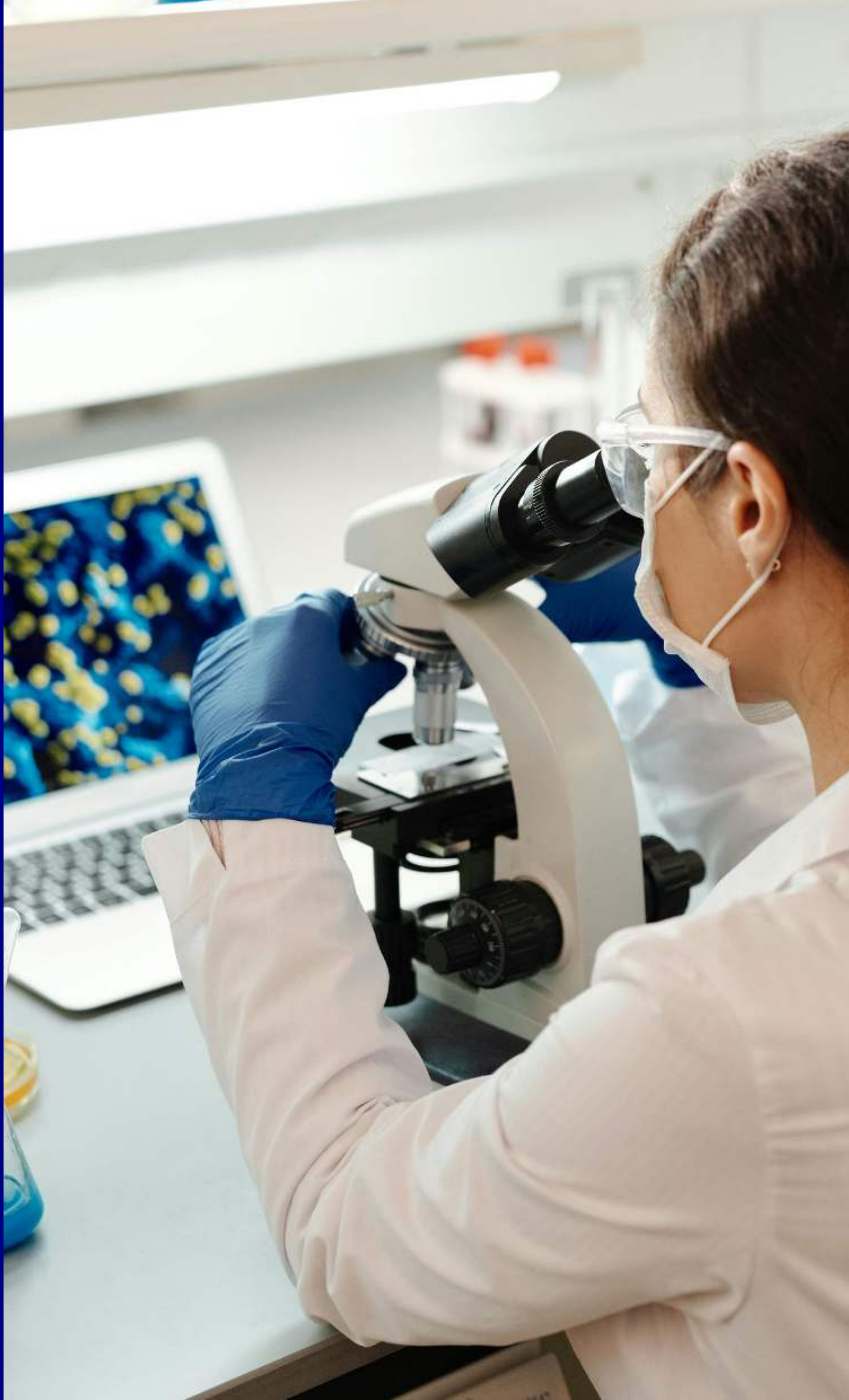
mnd
Motor Neurone
Disease NZ

Research Strategy

2025-2028

CURE • CARE • COMMUNICATE • COLLABORATE



Contents

Glossary

ALS = Amyotrophic lateral sclerosis
MND = Motor neurone disease
MND NZ = Motor Neurone Disease New Zealand
NZ = New Zealand

Foreword

Motor neurone disease (MND) refers to a group of progressive neurodegenerative disorders affecting motor neurones, the most common of which is amyotrophic lateral sclerosis (ALS).

There are over 400 people estimated to be living with MND in New Zealand (NZ).

Extrapolating from New Zealand research by Cao et al (2018)[1], it is likely that over 150 people will die of the disease each year. A similar number will be diagnosed each year. Research suggests that the incidence of MND is likely to be higher in NZ than elsewhere[1].

Median survival time from onset to either death, >23 hours per day of non-invasive ventilation or tracheostomy is around three years for ALS.[2] The time is even shorter from diagnosis.

Motor Neurone Disease New Zealand (MND NZ) is a not-for-profit organisation established to help support people with MND and their family and whānau.

In the absence of a cure, we focus on making time count for people affected by MND by offering personal support, advocacy, education, and supporting research.

The MND NZ Research Strategy builds on the previous research strategy (2019-2022). It encourages research in NZ that improves evidence-based care and support for people with MND, aids access to clinical trials and contributes to the international effort to identify the causes of MND, find better treatments, and ultimately, a cure for MND.

Dr Natalie Gauld ONZM
Research Advisor & Best Practice
Advocate, Motor Neurone Disease NZ

Diagnosed with MND March 2022

Mark Leggett
Chief Executive
Motor Neurone Disease NZ

Summary

This refreshed Research Strategy reflects on the progress made under the previous strategy, considers the current environment, and responds to the needs of both the MND community and researchers.

Thanks to the foundation laid by earlier efforts and the dedication of individuals across the sector, meaningful progress has already been achieved. This updated strategy builds on previous work continuing to direct funding and support toward areas that are important to people living with MND and their families and whānau.

The strategy will foster the growth and development of MND research in NZ by encouraging collaboration — locally, nationally, and internationally — and by promoting participation and the timely sharing of findings. It aims to grow expertise in MND across a range of health professions and to encourage research about management of the disease that will result in improvement in care and quality of life for people with MND.

We are deeply grateful for the generous donations that make this work possible. In honouring that support, MND NZ takes a multi-pronged approach to research investment — combining funding, internal expertise, and careful consideration of funding allocations to ensure that every dollar contributes to meaningful outcomes.

Through this strategy, MND NZ will encourage research that will enable more people with MND in NZ to have access to new treatments as they develop through clinical trials, while also supporting efforts to progress towards better treatments — and ultimately, a cure.

About us

Motor Neurone Disease NZ is a charitable trust built on the ethos of helping people affected by motor neurone disease — and that remains the cornerstone of everything we do.

Our Vision for the future

We envision a world where no one faces motor neurone disease (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.

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.

Impactful Research – The Strategy Behind It

The 2025-28 MND NZ Research Strategy uses a collaborative approach to funding and supporting MND research.

Our goal is to bring treatment studies to NZ, support policy decisions, improve quality of life, and support the discovery of effective therapies and finding a cure.

The why, how and what of this strategy remains very aligned to the previous MND NZ Research Strategy.

WHY – High quality care and support until a cure is found

HOW – Fund, promote, encourage and translate quality research into action

WHAT – Research that benefits our community, develops research capability and is disseminated in a timely way

Background

MND research in NZ faces challenges due to its small population, challenging environment for funding medicines, remote location, and limited funding for research. Thus, the scale of research here is smaller than in other developed countries.

However, recent progress has been encouraging.

Associate Professor Emma Scotter MNZM leads the Scotter Lab which investigates MND at the Centre for Brain Research at the University of Auckland.

This Lab has 10 researchers, works at a pre-clinical level and has published over 20 research papers, including in prestigious international journals. The team's genetics study is valuable for understanding the frequency of genetic mutations in MND in NZ.

The Scotter Lab benefits from the Neurological Foundation's Human Brain Bank, a world-class resource in NZ which includes brain and spinal cord tissue from people with MND.

The NZ MND Registry, funded by MND NZ and now hosted at the University of Otago, is led by Principal Investigator, Dr Sarah Buchanan, with Dr Margaret Ryan as the Curator. Data has been migrated from Australia to NZ, and recruitment is increasing. Established in 2017, the Registry now holds data for more than 500 people.

The Registry has aided recruitment for research, for example, the Lighthouse II clinical trial, genetics research and surveys. The Registry remains an important resource, including over 200 active registrants with MND in early 2025, around half of the estimated cases of MND at any time.

Also launched in 2017, the MND Research Network profiles researchers and projects across NZ. Though less active in recent years, it is expected to be revitalised late 2025 to help disseminate MND research findings and encourage further MND research and collaboration.

Dr Grace Chen and collaborators published multiple papers of their research on risk factors for MND in NZ.[3-5]

In late 2022, MND NZ released the Best Practice Recommendations for the Care of People with MND.[6] These recommendations will be useful to researchers investigating management in NZ, including potential for audits against these guidelines. We look forward to seeing further research relevant to MND that is underway around NZ being published.

We hope that this research strategy will help encourage more research published to help understand and improve outcomes for people with MND in NZ and internationally.

First Phase 3 Clinical Trial in NZ

In an important first in 2022, four sites in NZ participated in the multi-centre Lighthouse II Phase 3 study of Triumeq (antiretroviral treatment) with Dr Alan Stanley as Principal Investigator.

Advocacy and funding from MND NZ alongside funding from the Neurological Foundation brought this study to NZ.While Lighthouse II finished early after interim analysis showed lack of effect, this study showed capability and desire for clinical trials in MND in NZ.

Success of Tofersen

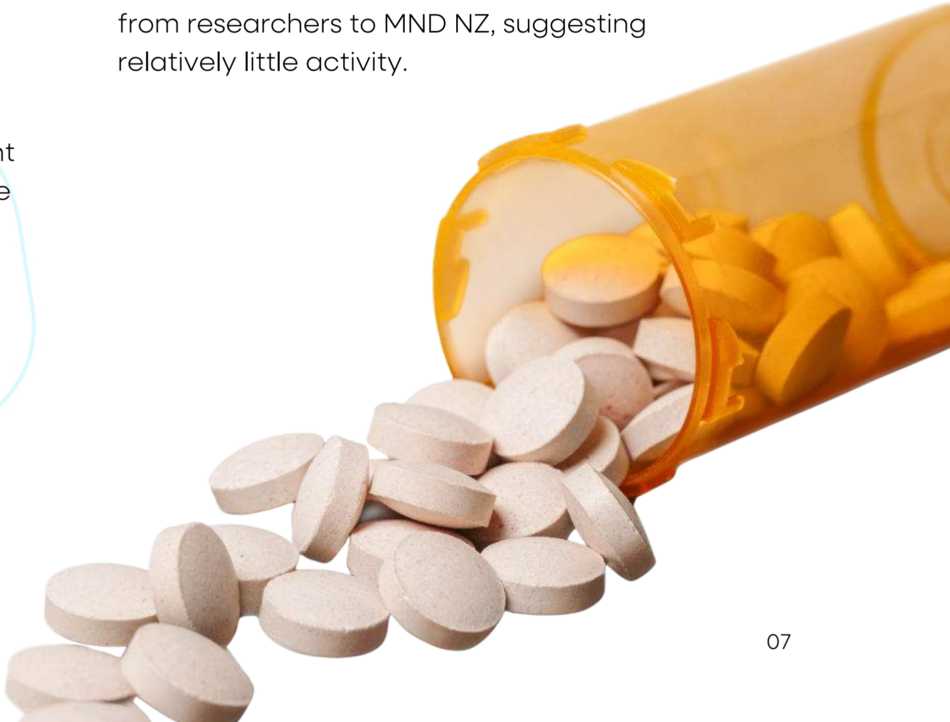
While not researched in NZ, the success of tofersen, an antisense oligonucleotide for SOD-1 ALS, is a significant advance in therapy.[7] While limited to the very small number of people with ALS who have the SOD-1 gene mutation, tofersen provides hope that other treatments will be discovered that change the course of the disease.

The only medicine currently available and funded in NZ to extend life in people with sporadic or familial ALS, riluzole has an average 7–11-month survival benefit.[8] There is an urgent need for additional treatments.

Understanding the MND Experience

In early 2025, the landmark MND Insight Research was conducted by Dr Natalie Gauld, funded by the Health Research Council and MND NZ. It included three large questionnaires involving people with MND, their families, whānau, and bereaved family members developed with considerable input from the community and researchers, and informed by international literature. Experiences, opinions, management and care of people with MND and their families and whānau were examined. Resulting evidence from this research will help highlight further areas for research. Preliminary data show 75% of people with MND want the opportunity to be on a clinical trial.[9]

Despite this momentum, a literature search in mid-2025 found only 14 MND-focused papers from three NZ research groups over five years. Research activity in 2024 was limited, with few contacts from researchers to MND NZ, suggesting relatively little activity.



Strategic Foundations

Dr Claire Reilly QSM from MND NZ was instrumental in developing the first MND NZ Research Strategy (2019-2022), fundraising for MND research, initiating the NZ MND Registry (with the University of Auckland's Centre for Brain Research), and bringing the Lighthouse II trial to NZ, in collaboration with others. Fundraising through MND NZ has enabled this development. Continued fundraising and support from MND NZ and donors remain vital to future progress.

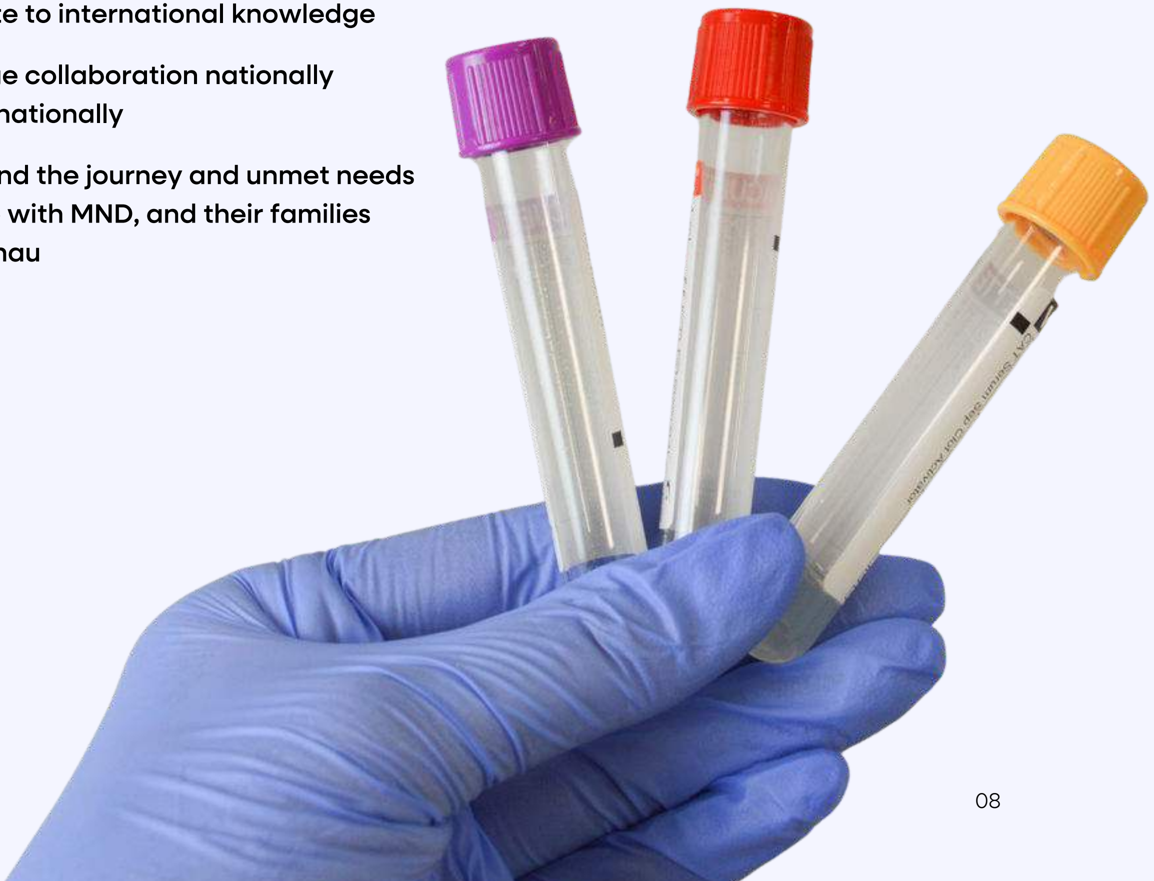
Other Funding

The Neurological Foundation supports neuroscience research and education, granting over $4 million annually using a robust process. Grants vary in size and primarily focus on neuroscience and clinicians rather than the allied health area of patient management. Large grants are available both locally and internationally, though competition is high.

Globally, organisations like Fight MND (Australia), Target ALS (US), and My Name'5 Doddie (UK) invest tens of millions annually, typically concentrating on MND treatment discovery. The pharmaceutical industry also funds many clinical trials, though Lighthouse II was supported by MND organisations, foundations and government funds worldwide.

Increasing MND research in NZ will:

- **Provide NZ evidence for advocacy**
- **Improve management and care for people with MND**
- **Increase knowledge about MND management – for researchers, health professionals, MND NZ and the MND community**
- **Increase interest in MND across health professionals and allied health who manage MND, including increasing specialism of MND within neurology**
- **Develop local experts in MND management and neuroscience**
- **Enable people with MND to participate in research**
- **Contribute to international knowledge**
- **Encourage collaboration nationally and internationally**
- **Understand the journey and unmet needs of people with MND, and their families and whānau**



Our research strategy

The search for a cure and better treatments remains important. At the same time, there is a significant opportunity to improve care for people living with MND.

MND is a complex condition that involves many health professionals, specialised equipment, and changing needs for individuals and their whānau.

These complexities highlight the need for research — especially research that brings together frontline providers and researchers, as encouraged in this strategy.

This strategy builds on the work of Dr Claire Reilly QSM and others. It reflects input from both the MND community and researchers, and is designed to ensure research funding has the greatest impact for the MND community.

The first MND NZ Research Strategy was guided by four key themes: *Cure, Care, Communicate, and Collaborate.* These remain central today.

This updated strategy takes a collaborative approach to funding and supporting MND research in Aotearoa. It aims to help bring treatment studies to New Zealand, inform policy, improve quality of life, and support the discovery of effective therapies — and ultimately, a cure.

Key goals

1. **Improve care for people with MND**
2. **Progress towards better treatments and, eventually, a cure**
3. **Ensure clinical trial opportunities are available for New Zealanders with MND**
4. **Have an active and collaborative MND research workforce**

Goal one

Improve care for people with MND

Why is this important?

Because while work continues toward better treatments, we must support those affected now or soon by MND.

Research on care will also develop increased interest and expertise in MND amongst health professionals and academics, developing leaders in MND care to help share best practice across the professions and undergraduates nationwide to benefit people with MND.

NZ-based evidence also strengthens advocacy efforts.

Over the next three years we will:

- Encourage development of research projects related to MND by academics in areas such as occupational therapy (OT), speech language therapy (SLT), physiotherapy (PT), nutrition, hospice and MND nursing.
- Support collaborative research projects between frontline providers and academics.
- Use learnings from the MND Insight Research to help identify areas of interest for further research and use considered dissemination to aid MND research interest.
- Promote use of the Best Practice Recommendations for the Care of People with MND (2022) for research, including audits.
- Continue to support the NZ MND Registry to aid study recruitment and provide data for research.
- Offer small grants (e.g. Masters fees, summer studentships, co-funding) to support research, particularly encouraging allied health working with MND clients.
- Encourage timely sharing of research findings, particularly NZ research, to health professionals and the MND community. The NZ MND Registry will continue to disseminate information through the MND Research Network.

Goal two

Progress toward better treatments and, eventually, a cure

Why is this important?

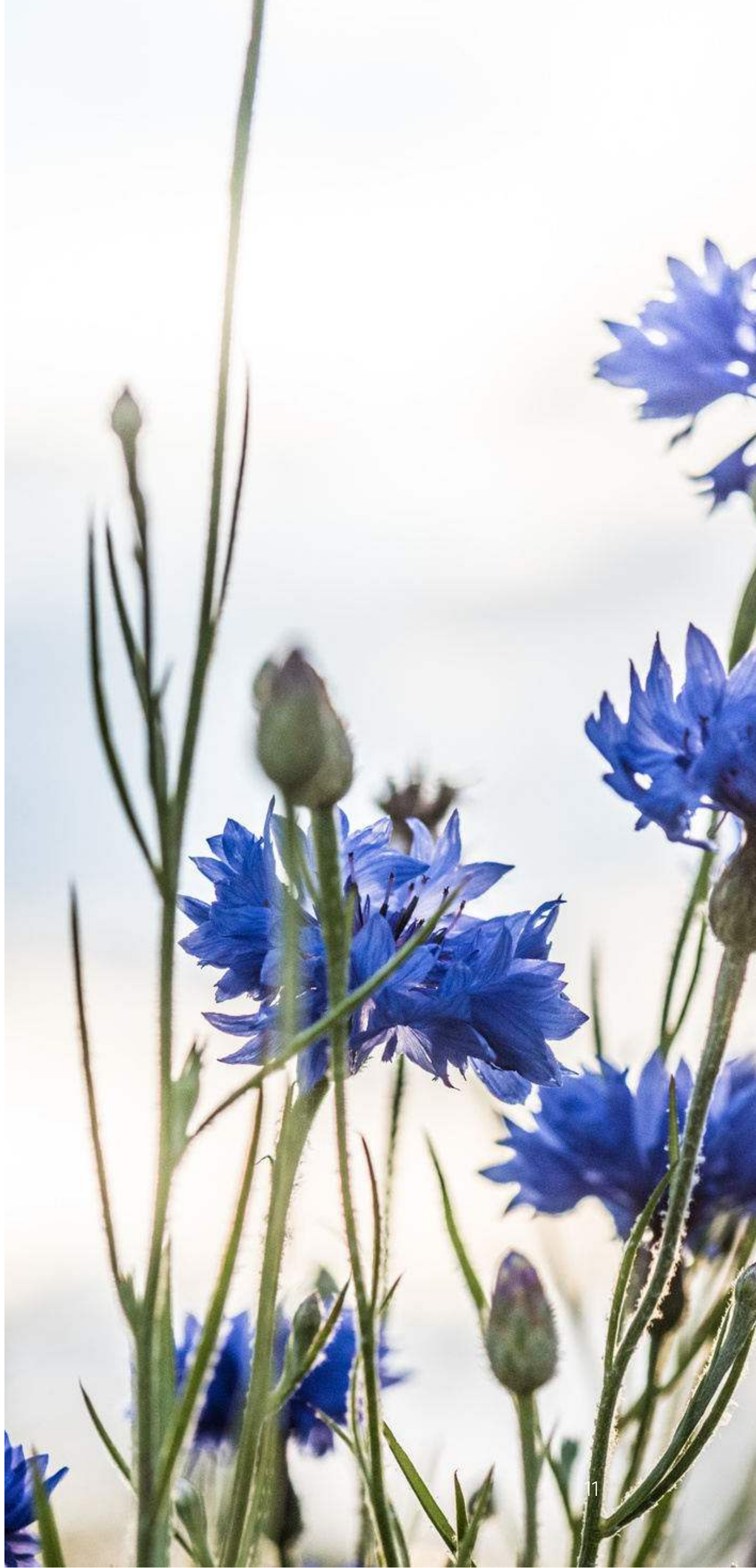
We aim for a future where MND is either curable or significantly better managed.

Preclinical research helps understand the disease and identify targets for new therapies, while clinical research aims to bring potential treatments closer to reality.

Supporting NZ-based researchers contributes to both national and international progress and reflects the strong desire within our community to have development of and access to new therapies.

Over the next three years we will:

- Support preclinical research through regular funding to the Scotter Lab, NZ's dedicated MND research lab at the Centre for Brain Research, to assist with grant writing and conference attendance.
- Continue to fund and support the NZ MND Registry to aid recruitment for research and clinical trials.
- Inform people with MND about opportunities to participate in research, including brain and spinal cord donation.
- Disseminate NZ research findings to health professionals, allied health, and the MND community.



Goal three

Ensure clinical trial opportunities are available for New Zealanders with MND

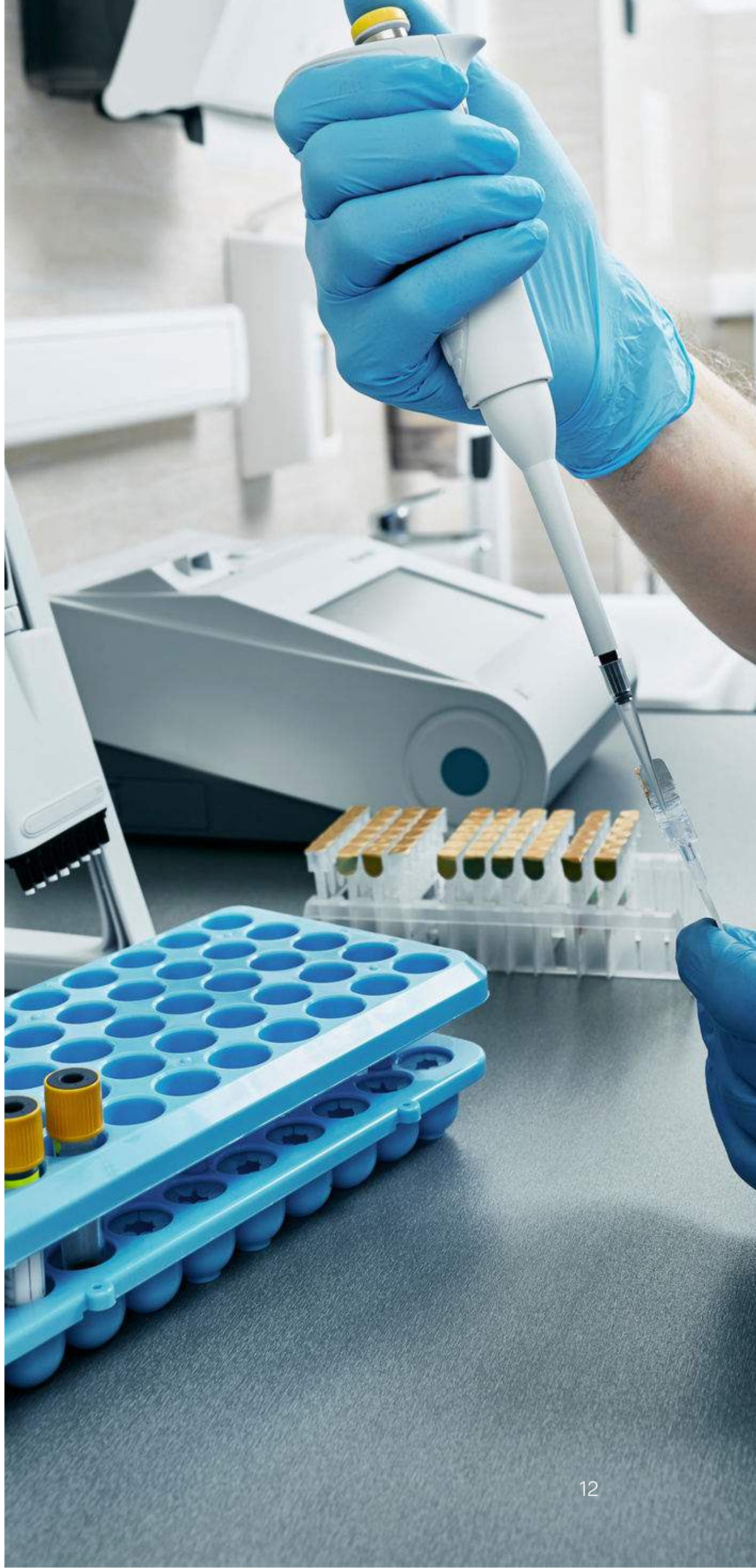
Why is this important?

Many people with MND want the opportunity to participate in a clinical trial. Running trials in NZ may offer earlier access to promising treatments, build expertise and interest in MND among neurologists, and strengthen international research connections.

Participation in clinical trials also aids progress toward better therapies and a cure.

Over the next three years we will:

- Continue to fund and support the NZ MND Registry to aid trial feasibility and participant recruitment.
- Take a proactive role to attract clinical trials to NZ.
- Inform the MND community about NZ trial opportunities and their outcomes.
- Facilitate connections between researchers, organisations, and trial sponsors to help bring studies to NZ.
- Advocate for integration of research and care, so eligible individuals are routinely offered the opportunity to participate in trials as part of their care journey.



Goal four

Have an active, collaborative MND research workforce

Why is this important?

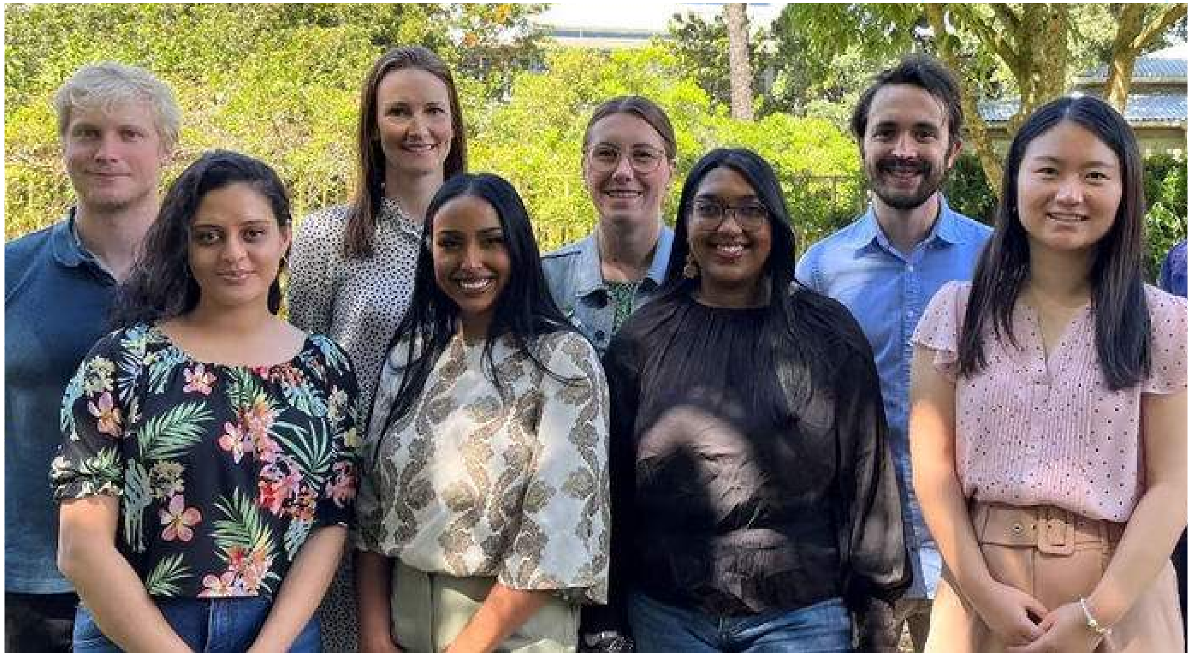
A strong, connected research workforce is essential to achieving all other strategy goals. Collaboration between academics and health professionals will mix quality design and practical purpose for research related to care.

Such collaboration will increase knowledge about MND for both groups, then benefiting undergraduates and the workforce. Collaboration is encouraged at a local, national and international level.

Over the next three years we will:

- Use the NZ MND Research Network to foster collaboration and share findings.
- Host a research symposia and/or webinars to encourage dissemination and discussion of research and stimulate new collaborations and ideas.
- The MND NZ Research Advisor will build relationships and support researcher engagement.
- Provide grants to encourage allied health professionals to collaborate with academics and gain research skills.
- Continued support for the Scotter MND Lab will help maintain global research connections.
- Encourage timely publication of NZ research through connection with researchers and small grants.

Pictured: *Associate Professor Emma Scotter (third from left) with members of the Scotter MND Lab.*



How we support MND research in NZ

Distant future possible benefit
More attractive to large funding grants
Higher international benefit
Generally higher cost
Generally higher risk

Present or near-future benefit
Less attractive to large funding grants
Higher local benefit
Generally lower cost
Generally lower risk

Types of MND research	**Disease mechanisms** Includes genetics, cellular functions, biomarkers, risk factors	**Pre-clinical** Developing possible treatments or cure in the lab	**Clinical trials - treatment / cure** In humans, Phase I/II, medication, gene editing	**Clinical trials - treatment / cure** In humans, Phase III/IV, medication, gene editing	**Clinical trials - patient management** Intervention studies	**Patient management** Diagnosis to end of life care, procedures and equipment, observational studies, e.g. surveys, audits, data linkage	**Experiences and views from people with MND and family / whānau**
MND NZ Support Funding	NZ MND Registry MND NZ promotion to people with MND where applicable Letters of support			MND NZ input into design where applicable and desired MND NZ dissemination of research findings to MND community MND NZ research network/symposium			
MND NZ Research Grants	Financial support for travel grants or funding grant writing time			Co-funding NZ arm of phase III trial and encouraging trials to come to NZ	Consider co-funding	Small grants where value is seen, e.g. summer studentships, co-funding, travel grants	

Types of MND research

Explanation and examples

Disease Mechanisms

Research in this area includes genetics, cellular function, biomarkers, and risk factors.

Examples:

- Lab studies exploring biological pathways that may lead to treatments
- Genetic studies
- Surveys investigating environmental or lifestyle risk factors
- Research to discover biomarkers for diagnosis or to support clinical trials

Pre-clinical Research

This involves developing and testing potential treatments or cures in the laboratory before they're trialled in humans.

Examples:

- Studies using mouse models to test new therapies
- Research on motor neurone cells or other cells derived from people with MND

Note: There is some crossover between disease mechanisms and pre-clinical research.

Clinical Trials – Treatment/Cure (Phase I/II)

Early-stage trials in humans to study safety, pharmacokinetics (how the drug behaves in the body) and sometimes early effectiveness of potential medication. These trials involve small groups and typically start with low single doses before progressing to higher doses and multiple doses. They may have no potential benefit to the participant.

Example:

- A study comparing treatment versus placebo in healthy volunteers or people with MND

Clinical Trials – Treatment/Cure (Phase III/IV)

Larger trials that test how well a treatment works and monitor side effects. Typically they examine survival and functional outcomes and biomarker changes over a minimum of six months, often with an extension phase for longer follow-up.

Example:

- The Lighthouse II trial in NZ, which tested Triumeq for MND

Clinical Trials – Patient Management Interventions

These studies examine a change in management. The design could randomise patients to the intervention or standard treatment or compare before and after the intervention in one location or compare different regions with and without the intervention. The intervention will usually be deliberate for the purposes of research.

Examples:

- Comparing different methods for placing feeding tubes
- Testing earlier use of breathing support (NIV or Bipap)
- Evaluating exercise therapy or telehealth with fitting a power wheelchair.

Observational Studies – Patient Management & Health Professionals and Allied Health

These studies look at real-world care, services, and equipment — what people receive, how timely and suitable it is, and, in some cases, how it affects outcomes. This could include studies from diagnosis to end of life care.

Examples:

- Surveys of people with MND or health professionals about care practices
- Audits of existing data or service changes, including data linkage
- Studies using the NZ MND Registry data to explore patterns in care

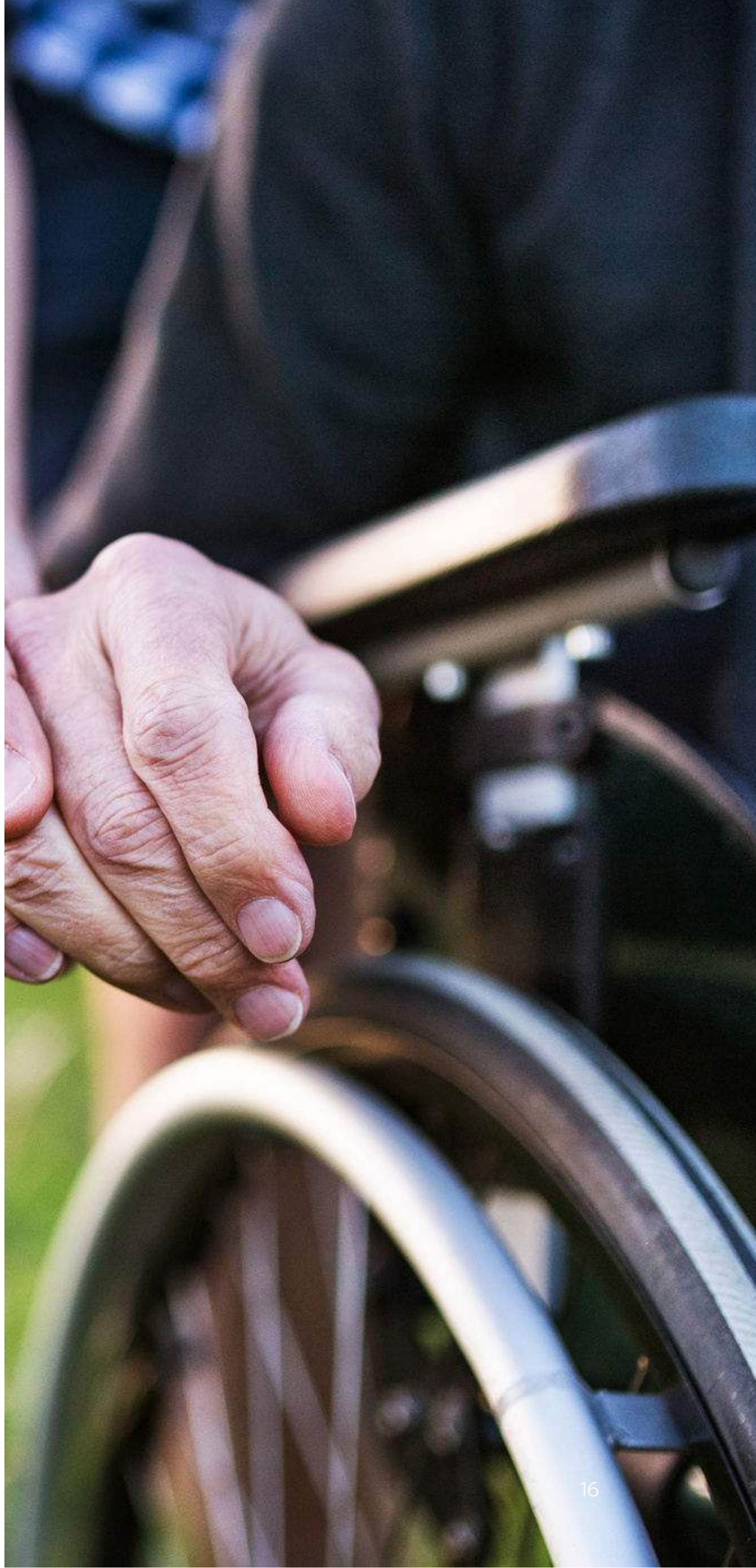
People with MND and Family/Whānau Experiences

Research in this area explores the lived experience of MND — including quality of life, carer burden, and opinions on different aspects of their illness.

Examples:

- Studies on psychological and physical coping strategies
- Opinions on assisted dying or community support
- Carer perspectives on their roles, challenges and unmet needs

Note: There may be overlap with observational studies when discussing services, equipment and care.



Our strategy in action

At MND NZ, we recognise how important research is to our community. All staff are aware of the role we play in encouraging, supporting, and sharing research that can improve lives and lead to better outcomes for people with MND.

Research Grant Administration

MND NZ research grants are managed through our national office. Funding requests are assessed through a competitive peer review process, led by the Chief Executive and the MND Research Advisor, with input from experts. Final recommendations are submitted to the MND NZ Board for approval.

We follow a clear and transparent process for grant applications. This includes assessing:

- The applicants' track record
- Feasibility of the proposed research
- The need for and potential benefit of the research
- Planned dissemination
- Collaboration, e.g. between academics and health professionals working with people with MND

Honouring Donor Support

We deeply value the donations that make this research possible. Every investment is carefully considered to ensure it delivers meaningful benefit to our MND community — whether in the short term or through long-term impact.

Examples of potential benefits include:

- Improvements in clinical care or management
- Better understanding of the patient and carer experience
- Advancing scientific knowledge
- Supporting collaboration and sharing of research findings

Funding

Each financial year (1 July – 30 June), MND NZ will make the following funding available to support MND research in NZ:

Research Grants – Up to $10,000 each
For postgraduate fees, summer studentships, or co-funding to support an additional MND-related project within a larger research grant.

- Total available: Up to $50,000 per year
- Example focus areas could include allied health, and encouraging MND specialism within neurology

Publishing Bursary – $1,500 each*
For lead authors publishing NZ-based MND research in a peer-reviewed journal indexed in PubMed, with or without open access.

- Must be accepted for publication within 18 months of completing the research
- Capped at two papers per individual over two years
- Not available to those with academic appointments or where writing the paper is funded
- May consider level of research funding for the person's time

Scotter MND Lab Grant – $15,000 per year
To support NZ's dedicated MND research lab at the Centre for Brain Research through research-related travel or grant applications where no other funding is available.

- No application required
- Annual impact and outcome report required

Funding for the NZ MND Registry
To support its ongoing operation, recruitment, and data management.

Funding for the MND NZ Research Advisor*
To lead research engagement and strategy implementation.

Support for MND NZ Staff Attendance at Research Meetings*

- Where beneficial and prudent, to stay informed and connected with current research and researchers, and disseminate learnings.

Funding for Surveys and Dissemination*
Including surveys of people with MND, families, and health professionals, with academic rigour and planned peer-review publication.

Funding for Webinars and Consideration of an MND Research Symposium*
To share research findings, encourage collaboration, and build awareness.

*Please note: where no maximum amount is provided, the amount allocated to each area will depend on funding available. Funding for the NZ MND Registry will be approved in advance.

Details of MND NZ's research strategy, along with summaries of all funded projects and proposals, will be available on the MND NZ website.

An annual research update, led by the MND NZ Research Advisor, will summarise progress, milestones, and alignment with the strategy.

Other support

Beyond funding, MND NZ provides practical support to help grow and connect the MND research community:

- Promoting the NZ MND Registry and helping facilitate enrolments
- Advising researchers on research involving the MND community
- Providing letters of support for grant applications
- Informing the MND community about research opportunities
- Bringing researchers and the MND community closer together
- Sharing research findings with the MND community
- Encouraging collaboration and timely publication of research
- Highlighting potential research ideas to researchers
- Communicating with sponsors, trial facilities, and researchers to encourage clinical trials to come to NZ.

For intervention trials, or research involving tissue or genetic testing, MND NZ relies on due diligence through ethics committees, the Health Research Council's Standing Committee on Therapeutic Trials (SCOTT), Principal Investigators, and universities. MND NZ does not assess or endorse these trials but encourages these trials to be available in NZ and helps inform people with MND about them.

For more information about our research strategy, visit our website or get in touch via email at **research@mnd.org.nz.**

What Success Looks Like

By implementing this strategy, MND NZ aims to achieve the following outcomes:

- **NZ MND Registry Growth**
  At least 300 current people with MND enrolled in the NZ MND Registry by end of 2026.
- **Research Output**
  Published papers from at least six different research groups or researchers relating to MND in NZ by end of 2028.
- **Clinical Trial Access**
  Two clinical trials brought to NZ and made available to people with MND by end of 2026.
- **Effective Grant Allocation**
  All available MND NZ research grants allocated to high-quality, relevant projects between July 2026 and June 2028.
- **Active Research Engagement**
  Regular contact (e.g. monthly) from researchers to MND NZ regarding research that is being planned or conducted.

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How you can help

We can only continue to drive research forward — towards a future where MND is treatable, curable, or preventable — with your support. Whether you host a fundraiser, or make a regular donation, every action helps bring us closer to that goal.

Regular giving

A monthly donation provides steady, reliable funding that helps us plan and sustain long-term research. Even small amounts make a big difference over time.

Gift in Will

By leaving a gift in your Will to Motor Neurone Disease New Zealand, you can help unlock answers. Letting us know about your intentions also helps us plan research funding into the future.

Fundraise for MND NZ

Run, bake, host a cuppa tea, or take on a DIY challenge for MND. Sign up to fundraise at **https://fundraise.mnd.org.nz.**

For more information or advice please contact us at **community@mnd.org.nz** or visit **www.mnd.org.nz.**