syrup and has been used to treat respiratory conditions for over 30 years with an excellent safety profile. Ambroxol is a mucolytic agent (drug that helps to clear mucus from the respiratory tract) which helps break down phlegm and acts as a cough suppressant.

Now, research led by Professor Brad Turner at the Florey Institute, University of Melbourne, has discovered a novel action of Ambroxol for MND. His group has shown that Ambroxol works by reprogramming metabolism inside motor neurons, leading to stronger physical connections between motor neurons and muscles. These connections are thought to be disrupted early in MND, leading to characteristic muscle weakness and wasting. Accordingly, Ambroxol treatment improved disease in models of MND across different laboratories, supporting its potential for slowing down MND progression.

This Phase 2 trial called AMBALS will launch in March 2023. This clinical, multi-centre trial will recruit 50 MND patients across Australia for treatment with escalating oral doses of Ambroxol for 6-months with an option for a 6-month open label extension. Participants will receive either Ambroxol or a placebo treatment. The effectiveness of Ambroxol will be measured using clinical rating scores, questionnaires, electrodiagnostic tests and blood biomarkers of disease progression.

Professor Turner said, "We are excited to lead this trial which represents five years of extensive research across an international team of collaborators. Ambroxol is an ideal drug candidate for MND. It is a safe drug, taken orally as a syrup and readily enters the brain. We will repurpose Ambroxol for MND for the first time. We look forward to working with the MND community in this trial."



The AMBALS trial is funded by FightMND. Patient recruitment for this trial opens February to September 2023 at 5 clinical sites, including Calvary Health Care Bethlehem, VIC; Concord Hospital, NSW; Brain and Mind Centre, NSW; Flinders University Medical Centre, SA; and Launceston General Hospital, TAS. The expected trial completion will be late 2024. Please speak with your neurologist if you are interested in participating in this trial. of collaborators.

PERSONAL STORY



Something *to* Say

By Marilyn Martyn

Marilyn volunteers for MND Victoria in our Life Stories Program, helping people living with MND to record, transcribe and prepare stories of their life for printing, so that the stories of their life can be recalled, celebrated and shared.

We are currently seeking to build our team of Life Story volunteers across the state.

If you would like more information about this role, please email Deb at volunteer@mnd.org.au or phone 0432 053 287.

If you are living with MND and would like to work with one of our Life Stories volunteers to record the stories of your life, please contact your MND Advisor/Support Coordinator.

The time has come to put my grief aside and share my experience with people facing the same situation.

I first heard of MND in the mid-eighties when a colleague's wife suffered from this insidious disease. My colleague was distraught, feeling helpless and without a lot of support.

I remember thinking I could not face that situation. I could never cope.

Thank goodness we have no idea what is ahead of us.

Sol was my second husband. We met in our fifties, both of us experiencing the despair of a broken marriage. We had rebuilt our lives and were busy and content (well, sort of).

A mutual friend arranged for us to meet for dinner before we went to her daughter's wedding. I was not a romantic at heart but thought it would be good to have someone with whom to attend the wedding.

Sol was in the kitchen when I arrived for dinner. I was expecting to see a short, rotund, middle-aged man. I turned around to face the door as this tall, slender, attractive man entered the dining room and introduced himself. He also had this deep, melodic voice. I fell in love at first sight! It was a mutual attraction. After a two-year friendship, we decided to live together. After twelve years, we decided to get married.

Marriage was something I wanted. We were in our sixties and knew that we had to make the most of the time that we had left. We were committed to marriage and were the best of friends. I am a mother of two sons, and motherhood was a joy. I learned that my love for my husband was just as strong.

One day I noticed Sol's voice had changed. It had lost its depth. Initially, I thought it was because he was a man in his seventies. He also appeared withdrawn. Sol started to experience odd symptoms. In retrospect, his doctors knew what they indicated but they wanted to be sure before giving us a formal diagnosis. Sol passed away from MND on the 2nd of May 2017. I think of him every day and miss him enormously, but I am grateful that he is free from this dreadful disease.

I faced the situation and coped. Why? Because I didn't face it alone. I experienced the courage and fortitude of one man and how caring human beings can be for one another.

Sol displayed courage, sensitivity, and a practical attitude; I am sure he felt fear as I did. He announced that he could no longer drive his car, and he accepted the wooden walking stick which he needed and then the walker. But he wasn't too happy about the wheelchair!

Continued on page 7

VOLUNTEER RECRUITMENT

MND Victoria is proud of the services we are able to provide through the support of our fabulous volunteers. MND Victoria volunteers in client support roles provide a range of services that assist people living with MND and their families.

We are experiencing increasing numbers of requests for volunteer support and thus need to grow our volunteer teams to be able to better meet these requests.

Current volunteer opportunities available

Hand and Foot Massage Volunteers provide gentle massage for people living with MND. While our massage volunteers are not providing a therapeutic massage, feedback from our clients tells us that the massage our volunteers provide helps them feel more comfortable and relaxed. MND Victoria provides training in massage techniques as well as massage lotions and creams. Ongoing support and education is also an essential part of MND Victoria volunteer programs.

Social Visiting Volunteers are a regular highlight for people living with MND at home and in residential facilities. A social visiting volunteer may be a regular visitor for activities such as a chat, cards, crosswords or crocheting. Shared experiences, and time spent in conversation or just sitting quietly together, are the focus for this volunteer role. Again, MND Victoria provides training to prepare volunteers for this role, and provides ongoing support for our volunteers and opportunities to meet and learn with other volunteers.

Please contact Deb, Coordinator of Volunteer Programs, on 0432 053 287, or at volunteer@mnd.org.au to find out more about the volunteer roles we have available.

Continued from page 6

I had to call the ambulance when he couldn't breathe. He wanted to go home when we both knew that he couldn't. When he could no longer speak, he wrote, 'the situation must be difficult for you!' He indicated how he was feeling. I didn't have to guess. I knew what he wanted, and he didn't argue if it wasn't possible. He showed me the gracious and loving man I knew him to be.

We appreciated the support from MND Victoria and Bethlehem Hospital, our church community and medical attendants. A loving family and friends also cared for us.

I have a joyous memory. Sol was a meticulous man. I saw that he needed an electric shaver.

"I am going to 'The Good Guys' to get you an electric shaver. I will bring it in the morning," were the last words I said to him. Supported by nurses, he nodded and gave me his V for victory sign. Sol passed away that night.

I am still associated with MND Victoria. I have the privilege of working with people recording their life stories, the perfect legacy to leave a family.

I received a beautiful card from my niece. On it was a quote from Kahlil Gibran:

"Ever has it been that love knows not its own depth until the hour of separation."

I have experienced this to be true.



UPCOMING EVENTS

Help us to raise more, whilst you save more, with 'Entertainment'

An "Entertainment" Membership is your key to 1000s of exclusive offers on dining, travel, activities, shopping and more.

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* T&Cs apply. Visit www.entertainment.com.au/promotions for more information.



Larapinta Trek

Join us in the Red Centre this August and experience the rich history of Australia's First Peoples, trekking scenic landscapes along well-worn red dirt tracks. At night, you'll camp under the Milky Way and fall asleep to the nocturnal sounds of the desert. Not only is this an incredible experience but, with every step you take, you'll be supporting Victorians living with MND. It's sure to be an unforgettable adventure! But don't just take our word for it.

"I did the Larapinta Trek because my wonderful husband had motor neurone disease, and I wanted to do something challenging because he had it hard. MND Victoria helped us hugely so I could care for John and keep him as safe and comfortable as possible."

Jenny, 2022 participant

"My mum was diagnosed with MND in April 2012. I walked Larapinta in her memory and to raise money for the rest of the people who are living with this disease at the moment, and those who will be in the future."

Sarah, 2022 participant

Now's your chance to do something extraordinary. More details are available at <https://inspiredadventures.com.au/event/mndvic-larapinta-2023/> or scan the QR code to the right.



GIVING



The Great MND Relay is back in 2023!

When: Saturday 27th May
9:00 am – 5:00 pm

Where: Lakeside Stadium,
Albert Park

The Relay starts at 9:00 am with event celebrations kicking off at 4:00 pm

The Challenge: Gather your family, friends, or colleagues to fundraise and take on 105 laps! Smash out a marathon solo or gather your tribe: more people = less laps.

Ticket Price:

Adult: \$60

Kids (aged 5 - 18): \$35

Your Entry Includes:

- Exclusive t-shirt
- Finishers medal
- Lap results tracked by Timing Solutions technology
- Opportunity to win prizes
- Entertainment and activities on the day

We are thrilled to be able to hold the popular Great MND Relay again in 2023, on Saturday May 27th. Held at the picturesque Lakeside Stadium in Albert Park, we welcome all challengers to walk, run and have fun!

Take on the 42km (105 lap) relay challenge alongside our inclusive and supportive community. Sign up solo and smash out a marathon, or gather your family, friends and colleagues - the more people in your team, the less laps you each have to do.

Smash personal goals, spread your good vibes, and make an impact for Victorians affected by motor neurone disease.

The Great MND Relay is YOUR chance to do something great.

The goal isn't to beat others but to challenge yourself, have fun, and make a difference to the MND community. You're not only showing up for yourself but also for the 503 Victorians who are currently living with motor neurone disease.

So, what are you waiting for? Sign up and change lives.



For more details and to register, visit www.mndrelay.org.au/ or scan the QR code above

It's time to get the gang together!



We are excited to welcome back our Walking Warriors to the South East Melbourne Walk to D'Feet MND this May!

When: Sunday 7th May 2023
10:30 am – 3:00 pm

**Where: Lakeside Amphitheatre,
Lakeside Blvd, Pakenham VIC 3810**

Registrations open at 10:30 am for a 12:30 pm start.

Ticket Prices:

Adults - \$40.00

Child (under 18) - \$20.00

Family of 4* - \$100.00

**1 adult and 3 children, or 2 adults and 2 children*

Every registration includes a free "Walk to D'Feet MND" T-Shirt or "Never Give Up" Beanie.

Register with all of your family, friends and colleagues and create your own team. There are no limits to how small or large teams can be, so spread the word and gather your tribe for a fabulous day out to support people living with MND. Dogs are more than welcome to attend.

The Walk is an easy 1.3km flat walk around the Lakeside Amphitheatre and is wheelchair and pram friendly. Disabled parking is available for people with MND.

For more details and to register, visit www.mnd.org.au/sewalk or scan the QR code on the right.



MND VICTORIA

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We acknowledge Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of the lands in which we live, work, and learn. We recognise and respect the enduring relationship they have with their lands and waters, and we pay our respects to Elders past, present, and emerging.