

# Impact Report

## 2022-2023

[mnd.org.nz](https://mnd.org.nz)





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

Incorporated Society: 269718  
Charity number: CC35320

1 July 2022 – 28 February 2023

**Motor Neurone Disease New  
Zealand Charitable Trust**

Incorporated Society: 50109950  
Charity number: CC60169

1 March 2023 – 30 June 2023

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# Chairperson's Report

The financial year of 2022/23 saw significant change in the organisation as we finalised the shift from Incorporated Society to a Charitable Trust.

This required technical organisational changes relative to the Companies Office, Services and a financial restructuring, that was completed later in the year.

## SHIFTING ENVIRONMENT

The change was undertaken to reflect the nature of Motor Neurone Disease NZ in the current environment, no longer operating as a member-based entity, as we shift to respond to changes in the wider health and support sector.

The Board of Trustees and MND NZ team are to be congratulated for the exemplary nature of the management of this process, delivering a seamless change that was not without its challenges.

We are now set up to be internally and externally responsive, as we look forward to enhancing our service base and working more closely with our important charity partners.

## ADVOCATING FOR BEST CARE

In terms of our purpose and strategic direction, the year was also full of progress, not the least of which was the delivery of a hui in the Grand Hall of Parliament in June – supported and hosted by MP and supporter Tamati Coffey.

The hui was the vehicle for the announcement of our Best Practice Recommendations for the Care of People with Motor Neurone Disease.

Our goal is to have this document reside within the wider recommendations and support materials across the health and disabilities sector, being a blend of real-world, experience-based information and clinically relevant care and treatment aspects. The clinical working group that supported and drafted the document worked tirelessly to produce the document that is now in play nationally.

## RAISING AWARENESS

Awareness Month in June 2023 raised around \$116,000 and this was fully due to the extraordinary work done around the country by supporters, clients, family, whānau, colleagues and the team at MND NZ.

The new funds provided support the ongoing research and service delivery projects through MND NZ.

## PRACTICAL SUPPORT

Our clients and their families also continue to benefit from the generosity of the MND Support Fund, which provides for support and equipment not funded from other sources.

The MND Support Fund is sponsored by Fulton Hogan, and works within clear criteria. In this last year, we reviewed and responded to 59 applications.

We are confident that the recipients of support saw real, practical benefit delivered in a timely manner – this is one of those few areas where application and response work relatively seamlessly, and we do thank our benefactors, Fulton Hogan, for that ability.

## BUILDING RESILIENCE

We look forward to the next year with an eye on improving how we work and building resiliency in the organisation and within our stakeholder relationships, given recent significant changes in the health and disability sectors. .



Thank you once again to all our stakeholders, our small MND NZ team, and of course the people who engage with us in the most challenging of circumstances – we're here for you.

*Lucy*

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

## Changes To Our Structure

After consulting the legal structure, The Motor Neurone Disease Association of New Zealand (Incorporated) resolved to restructure as The Motor Neurone Disease New Zealand Charitable Trust (Incorporated) from March 1, 2023.

Charitable trusts are preferred by many new organisations due to similarities with incorporated societies, such as having a governing body and tax-exempt status. However, a key difference lies in membership: while a trust benefits a defined class without inherent membership, societies require membership to function.

Transitioning to a trust structure alleviates administrative burdens, as seen with significant organisations like Whānau Āwhina Plunket and Arthritis New Zealand in recent years.

# 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 NZ 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.



**477**

**Total People With MND Supported This Year**

**108**

**People Diagnosed With MND This Year**

**129**

**People Died From MND This Year**



**5,724**

**Total People Supported By MND NZ This Year**

# What We Want To Achieve

## Our Vision

Together we provide the best quality support for those living with MND.

## Our Purpose

To provide support to people living with MND and their families in New Zealand.

## Our Values

People first; supportive, professional, honesty, partnership.

### Goal 1

Deliver a service that supports people living with MND, their whānau, family and carers.

- The community-based support services we provide to people living with MND are the best quality possible, meets their needs, are aligned with other providers.
- Our cultural competencies are developed to support equitable access and our commitment to Te Tiriti O Waitangi.

### Goal 2

Sustain our strong, collaborative relationships that ultimately benefit clients.

We develop and maintain strong, collaborative relationships that:

- Supports our leadership role in the sector
- Enables connectivity across stakeholders (nationally and internationally)
- Expands the ability for people living with MND to have a fully supportive model of care and support.

### Goal 3

Influence using our recognisable brand and presence to advocate for people with MND.

- We have a consistency of messaging (visual, written and spoken) that clearly demonstrates our commitment to supporting people living with MND.
- We have a national presence that strengthens our position as experts when it comes to providing community based MND support services and our cultural competencies which enable us to provide leadership to influence future service models.

### Goal 4

Lead and support research initiatives.

Our research plan is aligned with the organisational strategy and defines the research objectives prioritised over the next 3 years (2022-25).

## Enablers

Our people have the skills, knowledge, and development opportunities to carry out their work competently and confidently, are able to meet the demands of their role and operate within a supportive, continuously improving Team MND environment.

## Enablers

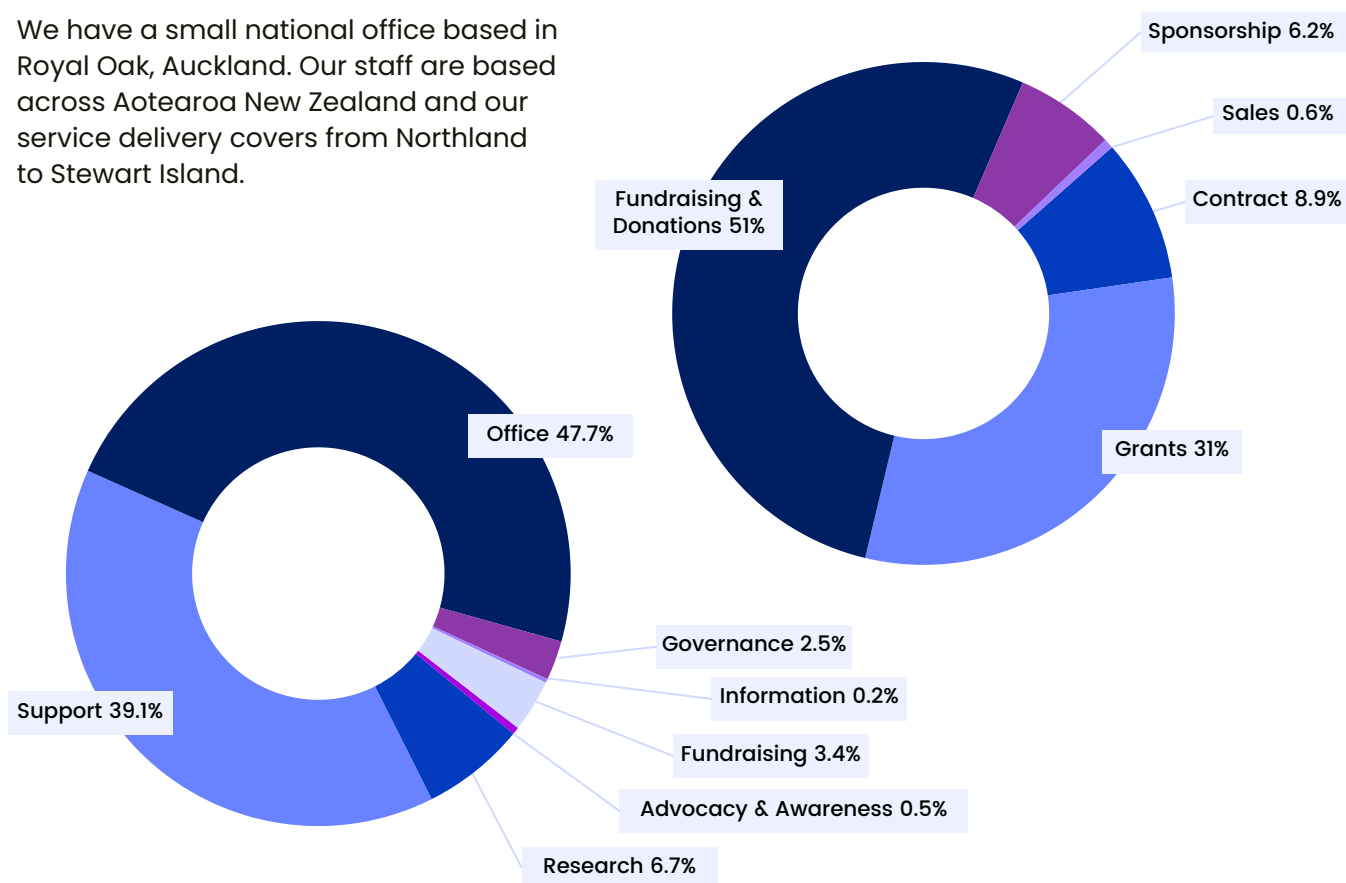
Establish and implement a technology strategy so our information and communication (ICT) platform is an enabler of the work we do, the services we provide and supports us in operating as effectively and efficiently as possible.

# How We're Doing It

At end of June 2023, Motor Neurone Disease NZ employed 13 staff across three portfolios - Support Service (54% of staff), Operations (23% of staff) and Engagement (23% of staff).

Most 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.



## We Support

We connect people to the services and support they need; emotional, social, and practical.



## We Educate

We create and provide accurate and reliable information about MND to all who need it.



## We Advocate

We raise awareness of MND; for better understanding, better care, greater visibility, and vital funding.



## We Invest

We invest in research to improve quality of life, find meaningful treatments, and bring hope for the future.



# 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**

**11,088** 

**Hours of Community-Based Support Provided by Advisors**

**121** 

**MND Information Packs Provided**

**108** 

**Newly Diagnosed Individuals Supported**

**653**

**Face to Face Meetings with Clients and Family**

**50** 

**MND Support Fund Grants Distributed**

**40%**

**Support Fund Requests Were For Equipment**

**11%** 

**Support Fund Requests Were For Home Modifications**

**\$52,951**

**In Practical Support Granted**

**61,380** 

**Website Views From People Looking for Information**

# Impact Area: Personalised Support

## 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.

“

I find that it is good to have someone to talk to who understands what you are going through. It is a lonely and difficult road for the patient as well as families.

**477**

people with MND supported and advocated for

**653**

face to face contacts with clients and their family

**8896**

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



# Impact Area: Practical Assistance

## MND SUPPORT FUND

The MND Support Fund funded 53 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.

## FOUNDATION SPONSOR

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



<b>8</b>	<b>grants towards transport and accommodation</b>
<b>6</b>	<b>grants to help towards house modifications</b>
<b>23</b>	<b>grants towards the cost associated with equipment</b>
<b>15</b>	<b>grants towards wellbeing and quality of life</b>



# Impact Area:

## Information and Engagement

### Our website: [mnd.org.nz](http://mnd.org.nz)

- 32,400 unique visits  
66,000 page views
- Most read pages:  
#1 Basic Facts About MND  
#2 What Causes MND  
#3 Support Advisors
- 2,218 information resources were downloaded

### Our Newsletters And Emails

- 504 people received a printed copy of the MND News magazine
- 9,568 people received an electronic copy of the MND News magazine
- 13 direct emails (excluding e-newsletters) with updates and opportunities

### Our Social Media Pages

- 320,300 people reached through Facebook  
26,400 people through Instagram.
- 630 new Facebook likes  
31 new Instagram followers.
- 404.4% more visits to our Instagram page vs the previous year.
- 113.5% more visits to our Facebook page vs the previous year

### Educational Talks And Webinars

- 15 awareness and education talks were given in the community
- 248 people registered to watch our webinar update to hear leading researchers give an update on research happening on both sides of the Tasman.



*“As an early stage slow progressing MND patient, a health care professional and a researcher, I thought your webinar today was perfect. Thank you so much. I am also very appreciative of your guidelines. There was information within the guidelines that I would have appreciated my neurologist following at diagnosis and since then. I hope practice will change with the support these guidelines provide to good practice for health care professionals.”*

# Impact Area: Research and Advocacy

## BEST PRACTICE RECOMMENDATIONS

In November 2022, the first-ever New Zealand based best practice recommendations (BPRs) for the management of MND were published by Motor Neurone Disease NZ.

Developed over several years by a working group of New Zealand MND clinicians, this document represents what specialists in MND care agree should be the standard of care for any New Zealander diagnosed with MND.

In drawing up their recommendations, the working group have consulted widely with other appropriate clinical experts across New Zealand as well as drawing on best practice clinical guidelines on MND care from the United Kingdom and Canada.

Motor Neurone Disease NZ would like to acknowledge the significant time and effort contributed by the Motor Neurone Disease Clinical Working Group (MNDCWG) in the development of these Best Practice Recommendations.

The group includes 18 members from different health sectors around Aotearoa, who have an interest in improving care for people with MND and their whānau. The MNDCWG was co-chaired by Claire Reilly and Chris Drennan in 2020, and Claire Reilly and Alan Stanley in 2021.



18 

**MND Care Specialists Helped Develop The BPRs**

218 

**Active Participants On The MND Registry**

20 

**New Zealanders With MND Participating Lighthouse Trial**

## FIRST PHASE III MND TRIAL IN NZ

We're proud to have been able to contribute funding to secure access to Lighthouse II, an international clinical trial looking at whether human endogenous retroviruses (HERVs) play a role in motor neurone disease (MND).

This trial is the first-ever phase 3 clinical trial to be offered to people with MND in New Zealand, across multiple locations. Phase 3 of Lighthouse II is expecting to enroll 390 participants worldwide, with participants taking Triumeq (or placebo) for a maximum of 24 months.

Of the 390 participants worldwide, 20 of these participants will be MND patients from New Zealand.

Research teams in Bay of Plenty, Wellington, Christchurch and Dunedin elected to participate in this trial, which is currently underway. Dr Alan Stanley, Hawkes Bay neurologist and MND NZ Board member is the New Zealand Principal Investigator for this trial.

## PHARMAC PROPOSES DE-FUNDING OF FOOD THICKENERS

In February 2023 Pharmac published its proposal to phase out funding of food thickeners for people with MND from 1 June 2023.

Two thirds of people with MND experience difficulties swallowing, with thin liquids often causing aspiration and recurrent chest infections arising from aspiration.

Food thickeners have been funded in the community for almost 30 years for people with MND. They are a useful component in the management of MND, with evidence supporting improved life expectancy for people with MND who maintain good nutrition and weight.



*"I am extremely appreciative of the work MND NZ has been doing trying to get clinical trials here,"*

*- Person with MND.*

Following several months of engagement with Pharmac, including Motor Neurone Disease NZ presenting to the Pharmacology and Therapeutics Advisory Committee, Pharmac confirmed in November 2023 it would continue to fund food thickeners for people with MND.

## NZ MND REGISTRY

We continued to support the NZ MND Registry and the NZ MND Research Network, crucial pillars of our research programme. We thank Dr. Emma Scotter and her team at the University of Auckland's Motor Neurone Disease Research Lab for their vital work.

The NZ MND Registry provides an important picture of MND in New Zealand. This confidential information from patients with MND helps to answer questions about how many people have MND in different areas, how the condition progresses, and how the disease can affect people.

The MND Registry also helps MND research grow in New Zealand through access to anonymised patient data and by informing people who wish to be involved in research about research projects that they would be suitable for.

There were 45 new people added to the Registry in 2022-23. There were 218 active participants and 395 total enrolments.

The MND Registry was used to recruit participants for 16 research studies, of which 5 of them were NZ based. The MND Registry captures approximately 50% of the MND population in NZ at any one time

# 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 & 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.

- AD Hally Trust – proudly managed by Perpetual Guardian
- Community Organisation Grants Scheme
- Dragon Community Trust Ltd
- Four Winds Foundation Ltd
- Guy Anson Waddel Charitable Trust – proudly managed by Perpetual Guardian
- James Maxwell Heron Charitable Trust – proudly managed by Perpetual Guardian
- Lottery Grants Board
- LW Nelson Charitable Trust
- Mainland Foundation
- Maurice Paykel Charitable Trust
- New Zealand Community Trust
- North & South Trust Ltd
- Pub Charity Ltd
- South Canterbury Trusts – proudly managed by Perpetual Guardian
- Southland Care & Welfare Trusts – proudly managed by Perpetual Guardian
- TG Macarthy Trust
- Trust Waikato

## MND ACTION MONTH

June is the **annual awareness campaign** for Motor Neurone Disease NZ, and the 2023 campaign was bigger than ever.

Combining the MND Ice Bucket Challenge and Cuppa Tea for MND campaigns under the 'MND Action Month' banner meant New Zealanders saw the campaign **over 3.4 million times** through social media, display, and search. **Over 1,300 individuals engaged** with the campaign, either by donating or creating a fundraising profile. The total raised was \$120,000.

It was also great to see peripheral services such as TalkLink Trust, West Coast Disability Resource Centre, and Te Whatu Ora – Nelson (pictured) get involved, helping to elevate our relationships and awareness.



# Organisation Structure

## Board

Chairperson/Treasurer – Lucy Haberfield

Board Members – Alan Stanley, Estelle Arts, Patricia Sloan (from August 2022) Mark Leggett (from February 2023)

Retired Board 2022–2023 – Caron Palmer (November 2023),  
Melanie Glenn (October 2023), Christine Sawers (July 2022)

## Operations and Engagement

Chief Executive – Scott Arrol

Office Manager – Hayley Forrest

Community & Research Advisor – Claire Reilly

Marketing & Fundraising Manager – Laura Huet (from October 2022)

Fundraising & Event Coordinator – Rob Bloch

Grants Coordinator – Jeanette Franklyn (from March 2023)

## Support Service

Support Services Manager – Jo Kelly

Support Advisors – Kate Moulson (until September 2022), Moira Young, Linda Oliver (until April 2023), Jane Kay (until December 2022), Sally King, Hefina Malone (until December 2022), Megan Te Boekhorst, Chevonne Stringer (from March 2023), Angela Callahan (from January 2023), and Tammy Gardiner (from May 2023).

## 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, Dennis Hall, Edith McCarthy, Helen Palmer, Mary Parker, John Roxburgh, Nedra Shand, Geoff Thompson, and Beth Watson.



# Performance and Financial Information

## STATEMENT OF SERVICE PERFORMANCE

Motor Neurone Disease Association of New Zealand (Jul 22 – Feb 23)

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

Consolidated service performance for the year ended 30 June 2023

### Description of Outputs

Motor Neurone Disease NZ provides a personalised support service to people diagnosed with MND, their family and whānau, and the health professionals providing care for them, through support, education, advocacy, and research. 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.

There are six support advisors nationwide, with support offered on a local and outreach basis. 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 equal support nationwide, provides resources to health professionals, and fosters collaboration to improve health outcomes and prolong independence for those affected.

<b>Quantification of outputs</b>	<b>Actual 2022-2023</b>	<b>Actual 2021-2022</b>
<b>1</b> Total individuals* supported by MND NZ	5,724	4,752
<b>2</b> Total clients registered to MND NZ	477	396
<b>3</b> Hours of community outreach by support service	11,088	12,740
<b>4</b> MND Support Fund grants distributed	50	53
<b>5</b> MND Information Packs provided	121	143
<b>6</b> Awareness and education talks given	15	25
<b>7</b> Contacts** with clients and their family	8,896	7,311
<b>8</b> Contacts** with health professionals	6,543	5,365
<b>9</b> People registered on the MND Registry	395	350
<b>10</b> Visits to the mnd.org.nz website	61,380	42,616

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

\*\* Email, phone, or text.

# STATEMENT OF FINANCIAL PERFORMANCE

Motor Neurone Disease Association of New Zealand (Jul 22 – Feb 23)  
Motor Neurone Disease New Zealand Charitable Trust (Mar 23 – Jun 23)

Consolidated accounts for the year ended 30 June 2023

	Actual 2022–2023 \$	Actual 2021–2022 \$
<b>Revenue</b>		
Donations, fundraising and other similar revenue	396,517	310,279
Grants	258,669	334,354
Bequests	61,930	28,778
Sponsorship	55,000	50,000
Ministry for Disabled People Contract	81,065	78,536
Interest, dividends and other investment revenue	29,681	27,206
Other income	643	38,297
<b>Total Revenue</b>	<b>883,504</b>	<b>867,450</b>
<b>Expenses</b>		
Support related expenses	498,853	469,160
Information related expenses	3,719	-
Advocacy and awareness	5,822	20,517
Research related expenses	84,814	107,819
Fundraising expenses	42,350	8,432
Office expenses	609,291	756,565
Governance expenses	32,253	32,181
<b>Total Expenses</b>	<b>1,277,102</b>	<b>1,394,674</b>
<b>Surplus/(Deficit) for the Year</b>	<b>(393,598)</b>	<b>(527,224)</b>

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 \[link\]](#)

# STATEMENT OF FINANCIAL PERFORMANCE

Motor Neurone Disease Association of New Zealand (Jul 22 - Feb 23)

Motor Neurone Disease New Zealand Charitable Trust (Mar 23 - Jun 23)

Consolidated balance sheet for the year ended 30 June 2023

	Actual 2022-2023 \$
<b>Balance Sheet</b>	
Cash	473,836
Accrued income	9,433
Accounts receivable	10,435
Fixed assets	39,622
Investments	728,185
GST refund due	9,531
<b>Total Assets</b>	<b>1,271,042</b>
Unspent grants	18,717
Accruals	11,570
Accounts payable	30,444
Holiday pay	47,050
<b>Liabilities</b>	<b>107,781</b>
<b>Net Assets</b>	<b>1,163,261</b>

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 \[link\]](#)

**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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