



**THE MOTOR NEURONE DISEASE  
ASSOCIATION OF NEW ZEALAND**

# **ANNUAL REPORT 2018/19**





# Contents

## Motor Neurone Disease Association of New Zealand

1 July 2018 – 30 June 2019

Incorporated Society number 269718

Charity number CC35320

PO Box 24 036, Auckland 1345.

[www.mnd.org.nz](http://www.mnd.org.nz)



Vision, Values, and Strategic Plan	2
Chairperson's Report	3
General Manager's Report	4
Key Statistics	6
Graeme's Story	7
Community Survey	8
Research	10
Fundraising and Awareness	11
Partnerships	12
Treasurer's Report	13
Team MND List	14
Performance Report	15





# Vision, Values, and Strategic Plan

## OUR VISION

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

## OUR VALUES

- People first
- Supportive
- Professional
- Honesty
- Partnership

## STRATEGIC PLAN 2019–2022

The strategic plan 2019–2022 details our commitment to successfully delivering six strategic priorities, continuing to work towards achieving our vision, and maintaining our values. People living with MND will always remain at the centre of everything we do.

The plan is designed to support not only those living with MND today, but also those who have yet to be diagnosed, and their carers and families. It shows how we will maintain our commitment to ensuring that people living with MND, as well as carers and families, receive the best quality support, and championing their right to access the best healthcare and social assistance throughout New Zealand.

### STRATEGIC PRIORITIES

- |  |   |
|--|---|
| <b>1</b> To strive to provide the best quality support to people living with MND   | <b>4</b> To develop effective strategic partnerships and collaborations, working together to achieve more for people living with MND  |
| <b>2</b> To help guide health professionals so they can provide the best support and care for people living with MND       | <b>5</b> To develop a globally connected, comprehensive, national MND research programme  |
| <b>3</b> To raise awareness of MND and strengthen our presence and capacity as the leading authority on MND in New Zealand | <b>6</b> To continue to improve the way we run MND New Zealand with a focus on effectiveness and sustainability, and ensuring our staff have the right tools to do the job. |

# Chairperson's Report

This year was another exceptionally busy one. Some changes to Council at the Annual General Meeting saw me take on the role of Chair, and Greg Horton appointed as Treasurer.

Greg Horton joined the Council two years ago. We are very fortunate that Greg brought with him considerable skill and networks that were instrumental in developing relationships with Fulton Hogan and Emirates Team New Zealand. We are excited about partnering with such high-calibre organisations and look forward to working with them to raise awareness and improve the lives of people living with MND.

This year we commissioned a comprehensive client survey to improve our understanding of the needs and expectations of our community. The survey responses showed that most people find the support team very helpful, which is positive. Most people also said their practical support needs were being met, but there is an opportunity to improve on meeting information needs. We received a lot of valuable feedback which has helped to inform our future direction.

In February, we held a very productive strategy session, bringing together staff and Council members to collaborate at our national office. Throughout the day, we talked through the highs and lows of our work and discussed ideas on the future direction of our organisation. The rare opportunity for everyone to meet face to face was extremely valuable in helping to develop our strategy for 2019–2022.

Successful Walk to D'Feet MND events were held in communities throughout the country on Sunday 11th November. The weather was terrific for the Wellington event, which I thoroughly enjoyed attending.

This year was one of consolidation for our team. Carl, Kate, and Toni all settled into their roles at national office. Significant investment in the organisation also happened this year, and I am confident we are doing the right things with the funding we have received. We are well-placed to deliver better and more targeted support services to our clients.

I want to thank the staff for their ongoing dedication to people with MND and their families. Our team have a tough job and go above and beyond in their roles.

It's also important that I take this opportunity to acknowledge my fellow Council colleagues for their support and dedication to this cause. Each member of the Council brings a unique perspective and skill set, which is incredibly valuable.

Thank you.



**Lucy Haberfield**





# General Manager's report

Dear members and supporters of MND New Zealand,

This year was the final year of implementing MND New Zealand's 2016-2019 strategic plan, which had four key areas: *Value, Clients, Internal Processes, and People*.

## Value

We continue to rely almost entirely on the generosity of New Zealanders through donations and fundraising to provide our core services: free, personalised support and information, advocacy for our community, raising awareness, and encouraging research. This generosity has seen the organisation hitting the \$1 million income mark for the second year running.

Because we rely on fundraising for long-term service provision, a full-time Fundraising Manager was appointed in September, who hit the ground running coordinating our flagship annual event series, Walk 2 D'Feet MND, in November. The walks were again very successful, taking place in 18 locations. More than 5000 people attended, and a net income of \$220,532 was raised for MND support and research.

Our 2019-2022 fundraising strategic goals – becoming sustainable, supporter-focussed, and future-proof, emphasise the importance of creating ownership in the MND community. Working as one team on year-round, inclusive fundraising opportunities, ensuring we can provide our vital services now and well into the future, is essential.

We have increased our commitment to New Zealand MND research, and in June launched our three-year research strategy focussing on cure, care, communication, and collaboration. The strategy aims to develop a globally connected, comprehensive, national MND research programme.

We identified a lack of research personnel, particularly those required to bring clinical trials to New Zealand. To address this issue, we began by hosting "An Update on MND Research – Homegrown & Abroad" (June 2019). This event was a chance for MND health care professionals, researchers, and the MND community to connect.

We are looking forward to continuing this momentum in the coming year.

We continue funding and working closely with the MND Research Network and the MND Registry. The Registry enrolled a further 64 participants during the year, bringing current enrolments to 172. We are also proud to have made a three-year commitment to help fund a study of the genetics of MND at the Centre of Brain Research,

University of Auckland. The study aims to understand the genetic causes of MND in New Zealanders and to test how specific MND gene mutations affect human cells.



## Clients

The number of clients and their families we support has increased, with the average number per month rising from 315 (2017/18) to 345 (2018/19). Support needs vary greatly between different clients and families, and for individual clients and families over time.

Ensuring we provide targeted, timely support, our increasing client numbers, and covering large geographical areas remain continual challenges for the Support Team.

To better understand clients' needs, we conducted the MND Community Survey in late 2018. Five surveys were distributed to all MND New Zealand stakeholders to capture feedback from our whole community – people living with MND, their carers, healthcare professionals, and supporters/volunteers. A summary of the survey findings and our commitment to address them can be found on page eight.

A significant theme identified for people with MND and their families and carers was unmet practical needs. In May we proudly announced Fulton Hogan as our corporate sponsor, with the establishment of the Fulton Hogan MND New Zealand Support Fund. This three-year commitment provides additional practical assistance to people living with MND and their families. We thank Fulton Hogan for their generous ongoing support.

## Internal processes

In February, all MND New Zealand staff and National Council members met for a full-day workshop. During the workshop we took the findings from the MND Community Survey, direct community feedback, and relevant personal experience to develop our Strategic Plan for 2019-2022. Collaboration with our whole community, working as a team to shape the organisation's future direction and growth, was paramount.

The focus of the next three years is on improvement, development, and sustainability. Through this plan, we are confident we can make as much difference as possible in the lives of those living with MND.

As a result of the survey findings, we began a review of our support service to understand how we can provide better support to people with MND, their families and carers, and health professionals throughout New Zealand. The review will also focus on the role of the support team member to ensure that our support team are adequately resourced, trained, and supported now and in the future to continue meeting the needs of our expanding community.

We have continued reviewing and updating policies and procedures throughout the year to ensure they remain clear, consistent, and relevant. We engaged an external HR advisor to review the remuneration policy for all employees and have updated our recruitment and fraud policies during this period.

Our bi-monthly internal newsletters provide a channel for regular communication within the team, and all staff and council members are kept up to date with key developments across the whole organisation.

## People

We welcomed Jodie O'Doherty to Council in October, and Kate Dalders (Fundraising Manager), Sally King, Jane Kay, Elise Doyer (Support Team Members), and Patricia Bell (Grants Administrator) to the operational team. Claire Reilly moved to the role of MND Community & Research Advisor in late 2018. At year-end there were 13 employees, most working part-time, with an overall FTE of 9.

Role clarity and performance expectations remain a continued focus, with all staff completing successful annual performance reviews. Pay reviews were conducted per our current remuneration policy, and increases were awarded accordingly.

Professional development opportunities included attendance at the MND Australia Conference in Adelaide, the International Alliance of ALS/MND Associations meeting in Glasgow, support team training days, the FINZ annual conference, and a variety of educational workshops and courses.

We continue working hard to maintain and develop relationships.

As well as our partnership with Fulton Hogan, we were honoured to end the financial year being named as the official charity partner of Emirates Team New Zealand and the 36th Americas Cup. Being selected is a massive achievement for our small organisation. We are looking forward to working with the team on some exciting projects to help raise awareness of this devastating disease and hopefully, much-needed funds.

Our amazing volunteers have continued to add huge value within the MND community, being involved in a broad range of regional activities throughout the year, including Walk 2 D'Feet MND events, MND support groups, and Cuppa Tea for MND events during 2019 Awareness Month.

Such a big year was made possible by the continued support from you, the MND community. A huge thank you to all our volunteers, supporters, fundraisers, and team for your valued contributions and efforts. I look forward to working hard for "Team MND" in the coming year, delivering our new strategy, fostering organisational growth, and uniting and empowering our community.

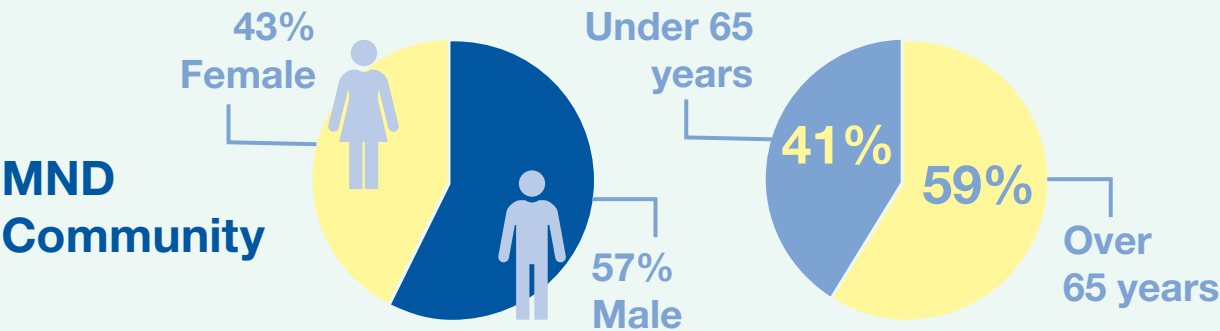
## **Ehara taku toa, he takitahi, he toa takitini**

*My success should not be bestowed onto me alone, as it was not individual success but success of a collective.*



**Carl Sunderland**  
General Manager

# Key Statistics



**345** Average number of clients supported

## Face to Face Contacts

**1,932**  
Clients and families

**1,837**  
Health Professionals

**5,162**  
No. of contacts  
(Email, phone, text)

**3,697**  
No. of contacts  
(Email, phone, text)

**120**  
Deaths

**193**  
New Diagnoses

**38**  
Awareness & Education Talks

**36,643**  
Website Visits

**5,107**  
Facebook Likes

**10,433**  
Email Newsletters

**1,088**  
Hard Copy Newsletters



# Graeme's Story

In 2009 I was 50 years old, enjoying a full and busy life with my wife Leeann and our two daughters.

I began noticing weakness in my hands and was also tripping over frequently, so I booked an appointment with my GP for a check-up.

What followed over the next two months was a process of elimination, ruling out a variety of causes for my symptoms.

When a diagnosis of MND finally came, my whole world changed, and I sank into a dark place. Unfortunately, it wasn't one of those dreams that you wake up from saying, "Thank goodness it's not real."

Adjusting to the diagnosis was tough. I guess I was in a state of shock and denial for a time. For about two years I didn't want to get involved with anyone else with MND.

Now I know I was lucky to have those two years to come to terms with having MND. I soon learned that many don't live that long. This insight sparked something in me, and I began to get involved with MND Support Group gatherings. Through the Support Group I made some good friends, sadly losing them too soon. Each one has inspired me to be a voice for this cruel disease and to try to make a difference.

Currently I organise an afternoon tea group approximately every two months with those impacted by MND. I'm also on the committee of my local Walk 2 D'Feet MND event, along with a wonderful group of caring volunteers.

Raising awareness of MND is vital, so I get involved in radio and TV discussions about MND where I can and give group talks to share my experience of living with MND.



I've found the MND New Zealand support team outstanding. They are so supportive, really understanding what you as a family are going through. They always have a listening ear and put you in touch with whomever you need to get the right support.

Because MND is continually changing, reducing the ability to function, the MND support team are crucial in my world, where something is often in need of adjustment.

My motto in life is: "The most important thing you will ever do in life is to help someone."

I try to live my motto by helping others where I can, smiling at strangers, cooking for elderly neighbours and enjoying their wisdom and friendship.

I live for my family: my wife, daughters, and grandchildren, trying to instil some of what life's journey has taught me. I am hopeful for the day when there is a cure for MND.

---

**"Thanks to the support of family, friends, and the MND Support Group, we raised our heads above the clouds. I guess in the end it's a case of sink or swim."**

---

# Community Survey

Understanding the needs of our community is vital, so in late 2018 we commissioned the MND Community Survey.

Point Research were engaged to develop and conduct the survey on our behalf. The survey was distributed nationwide to 4,963 people, including people with MND, their carers, previous carers of people with MND, health professionals, and other supporters and stakeholders.

It was pleasing to note that response rates were very high amongst those who were invited to participate: people with MND (70%), their families and carers (70%) and health professionals (41%). We appreciate the time and effort given by everyone who shared their views with us.

The survey focused on six key areas:

- Supporting people with MND
- Needs of people with MND
- Connecting with MND New Zealand – people with MND & health professionals
- MND New Zealand – supported research
- MND New Zealand's purpose
- Fundraising & campaigns

## Supporting people with MND

67%

of people with MND found the support team very helpful. People with MND who live close to their support workers base were significantly **more likely** to say the organisation was very helpful.

## Needs of people with MND – information

60%

of people with MND, family and current carers have **unmet information needs**.

People with MND, family and carers get about **as much information from MND New Zealand's website, support workers and publications** as they do from neurologists and other medical specialists.



All respondent groups wanted **information in a timely manner**.



People with MND needed **more information about the disease and treatments**.



Family and carers needed to know **how to help** the person with MND, practically and emotionally. They also wanted to know how to cope, and how to help other family members cope.

90%

In addition, 90% of **previous carers** stated they had unmet information needs.

## Needs of people with MND – Practical

40%

of people with MND, family and current carers have **unmet practical support needs**



Many people said practical support is provided through their DHB and its allocated service provider.



Help with practical needs included assistance with **work around the home** and **equipment** for home-based care and movement.



**Younger respondents** reported needing more help with **transport, personal care, financial hardship and employment issues**.



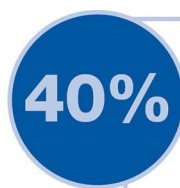
**Older people** and people with MND living alone reported **daily struggles** and **safety concerns** caused by these unmet practical support needs

## Needs of people with MND – social and emotional



People with MND, family members and carers, and previous carers reported **needing less social, relationship, emotional and psychological support** than physical and information support.

**Young people** with MND, family members and carers (i.e. people under 55 of age), however, reported a **need for more social and emotional support** than older people with MND or family and carers.



of people with MND, family and carers said they know of, or **use a local support group**. Those who do use the groups find them helpful.



Previous carers reported having **more unmet social and emotional needs during the later stages** of the disease.



Some people with MND said they had become **isolated and lonely** because they were no longer able to work, and connect with people who understood.

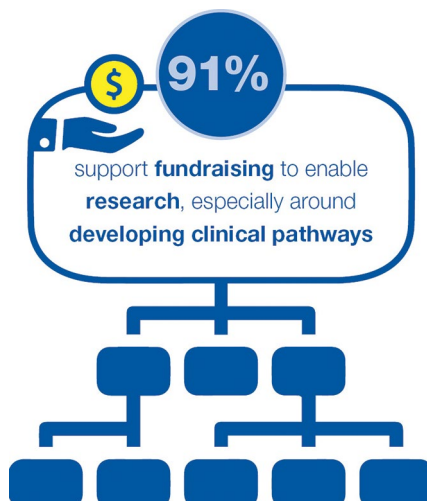
### Connecting with MND New Zealand – people with MND & Health professionals

Most people with MND (63%) said they heard about MND New Zealand at diagnosis with over half (54%) being told by their neurologist.

Fewer families and carers said they heard about MND New Zealand at diagnosis (41%) and many discovered MND New Zealand via the organisation's website (30%).

Most **health professionals** (84%) reported that **MND New Zealand works well or very well** with them to care for and support people with MND. The majority said MND New Zealand adds **valuable care and support** in addition to what clinical services provide.

### MND New Zealand – supported research



### MND New Zealand's purpose



All MND New Zealand's key purposes were considered important, but **support services, advocacy and research** were considered the most important of all.

## Fundraising & campaigns



90%

of supporters have **participated** in MND New Zealand events. More than half of these took part in **Walk 2 D'Feet MND**.

Overall, the results show that "MND New Zealand plays an important role in providing care and support to people with MND and their families and carers" (Point Research, 2018). However, the survey also identified a clear need for development in some areas, such as information provision, increased practical support, and our use of current technology.

# Research

This year we launched the MND Research Strategy 2019–2022, which is underpinned by four key components: cure, care, communication, and collaboration. The research strategy aims to develop a comprehensive, globally-connected, national MND research programme.

MND research has grown exponentially in the last decade. There is a strong desire to understand the causes of this complex condition and find new therapies for it. To stimulate interest in conducting MND research in New Zealand, this year we developed some key events.

In June we held a research afternoon in Auckland, entitled “An update on MND Research – Homegrown & Abroad”, featuring prominent MND researchers Professor Chris Shaw and Dr Emma Scotter.

Planning also began on two key events to be held in the next financial year. The MND Hui to be held at Parliament, and the Inaugural MND New Zealand Research Conference.

Both events are aimed at creating a forum for discussion to stimulate interest in research and standardising care pathways for people with MND.



We also proudly provided financial support to a new three-year genetic study currently underway at the Motor Neuron Disease Lab within The Centre for Brain Research at The University of Auckland. The objectives of the study, led by Dr Emma Scotter, are to understand the genetic causes of MND in New Zealanders. The study also aims to test how specific MND gene mutations affect human cells.

After receiving client feedback that available neck braces were not ideal for people with MND, we wanted to be involved in researching and designing an appropriate solution for this significant issue.

Support Team Member Kate Moulson has worked with a physiotherapist and final year students at the Engineering faculty at the University of Canterbury developing a neck brace specifically designed to meet the needs of people with MND.

A neck brace prototype is currently being tested by health professionals and clients. Feedback will be considered and implemented before further development happens and the neck brace becomes available for clients to use.

We continue to work closely with and provide funding to organisations involved with MND research, such as the NZ MND Research Network and the NZ MND Registry.

To intensify the focus on research, we have been working with the MND Research Network to develop the Inaugural MND New Zealand Research conference, featuring both local and international experts on MND.

Both the NZ MND Research Network and the NZ MND Registry have played a crucial role in establishing a platform for MND research in New Zealand.



# Fundraising and Awareness



In October, we appointed a full-time Fundraising Manager, Kate Dalders, for the first time in our history.

Because fundraising is crucial to our organisation, appointing a Fundraising Manager was vital for the ongoing development of this area.

The fourth annual Walk 2 D'Feet MND was held in 18 locations across New Zealand on 11th November 2018, increasing from 15 in locations in 2017.

The walks raised over \$220,000, with the average online donation increasing by 26% from \$75 in 2017 to \$95 in 2018.

During MND Awareness Week in June, our community came together to take part in our second Cuppa Tea for MND campaign. Over 30 events happened across the country, including one at Parliament. The Cuppa Tea for MND events raised over \$24,000 and helped increase public awareness of MND.



There was an overall increase in community fundraising and donation activity throughout the year. Donations were gratefully received from several community events organised by volunteer supporters, including a comedy fundraiser in Marlborough that raised over \$6,000 and a Sheep Shearing Challenge in Hawkes Bay which raised over \$16,000.

The Catholic Women's League of Aotearoa New Zealand named MND New Zealand as the charity beneficiary for their 2018 "At Home" Appeal. Members across New Zealand learned about the disease and spread the word about MND New Zealand's vital work and need for funding, raising over \$13,000.

Thank you to everyone who has fundraised, attended events, or donated their time and resources throughout this year. Your support is vital in helping us make a difference for people living with MND and their families/whānau.



# Partnerships

This year we have been fortunate in securing the support of two high-profile organisations, Emirates Team New Zealand and Fulton Hogan. We're delighted and deeply honoured to have established these significant relationships, which we believe will be instrumental in raising greater awareness of MND and providing additional support to people with MND and their families.

## Emirates Team New Zealand



We announced during Awareness Week that MND New Zealand had become the official charity partner of Emirates Team New Zealand and the 36th America's Cup.

Emirates Team New Zealand have witnessed the devastation of MND first-hand: teammate and former Emirates Team New Zealand Director and current Director of America's Cup Event Ltd (ACE) Greg Horton is living with the condition. Greg is also a member of the MND New Zealand National Council.

The announcement attracted considerable media interest, with Greg Horton appearing on TV One's Seven Sharp.

---

**Grant Dalton – CEO, Emirates Team New Zealand:** “Through Greg you can see the amazing work MND New Zealand does for the 300-plus New Zealanders who are living with MND, so we are really proud to be supporting them and everything they do.”

---

## Fulton Hogan



During Awareness Week we also announced a partnership with Fulton Hogan.

As foundation corporate sponsor, Fulton Hogan has committed to a three-year partnership, providing funding to assist in the provision of home care for people living with MND, their families/whānau, and carers.

The Fulton Hogan MND New Zealand Support Fund offers grants to assist with practical home-based help, like modifications to a house, in-home support, or specialised equipment.

The changing nature of the disease makes practical assistance vital. The Fulton Hogan MND New Zealand Support Fund is designed to ease financial pressure, helping to enhance the quality of life for people living with MND.

---

**Cos Bruyn – Managing Director, Fulton Hogan:** “This sort of practical teamwork in the community is something we do every day, and we're pleased to help a charity that's doing something similar in a critically important area of health.”

---



# Treasurer's Report

We remain almost entirely reliant on donations, fundraising and grants for our revenue, which was down approximately \$75,000 for the year, yielding total revenue of \$1,016 million.

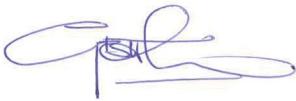
Costs increased by approximately \$150,000, driven principally through expansion of the team and higher expenditure on research-related activities.

Overall, the Association continues to experience increasing demand for services which is reflected in rising costs.

The net result was a deficit of approximately \$100,000 for the year, against a surplus of approximately \$127,000 for the previous year.

The Association has total assets of \$1.052 million and total liabilities of \$95,000. Cash and term deposits decreased by \$81,000, while the term investment portfolio increased in value by \$67,000.

Overall, the Association's financial position remains stable, and we have had an excellent start to the 2019/20 financial year.



**Greg Horton**

# Team MND 2018/2019

## **Patron**

Hon Ruth Dyson MP

## **Medical Patron**

Sir Richard Faull KNZM FRSNZ

## **Honorary Medical Advisor**

Andrew Chancellor MBChB, MD, FRACP, FRCP

## **Honorary Solicitor**

Scott Moran, Partner, Duncan Cotterill

## **Chairperson**

Lucy Haberfield

## **Vice Chairperson**

Anna Chalmers

## **Secretary / Treasurer**

Greg Horton

## **Council**

Fiona Hewerdine, Tony Treloar, Jodie O'Doherty, Steve Green, Beth Watson

## **General Manager**

Carl Sunderland carl.sunderland@mnd.org.nz

## **Office & Accounts Administrator**

Hayley Watkinson admin@mnda.org.nz

## **Fundraising Manager**

Kate Dalders

## **Grants Administrator**

Patricia Bell

## **Support Team Leader**

Toni Foster

## **Community & Research Advisor**

Claire Reilly

## **Support Team**

Sally King, Linda Oliver, Carol Matthews, Jane Kay, Moira Young, Elise Doyer, Kate Moulson

## **Life Members**

Reima Casey, Robina Davies, Dennis Hall, Edith McCarthy, Helen Palmer, Mary Parker, John Roxburgh, Nedra Shand, Geoff Thompson.

Thank you to the following funders for their highly valued support over the past year:

BW & SW Picot Charitable Trust

Community Organisation Grants Scheme

Eastern and Central Community Trust

EM Pharazyn Trust

FM Muter Trust

Foundation North

Four Winds Foundation

Hugo Charitable Trust

Iris & Eric Wilfred Nankivell Charitable Trust

Lion Foundation

NZ Lottery Grants Board

NZ Post

One Foundation

Page Trust

Sir John Logan Campbell Residuary Estate

Southern Trust

Thomas George Macarthy Trust

Trust Waikato

W. Duncan Bickley Trust Fund

# **Performance Report**

The Motor Neurone Disease Association of New Zealand Inc  
For the year ended 30 June 2019

Prepared by Go Figure 2005 Limited

# Contents

3	Compilation Report
4	Entity Information
6	Approval of Financial Report
7	Statement of Service Performance
8	Statement of Financial Performance
9	Statement of Financial Position
10	Statement of Cash Flows
11	Statement of Accounting Policies
12	Notes to the Performance Report



# Compilation Report

## The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2019

Compilation Report to the Members of The Motor Neurone Disease Association of New Zealand Inc.

### Scope

On the basis of information provided and in accordance with "Public Benefit Entity Simple Format Reporting - Accrual (Not-For-Profit) Reporting Standards", we have compiled the financial statements of The Motor Neurone Disease Association of New Zealand Inc for the year ended 30 June 2019.

These statements have been prepared in accordance with the accounting policies described in the Notes to these financial statements.

### Responsibilities

The members are solely responsible for the information contained in this financial report and have determined that the accounting policies used are appropriate to meet your needs and for the purpose that the financial statements were prepared.

The financial statements were prepared exclusively for your benefit. We do not accept responsibility to any other person for the contents of the financial statements.

### Independence

We have no involvement with The Motor Neurone Disease Association of New Zealand Inc other than for the preparation of financial statements and management reports and offering advice based on the financial information provided.

### Disclaimer

We have compiled these financial statements based on information provided which has not been subject to an audit or review engagement. Accordingly, we do not accept any responsibility for the reliability, accuracy or completeness of the compiled financial information contained in the financial statements. Nor do we accept any liability of any kind whatsoever, including liability by reason of negligence, to any person for losses incurred as a result of placing reliance on this financial report.

  
Go Figure 2005 Limited

Level 4

85 Ghuznee Street

Wellington

Dated: 20/09/19

# Entity Information

## The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2019

### Legal Name of Entity

The Motor Neurone Disease Association of New Zealand Incorporated

### Entity Type and Legal Basis

Incorporated Society  
Incorporated 21 March 1985

### Registration Number

CC35320

### Entity's Purpose or Mission

Together we provide the best quality care and support to those living with MND so they can live their life to the fullest.  
People First

- People are at the centre of all we do
- Our decisions always take into account the needs of our people (external and internal)

Supportive

- Positive yet aware
- Having empathy

Professionalism

- Excellence
- High standards of work
- High standards of behaviour
- Being respectful in our dealings with each other

Honesty

- Transparency
- Providing open feedback
- Being open about our views and willing to receive feedback
- Being willing to take a broader perspective to ensure we are well informed

Partnership

- Team players
- Working together towards the same goal
- Collaborating to achieve better outcomes for our people

### Entity Structure

The MND Association is incorporated under the Incorporated Societies Act. The national council are elected annually by members and the council meets at least four times per annum.

### Main Sources of Entity's Cash and Resources

The MND Association's income is derived predominantly from grants and donations, including the Community Organisation Grants Scheme (COGS).

A smaller portion is derived from a government contract, fundraising events including the Walk 2 D'Feet MND, and other sources.

### **Main Methods Used by Entity to Raise Funds**

MND applies for COGS and other grants on an annual basis. The entity also holds the Walk 2 D'Feet MND around the country on an annual basis.

### **Entity's Reliance on Volunteers and Donated Goods or Services**


The entity relies on gifts of volunteer time and expertise to complete work in many essential roles such as governance, fundraising and administration.

# Approval of Financial Report

## The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2019

The members are pleased to present the approved financial report including the historical financial statements of The Motor Neurone Disease Association of New Zealand Inc for year ended 30 June 2019.

APPROVED



Lucy Haberfield

President

Date 26/09/2019

# Statement of Service Performance

## The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2019

### Description of Entity's Outcomes

To provide practical, social and emotional support to people living with Motor Neurone Disease , their families and carers and the health professionals who support them.

	2019	2018
<b>Description and Quantification of the Entity's Outputs</b>		
Average number of clients and families during the year	345	315
Walk 2 D'Feet MND	18	18



# Statement of Financial Performance

## The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2019

	NOTES	2019	2018
<b>Revenue</b>			
Donations, fundraising and other similar revenue	1	918,014	985,657
Fees, subscriptions and other revenue from members	1	209	1,522
Revenue from providing goods or services	1	81,634	78,652
Interest, dividends and other investment revenue	1	16,545	27,111
Other revenue		-	(773)
<b>Total Revenue</b>		<b>1,016,401</b>	<b>1,092,168</b>
<b>Expenses</b>			
Expenses related to public fundraising	2	100,963	100,269
Volunteer and employee related costs	2	651,133	567,992
Costs related to providing goods or service	2	189,050	191,094
Grants and donations made	2	9,472	5,510
Research Expenses	2	126,989	59,968
Other expenses	2	39,704	40,552
<b>Total Expenses</b>		<b>1,117,310</b>	<b>965,385</b>
<b>Surplus/(Deficit) for the Year</b>		<b>(100,909)</b>	<b>126,783</b>

This statement has been prepared without conducting an audit or review engagement, and should be read in conjunction with the attached Compilation Report.

# Statement of Financial Position

The Motor Neurone Disease Association of New Zealand Inc  
As at 30 June 2019

	NOTES	30 JUN 2019	30 JUN 2018
<b>Assets</b>			
<b>Current Assets</b>			
Bank accounts and cash		351,144	530,960
Debtors and accrued income	3	8,634	8,715
Inventory		4,388	8,431
Other Current Assets	3	1,355	22,023
Craig & Co Managed Portfolio (Current)	3	117,401	126,545
<b>Total Current Assets</b>		<b>482,921</b>	<b>696,674</b>
<b>Non-Current Assets</b>			
Property, Plant and Equipment	5	72,818	96,434
Craig & Co Managed Portfolio	3	496,674	439,786
<b>Total Non-Current Assets</b>		<b>569,492</b>	<b>536,220</b>
<b>Total Assets</b>		<b>1,052,413</b>	<b>1,232,893</b>
<b>Liabilities</b>			
<b>Current Liabilities</b>			
Creditors and accrued expenses	4	48,011	70,182
Employee costs payable	4	37,426	23,405
Unused donations and grants with conditions		9,921	118,363
<b>Total Current Liabilities</b>		<b>95,358</b>	<b>211,951</b>
<b>Total Liabilities</b>		<b>95,358</b>	<b>211,951</b>
<b>Total Assets less Total Liabilities (Net Assets)</b>		<b>957,055</b>	<b>1,020,942</b>
<b>Accumulated Funds</b>			
Capital contributed by owners or members	6	353,905	353,905
Accumulated surpluses or (deficits)	6	378,446	363,728
Reserves	6	224,704	303,310
<b>Total Accumulated Funds</b>		<b>957,055</b>	<b>1,020,942</b>

APPROVED



Lucy Haberfield

President

Date 26/09/2019

This statement has been prepared without conducting an audit or review engagement, and should be read in conjunction with the attached Compilation Report.

# Statement of Cash Flows

The Motor Neurone Disease Association of New Zealand Inc  
For the year ended 30 June 2019

	2019	2018
<b>Cash flows from operating activities</b>		
<i>Cash was received from:</i>		
Donations, fundraising	918,014	985,657
Fees, subscriptions and other receipts from members	209	1,522
Receipts from providing goods or services	81,634	78,606
Interest and dividends	16,626	25,816
Net GST	12,420	(8,391)
<i>Cash was applied to:</i>		
Payments to suppliers and employees	1,193,891	966,976
Donations or grants paid	9,472	5,510
Net GST	-	-
<b>Net cash flows from operating activities</b>	<b>(174,460)</b>	<b>110,725</b>
<b>Cash flows from investing &amp; financing activities</b>		
<i>Cash was received from:</i>		
Receipts from the sale of property, plant and equipment	-	-
Receipts from the increase of investments	37,022	35,200
Receipts from term deposits matured	-	118,816
<i>Cash was applied to:</i>		
Payments to acquire property, plant and equipment	(5,367)	42,849
Payments to purchase investments	47,744	47,101
Payments to reinvest term deposits	-	-
<b>Net cash flows from investing &amp; financing activities</b>	<b>(5,355)</b>	<b>64,066</b>
<b>Net increase/(decrease) in cash</b>	<b>(179,816)</b>	<b>174,790</b>
Opening bank accounts and cash	530,960	356,170
<b>Closing bank accounts and cash</b>	<b>351,144</b>	<b>530,960</b>
<b>This is represented by:</b>		
Bank accounts & Cash	351,144	530,960

# Statement of Accounting Policies

## The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2019

### Basis of Preparation

The entity has elected to apply PBE SFR-A (NFP) Public Benefit Entity Simple Format Reporting - Accrual (Not-For-Profit) on the basis that it does not have public accountability and has total annual expenses equal to or less than \$2,000,000. All transactions in the Performance Report are reported using the accrual basis of accounting. The Performance Report is prepared under the assumption that the entity will continue to operate in the foreseeable future.

### Goods and Services Tax (GST)

The entity is registered for GST. All amounts are stated exclusive of goods and services tax (GST) except for accounts payable and accounts receivable which are stated inclusive of GST.

### Income Tax

The Motor Neurone Disease Association of New Zealand Inc is wholly exempt from New Zealand income tax having fully complied with all statutory conditions for these exemptions.

### Bank Accounts and Cash

Bank accounts and cash in the Statement of Cash Flows comprise cash balances and bank balances (including short term deposits) with original maturities of 90 days or less.

### Specific Accounting Policies

Fixed assets are stated at cost less aggregate depreciation.

Depreciation has been calculated using the following rates:

Motor vehicles 13.5% - 30.0%

Website 50%

Computer Equipment 40.0% - 60.0%

Office Furniture & Fitout 11.0% - 30.0%

Investments are initially recorded at cost and subsequently revalued to market value at balance date. The difference between the cost of the investment and the market value at balance date has been taken to the Investment Revaluation Reserve.

Grants are received and held on a cash basis. Where specific grants are not fully spent by the end of the financial year, the unspent portion is separated as Unspent Grants in current liabilities in the Statement of Financial Position.

Where a stock item purchased for resale/distribution costs more than \$5000 over a 12 month period the stock item will be treated as an inventory item and an adjustment for stock on hand will be made. Should the value of the stock on hand at the end of the financial year drop below \$5000 then that stock item will be treated as an expense in that financial year.

### Changes in Accounting Policies

There have been no changes in accounting policies. Policies have been applied on a consistent basis with those of the previous reporting period.

# Notes to the Performance Report

## The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2019

	2019	2018
<b>1. Analysis of Revenue</b>		
<b>Donations, fundraising and other similar revenue</b>		
Grant monies received	319,030	329,596
Tagged Donations	-	22,035
Donations and bequests	356,215	347,320
Walk Registrations	43,020	53,164
Sponsorship and fundraising	192,039	187,503
Other	7,710	46,039
<b>Total Donations, fundraising and other similar revenue</b>	<b>918,014</b>	<b>985,657</b>
<b>Fees, subscriptions and other revenue from members</b>		
Subscriptions from members	209	1,522
<b>Total Fees, subscriptions and other revenue from members</b>	<b>209</b>	<b>1,522</b>
<b>Revenue from providing goods or services</b>		
Ministry of Health Contract	73,957	73,957
Merchandise sales	6,661	1,349
Other	1,015	3,345
<b>Total Revenue from providing goods or services</b>	<b>81,634</b>	<b>78,652</b>
<b>Interest, dividends and other investment revenue</b>		
Interest - Westpac	425	2,334
Interest Received - Craigs Managed Portfolio	9,012	11,271
Dividends Received - Craigs Managed Portfolio	12,285	11,698
Foreign Currency Gains/Losses	(4,798)	1,291
Profit/(Loss) on disposal of investment	(379)	517
<b>Total Interest, dividends and other investment revenue</b>	<b>16,545</b>	<b>27,111</b>
	<b>2019</b>	<b>2018</b>

## 2. Analysis of Expenses

<b>Expenses related to public fundraising</b>		
Stock movement - Hope Puppies	4,043	3,685
Walk Merchandise	5,418	9,685
Advertising	47,412	44,495
Other	26,486	23,205
Walk Co-Ordinator	17,604	19,200
<b>Total Expenses related to public fundraising</b>	<b>100,963</b>	<b>100,269</b>
<b>Volunteer and employee related costs</b>		
Field Worker Salary	307,457	234,728
National Office Salaries	304,538	193,309
Kiwisaver	13,022	6,584
ACC Levies	1,021	1,263



Meeting expenses	6,129	9,763
Professional development	15,467	34,150
Staff Expenses	2,223	3,051
Other	1,275	85,143
<b>Total Volunteer and employee related costs</b>	<b>651,133</b>	<b>567,992</b>

**Costs related to providing goods or services**

Accountancy Fees	24,960	45,866
Field Worker Mileage & Motor Vehicle Expenses	31,686	23,638
Field Worker Travel Expenses	14,223	8,485
Rent	25,850	30,709
Postage, Printing and stationery	16,183	12,538
Other	76,148	69,858
<b>Total Costs related to providing goods or services</b>	<b>189,050</b>	<b>191,094</b>

**Grants and donations made**

Other	9,472	5,510
<b>Total Grants and donations made</b>	<b>9,472</b>	<b>5,510</b>

**Research Expenses**

Research	126,989	59,968
<b>Total Research Expenses</b>	<b>126,989</b>	<b>59,968</b>

**Other expenses**

Audit Fees	3,945	3,500
Depreciation	27,435	25,527
Portfolio Fees	5,858	5,490
Other	2,465	6,034
<b>Total Other expenses</b>	<b>39,704</b>	<b>40,552</b>

2019                      2018

**3. Analysis of Assets****Debtors and accrued income**

Accounts Receivable	7,088	7,088
Accrued Income	1,546	1,627
<b>Total Debtors and accrued income</b>	<b>8,634</b>	<b>8,715</b>

**Other Current Assets**

GST	1,355	14,606
Prepayments	-	7,417
<b>Total Other Current Assets</b>	<b>1,355</b>	<b>22,023</b>

**Investments - Craig & Co Managed Portfolio (Current)**

Call Accounts	45,733	25,014
Fixed Interest Bonds	71,668	101,531
<b>Total Investments - Craig &amp; Co Managed Portfolio (Current)</b>	<b>117,401</b>	<b>126,545</b>

**Investments - Craig & Co Managed Portfolio (Non-Current)**

Fixed Interest Bonds	174,399	124,280
NZ Shares - Equities	128,236	129,850
NZ Shares - Property	19,767	15,685

AU Shares - Equities	81,116	85,875
AU Shares - Property	13,072	13,025
International Shares - Equities	80,084	71,071
<b>Total Investments - Craig &amp; Co Managed Portfolio (Non-Current)</b>	<b>496,674</b>	<b>439,786</b>

2019 2018

#### 4. Analysis of Liabilities

##### Creditors and accrued expenses

Accounts Payable	25,890	32,258
Accrued Expenses	22,121	37,925
<b>Total Creditors and accrued expenses</b>	<b>48,011</b>	<b>70,182</b>

##### Employee costs payable

PAYE Payable	6,670	7,146
Provision for Holiday Pay	30,756	16,259
<b>Total Employee costs payable</b>	<b>37,426</b>	<b>23,405</b>

#### 5. Property, Plant & Equipment

This Year	Cost	Opening Carrying Amount	Purchases	Sales/Disposals	Current Year Depreciation	Closing Carrying Amount
Motor Vehicles	134,334	81,151		1,248	18,612	61,291
Website	7,850	931			465	466
Computer Equipment	35,727	13,319	5,068		7,644	10,743
Office Furniture	6,123	1,035			715	320
<b>Total</b>	<b>184,034</b>	<b>96,435</b>	<b>5,068</b>	<b>1,248</b>	<b>27,436</b>	<b>72,819</b>

Last Year	Cost	Opening Carrying Amount	Purchases	Sales/Disposals	Current Year Depreciation	Closing Carrying Amount
Motor Vehicles	115,151	52,644	48,000	1,222	18,271	81,151
Website	7,850	1,861			931	931
Computer Equipment	17,428	5,563	13,231		5,475	13,319
Office Furniture	6,123	1,885			850	1,035
<b>Total</b>	<b>146,552</b>	<b>61,953</b>	<b>61,231</b>	<b>1,222</b>	<b>25,527</b>	<b>96,435</b>

## 6. Accumulated Funds

This Year	Capital Contributed by Members	Accumulated Surpluses or Deficits	Reserves	Total
<b>Opening Balance</b>	353,905	363,728	303,310	1,020,942
Gain on investments for the year			37,022	37,022
Surplus/(Deficit)		(100,909)		(100,909)
Transfer from Reserves		115,628	(115,628)	
<b>Closing Balance</b>	<b>353,905</b>	<b>378,447</b>	<b>224,704</b>	<b>957,055</b>

Breakdown of Reserves			
Name	Actual This Year	Actual Last Year	
Research Reserve	88,863	204,491	
Investment Revaluation Reserve	135,841	98,819	
<b>Total</b>	<b>224,704</b>	<b>303,310</b>	

Last Year	Capital Contributed by Members	Accumulated Surpluses or Deficits	Reserves	Total
Opening Balance	353,905	329,379	175,676	858,960
Gain on investments for the year			35,200	35,200
Surplus/(Deficit)		126,783		126,783
Transfer to Reserves		(92,434)	92,434	
<b>Closing Balance</b>	<b>353,905</b>	<b>363,728</b>	<b>303,310</b>	<b>1,020,942</b>

	2019	2018
--	------	------

## 7. Commitments

### Commitments to lease or rent assets

MND leases the premises located at Yarnton House, 14 Erson Avenue, Royal Oak, Auckland. The lease is for an initial term of 3 years from 1 June 2018, with rights of renewal for two further terms of 3 years each. The annual rent is \$24,849.92 plus GST	49,700	72,479
Everyday Hero fundraising suite has been contracted for 3 years from June 2016 at \$375 per month.	4,500	4,500
<b>Total Commitments to lease or rent assets</b>	<b>54,200</b>	<b>76,979</b>

## 8. Contingent Liabilities and Guarantees

There are no contingent liabilities or guarantees as at 30 June 2019 Last year - nil).

## 9. Goods or Services Provided to the Entity in Kind

Description	2019	2018
Hound & Steed - Pro-bono project design and media management	\$18,450	\$11,558
Fairfax Media/Stuff.co.nz - Print & online advertising gifted	\$23,000	-
Sue Hobbs - Gifted design work for newsletters	\$3,120	\$3,040
Duncan Cotterill - Pro-bono legal advice	\$2,692	\$3,977
Media Works/TV3/Bravo - Advertising airtime gifted	\$24,275-	-
National Radio - Radio airtime gifted	\$45,000	-
NZME - Herald online & print advertising gifted	\$10,471	-
Go Media Billboards - Billboard site gifted	\$6,000	-
Walton Railton - Accounting Fees discounted by 50%	-	\$23,007
<b>Total</b>	<b>\$133,008</b>	<b>\$41,582</b>

## 10. Related Parties

There were no transactions involving related parties during the financial year.

## 11. Events After the Balance Date

There were no events that have occurred after the balance date that would have a material impact on the Performance Report (Last year - nil).



