

# MNDnews

The newsletter of the Motor Neurone Disease Association of Victoria



**COMMUNITIES  
COMING BACK  
TOGETHER**



Until there's a cure, there's care

# MESSAGE FROM THE CEO

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Welcome to the Winter edition of MND News. As I write this, we are once again in a “circuit-breaker” lockdown which we hope will only last for 7 days.

May saw the recognition of MND Awareness Week. It is an important week for the MND Community and an opportunity to raise awareness in the broader community of MND, and the impact it has on those living with the disease and those around them. Our South East Melbourne Walk to D’Feet – part of the first National Walk – and our Day of Hope and Remembrance were both wonderful events – which you can read more about in this edition.

National Volunteer Week was held from Monday 17th - Sunday 23rd May. MND Victoria is very fortunate to have so many dedicated volunteers who are critical to the support and services we provide for people living with MND. We had four great events during this special week to recognise and thank our volunteers. It was really lovely to be able to see so many of them face-to-face again.

I had the opportunity to visit our friends at Vitality Brands and talk with them about the impact their donations for the Take-A-Break program make to people living with MND. Take-A-Break provides an opportunity for clients to access some funds quickly and with no “red-tape”, to purchase or do something that will improve their quality of life. Vitality Brands have generously supported Take-A-Break for over ten years, and it was great to have the opportunity to thank them and share some stories about how these funds have been used to make positive differences.

In May, the MND Victoria State Council were able to come together to celebrate the 20-year service of David Ali as a State Councillor. David has held the role of President of MND Victoria’s State Council, President of MND Australia Board and roles on the ALS/MND International Alliance. David left our State Council in February to take the role of Chief



Executive Officer of MND Australia. We sincerely thank him for his dedicated service to MND Victoria and look forward to working closely with him in his new role.

We continue to work with MND Australia and our colleagues at the MND Associations around Australia to advocate for the needs of people living with MND. The last few months have seen us respond to the recommendations in the Royal Commission into Aged Care and provide commentary through an opinion piece in Pro-Bono news regarding the need for people over 65 to have equal access to funding, in particular for assistive technology. We are also working to advocate around our concerns about the proposed Independent Assessments in the NDIS and the negative impacts these would have on people living with MND who are supported by the NDIS. If you would like to help us to raise awareness of the impact of MND and help to advocate for better government support by sharing your stories or experiences, please feel free to make contact with me at [kjohnson@mnd.asn.au](mailto:kjohnson@mnd.asn.au) or on 9830 2122.

Stay warm this winter and enjoy this edition of MND News.

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

# MND VICTORIA SAYS THANK YOU

## MND Week 2021

The first week of May is MND Awareness Week throughout Australia. MND Victoria, MND Australia and all the other MND State Associations, undertake a variety of media, fundraising and awareness activities to raise community recognition and understanding of the disease.

This year, MND Week ran from Sunday 2nd May to Saturday 8th May. Many exciting events were held to give insight, hope, and the opportunity to help support the lives of those impacted by MND.



## Day of Hope

Over 40 people from our MND Community came together as one at the Melbourne Town Hall for our Day of Hope | Service of Hope and Remembrance on Sunday 2nd May. The Service was an opportunity to reflect and light a candle to help share the past and express hope for the future.



During the Service, we had the privilege of hearing from Peter Chambers and his wife, Lisa Emrose, about their MND journey since Peter was diagnosed in December 2019. A beautiful musical performance by Sienna Cross proceeded our candle lighting ceremony, where people were invited to come up and light a candle. The flame of the candles symbolised hope and remembrance for those who have been touched by MND. Overall, it was a wonderful afternoon of reflections, readings, music, candle lighting and afternoon tea that was enjoyed by all.



## South East Melbourne Walk to D'Feet MND

We were very excited to once again have the South East Melbourne Walk to D'Feet MND kick off MND Week. This Walk also doubled as our first-ever national Walk, with each State Association hosting their own event. Nationwide, our Walking Warriors joined forces and came together as one united MND community across Australia.

We loved having over 300 Walking Warriors walk together around the Lakeside Amphitheatre in Pakenham. Together, they raised over \$47,500 which will help us fund the best possible care and support for people living with MND. A special thank you goes out to Joanne and Sonya for all the hard work they put into organising the Walk and for ensuring everyone had a great time.

## Reconciliation Action Plan

MND Victoria team members and members of the State Council have worked together this year to develop our first Reconciliation Action Plan (RAP).

We have started with a Reflect RAP which is designed to prepare us for future reconciliation initiatives. We introduced the Reflect RAP to the team during Reconciliation Action Week on Wednesday 2nd June. The RAP will also be sent to Reconciliation Australia for review and endorsement.

We will continue to seek guidance along the way as we learn more about reconciliation and making our service accessible for all. If you have any questions or would like to join us as we work through our Reflect RAP, please touch base via email at [info@mnd.org.au](mailto:info@mnd.org.au) or on 1800 777 175.



## National Volunteer Week 2021

This National Volunteer Week (17 May – 23 May 2021) with the theme of ‘Recognise, Reconnect and Reimagine’, we celebrated the fabulous job that each and every one of our volunteers do.

We can only do the work we do because of the dedication of our volunteers and their commitment to helping provide people living with MND with the care and support they need to live better for longer.

To recognise just how awesome they are, we held several events to celebrate our volunteers, including:

- a guided tour of Government House Melbourne, followed by morning tea
- breakfast in Ballarat
- afternoon tea in Bendigo
- morning tea at our office in Canterbury for an acknowledgement and celebration of 40 years of volunteering at MND Victoria.

We also recognised years of service awards for the following volunteers:

- 5 Year Service Awards: Peter Hillman (Reception, Life Stories); Alain Gaspard (Events); Joseph Mantella (Walk to D’Feet MND, Merchandise); Colleen Hanifan (Bereavement Calls, Projects); Chloe Williams (State Council); Angeline Kuek (State Council); Jodie Harrison-Fitzgerald (State Council); Mark Anderson (Mailout); Natalie Patterson (Massage, Events).
- 10 Year Service Awards: Bob Haywood (Barwon/Geelong Support Group, Walk to D’Feet MND); Linda Lee (Events)
- 15 Year Service Awards: Fran Mann (Program Support); Jan Rich (Walk to D’Feet MND, Bereavement Support Program administration); Katherine Wilson (Events, Walk to D’Feet MND).

Thank you to every one of our volunteers who assist us in many ways - you truly make a difference in the lives of people living with MND.



## Play for Patto Golf Day

In early May, the inaugural Play for Patto MND Charity Golf Day was held at the Rosedale Golf Club, in memory of Michael Patterson who lost his battle with MND in March this year.

A great day of fun was had by all who attended, with lots of golf, novelty holes, and a dinner and auction to round off the event. A number of MND Victoria volunteers also helped out on the day, selling merchandise, collecting donations, and being spotters for the Hole in One competition. In the end, \$10,000 was raised! A massive congratulations and thank you to Dean and his team at Prestige Golf Tours for organising such a wonderful and successful event. We can’t wait to attend again next year!



## Are you interested in volunteering at MND Victoria?

Volunteers have always been central to MND Victoria and fulfil a range of roles contributing to the vibrant, energetic, and successful Association we are today.

Our volunteers are involved in a range of roles providing support for people with MND, their carers, and the Association. Volunteers work in the community, at our Canterbury office, and in their local areas across the state. To find out more information about our volunteer programs, call 03 9830 2122 or email: [volunteer@mnd.asn.au](mailto:volunteer@mnd.asn.au)



# LIVING BETTER

## Communication and MND

Communication is an integral part of our daily lives. Communication involves more than communicating by speech and using our voice.

Social communication is how we interact and engage with the people in our lives and the broader community. If you are experiencing communication changes due to MND, it is helpful to know that there are lots of strategies and supports available.

Here are some practical tips to help you communicate:

- \* **Be mindful of the environment** – reduce noise, face your communication partner, allow yourself extra time.
- \* **Consider using technology to support you to communicate a different way** – this may be using a text to speech app (on mobile phone or tablet) or using a communication software with an eye gaze device.
- \* **Have other ways of communicating beyond talking** – using a pen/paper, pointing to a photo on a board, using gesture, or responding to yes/no questions.
- \* **Conserve your energy to support your communication abilities.** Some examples include – resting before social events to enable you to communicate more easily; or connect with your friends/family through text messages rather than phone calls if you find this easier.
- \* **Pictures are worth a thousand words!** Use photos to enhance your social communication. Take photos of activities that you do throughout the day. Send the photos to a family member, friend or community group. Ask that they send you photos back. See how this has a positive impact on your social interaction!
- \* **Use social media (e.g. WhatsApp, Facebook Messenger) to create private groups.** Private groups are a great way to keep in touch with family, friends or other community groups you are involved in (e.g. cricket club, Rotary club, etc.). It allows you to easily send messages and/or photos so that you can stay socially engaged with the people in your life.



- \* **Spend some time in nature.** Nature has been shown to positively contribute to wellbeing and provides an opportunity to slow down, reflect, and create a 'mindful moment'. You may feel inspired to take a photo of something that you find beautiful or that catches your eye. Share this photo with the people in your life. You may like to create an Instagram page, public or private Facebook group, or send it around to your family or friends.
- \* **Send a daily or weekly email around to the people in your life.** Like a newsletter, include a summary of things that you find funny, quotes, photos, or anything! Let your personality shine through.

A speech pathologist can support you to communicate as effectively as possible with the people in your life. We will listen to what is important to you, who are the meaningful people in your life, and assist you to come up with ways to communicate and stay socially connected with the people who matter to you. An occupational therapist may also be involved to explore new ways of accessing your communication equipment or technology if your hand/arm function is changing.

**Kaela Gomizel**  
Speech Pathologist,  
Calvary Health Care Bethlehem



# PERSONAL STORY

## Keeping Our Eyes on the Stars

by William Pridmore (MChD) Royal Hobart Hospital  
Hobart, Tasmania, Australia

Originally published in RRNMF Neuromuscular Journal  
2021;2(1):8-9

The real problem is time.

She was finding it a bit harder to lift her foot. It was irritating, and she found she was limping. She made passing comments to her husband and son of some "electrical shocks" in her legs, which she thought were due to anxiety. That combination worried me, but I didn't tell her. It couldn't be.

A "foot drop" is a symptom in which the muscles that lift the toes towards the head lose this ability. There are many causes for such a presentation, and determining the culprit is challenging. Things didn't improve, and so she underwent a series of investigations. The neurologists who administered the nerve conduction studies were kind, but she noticed they exchanged serious looks throughout the test. She'd have to wait for the full report.

The full report was not good.

When the diagnosis of motor neurone disease is made in a family member, the world changes. It darkens around the edges, and loses some of its lustre. One can deal with the impending physical challenges as they arise. But it's the time that gets you. For most patients, lifespan is between two and five years from diagnosis. Nothing stops the march towards oblivion. We know how this story goes.

Massachusetts native Dr Stanley Appel is one of the rock stars of this condition. At 87, he valiantly continues the research and clinical work he began as a young doctor. He calls MND "nice guys' disease", based on his observations that MND patients are typically driven, empathetic, generous, and otherwise healthy. Scientific studies, comparing patients with a healthy control population, confirm his notion<sup>1</sup>. MND patients are card-carrying nice guys – that's part of the injustice.

Research into MND has been frustratingly slow since the condition was first described by French neurologist Jean-Martin Charcot in the 1860s. Degeneration and death of motor neurones (nerve cells that control muscle movement) in the brain and spinal cord leads to progressive paralysis of voluntary muscles. The causes have remained elusive, and the biological processes that go astray are highly complex.

Most cases occur at random, but a minority run in families. When the first known genetic contributor was identified in the 1990s, it inspired the first animal model of MND, using laboratory mice. Such mouse models of MND have provided important insights about the injury of motor neurones, and have offered a useful way to test for the beneficial effects of various drugs. Unfortunately, these models have failed to bear much fruit. Contributing factors include poor experiment design, incompatibilities between mouse and human disease, and inadequate understanding to allow for informed therapeutic proposals<sup>2</sup>.

My name is Will, and I was thrust into the MND community after my mother, Mary, was diagnosed in June last year. I am a doctor by trade and wrote this article to share the impact of this diagnosis on a family, as well as to provide some context and optimism regarding the hunt for treatments. We are grateful for the support provided by MND Tasmania as we navigate this condition.





But something is shifting.

Decades of work by devoted researchers have discovered much of what leads to MND. There is more optimism than ever before. Slowly but steadily, scientists are developing a working knowledge of motor neurone death. In the same way MND insidiously takes over a body, research is progressively uncovering its secrets – and will eventually banish it. Several drugs and treatments show early promise.

2020 saw the launch of three MND “platform trials”: one in the UK, one in the USA, and one in Europe. Regularly used in cancer research, platform trials allow several drug candidates to be compared to a single placebo (fake drug) group at the same time. Contrasted with traditional clinical trials, platform trials may cut testing time in half, and expense by a third. The arrangement also means fewer patients who participate in trials will receive placebo. For a platform trial to be viable, there must be enough medications in development. For a drug company to develop a medication, it must know enough about a particular condition to identify a likely therapeutic target. Drug company interest in MND has increased out of sight over the last five years<sup>3</sup>.

University of Michigan linguist John M. Lawler offers the term “railroad time”. It describes how, when science and technology is sufficiently advanced, it is natural for several people to make a discovery concurrently. Railroads were invented when it was “time for the railroads”. I guess it is “railroad time” for MND platform trials.

Key discoveries hint that laboratory tests to reliably diagnose and monitor nerve damage may soon be available<sup>4</sup>. “Biomarkers” like these are desperately lacking. Implementation of such tests would revolutionise drug development, as researchers could tell quite quickly whether their medication was having an effect. The code is being cracked. You can hear the pins falling into place.

For now, we have learned to celebrate the small things, and seek joy. A new orthotic has stabilised her walking. Her arms are still strong – suddenly her love for kayaking is amplified. Her painting studio, always a special place, is now her salvation.

It is clear that MND is increasing in prevalence<sup>5</sup>. Despite its dramatic effects, the condition remains relatively underfunded. The Fight MND Foundation, championed by Australian Football League great Neale Daniher, has brought needed attention to our plight – and other excellent organisations around the world continue to raise funds.

More is needed, and needed quickly. Two Australians are diagnosed with, and die from, MND every day. The battle against this condition has felt like Sisyphus eternally pushing his boulder up a hill, only for it to roll back down when it nears the top. But now there is a difference. With renewed awareness and financial support, we may actually, finally, reach the summit.

And hopefully Mum will be standing with us, waving the flag of victory.

## References

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# MND RESEARCH

## Unravelling the genetic origins of MND

**While the understanding and awareness of MND continue to grow, the underlying causes remain largely unknown. To date, the only proven cause of MND is gene mutations that are essentially typos in the letters of our DNA sequence.**

Clinicians first described MND in the mid-1800s and, soon after, a large family from Vermont was identified in which multiple individuals were affected by MND. This family provided the first clue that there is a hereditary or genetic component of MND, and we now know that approximately 10% of all individuals affected by MND have a similar family history, and are classified as having familial MND. Though clinicians gradually expanded the understanding of the clinical presentation of MND, the first major breakthroughs in understanding the biology of MND did not come until the 1990s. It took 113 years from the identification of the Vermont family, to finally solving their cause of MND as a genetic mutation within the SOD1 gene, representing the very first MND gene discovery in 1993. In 2006, the principal component of protein clumps apparent in MND was found to be a protein called TDP-43. This led to genetic investigations of the gene encoding this protein, TARDBP, which in 2008 revealed that mutations within this gene do, in fact, cause MND. These discoveries demonstrated the crucial interplay of the genetics and biology of MND, and researchers have continued to use genetics to inform the further study of the biological mechanisms involved in MND.

In 2009, a powerful DNA sequencing technology called next-generation sequencing was developed, which can produce enough genetic data to provide a complete genomic profile of an individual within just a few days. This technology has facilitated an explosion in the number of MND genes discovered over the past decade, both by our Australian research team and by geneticists across the world. However, these known MND genes still only explain two-thirds of families afflicted with MND, and ~7% of individuals affected by the non-familial or sporadic form of MND, leaving up to 90% of all people affected by MND without any identified genetic predisposition to MND. However, it has been shown that ~50% of the risk for any form of MND, whether familial or sporadic, is attributable to inherited factors. Therefore, the identity of many of the genetic changes contributing to the cause of MND remains to be discovered.

An important theory has been postulated by our collaborators in the UK stating that six individual events or “hits” need to accumulate within an individual to trigger the onset of MND. These hits could be genetic risk factors or

environmental exposures we are yet to identify. Supporting this theory, our research team has recently shown that among people affected by MND, those who carry multiple MND mutations and/or genetic risk factors develop MND earlier in life than those without any such genetic alterations.

Our research team has collected DNA samples from over 600 Australians affected by MND and have utilised next-generation sequencing to determine the complete genetic profiles of each of these individuals. This is an incredibly powerful resource containing a huge amount of genetic information. In addition to analysing families affected by MND using approaches similar to those used to identify SOD1 as the first MND gene, we are also looking for MND genetic risk factors, which are genetic alterations that, while present in the general population, are more common among people affected by MND. However, as these genetic risk factors only contribute to small levels of MND risk, they are very difficult to identify, and very large numbers of study participants are required for their discovery. Our team is involved in a large international consortium called Project MinE, which collects genetic profiles from individuals affected by MND from across the world. So far, over 10,000 genetic profiles have been collected for analysis in a coordinated effort to discover novel genetic risk factors for MND.

MND genes are used for diagnostic testing and facilitate early diagnosis of MND, which allows clinicians to provide efficient management strategies with a view to delaying progression. This affords family members opportunities to utilise genetic testing if they so wish, under the guidance of skilled genetic counsellors. This includes pre-symptomatic testing to understand their own risk of developing MND, and/or the ability to utilise preimplantation genetic diagnosis together with IVF to prevent future generations from inheriting MND-causing mutations. MND genes and the proteins they encode are also prime targets for developing effective therapeutic interventions to treat MND. While not yet a reality, we are working towards using genetic profiling to tailor treatment strategies for each individual. Together, these benefits of MND gene discoveries are driving us toward personalised medicine approaches to treating MND within individuals and families in the hope that we can ultimately outsmart and beat the beast that is MND.

**Emily McCann, PhD**  
**Beryl Bayley MND Postdoctoral Research Fellow**  
**Centre for Motor Neuron Disease Research,**  
**Macquarie University**





INSPIRED  
ADVENTURES®

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40<sup>TH</sup>  
YEARS OF CARE & SUPPORT

**Join MND Victoria's Never Give Up New Zealand Trek to help provide and promote the best possible care and support for people living with MND.**

As part of this incredible adventure, you will discover the history and majesty of New Zealand's South Island, from Christchurch to Queenstown. Traversing the Southern Alps, you will trek through lush alpine meadow and into steep, glaciated valleys. You will gaze upon the turquoise surface of Lake Tekapo and stand in the shadow of awe-inspiring Aoraki, New Zealand's highest mountain.

Best of all, with every step you take, you'll raise vital funds that will continue enabling the best possible care and support to be delivered to the 470 Victorians currently living with MND and those who will be diagnosed in the future.

## Highlights

- » Discover New Zealand's South Island, from Christchurch to Queenstown
- » Experience the beauty of Lake Tekapo and other World Heritage-listed sites
- » Stand in the shadow of Aoraki, New Zealand's highest mountain
- » Raise vital funds to provide care and support to people living with MND



**3–8 April 2022**



Moderately challenging (3/5)



Fundraising target: \$3,000

Travel package: \$2,899

*Land only and subject to change*

Registration fee: \$340

*Non-refundable*



Twin-share in 3-star motels and lodges



Register before 4 July 2021 and get **\$100 off** your registration fee

For more information, scan the QR code or contact Steph at [scross@mnd.asn.au](mailto:scross@mnd.asn.au)

# UPCOMING EVENTS

## Run Melbourne

Calling all champions! Do you love running? Do you hate running? Or are you somewhere in between? No matter where you sit on the scale, we know you want to help others.

This year, we are a Champion Charity at Run Melbourne and would love as many people as possible to become part of Team MND Victoria.

**When:** Sunday 25 July 2021

**Where:** Federation Square | Swanston Street & Flinders Street, Melbourne VIC 3000

There are three events to choose from, including a 5K Walk or Run, 10K Fast and Flat, and a 21.1K Half-Marathon.



Visit <https://runmelbourne21.grassrootz.com/mnd-victoria> or scan the QR code on the right now to register and start fundraising!



## 2021 MND Charity Superball XIV

The 14th Annual MND Charity Superball is back to help raise funds for motor neurone disease research.

This incredible team have hosted this fantastic event for 13 consecutive years, including a virtual edition last year! The Superball was created all those years ago for one reason - to fund the best and brightest researchers in Australia to help them find a cause, treatments and ultimately

a cure for MND. So far, **this event has raised a whopping \$850,000!**

Research has come a long way in recent years, and we can certainly thank the Superball for really getting the ball rolling.

Who wants to be a MILLIONAIRE? Help us raise \$1 Million to continue our fight against MND.

**When:** Saturday 2 October 2021 | 7:30 pm sharp

**Where:** Pullman Albert Park | 65 Queens Road, Albert Park VIC 3004

**Theme:** 'Dress like a Millionaire'

**Cost:** \$170 per person (includes all meals and drinks. Cash bar from 11:30 pm)

**Entertainment provided by:** The Chrome Donuts, the ever-popular singer/guitarist Bernard Mogg, and others. Live and silent auction items!

**To find out more or to book your table, contact:**

**Russell Higgins:**

e: [russellhigginsconsulting@gmail.com](mailto:russellhigginsconsulting@gmail.com)  
ph: 0434 609 138 or

**Louise Mogg:**

e: [louise.mogg@mh.org.au](mailto:louise.mogg@mh.org.au) or  
ph: 0417 571 457



# GIVING

## Graham Casson's Story – Tax Appeal 2021

Graham is a loving father of two and grandfather of five. His family is his world, but Graham only has limited time left to spend with them all. In July 2019, Graham was diagnosed with motor neurone disease, a disease he had never even heard of. Unfortunately, he now knows it all too well.

MND is terminal, there is no remission and the average time from diagnosis to death is 2.5 years.

Graham tries to live his life as though there's nothing wrong, but he is slowly losing the ability to complete basic everyday tasks. He struggles with ordinary things most people take for granted, like getting out of bed each morning or making a cup of coffee, and unfortunately, these tasks are only going to get more difficult as the disease progresses.

On top of being diagnosed with a disease that has no known cause, treatment or cure, Graham is over 65 years old which means he does not qualify for the National Disability Insurance Scheme (NDIS) and the huge amount of support and equipment that it would provide. Instead, Graham can only access the Aged Care system which is ill-equipped to support anyone living with a degenerative disease like MND.

Due to the rapidly progressing nature of MND, equipment needs are ever-changing and are always urgent - and that's where MND Victoria comes in. Graham and his family rely on us to help provide the best possible care and support, and we rely on your generosity.

Graham and his family wanted us to share his story as they know how important it is to raise awareness and funds for other families going through MND now and in the future.

If you are in a position to contribute, your gift can provide much-needed support for Victorians living with MND, just like Graham.



Visit [www.mnd.org.au/tax](http://www.mnd.org.au/tax) or scan the QR code below to watch Graham's Story and to donate to MND Victoria.



Please dig deep so that those who hear the fateful words  
"You have motor neurone disease" can still enjoy life and remain independent,  
safe, and engaged with their community for as long as possible.

# 40 YEARS OF CARE AND SUPPORT



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

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

In each newsletter this year, we are going to look back on a decade in our history to reflect on the journey that has led us to where we are today. **Below are our milestones from 1991 – 2000.**



**\* 1991** Our national body, the Motor Neurone Disease Association of Australia (MNDAA), was established to undertake work that would assist the state associations (like MND Victoria) to provide services to people with MND.

**\* 1992** Following the 3rd International Symposium on ALS/MND, the International Alliance of ALS/MND Associations was established.

**\* 1993** The Society officially adopted a new name - The Motor Neurone Disease Association of Victoria. Rod Harris was appointed as Executive Director to guide us into this new era and ended up leading MND Victoria for over 25 years.

**\* 1994** Sarah Ferguson, Duchess of York, met with members and friends of MND Victoria at the Caulfield Town Hall. She was named Patron of the Motor Neurone Disease Association in the UK in the 1990s and did a lot of work around promoting research.

**\* 1995** Our very own Mavis Gallienne was elected as the Chairman of the International Alliance of ALS/MND Associations. Mavis helped found MND Victoria after her sister passed away from MND.

**\* 1996** Named after Nina Buscombe, the "Nina's" debuted. The Nina's are awarded to an individual for their contribution and commitment to improving services, management, and research for people living with MND through travel, training, and attending international conferences.

**\* 1997** The first ALS/MND Global Awareness Day was held on 21 June.

**\* 1998** MND Victoria relocated to new premises at 265 Canterbury Road, Canterbury.

**\* 1999** The 'Equipment - it's a corker' recycling project commenced to collect and sell recycled cork. The funds received from the sales were used to purchase much-needed equipment items, like wheelchairs.

**\* 2000** The first Living Well Program was held, creating a space where people had the opportunity to connect with others and gather support from those with shared experiences of MND.







**Our next newsletter will cover our milestones from 2001 – 2010.**



## MND VICTORIA

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