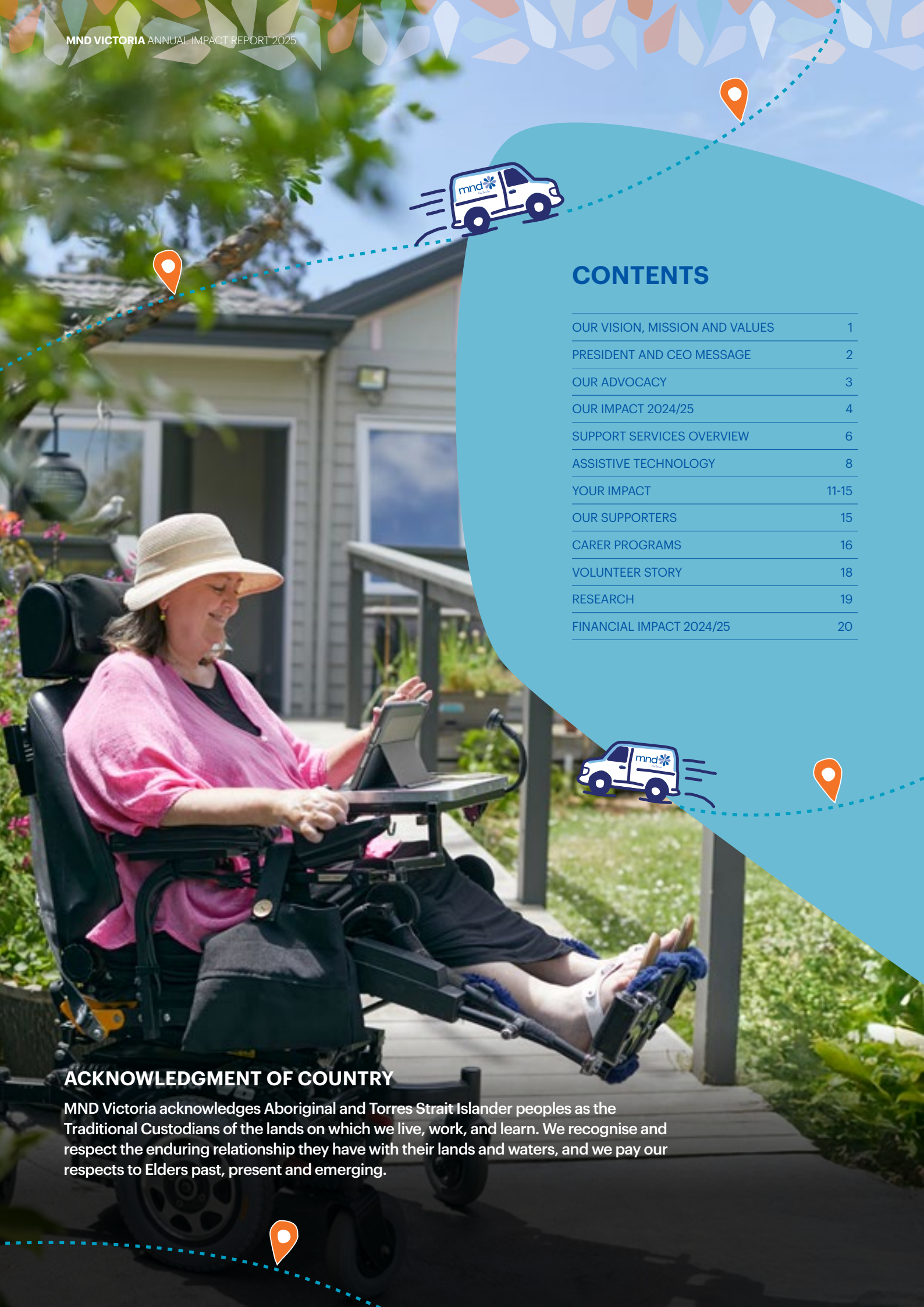
mnd Victoria

ANNUAL IMPACT REPORT 2025



CONTENTS

ACKNOWLEDGMENT OF COUNTRY

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

OUR VISION, MISSION AND VALUES

OUR VISION

The best care until the world is free of MND.

OUR MISSION

To provide and promote the best possible care and support for people living with MND.

"People living with MND" includes people who have been diagnosed, those yet to be diagnosed, carers, former carers, families, friends, workmates, and any other person whose life is—or has been—affected by MND.

OUR VALUES

OUR OBJECTIVES

We will focus on the things that matter.

1 OUR SERVICES

We provide accessible care and support to ensure people impacted by MND receive the best possible services that meet their needs.

2 OUR PEOPLE

We are a passionate, dedicated, and highly skilled workforce.

3 OUR IMPACT

We are regarded and understood as the expert organisation that people impacted by MND turn to.

4 SUSTAINABILITY

We invest in our future viability and relevance to ensure that people impacted by MND can access our services until a cure is found.

THE CORNFLOWER

The blue cornflower (Centaurea cyanus) is the symbol of hope for people living with MND around the world—hope for finding the cause; hope for the development of treatments; and hope for a cure. The cornflower represents positive hope for the future—a future without MND. The cornflower was chosen for its fragile appearance but hardy nature. Like the cornflower, people living with MND show remarkable strength in coping with this devastating disease.

PRESIDENT AND CEO MESSAGE

The 2024/25 financial year has once again been a year of growth, advocacy, and impact for MND Victoria.

We have continued to see an increase in the number of people registering with our service following a diagnosis of motor neurone disease (MND). Our commitment remains unchanged: to provide services as and when they are needed, with no waitlists or delays.

Every person living with MND deserves the best possible care and support, and we are proud that MND Victoria continues to deliver on this promise.

Alongside service delivery, we have maintained a strong focus on supporting research and advocating for the needs of people living with MND and their families. Our voice has been heard at the highest levels of government, within the health and aged care sectors, and through the lived experience stories of our community.

Strengthening Care and Collaboration

MND Victoria continues to contribute to sector-wide initiatives to improve care for people with MND. Through the **Victorian MND Community of Practice**, we are working with partners to develop a consumer-led, collaborative approach to MND care. Attendance at the first two online forums exceeded 100 professionals, reflecting the strong appetite for shared learning and innovation.

Our involvement in the development of the new **Australian Motor Neurone Disease Clinical Guidelines**, funded by FightMND, is another important milestone. We are proud that Jo Whitehouse – General Manager of Support Services has been appointed **Co-Chair of the Project Steering Group**, ensuring that the lived experience of people with MND remains central to this work.

We have also continued our vital **carer respite program**, giving family carers much-needed breaks from their caring role. We have received an additional respite grant from the Victorian government to provide support and counselling to family carers of people living with MND, an essential service that reduces stress on families and prevents isolation.

Pictured: Wayne Pfeiffer, Chris Beeny, Jodie Harrison, David Lamperd and Kate Johnson

Our State Council

This year, we farewell three long-serving State Council members: **David Lamperd, Chris Beeny,** and **Jodie Harrison**.

David has served on the State Council for over 20 years and, as President since 2017. He has been an outstanding advocate, fundraiser, and leader. Chris served for 23 years, generously sharing his legal expertise through Maddocks and providing invaluable pro-bono support. Jodie served for 8 years, bringing energy, networks, and communications expertise, along with hands-on support at events and for fundraising.

We thank them deeply for their dedication and impact, and look forward to their ongoing involvement as friends of MND Victoria. As the partner of a person living with MND, who sadly passed away, she also brought her personal lived experience of MND to State Council.

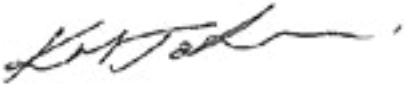
Looking Ahead

As we look to 2025 and beyond, our priorities are clear:

- Continue innovation in the supports we provide.
- Secure sustainable funding and partnerships.
- Ensure that the voices of people living with MND and their families shape everything we do.

We remain deeply grateful to our staff, volunteers, donors, and partners for their commitment and generosity. Together, we are building a future where people living with MND have access to the care and support they need, until the day the world is free of MND.

Wayne Pfeiffer, President



Kate Johnson, Chief Executive Officer

STATE COUNCIL
(AS AT 30TH JUNE 2025)

Wayne Pfeiffer* – President (from November 2024)
David Lamperd* – President (retired November 2024)
Katharine Barnett* – Vice President
Jeremy Urbach* – Treasurer
Napier Thomson
Chloe Williams
Maryanne McPhee
Ann Elkins*
Todd Johnson*
Elizabeth Mulhall*
Julia Tonkin
Chris Beeny (retired November 2024)
Jodie Harrison* (retired November 2024)

**Has a personal association with MND*

OUR ADVOCACY

STATE ADVOCACY AND ENGAGEMENT

On 31 July 2024 we hosted a Victorian Parliamentary Event, inviting all members of Victoria's parliament to meet people with lived experience of MND, hear about the gaps in the system, and learn about MND Victoria.

MND Victoria staff members, volunteers, carers, fundraisers, and people with MND attended the event at Parliament House, sharing the importance of the work we do with notable Members of Parliament including Victorian Premier Jacinta Allan.

Iwan Walters, Parliamentary Secretary for Disability, helped coordinate the event in the lead-up, and acted as MC throughout. Emma Vulin, Member for Pakenham, shared her personal journey with MND, and nine-year-old Finn Cadman highlighted the funding gaps his "Glampa" has experienced due to being diagnosed with MND after turning 65. Both speeches highlighted the need for improved MND care, and inspired further conversations with MPs in attendance.

Over the whole financial year Emma Vulin made sure to keep MND front-of-mind for MPs, inviting further MND-focused events at Parliament House, inspiring dozens of MPs to attend the Pakenham Walk to Support and fundraisers run by Finn Cadman's family. Finn and the Cadman family, alongside Emma and MND Victoria, have passionately advocated on the need for greater funding.

We also welcomed MPs in attendance at the unveiling of our second equipment delivery van, and the Bendigo Walk for Care—where we unveiled our "Treat Age Equally" campaign.

The "Treat Age Equally" campaign highlighted the vast difference in government-funded support for those diagnosed before and after turning 65, due to the differences in the NDIS and My Aged Care systems and served as an awareness piece for MND Victoria.

As a result of the increased awareness of the need for greater funding, and with thanks to Iwan Walters, Emma Vulin, Finn Cadman, and those in the community who approached their representatives, MND Victoria have been allocated $600,000 (to be paid over two years) in the latest Victorian Government Budget.

FEDERAL ADVOCACY AND ENGAGEMENT

We worked closely with MND Australia and the State Associations for national brand awareness and advocacy efforts including the coordinated campaign ahead of the Federal election and preparatory work for the "Every Moment Matters" economic report.

Prior to, during, and following the election campaign, we supported people living with MND to share the national advocacy priorities with their MPs, and MND Victoria representatives met with Federal Members of Parliament in Canberra and Victoria—including Aaron Violi, Helen Haines, and Kate Thwaites.

OUR IMPACT 2024/25

MND Victoria's Support Services are delivered to people living with MND in Victoria, New South Wales (bordering with Victoria) and Tasmania. Services focus on supporting people to live better for longer, remain active in their community, and remain safe in their environment, through the provision of six key program areas.

Here are some statistics that demonstrate our impact across the 2024/25 year.

ASSISTIVE TECHNOLOGY PROVISION

NEW CLIENTS RECEIVING EQUIPMENT:
183

EQUIPMENT ITEMS PROVIDED:
6,577

CLIENTS WITH EQUIPMENT AT 30 JUNE:
368

REQUESTS FROM ALLIED HEALTH PROFESSIONALS TO THE EQUIPMENT SERVICE:
2,289
(often for more than one piece of equipment)

EQUIPMENT ITEMS RECOVERED:
2,844

COUNSELLING SERVICE

NUMBER OF COUNSELLING HOURS:
888

NUMBER OF PEOPLE SUPPORTED BY COUNSELLING SERVICE:
133 clients
108 carers

Our Equipment Delivery Reach

WE DELIVER TO OVER
300
suburbs across Victoria

OUR TEAM TRAVEL
84,000km
a year delivering equipment across Victoria

IT COSTS
$143,640
to run our Equipment Delivery Service each year

ADVISOR AND SUPPORT COORDINATION

PEOPLE SUPPORTED BY MND VIC:

859

VIC: 753, TAS: 82, NSW: 24

HOURS DELIVERED TO CLIENTS BY MND ADVISORS:

27,047

VIC: 24,022, TAS: 2,448, NSW: 577

NEW MEMBERS WITH MND:

251

VIC: 219, TAS: 27, NSW: 5

PEOPLE WITH MND REGISTERED AT 30 JUNE:

615

VIC: 535, TAS: 59, NSW: 21

REPORTED MND DEATHS:

213

VIC: 206, TAS: 23, NSW: 2

EDUCATION, CLIENT AND CARER SUPPORT

TYPE OF RESOURCE SENT OUT:

489

Welcome Packs

257

GP Information kits

7,759

MND e-news (12 editions)

8,914

Health Professionals e-news (4 editions)

432

Number of carers supported through respite and wellness/ education activities (1,340 hours)

VOLUNTEER ENGAGEMENT

VOLUNTEER HOURS:

3,433

Contributed

REGISTERED/ACTIVE VOLUNTEERS:

99

Includes 8 new volunteers

DONATIONS AND FUNDRAISING

BEQUESTS:

$1,124,870

GRANTS AND TRUSTS:

$203,341

INVESTMENTS:

$765,864

DONATIONS:

$871,153

MND VICTORIA EVENTS:

$653,453

COMMUNITY EVENTS:

$433,453

MERCHANDISE

$28,413

SUPPORT SERVICES OVERVIEW

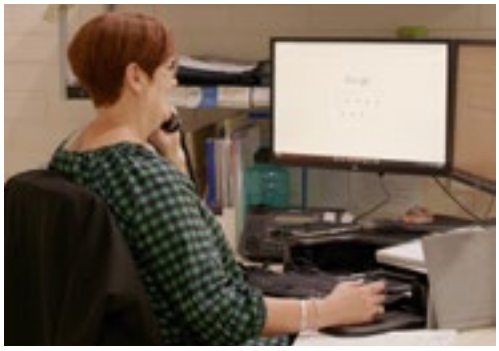
MND Victoria's Support Services are central to what we do and why we do it.

Our services aim to be prompt—so that people get the high quality support they need, when they need it, supporting people with MND to live as safely and as well as possible in the environment of their choosing.

Our key supports include:

ACCESS AND EDUCATION

The first point of contact for people diagnosed with MND and their families is our Access and Education Team. The team have a reassuring and gentle approach to informing people about our services and what to expect from MND Victoria's supports. In addition, this team delivers education to people diagnosed with MND, families and friends, as well as health professionals supporting someone with MND, regardless of the setting.



COUNSELLING

Our Counselling Service is in its second year. Our counsellor Beth supports clients and carers through the MND journey, ensuring those that need an outlet for the emotions that the MND journey brings are able to receive support from a specialist counsellor who understands the impacts of living with an MND diagnosis.

ADVISOR AND SUPPORT COORDINATION

Our team of 26 MND Advisors and Support Coordinators partner with people diagnosed with MND to ensure that they get the advice, support, and services they need to ensure they live as well as possible.

CARER SUPPORT

Family carers are the backbone of support to the person diagnosed with MND and are also experiencing their own journey with MND. Providing support and respite for carers is critical to ensure that they can maintain their caring role and helps them have a break away from caring to refresh and reenergise.

VOLUNTEER ENGAGEMENT

MND Victoria was started 44 years ago by volunteers, and they remain at the heart of our Association. Our 100 strong volunteer team continue to support our clients through hand and foot massage, life story writing, and social visiting, as well as supporting our events and administration. Volunteers remain a vital part of the work that we do.

ASSISTIVE TECHNOLOGY

People living with MND have constantly changing needs for assistive technology as their disease progresses. Our Equipment Loan Service ensures that we can provide the needed equipment as quickly as possible at no direct cost to the person living with MND or their family.

8

ASSISTIVE TECHNOLOGY

OUR EQUIPMENT LOAN SERVICE

We've officially been running our Equipment Loan Service in-house for a full year now, with thousands of items being delivered across 313 suburbs to over 450 people living with MND. Deliveries are made every weekday, with an average of 8 requests for item delivery made per day—a number that's grown throughout the year.

From jellybean switches and call bells, to cough assists, wheelchairs and powerbeds; every piece of equipment helps improve the comfort and independence of a person living with MND, while helping their loved ones and carers to better support them.

Our drivers have travelled roughly 84,000 kms, to get vital equipment to people like Shane in Alexandria, Shirley in Heidelberg, Neil in Bendigo, and Maxine in Shepparton.

These four people value the service so highly, that they appeared in our 2025 Tax Appeal, which highlighted the impact of our Equipment Loan Service and asked donors to help us fund a full year of the delivery aspect of the service (at a cost of $150,000).

Hear from Shane, Shirley, Neil, and Maxine in the orange quote bubbles below.

I live in a small country town and rely upon an Aged Care Package, so there's not enough funds and not much support for someone with MND. If I didn't have MND Victoria's Equipment Service, I'm not sure what my family would have done. The service is prompt, the drivers are polite, they have always been fantastic."

Shane

The service is a fantastic resource for us to draw on as we need. As a retiree, I would find it very hard to afford the special equipment and wouldn't know where to start re selecting appropriate items to buy. The service takes a lot of the anxiety out of trying to plan for an uncertain but difficult future."

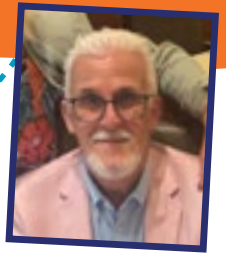
Shirley

"It's great that the equipment loan service exists, and I think it's clear how important it is to have. Even if you've only gotten one or two pieces of equipment, it provides real peace of mind."

Maxine

It is so comforting knowing that we can get some help with equipment from MND Victoria. We know our OT can help us with assessing the equipment and ordering for us, so we are confident that it will be useful. However, it is great to know we can try items and if they're not quite right we can send them back, and not have to purchase them."

Neil



Shortly after the publication of our 2025 Tax Appeal, Maxine sadly lost her battle with MND. Maxine was an incredible supporter of MND Victoria's work and a great advocate for the MND community. She is sorely missed.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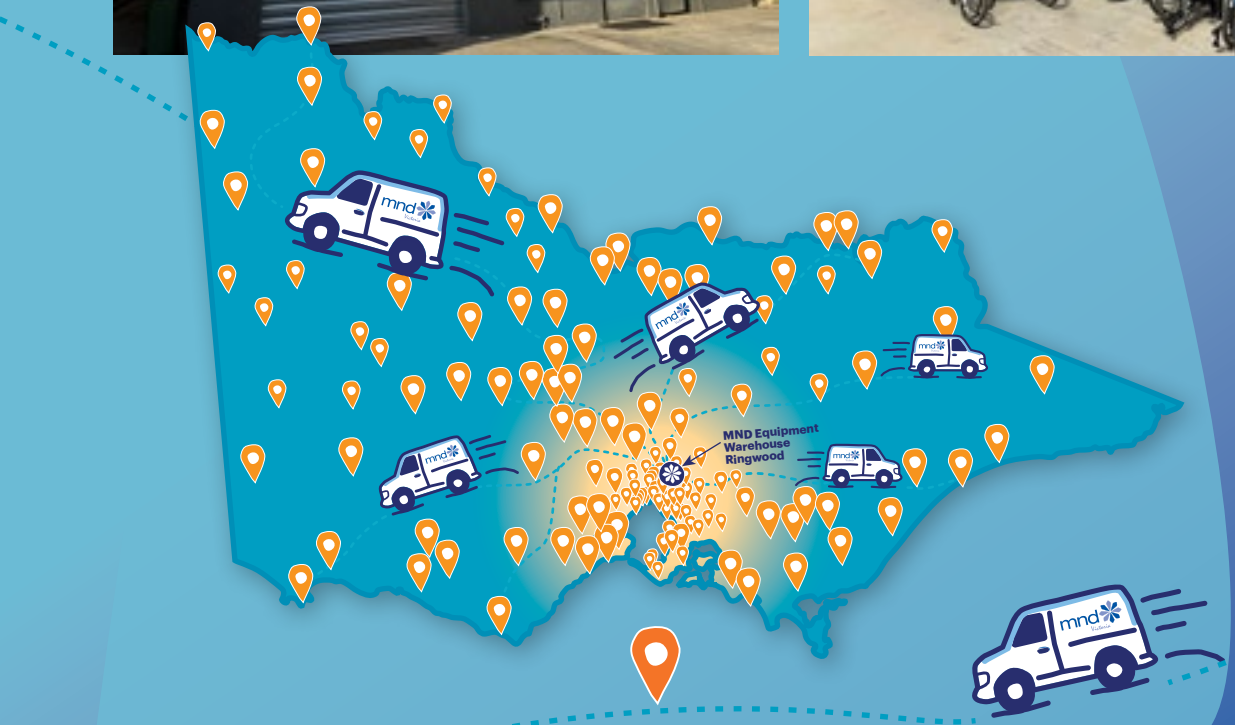

MND Equipment
Warehouse
Ringwood

THE STORY OF JANE THE VAN

Jane Broughton was diagnosed with MND in 2023, and sadly passed away before the year was out. Due to the relief that MND Victoria's equipment delivery service provided to Jane, the Broughton family decided to organise a fundraiser for MND Victoria in Jane's honour in 2024.

This small country town fundraiser hit a fundraising record—raising a phenomenal $120,000, which was enough money for us to buy a much needed second equipment delivery van. This van, named "Jane", was branded to acknowledge the important work our equipment service does, and to thank the Broughton family.

Jane the Van was unveiled at a special event for the Broughton family, where they were the special guests amongst staff, media, and a state MP.

Ever since this special event, Jane's been seen all around Victoria, delivering important equipment to people who need it.

She's a special member of our fleet, and we thank the people of Strathbogie who helped us get her.

EQUIPMENT SERVICE

"So grateful for the equipment service, the staff delivering the equipment are always really thoughtful and considerate and always happy to help."

Person living with MND

YOUR IMPACT

COMMUNITY FUNDRAISERS

Community fundraisers have always been at the core of MND Victoria's success. In 2024–25, an incredible 20% of our total fundraising income came from people in the community who went the extra mile to show their support for MND Victoria and those impacted by motor neurone disease.

Mirroring how widespread our services are, **our community fundraisers happen all around the state and take on many different forms.** This year some of our community fundraisers have ridden jetskis down the Murray River, played Lawn Bowls in Echuca, competed in target shooting in Horsham, dunked themselves in water in Shepparton, put on art exhibits at galleries in Bendigo and Pakenham, and held trivia nights in the suburbs of Melbourne.

From big events to small gestures, every effort added up to something remarkable, demonstrating the power of individuals and groups rallying together to ensure all Victorians impacted by MND can continue to receive the best possible care and support.

One of the most special moments of the year was welcoming the Broughton family to our Equipment Warehouse to unveil our new and much-needed delivery van, funded by their incredible community dinner—a perfect example of how much impact our community fundraisers make. Their generosity has left a lasting legacy that will benefit hundreds of Victorians living with MND through our vital Equipment Loan Service.

Just as importantly, every community fundraiser, whether it's a small morning tea at a primary school or aged care facility, or a major event like the Strathbogie dinner, is valued equally. Each one reflects the care and commitment of people who want to make a difference, and together, they create a powerful collective impact.

We are continually inspired by the creativity, generosity, and determination of our supporters, and we love celebrating these efforts through our social media channels and whenever possible in person. **Every fundraiser not only raises vital funds but also spreads awareness, sparks conversations, and strengthens the community around people living with MND.** If you're thinking about getting involved, we'd love to see you join this amazing group of fundraisers and create your own event in the year ahead. Together, we can continue to make a lasting difference.

YOUR IMPACT

THE GREAT MND RELAY

On Saturday 8 February 2025, our incredible community came together for the fourth Great MND Relay event in support of those living with MND.

With over 1,300 participants, this was our largest and most powerful event yet!

From the moment the event kicked off at Lakeside Stadium, there was an undeniable energy in the air. Participants took on the 2.5-hour challenge, pushing themselves every lap in honour of those living with MND.

Together, we not only raised awareness about the average life expectancy that comes with an MND diagnosis, but we also achieved a remarkable fundraising milestone. **Over $398,000 was raised to help MND Victoria continue providing vital care and support services for those impacted by MND.**

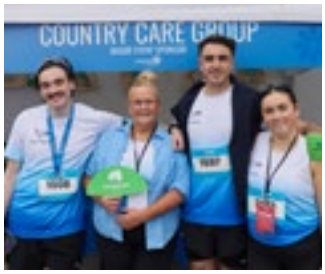
Throughout the event, an incredible 27,175 laps were completed, adding up to more than 10,870 kilometres walked, ran, or rolled! Each lap carried meaning, and thanks to our Major Sponsor, Country Care Group—who initially pledged $1 per lap before doubling their support to $2 per lap during the second wave—our collective impact was even greater.

After weeks of fundraising and event preparation, it was incredibly moving to see our community all coming together to #MakeItMatter. **The Great MND Relay is a powerful reminder that no one is alone in their journey with MND**, and we are inspired by our community's commitment to making an impact.

Alongside the in-person Relay, we had our virtual 'Your Relay, Your Way' option for those who could not make it on the day to the event. It was incredible to hear and see the 2.5-hour challenges you all set and conquered.

Thank you to everyone who was involved in this year's Great MND Relay. Whether you participated, donated, or spread the word—or if you were a volunteer, sponsor, performer, or staff member—it's thanks to everyone involved that The Great MND Relay was such a success! Together, we Made It Matter! We can't wait to do it all again next year, together.

THE GREAT MND Relay



SHUT UP! FOR MND

2024 marked the fourth year of the Shut Up! For MND Challenge, where participants chose to give up speaking for a 6 or 12 hour period.

For the first time, we expanded the campaign from a single Shut Up! day to a full Shut Up! week in September, providing participants with more flexibility to take on this challenge.

The Shut Up! For MND challenge has a huge impact, raising awareness that more than 80% of people with MND lose their voice or have difficulty speaking due to this disease.

Our inspiring challenge-takers helped raise over $165,000 towards providing care and support services for those living with MND.

SHUT UP! FOR MND

This year was my first time in the Shut Up! For MND Challenge. Leaving for work, my fiancé said "I love you" and I felt a pang knowing I couldn't say it back. At the office, hearing colleagues chat and laugh made me realise how hard it was to join in when I had to write my words instead of speak. The challenge gave me a deeper appreciation of the social and emotional difficulties faced by those who can't speak freely, and I'm proud to have taken part."

Monica, Shut Up! For MND challenge-taker

SOFIA LEVIN, OUR MASTER AMBASSADOR

For the last couple of years, we have been fortunate to have Sofia Levin, well known for her role as a judge on MasterChef and her career as a food journalist, as an ambassador for MND Victoria.

Sofia was first connected with MND Victoria due to her beloved dad, Greg, receiving an MND diagnosis, and she became passionate about Shut Up! For MND after he lost his ability to speak. Sadly, Greg passed from MND not long before Shut Up! 2024.

As a key supporter of the Shut Up! For MND campaign, Sofia dedicated time to appear in our campaign video, took part in media opportunities that we secured, and posted regularly about the challenge on her social media accounts.

Due to her personal dedication to MND Victoria, she took her ambassadorship even further by hosting an exclusive Shut Up! dinner, where attendees had to sit in silence for a certain amount of time, and an online auction with donated prizes—including a special painting by Sofia's dad, Greg Levin.

Sofia's special Shut Up! event inspired a second exclusive dinner hosted by celebrity chef Jamie Oliver.

We're extremely thankful to have Sofia as our ambassador, and look forward to continuing to work with her in the future.

YOUR IMPACT

MEET FINN – OUR JUNIOR AMBASSADOR!

Finn has become a well-known face at MND Victoria, because over the last two years (since he was 9 years old!) he's been a devoted fundraiser—alongside his mum, little sister, and extended family.

His "Glampa" Shane was diagnosed with MND, so Finn's family know firsthand about the difficulties in accessing care when you live outside of a metropolitan city, and the lack of support funding given to those diagnosed over the age of 65.

With MND Victoria looking after Glampa, Finn wanted to help look after MND Victoria. So when he learned about The Great MND Relay (2024), he set himself a nice goal: to be the highest individual fundraiser, which he achieved!

After the 2024 Great MND Relay, Finn educated his school on what MND was, and rallied his footy club to partake in a now-annual fundraiser. Excitingly, with the support of his mum and Emma Vulin MP for Pakenham, several politicians have gone to both the 2024 and 2025 footy club fundraiser.

Ready and willing to speak to every politician, we invited Finn to speak during our lunch event at Parliament House. He chose to focus his talk on his Glampa, sharing how important he is to him, and how important it is to everyone that there's better funding for everyone with MND.

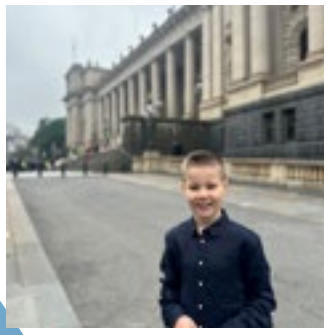
"I am so grateful that my Glampa has been able to have MND Victoria's support. He received a wheelchair, special bed, recliner chair and other items he now needs every single day. Could you imagine if MND Victoria didn't exist? How would we be able to keep my Glampa at home and comfortable?"

This got the attention of many of the politicians in the room, with relevant MPs setting up meetings with Finn later on, and the Victorian Premier Jacinta Allan making sure to shake his hand.

As an advocate, Finn has been invaluable. He's continued to meet with new MPs and kept up relationships with those he's already met; he wrote a letter to state MPs retelling his Glampa's story and asking for the government to provide funding to MND Victoria; and he's continued to take on any fundraising or speaking opportunity made available to him—all before he's started highschool.

This financial year we made Finn our first official junior ambassador, as a way to acknowledge all of the work he's done to raise money for MND Victoria and awareness of the issues impacting people like his Glampa.

From all of us at MND Victoria, we want to say a big thank you to Finn. We're excited to keep working together, advocating for the best support possible.



OUR SUPPORTERS

BEQUESTS

The Estate of Annemaree Foley
The Estate of Dorothy Eileen Ware
The Estate of Edna May Bastian
The Estate of Eileen Mcclelland Mitchell
The Estate of Ivan Andrew Cotchin
The Estate of Jane Doreen Edna Bourke
The Estate of John F Andrew

TRUSTS AND FOUNDATIONS

AL & T Brorsen Family Foundation
Freemasons Foundation Victoria
Hanlon Foundation
Lord Mayor's Charitable Foundation
Marshall Fund, a Charitable Fund Account of Lord Mayor's Charitable Foundation
Nancy Isobel Foundation
Nigel & Patricia Peck Foundation
Oliver J Nilsen Charity
The Dimmick Foundation
The John & Mary McAlister Howden Charitable Trust
The Lionel Gell Foundation Ltd
The Will & Dorothy Bailey Charitable Fund

ORGANISATIONS

Automobility Pty
Express Insurance Brokers Pty Ltd
Fisher Lane Mobility
FightMND
Power Network
Ritchies Supermarket & Liquor Stores
Specsavers Pty Ltd
The Lottery Corporation

GOVERNMENT FUNDERS

Australian Government Department of Health
Victorian Government Department of Health
Victorian Government Department of Families, Fairness and Housing

THE GREAT MND RELAY EVENT SPONSORS

Country Care Group (Major Sponsor)
Neurizon Theraputics (Dollar Match Sponsor)
Rosy Fox (Photobooth Sponsor)
Link Assistive Pty Ltd (Tribute Wall Sponsor)
Brighten (Coffee Sponsor)
Prestige Inhome Care (Fuel Station Sponsor)

CARER PROGRAMS

MEET ELISSA | CARING FOR A LOVED ONE WITH MND

Elissa's partner, Campbell, was officially diagnosed with MND in September 2024 after three months of suspicion and ruling out other potential causes. As a successful business partner, wonderful father to three teenage sons and a very fit and active person, his diagnosis came as a shock. Within three months of the diagnosis, he was using a wheelchair and had retired as he was unable to work effectively or enter his office, which was up a flight of stairs.

Elissa and Campbell met as backpackers living in London—travel had always been their passion. Since the birth of their children, travel had taken a backseat. But once Campbell was diagnosed, his priority, other than time with his kids, was to travel and tick off as many of his bucket list destinations as possible.

Because of their extensive travel, as well as Elissa working full time up until recently to better support Campbell and their teenage sons, it took Elissa over a year to attend her first Carer's Lunch—and she's so pleased she did, despite initially being nervous to join in. She's happy to have had the time to invest in her own wellbeing, which is so important when caring for a loved one with MND, and she also had the opportunity to meet people who were going through what she is.

"I worried that it would be confronting, that I wasn't ready, or that I wouldn't be able to relate to these strangers despite having a common connection. I guess part of me thought it would make it all feel even more real too, and sometimes it's nice to be in a bit of a bubble of denial."

For Elissa, attending a Carer's Lunch was incredible. She felt an immediate connection to people who understood exactly what she was feeling, which was extremely comforting. Even though everyone in attendance was at different stages of caring for their partners in their MND journeys, they could all share their experiences and emotions.

"The support was just beautiful. Everyone had different stories, but they were also relatable. I received some great advice, and I got to offer some too. It was rewarding and insightful.

"To be surrounded by people who actually KNOW what it's like, on a day to day, moment to moment basis, was so comforting. I think until you're living and caring for someone with MND, it's hard to fathom the physical changes that occur every single day and how hard it is to watch your loved one go through it. I looked at these people and just remember thinking, 'they really get it.'"

One moment that stood out to Elissa in particular is when one of the other carers told her how important it is to take some time to care for herself too—after all, she can't look after Campbell if she isn't looking after herself too.

As a wife, a mum and a nurse, Elissa has often wanted to do it all, but that particular conversation got her thinking about taking some more time for herself and allowing people to help out when they can. She wants to be the strongest she can be for Campbell and her sons, and she has learned that means looking after herself too.

"I know as things progress with Campbell's illness that these things will become more challenging, but he is amazing and encourages me to take time out for me always. I'll always aim to do that for both our sakes."

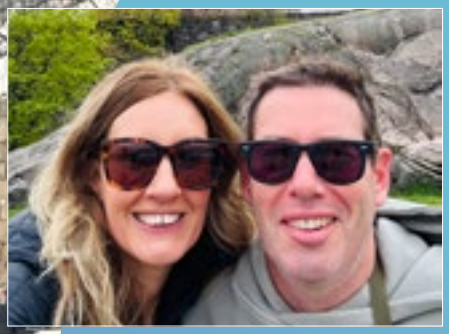
Elissa is looking forward to attending the next Carer's Lunch hosted at a café near her.

THE IMPORTANCE OF CARER PROGRAMS

MND Victoria recognise the importance of supporting carers, to assist in maintain their wellbeing as well as the wellbeing of the person they're supporting.

The Every Moment Matters economic impact report found that informal/family carers of people with MND provide 5.37 million hours of care annually. We know the carer role often becomes all-encompassing, and carers report a lower quality of life than people with MND.

In addition to our state-funded Support For Carers funding, we were again grateful to receive another 2 years of respite funding. These funding sources enables us to support carers through quality of life activities such as massages and home maintenance, which give carers a small break away from their carer role.



VOLUNTEER STORY

LORRAINE'S DECADE OF GIVING BACK

Lorraine has been volunteering for MND Victoria for a decade, primarily in the Newsletter Mailout team. Always ready to help if she can, she's also volunteered at our major fundraising events, and featured in awareness videos.

In 2010, Lorraine's husband Bill was diagnosed with MND.

"Bill struggled during his roller-coaster ride, quickly deteriorating and losing many abilities, such as his independence, being able to drive, loss of speech and not being able to use his arms and legs, which was very tough for Bill and everyone supporting him.

MND Victoria supported Bill and I during his journey. The loan of equipment was simply the best and I don't think we would have managed without it, because his needs were changing continually and so rapidly.

From when I returned to work until I retired at the end of 2013, I was thinking about volunteering and giving something back to MND Victoria. Once I saw an ad asking for volunteers, I phoned the Canterbury office and was warmly welcomed as a Newsletter Mailout Vollie!

I look forward to my Newsletter Mailout shifts. It's a nice time where we have some music playing in the background, while we pack and seal the newsletters.

It's always great to have a chat over morning tea. Some faces in the team have changed over the last ten years, but there are quite a few of us who have built a strong and supportive bond together.

Working as an MND Victoria vollie is very rewarding, especially to have previously lived through a journey, knowing what is involved and how quickly things can change.

We need a cure, but knowing there's care until there's a cure is so very important. Every time I am volunteering with MND Victoria, I feel treasured because all of the staff, including the CEO, treats us as equals, plus keeping us in the loop on all events, updates and changes in the organisation.

The Volunteer Engagement Team organise Volunteer Week outings to places like the Old Melbourne Gaol, State Library, Islamic Museum of Australia and the Seafarers Mission, and celebrations over special days for all of the volunteers. I'd say that these are some of my highlights of my time volunteering with MND Victoria.

I do love volunteering, I think it's important to give back, to show kindness to others and I will continue for as long as I possibly can."

Our volunteers bring a wide range of skills and experiences, that enhance the lives of those we support, and help the Association to thrive.

The roles and activities our volunteers do:

- **Social home and community visits**
- **Social phone chats**
- **Gentle hand and foot massages**
- **Making bereavement calls**
- **Capturing a person's life story**
- **Providing support with technology**
- **Packing wellness kits**
- **Preparing materials to be mailed out**
- **Supporting major events**

RESEARCH

We are proud to support several fundraising events that focus on raising money for MND research. These funds are allocated to research programs through MND Research Australia. In the 2024/25 financial year, the following grants were provided:

SUPERBALL XVII MND RESEARCH GRANT

Natalie Grima | Macquarie University

We have identified a subgroup of sporadic MND patients with a unique molecular signature in the cerebellum, a brain region with a lesser-known role in MND. Interestingly, this subgroup demonstrates the same pattern of hallmark TDP-43 pathology as MND patients who carry a mutation in the C9orf72 gene. We aim to uncover whether this sporadic MND subgroup, encompassing around one-third of all MND cases, shares other similarities with C9orf72-linked MND. Identification of similar genomic (DNA) or transcriptomic (RNA) signatures means that individuals belonging to this sporadic MND subgroup may have common therapeutic targets to the major genetic cause of MND.

JENNY SIMKO MND RESEARCH GRANT

Yuval Gurfinkel | Murdoch University

In SOD1-linked MND patients, as well as many sporadic MND cases, the SOD1 protein folds incorrectly, forming toxic aggregates that interfere with normal neuronal functioning. In this project, we will compare the genetic profiles of people with MND and healthy individuals in cells taken from a skin biopsy and use these cells to test the effect of our SOD1 suppression therapy. The findings will allow us to rapidly identify sporadic patients with genetic profiles that resemble SOD1-linked cases who may benefit from SOD1 suppression in future clinical trials, making our anti-SOD1 drug widely accessible to MND patients.

NINA BUSCOMBE AWARDS

With the Pan-Asian Consortium for Treatment and Research in ALS (PACTALS) annual congress and the MND Australia Care conference being held in Melbourne in September 2025, we received many applications from researchers and Allied Health professionals to support attendance at these events. We were thrilled to be able to support 26 professionals from all over Australia to attend. In addition, we supported 6 professionals to attend the International MND Symposium, to be held in December 2025 across Toronto and San Diego.

SUPERBALL 2025 AND GENETIC COUNSELLING

The MND Charity Superball is a longstanding community fundraiser, which has raised over $1.1million for MND research. For this year's event, the organisers decided to turn the Superball's focus to care, following research demonstrating a need for genetic counselling in the MND space.

Up to 15% of MND is 'familial', and there's many reasons why those who suspect familial MND may choose to access genetic testing. While genetic testing is available through Medicare, genetic counselling isn't. We believe it is imperative that people diagnosed with MND and their families have quick access to a genetic counsellor to support them through the testing process and understanding their results.

With the support of the 2025 Superball, and in consultation with genetic counsellors from Monash and the Austin, we have been planning a specialised genetic counselling program. We expect this service to commence in 2026.

FINANCIAL IMPACT 2024/25

An eventful FY24 that included the opening of our new equipment warehouse and the launch of new initiatives such as our Counselling Service has been followed by a year of consolidation in FY25. We've invested heavily in our people.

Our Advisor and Support Coordination team has grown considerably with six new staff members joining us throughout the year so that we can better serve those with MND and their families. Our Community Engagement team has also grown in numbers as we strive to give them all the tools and encouragement needed to reach for the stars in their search for new revenue streams. This work is vital for the long-term financial health of our charity given that the revenue generated by our support services work from the NDIS and government grants falls well short of the costs of providing the services people living with MND need and deserve.

Our audited Statutory Accounts highlight the importance of diversifying our income streams. We returned an operating deficit in the 2025 financial year of $616k. Fortunately this followed a tremendous FY24 in which we reported a surplus of $1.9m thanks to extraordinary bequest revenue.

Our total income for the year was $9.2m which is $1.2m less than in FY24 due mostly to a decline in bequest revenue. As can be seen on the page right, revenue from the NDIS, State and Federal grants account for a combined 48% of our total income which is simply not enough to provide the high-quality services that people living with MND need. The other 52% comes largely thanks to our strong community of supporters through donations and bequests, without which we just wouldn't be able to do what we do best.

Our total expenses for the year were $9.8m, an increase of $1.3m over FY24 due to an increase in staff numbers. During the year, 57% of our total expenses were allocated towards the provision of our advisory services and another 20% on our equipment service. Community engagement and communication expenses represent 18% of our costs which leaves 5% for administration and research combined.

Although the Association made a loss in FY25, we remain in a solid financial position thanks to the careful administration of our finances from the management team and State Councillors. At balance date we had over $12.8m of financial investments and a further $3m of cash and cash equivalents on hand. This financial buffer gives State Council the confidence to continue investing in our services despite returning a trading deficit in FY25. We do however remain dependent on our community of supporters, without whom we would simply not be able to deliver the high-quality care those impacted by MND deserve.

Callum Terrill

Chief Financial Officer

FY25 INVESTMENTS IN UNFUNDED PROGRAMS

NEW VAN
$64,750

Delivering vital equipment to people with MND

ADVISOR & SUPPORT COORDINATOR SERVICES
$1,850,000

Supporting clients beyond government grants and NDIS

VOLUNTEER TRAINING & SUPPORT
$112,500

Empowering volunteers to make a difference for those impacted by MND

NEW ASSISTIVE TECHNOLOGY EQUIPMENT
$414,500

Enhancing client comfort with:

- 4 new electric wheelchairs;
- 13 hoists;
- 14 new recliners;
- 18 new hospital beds;
- 3 cough assist machines;
- Plus hospital beds, mattresses, manual wheelchairs and more

9 NEW MOTOR VEHICLES
$208,600

Enabling advisors to conduct visits efficiently

24 NEW LAPTOPS
$54,350

Ensuring efficient work for Advisors and Coordinators, onsite and remote

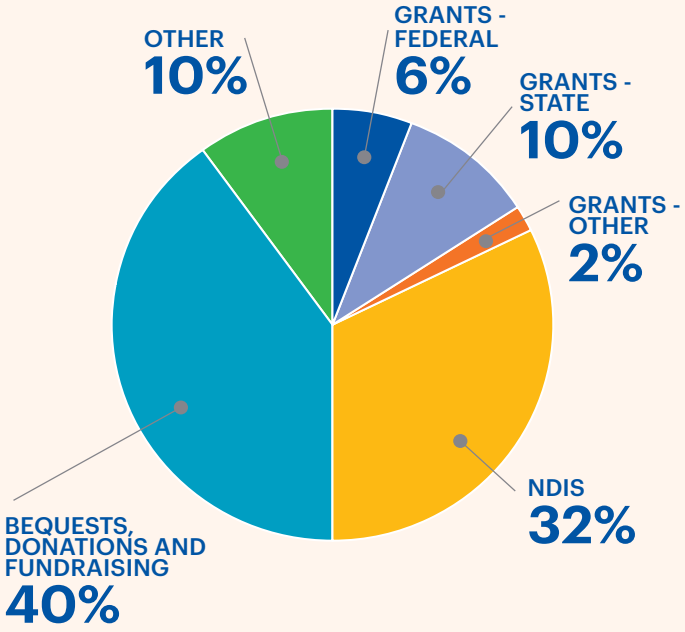
PROFESSIONAL SERVICES TO ALLIED HEALTH
$150,000

Supporting allied health professionals assisting people with MND

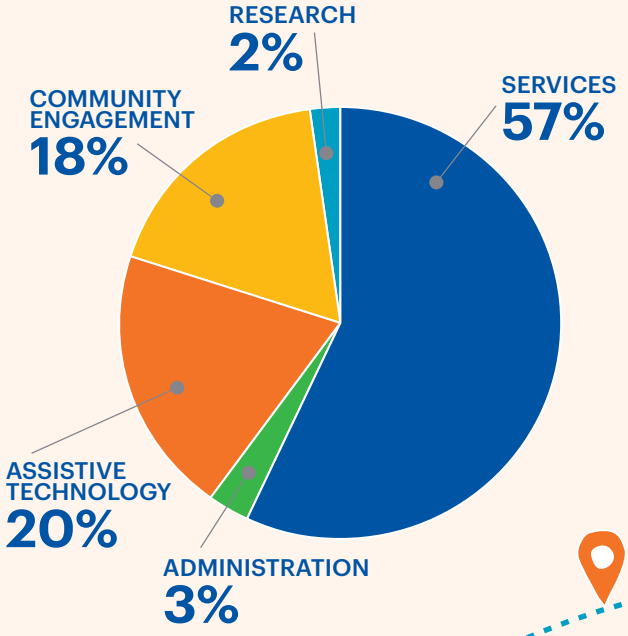
RESEARCH CONTRIBUTIONS
$174,000

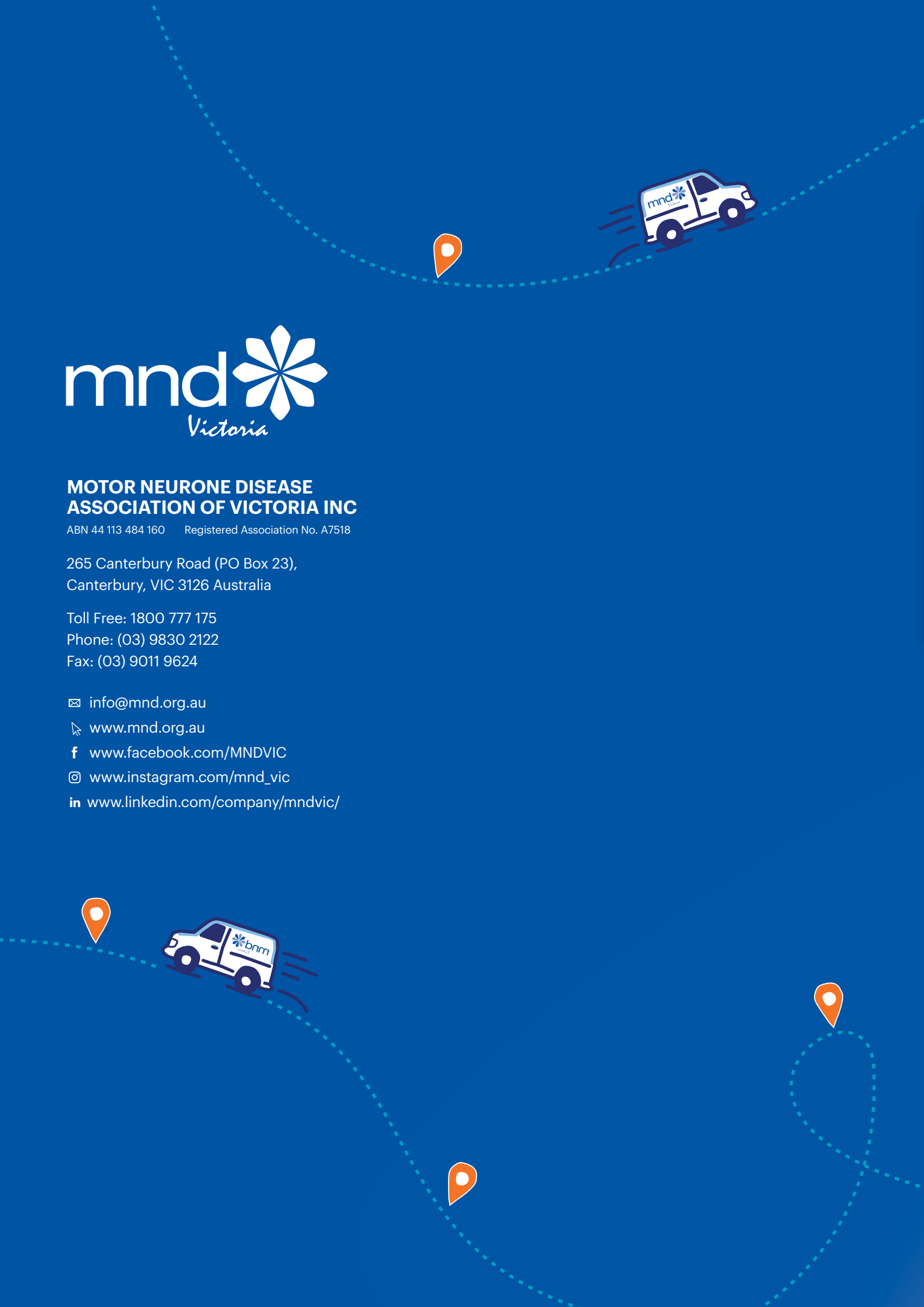
Supporting vital MND research toward a cure

INCOME BY SOURCE



EXPENDITURE BY TYPE





MOTOR NEURONE DISEASE ASSOCIATION OF VICTORIA INC

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