MNDNews

The newsletter of the Motor Neurone Disease Association of Victoria



MESSAGE FROM THE CEO



What a wonderful community the MND community is!!! It has been an amazing time since out last MND News. Our Great MND Relay was a phenomenal success, with over 1,000 participants and over \$350,000 raised for the delivery of care and support for people impacted by MND.

It was an absolutely incredible day with so much energy, support, entertainment, fun and engagement. It was amazing to see so many of the families we are supporting, or have supported in the past, attending the day to show their dedication and support of MND Victoria. We are so lucky to have such a committed community behind us. I just can't express how much the day has meant to us, and to me personally.

I have to express my immense gratitude to our Supporter Development and Communications team, led by Daniel and including Leah, Steph, Sarah, Lynn and Leonie; and the broader team, many of whom attended the day to volunteer or to participate in the Relay (or both!). To Deb and our volunteers – thank you all so much for the incredible amount of support provided, both in the lead up to the event and on the day. We have calculated that there were 214 volunteer hours contributed to the event, which is just extraordinary. My gratitude to everyone involved, and we look forward to seeing you all there again next year.

The "Rock Off MND" Gala Dinner was held at Kardinia Park on 20th May. This was another amazing event with so many magnificent supporters attending and contributing funds through the purchase of raffle tickets, participation in auctions, and donations. Attendees heard an enlightening discussion with Bruce and Natalie Parke. Bruce is living with MND, and he and Natalie gave great insight into their approach

and attitude in living with the disease. Our thanks to Peter Simko, Russell Lowe, and their team, for holding this event. Funds raised through Rock Off MND go towards funding the Jenny Simko MND Research Grant, awarded through MND Research Australia.

During May, we celebrated National Volunteer Week with the theme "The Change Makers". I spent some time with Deb and some of our volunteers at The Mission to Seafarers, and was privileged to be able to offer my thanks to our volunteers and present service awards to many of them. Our volunteers genuinely change the lives of people living with MND, through companionship, through massage and life story writing, and through assisting us to stay in touch with them through newsletter mail outs, events and reception. Everything that our volunteers do makes changes in the lives of those that we support, and we are grateful for their hard work and commitment.

June brings Global MND Day, on the 21st. All of the State MND Associations and MND Australia will attend Parliament House in Canberra to meet with the Parliamentary Friends of MND. With the assistance of people living with MND and others, we will talk to Parliamentarians and staffers about the impact that a diagnosis of MND has on a person and their family and networks, and how the current government could - and should - better support them, through both direct care and support, and research.

As winter draws in, I hope you keep warm and dry and enjoy reading this edition of MND News.

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

Kate Johnson
CEO, MND Victoria

MND VICTORIA SAYS THANK YOU

The Great MND Relay



Nearly one thousand people formed a sea of blue at the starting line at Lakeside Stadium track, smiles aplenty, on Saturday 27th May. While some were preparing to undertake a marathon solo effort, others were huddled with their teams preparing to smash out 42kms between them.

Regardless of the challenge our participants had set themselves, each and every one of our supporters had the same determination in their eyes. As the relay began with a fierce "GO!", our incredible participants set off to prove their bravery and willpower and to show everyone in attendance, as well as their families and friends back home, that they would #NeverGiveUp.

The unwavering resilience of our participants was truly a sight to behold. Every step taken in the 105 laps of the track was an inspiring testament to their strength, resilience and spirit, and we couldn't be more proud of everything our supporters achieved. Together, our 1,000 participants walked a total of 18,695 laps!

After weeks of fundraising efforts, it was so heartening to see the faces behind the figures and to bring our community together once again to show one another that no one is alone in their battle against motor neurone disease. Thanks to the incredible generosity of our participants and donors, we're able to continue to provide the best care and support services for those living with MND. Our community truly is a force to be reckoned with.



To everyone who participated and to everyone who donated their time, prizes and funds, thank you from the bottom of our hearts. We couldn't do what we do without your help, and we're forever grateful for everything you do to ensure Victorians living with MND are cared for in the best ways possible. Thank you also to those who couldn't be with us at the event and instead chose to do the virtual "Your Relay, Your Way"- it was fantastic to hear stories of the challenges you set yourselves and what you achieved.

We'd also like to acknowledge the Parke family for sharing their story with us. Additionally, a big thank you to the amazing volunteers, performers, raffle sponsors and staff who assisted on the day - and what a phenomenal day it was.

We really do have the best community of supporters, and everyone who made The Great MND Relay possible should be so proud of what they achieved.

Together, we raised a massive \$352,809 (and counting)! Whether you shared the event, donated, participated or spread awareness, know that your contribution will make an enormous difference to the lives of people with MND. We're already looking forward to The Great MND Relay in 2024!

Volunteers

MND Victoria volunteers add so much skill, empathy, time, and creativity to the services we are able to provide and the activities we are able to be engaged in. Over the past year, they have provided support and services for 142 people with MND.

Our volunteers assist to raise awareness of MND in the community, collect funds to enable us to continue to do our important work, and help ensure events and activities are successful. Our volunteers also provide specific support and connection for people living with MND and their families through a range of client support roles.

We are so grateful to our volunteers for all they add for our organisation. This year sees our volunteer engagement expanding as we build our volunteer teams and work more closely with other agencies to try and ensure people living with MND can access services. It has already been a busy year and we look forward to continuing to build and develop our volunteer teams.



The Great MND Relay – May 2023

MND Victoria volunteers were a big part of The Great MND Relay with some participating and others volunteering as part of this successful event. We thank all the 48 volunteers who helped with this event and contributed over 214 hours of support.

MND Victoria volunteers welcomed participants and spectators while collecting donations at the entrance to the Wandin Park Equestrian Event. With early starts over the two-day event, our volunteers collected over \$3,300 which supports our work in the community. Thanks to the Wandin Park committee for their continued support of MND Victoria.



Wandin Park Equestrian Event - March 2023



MND Victoria celebrated National Volunteer week with a number of events to recognise and

In addition, years of service awards were presented to fourteen of our volunteers who, together, have contributed over 140 years of service to MND Victoria.

- 5 Year Service awards Margaret, Napier, Geraldine, Elaine, Kath, Elizabeth
- * 10 Year Service awards - Katharine, Nick, Merilyn, Heidi

thank our volunteers for all that they contribute to our work.

- 15 Year Service awards Helen, Anne, Barbara
- 25 Year Service award Irene

Thank you to all of our volunteers. We appreciate everything you bring to our important work.

Volunteer with us!

Requests for our volunteer services continue to increase, particularly for volunteers in client support roles. We need to continue to grow our volunteer teams to be able to better meet these requests. MND Victoria works with individuals to identify volunteer roles that will suit their interests, skills and availability. We are happy to talk with you to explore volunteer opportunities.

Please contact Deb, Volunteer **Engagement Team Leader, on** 0432 053 287 or at volunteer@ mnd.org.au to find out more about the volunteer roles we have available.

Grounded for MND

We would like to say a very big thank you to Greg, Abby and Sofia Levin for all their generosity and hard work in putting on the "Grounded for MND" Exhibition at No Vacancy Gallery, Melbourne in late February. Countless hours were put in to make the event the great success it was, and we are truly humbled by the results.

What makes this event even more powerful is that Greg himself is currently living with MND, and the whole family wanted to give back to the organisation that are providing care, support and vital assistive equipment to all Victorians living with this disease.

We are delighted that through the sale of Greg's stunning photographs, four incredible dining events, a raffle, and numerous donations, over \$106,000 was raised!



Victorians currently living with MND, just like Greg.

We are in awe of the work Sofia put in to make Grounded for MND such a success. We also really appreciate the generosity of so many people around her. Over 60 businesses supported

Grounded for MND, providing everything from delicious food and drink right down to the cutlery and even the ice cubes. This incredible result wouldn't have been possible without them all, so thank you from the bottom of our hearts.

South East Melbourne Walk to D'Feet MND

Thank you to all of our Walking Warriors who attended the South East Melbourne "Walk to D'Feet MND" on Sunday 7th May. We are thrilled to announce that \$28,970.15 was raised!

Thank you to everyone who attended, donated, and bought merchandise, raffle tickets, sausages and cupcakes! It was a wonderful day. And a special thank you to Sonya and her wonderful team for organising another brilliant South East Melbourne Walk to D'Feet event. We're already looking forward to next year's event!



MND RESEARCH

The MIROCALS trial and beyond

By Ms. Pippa Pringuer¹ and Dr. Chien-Hsiung (Alan) Yu¹

Dr Alan Yu is Head of the Neuroinflammation Laboratory at The Florey Institute. Dr Yu studies the inner workings of the innate immune systems, including how they function against infection. His research investigates the molecular events behind the immune-mediated neurodegenerative pathway in MND. His work has been recognised internationally and he continues to secure grants to progress research into MND.

One in 10,000 Australians will be diagnosed with MND in their lifetime, and this number is projected to increase with time. Unfortunately, we do not yet have an effective therapy that is able to stop or slow down progression of the disease.

Abnormal build-up of proteins is a common feature across neurodegenerative diseases, including MND. This build-up of protein is associated with the death of motor neurons in the brain and spinal cord (known collectively as the central nervous system or CNS), which can impair our ability to move, swallow, breathe and speak. At present, scientists and neurologists are working together to understand how these harmful processes are triggered, in order to catch and treat the disease early enough to halt its progression.

Our immune system generates inflammatory responses that work to fight infection and maintain tissue health through coordination between multiple types of immune cells. These cells can promote and control inflammation in a 'seesaw' fashion to ensure sufficient defence against disease-causing agents, as well as to protect our body from excessive inflammation - not too little, not too much, but JUST RIGHT. Importantly, dysregulation of these immune responses can play a key role in damaging the health and function of motor neurons in MND. Therefore, modulating our immune system to avoid these disease-causing processes could provide a new therapeutic strategy for MND.

The clinical trial, "Modifying Immune Response and Outcomes in ALS" (MIROCALS), extended the use of Interleukin-2 (IL-2), a molecule involved in control and modulation of immune responses, in large-scale groups of patients with MND. Previous studies have shown that low-doses of IL-2 were well-tolerated, and increased the number and function of Regulatory T cells (Treas) in the blood of MND patients. These immune cells play an important role in controlling systematic inflammation by suppressing other cells in the immune system. For this reason, this new phase II trial was designed to validate the effectiveness and safety of low-dosage IL-2 in MND patients shortly after their diagnosis. Participants were randomly assigned

to a group that received IL-2 or a group that took a placebo tablet. The participants and the researchers were not told who received IL-2 and who received the placebo. The study went for 18-months, with 220 patients recruited from clinics across France and the United Kingdom. To assess the effect of IL-2 treatment, a range of outcomes, including survival time and the Revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS-R) score, were compared between the treatment and placebocontrol groups. The primary analysis of survival showed an overall 19% decrease in the risk of death in those who received IL-2, a finding which was not statistically significant.

Participants who took part in the trial had highly variable symptoms and this can make it difficult to measure the effect of new treatments on symptom severity and the speed of progression. To this end, the MIROCALS trial also evaluated levels of phosphorylated neurofilament heavy chain (pNFH) in the cerebrospinal fluid (CSF fluid that flows around the brain and spinal cord), which is a known brain biomarker for MND and other neurodegenerative diseases. When neurons become damaged or die, the building blocks of these neurons can begin to fall apart into fragments (Figure 1), which can be released into the CSF, or even the bloodstream. Measuring the pNFH building block in the CSF is therefore a useful measure

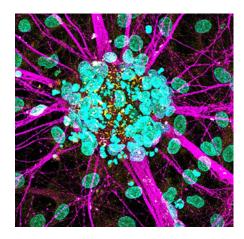


 Figure 1. Degenerating motor neurons in Motor Neurone Disease.

Using stem cell technology, scientists are now able to make motor neurons in a dish to study the biology of MND and treatment efficacy in humans. This image shows degeneration of motor neurons, as indicated by broken neuronal structure. (Cyan – cell nucleus; Magenta – neuronal axon; Yellow – motor neurone marker). Image provided by Dr. Alan Yu.

of neurodegeneration, and was used in this study to control for disease severity. The MIROCALS trial found a significant 40% decrease in the risk of death in those with low to moderate pNFH levels, corresponding to mild disease progression. No significant treatment effect could be detected in rapidly progressive patients with high pNFH levels. Overall, this first large-scale IL-2 trial delivered a proof-of-concept that neuroinflammation can be targeted by inducing Treg activation as a treatment option to reduce the risk of death in early-stage patients.

Despite the promising results of this study, there remain many considerations to address in evaluation of the applicability of IL-2 or Treg activation as a treatment for MND. It is known that IL-2 can activate not only Tregs but also other T cell populations that can cause inflammation and death of cells in the circulation. The neuroprotective effects observed in this trial by IL-2 treatment or Treg activation in the peripheral system remain to be investigated in detail. On the other hand, over-activation of Tregs may increase the risk of infection in the peripheral immune system, as these cells are involved in suppression of the immune response. Additional analyses of IL-2 treatment would be required to further assess the potential risks associated with this treatment. Furthermore, many studies have suggested differences in the mechanisms and nature of immune regulation in peripheral immune system compared to local cells in the CNS. Treg activation is likely a secondary, or even further downstream, immune effect.

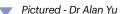
More significant effects may be observed by targeting primary responses in order to effectively slow or halt disease development. Therefore, it is worth questioning how effective it is to target regulatory T cells, which are involved in dampening peripheral immune responses, to treat inflammation in the brain and spinal cord.

The MIROCALS trial provides encouraging data, and has helped to advance our new therapeutic strategies by aiming to intervene in the onset and progression of MND. Indeed, recent discoveries from our group, and others, have demonstrated exciting preclinical potential therapeutics that block immune processes in the brain or spinal cord for new treatments of MND. Notably, existing biomarkers which occur upon death of neurons, including pNFH used in this trial, do not sufficiently catch disease development early enough and

are not specific to MND. We suggest that these cell signalling pathways in the CNS should continue to be assessed for new diagnostic biomarkers occurring before the death of neurons, to help detect and treat MND at the earliest possible timepoint.

The journey towards finding real cures and treatments is still challenging, as MND is a complex disorder with unknown causes and many triggers. Nevertheless, more and more interdisciplinary research programs have been established, bringing together the expertise of biomedical and clinical scientists, industrial partners, and patients, families, and carers. Use of this collective knowledge will continue to enable new discoveries, advancement of our understanding of the biology of this devastating condition, and new treatments and technologies which will be available to the medical and patient community. Support of innovative ideas and early- and mid-career researchers (EMCR) will remarkedly speed up the hunt for a cure, as exploration into new therapeutic targets allows us to see light at the end of the tunnel.

 Neuroinflammation Laboratory, The Florey Institute of Neuroscience and Mental Health, Parkville VIC 3052, Australia







Preventing and Managing Pain

This article is written with thanks and acknowledgements to the MND Clinic team at Northern Health, and is based upon a health professional webinar they presented for MND Victoria this autumn.

MND affects the neurones (nerves) that control movement, but not the neurones that carry sensory messages, including pain. This means that MND itself does not cause pain, but symptoms of MND can cause pain. There are often a combination of factors that can contribute to pain in MND. Pain can include physical and emotional aspects.

Causes of pain in MND include:

- Muscle cramps/spasms
- Spasticity (overactive muscles)
- Joint stiffness and pain related to difficulty moving and changing position
- Risk of injury to joints related to muscle weakness (e.g. arm weakness: shoulder joint injury)
- Pressure areas related to difficulty changing position
- Pain related to the emotional impacts of living with MND
- Itch
- Neuropathic (nerve) pain
- Headaches relating to breathing problems
- Issues related to previous joint or muscle injuries.

Preventing pain

The good news is that there are many things that can be done to prevent and manage some types of pain related to MND. Taking a whole team approach including a Neurologist, Allied Health Care Team (including Physiotherapist, Occupational Therapist etc), Nurse and sometimes Palliative Care team can be very helpful in managing pain.

Cause of pain

Shoulder injury due to not protecting the shoulder joint when moving/ lifting.

Weakened (underactive) shoulder muscles do not hold the top of the arm bone in the shoulder socket, making the shoulder vulnerable to injury.

How to prevent pain

- * Talk with a Physio or Occupational Therapist about how high you can safely lift your arm above your head
- * Make sure that your carers do not assist you under your arm or by pulling on your arm when changing position in bed or chair.
- Consider wearing a sling on your arm when walking/ sitting in a chair, to help protect your shoulder joint.
- * Use a pillow to support your shoulders in bed.

Pressure areas can occur when it is difficult to change your position in a chair or bed, and you are sitting/lying in the same position for long periods.

- * Let someone know when you feel uncomfortable and need some help to change your position.
- * Talk with an Occupational Therapist or Physio about getting a pressure care cushion if you use a wheelchair and a pressure care mattress. They can assess the best type of cushion/mattress for your needs
- ** Regular changes of position can help reduce the risk of pressure areas. This includes even slight changes of position e.g., the angle of recline of a chair.
- ** Talk with a Nurse or Occupational Therapist about how best to care for your skin.

Joint stiffness related to staying in the one position for long periods.

When muscles are very weak, tendons can become shortened causing contractures.

- * Exercise/regular changes of position and gentle assisted movement of body can help to reduce pain related to joint stiffness and can help to prevent contractures.
- The right mattress, pressure cushion and seating can also help to manage joint stiffness.
- Equipment to help you to move in bed.
- Medications can also help to prevent and manage pain associated with tendon shortening.





Complementary therapies

Some people find that massage and acupuncture can be helpful. It is helpful to look for a qualified therapeutic masseuse with experience working with people diagnosed with MND and other neurological conditions. View the massage recording on our website at www.mnd.org.au/page/114/carer-support or scan the QR code above for more information.

Cause of pain	How to prevent pain
Neck pain related to neck weakness.	Using a tilt in space chair with a headrest can help to rest your neck.
	* Sometimes using "recline" on a chair can also help.
	* Talk with a Physio about a plan to support your neck, including neck support cushions.
Constipation pain	* A Dietitian or Continence Nurse can assist.
	* Sometimes medications can assist.

Managing pain

There are medical treatments for many types of pain in MND. Neurologists and Palliative Care Specialist Doctors can work together to manage pain in people living with MND (not just at end of life). Palliative Care Doctors and Nurses are specialised in treating pain. Some drugs that can sometimes be prescribed in MND:

- Paracetamol
- Anti-inflammatory drugs
- 🐥 Opioid drugs
- Antidepressant and Anticonvulsant medications can also be used to treat pain.

Regular monitoring allows medications to be adjusted over time to best manage pain and limit side effects. It is important for the healthcare team to assess pain at different times for people living with MND.

If you have a community palliative care service involved, there is often afterhours telephone support that can be very helpful.

If you have swallowing problems, it is still possible to take pain medication. Pain medications can be given by mouth (chewable, dissolving in the mouth, in a liquid, mixed with fluids/foods), via a feeding tube, via a patch worn on the skin or via injections or syringe drivers (portable,

Cause of pain	How to prevent pain
Spasticity (overactive muscles)	** Magnesium, Oral Baclofen (if tolerated), Botox injections for localised spasticity, Cannabis products (limited evidence for Cannabis products at this stage)
	* Stretching and positioning
	Splints e.g., ankle knee orthosis if you have foot drop, resting hand splints etc.
Neuropathic pain (due to damage to the nerve) and itch Pins and needles Sensitive skin Stronger reactions to touch/pain etc.	Medications ** Pregabalin/Gabapentin ** Amitriptyline (also helps with mood and anxiety) ** Duloxetine (also helps with mood and anxiety). Itch (uncommon) ** Check it is not a side effect of drugs ** Turn/position to reduce itch on back.
Pain related to the emotional impacts of MND and grief	 Doing things for yourself whenever possible Counselling Multi-disciplinary team support Sometimes medications can also be used.

battery-operated pump that delivers medication under the skin). Your healthcare team can help advise you about the best way for you to take pain medication.

If speaking is difficult, ask a Speech Pathologist to set up a method so you can communicate if you have pain letting others know where your pain is, the type of pain and how severe it is.

First steps

If you have pain, talk with your GP, Neurologist and health-care team.

They can assess what is causing your pain and work together with you to come up with a plan to treat your pain.

PERSONAL STORY

Amy's Story

By Amy Lynch

I always dreamed of being a mother. I'm naturally very maternal and love spending time with kids and animals. So my husband, Simon, and I were overjoyed when we welcomed our first baby girl, Hannah, in December 2020. 17 months later, we welcomed our second baby girl, Georgia.

Motherhood is never quite what you expect it to be, and often it can be challenging. But for our little family, things are tougher than for most.

At only 27 years old, when Georgia was just 10 weeks old, I was diagnosed with motor neurone disease. Being so young it's quite rare, but not unheard of

MND is a prison. One of the hardest things is that I feel perfectly normal but then I go to take a step and my leg doesn't respond. Or I go to move my hand and it doesn't go where I've told it to. It's very frustrating to be trapped in my own body. My mind is fully active, but my hands, legs and tongue don't do what I ask them to.

I first noticed something wasn't right when I was pregnant with Georgia. I started walking a bit funny but, being pregnant, I didn't think much of it. I was still able to do everything - potter around our farm, chase after a 1 year old, renovate our house.

A few days after having Georgia, I started to have weakness in my hands, and when I left the hospital, I was walking a bit funny again and used the pram as a walker.

But then a couple of weeks later, I was playing around with Hannah and she pushed me over a couple of times. She was only 18 months old at the time so it was quite shocking that she was able to knock me off balance. That's when I went and saw our local GP. He sent me for every test under the sun to try and find out what was wrong.

He said: "Don't be alarmed. With the marvels of modern medicine, they can pretty much manage or treat anything. You'll have a normal life." Little did we know, I had one of the diseases that has no known treatment or cure.

When Trish, our MND Advisor/Support Coordinator called, it was a very sobering moment to realise that this is really what we're looking at. There's almost a bit of freedom when you don't know what's wrong with you yet because there's a chance that there's nothing wrong. You definitely never think it'll be what you end up with. MND really is the worst.

Right from that very first phone call, MND Victoria's support has made a lot of difference. Trish helps us navigate the NDIS and gets us connected with all of the support services which is invaluable. Because, without that bit of guidance, we wouldn't know where to start.

Living on a farm in rural Victoria can sometimes make it tricky to get access to things, but Trish has been terrific in sourcing services and suppliers who are happy to travel to the area to support me. Especially because often a carer isn't just caring for me – they're helping me while I care for the kids.

One silver lining of my diagnosis is that we get to spend so much time together as a family. Simon primarily works from home so that he can be there to take care of Hannah, Georgia and me. We go on as many holidays as we can and travel around to see all of our family and friends. We do all the things we want to do, but we know our timeline to do these things is shorter than for most families.

I'm quite a caring person and always put my energy into making other people's lives better, so it's quite surreal that now I'm the one being cared for. We have a young family and the last thing we want is to not have that together.

Our life's just starting off, not finishing up. So the longer I can be part of that and be in the middle of it all instead of watching from the outside, the better. We're trying to keep life as normal as it can be and make lots of memories with the kids. And the support we receive from MND Victoria really helps us to achieve that.





42 Years of Care and Support 9





"Shut Up! For MND" will return this September

"Shut Up! For MND" is a bold and unique way to bring attention to what people living with MND face on a daily basis. Each MND journey is different, but a number of people will lose their voice and become reliant on other forms of communication.

On **Thursday 21st September 2023**, we encourage you to take on The Challenge to not speak for 6 or 12 hours. You can take it on solo; or nominate your friends, family or colleagues to Shut Up! Keep an eye on our website for more details to follow - www.shutupformnd.org.au



11th National MND Australia Care Conference

Registrations are now open for the 11th National MND Australia Care Conference. The Conference is a one-day biennial event for healthcare professionals and service providers who support people living with motor neurone disease. People living with MND and their carers are welcome to attend. This conference's theme will be: Caring in a complex environment.

SAVE THE DATE!

The Conference will be held on **Monday, 28 August 2023** from 10 am–5.30 pm at The Florey Institute of Neuroscience and Mental Health in Melbourne, and will be co-hosted by MND Australia and MND Victoria.

To register, visit www.mndaustralia. org.au/careconference or scan the QR code below. Registration is free-of-charge for people with MND and their carers.





MND VICTORIA

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