

# Annual Impact Report

2024/25



**mnd**  
Motor Neurone  
Disease NZ

**Participants at the Wellington  
Walk to Defeat MND 2025.**



**Motor Neurone Disease New Zealand Charitable Trust**

**Incorporated Society: 50109950**

**Charity number: CC60169**

**1 July 2024 - 30 June 2025**

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# Chairperson's Report

The 2024/25 financial year marked a significant step forward in our work to support people living with MND and their families across Aotearoa New Zealand.

The Board approved an aspirational budget aimed at building our support and advocacy presence and with it, the trust of the MND community and our stakeholders. We committed to expanding services and deepening our impact – and we're proud of what has been achieved.

## **Strengthening support and connection**

We increased support advisor coverage in the lower South Island and launched new support groups in Otago, Auckland, Waikato and the Bay of Plenty. These groups continue to grow, offering vital connection and community support for those affected by MND.

Through our new partnership with the Jubilee Trust, in addition to foundation supporter Fulton Hogan, we doubled the funds available to the MND Support Fund. Demand on the MND Support Fund has remained strong, and the Board of Trustees agreed to top up the fund at year-end to ensure no one was left without support. We're especially proud that 100% of donations through this pathway go directly to meeting the needs of people with MND – where the health and disability services fall short.

## **Driving insight and advocacy**

A major milestone this year was the launch of the MND Insight Research initiated and led by Dr Natalie Gauld, our Research Advisor and Best Practice Advocate. This landmark study – the most comprehensive of its kind in New Zealand – captures the

lived experience of people with MND and their families, whānau and carers. The insights are already informing our advocacy strategy and will help shape better systems and support in the years ahead.

## **Building for the future**

We've seen a strong financial outcome this year, following several years of deficit. In response, the Board has introduced a Reserves and Bequest Management Policy to guide how we use surplus funds. This includes maintaining up to 12 months of operational reserves and tagging resources for research, strategic development, and infrastructure expenditure – ensuring we can remain a consistent source of support for the MND community, even during uncertain times.

## **Looking ahead**

We are confident that Motor Neurone Disease New Zealand has delivered strongly in 2024/25 – in support, advocacy, community engagement, relationship building, and research. We're also looking to the future with a clear development pathway and the resources to support it.

Thank you to the supporters, the MND NZ team, and Board who have contributed to this years' progress. Your support helps us make time count for people with MND.



*Lucy*

Lucy Haberfield  
**Chair of the Board of Trustees**  
**Motor Neurone Disease New Zealand**

# Why We're Here

Motor neurone disease (MND) is a devastating illness that moves fast — taking away the ability to walk, talk, eat, and eventually breathe. Most people live just two to three years after diagnosis.

Also known as ALS or Lou Gehrig's disease, MND is a group of rare, progressive neurological conditions.

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**“Every day, with the support of our community, we help people live with dignity, courage, and hope — and take another step toward a future without MND.”**

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While the causes of MND remain unclear, our determination to find answers has never been stronger. There is still no cure, and treatment options remain limited.

The impact is profound. MND changes everything – not just for the person diagnosed, but for everyone who loves them.

At Motor Neurone Disease NZ, we exist to bring light to the darkest of journeys.

We travel alongside people and whānau facing MND with compassion, trusted information, and fierce advocacy — offering strength when it's needed most, and connection when it matters most.

Every day, with the support of our community, we help people live with dignity, courage, and hope — and take another step toward a future without MND.



# What We Want To Achieve

## Our Vision:

We envision a world where no one faces MND alone – where people are supported to live with dignity and hope, and where, one day, MND is treated, cured or prevented.

## Our Mission:

Making time count for people affected by MND by offering personal support; advocacy; education; and supporting research.

## Every day, we work to make a difference through:

- **Support** – to make life easier for people living with MND and their loved ones.
- **Fundraising** – to support people impacted by MND now and provide hope for the future.
- **Advocacy** – to drive change and timely access to health and disability services.
- **Investing in research** – to improve quality of life, aid advocacy, and support research in New Zealand.
- **Education** – to increase knowledge, recognition, and understanding of MND.
- **Campaigning** – to raise awareness and build trust and support for our cause.

## Our key focus areas:

### Tailored Support

We will provide a personal, consistent support offering to every person affected by MND in New Zealand, that answers questions and solves challenges quickly.

### Meaningful Advocacy

We will raise awareness and champion our cause, campaign for change, and lead the way in making a difference.

### Practical Education

We will provide a broad range of education opportunities to increase knowledge, recognition and understanding of MND.

### Impactful Research

We will adopt a collaborative approach to funding and supporting MND research, with the goal of bringing treatment studies to NZ, supporting policy decisions, improving quality of life, discovering effective therapies, and finding a cure.

### Inspirational Engagement

We will be strong in our brand, engage with clarity and purpose, and achieve sustainable, diverse income for our work. We will grow our community and foster a sense of belonging.

### Organisational Excellence

We will grow our people, nurture collaborative relationships, build our reputation, and embrace a growth mindset. We will grow and develop our cultural competencies.

# How We Work to Achieve It

The blue cornflower is the international symbol for MND.

While the cornflower has a fragile appearance, it is both courageous and determined, able to withstand the most testing of environments. This vivid blue flower mirrors the remarkable strength shown by people affected by MND in coping with this devastating disease.

We draw inspiration from these traits and symbolism, and use them to guide how we approach delivering our mission.

## Our Values:

- **We are resilient:** we're not afraid to speak up on the issues that matter. We tackle challenges professionally and with integrity.
- **We are authentic:** we are open, transparent and consistent in our work. We use plain and understandable language.
- **We are bold:** the MND community is at the centre of everything we do. We speak with one proactive and dignified voice to represent the views of our community.
- **We are diverse:** we celebrate and embrace working together. We are respectful, inclusive, and friendly. We listen, we understand, and we don't judge.
- **We are strong:** we are experts in our field and provide robust, transparent advice and support wherever it is needed.

## Our Decision-Making Approach:

To ensure we are always focused on working towards our vision and mission, every decision we make is assessed against six key questions:

1. Will it make things easier for people with MND and their loved ones?
2. Will it increase our reach to ensure a wider awareness of MND and engagement with our mission of making time count?
3. Can the work be done within the current framework of our organisation?
4. Does it support our commitment to growing and developing our people?
5. Will it strengthen the diversity and sustainability of our funding base?
6. Does it build on our existing skills and strengths and support sustainable growth?

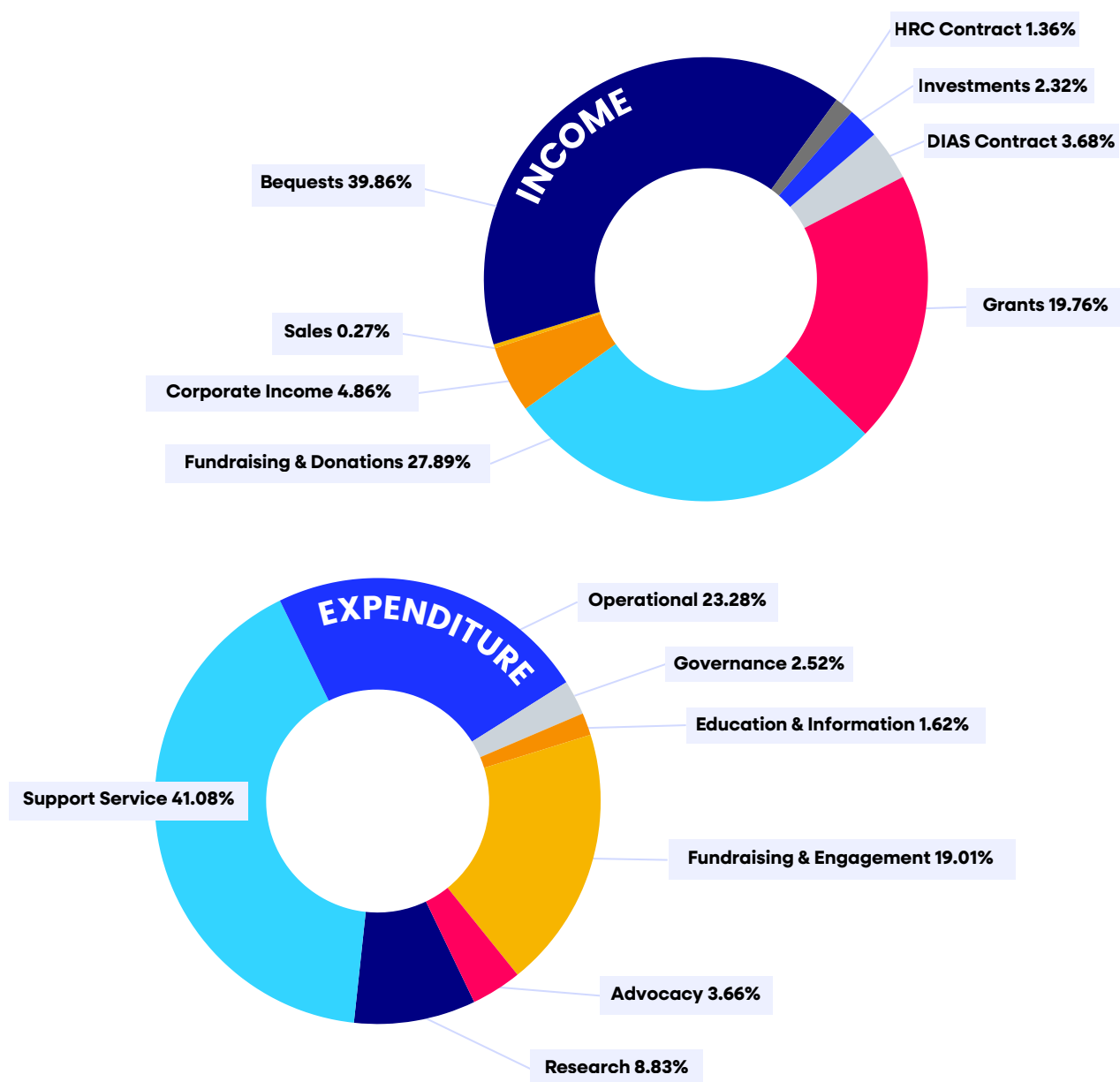


# How We're Doing It

At end of June 2025, Motor Neurone Disease NZ employed 15 staff across four portfolios - Support Service (53% of staff), Operations (13% of staff), Engagement (27% of staff) and Research (7%).

Most of our people work part-time, and salaries are funded primarily through grants and a small contract with Whaikaha – Ministry of Disabled People.

We have a small national office based in Royal Oak, Auckland. Our staff are based across Aotearoa New Zealand, and our service delivery covers from Northland to Stewart Island.



# Our Impact

Motor Neurone Disease NZ is a charitable trust dedicated to making time count for people living with MND and their loved ones, as well as supporting research for a future without MND.

Each of our operations, from support services to community engagement and funding, has a profound impact upon the community.

## Supporter impact – the year in numbers



# Focus Area:

## Tailored Support

We provide a personal, consistent support offering to every person affected by MND in New Zealand, that answers questions and solves challenges quickly.

### How we help

Our support advisors work with people living with MND, their carers, family and whānau to help them live the best life possible. They provide support through:

- **Home, community, and clinic visits** – seeing the environment helps us tailor advice and practical solutions.
- **Phone, text, email and video calls** – staying connected in the way that works best for each person.

We have seven regional support advisors and one support services manager based in Auckland. Each advisor travels across their region, spending up to three hours with a client when needed.

### Our impact this year

- **483** people with MND supported and advocated for
- **602** face-to-face contacts with clients and their family
- **5,820** contacts (email, phone, text) with clients and their family

“

“Rachel, we are so grateful for MND NZ and your support. It was a shock to learn of my brother-in-law's diagnosis, and we felt so helpless on so many levels. The MND NZ website helped us understand MND and it gave us the opportunity to help those facing such a disease, and us to feel less helpless. Thank you again so much for all you and your colleagues do, it is much appreciated.”

“Ngā mihi Sally. I have learnt so much from you about MND and so appreciate the Awhi and Manaaki you have provided throughout our journey with this disease.”

”



## MND Support Fund

When the health system can't meet every need, our Support Fund steps in. This year, we funded 120 applications for essentials that improve quality of life, including:

- Mobility equipment and home modifications
- Respite care and counselling
- Travel costs for treatment
- Help with power bills and heating

## Impact at a glance

This year, the Support Fund helped people with MND access essentials that improve daily life:

- **Mobility & equipment** – 55 grants for walkers, hoists, and assistive devices
- **Home & vehicle modifications** – 16 grants for housing changes and vehicle adaptations
- **Therapy & wellbeing** – 24 grants for treatments, counselling, and respite care
- **Travel & accommodation** – eight grants to cover costs for appointments and stays
- **Financial & lifestyle support** – 17 grants for power bills, pharmacy costs, and other essentials



*"I have had my first session with a counsellor from the Grief Centre. It went very well, and we have a plan moving forward to help. Thanks so much for arranging the funding for these sessions and initiating the contact."*

*"The lightweight walker is fantastic and allows me to retain my independence. So much easier for me to lift into and out of my car. Thanks for your support through this fund."*



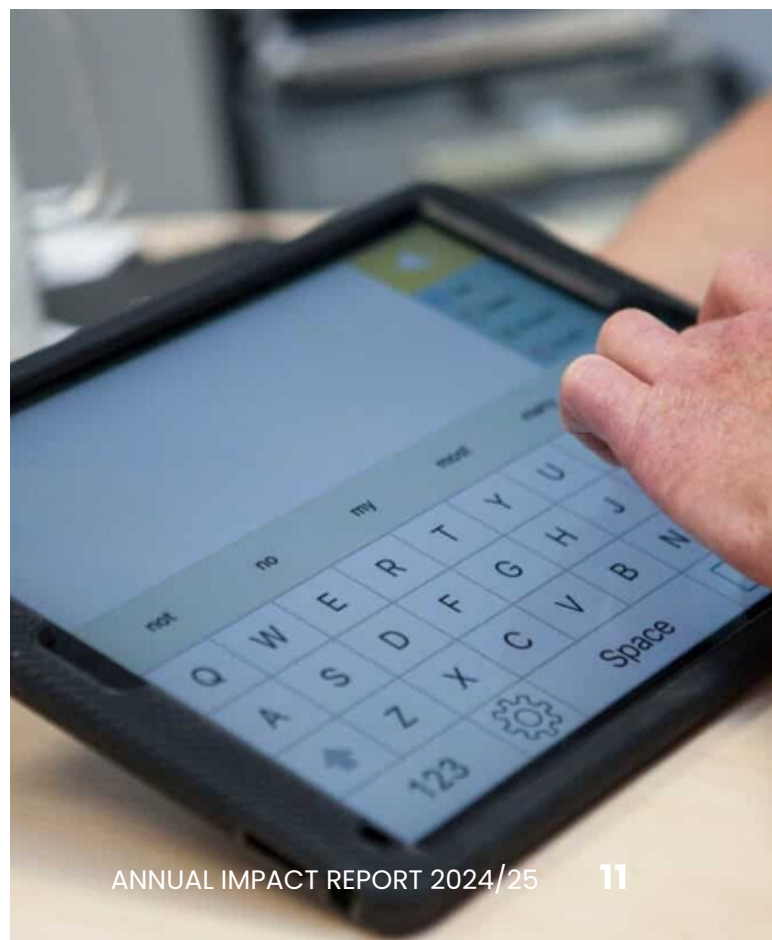
## Powered by partnership

The MND Support Fund was established with the foundational support of Fulton Hogan, who continues to be a vital partner in making this mahi possible.

In late 2024, the Jubilee Trust came on board as a second sponsor, matching Fulton Hogan's annual contribution. Together, these donations help us provide national coverage – with each sponsor supporting a specific geographic area, balancing support across the motu.

Their generosity – alongside donations and fundraising from our community – has enabled us to keep meeting growing needs. It has doubled the fund's capacity and ensured that more people receive timely, practical help.

We are deeply grateful to both Fulton Hogan and the Jubilee Trust for their commitment and care.



# Focus Area:

## Meaningful Advocacy

We raise awareness and champion our cause, campaign for change, and lead the way in making a difference.

Motor neurone disease (MND) is a relentless condition, and timely access to essential equipment and services is critical to maintaining quality of life. Sadly, delays in the current health and disability system often mean that people living with MND face long waiting lists for items like mobility aids and home modifications — sometimes receiving them too late to make a meaningful difference.

“

*"It took more than a year for the home modifications, including a ramp and bathroom changes, to be completed. By then, my condition had progressed significantly, making the adaptations far less useful. It was a missed opportunity to maintain some independence and get out of the house while I still had mobility."*

### Our focus this year

- **Driving consistency in care** – Advocating for national guidelines to be applied consistently across the health system.
- **Building the case for change** – Developed a strong evidence-based case for support, backed by clinical leaders and new research, to show why urgent improvements are needed.
- **Connecting with decision-makers** – Mapped key stakeholders and held meetings with agencies including Department of the Prime Minister and Cabinet, Enable, Accessable, and clinical leaders to influence policy and process.
- **Creating pathways for collaboration** – Progressed discussions toward formal agreements that will help deliver better outcomes for people with MND.

### Why it matters

Every delay in equipment or service provision impacts quality of life. Through advocacy, we aim to remove these barriers and ensure people with MND receive timely, equitable support—wherever they live.

“

*"By the time the equipment arrived, I could no longer use it. That delay stole precious independence from me."*

*"It was concerning that the first needs assessor did not seem to understand MND. When he said my needs would change once my condition improved, I had to explain that there is no improvement with MND, only ongoing progression."*

”

# Focus Area:

## Practical Education

We provide timely, practical and robust education opportunities to increase knowledge, recognition and understanding of motor neurone disease.

Knowledge empowers people to navigate MND with confidence. Our goal is to provide timely, practical education for individuals, families, and health professionals – so everyone involved understands what matters most.

### What we delivered

- **23 tailored education and awareness talks** for hospices, care facilities, health teams, public forums, and community groups – each adapted to the audience and their needs.
- **147 personalised information packs** provided to newly diagnosed clients and, where needed, their health professionals – helping people understand MND and plan ahead.
- **Growing online reach** – Our website continues to be a trusted source of information, with thousands of visits to pages like Basic Facts About MND, What Causes MND, and Support Advisors.
- **Regular updates** – Five e-newsletters and two editions of MND News kept our community informed and connected.

### Building for the future

- Approved a new education programme focused on newly diagnosed individuals and their carers.
- Recruitment for a dedicated educator role commenced after year-end — this role will lead expanded education for families and health professionals.
- Drafted programme content and supporting resources to ensure a strong start in 2025/26.

*"I've received lovely feedback from a colleague who particularly valued your approach. They appreciated your acknowledgment that while we work closely with clients living with MND, we may not always fully grasp the intricacies — from the anatomical causes to the various presentations, disease types, and progression patterns."*

*"Your description of MND as 'predictably unpredictable' resonated with many of us and underscored the complexity of supporting individuals with progressive conditions."*

*"Your presentation was incredibly informative, and while not all of our team could attend in person, many have shared their appreciation for the opportunity to catch up via the recorded session."*

# Focus Area:

## Impactful Research

We take a collaborative approach to funding and supporting MND research, with the goal of bringing treatment studies to NZ, supporting policy decisions, improving quality of life, discovering effective therapies, and finding a cure.

In New Zealand, it's estimated that more than 400 people are living with MND, with around 150 new diagnoses and 150 deaths each year. Research suggests the incidence here may be higher than in other countries. For most people with MND the median survival time from symptom onset to advanced ventilation or death is just three years, often less from diagnosis.

In the absence of a cure, every day matters. That's why we invest in research that makes time count: improving evidence-based care, enabling access to clinical trials, and contributing to the global effort to discover effective therapies and, ultimately, a cure.

### What we delivered

- **Research strategy foundations** – Work began on a 2025–28 research strategy, informed by consultation with researchers and the community.
- **MND Insight Research** – This collaborative study is the most extensive MND study ever undertaken in Aotearoa New Zealand. It captures the lived experience of people with MND and their family carers, highlighting what's working well, where improvements are needed, and how we can advocate for better systems and support. These findings are already informing advocacy efforts and future research priorities. This research is funded by Motor Neurone Disease NZ, Health Research Council, and Dr Natalie Gauld.

- **Regular updates** – Shared research news through newsletters and online platforms, keeping our community connected to global developments.
- **Registry growth** – Continued funding and support for the NZ MND Registry, a vital resource for understanding and researching MND in Aotearoa.

### Spotlight:

#### NZ MND Registry

Since its establishment in 2017, the Registry has provided critical insights into the prevalence, progression, and impact of MND in New Zealand.

Managed by the University of Otago and led by Dr Sarah Buchanan, it securely collects anonymised data that can be used for research and connects participants with research opportunities – including studies on genetic forms of the disease and clinical trials.

With over 400 people currently living with MND in New Zealand, our goal is to ensure as many as possible are represented, helping to drive meaningful research and improve outcomes.

# Focus Area:

## Inspirational Engagement

We are strong in our brand, engage with clarity and purpose, and achieve sustainable, diverse income for our work. We will grow our community and foster a sense of belonging.

We connect people, stories, and action to create a movement of hope. Through campaigns, events, and communications, we inspire New Zealanders to stand with those living with MND — and make every moment count. Every interaction, from a social media post to a community walk, helps build awareness, spark generosity, and strengthen the sense of belonging that drives our mission forward.

### Walk to Defeat MND

Our 2025 walk season was a huge success — bringing communities together across Aotearoa to raise awareness and vital funds for people living with MND.

- **\$149,288 raised**  
(up from \$124,582 in 2024)
- **1,515 donations** from generous supporters
- **446 sign-ups** and **1,068 tickets sold**, generating \$17,386 in ticket sales

This growth reflects the incredible commitment of our community and the power of collective action.

“The Walk to Defeat MND gave me a way to contribute. A way to do something and be part of something that could help in some way.”

“A huge amount of planning time and effort is put into the event by staff, and their commitment was very plain to see – amazing and special!”

### MND Action Month

June 2025 was our biggest awareness campaign yet. Under the banner of MND Action Month, we combined the Ice Bucket Challenge and Cuppa Tea for MND, inviting New Zealanders to learn more, speak up, and take action.

**Our vision:** Raise visibility, deepen understanding, and drive action for those impacted by MND.

**Our call to action:** Every cuppa poured and every bucket tipped helps provide support, education, advocacy, and research for the 400+ Kiwis living with MND.

#### Key highlights:

- **\$163,000+ raised** — funding vital support, advocacy, and research
- **5 million+ impressions** — the number of times our content was seen
- **100 sign-ups** with an 80% activation rate (up from 57% in 2024)
- **90+ community events** — from Cuppa Teas to Ice Bucket Challenges
- **42 Bunnings stores** engaged, amplifying reach and impact
- **Powerful storytelling** and news coverage
- **Strategic partnerships** that support income and service delivery

The campaign didn't just raise funds — it sparked hundreds of conversations, reduced isolation, and built a stronger, more connected community around MND.

# Our Supporters

Our supporters are valued members of the Motor Neurone Disease NZ whānau. Every donation, grant, and act of advocacy helps us provide personal support, fund research, and raise awareness - making a real difference for people living with MND.

## Special thanks: MND Support Fund sponsors

- **Fulton Hogan** – foundation sponsor of the MND Support Fund
- **Jubilee Trust** – sponsor of the MND Support Fund

## Gifts in Will

We acknowledge those who have chosen to leave a gift in their Will - creating a legacy of care and hope for people living with MND. These lasting contributions help ensure care and research for future generations.

- Estate of Cyril William Ivan Hancock and Phyllis Rosemary Hancock
- Estate of Gail Godso
- Estate of Alison Mary Thurlow
- Estate of A M McCarlie
- Estate of Paul Anthony Schollum
- Estate of KM Philp
- Estate of Jennifer Duncan
- Estate of Nellis Rowena Bason-Lambert
- Estate of Simon Glynn
- Estate of Doris Crooke
- Estate of John Hill
- Estate of Gail Godso
- Estate of P S Beau

## Corporate donors

Bunnings, Bolster Risk Management Ltd, Aggregate Receivables Group Members, Downer, Naylor Love, Plus Energy, Simplicity Foundation, Go Media, Dilmah.



## Trusts and foundations

This growth reflects the incredible commitment of our community and the power of collective action.

- AD Hally Trust, proudly managed by Perpetual Guardian
- Aoraki Foundation
- Aotearoa Gaming Trust
- Blue Sky Community Trust Ltd
- Community Organisation Grants Scheme
- Community Trust of Mid & South Canterbury
- Community Trust South
- Dragon Community Trust Ltd
- DV Bryant Trust
- Eastern & Central Community Trust
- Estate of Ernest Hyam Davis & The Ted and Mollie Carr Endowment Trust, proudly managed by Perpetual Guardian
- First Light Community Foundation
- Four Winds Foundation Ltd
- Frimley Foundation
- Grassroots Trust Central Ltd
- Guy Anson Waddel Charitable Trust, proudly managed by Perpetual Guardian
- Higgins Bequest Trust
- Hutt Mana Charitable Trust
- John Ilott Charitable Trust
- John Stewart Booth Trust
- Kiwi Gaming Foundation Ltd
- Lindsay Foundation
- Lottery Grant Board community fund
- Louisa & Patrick Emmett Murphy Charitable Trust
- LW Nelson Charitable Trust
- Mainland Foundation
- Maurice Paykel Charitable Trust
- Milestone Foundation
- New Zealand Community Trust
- Norah Howell Charitable Trust
- Oxford Sports Trust
- Pub Charity Ltd
- Rano Community Trust Ltd
- Redwood Trust Inc.
- Rotorua Trust
- Roy Owen Dixey Charitable Trust
- Royston Health Trust
- Southland Care and Welfare Trusts, proudly managed by Perpetual Guardian
- Stewart Family Charitable Trust, proudly managed by Perpetual Guardian
- The Lion Foundation
- The North & South Trust Ltd
- The Trusts Community Foundation
- Trust House Foundation
- Trust Tairāwhiti
- Trust Waikato
- We Care Community Trust Ltd
- Whanganui Community Foundation

Everything we achieve - from personalised care to groundbreaking research - is only possible because of your generosity.

**Thank you for standing with us and making hope a reality for people living with MND.**



# Organisation Structure

## Board

- **Chairperson/Treasurer** – Lucy Haberfield
- **Board Members** – Alan Stanley, Estelle Arts, Patricia Sloan, Peter Brown

## Support Service

- **Support Services Manager** – Toni Foster
- **Support Advisors** – Moira Young, Sally King, Megan Te Boekhorst, Jasmine Chua, Jeanette Tioke, Rachel Woodworth, Sarah Mathieson (from August 2024).

## Operations and Engagement

- **Chief Executive** – Mark Leggett
- **Business Support Manager** – Hayley Forrest
- **Fundraising and Marketing Manager** – Laura Huet
- **Fundraising and Events Coordinator** – Rob Bloch
- **Grants Coordinator** – Jeanette Franklyn
- **Communications Specialist** – Katya Old (until November 2024), Myrddin Gwynedd (from January 2025)

## Research

- **Research Advisor & Best Practice Advocate** – Dr Natalie Gauld

## Honorary Positions

- **Medical Patron** – Sir Richard Faull KNZM FRSNZ
- **Honorary Medical Advisor** – Dr James Cleland FRACP
- **Honorary Solicitor** – Scott Moran, Partner, Duncan Cotterill

## Life Members

Reima Casey, Andrew Chancellor, Robina Davies, Graham East (decd.), Dennis Hall, Edith McCarthy, Helen Palmer, Mary Parker, John Roxburgh, Nedra Shand, Geoff Thompson, and Beth Watson (decd).

# Performance and Financial Information

## Service performance 2024/25

### Description of outputs

Motor Neurone Disease New Zealand (MND NZ) is a charity built on the ethos of helping people affected by motor neurone disease (MND) – and it remains the cornerstone of all that we do today. Since being established in 1985 by a group of volunteers with their own personal experience of the disease, the organisation has grown into the vibrant and passionate community we know today.

#### Every day, we work to make a difference through:

- **Support** – to make life easier for people living with MND and their loved ones.
- **Advocacy** – to drive change and timely access to health and disability services.
- **Education** – to increase knowledge, recognition, and understanding of MND.
- **Campaigning** – to raise awareness and build trust and support for our cause.
- **Fundraising** – to support people impacted by MND now and provide hope for the future.
- **Investing in research** – to improve quality of life, aid advocacy, and support research in New Zealand.

MND NZ provides a personalised support service to people diagnosed with MND, their family and whānau, and the health professionals providing care for them. Information packs are sent to newly diagnosed individuals and general practitioners. Our free flagship publication MND News is produced twice-yearly online and in hard copy format and aims to inform and inspire our community by sharing personal stories, news and research of relevance to MND.

There are seven support advisors nationwide, with support offered on a local and outreach basis. This support is provided through face-to-face visits, phone calls, text messages, and emails and is provided free of charge from diagnosis to end-of-life.

MND NZ ensures that individuals living with MND have consistent access to practical, emotional, and social support, as well as timely access to medical equipment and services within their communities. The organisation ensures equitable support nationwide, provides resources to health professionals, and fosters collaboration to improve health outcomes and prolong independence for those affected.

# Performance and Financial Information

## Service performance 2024/25

### Quantification of outputs

|                                                  | Actual<br>2024-2025 | Actual<br>2023-2024 |
|--------------------------------------------------|---------------------|---------------------|
| 1 Individuals* supported by MND NZ               | 5,796               | 5,568               |
| 2 Clients registered to MND NZ                   | 483                 | 464                 |
| 3 Hours of community outreach by support service | 12,500              | 8,720               |
| 4 MND Support Fund grants distributed            | 120                 | 44                  |
| 5 MND Information Packs provided                 | 147                 | 140                 |
| 6 Awareness and education talks given            | 23                  | 15                  |
| 7 Contacts** with clients and their family       | 5,820               | 5,459               |
| 8 Contacts** with health professionals           | 7,153               | 4,092               |
| 9 People registered on the MND Registry          | 498                 | 433                 |
| 10 Visits to the mnd.org.nz website              | 129,176             | 66,664              |
| 11 New people diagnosed with MND                 | 134                 | 129                 |
| 12 People who died with MND                      | 97                  | 81                  |

\* For every one person diagnosed, there are on average 12 people who will be impacted in some way.

\*\* Email, phone, or text.

# Performance and Financial Information

## Financial performance 2024/25

|                                                  | Actual<br>2024-2025<br>\$ | Actual<br>2023-2024<br>\$ |
|--------------------------------------------------|---------------------------|---------------------------|
| <b>Revenue</b>                                   |                           |                           |
| Donations, fundraising and other similar revenue | 619,974                   | 584,040                   |
| Grants                                           | 435,428                   | 354,207                   |
| Bequests                                         | 878,210                   | 191,040                   |
| Sponsorship                                      | 107,161                   | 82,833                    |
| Ministry for Disabled People Contract            | 81,065                    | 81,065                    |
| Interest, dividends and other investment revenue | 51,216                    | 31,956                    |
| Health research Council Contract                 | 30,000                    | -                         |
| Other Income                                     | -                         | 1565                      |
| <b>Total Revenue</b>                             | <b>2,203,054</b>          | <b>1,326,706</b>          |
| <b>Expenses</b>                                  |                           |                           |
| Support related expenses                         | 670,696                   | 419,276                   |
| Information related expenses                     | 26,439                    | -                         |
| Advocacy and awareness                           | 59,800                    | -                         |
| Research related expenses                        | 144,218                   | 69,044                    |
| Fundraising expenses                             | 310,286                   | 68,487                    |
| Operational expenses                             | 379,985                   | 665,679                   |
| Governance expenses                              | 41,059                    | 32,386                    |
| <b>Total Expenses</b>                            | <b>1,632,483</b>          | <b>1,185,828</b>          |
|                                                  |                           |                           |
| <b>Surplus/(Deficit) for the Year</b>            | <b>570,571</b>            | <b>140,878</b>            |
| <i>* Read note on surplus on next page.</i>      |                           |                           |

This summary financial statement has been extracted from the full financial statement.  
For the full audited statement, please visit the Charities Services website.  
[Motor Neurone Disease New Zealand Charitable Trust](#)

## Note on surplus

The Trust has recorded a strongly positive financial outcome for the 2024/25 financial year, driven by a successful grants programme and a mix of anticipated and unanticipated bequests. This surplus reflects the impact of our strategic fundraising plan. On the expenditure side, we committed to expanding our support services by employing an additional support advisor in the lower South Island and strengthening key office-based roles to enhance overall performance. These investments have contributed to improved service delivery and increased trust within both the community and the sector.

Given the deficit outcomes of previous years, we recognise that surplus years such as this are rare in our sector. In response, the Board of Trustees has approved and implemented a Reserve and Bequest Management Policy. This policy ensures prudent financial stewardship, including maintaining up to 12 months of operational reserves and allocating tagged funding for research, strategic development, and infrastructure.

### In line with this policy, for the 2025/26 financial year:

- \$110,000 has been allocated to support our mission by funding the employment of an MND educator and an additional support advisor, in anticipation of a growing population aged 65+ in New Zealand by 2028 and a corresponding increase in MND diagnoses.
- \$259,000 will be invested in increasing our fundraising capacity, and supporting internal and external research initiatives.
- The remainder (~\$200,000) has been allocated to build operational reserves via the Trust's longstanding investment approach, strengthening our reserves to ensure long-term sustainability

|                      | Actual<br>2024-2025<br>\$ | *Actual<br>2023-2024<br>\$ |
|----------------------|---------------------------|----------------------------|
| <b>Balance Sheet</b> |                           |                            |
| Cash                 | 1,127,028                 | 502,116                    |
| Accrued income       | 35,153                    | 1,774                      |
| Accounts receivable  | 7,769                     | 11,724                     |
| Fixed assets         | 16,628                    | 34,064                     |
| Sundry Debtors       | 500                       | -                          |
| Investments          | 829,703                   | 772,618                    |
| GST refund due       | 28,026                    | 25,916                     |
| <b>Total Assets</b>  | <b>2,044,807</b>          | <b>1,348,212</b>           |
| Unspent grants       | 62,272                    | 50,357                     |
| Accruals             | 23,814                    | 2,300                      |
| Accounts payable     | 40,111                    | 9,928                      |
| Holiday pay          | 54,235                    | 26,669                     |
| <b>Liabilities</b>   | <b>180,432</b>            | <b>89,254</b>              |
| <b>Net Assets</b>    | <b>1,864,375</b>          | <b>1,258,958</b>           |

This summary financial statement has been extracted from the full financial statement. For the full audited statement, please visit the Charities Services website. [Motor Neurone Disease New Zealand Charitable Trust](#)

\*Note: 2023-2024 totals are the consolidated figures from the Motor Neurone Disease Association of New Zealand Incorporated and the Motor Neurone Disease New Zealand Charitable Trust.



## **The Motor Neurone Disease New Zealand Charitable Trust**

Our charity was built on the ethos of helping people affected by motor neurone disease – it's the cornerstone of all that we do. If you or a loved one has motor neurone disease, we're here for you.

**PO Box 24 036, Royal Oak, Auckland 1345**

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