

# MNDnews

The newsletter of the Motor Neurone Disease Association of Victoria

**Hope,  
Resilience,  
Strength**



**mnd**   
Victoria

Until there's a cure, there's care

# MESSAGE FROM THE CEO



**Welcome to the Spring edition of MND News. I hope that you find the information and stories in our newsletters to be helpful and interesting!**

MND Australia, with MND Victoria, hosted the National MND Care Conference on Monday 28th August at the Florey Institute in Parkville. There were 250 people in attendance, including allied health professionals, Association staff from around the country, and others with an interest in MND.

The presentations and posters at the conference were varied, informative and interesting, and I am sure that everyone took away new learnings from the day. It is so heartening to hear of the amazing work going on across the country to improve the care and support for people living with MND and their families.

The MND Australia Board and CEO met with the State Associations' CEOs in Sydney on the 10th of August for a joint discussion to establish priorities and directions for MND Australia into the future. It was a collaborative and fruitful discussion which will lead to a focussed strategy at a national level for the coming years. It is so valuable that we can collaborate and share across all of the Associations to ensure that we are doing the best possible work to advocate for the needs of people impacted by MND, support research, and provide the best possible care and support.

You may have seen news coverage recently (early August) of a new drug trial in MND. The drug is called SPG302 and the trial is being conducted by the Nucleus Network in Melbourne on behalf of Spinogenix, the US manufacturer of the drug. The drug is only being tested on healthy volunteers at

present to check for toxic effects and how long it stays in the body. Early next year there will be a small trial testing the drug in MND patients – but only for a very short period (4 weeks). You can read more about this on pages 3 - 5 in this newsletter.

It is very positive news, however it will be some years before the drug might make it to clinics - and that's only if it is found to be effective. If you hear information about MND research, drug trials or other discoveries in the news and want to know more – please contact our team at [info@mnd.org.au](mailto:info@mnd.org.au) or on 1800 777 175.

I had the privilege of attending the Blackburn Vikings basketball game in July, honouring player Kate Pattison's mum Julie who had MND and died just days before the game. The event raised funds and awareness for MND Victoria, and was just another example of the amazing generosity of our community. You will read more about this on page 2.

Many thanks to all of the groups in our community who hold events and raise funds to support the important work we do at MND Victoria in providing services to ensure that people with MND are able to live as well as possible for as long as possible. We are proud of the work we do and so value the support of our community.

Have a lovely Spring.

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

**Kate Johnson**  
**CEO, MND Victoria**



# MND VICTORIA SAYS THANK YOU



## Celebrating MND Week 2023

**MND Week is a time for reflection, recognition and raising awareness to help support those living with MND today, tomorrow, and those who will be diagnosed in the future.**

MND Week was held from 19th to 25th June this year, and in recognition of Blue Cornflower Day (the Friday of MND Week), we held a special Paint n' Sip event at Frida's Camberwell. It was a lovely evening connecting with those in our incredible community, reflecting on MND Week, and immortalising the blue cornflower in our artwork.



## Larapinta Trek Challenge Event 2023

After months of fundraising, an amazing group of supporters headed off to the Larapinta Trail in the Northern Territory as part of our latest challenge event. Alongside our friends from MND South Australia, our three trekkers explored the scenic landscapes of the Australian Outback, hiking rocky, undulating trails and even completing a hike up Mount Sounder via torchlight to see the sunrise. In the lead up to the trip, these legends raised an impressive \$10,000 for the care and support of people living with MND.



## Footy & Feed

We are incredibly grateful to Paul Reid, Erin Gogerly, and the team for running their Footy & Feed – MND Fundraiser back in June at the Edinburgh Gardens Community Rooms. Both Erin and Paul lost their fathers to MND and had wanted to give back to aid families during their struggles with MND.

Last year, when the group got together to watch the footy and host a lunch, they raised \$5,000. This year, they wanted to make the event bigger and better, and set themselves the goal of doubling that total. Through the generosity of many businesses and individuals, over \$25,000 was raised!

They accomplished this through a BBQ and cash bar, raffle, auction, and various activities including an ice bucket punishment for the person with the most bids - this generated in excess of \$5,000 on its own!

The event received a fantastic turn out of over 80 people made up of family, friends and businesses involved, with a large contingent generously donating their time to staff the money raising initiatives throughout the day.

Thank you to everyone who contributed and made the day a success.



# Community Fundraising

June was a very busy month for our MND Community! Not only was it MND Week, but a number of people held their own fundraising events and initiatives to raise vital awareness and funds for MND Victoria. Through raffles, morning teas, fun runs and even a hot dog eating competition, a combined total of over \$40,000 was raised!

Thank you to the following people who helped in achieving such an incredible result:

- Felicity Rush and Queenscliff Football Netball Club
- Adiel Barbutt
- Kings College Warrnambool
- Cecile Lablache
- Craig Buckingham and City Safety, Security and Amenity Branch
- Crown VIP Services
- Rosebud Country Club
- Paul Reid, Erin Gogerly and the Footy & Feed Team
- Karyn Martin and Wandin Football Club
- Greenwood Village Mews
- Spring Valley Golf Club
- Spiffy Spouts Gutter Cleaning
- Barellan Central School
- Massimo Tocci and the Southbank Trammies
- Nexus Primary Health
- Kate Pattison and Blackburn Vikings Basketball Association

We would also love to say a very big thank you to everyone who shared, participated, and donated to these wonderful fundraisers. You're all superstars!



## Blackburn Vikings Basketball Association

**After months of hard work, planning and anticipation-building, the Blackburn Vikings Basketball Association held their special MND Round on Sunday July 2nd.**

This round came about because the mother of a much-loved player within the club was living with MND. Kate Pattison is a star player on the Senior Women's Big V team and has openly shared her family's heartbreaking story. Like all good sporting clubs do, the Blackburn Vikings' family wrapped their arms around Kate and wanted to help in any way that they could. Kate has been a huge advocate for MND Victoria over the last couple of years because she sees first-hand the care, support and equipment that has been provided to her mum, Julie, to enable her to live as well as possible for as long as possible. So there was no hesitation in creating a big event to raise funds and awareness for MND Victoria.

The event took a big turn on the Monday prior to the big day when Julie passed away. This was such a tough time, not only for Kate and her family, but also for the whole Blackburn Vikings family. The big day came around and, as you can imagine, it was a more sombre occasion than initially planned. There was a very moving memorial for Julie on the side of the court and a whole heap of emotion from players and spectators alike as proceedings got underway.

Through the sale of tickets, merchandise, a silent auction, a raffle and so much incredible generosity from many donors, an amazing \$22,468 was raised. These funds will help MND Victoria to continue providing the best possible care and support for all Victorians living with MND.

We are very thankful to everyone who helped put on the inaugural MND Round, and to everyone who contributed to the overall fundraising total. We know Julie would have been super proud, and we look forward to another special event next year!

## Jerilderie Golf Club

The Ian Sneddon MND Golf Day has been run and won once again up at Jerilderie Golf Club. This incredible fundraising event has been embraced over the years by the local community, with participants coming from far and wide. The golf is fun, the dunk tank participants are brave, and the generosity of so many is incredibly special. The day is all about remembering the legacy the great Ian Sneddon left in the local area after he sadly lost his battle with MND in 2019. The event also aims to raise funds so

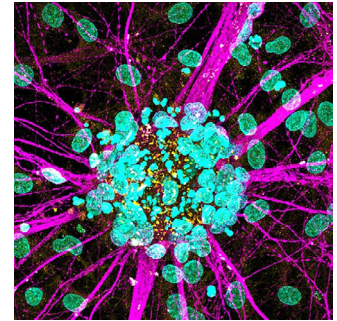


that people living with MND now can continue to receive the best possible care and support. This year, the event raised a phenomenal \$16,881. Everyone at MND Victoria thank the organising committee who continue to go above and beyond to grow the event each year. We can't wait to see what next year looks like!

# MND RESEARCH

## How research and the medical system develop medicines for MND in Australia

By Dr Gethin Thomas, MND Australia



### Clinical trial of SPG302

Recent media stories have highlighted a new clinical trial currently underway in Melbourne. The trial, for a drug called SPG302, is being run on behalf of Spinogenix, the US company which makes the drug, by Nucleus Network.

**SPG302 has been developed to target the synapse in nerve cells. The synapse is the site of contact between two nerve cells, or the nerve cell and muscle, that enables communication via chemical signals, and is key for the brain control of muscles for movement. One major aspect of MND is the loss of these synapses.**

This drug has been designed to increase the number of synapses in nerve cells. The trial is a Phase 1 trial, which is the first step in testing whether a drug can develop into a viable treatment.

It will initially test how the drug behaves in healthy volunteers, to check for any toxic effects and how long it lasts in the body.

Early next year, there will also be a small part of this study which will test the drug in MND patients, but only for a very short period (4 weeks) to make sure that the drug behaves in the same way in patients as it does in healthy volunteers, and to measure any changes in patients that may occur.

It should be noted that, although it is exciting to have new drugs being tested, this is at a very early stage, and it will be a number of years before this drug, if successful, might make it into the clinic for patients.

According to research, the medicine Riluzole can prolong life with motor neurone disease (MND).<sup>1</sup> Riluzole is the only medicine for treatment of the disease available in Australia.<sup>2</sup>

By contrast, people living with MND in the United States of America (USA) can access three medicines: Riluzole, Edaravone and Relyvrio, and, just this month, Qalsody (previously Tofersen) which can all slow the progress of MND.<sup>3,4,5</sup> But currently, Australians cannot access Qalsody, Edaravone and Relyvrio through our medical system.

Why don't people living with MND in Australia have access to medicines like Edaravone? And how can scientists develop medicines sooner?

We have looked at what helps a medicine progress from scientific experiments to doctors being able to prescribe it for MND in Australia. With better access to medicines, more people with MND can have greater choice over living with such a terrible disease.

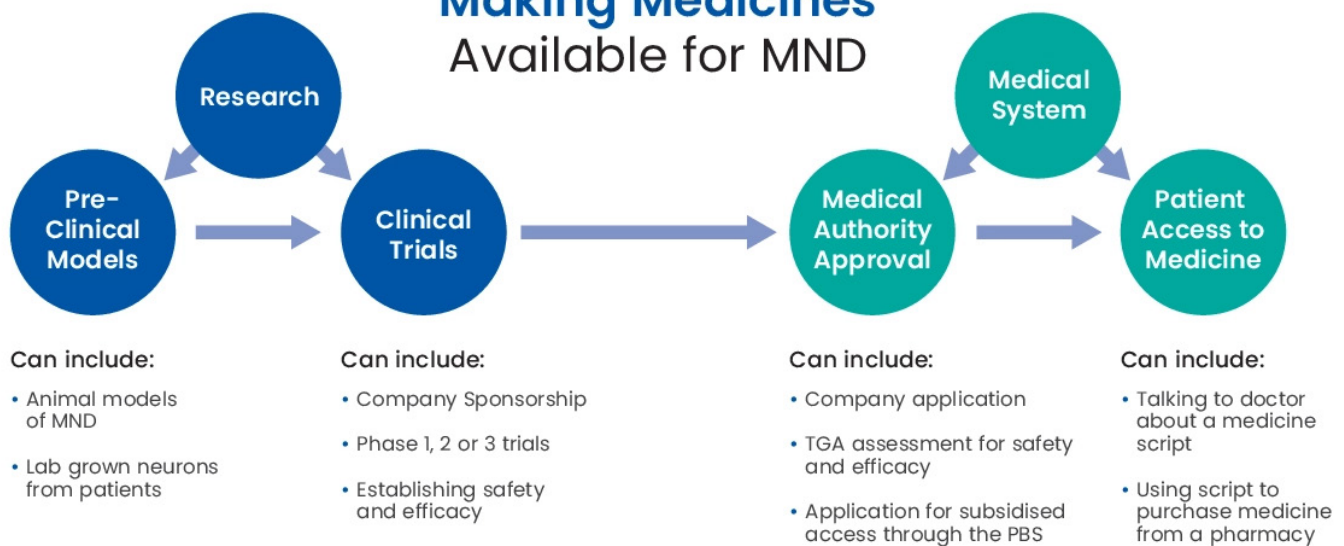
### How do we find a new medicine?

Research is fundamental for developing new medicines and treatments for MND or any other disease or condition. Research is where a medicine for MND begins.

Scientists must rigorously test any potential treatment before its use by patients. First steps in testing often involve seeing if the new treatment works in "pre-clinical models". Models include lab grown neurons from patients and animal models of MND. If everything looks good after these early steps (also known as pre-clinical testing) the organisation developing the treatment may consider it for clinical trial.

Clinical trials are major research projects.<sup>6</sup> Therefore, starting a clinical trial for a potential treatment requires approval. The organisation developing a treatment (usually a pharmaceutical or biotechnology company) is termed

## Making Medicines Available for MND



the “sponsor”, and decides if they think the potential treatment is promising enough to take to trial.

They then apply for approval to the regulatory authorities in the country or countries where they want to run the trial. In Australia, for example, it is the Therapeutic Goods Administration (TGA). In the US, it is the Federal Drug Agency (FDA).

Clinical trials consist of phases. Usually, in Phase 1 or Phase 1/2 of a trial, testing determines treatment safety and that it won't cause harm. Scientists may also study what medicine dose might be best (the exact amount taken at one time) as part of the trial.

Phase 1 of a trial is usually very small. The trial will not involve sufficiently high numbers of participants to provide information on the effectiveness of a treatment. In fact, scientists often run Phase 1 trials on healthy volunteers rather than actual patients. A Phase 2 trial begins after Phase 1 research shows a medicine is safe.

Phase 2 trials mainly aim to finalise the best plan for medicine doses. Trials can also provide some provisional information on the potential effectiveness of a treatment. Scientists often design Phase 2/3 trials to help in starting to understand treatment effectiveness. Phase 2 trials are larger than Phase 1, especially if they are Phase 2/3, as they gather more data.

It is worth noting that it is not just the decision of the sponsor in determining if a treatment progresses to a clinical trial and through all its stages. At each stage, data must be presented to the local regulatory authority to show whether the treatment merits progression through the clinical trial pathway.

Phase 3 trials are the final phase of the clinical trial pathway. This trial is the last stage before a sponsor seeks approval to make the treatment available to the public. Scientists specifically design Phase 3 trials to show whether a drug works. The trials need to be much larger than Phase 1 or 2 trials. The reason for the larger size is to establish statistical certainty for definitively saying whether a medicine works or not.

Phase 3 of trials are very expensive (often in the 100s of millions of dollars). In addition to the cost, the trials can take well over 12 months. Trials must be set-up, participants recruited for treatment, and analyses conducted. The time and cost are necessary to try and make sure that medicines actually work and are safe to use.

### From research to pharmacy shelves: making a new treatment available to patients

Once a treatment has been through the clinical trial pipeline and found to be safe and effective, what happens next? How do patients access medicines?

Unfortunately, it is not an automatic progression from trial success to availability to patients. Often, at first glance, the outcomes of clinical trials may appear to be positive. But on closer analysis, trial results may indicate that the benefits were not as great as first thought. Conversely, there may have been confounding reasons that resulted in a trial outcome appearing worse than it really was.

To best determine the quality of trial outcomes, a local regulatory authority requires the trial sponsor to submit an application for medicine approval. The application allows the authority to objectively and independently review the data.

The authority make their own decision on the benefit of a particular treatment. Such assessment will involve a number of experts in clinical trials, statistics, and the disease area in question.

Assessments are very involved considerations, and can often take 6 months or more. As well as considering the effectiveness and safety profile of the treatment, the process considers how medicines are scheduled for prescribing by doctors, and whether they are listed on the Pharmaceutical Benefits Scheme (PBS), which helps to make medicines available at a lower cost.

Currently, the TGA grants initial approval based purely on whether the evidence shows a treatment is safe and effective.<sup>7</sup> The TGA offers very limited opportunity for input into their approval decisions by advocacy organisations such as MND Australia.



The organisation sponsoring development of the medicine completes the application. Some organisations keep applications confidential, making it hard to even know an application is underway. However, in the MND community, which tends to work collaboratively whenever possible, it would be unlikely for an application to proceed without the MND community knowing.

## What can help make more medicines available for MND

Clinical trials and regulatory authority approval can take quite a long time. But there are ways to make more MND medicines available sooner.

Ongoing investment in the work of MND scientists in Australia and across the world is critical. Research is best for finding safe and effective medicines that benefit people with MND. Donations, fundraising campaigns and other opportunities to support MND research remain vital for research into medicines.

Beyond research, working with organisations sponsoring medicines can influence the process of TGA approval in Australia. MND Australia and others can, and do, work with sponsors when they are preparing their submissions. MND Australia provides data and brings the experiences of those with lived experience to the table. Sharing data and experience helps to increase the likelihood of approval for a submission.

Working to persuade sponsors to come to Australia, to help them understand our system, and to offer support helps too. Some companies developing new treatments do not have deep

resources, making targeting multiple countries simultaneously for approval difficult.

This is the case for Amylyx, the company which developed Relyvrio, which was recently approved for MND treatment in Canada and USA. They need to build up their manufacturing capacity to service the USA and Canada, which will then establish a steady income stream so that they can then look to expand their reach. MND Australia is already scoping how we can best support companies which are considering applying for medicine approval with the TGA.

In addition to medicine approval, MND Australia and other organisations can help with making medicines more affordable. The application process for subsidised treatment through the PBS does provide an opportunity for organisations to lobby for change.

Lobbying normally takes the form of an organisation completing a written submission about the need for a treatment and its benefits. Organisations submit applications to the TGA review committee. The testimonials of people with, or affected by, MND, can support submissions, because they help to share the experiences of daily life from living with a terrible disease like MND, and why an affordable medicine is so important.

MND Australia are also lobbying for greater involvement of people with MND in TGA decision making more broadly. MND Australia is participating in the review of Australia's Health Technology Assessment. The review seeks to help reduce the wait times for patients wanting to access new and innovative medicines.

## Stay informed

Creating a world without MND, through the search for better medicines, and a cure, is a complicated and difficult challenge. Work is underway though, and there are many opportunities to improve access to medicines and life with MND.

It can help to stay informed about what the TGA is considering for MND medicines. Being aware of medicines already available, including Riluzole and medicines for pain relief, is important.

Doctors, neurologists and other members of the healthcare team for a person living with MND can advise on how to access and use Riluzole and other medicines.

### Sources

1. A. Chio, L. Mazzini and G. Mora. 2020. "Disease-modifying therapies in amyotrophic lateral sclerosis." *Neuropharmacology*. 167:107986. doi: 10.1016/j.neuropharm.2020.107986.
2. T. Dharmadasa et al. 2017. "Motor neurone disease: progress and challenges." *Med J Aust*. 206(8): 357-362. doi: 10.5694/mja16.01063.
3. X. Xu et al. 2021. "A perspective on therapies for amyotrophic lateral sclerosis: can disease progression be curbed?" *Transl. Neurodegener.* 10(1): 29. 10.1186/s40035-021-00250-5.
4. Y. Sun, X. Li, and R. Bedlack. 2023. "An evaluation of the combination of sodium phenylbutyrate and taurursodiol for the treatment of amyotrophic lateral sclerosis." *Expert. Rev. Neurother.* 23(1):1-7. doi: 10.1080/14737175.2023.2174018.
5. T. M. Miller et al. 2022. "Trial of Antisense Oligonucleotide Tofersen for SOD1 ALS." *N Engl J Med*. 387(12):1099-1110. doi: 10.1056/NEJMoa2204705.
6. Australian Government. 2023. "Why conduct a clinical trial in Australia." *Australian Clinical Trials*. Apr. 14: <https://www.australianclinicaltrials.gov.au/why-conduct-clinical-trial-australia> (accessed Jan. 05, 2023).
7. S. J. Ayre, C. Bonner, D.M. Muscat, A.G. Dunn, E. Harrison, J. Dalmazzo, D. Mouwad, P. Aslani, H.L. Shepherd, K. J. McCaffery. 2023. *Automated Health Literacy Assessments of Written Health Information: Development of the SHeLL (Sydney Health Literacy Lab) Health Literacy Editor v1*. *JMIR Formative Research*. e40645. DOI: 10.2196/40645
7. Therapeutic Goods Administration. 2021. "Prescription medicines registration process." Therapeutic Goods Administration, Aug. 12: <https://www.tga.gov.au/how-we-regulate/supply-therapeutic-good/supply-prescription-medicine/application-process/prescription-medicines-registration-process>.

# FUNdraise for MND Victoria

Are you interested in becoming a community fundraiser for MND Victoria? You could host an event, get active, set a challenge, celebrate an occasion, have a bake sale... ideas are only limited by your imagination!

When you sign up to fundraise for us, you'll receive your own online fundraising page to help spread the word about your activity and to receive donations. You'll also have access to support from our team as well as a number of resources to make it a fun experience! Get in touch with us by emailing [community@mnd.org.au](mailto:community@mnd.org.au) or calling 03 9830 2122 to chat today.



# LIVING BETTER

## Volunteers and MND Victoria

**MND Victoria acknowledges the support and involvement of our talented and committed volunteers. Our volunteers work in a variety of roles supporting the work of our organisation. Over the 2022-23 Financial Year, our volunteers contributed over 3,400 hours of time and skills to our work.**

We see a growing number of requests for volunteers to support our clients in specific roles such as Social Visiting, Hand and Foot Massage, and Life Stories; and continue to seek to increase our number of volunteers across the state to meet these requests.

### Introducing our Volunteer Engagement Team

**Deb** – I have been with MND Victoria for 5 and a half years, and have worked with a range of organisations involving volunteers across several states for more than 30 years. I continue to be inspired and humbled by the contributions made by volunteers to the work of MND Victoria, and the community at large. It is exciting to have the opportunity to grow our volunteer programs to better meet the needs of people living with MND.

**Jacinta** – I started with MND Victoria in July 2023 in the new role of Volunteer Engagement Coordinator. I have previously had experience working within the Volunteer Engagement Team at Austin Health, and at Lort Smith Animal Hospital. I really enjoy working alongside volunteers and have a passion for community-focused roles. I have a lot of experience with recruitment of volunteers, as well as change management and providing engaging programs focused on fulfilling volunteer roles.

We are looking forward to working closely together to action the new MND Victoria Volunteer Engagement Strategy. Our aim is to increase MND Victoria's volunteer workforce and, in turn, increase access to our volunteer programs for our clients across the state who are living with MND.





# VOLUNTEER OPPORTUNITIES

Volunteer opportunities currently available with MND Victoria include:

## Hand and Foot Massage Volunteers

Hand and Foot Massage Volunteers provide hands-on connection for people living with MND through gentle massage. Regular massage sessions may be a quiet time or time for a chat. Our volunteers are guided by their client. Clients report that the massage our volunteers provide helps them to feel more comfortable and relaxed.

No previous experience in massage is required for this role. MND Victoria provides training in massage techniques and basic equipment for the role. Ongoing support and education is provided as part of our commitment to our volunteers.

## Social Visiting Volunteers

Social Visiting Volunteers make regular visits to clients for 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 with clients at home or in residential care.

Again, MND Victoria provides training to prepare volunteers for this role, and ongoing support and connection for our volunteers.

MND Victoria works with individuals to identify volunteer roles to suit their interests, skills and availability. We are happy to talk with you to explore volunteer opportunities. Please call the Volunteer Engagement Team on 03 9830 21122, or email [volunteer@mnd.org.au](mailto:volunteer@mnd.org.au) for more information.

## An overview of MND Victoria's Volunteer Engagement Strategy 2023-2026

MND Victoria recognises that our organisation has had a strong history of volunteer involvement. The new strategy seeks to build on this experience while responding to changing community needs and expectations, organisational objectives, and the needs of people living with MND.

We will do this by identifying gaps by geographical locations, and engaging internal and external stakeholders - such as tertiary institutions with allied health and medical students, communications, and tech students; and by exploring new models of volunteer involvement. The aim will always be to provide mutually beneficial outcomes for our clients, volunteers, and MND Victoria.

We will seek to develop links with culturally and linguistically diverse communities in metropolitan and regional Victoria, and to foster relationships with other service providers such as palliative care services, hospital, and community-based organisations. This will enable us to provide training and resources to raise awareness about MND, and prepare volunteers to work with people living with MND across communities.

Many of our volunteers come with personal experience of MND and a desire to give back. We will continue to encourage and support members of our MND community to volunteer. We will also work to provide our staff with opportunities to develop skills to confidently work with volunteers.

We will continue to seek to increase the visibility of our volunteer workforce, promoting the work and impact of our volunteers. Capturing feedback from our volunteers, and those whom our volunteers support, will help to inform us of future volunteer strategies and direction for MND Victoria's volunteer engagement.

**If you would like to read the full MND Victoria Volunteer Engagement Strategy, contact Deb or Jacinta at [volunteer@mnd.org.au](mailto:volunteer@mnd.org.au).**

# PERSONAL STORY

## WHY DID YOU SHUT UP! FOR MND?

Thursday 21st September was very quiet, as a number of people “Shut Up! For MND”. The next edition of MND News will include a bigger summary of the Shut Up! For MND Challenge, but for now we’d love to say a massive thank you to every single person who registered, donated, and supported this educational and awareness raising campaign.

Here are the stories from some of our wonderful participants on why they decided to take on the Shut Up! For MND Challenge.



### Raksha Sen

I lost my beautiful mum, Vijay, to MND in 2020. She loved getting decked out in her finest silk saris and heading to gatherings. Before her diagnosis in March 2019, I had never heard of MND.

It was so very difficult for her to speak during the last few weeks of her earthly life and, for someone who loved to converse with everyone who she came across, it was hard for me and my family to see.



### Tiarna Cunningham

This year I’ll be taking part in the Shut Up! for MND Challenge to raise funds and awareness for those who are battling the cruel disease.

Earlier this year, I lost someone very important to me to the disease, and it was heartbreaking watching everything unfold. It was particularly difficult watching him lose his voice and the ability to sing – something he’d previously loved doing.

Many people like him, battling MND, lose the ability to speak and communicate vocally. I want to stand beside those who are fighting, try to understand the smallest bit of what they are experiencing, and advocate for those who have lost their voices completely.





## Simone Senisin

I decided to take on this challenge in memory of my beautiful life partner, John Carmichael, who passed peacefully at home on Feb 5, 2019. John was diagnosed with MND in 2017. It was important for both of us that John was able to undertake the tumultuous MND journey, including dying, in the comfort and security of his own home. MND Vic were crucial in providing the necessary equipment as the progression of the disease robbed John of his mobility.

John lost his ability to speak very quickly. John was an engaging and humorous storyteller, had a sharp wit, and loved conversing with friends over matters of history, music, sport and politics. He was widely read, intelligent and articulate, and enjoyed sparring in matters of local and global politics. He was kind, compassionate, wise, and his being was acutely aware and vocal in the arena of social justice. John dealt with his MND journey with such courage, dignity and grace. He never complained and saw it as his cross to bear. Such gifts were somehow born of grief, as it was unconditional love that encompassed and nurtured us in the last few months of this journey.

Not a day passes in which I do not sorely miss John. It is my hope that people understand that grief and gratitude are equal expressions of love, gratitude affording people the grace to manage grief and feel the connections that remain and continue to grow after we lose loved ones. Finally, I can see John's beautiful smile as he imagines me shutting up for 12 hours, for there is also much laughter to be found in the gifts that grief can bring.

# SHUT UP! FOR MND



## Katie Kirby

My name is Katie, and I am participating in Shut Up! for MND Challenge.

We lost my mum, Gerry, to MND four years ago. Our mum raised 7 children - 5 sisters and 2 brothers. She also cared for her sister, Mary, and her mum, Eileen, until they passed away.

Now, it was our mum's time to focus on herself. When she was diagnosed with MND, her motto was 'shit happens.' We asked her once about what she thought about her having MND. She said: 'why not me'? Our mum never let having MND stop her from living her life. She was selfless, strong, resilient and very brave. As a big family, we all cared for mum at home until she passed away.

Her memories will live on in all of us forever. Our mum is our angel in heaven. Our dad, Max, is going OK and, as a family, we are close and support each other.

Never Give Up until there is a cure.



## Cassandra Sheppard

As a busy working mum of two, the Shut Up! for MND fundraiser is the perfect opportunity for me to contribute to this noble cause by joining a community of dedicated individuals who are committed to raising awareness and funds for MND research and support. By abstaining from speech, I will not only experience a small fraction of the challenges faced by those with MND, but also showcase empathy and solidarity towards their struggles.

The funds raised will go towards supporting MND research initiatives, providing essential care and assistance to patients, and ultimately working towards finding a cure for this devastating disease. Together, we can create awareness, raise vital funds, and bring hope to individuals and families affected by this challenging condition.



# Walk to D'Feet MND this October/November!

We are very excited for the three upcoming "Walk to D'Feet MND" events being held at various locations across Victoria in October and November. It's time to get your walking shoes ready and come together to show your support for people impacted by MND.



## Latrobe Valley

**When:** Sunday 1st October 2023 | 10:30 am – 5:00 pm

**Where:** Victory Park, Traralgon VIC 3844



## Melbourne

**When:** Sunday 19th November 2023 | 9:30 am – 12:00 pm

**Where:** Princes Park, Carlton North VIC 3054



## Bendigo

**When:** Sunday 26th November 2023, 10:30 am – 12:30 pm

**Where:** Lake Weeroona Park, Bendigo VIC 3550

We look forward to welcoming back our "Walking Warriors" at the Latrobe Valley, Melbourne, and Bendigo Walks to D'Feet MND.

To find out more and register, visit [www.mnd.org.au/events](http://www.mnd.org.au/events) or scan the QR code on the right.



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