



Impact Report

2023-2024

mnd.org.nz



mnd
Motor Neurone Disease
New Zealand



**Dr. Natalie Gauld, Research Advisor
& Best Practice Advocate for MND NZ.
Natalie also lives with MND.**

Front cover: Supporters at the 2024
Auckland Walk to Defeat MND

**Motor Neurone Disease New
Zealand Charitable Trust**

Incorporated Society: 50109950
Charity number: CC60169

1 July 2023 – 30 June 2024

**The Motor Neurone Disease
Association of New Zealand**

Incorporated Society: 269718
Charity number: CC35320

1 July 2023 – 30 June 2024



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Chairperson's Report

I'm delighted to report to our motor neurone disease (MND) community that we have had a year of real progress.

We made a critical appointment in our new Chief Executive – Mark Leggett. Mark comes to Motor Neurone Disease New Zealand (MND NZ) with strength in the health sector, strategy setting, senior management and all-round enthusiasm.

We are grateful for the foundational work carried out by Scott Arrol in his time with the organisation. Scott worked hard to change the narrative around the disease moving us in a more positive direction with our first parliamentary hui.

“We are always humbled by the effort people put into these events and we know in many cases it's because you've been touched in some way by this disease.”

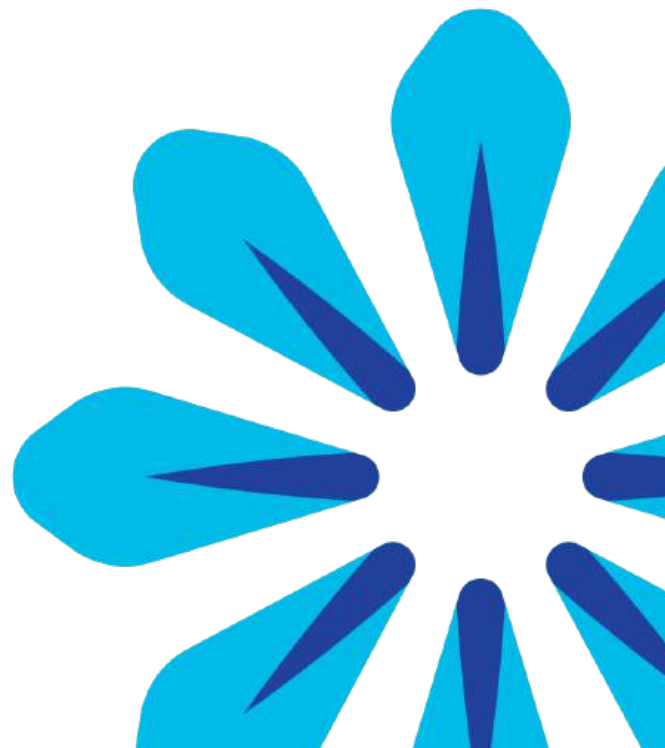
Maintaining staffing levels proved challenging throughout the year and this has been set as a key priority for Mark for the year ahead. Our community is grateful to have wonderful, caring MND Support Advisors in their communities, and this is backed up by a strong team of administration and fundraising staff; because let's face it we can't provide the support without adequate funding.

Fulton Hogan agreed to continue funding the provision of equipment and services (through the MND Support Fund) that fill the gaps in funding from central government. This fund has been very well subscribed.

We are very grateful to the many trusts and community organisations that have supported us with grant funds and financial donations. Without your generosity we could not do our work.

Walk to Defeat MND, Cup of Tea for MND and the Ice Bucket Challenge were great successes. We are always humbled by the effort people put into these events and we know in many cases it's because you've been touched in some way by this disease.

It costs the organisation nearly \$1.2M to deliver core services with much of the focus on face-to-face support and associated costs. We also aim to contribute to research in a meaningful way in a New Zealand context. This involves supporting the contribution to the worldwide body of knowledge about MND through the MND NZ Registry and partnering with our Australian colleagues in the Lighthouse Trial. This year, the MND Registry has been transferred to the University of Otago and is being actively curated.



We have also continued our long-standing relationship with Dr Emma Scotter and her team supporting ongoing MND Research through the Centre for Brain Research at the University of Auckland.

As we appoint high calibre individuals to the MND staff we have been able as governors to step more into strategy and future focus. We have been lucky to attract some skilled governors with a range of experience in the health and commercial sectors and with strong governance experience.

Looking forward we are focused on delivering face-to-face support as well as exploring opportunities to expand our reach through technology. We will continue to develop partnerships with our NZ based health care providers as well as link into our international colleagues.

We all have limited resources and will only be able to deliver the best through working together.



Lucy

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

Notes on our operating structure

From 1 March 2023 The Motor Neurone Disease Association of New Zealand (Incorporated) restructured as The Motor Neurone Disease New Zealand Charitable Trust (Incorporated). Transitioning to a trust structure alleviates administrative burdens, whilst still requiring us to be accountable and transparent to our funders, donors, supporters and community. The 2023-24 financial year involved tying up the loose threads between the transfer of the entity, with the intention to fully close the Association in the 2024-25 financial year.

Why We're Here

Motor neurone disease (MND) is a fatal, rapidly progressing neurodegenerative disease that robs people of their ability to move, talk, and eventually breathe.

Often known as ALS or Lou Gehrig's disease, MND is actually a group of conditions with ALS being by far the largest proportion. Little is understood about the causes of MND.

There are currently very few treatment options available, and no cure. The average life expectancy is two to three years after diagnosis.

MND presents significant personal, social and financial challenges to people living with the disease and their families.

Motor Neurone Disease New Zealand is a beacon of light for families devastated by a diagnosis of MND.

With the help of donors and fundraisers, we are steadfast in our commitment to providing compassionate support, information, and advocacy until a cure is found.



464

Total People With MND Supported This Year

129

People Diagnosed With MND This Year

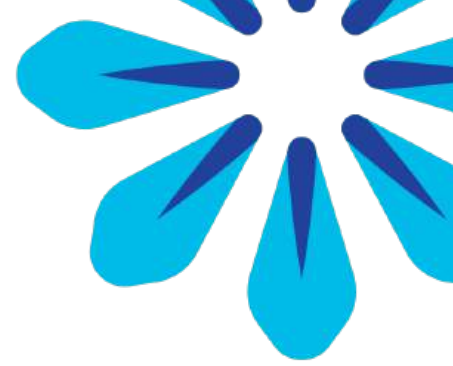
81 

People Died From MND This Year

 5,568

Total People Supported By MND NZ This Year

What We Want To Achieve



Our Vision:

A world where everyone who faces motor neurone disease (MND) are empowered to live with dignity and hope. We champion a future where 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.
- **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.

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:

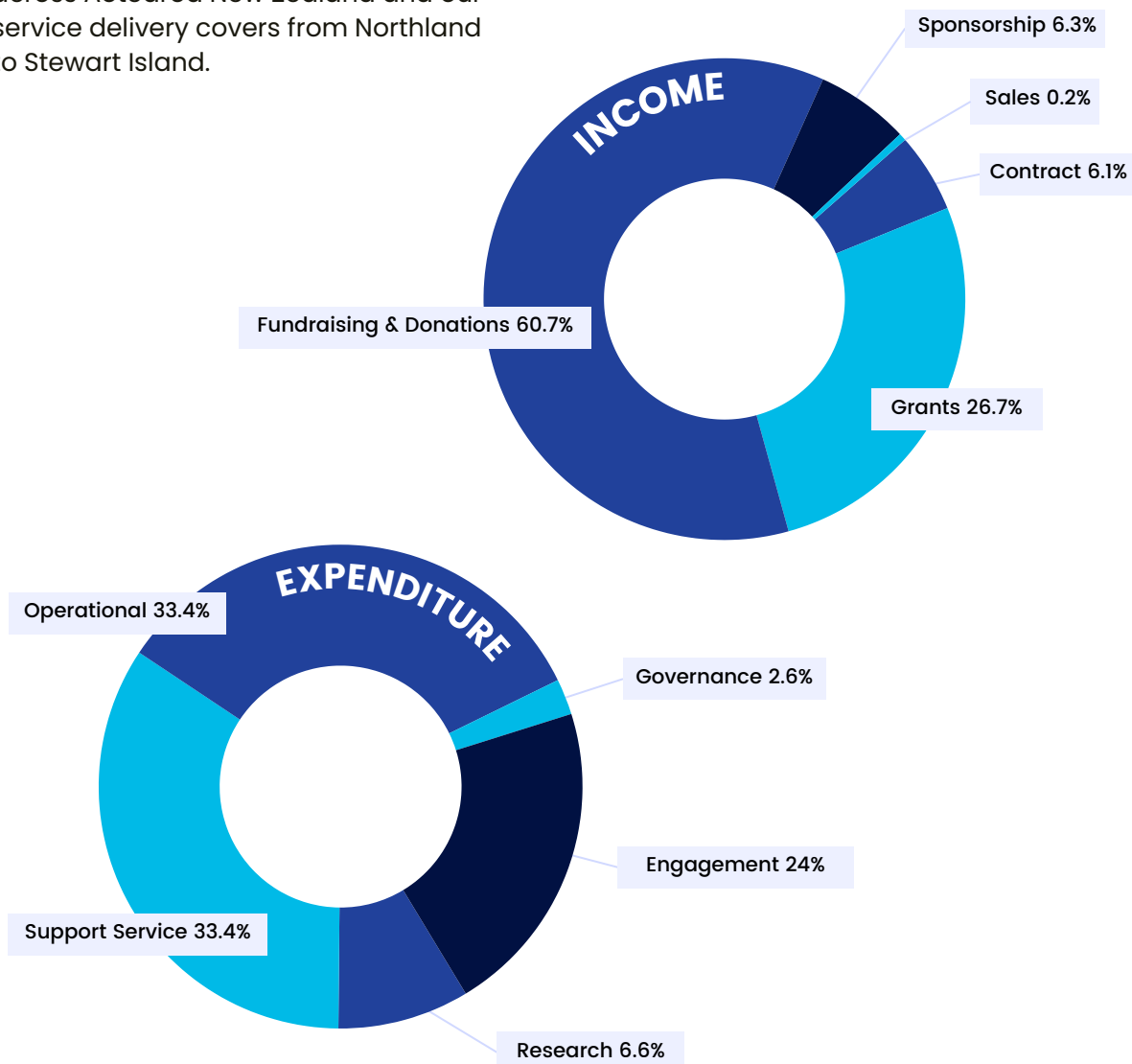
1. Will it make things easier for people with MND and their loved ones?
2. Will it increase our reach to ensure a wider awareness of MND and engagement with our mission of making time count?
3. Can the work be done within the current framework of our organisation?
4. Does it support our commitment to 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 2024, Motor Neurone Disease NZ employed 14 staff across four portfolios – Support Service (50% of staff), Research (7% of staff), Operations (14% of staff) and Engagement (29% of staff).

Most of our people work part-time, and salaries are funded primarily through grants.

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.

Below is a snapshot of how, thanks to your donations and fundraising, we've supported people with MND and their loved ones.

15 

Awareness and Educational Talks

8,720 

Hours of Community-Based Support Provided by Advisors

140 

MND Information Packs Provided

129 

Newly Diagnosed Individuals Supported

519

Face to Face Meetings with Clients and Family

44 

MND Support Fund Grants Distributed

34%

Of Support Fund Requests Were For Equipment

19% 

Of Support Fund Requests Were For Wellbeing

\$48k+

In Practical Support Granted

66k+ 

Website Views From People Looking for Information

Focus Area: 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.

MND SUPPORT ADVISORS

Our Support Advisors work together with people living with MND, their carers, family and whānau to enable them to have the best quality of life possible.

Support Advisors provide support through in-person home and clinic visits, phone calls, text messages, email, facetime video calls and online meetings. Home visits and attending clinic with clients, their families, whānau and carers, are an essential and valuable part of the support service. Home visits provide the opportunity for Support Advisors to understand the living environment, enabling the provision of better personalised support for the person with MND, their family, whānau and carers.

We have six Regional Support Advisors (regional home offices) and one Support Services Manager based at the Auckland office. Each Support Advisor is provided with a vehicle and can spend between one and three hours at a home visit depending on the needs of the family.



"Thank you for your kindness and understanding. You have no idea how much that chat on the deck with me and mum helped. Mum and I just felt this huge weight be lifted, was so nice to have someone listen to us. You are amazing at your job!!"

464 people with MND supported and advocated for

519 face to face contacts with clients and their family

5,459 contacts (email, phone, text) with clients and their family



MND SUPPORT FUND

The MND Support Fund funded 44 applications this financial year. This fund offers financial assistance to our community that contributes towards:

- bidets
- heat pumps
- massage
- travel costs
- respite for caregivers
- repairs to van hoists
- contributions towards mobility vans
- bathroom modifications
- seals and cushions for NIV masks
- firewood
- power bills
- counselling
- mobility parking cards
- pharmacy and medical expenses
- and other quality of life improving items

This fund is greatly valued by our clients and support team members, to help enable access to services and equipment that is not always available through the health system.



"Thank you so much for your support to purchase a bidet. That's absolutely wonderful news and I really appreciate it. Anything that can help me be as independent as possible for as long as possible means a huge amount to me. The MND Support funding is very generous and provides some light in what can otherwise feel a somewhat dismal path."

FOUNDATION FUND SPONSOR



Fulton Hogan have been foundation fund sponsors since 2019, helping to make life easier for people affected by MND.

9

grants towards transport and accommodation

2

grants to help towards house modifications

18

grants towards the cost associated with equipment

9

grants towards wellbeing and quality of life



Focus Area: Meaningful Advocacy

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

ADVOCATING FOR: TIMELY SUPPORT

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.

This year, we have worked closely with health and disability providers to improve the speed and efficiency of access to these vital resources.

“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”

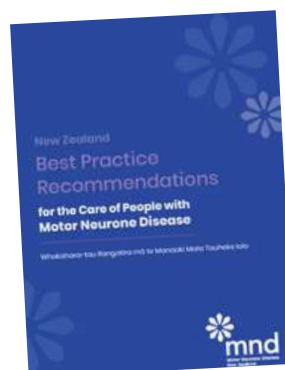
We are also advocating for increased financial support, ensuring that people with MND can focus on what matters most: spending precious time with their families and loved ones.

ADVOCATING FOR: BEST PRACTICE

In November 2022, Motor Neurone Disease NZ published New Zealand’s first-ever Best Practice Recommendations (BPRs) for managing MND. Developed collaboratively by a dedicated group of local clinicians, the BPRs set the standard for quality care for people living with MND across Aotearoa.

Over the past year, Dr. Natalie Gauld, our Research Advisor and Best Practice Advocate, has been working with clinicians, experts, and our support advisors to review the BPRs’ effectiveness and identify areas for improvement. A new survey has been designed to gather insights into their use and impact.

In addition, Dr. Gauld has explored ways to leverage research funding to increase academic interest in MND and enhance education for students and professionals, ensuring future generations of healthcare providers are well-equipped to deliver excellent care.



Focus Area: Practical Education

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

AWARENESS AND EDUCATIONAL TALKS

Across the year we provided 15 awareness and education talks. These varied from talks to hospices, care facilities, health teams, public forums, and community groups. Each talk was tailored to the audience, and where appropriate, information was tailored to relevant clients under their care.

PRACTICAL INFORMATION PACKS

We provided 140 tailored information packs to newly diagnosed clients and where needed, their health professionals. Each pack is tailored for the audience, containing information pertinent to their role.

OUR WEBSITE: MND.ORG.NZ

Our website traffic continued to increase, with 32,400 unique visits, and a total of 67,000 individual page views.

The most read pages were:

- #1 Basic Facts About MND
- #2 What Causes MND
- #3 Support Advisors

In addition, 1,319 copies of information resources were downloaded, including the Best Practice Recommendation and fundraising guide.

“

“Thank you both so much for taking the time to visit and speak with our team yesterday. 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.

I've also 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.”



Focus Area: 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.

HEALTH RESEARCH COUNCIL

Health Research Council (HRC) funding for a project led by Dr. Natalie Gauld, our Research Advisor and Best Practice Advocate, was obtained in 2024. This research is supported by a team of health researchers, neurologists, and other healthcare professionals.

In early 2025, we will launch two important surveys—one for people living with MND and another for families and carers. These surveys aim to deepen our understanding of the experiences, impacts, and needs of those affected by MND in New Zealand.

The survey findings will provide valuable insights, including:

- Identifying what is working well and areas for improvement in care.
- Highlighting regional differences in experiences and management.
- Offering a clearer picture of how MND affects New Zealanders.

This knowledge will help us:

- Advocate more effectively for the MND community.
- Support healthcare professionals in meeting the needs of people with MND.
- Inspire further research on MND in New Zealand.

NZ MND REGISTRY

Since its establishment in 2017, the MND Registry has been a vital resource for understanding MND in New Zealand, with MND NZ playing a key role in its creation.

The Registry collects confidential, anonymised data from people living with MND, securely managed by the University of Otago. This data provides insights into the prevalence, progression, and impact of MND on individuals and their whānau.

Run by Dr. Sarah Buchanan of Dunedin Hospital and the University of Otago, the Registry also connects participants with relevant research opportunities. People with familial links to MND can contribute as well, supporting studies on genetic forms of the disease.

“There are 433 people enrolled in the NZ MND Registry, with 181 active participants as at the end of June 2024”

– Dr Margaret Ryan, MND Registry Curator

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.

LIGHTHOUSE TRIAL II

Motor Neurone Disease NZ is proud to have supported access to Lighthouse II, a groundbreaking international phase 3 clinical trial investigating whether human endogenous retroviruses (HERVs) play a role in MND and whether targeting HERVs could slow disease progression.

This is the first phase 3 clinical trial available to people with MND in New Zealand, with 20 participants enrolled across research centers in Bay of Plenty, Wellington, Christchurch, and Dunedin. Dr. Alan Stanley, a Hawke's Bay neurologist and MND NZ Board member, serves as the New Zealand Principal Investigator.

The trial involves 419 participants worldwide, exceeding the initial goal of 390. Participants are randomly assigned to receive either the investigational drug Triumeq or a placebo in a 2:1 ratio. Triumeq, a combination of three active ingredients (dolutegravir, abacavir, and lamivudine), is already used to treat HIV and shows potential to target HERVs. Over two years, participants undergo regular assessments every three months to evaluate the drug's impact on ALS progression.

Global leaders in the study, including Julian Gold, Coordinating Investigator for Australia and New Zealand, emphasise its importance:

"Participants and sites in Australia and New Zealand are pleased to be part of this important international collaboration, exploring new frontiers in finding the possible cause and an effective treatment for ALS."

The success of Lighthouse II, including its record-breaking recruitment, marks a significant step toward understanding and treating MND. By contributing to this effort, MND NZ continues to advocate for improved care and hope for those living with MND.



Focus Area: 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.

WALK TO DEFEAT MND

Each February the nationwide Walk to Defeat MND events take place, bringing people together to walk in honour, in memory, and in support of people affected by MND. Over 1,000 individuals engaged with the campaign, either by participating or donating, raising over \$125,000 for support and research.



MND ACTION MONTH

June is the annual awareness campaign for Motor Neurone Disease NZ, and the 2024 campaign was bigger than ever. Bunnings came on board, hosting a nationwide Sausage Sizzle, helping to raise over \$33,000 towards the campaign. Over 1,300 individuals engaged with the campaign, either by donating or creating a fundraising profile. The total raised was \$175,000.



NEWSLETTERS AND EMAILS

- 508 people received the printed MND News magazine
- 9,623 people received the electronic MND News magazine
- 28 direct emails (excluding e-news) with news and opportunities

ONLINE COMMUNITY

- 359,340 people reached through Facebook (320,300 previous year)
- 47,332 people through Instagram (26,400 previous year)
- 441 new Facebook likes
- 94 new Instagram followers
- 16.5% more visits to our Instagram page vs the previous year
- 204.4% more visits to our Facebook page vs the previous year



"I loved being able to give back to MND NZ through helping out at the (Bunnings) sausage sizzle. Thank you!"



Focus Area: 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.

Each year, the whole Motor Neurone Disease New Zealand team gets together in one place for two or three days of reflection, planning and development.

We use this time to discuss the MND landscape from different perspectives – support, education, advocacy, research, and engagement – and fine-tune our priorities to ensure we're always responding to the most urgent needs based on what the MND community tells us.

As part of developing our research and engagement, the team joined Sue Giddens, Research Engagement Manager at the Centre for Brain Research, for a day of education on MND research.

This included a tour of the Human Brain Bank, where we learned the process involved with donating your brain to research, so we can better support our clients who wish to take this option.

We also learned how the NZ MND Registry (funded by MND NZ) is directly contributing to the genetic MND research work being undertaken by Dr Emma Scotter. This rich source of data is imperative to growing current and future research for MND.

Thank you to the Centre for Brain Research staff for helping us to grow our knowledge and understanding of MND research, so we can better support people with MND.

Below. The MND NZ team with Marika Eszes (far left), Neurological Foundation Brain Bank Manager at the Centre for Brain Research



Our Supporters

Our supporters are all valued members of the Motor Neurone Disease NZ family. We thank them all for the support given, funds donated, and awareness raised which makes a real difference.

TRUSTS AND FOUNDATIONS

We extend our thanks to the trusts and foundations whose ongoing support, provided through grants, enables us to continue providing personal, community-based support and advocacy to families with an MND diagnosis.

- Air Rescue Services Ltd
- Akarana Community Trust Ltd
- Aotearoa Gaming Trust
- Bay Trust
- Blue Sky Community Trust Ltd
- Blue Waters Community Trust Ltd
- Community Organisation Grants Scheme
- Dragon Community Trust Ltd
- DV Bryant Trust
- Eastern & Central Community Trust
- Eastern Bay Community Foundation via the Starfish Fund
- EH Davis & T&M Carr Legacies proudly managed by Perpetual Guardian
- First Light Community Trust
- Four Winds Foundation Ltd
- Frimley Foundation
- Grassroots Trust Ltd
- John Ilott Charitable Trust
- Kiwi Gaming Foundation
- Lindsay Foundation
- Lottery Grant Board
- LW Nelson Charitable Trust
- Maurice Paykel Charitable Trust
- Milestone Foundation
- New Zealand Community Trust
- Norah Howell Charitable Trust
- North & South Trust Ltd
- ONE Foundation
- Oxford Sports Trust
- Pelorus Trust
- Pub Charity Ltd
- Rata Foundation
- Rotorua Trust
- South Canterbury Trusts proudly managed by Perpetual Guardian
- Stewart Family Charitable Trust proudly managed by Perpetual Guardian
- Taranaki Foundation
- The Lion Foundation
- TG Macarthy Trust
- Trillian Trust
- Trust Waikato
- The Trusts Community Foundation
- We Care Community Trust Ltd

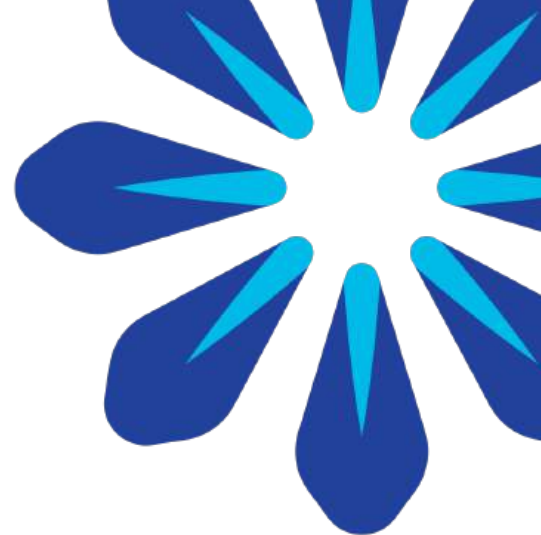
CORPORATE DONORS

Fulton Hogan, Bunnings, Affordable Group, Emirates Team New Zealand, Bolster Risk Management Ltd, AS Colour, Barfoot & Thomson Wynyard Quarter, Te Rourou, One Aotearoa Foundation.

ESTATES

Estate of John Hill, Estate of Gail Godso, Estate of Ailsa McCarlie, Estate of Susan Rebecca Lloyd, Estate of Paula Vegh, Estate of Wayne Phillip, Estate of Mr M E Chi.

Organisation Structure



Board

Chairperson/Treasurer – Lucy Haberfield

Board Members – Alan Stanley, Estelle Arts, Patricia Sloan, Mark Leggett (to May 2024), Peter Brown (from June 2024)

Retired Board 2023–2024 – Melanie Glenn (October 2023), Caron Palmer (November 2023)

Operations and Engagement

- Chief Executive – Scott Arrol (until December 2023),
- Interim Chief Executive – Mark Leggett (January 2024 to May 2024 before being appointed as the Chief Executive in June 2024)
- Office Manager – Hayley Forrest
- Marketing & Fundraising Manager – Laura Huet
- Fundraising & Event Coordinator – Rob Bloch
- Grants Coordinator – Jeanette Franklyn
- Communications Specialist – Katya Old (from November 2023)
- Community & Research Advisor – Claire Reilly (until August 2023)
- Research Advisor & Best Practice Advocate – Natalie Gauld (from October 2023)

Support Service

- Support Services Manager – Jo Kelly (to January 2024), Toni Foster (from June 2024)
- Support Advisors – Moira Young, Sally King, Megan Te Boekhorst, Chevonne Stringer (until August 2023), Angela Callahan (until November 2023), Tammy Gardiner (until February 2024), Jasmine Chua (from January 2024), Jeanette Tioke (from March 2024), Rachel Woodworth (from April 2024).

Honourary Positions

Patron – Ruth Dyson

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

STATEMENT OF SERVICE PERFORMANCE

Motor Neurone Disease Association of New Zealand (Jul 23 – Jun 24)

Motor Neurone Disease New Zealand Charitable Trust (Jul 23 – Jun 24)

Consolidated service performance for the year ended 30 June 2024

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.

Quantification of Outputs

	Actual 2023-2024	Actual 2022-2023
1 Total individuals* supported by MND NZ	5,568	5,724
2 Total clients registered to MND NZ	464	477
3 Hours of community outreach by support service	8,720	11,088
4 MND Support Fund grants distributed	44	50
5 MND Information Packs provided	140	121
6 Awareness and education talks given	15	15
7 Contacts** with clients and their family	5,459	8,896
8 Contacts** with health professionals	4,092	6,543
9 People registered on the MND Registry	433	395
10 Visits to the mnd.org.nz website	66,664	61,380

* For every 1 person diagnosed, there are on average 12 people who will be impacted in some way.

** Email, phone, or text.

Notes:

The variance of activity between the last two years reflects a range of vacancies within the Support Advisor service, particularly where staff provided cover for other regions, thereby affecting their ability to service their own client group as well as they normally would. The vacancy challenges (around 20% reduction in available FTE across the year), were corrected by the beginning of the fourth quarter and an additional Support Advisor was added to the South Island team as the next year began (i.e. 2024/25).

MND NZ remains committed to the delivery of as much direct support and service to our client group as possible, and to the continual growth and improvement of our service reach and performance.

STATEMENT OF FINANCIAL PERFORMANCE

Motor Neurone Disease Association of New Zealand (Jul 23 – Jun 24)
 Motor Neurone Disease New Zealand Charitable Trust (Jul 23 – Jun 24)

Consolidated service performance for the year ended 30 June 2024

	Actual 2023-2024 \$	Actual 2022-2023 \$
Revenue		
Donations, fundraising and other similar revenue	584,040	396,517
Grants	354,207	258,669
Bequests	191,040	61,930
Sponsorship	82,833	55,000
Ministry for Disabled People Contract	81,065	81,065
Interest, dividends and other investment revenue	31,956	29,681
Other income	1,565	643
Total Revenue	1,326,706	883,504
Expenses		
Support related expenses	419,276	498,853
Information related expenses	-	3,719
Advocacy and awareness	-	5,822
Research related expenses	69,044	84,814
Fundraising expenses	68,487	42,350
Operational expenses	665,679	609,291
Governance expenses	32,386	32,253
Total Expenses	1,185,828	1,277,102
Surplus/(Deficit) for the Year	140,878*	(393,598)

* Read note on surplus on next page.

These summary financial statements have been extracted from the full financial statements from both entities and consolidated. For individual, audited statements, please visit the Charities Services website.

[Motor Neurone Disease Association of New Zealand \[link\]](#)

[Motor Neurone Disease New Zealand Charitable Trust \[link\]](#)

Note on Surplus

The surplus in this financial year, following two years (these two years includes the Association, as the Trust was only established in 2023 and been operating for less than two years) of significant deficits, relates in most part to two expenditure items – staff salaries (via a range of vacancies across the year, and allocation of research expenses of around \$69,000. Like all NGO's of our type, we aim to utilise as much of the income available to us in the delivery of services to our target community. In 2023/24 FY, vacancies required us to reallocate staff to provide cover, but this was fully rectified as we approached the completion of the year, with full employment and an increase in Support Advisor FTEs allocated at the beginning of 2024/25 FY.

STATEMENT OF FINANCIAL PERFORMANCE

Motor Neurone Disease Association of New Zealand (Jul 23 – Jun 24)

Motor Neurone Disease New Zealand Charitable Trust (Jul 23 – Jun 24)

Consolidated balance sheet for the year ended 30 June 2023

Balance Sheet	Actual 2023-2024 \$	Actual 2022-2023 \$
Cash	502,116	473,836
Accrued income	1,774	9,433
Accounts receivable	11,724	10,435
Fixed assets	34,064	39,622
Investments	772,618	728,185
GST refund due	2,5916	9,531
Total Assets	1,348,212	1,271,042
Unspent grants	50,357	18,717
Accruals	2,300	11,570
Accounts payable	9,928	30,444
Holiday pay	26,669	47,050
Liabilities	89,254	107,781
Net Assets	1,258,958	1,163,261

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[Motor Neurone Disease Association of New Zealand \[link\]](#)

[Motor Neurone Disease New Zealand Charitable Trust \[link\]](#)



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.

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