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MOMENTUM

ISSUE 001

COVER STORY:

FINDING STRENGTH *together*

mnd Australia

Cause.Care.Cure

MND Australia acknowledges Traditional Owners of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respect to Aboriginal and Torres Strait Islander cultures; and to Elders past and present. Aboriginal and Torres Strait Islander peoples should be aware that this document may contain images or names of people who have since passed away.

Front Cover Photo credit: Hayley Durack

CONTENTS

What is MND?

Motor neurone disease (MND) encompasses a group of neurological disorders where motor neurons—nerve cells that control voluntary muscle movement—progressively weaken and die. As the disease progresses, individuals lose the ability to walk, speak, swallow, and even breathe. The lifetime risk of developing MND is about 1 in 300 by the age of 85. Currently, approximately 2,688 Australians are living with the disease, with over half diagnosed after the age of 65.

MND is a progressive condition that presents unique challenges. For most people, MND progresses rapidly, leading to significant disabilities and complex, constantly evolving needs. The average life expectancy from diagnosis is just 27 months, and around a third of people diagnosed die within a year.

Current research suggests that MND develops due to multiple risk factors. Some of these are genetic, and some are environmental. Ageing is also a factor. In up to 15% of MND cases, a 'faulty' gene is present and inherited from a parent. This is referred to as 'familial' or inherited MND.

Coordinated, multidisciplinary care is crucial for those living with MND. This approach often involves a team of specialists, including neurologists, physiotherapists, occupational therapists, dietitians, respiratory experts, and more. Assistive technologies, such as power wheelchairs, neurological care beds, and augmentative and alternative communication (AAC) devices to assist with speech and interaction are essential, as are home modifications like ramps. The progressive nature of MND demands immediate and dynamic support systems to address these needs.

Every day in Australia, two people learn they have MND, and two people die from the disease. With no known cure, MND Australia remains committed to driving research, advocacy, and care and support, to create a future free of MND.

MND in Australia

$50m

Over $50 million invested in Australian MND research since 1987 to discover causes, improve care, develop treatments and a cure

25k+

MND Australia's total social following across Facebook, Instagram and LinkedIn. Plus over 15,000 email subscribers

2,688

Approximately 2,688 Australians are currently living with MND. This equates to around 1 in 10,000 Australians

30%

In comparison to NDIS funding, aged care funding provides approximately 30% of funding that is available through the NDIS for people with MND

867

An estimated 867 Australians die from MND every year

-18yrs

MND typically reduces life expectancy by an average of 18 years

24

Nationwide, there are 24 specialist motor neurone disease clinics

2-5 days

NDIS access through the MND priority pathwayis typically approved within 2-5 business days

30+

Over 30 Australian MND researchers are funded through our grants program every year,including early career fellowships

430

Around 430 people currently living with MND are from a CALD background

2

There is currently only 2 medications available in Australia to slow the progression of MND

218

Every year the MND network runs over 200 information and peer support groups for people with MND, their family and their carers

8,700

The State MND Associations' AT libraries maintain over 8,700 pieces of equipment, at no-cost for people with MND

150+

Over 150 MND resources, publications, and website information pages are available, for both people with MND and health professionals

126k

Our national website receives over 126,000 visits per year to access a wealth of content for patients, carers & health professionals

WHO WE ARE

For over three decades, MND Australia has been at the heart of the fight against motor neurone disease (MND). Established in 1993 as the national peak body, MND Australia represents state-based organisations supporting individuals and families impacted by this devastating condition. Through advocacy, awareness, and unwavering community support, MND Australia has become a powerful voice both nationally and internationally.

Central to our mission is a commitment to funding world-class research—building momentum that seeks to improve treatments, enhance care, and, ultimately, find a cure. In 2024 we celebrated 30 years of progress, passion, and partnership, MND Australia remains focused on creating a future where no one faces MND alone.

MND CARE: SUPPORT STARTS HERE
State MND Associations offer essential care and guidance to people living with MND, their families and carers. Connecting early ensures access to vital resources, expert support, and a compassionate community from the moment of diagnosis.
MND Info Line 1800 777 175 9am to 4:30pm Monday to Friday. Or visit mndaustralia.org.au

message FROM OUR CEO

The past year has been transformative for MND Australia, marked by celebration and progress. At our 30th anniversary event at Parliament House, we honoured three decades of achievements, awarding 30 lifetime achievement medals to Australians who have significantly contributed to MND research, support, and healthcare.

We launched impactful initiatives, including advocacy priorities, government submissions, and a grassroots campaign ahead of the federal election. A testament to these efforts was the NDIS priority eligibility pathway program, announced by then Minister for Disability Bill Shorten, ensuring faster support access, with 18 assessors dedicated to assisting people with MND.

This year, we also launched the National MND Lived Experience Network, connecting people with MND and fostering collaboration. Our ambassadors, Peter Russo and Jane Simpson, continue to champion funding, equitable care, and community support.

Our commitment to research remains strong, with $2.55 million allocated to 20 innovative projects in 2025, driving discoveries in MND causes, treatments, and care improvements.

Lastly, our ‘Until There’s a Cure, There’s Care’ campaign spotlighted MND through emotive advertising across media channels. Huge gratitude to Eric, Tom, and Bruce for producing the campaign’s video pro bono, and Avenue C, whose $400,000 in pro bono media value ensured broad reach. These efforts continue to drive awareness and research donations.

With ambitious goals and unwavering dedication, we remain committed to a future free of MND.

– Clare Sullivan, CEO.

VOICES OF STRENGTH

The Impact of MND Australia’s Ambassadors

At the heart of MND Australia’s advocacy and awareness efforts are its ambassadors—individuals who live and have lived through the reality of MND first-hand. Their stories bring depth, urgency, and authenticity to the fight against MND, using their personal experiences to drive policy change, increase research funding and strengthen community support.

Through their resilience and courage, these ambassadors challenge misconceptions, amplify the voices of those affected by MND, and inspire action among policymakers, researchers, and the wider public. By sharing their journeys, they remind us that MND is not just a medical condition—it’s a human experience that deserves unwavering commitment and support.

A MESSAGE FROM

PETER RUSSO

MND AUSTRALIA AMBASSADOR

Every day with MND is a balancing act between determination and adaptation. My diagnosis in 2022 changed the course of my life entirely. Tasks I once took for granted, like tying my shoes or enjoying a conversation without pausing to catch my breath, are now daily challenges. MND robs you of control in so many ways, but I have chosen to focus on what I can still do and the difference I can still make.

What keeps me motivated are the incredible people I've met within the MND community—those living with the disease, their families, and the caregivers who pour their hearts into providing support. Their strength inspires me every day. My wife and children are also my constant pillars, reminding me that even in the face of adversity, there is love, purpose, and joy to be found.

Through my role as an ambassador for MND Australia, I've been given the chance to turn my journey into advocacy. It has become my mission to raise awareness of this disease and shine a light on the urgent need for better treatments, research funding, and equitable care. I share my story openly to help people understand the realities of MND—not just for individuals, but for their families who live with its relentless impact.

Much of my time is dedicated to public speaking, meeting policymakers, and participating in events to garner support for MND initiatives. Being part of campaigns that amplify the voices of those affected has given me a renewed sense of purpose. It's about ensuring that MND is no longer an invisible disease, but one that demands action, compassion, and change.

MND may have reshaped my life, but it will never define my spirit. Together, as a community, we can create hope, drive progress, and work towards a world without MND.

Scan the QR code to hear his words firsthand and gain a deeply personal glimpse into life with MND.

a message from

JANE SIMPSON

MND AUSTRALIA AMBASSADOR

Losing my husband to MND was the most heartbreaking experience of my life. Watching someone I love face the relentless challenges of this disease, knowing there was no cure, was devastating. His courage and resilience through it all continue to inspire me every day, and I am determined to honour his legacy by supporting others affected by MND.

As an ambassador for MND Australia, I've found purpose in sharing our story. I speak not only as a widow but as a former carer, giving voice to the often-unseen struggles faced by families and caregivers. MND is not just an individual diagnosis—it profoundly impacts loved ones, who shoulder the emotional and physical weight of caring for someone through their most vulnerable moments. Through my role, I aim to amplify the voices of carers and advocate for the resources, support, and recognition they deserve.

My work involves raising awareness about MND and its far-reaching impact, ensuring that people understand the urgency of funding research and improving care systems. I participate in public speaking engagements, work alongside policymakers, and collaborate on initiatives that prioritize the needs of those living with MND and their families.

What keeps me going is the incredible community I have connected with. Families, carers, researchers, and healthcare professionals all share a passion for creating change. Together, we fight to ensure no one faces this journey alone.

Being part of MND Australia has given me hope and a way to channel my grief into action. I believe that through advocacy, awareness, and a shared commitment to funding research, we can move closer to a world free of MND. For me, this mission is deeply personal, and I will continue to use my voice to make a difference.

Listen to Janes Let's Talk MND podcast on Spotify.

FINDING STRENGTH *together*

Ronald's journey with MND

For Ronald Hobden, a 35-year-old father from Gunnedah, NSW, life was once filled with simple joys—bedtime stories, backyard adventures, and dreams of the future with his wife, Annie, and their two young children. However, in 2023, everything changed when Ronald was diagnosed with Bulbar Onset Amyotrophic lateral sclerosis, an uncommon form of MND.

Ronald was given just six months to live, and the disease has taken a significant toll. Ronald can no longer walk or speak and now communicates using an eye-tracking device. Yet, the Hobden family's spirit remains unbroken. They have embraced each day with newfound courage, finding joy in the present, creating precious memories, and discovering strength they never knew they had.

Now, Ronald is using his voice—through technology—to advocate for increased government funding for MND research and care. He emphasises the urgent need for immediate support services, highlighting the bureaucratic delays that many families face.

In this candid Q&A, Ronald and Annie share their journey—the challenges, the triumphs, and the unwavering love that binds their family together. Their story is not just one of adversity but of resilience, connection, and hope in the face of uncertainty.

Photo credit: Creative by George

Photo credit: Creative by George

How has MND affected your life?

MND doesn't affect your life, it steals it. Slowly, brutally, piece by piece. Over the past 20 months I have gone from being a healthy, active father, working full time, training for a marathon to needing a wheelchair and help to do every single, basic daily activity. It has taken away my independence, my voice, and many of the simple joys I once took for granted. I've lost the ability to hug my wife Annie the way I used to, to hold my five –year-old daughter Lizzie's tiny hand as we cross the street and to scoop my three-year-old son Henry up into my arms. My body has become my prison, and no matter how much I fight, it's only getting worse every single day.

However, MND hasn't just affected me, it's affected absolutely everyone I love. My wife, my children, my family, and friends have all had to adapt, to grieve, and to carry a burden they never expected. But while MND has taken so much from me, it has also reminded me of how precious life really is and how you must enjoy every single moment.

What were the biggest hurdles you have had to overcome?

The biggest hurdle has been coming to terms with how rapidly MND progresses, how quickly things change and how little control you have over it. Letting go of the life I thought I would have and still find purpose in the life I now live has been incredibly difficult. Losing my voice was one of the hardest things I've ever faced. There is something deeply personal and unique about being able to easily speak your thoughts or say "I love you" to your children. But I've learned new ways to connect, with a lot of patience, with technology, and with just simply being present. Emotionally, one of the hardest challenges is the feeling of isolation, being in a room full of people but struggling to participate in the way I used to because you simply can't communicate quickly enough to keep up with the conversation.

Another challenge has been accepting help when previously I was the one helping my family and learning to lean on others without feeling like a burden. And perhaps most difficult of all is holding onto hope while facing a disease that offers none in return. But I do so for Annie, Lizzie and Henry and everyone else who has MND.

What is the hardest part about living with MND?

The hardest part without a doubt is watching what this disease has done to the people I love. Annie has been forced to become so much more than my wife. She's had to take on absolutely everything, running our home, raising our children, looking after me. She does it with so much love, so much strength, but I know the toll it takes. And then there's my darling Lizzie and Henry. No child should have to watch their dad fade away like this. MND is a disease that doesn't just affect the person diagnosed, it devastates everyone around them.

But while MND is incredibly and indescribably hard, it has also shown me the absolute depths of love, kindness and resilience. My family, my friends, my community, they have held me up when my own body could not. MND tests the limits of love Annie most of all hasn't just become my carer she has become my hero and my reason to keep going. Lizzie and Henry have shown me a kind of love that words can't capture. They don't see a man in a wheelchair, a husk of the man I used to be, they see what remains and most importantly of all they just see their Dad and show me so much love. They still curl up beside me, still chatter on about their days just like they used to prior to my diagnosis.

> **“MND takes so much. But funding into research and care give something back. It gives back dignity, joy and memories. But most importantly it gives back hope.”**

What do you wish more people understood about MND?

I wish people understood how devastating this disease really is, how quickly it steals your ability to live your life, how unforgiving it is, and how much it affects not just the person diagnosed, but everyone around them. While there is no treatment that stops it, those of us living with it still have so much life left in us. We still laugh, love, and feel. I wish more people understood that MND doesn't take away our humanity, it just makes it harder to show it in the ways most people are used to.

I wish they could see beyond the wheelchair or the computer screen and know that I fully understand everything that they are saying, and I am cognitively fully aware. Most of all, that we are still people who wish to actively pursue life.

How do you think increased government funding could change the lives of people currently living with MND?

Increased funding could be life-changing not just in the search for a cure, but in the quality of care available today. Right now, MND is a death sentence. But it doesn't have to be that way.

Because I truly believe that with the right investment, with the brightest minds focused on the task, we will find a cure. Every trial, every breakthrough, every dollar invested in research brings us closer to changing the future.

I know the odds are that research most likely won't save me. But maybe it will save someone else's dad, someone else's husband or someone else's child. Maybe it will mean that Lizzie, Henry and all the people who read this article will never have to fear this disease. And that thought that possibility, is what keeps me going.

At the same time, research takes time, time that people like me don't have. That's why care funding is just as critical. It means wheelchairs, communication devices, in-home support, palliative care, everything that helps people with MND live with dignity. It means support for Annie, Lizzie and Henry as they adapt to our new life and the ability for me to still be an active participant in our family.

MND takes so much. But funding into research and care give something back. It gives back dignity, joy and memories. But most importantly it gives back hope.

If you could speak to policymakers or funders, what would you tell them about why MND research deserves more funding; and why we need improved national data collection in Australia?

Every day, more Australians are diagnosed, and without better research funding, we are condemning people to a future without hope. The national data collection and research being undertaken is not just about a cure it's about understanding what causes the disease better, creating earlier interventions, improving care models, and giving people time, time with their children, time with their partners, time to live with dignity.

I would ask them to be brave enough to act, not because it's easy, but because it's the right thing to do.

Photo credit: Creative by George

RESEARCH

MND Australia has invested over $50 million in research grants, driving critical advancements in understanding the causes of MND, improving care, developing treatments, and ultimately striving for a cure. Through funding opportunities for students and researchers at universities across the country, MND Australia empowers researchers to explore groundbreaking ideas, foster collaboration, and accelerate scientific discovery. By supporting academic excellence and innovation, these grants ensure that the brightest minds in science and healthcare can contribute to the fight against MND, bringing hope to those affected by this devastating disease.

For more information visit mndaustralia.org.au/currentresearch

Dr Lotta Oikari

INVESTIGATING THE TDP-43 PROTEIN IN THE BLOOD-BRAIN BARRIER IN ALS

My aim is to investigate a protein called TDP-43 in the blood-brain barrier (BBB) of people with Amyotrophic Lateral Sclerosis (ALS), a progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord.

The BBB is a crucial defence system located in the blood vessels of the brain and its function is impaired in people with ALS. An impaired BBB in ALS likely contributes to the progression of ALS, but we don't know yet what causes BBB dysfunction in ALS. TDP-43 protein is abnormally aggregated in the brain cells of people with ALS so there is a high likelihood it also affects the BBB.

In my MND Australia–funded research project I am investigating if TDP-43 plays a role in abnormal function of the BBB in ALS and how we could target this for potential new treatments. In my research I will use stem cells that have been obtained from people with ALS allowing the faster application of my research findings to people with ALS. In addition to studying the role of the TDP-43 in the BBB, I will also investigate potential new therapies in restoring BBB function in ALS.

I'm hoping that my research will result in a new understanding of the causes of ALS, which is critical to developing new treatments. I am highly motivated by the fact that the new research I'm doing will one day contribute to a breakthrough in treating ALS, helping patients and carers worldwide to overcome this devastating disease.

Investing in
THE FUTURE OF MND RESEARCH

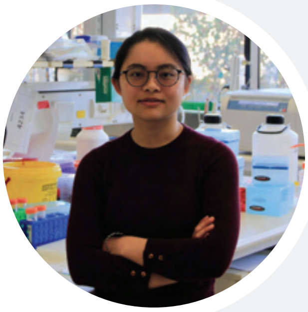
Groundbreaking discoveries begin with exceptional minds, and fostering innovation in MND research requires dedicated talent, resources, and support. PhD Top-Up Scholarships serve as a vital incentive for outstanding PhD students, allowing them to focus fully on advancing knowledge, exploring novel therapies, and driving progress toward treatments and a cure.

By supplementing their income, these scholarships remove financial barriers and empower the next generation of MND researchers to commit to high-impact studies that improve diagnosis, care, and treatment pathways. The following recipients represent the future of MND research, each bringing unique expertise and a fresh perspective to the field.

PHD TOP-UP SCHOLARS **2025**

Anastasiya Potapenko / MACQUARIE UNIVERSITY

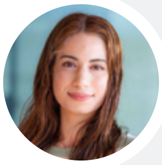
In almost all people living with MND, a protein called TDP-43 malfunctions, forming toxic clumps and losing its ability to perform critical functions in cells. There is currently no way to stop or treat this, however, emerging evidence suggests that another protein called ataxin-3 may be able to help. This project will be the first to establish how the ataxin-3 protein may have beneficial effects against toxic, malfunctioning TDP-43 protein in both human cell and zebrafish models of MND. This knowledge could guide future research on a treatment for malfunctioning TDP-43, which would likely benefit most people living with MND.



Yi Ling Clare Low / UNIVERSITY OF MELBOURNE

Emerging evidence suggests that small fat-storing structures in cells, called lipid droplets, may play a role in MND. This project aims to explore how changes in fat metabolism are connected to neurodegeneration and inflammation in MND using models and advanced techniques in neuroimmunology, fat metabolism, and computational biology. By mapping these changes in unprecedented detail, the project hopes to uncover new clues about the causes of MND and identify potential targets for future treatments. This research will not only improve our understanding of MND, but also help in developing better therapies for those affected by the disease.

MNDA 2025 RESEARCH *fellows*



Dr Azin Amin / UNIVERSITY OF MELBOURNE
Bill Gole MND Research Fellowship

Dr Nathan Pavey / UNIVERSITY OF SYDNEY
MND Australia Postdoctoral Fellowship

Dr Sophia Luikinga / UNIVERSITY OF QUEENSLAND
Scott Sullivan MND Research Fellowship

INNOVATOR GRANT *recipients*

Dr Lotta Oikari / QIMR Berhofer
NTI MND Research Grant

A/Prof Dominic Ng / UNIVERSITY OF QUEENSLAND
Charcot, supported by Fat Rabbit

Dr Abigail Pfaff / MURDOCH UNIVERSITY
Dr Paul Brock MND Research Grant

Dr Andrew Phipps / UNIVERSITY OF TASMANIA
Linda Elphick MND Research Grant

Dr Eduardo Albornoz / UNIVERSITY OF QUEENSLAND
Murray Geale MND Research Grant

Dr Neville Ng / UNIVERSITY OF WOLLONGONG

MonSTaR MND Research Grant

Dr Nirma Perera / UNIVERSITY OF MELBOURNE

The Elizabeth and Peter John Cahill MND Research Grant

Dr Rita Mejzini / MURDOCH UNIVERSITY

Peter Stearne Familial MND Research Grant

Dr Sayanthooran Saravanabavan / MACQUARIE UNIVERSITY

Daniel Veysey MND Research Grant

Dr Sonam Parakh / MACQUARIE UNIVERSITY

Col Bambrick MND Research Grant

Natalie Grima / MACQUARIE UNIVERSITY

Superball XVII MND Research Grant

Prof Peter Catcheside / FLINDERS UNIVERSITY

Eileen Grace Bignall MND Research Grant

Dr Grant Richter / MACQUARIE UNIVERSITY

Ian Sneddon Two Rivers Run MND Research Grant

Rebecca Francis / FLINDERS UNIVERSITY

MND South Australia MND Care Research Grant

Yuval Gurfinkel / MURDOCH UNIVERSITY

Jenny Simko MND Research Grant

A LEGACY OF hope

At MND Australia, we often talk about the power of research—the breakthroughs, the dedication of scientists, and the relentless pursuit of answers. But behind every research project, there's something just as powerful: the generosity of those who believe in a future without MND.

The late Daniel McLoone was one of those believers. His extraordinary $3.5 million bequest to MND Australia has already made a profound impact, funding two major research initiatives, two research prizes, and eight innovator grants. This generous gift has strengthened MND research in Australia, supporting the brilliant minds working to understand, treat, and ultimately cure this disease.

Research is our greatest weapon against MND, but it requires sustained funding. Grants provide researchers with the stability they need to explore bold ideas, test new treatments, and drive discoveries forward.

Daniel's bequest has helped ensure that some of Australia's best scientific minds can continue their critical work, and his generosity will be felt for years to come.

Bequests like Daniel's don't just fund research—they sustain hope. They remind people living with MND, their families, and the research community that they are not alone in this fight. Every bequest, big or small, plays a crucial role in keeping research moving forward and bringing us closer to a future free from MND.

Leaving a gift in your Will to support MND Australia's research grants program is a simple but deeply meaningful way to make a lasting impact. If you'd like to learn more, we'd love to have a conversation with you. Because every gift, like every discovery, brings us one step closer to a world without MND.

Visit mndaustralia.org.au/donate for more info or email us at research@mndaustralia.org.au

Daniel McLoone

RESEARCH INITIATIVE

MND Australia proudly acknowledges the recipients of the prestigious Daniel McLoone Major Research Initiative, Dr Thanuja Dharmadasa and Professor Brad Turner. Their groundbreaking projects, jointly funded by MND Australia and FightMND, will each receive $1 million over four years, driving forward critical advancements in understanding and treating MND. Additionally, MND Australia awarded the Daniel McLoone Research Prize to Dr Catherine Blizzard. These investments reflect a continued commitment to accelerating scientific discovery, fostering collaboration, and ultimately finding a cure for MND.

Making a Lasting Impact: The MonSTaR Foundation's Contribution to MND Research

Since 2016, MND Australia has been fortunate to receive generous and ongoing support from the MonSTaR Foundation for our MND research grants program. Formed in 2007 by three friends–one of whom lost their wife to MND–the MonSTaR Foundation is driven by a shared passion for making a difference and creating community. While they support several important causes, their contributions to MND research have been truly transformative.

Thanks to the remarkable MonSTaR Team's fundraising efforts, MND Australia has been able to award up to two "MonSTaR MND Research Grants" every year since 2016. These grants have funded crucial studies investigating potential biomarkers, faulty genes linked to MND, the molecular and cellular mechanisms behind the disease, and promising therapeutic strategies.

Most recently, we were thrilled to award a MonSTaR MND Research Grant in 2025 to Dr Neville Ng from the University of Wollongong.

Support like this is vital in driving research forward, and we're always grateful for those who choose to contribute in a meaningful way. Individuals and organisations making donations of $50,000 or more can establish a named research grant, creating a lasting legacy in the fight against MND. With ongoing support from generous donors like the MonSTaR Foundation, we look forward to the breakthroughs that the future holds.

If you'd like to learn more about how your donation can fund vital research, or are interested in hearing more about named grants, please reach out to us at research@mndaustralia.org.au.

MonSTaR founders Mark Golding, Hamish Pearce, Greg Hargreaves.

LIFTING VOICES

Driving Change

THE POWER OF LIVED EXPERIENCE

Launched in 2024, the National MND Lived Experience Network (LEN), is more than just a program—it's a powerful movement bringing the human side of MND to the forefront. Co-funded by MND Australia and Fight MND, the LEN unites over 130 voices from across the country—people living with MND, genetic carriers, current and former carers—to turn experience into impact.

At its heart, the LEN was created to answer a critical need: to connect professionals with the real experts, those who've lived through MND. By providing a national pathway for authentic engagement, the LEN is helping reshape how we talk about, understand, and act on MND.

> ***"Personal stories and experiences bring data and research to life and help connect the dots in our work."***
> ***— MND Researcher***

Whether it's sharing stories in the media, sitting on advisory panels, or providing insight into research, our members are sparking change at every level. From influencing policy to improving care, their lived experience is helping drive more compassionate, informed, and impactful outcomes.

> ***"I'm linking with so many great people — professionals and those with lived experience." — LEN Member***

Over the past year alone, more than 50 professional engagement requests resulted in over 200 moments where lived experience made a difference. That's 200 real conversations, perspectives, and voices shaping the future of MND in Australia.

And for our members? The LEN is more than an initiative—it's a community.

They tell us they love the flexibility, the diversity of opportunities, and the sense of purpose it brings. It's a place where they feel heard, supported, and empowered to turn their experience into something that matters.

> ***"It's a journey none of us choose, but I am getting significant joy from being involved and having my contribution valued."***
> ***— LEN Member***

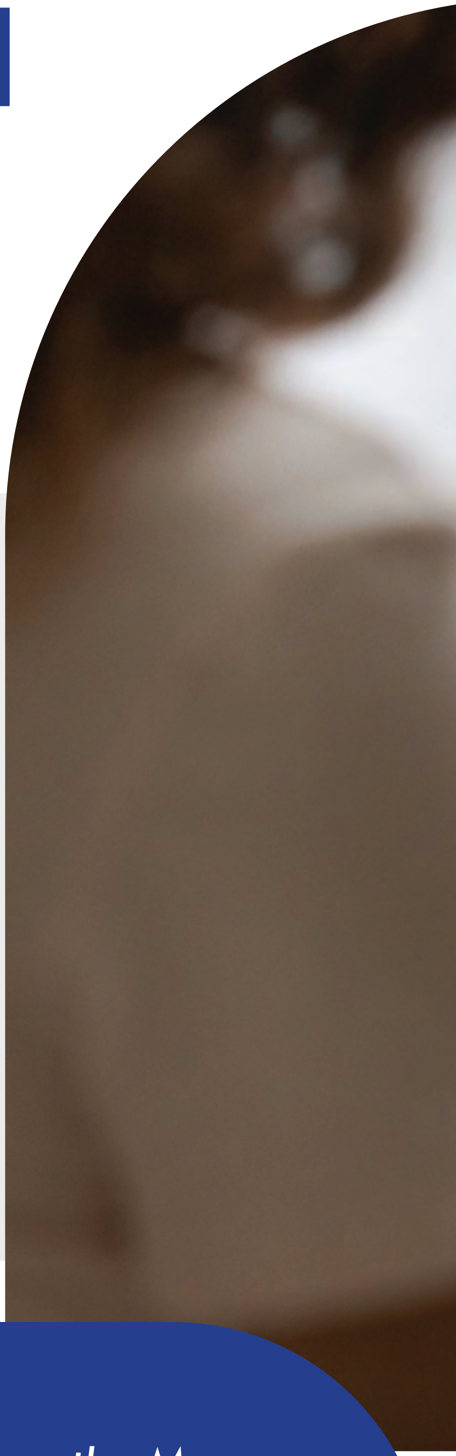
At MND Australia, the LEN is now embedded at the core of what we do. Together with our national network of state MND Associations we're ensuring that lived experience isn't just acknowledged—it's amplified. From advocacy campaigns to national research conversations, the LEN is paving the way for a more inclusive, connected, and compassionate future.

Here's to the voices shaping change—and the people behind them.

— Julie Labra Program Manager
National MND Lived Experience Network

INFORMATION AND SUPPORT

ADVICE YOU CAN TRUST



In collaboration with the State MND Associations and people living with MND, MND Australia offers a suite of evidence-based, easy to use information resources for people living with MND, their families and friends.

Through our information and support portal, we offer resources in a variety of formats, including web pages, animations, videos and downloadable guides. Our resources are designed to give people a better understanding of MND, including causes, symptoms, treatments, and planning ahead.

We also offer a range of tools to self-advocate within the health system, make decisions about care and assist people to live as well as they can for as long as they can. We also connect people impacted by MND with services and support to ensure they get the best possible care.

MND Australia is a Healthdirect Australia trusted information partner.

> *"Resources such as the More About MND booklet are vital for people who have been impacted by MND, guiding us through the post-diagnosis fog and the journey ahead."*

MND Connect

MND Info Line
1800 777 175
9am to 4.30pm Monday to Friday

Information & Support

MND Connect provides resources, information and service linkage for people living with MND, their carers and family, as well as the health professionals and services providers who support them to live well.

The MND Info Line and mndconnect.org.au are
funded by the Australian Government Departme
Social Services through an Information, Linkage
Capacity Building (ILC) grant.

Federal ELECTION

MND Australia's federal election plan was a strategic effort to advocate for improved policies, funding, and support systems for people living with MND and their families. The policy initiatives will remain key strategic advocacy priorities moving forward.

Ahead of the election, MND Australia outlined five key priorities to address critical gaps in care and resources, ensuring that the voices of the MND community are heard at the highest levels of government.

One of the central goals was to establish the National MND Insights Platform, which requires $12 million in funding over four years. Better quality linked MND data will transform and accelerate our MND researchers' understanding of MND, leading to better treatments.

MND Australia also advocated for the continuation of the NDIS Priority Eligibility Decision Pathway, which fast-tracks access to the National Disability Insurance Scheme (NDIS) for people living with MND. We called for comparable funding levels for aged care support to match those provided through the NDIS, ensuring people aged 65 and over have the same access to support and funding as those on the NDIS.

The final priority was the inclusion of genetic counselling under Medicare, enabling informed decision-making regarding genetic testing and protecting future generations.

These measures reflect MND Australia's commitment to addressing the complex needs of the MND community through targeted advocacy and collaboration with policymakers.

To influence funding and policy, our CEO, Chair and State Assocation CEOs, have met with federal politicians and candidates, highlighting the urgent needs of people affected by MND.

MND Australia has strategically used social media campaigns to raise awareness about MND, share personal stories of those affected, and mobilise community support. By combining direct advocacy with community-driven initiatives, MND Australia continues to champion meaningful change for people impacted by this devastating disease.

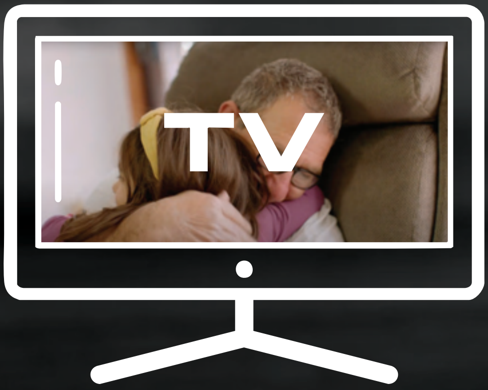
NATIONAL AWARENESS CAMPAIGN

MND Australia's 2025 media campaign, Until there's a Cure, There's Care raised public awareness of MND and highlighted the critical role MND Australia and State MND Associations play in providing care and support. The campaign utilised a highly emotive advertisement, shared across various media platforms, to maximise reach and impact. Leveraging a generous $1 million in pro-bono media placements, the initiative launched in March and running until the end of July 2025, engaging audiences nationwide.

The campaign aims to educate the public about MND, emphasising its profound impact on those affected, and the importance of support systems and research in the fight against the disease. It also showcases the collaborative efforts of MND Australia and State MND Associations, illustrating their role in delivering care and fostering community support.

The media placement strategy is both comprehensive and strategic. Advertisements are being aired on key national and regional television channels, while pre-movie ads ensure a presence in local theatres. Out-of-home advertising targeting high-traffic areas, including transit hubs, shopper locations, and streets, through partnerships with organizations like Alliance Media, JCD, Westfield, oOh! Media, and Cartology. Digital ads appeared on popular platforms such as 7Plus, Foxtel Network, and TenPlay, and radio spots reached listeners via networks like KIIS, Gold, Nine, and regional stations. Print advertisements in national publications further extended the campaign's visibility.

Overall, this campaign exemplifies MND Australia's dedication to driving awareness and fostering meaningful change. Through strategic media outreach and powerful storytelling, we hope to make a significant impact in the battle against MND.



Watch "Until there's a Cure, There's Care"

INDUSTRY SPOTLIGHT

TOFERSEN OFFERS HOPE FOR SOD1 MND

Biogen's Tofersen, marketed as QALSODY®, is a new treatment developed for people with MND linked to changes in the SOD1 gene. SOD1 accounts for around 2% of all MND cases and is usually found in inherited familial MND.

In SOD1-MND the change or fault triggers the production of toxic proteins that damage motor neurons. Tofersen works by reducing these harmful proteins through an innovative 'antisense' approach, effectively "switching off" the production of the disease-causing substance.

Clinical trials have shown that Tofersen can slow the progression of MND, including declines in physical and respiratory function—especially when started early.

Tofersen is the first drug that addresses the genetic root cause of SOD1 MND and underscores an innovative treatment approach that has potential to be translated to other types of MND genetic faults.

The next step is better defining the most effective time to begin treatment. A Phase 3 clinical trial called ATLAS is currently underway worldwide (including Australia) to determine whether Tofersen can delay the onset of MND in pre-symptomatic SOD1 gene carriers.

STRENGTHS

Targeted therapy: As the first drug addressing the genetic root cause of SOD1-related MND, Tofersen offers fresh hope to those impacted by this gene fault.

Potential to slow progression: Clinical trials show it can slow declines in physical ability, respiratory function, and quality of life—especially when started early.

Biomarker benefits: Reductions in neurofilament light chain (NfL) levels suggest Tofersen may help preserve motor neuron health.

LIMITATIONS

Limited applicability: Its benefits are restricted to patients with the SOD1 mutation, representing a small portion of the broader MND population.

Potential side effects: Common issues include pain, fatigue, fever, and muscle or joint discomfort. In rare cases, more serious events like meningitis or elevated intracranial pressure have been reported.

Invasive delivery: Administered via lumbar puncture, the procedure may be a barrier for some patients.

SUMMARY:

Tofersen marks a breakthrough in targeted treatment for a specific subset of MND patients, bringing renewed optimism to those living with the SOD1 mutation. While challenges such as limited applicability, side effects, and delivery methods remain, the drug's innovative approach underscores the exciting progress in MND research. Continued focus on broadening treatment options will be crucial as the fight against MND advances.

- Prof Paul Talman, Neurologist, Barwon Health

AUSTRALIAN BIOTECH **TESTING NOVEL ALS DRUG USE**

Amyotrophic lateral sclerosis (ALS), a type of MND, is a progressive neurodegenerative disease affecting motor neurons, leading to muscle weakness and eventual paralysis. Research into potential therapeutic approaches continues to evolve, with a focus on understanding disease mechanisms and identifying compounds that may support neuroprotection.

One such investigational compound, NUZ-001, is currently being studied for its potential role in modulating cellular pathways associated with ALS. NUZ-001 has been observed in preclinical studies to interact with pathways related to proteostasis and autophagy, which are involved in the clearance of misfolded proteins. Ongoing research aims to further explore its effects in clinical settings.

Early-stage clinical studies have assessed the safety and pharmacokinetics of NUZ-001 in patients with ALS. Further Phase 2/3 trials are planned through HEALEY ALS Platform Trial to evaluate its potential impact on disease progression and patient outcomes. These studies are conducted under rigorous scientific and regulatory oversight to ensure adherence to established research protocols.

MND Australia remains committed to sharing developments in ALS research with the community, fostering awareness of scientific advancements while adhering to regulatory guidelines. For more information on ALS research and clinical studies, please visit mndaustrailia.org.au

RADICAVA® IV INFUSION (EDARAVONE) NOW LISTED ON PBS FOR ELIGIBLE AUSTRALIANS WITH ALS:

A STEP FORWARD FOR TREATMENT ACCESS

MND Australia acknowledges the recent inclusion of RADICAVA® IV infusion (edaravone) on the Pharmaceutical Benefits Scheme (PBS) for adults diagnosed with amyotrophic lateral sclerosis (ALS), the most common form of motor neurone disease (MND). This listing marks an important development in treatment access for a defined group of Australians living with ALS.

KEY FACTS:

RADICAVA® IV is now PBS-listed for adults with ALS who:
- Are independent in daily activities
- Have normal respiratory function
- Commence treatment within 2 years of symptom onset

This decision enables subsidised access to eligible patients, improving affordability of treatment that may slow disease progression in its early stages.

MND Australia supports the principle of timely and equitable access to therapies for all people living with MND. The PBS listing of RADICAVA® IV provides an option for those who meet the specific eligibility criteria. We also recognise that many people living with MND may fall outside of this criteria and continue to face limited treatment choices.

Like all medications, RADICAVA® IV may cause side effects, ranging from minor to serious. We encourage people living with ALS and their caregivers to consult their healthcare team and refer to official Consumer Medicines Information before starting treatment.

lifetime ACHIEVEMENT AWARDS

In recognition of MND Australia's 30th anniversary, we awarded 30 Australians who have made a significant contribution to the MND community over the last 30 years with lifetime achievement medals

- Dr Peter Allcroft
- Professor Samar Aoun
- The Hon Guy Barnett
- Professor David Berlowitz
- Carol Birks
- Dr Paul Brock AM
- Professor David Burke AC
- Neale Daniher AO
- Judith Durham AO
- Mavis Gallienne
- Dr Kirsten Harley
- Marjorie Harrap
- Rod Harris
- Dr Anne Hogden
- Professor Matthew Kiernan AM
- David Lamperd
- Dr Graham Lang
- A/Professor Susan Mathers
- Janet Nash
- A/Professor Shu Ngo
- Professor Garth Nicholson
- A/Professor Roger Pamphlett
- Ian Rodwell AO
- Professor Dominic Rowe AM
- Helen Sjardin
- Dr Derik Steyn
- Professor Paul Talman
- Geoff Thomas OAM
- Ralph Warren
- Professor Justin Yerbury AM

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mnd Australia

YOUR SUPPORT CHANGES LIVES

Your generosity drives vital research to better understand, treat, and ultimately cure MND. Your tax-deductible donation helps maintain momentum—every dollar makes a difference.

DONATE NOW. CLAIM YOUR TAX BENEFIT BEFORE JUNE 30.

Clare Sullivan
MND Australia CEO

PAYMENT DETAILS

Cheque – Payable to MND Australia
Direct Deposit – BSB: 062-152
Account: 00902053

Donate Online

Scan the QR code or visit mndaustralia.org.au/donate to make a secure donation instantly.