



THE MOTOR NEURONE DISEASE
ASSOCIATION OF NEW ZEALAND

ANNUAL REPORT

2020/2021



Contents

Motor Neurone Disease Association of New Zealand

1 July 2020 – 30 June 2021

Incorporated Society number 269718

Charity number CC35320

PO Box 24 036, Auckland 1345

www.mnd.org.nz



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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, but also their carers and families/whānau, and those who have yet to be diagnosed. It shows how we will maintain our commitment to ensuring that people living with MND, as well as their carers and families/whānau, receive the best quality support, and how we will continue to champion their right to access the best healthcare and social assistance throughout New Zealand.

Strategic Goals

1. Enhancing our support services
2. Improving our information and engagement
3. Strengthening our organisation's capacity and sustainability.

Strategic Priorities

1. To strive to provide the best quality support to people living with MND
2. To help guide health professionals so they can provide the best support and care for people living with MND
3. To raise awareness of MND and strengthen our presence and capacity as the leading authority on MND in New Zealand
4. To develop effective strategic partnerships and collaboration, working together to achieve more for people living with MND
5. To develop a globally connected, comprehensive, national MND research programme
6. 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 and Acting CEO's Report



Natalie Thain
Chair



Greg Horton
Acting CEO

To our special community,

A big thank you!

Our report this year is unashamedly replete with the words: "thank you".

First, to all of those living with MND, their whānau, carers and supporters, your resilience in the difficult times of COVID-19 has been inspirational. We have deeply appreciated the way in which you have adapted to operating remotely, and we thank you. It has been a difficult past year, and as that continues, we will face the challenges together.

To our wonderful team at MND New Zealand, your skills, compassion, and empathy are and remain remarkable, along with your commitment to the MND community over these challenging times. We cannot thank you enough.

A special thank you to Carl Sunderland, who has left the role of CEO after four years of generating significant growth for our organisation. Carl worked tirelessly for MND New Zealand and for our community, and we wish him all the very best for the next phase of his career.

Kate Dalders, who has spearheaded our fundraising over the last four years, sadly also leaves us for a career move. Kate's achievements with our fundraising have allowed MND New Zealand to grow and grow, and she will be missed. Thanks Kate, and you leave with our very best wishes.

And finally, to our National Council, a group of volunteers who freely give of their time, energy,

and acumen to support people living with MND and MND New Zealand, the association could not do what it does without you. To Samarra Wright-Scott, Wayne Philip, and Nick Molcson, who have stepped down from Council this year, we thank you for your time commitment and contribution.

As you will see from this report, we have had a solid year from a financial perspective, and our supporters have rallied around us and the important work that we strive to do with some incredible fundraising, highlighted later. We also extend our thanks to Fulton Hogan, The Heart of Racing, Colliers, David Seymour, Special Group, and Emirates Team New Zealand for going above and beyond in the past year.

The Fulton Hogan MND New Zealand Support Fund helps families across New Zealand with additional support to cover transport costs, home improvements and maintenance, respite care, counselling, specialised care, medical equipment, and other practical needs. We are extremely grateful for Fulton Hogan's generous support, and 53 applications have been processed this financial year.

Additionally, we had our busiest and most successful Motor Neurone Disease Awareness Month in June, raising over \$245,000. The support we received through the MND Ice Bucket Challenge, led by Greg Goldfinch from Colliers, the Cuppa Tea for MND, and the success of the "David's Unusables" Trade Me campaign was inspiring. Thank you to everyone who took part.

The year ahead

As you read through this report, you will gain a sense of the massive amount of work in which we participate, and the contributions from a wide range of people.

As always, we are looking ahead and there is always more to do. We are about to embark on our strategic planning process for the years ahead, and we will report on that further in our upcoming newsletters.

Our number one priority is our support service, as well as our role in advocacy and communications, and these will always remain the cornerstones of our work.

In this area, we are currently working on projects that relate to:

- ✎ a review of our resourcing in the community, given increasing client numbers and the tyranny of distance between our support workers and our clients in many cases
- ✎ improving our information resources and engagement
- ✎ professional development for our team
- ✎ a longer-term solution for our support fund, given the value it adds and a steady increase in applications
- ✎ enhancing community education programmes and opportunities
- ✎ support of research projects directed at service provision.



Natalie Thain
Chair



Greg Horton
Acting CEO

We have continued our focus on the MND Clinical Working Group and our support of research. One of the most distressing aspects of motor neurone disease is the lack of disease-modifying or curative therapy. Patients often ask if there are any new medications for them to try or new research in which they can become involved. To date, access to clinical studies of therapies for motor neurone disease has been poor. This is largely due to the complexity of trial administration and approval, but also to the lack of time for primary investigators to commit to running the studies. We have started initial enquiries with the neurology clinical community to identify ways we might be able to support improved access to clinical trials for people living with MND.

He waka eke noa – We're in this together.

Our structure

MND New Zealand has been examining its legal structure as an incorporated society, and considering what might be the best structure for the organisation as we look to the future.

Most newly established charitable or community organisations select as their legal and operational structure a charitable trust as opposed to an incorporated society. There are many similarities between the two structures. Both, for example, have a governing body, but in an incorporated society it is called a council, while in a trust it is a board of trustees. Both can be registered as tax-exempt bodies by virtue of their charitable status, and both can carry on an undertaking, business, or other activity in the pursuit of their objects or purposes. Both have legal standing – meaning they can own assets, lease property, enter into contracts, employ people, and do anything else that any other corporate body or person can do.

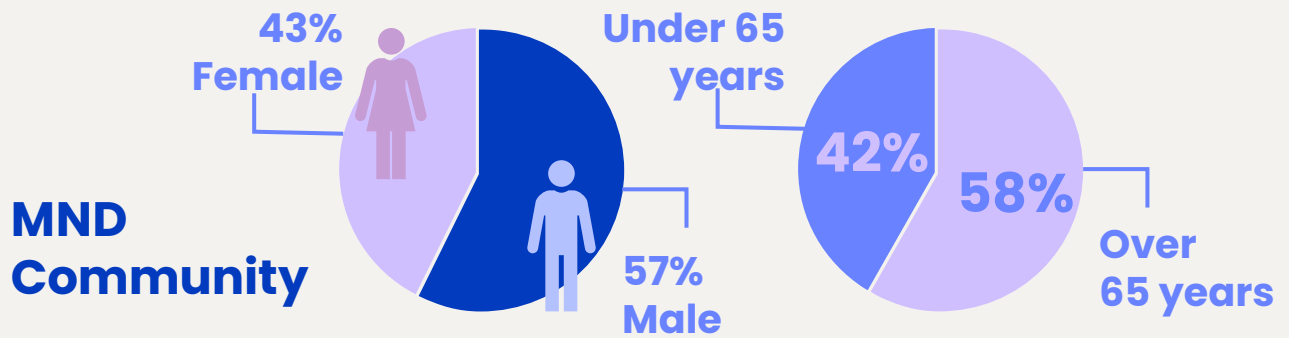
The key difference between a charitable trust and an incorporated society is the concept of membership. While a charitable trust can exist for the benefit of a defined class of persons, such as persons affected by motor neurone disease and their families, carers and related medical professionals, it does not naturally have

a concept of membership. Similar structures can be replicated; for instance, “members” can become “friends” or “patrons” of the trust, and on payment of agreed “fees” or “dues” can access services not otherwise available to members of the public, and information can be made available to such persons – or to the public at large – in the same way as to members of a society (by email, mailing list, website information, public meetings and the like). On the other hand, a society must have a membership to exist. For some societies, this becomes a burden and an unnecessary administrative hassle, consuming management time and resources that could otherwise be put to use for the objects of the society. For these societies, the trust structure offers the same benefits but without this administrative burden.

Examples of significant societies that have in recent years transitioned their operations from a society structure to a charitable trusts structure include Plunket and Arthritis New Zealand.

Therefore, MND New Zealand intends to propose to members that we move our structure to a modern charitable trust. We will keep you updated on developments.

Key Statistics



396 Average number of clients supported

Face-to-Face Contacts

1,675
Clients and families

899
Health professionals

7,311
No. of contacts
(email, phone, text)

5,365
No. of contacts
(email, phone, text)

103
Deaths

136
New clients

25
Awareness & education talks

42,616
Website visits

227
New Facebook page followers

15
eDMs sent

5,862
Newsletters emailed

600
Hard copy newsletters

Our Impact: Support

Fulton Hogan

The Fulton Hogan MND New Zealand Support funded 53 applications this year, bringing the total number of applications since the fund started to 101. It is fantastic to be able to offer financial assistance to our community that contributed towards bidets, heat pumps, massage, travel costs, respite for caregivers, repairs to van hoists, contributions towards the purchase of mobility vans and bathroom modifications, new seals, and cushions for NIV masks, firewood, power bills, counselling, mobility parking cards, pharmacy and medical expenses, and more! 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.

Bruce applied for funding to help him participate in the Americana Car Rally Event.

"Wow, I can't believe this and am ever so grateful, thank you Fulton Hogan."



Bruce and his Americana Car



Sally King, Megan TeBoekhorst, Linda Oliver, Jane Kay, Kate Moulson, Toni Foster, Hefina Malone and Moira Young

Team Days

Our Team Days were held in Auckland in May 2021. Our Team Days are a great opportunity for the MND New Zealand Support Advisors from around the country to come together and share knowledge, hear guest speakers, and discuss updates in treatment and client care. It was the first time the support team had been able to get together since August 2019 because of COVID-19. Guest speakers included Alison Charleston, a geriatrician and neurologist at ADHB, Maukakala Ofa, a NIC nurse specialist at ABHB, Penny Bavage, a Professional Advisor Team Leader at Accessible, and Claire Reilly, MND Community and Research Advisor. Their talks covered updates in the clinical management of MDN, non-invasive ventilation for MND, equipment funding criteria, and the development of national clinical guidelines for the management of MND.

Ministry of Health

In December, the Ministry of Health acknowledged our annual Performance Monitoring Report, which we prepare as a requirement under our contract as a Disability Information Advisory Service.

The Ministry congratulated us on being able to continue to provide support for our clients throughout the COVID-19 lockdown periods, and indicated their interest in the development of the clinical guidelines. These guidelines are in development and will provide best practice guides for health professionals to follow to ensure consistent care for people living with MND in New Zealand.

Stories from our Community



Lisa Brown

Lisa Brown

Lisa Brown hasn't let her MND diagnosis stop her, racing motorbikes competitively and working with a physiotherapist to help her continue to ride.

Lisa started racing two years ago with her partner Andrew. Since then, the pair have been traveling around the North Island competing in NZ Classic Racing Events, with Lisa taking home second place in the 2020 championship season in the 350cc Clubmans class.

Lisa says it is important for her to feel part of the team; an integral member of the wonderful racing community, who have rallied around her since she was diagnosed with MND. The team are even in the process of developing another slightly smaller bike so she can continue to race.

"You've got to have a goal, and you've got to stay positive to help you carry on," says Lisa.

Lisa knows what her goals are and hopes to compete in the next three NZ Classic Racing Events this year. We wish her the best of luck!

Penny Parsons

My husband Ian was diagnosed with MND in October 2019 passed away after a short but valiant fight against this dreadful disease on 11th January 2021. He was an amazing man, a talented musician, inspirational music teacher, loving and very proud father of three grown up children, and my wonderful husband for nearly 30 years.

I promised him from the start that I would care for him at home, and we managed this,

apart from the last five days, when he was admitted to our local hospice. He died very peacefully, and my two children and I were with him until the end. His daughter in the United Kingdom not able to visit her beloved dad due to the COVID-19 situation, but with the help of technology and a wonderful hospice nurse, she was able to be with us and say her goodbyes. Sadly, none of our family in the U.K. could visit Ian, another heartbreaking legacy of COVID-19. As a registered nurse I knew a bit about MND, but until Ian was diagnosed, I had little idea of the devastation this awful disease could cause. We called it "The Robber", as it robbed Ian of his music, his mobility, his independence, his ability to eat and drink, his ability to breathe unaided, and finally his voice.

Throughout Ian's all-too-short battle with MND, we were blessed to have the support of our MND Support Advisor who kept in touch, visited, and gave advice, information, and encouragement to both Ian and me. The visits and phone calls were a lifeline to us, and the care and support were so well coordinated. To go through this alone and without MND support services would have been unbearable! We had amazing support from all the health professionals involved in Ian's care, and I cannot speak too highly of their practical assistance and compassionate care.

Our story is deeply sad, but it is also a story of courage and tenacity, and acceptance of the totally unacceptable. Amongst these things there was also humour, and recognition of the amazing power of love triumphing over adversity.



Ian and Penny Parsons

Our Impact: Fundraising and Awareness



This year was one of adaptation. Our donors and fundraising supporters stood with us through the uncertainty of COVID-19 alert level restrictions, and adjusted plans when necessary to make sure MND New Zealand could continue to make a difference every day for those living with motor neurone disease.

In August, The Malvern Mullet Dudes fundraising hair shave took place, raising over \$42,000. Tobin (13) and a few of his mates decided to shave off their mullets to raise money in support of MND New Zealand, after Tobin's uncle, George Redmond, passed away from MND. The whole community came together for the mullet shave and charity auction, and All Black and Canterbury Crusaders rugby player Jack Goodhue attended, shaving the Mullet Dudes'

hair, and donating a signed Canterbury rugby jersey to be auctioned.

In October, Tweet Bird organised a fundraising dinner and auction. His friend, Ian MacLennan, died of MND 18 years ago, and his friend Morris Edwards had been diagnosed with MND earlier in the year. Morris passed away not long after the event took place. Tweet rallied the community and held the event in Masterton, catering for 300 guests and auctioning some incredible items. Like Tweet, Ian, and Morris, many of the event volunteers came from an ex-military background. Together they raised over \$62,000 in support of MND New Zealand.

Our annual Walk 2 D'Feet MND event series looked a bit different this year, with events spread out across summer in various locations. Events





took place between November and February in Tauranga, Palmerston North, Invercargill, Nelson, Greymouth, Christchurch, and Napier. The season closed with a Virtual Walk 2 D'Feet MND, held on 28th Feb 2021. Our supporters raised over \$50,000 through Walk 2 D'Feet MND events and activities.

Summer also saw our partnership with Emirates Team New Zealand really swing into action for the 36th Americas Cup. In December, MND New Zealand held a raffle with an incredible first prize: a VIP experience on the ETNZ hospitality boat during the Prada Cup Challenger Selection Series. The raffle raised \$16,000. The Americas Cup race series took place in March, and volunteers in the race village during that month raised awareness of MND and over \$1,000.

The Heart of Racing, one of ETNZ's sponsors, generously donated \$500,000 to MND New Zealand in honour of the partnership. All up, MND New Zealand's connection with Emirates Team New Zealand in the two-year lead-up to the 36th Americas Cup has directly led to \$826,000 in donations and fundraising. The partnership has been an amazing success, raising not only funds, but also awareness of MND amongst a wider audience.

In June, Motor Neurone Disease Awareness Month fundraising campaigns included David's

Unusables, Cuppa Tea for MND, and the MND Ice Bucket Challenge. It was our most successful Motor Neurone Disease Awareness Month ever, raising a record \$245,000.

More than thirty Cuppa Tea for MND events were held across New Zealand. These events raised over \$16,000 and promoted MND awareness to hundreds in the community.

Several companies took on the MND Ice Bucket Challenge, and each set themselves a fundraising goal. A special thank you to Active VMA (who raised over \$7,000), Bluff Country Contractors (who raised over \$8,000), and Colliers Highbrook, who raised an astounding \$200,000. Greg Goldfinch, National Director of Industrial at Colliers, reached out to express his desire to take part following his father being diagnosed with MND. His colleague Ryan also has first-hand experience of MND: his father is living with the disease. The team at Colliers Highbrook banded together in support of them, and twenty Colliers Highbrook staff took the icy drenching while dressed in their suits.

More than 90 supporters held their own events or fundraised online in support of MND New Zealand this year, raising over \$178,000.



Our Impact: Information and Communication

Even though social gatherings were drastically affected by COVID-19, our support team members still managed to lead 25 education presentations to health professionals, community groups, and service providers.

We distributed 195 information packs, 600 About MND pamphlets, and 60 A problem-solving approach for GPs and health professionals booklets.

Our website had 42,616 visits. The top three most-read pages on our website were About MND, What causes MND, and Living better for longer.

We posted 217 times on Facebook. The number of people who Like our Facebook page grew from 5,877 to 6,098. Each of our posts was seen by an average of 1,387 people. Over the year, all our Facebook posts were seen a total of 300,988 times and received 24,773 comments, likes, shares, and clicks.

The Winter and Spring issues of MND News were posted to 600 people and emailed to 5,862 people. Additionally, we created an email newsletter specifically for health professionals, which will be sent three times per year.

Throughout the year we sent a total of 15 direct marketing emails (excluding our e-newsletters).



Our Impact: Research and Advocacy

This was another big year for MND New Zealand research, during which we continued our focus on implementing the 2019–2022 research strategy.

NZ MND Registry and MND Research Network

MND New Zealand continued to fund the two key foundations of our research programme: the NZ MND Registry and the NZ MND Research Network. MND New Zealand is grateful to Dr Emma Scotter and her team at the Motor Neuron Disease Research Lab at The Centre for Brain Research, University of Auckland, for their ongoing research initiatives and important work in this field.

We also welcomed Dymphna Mulroy into her new combined role, working with the research network and as the registry curator.

The NZ MND Registry recruits for both the genetics and MRI studies that are run by the Scotter Lab. As of June 2021, there were 190 active participants enrolled in the registry; 55 people enrolled during this financial year. The NZ MND Registry aim is to have New Zealanders “clinical trial ready” for potential future therapies.

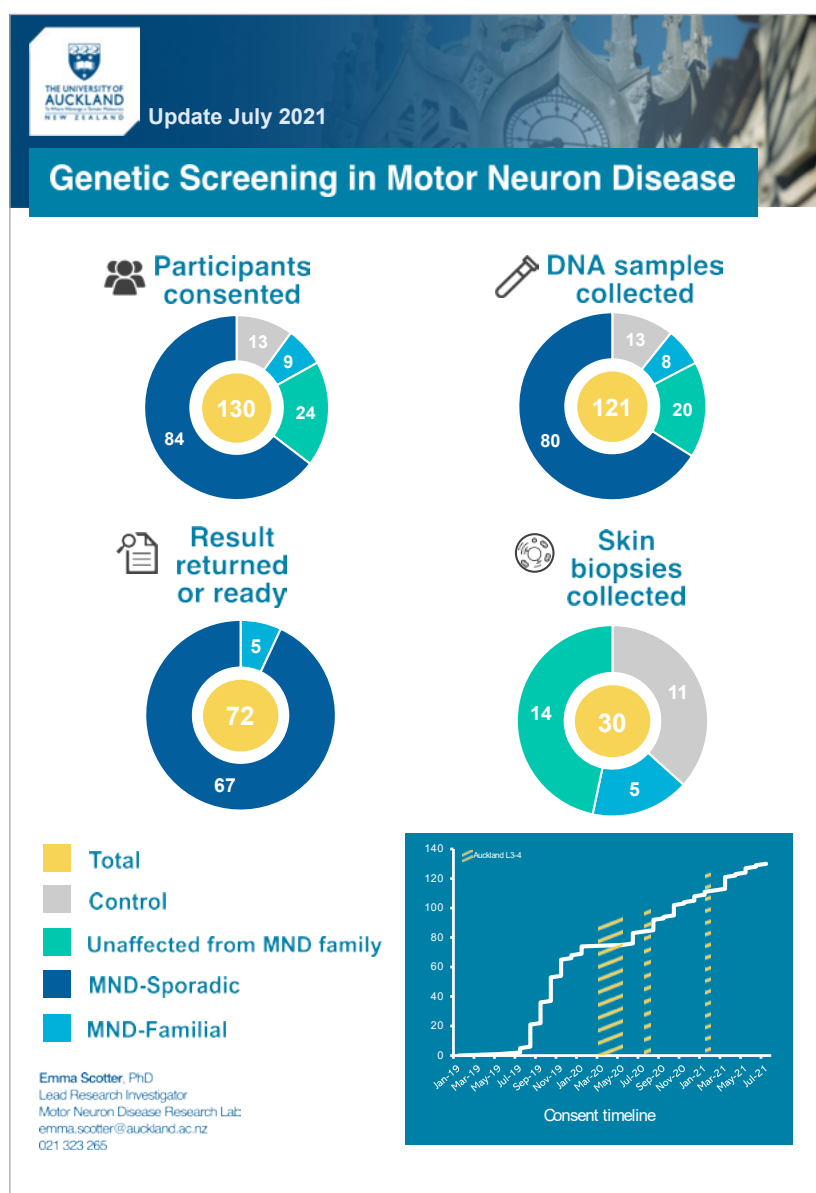
Year two of the three-year genetic study that was co-funded by MND New Zealand was completed by Dr Emma Scotter, Dr Richard Roxburgh at the Neurogenetics Clinic, and collaborators. As of June 2021, 129 out of the 330 participants required had been recruited. Unfortunately, the COVID-19 pandemic did adversely affect the recruitment process.

Overall, throughout the year the registry connected New Zealanders with four research studies. It reached out to an additional eight studies, asking them to consider New Zealand as a site for their trial, and promoting the benefits of the NZ MND Registry to assist with recruitment.

The NZ MND Research Network website is kept up to date with

research happening in New Zealand, information on grants, scholarships and resources. Activity on the NZ MND Research Network Social Media sites (Facebook, Twitter) increased throughout the year, with weekly posts and more interaction with its followers.

The Research Network continues to grow, with 105 people on the mailing list at time of going to print, and aims to increase communication and networking opportunities for researchers interested in MND. They have launched a newsletter with a series of teleconferences providing an exciting opportunity to hear first-hand about research happening in NZ, and offering a chance for researchers to share ideas and network.



Ministry of Health and the MND Clinical Working Group: a vital partnership

One of the results from the 2018 Information Survey was that people with MND wanted to see an increase in advocacy at a national level to improve health care, and the development of standardised clinical guidelines. In September, the MND New Zealand hui brought together health care professionals from all over New Zealand to discuss opportunities to improve healthcare for people with MND.

A key outcome of the day was the development of the MND Clinical Working Group, intended to develop standardised national guidelines to improve care for people living with motor neurone disease and their families.

The group is made up of 14 members from all around the country, including neurologists, respiratory and palliative care physicians, nursing and allied health professionals, and MND New Zealand team members.

Expected to span two years, the vision of this collaborative project was framed as "Improving care, improving lives". The key focus areas were developing national guidelines for the management of MND, working with the Ministry of Health to improve access to practical support, and reviewing resources available for health care professionals.

The group has now finished the draft national "New Zealand Guidelines for Motor Neurone Disease Care, Ngā Aratohu mō te Manaaki Mate Tauheke Ioio". They have been distributed to various health professional organisations for feedback and endorsement, including the Neurological Association of New Zealand (NANZ), the Australian and New Zealand Society of Palliative Medicine (ANZSPM), and the Thoracic Society of Australia and New Zealand (TSANZ), which will help with raising awareness of the guidelines with clinicians.

The guidelines will be hosted on the MND New Zealand website once they are finalised, and the team are working on a summary document suitable for publication in the New Zealand Medical Journal, again aimed at increasing awareness.

In May, Co-Chairs of the Clinical Working Group Alan Stanley and Claire Reilly began meeting regularly with Chief Allied Health Officer Martin Chadwick from the Ministry of Health to discuss recommendations from the guidelines, with a focus on the difficulty people with MND have accessing practical support such as equipment and modifications.

New Research Projects

Research Project Study: "Costs Associated with Motor Neurone Disease in New Zealand"

In August, MND New Zealand started to work with health economist Braden Te Ao to investigate the costs associated with caring for people with MND. Currently there is no information available on what health and social services people diagnosed with MND are using, and the cost of these to government and to people with MND and their families. The purpose of this study is to understand MND health care and support costs, and whether any funding gaps exist in health care and social support for people with MND. This information will assist MND New Zealand in advocating for the needs of people living with MND in New Zealand. All people with MND will be invited to participate in an online survey, which will ask a series of questions about the health services they have used over the last 12 months and any out-of-pocket expenses.

Research project: The role and impact of the MND clinical nurse specialist – a combined quantitative and qualitative study

Background

Prior research performed in Canterbury showed a rising incidence of MND between 1985 and 2006, with a median survival of 17.6 months from diagnosis. Since that time, there has been the introduction of a disease-modifying agent, riluzole. Additionally coordinated multi-disciplinary care delivered in a specialised clinic setting is one of the few interventions that has been shown to improve survival in MND (NICE Guideline). In July 2013, a Key Worker/Clinical Nurse Specialist (CNS) role and multidisciplinary MND clinic was established in Canterbury, aligning service provision with international best practice. The overall purpose of this study is to assess the quantitative and qualitative impact of this model of care.

Treasurer's Report



Lucy Haberfield

Total revenue for the year topped \$2.085M, with much of this being grants, donations, and fundraising (\$1.987M). We are heavily reliant on this source of income to ensure our financial sustainability. MND New Zealand was very fortunate this year to be supported by Emirates Team New Zealand and Fulton Hogan. Emirates Team New Zealand's support led to some very generous donations. The Government's contribution was \$70K. We appreciate the many contributions we receive from individuals and groups, and the effort that

goes into raising funds on our behalf.

As well as providing support and advocacy to people with MND and their families, we aim to contribute to the growing body of research. We can only do this through raising awareness and that involves stakeholder engagement and participation in the health sector.

The team manages costs very carefully in meeting these goals. Our staffing costs are \$630K, fundraising costs are \$93K and research costs are \$102K. Overall surplus for the year was \$762K. Underlying administrative costs were 14.2% of total revenue. Whilst these costs were fairly similar to last year in total, revenue increased significantly leading to a lower percentage.

The balance sheet remains strong with net assets of \$2.031M. Funds invested with Craigs have increased to \$727K (+\$17k) and short-term funds ended the year at \$1.359M. A substantial donation at year end is earmarked for investment in Managed Funds. MND New Zealand holds minimal fixed assets at \$36K.

Overall this is an exceptional result for the year.

A handwritten signature in black ink, appearing to read 'Lucy Haberfield'.

Lucy Haberfield

Team MND 2020/2021

(as of 30 June 2021)

Patron – Ruth Dyson

Medical Patron – Sir Richard Faull KNZM FRSNZ

Honorary Medical Advisor – Dr James Cleland FRACP

Honorary Solicitor – Scott Moran, Partner, Duncan Cotterill

Chairperson – Natalie Thain

Deputy Chairperson – Caron Palmer

Secretary/Treasurer – Lucy Haberfield

Council – Alan Stanley, Melanie Glenn, Michael Fuyala, Samarra Wright-Scott

Retired Council 2020 – 2021 – Chris Drennan, Nick Molcsan, Wayne Philip

CEO – Carl Sunderland

Office Manager – Hayley Watkinson

Fundraising Manager – Kate Dalders

Communications Specialist – Emily King

Grants Administrator – Patricia Bell

Support Team Leader – Toni Foster

Community and Research Advisor – Claire Reilly

Support Advisors – Kate Moulson, Moira Young, Linda Oliver, Jane Kay, Sally King, Hefina Malone, Megan TeBoekhorst, Elise Doyer

Life Members – Reima Casey, Andrew Chancellor, Robina Davies, Graham East, Dennis Hall, Edith McCarthy, Helen Palmer, Mary Parker, John Roxburgh, Nedra Shand, Geoff Thompson, Beth Watson

Thank you to the following trusts and foundations for their highly valued support over the past year:

Bendigo Valley Sports and Charity Foundation

BlueSky Community Trust

Community Organisation Grants Scheme

Community Trust South

Dragon Community Trust

Eastern and Central Community Trust

F H Muter Trust and E M Pharazyn Trust

Foundation North

Four Winds Foundation

Frimley Foundation

Guy Anson Waddel Charitable Trust

Grassroots Central Trust

Higgins Bequest Fund

Lindsay Foundation

Lion Foundation

Lottery Community

Louisa and Patrick Emmett Murphy Foundation

Ministry of Social Development Community Capability and Resilience Fund

Oxford Sports Trust

Pub Charity

Rata Foundation

Stewart Family Charitable Trust

Southern Trust

The Trusts Community Foundation

Trust Waikato

W. Duncan Bickley Trust Fund

Performance Report

The Motor Neurone Disease Association of New Zealand Inc
For the year ended 30 June 2021

Prepared by Go Figure 2005 Limited

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Compilation Report

The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2021

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 2021.

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 subjected 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: 10 September 2021

Entity Information

The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2021

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**Vision**

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

Values**People First**

- People are at the centre of all we do
- Our decisions always consider the needs of our people (externally and internally)
- Recognising, understanding and respecting the diversity of all people in our community
- Upholding our responsibilities under the Treaty of Waitangi

Supportive

- Positive yet aware
- Having empathy
- Enabling and empowering

Professionalism

- Excellence
- High standards of work
- High standards of behaviour
- Being respectful in our dealings with others (externally and internally)

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
- Communicating and 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 from grants, fundraising and donations. A smaller portion is derived from a government contract, merchandise sales and other sources.

Main Methods Used by Entity to Raise Funds

The MND Association applies for grants, including the Community Organisation Grants Scheme (COGS) on an annual basis. The entity also holds the national annual fundraising events Walk 2 D'Feet MND and Cuppa Tea for MND.

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 2021

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 2021.

APPROVED



Greg Horton

Chairperson for the relevant financial year

Date 12/10/21

Statement of Service Performance

The Motor Neurone Disease Association of New Zealand Inc

For the year ended 30 June 2021

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.

	2021	2020
Description and Quantification of the Entity's Outputs		
Average number of clients and families during the year	396	386
Walk 2 D'Feet MND	8	12



Statement of Financial Performance

The Motor Neurone Disease Association of New Zealand Inc
For the year ended 30 June 2021

	NOTES	2021	2020
Revenue			
Donations, fundraising and other similar revenue	1	1,987,140	1,325,261
Revenue from providing goods or services	1	60,530	128,599
Interest, dividends and other investment revenue	1	37,401	25,579
Total Revenue		2,085,072	1,479,439
Expenses			
Expenses related to public fundraising	2	92,623	69,406
Volunteer and employee related costs	2	630,445	749,494
Costs related to providing goods or service	2	262,895	280,975
Grants and donations made	2	37,833	36,293
Research Expenses	2	101,798	61,002
Other expenses	2	197,429	35,197
Total Expenses		1,323,025	1,232,367
Surplus/(Deficit) for the Year		762,047	247,072



The financial statements should be read in conjunction with the accounting policies, explanatory notes and the Auditor's Report.

Statement of Financial Position

The Motor Neurone Disease Association of New Zealand Inc

As at 30 June 2021

	NOTES	30 JUN 2021	30 JUN 2020
Assets			
Current Assets			
Bank accounts and cash		1,359,113	612,453
Debtors and accrued income	3	15,882	13,659
Inventory		3,004	5,408
Craig & Co Managed Portfolio (Current)	3	107,124	120,992
GST Receivables	3	15,347	-
Total Current Assets		1,500,470	752,512
Non-Current Assets			
Property, Plant and Equipment	5	35,702	52,970
Craig & Co Managed Portfolio	3	620,453	535,801
Total Non-Current Assets		656,155	588,771
Total Assets		2,156,625	1,341,283
Liabilities			
Current Liabilities			
Creditors and accrued expenses	4	74,095	25,725
GST	3	-	1,589
Covid-19 Wage Subsidy		-	42,178
Holiday Pay Provision	4	51,272	43,807
Total Current Liabilities		125,367	113,299
Total Liabilities		125,367	113,299
Total Assets less Total Liabilities (Net Assets)		2,031,258	1,227,984
Accumulated Funds			
Capital contributed by owners or members	6	353,905	353,905
Accumulated surpluses or (deficits)	6	1,476,429	661,226
Reserves	6	200,925	212,853
Total Accumulated Funds		2,031,258	1,227,984



Greg Horton

Chairperson

Date 12/10/21



The financial statements should be read in conjunction with the accounting policies, explanatory notes and the Auditor's Report.

Statement of Cash Flows

The Motor Neurone Disease Association of New Zealand Inc
For the year ended 30 June 2021

	2021	2020
Cash Flows from Operating Activities		
Donations, fundraising and other similar receipts	1,934,420	1,264,094
Receipts from providing goods or services	-	14,050
Interest, dividends and other investment receipts	18,997	19,550
Cash receipts from other operating activities	165,209	218,743
GST	4,752	13,004
Payments to suppliers and employees	(1,337,143)	(1,271,518)
Total Cash Flows from Operating Activities	786,236	257,924
Cash Flows from Investing and Financing Activities		
Receipts from sale of investments	110,957	79,937
Payments to acquire property, plant and equipment	(3,812)	(3,220)
Payments to purchase investments	(181,741)	(122,655)
Cash flows from other investing and financing activities	35,020	49,324
Total Cash Flows from Investing and Financing Activities	(39,576)	3,386
Net Increase/(Decrease) in Cash	746,659	261,310
Bank Accounts and Cash		
Opening cash	612,453	351,144
Closing cash	1,359,113	612,453
Net change in cash for period	746,659	261,310



The financial statements should be read in conjunction with the accounting policies, explanatory notes and the Auditor's Report.

Statement of Accounting Policies

The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2021

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.

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.

Revenue Recognition

Revenue is measured at the fair value of the consideration received or receivable for the sale of goods and services, excluding goods and services tax rebates and discounts, to the extent it is probable that the economic benefits will flow to the entity and revenue can be reliably measured.

Sales of services are recognised in the period by reference to the stage of completion of the transaction at the end of the reporting period.

Interest received is recognised as interest accrues, gross of refundable tax credits received.

Government grants are recognised as revenue on receipt where no performance conditions have been specified on receipt of the grant.

Property, Plant & Equipment

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% - 50.0%

Office Furniture & Fit out - 11.0% - 30.0%



Investments

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 no more than \$5000 over a 12 month period the stock item will be treated as an expense and no adjustment for stock on hand will be made.

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.

Comparatives

The statement of Cash Flow comparatives have been reclassified to reflect management's understanding of the Cash Flow more accurately.



Notes to the Performance Report

The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2021

	2021	2020
1. Analysis of Revenue		
Donations, fundraising and other similar revenue		
Grant monies received	447,528	420,270
Corporate Donations	50,000	-
Donations and bequests	1,036,052	463,368
Sponsorship and fundraising	437,874	432,795
Other	15,686	8,828
Total Donations, fundraising and other similar revenue	1,987,140	1,325,261
Revenue from providing goods or services		
Merchandise sales	60,530	128,599
Total Revenue from providing goods or services	60,530	128,599
Interest, dividends and other investment revenue		
Interest -Westpac	493	310
Interest Received - Craigs Managed Portfolio	9,197	8,679
Dividends Received - Craigs Managed Portfolio	9,307	10,561
Foreign Currency Gains/Losses	18,404	6,029
Total Interest, dividends and other investment revenue	37,401	25,579
	2021	2020
2. Analysis of Expenses		
Expenses related to public fundraising		
Hope Puppy Purchases	-	2,620
Stock movement - Hope Puppies	2,405	(1,021)
Walk Merchandise	1,985	4,639
Awareness (Advertising)	-	3,452
Other	88,234	59,716
Total Expenses related to public fundraising	92,623	69,406
Volunteer and employee related costs		
Support Team Salaries	208,753	372,994
National Office Salaries	385,066	330,401
Kiwisaver	20,351	19,088
ACC Levies	1,842	1,730
Meeting expenses	3,628	3,646
Professional development	7,894	16,959
Staff General Expenses	2,888	2,280
Other	23	2,396
Total Volunteer and employee related costs	630,445	749,494
Costs related to providing goods or services		
Accountancy Fees	24,960	24,960



	2021	2020
Field Worker Vehicle Expenses	34,312	28,724
Field Worker Travel Expenses	9,193	11,072
Rent	25,850	25,850
Postage, Printing and stationery	13,449	10,057
Other	155,132	180,312
Total Costs related to providing goods or services	262,895	280,975
Grants and donations made		
Other	37,833	36,293
Total Grants and donations made	37,833	36,293
Research Expenses		
Research	101,798	61,002
Total Research Expenses	101,798	61,002
Other expenses		
Audit Fees	3,350	3,263
Bank Fees	679	1,098
Depreciation	20,480	23,069
Loss on Sale of Fixed Assets	600	-
Office Sundries/General Expenses	2,383	1,385
Portfolio Fees	7,086	6,382
Wages - Covered by COVID 19 Wage Subsidy	162,852	-
Total Other expenses	197,429	35,197
	2021	2020

3. Analysis of Assets

Debtors and accrued income

Accounts Receivable	7,158	12,088
Accrued Income	8,724	1,571
Total Debtors and accrued income	15,882	13,659

Other Current Assets

GST	15,347	(1,589)
Total Other Current Assets	15,347	(1,589)

Investments - Craig & Co Managed Portfolio (Current)

Call Accounts	46,128	49,657
Fixed Interest Bonds	60,996	71,335
Total Investments - Craig & Co Managed Portfolio (Current)	107,124	120,992

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

Fixed Interest Bonds	234,320	185,108
NZ Shares - Equities	145,676	143,888
NZ Shares - Property	33,167	28,689
AU Shares - Equities	112,632	91,110
AU Shares - Property	7,512	10,635



International Shares - Equities	87,146	76,371
Total Investments - Craig & Co Managed Portfolio (Non-Current)	620,453	535,801

2021 2020

4. Analysis of Liabilities

Creditors and accrued expenses

Accounts Payable	30,845	15,675
Accrued Expenses	43,250	10,050
Total Creditors and accrued expenses	74,095	25,725

Employee costs payable

Provision for Holiday Pay	51,272	43,807
Total Employee costs payable	51,272	43,807

5. Property, Plant & Equipment

This Year	Cost	Opening Carrying Amount	Purchases	Sales/Disposals	Current Year Depreciation	Closing Carrying Amount
Motor Vehicles	119,334	46,233		579	12,690	32,964
Website	7,850	232			116	116
Computer Equipment	31,044	6,220	3,812	21	7,643	2,368
Office Furniture	6,123	285			31	254
Total	164,351	52,970	3,812		20,480	35,702

Last Year	Cost	Opening Carrying Amount	Purchases	Sales/Disposals	Current Year Depreciation	Closing Carrying Amount
Motor Vehicles	134,334	61,291			15,058	46,233
Website	7,850	466			233	233
Computer Equipment	35,727	10,743	3,220		7,743	6,220
Office Furniture	6,123	320			35	285
Total	184,034	72,820	3,220		23,069	52,970



6. Accumulated Funds

This Year	Capital Contributed by Members	Accumulated Surpluses of Deficits	Reserves	Total
Opening Balance	353,905	661,226	212,854	1,227,985
Gain on investments for the year			41,227	41,227
Surplus/(Deficit)		762,047		762,047
Transfer to Reserves		53,156	(53,156)	
Closing Balance	353,905	1,476,429	200,925	2,031,259

Breakdown of Reserves		
Name	Actual This Year	Actual Last Year
Research Reserve	0.00	53,156
Investment Revaluation Reserve	200,925	159,698
Total	200,925	212,854

Last Year	Capital Contributed by Members	Accumulated Surpluses of Deficits	Reserves	Total
Opening Balance	353,905	378,447	224,704	957,056
Gain on investments for the year			23,856	23,856
Surplus/(Deficit)		247,072		247,072
Transfer to Reserves		35,707	(35,707)	
Closing Balance	353,905	661,226	212,854	1,227,985

2021

2020

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 \$25,849.92 plus GST

Total Commitments to lease or rent assets

25,850

23,850

25,850

23,850

8. Contingent Liabilities and Guarantees

There are no contingent liabilities or guarantees as at 30 June 2021 (Last year - nil).



9. Goods or Services Provided to the Entity in Kind

Description	2021	2020
Hound & Steed - Pro-bono advertising and discounted TV/Radio	-	\$2,500
Sue Hobbs - Gifted design work for newsletters	\$2,320	\$2,520
Fairfax Media/Stuff.co.nz - Print & online gifted	-	\$22,499
Duncan Cotterill - Pro-bono legal advice	\$647	\$2,798
Media Works/TV3/Bravo - Advertising airtime gifted	-	\$24,275
National Radio - Radio airtime gifted	-	\$323,343
TVNZ - Advertising airtime gifted	-	\$25,000
NZME - Herald Online & Print advt gifted	-	\$7,057
Weave Digital Studio - Website support and design	\$11,050	-
Said & Done - Brand identity work	\$6,635	-
Special Group - Campaign Media and Creative	\$102,723	-
Total	\$123,375	\$382,919

10. Related Parties

The Chairperson is also a Director/Trustee of Duo Trust for which donations were received.

The interim Chairperson is also Director of Three Sixty Consulting Limited which has been engaged by MND to support the CE Annual Performance Review process for 2020/21. Three Sixty Consulting Limited has engaged Hound & Steed in the past to support brand and website development of which the Deputy Chairperson is a director.

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).





INDEPENDENT AUDITOR'S REPORT

To MEMBERS of the MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND
(INCORPORATED) BOARD

Report on the Performance Report

Qualified Opinion

We have audited the performance report of MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND (INCORPORATED) on pages 4 to 17, which comprise the statement of financial position as at 30 June 2021, the statement of financial performance, statement of cash flows for the year ended, the statement of accounting policies and other explanatory information.

In our opinion except for the matters outlined in Basis for Qualified opinion:

- a) the reported outcomes and outputs, and quantification of the outputs to the extent practicable, in the statement of service performance are suitable.
 - b) the performance report on pages 4 to 17 presents fairly, in all material respects:
 - the financial position of MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND (INCORPORATED) as at 30 June 2021 and of its financial performance and cash flows;
 - the entity information and the service performance, for the year ended,
- in accordance with Public Benefit Entity Simple Format Reporting – Accrual (Not-For-Profit) [PBE-SFR-A-NFP] issued in New Zealand (NZ) by the NZ Accounting Standards Board.

Basis for Qualified Opinion

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion, except that our audit work has been limited in the:

- Verification of cash income over income from Walk Donations of \$13,883 included as part of the “Donations and bequests” total of \$1,036,052 prior to being recorded and there are no practical audit procedures to determine the effect of this limited control. Consequently, we are unable to determine whether any adjustments to these amounts were necessary.

We conducted our audit of the statement of financial performance, statement of financial position, statement of cash flows, statement of accounting policies and notes to the performance report in accordance with International Standards on Auditing (NZ), and the audit of the entity information and statement of service performance in accordance with the International Standard on Assurance Engagements (NZ) ISAE (NZ) 3000 (Revised). Our responsibilities under those standards are further described in the *Auditor's Responsibilities for the Audit of the Performance Report* section of our report. We are independent of MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND (INCORPORATED) in accordance with Professional and Ethical Standard 1 (Revised) *Code of Ethics for Assurance Practitioners* issued by the NZ Auditing and Assurance Standards Board, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion. Other than in our capacity as auditor we have no relationship with, or interests in, MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND (INCORPORATED).

Restriction on responsibility

This report is made solely to the governance. Our audit work has been undertaken so that we might state to the governance those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the governance as a body, for our audit work, for this report, or for the opinions we have formed.

Governance Responsibility for the Performance Report

The governance is responsible for:

- a) identifying outcomes and outputs, and quantifying the outputs to the extent practicable, that are relevant, reliable, comparable and understandable, to report in the statement of service performance.
- b) the preparation and fair presentation of the performance report which comprises:

- the entity information, the statement of service performance; and
 - the statement of financial performance, statement of financial position, statement of cash flows, statement of accounting policies and notes to the performance report in accordance with PBE-SFR-A-NFP issued in NZ by the NZ Accounting Standards Board, and
- (c) for such internal control as the governance determines is necessary to enable the preparation of a performance report that is free from material misstatement, whether due to fraud or error.

In preparing the performance report, the governance is responsible for assessing the entity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the governance either intends to liquidate the entity or to cease operations, or have no realistic alternative but to do so.

Auditor's Responsibilities for the Audit of the Performance Report

Our objectives are to obtain reasonable assurance about whether the performance report is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (NZ) and ISAE (NZ) 3000 (Revised) will not always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of this performance report. We are also required to apply the explanatory guide EG Au 1 & 9. As part of an audit in accordance with ISAs (NZ) and ISAE (NZ) 3000 (Revised), we exercise professional judgement and maintain professional skepticism throughout the audit. We also:

Identify and assess the risks of material misstatement of the performance report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.

Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control.

Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by management.

Conclude on the appropriateness of the use of the going concern basis of accounting by the governance and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the entity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the performance report or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the entity to cease to continue as a going concern.

Evaluate the overall presentation, structure and content of the performance report, including the disclosures, and whether the performance report represents the underlying transactions and events in a manner that achieves fair presentation.

Perform procedures to obtain evidence about and evaluate whether the reported outcomes and outputs, and quantification of the outputs to the extent practicable, are relevant, reliable, comparable and understandable.

We communicate with the governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

Audit Integrity

Audit Integrity Ltd
Chartered Accountants
East Tamaki, Auckland
12 October 2021

