

THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND ANNUAL REPORT 2017/18



Contents

Motor Neurone Disease Association of New Zealand

1 July 2017 – 30 June 2018 Incorporated Society number 269718 Charity number CC35320 PO Box 24 036, Auckland 1345.

www.mnd.org.nz



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Vision – Together we provide the best quality care and support for those living with MND

Values – People first, Supportive, Professional, Honest, Partnership

Strategic Priorities 2016–19

Dimension Value		Priority	
	Provide the services stakeholders need Contribute to resea in a meaningful wa the NZ context		Maintain contact over time
Clients	Understand client needs	Develop a stakeholder engagement strategy	Communicate in a culturally sensitive way
Internal Processes	Provide clear guidelines and consistent processes	Be clear about governance vs management	Provide fit for purpose equipment
People	Provide adequate training & development	Ensure we have role clarity	Ensure we are adequately resourced now and in the future

President's report

Tēnā koutou katoa

It is with some sadness, but mostly excitement and great optimism, that I write this report that will be my last. After 11 years on Council, with 6 of those as President, I am stepping down, although I will continue on Council for another year. I am delighted that Lucy Haberfield, our current Treasurer/Secretary, has put herself forward for President. Lucy has a sound understanding of our Association and is an experienced leader.

My highlights from the year in review, 1 July 2017–30 June 2018:

- Congratulations to Helen Palmer being made a Life Member at the AGM in 2017. Helen has a nursing background. She served on the Waikato Branch from 2003 to 2017, for many years as chair. From 2006 to 2017 she served on National Council, and was a very capable President from 2008 to 2012. Our Association has benefited indeed from her service.
- Congratulations to The TalkLInk Trust for being awarded the 2017 David Oliver Beacon Award

 A Shining Light in MND Care. A well-deserved recognition for a Trust that is respected in the MND community for the understanding the therapists have of the needs of people with MND and their commitment to helping
- The Walk 2 D'Feet MND on 12 November 2017. Our Walks are going from strength to strength. We had 17 locations with approximately 6000 participating; additionally Palmerston North fire fighters did an Extreme Walk (in full breathing kit) of 170km to Wellington. In total, \$307,000 was raised.
- Our staff attended a Fight MND symposium in Melbourne in March 2018, which brought world leaders in ALS/MND research together. An exciting event so close to home.
- On International MND/ALS Awareness Day, 21 June, MND had extensive media coverage in New Zealand. Thanks to brave people from all parts of New Zealand who shared their stories.

Achieving public awareness and raising funds for the work of our Association is very much a team effort and we are fortunate that so many people are willing to help us.

Delivering our support service also requires a team effort, and my sincere thanks to the staff who work so hard to provide our service. Firstly I sincerely thank and acknowledge the work of our "coal face" team of Kate Moulson, Moira Young, Carol Matthews, Linda Oliver and Toni Foster. I appreciate the additional work you have all done this year to cover vacancies as we get our full resourcing

in place. I also thank Jacqui Drinkwater and Gilly Noon, important contributors to the team until June 2018. The work of our support team members is truly valued.

I also take this opportunity to recognise and thank the national office team of Hayley Watkinson, Noelann Davies, Annabel McAleer, Claire Reilly and Carl Sunderland. You each do amazing work in your particular areas and I know that our Association is indebted to each and every one of you for the extra hours you put in to see that the job gets done. This generosity of spirit is appreciated.

I also wish to thank and acknowledge the work of:

- Kerry Walker and Richard Roxburgh in running the New Zealand MND Registry. It is exciting that being enrolled in the Registry has already enabled some people to be involved in research.
- Jayne McLean and Dr Emma Scotter running the MND Research Network, reaching out to researchers in New Zealand and growing MND research here.

And finally I thank my colleagues on Council for their support and their work during the year. Council is another team working together for people with motor neurone disease.

It has been a privilege and a pleasure to work with and for people with motor neurone disease. Over the years I have met many unforgettable people who have helped me grow and learn. I have been challenged and supported, saddened and gladdened. I tried to listen well. We have taken long strides together to grow our Association. I thank you for your work and your support.

Ngā mihi nui ki a koutou

Nō reira, tēnā koutou, tēnā koutou, tēnā koutou katoa.

Bill We

Beth Watson President

Our impact: SUPPORT

Norm's first symptoms of motor neurone disease (MND) started 5 years ago, in winter 2013, with muscles twitching, shortage of breath and tiredness. He initially thought that older age was the problem – although he was just 69 at the time.

It took almost two years, and many tests, to finally be diagnosed with MND.

Norm and his wife were shattered by the diagnosis. "We felt very much alone," he says. "My wife and I were very upset, emotional and felt isolated."

"On finding out about MND New Zealand, we contacted our local support team member, Kate, who quickly visited us and provided information both about MND and the MND Association. Since then, Kate has visited regularly, provided useful tips and information, and has always been positive. I always feel much better after her visits."

Because Norm's ability to breathe was deteriorating due to his MND, Kate helped him access a bipap machine. He uses this crucial piece of equipment to help him breathe while he sleeps, and to boost his energy during the day.

Kate also arranged meetings where information was provided by specialists and others, and dinners that are most enjoyable. "These get-togethers are greatly appreciated by people with MND and their carers," says Norm.



"Being able to share experiences is a great help, as well as realising that you are not on your own. Without MND New Zealand and especially Kate, it would have taken us much longer to access local contacts and information on MND. We would have felt alone for much longer."

This year, MND New Zealand was pleased to finally appoint a second support team member in the South Island this year, covering the Nelson/Marlborough, Canterbury and West Coast DHB areas.

This year we supported an average of **315** clients, and their whanau and health professionals

We supported **157** families through the shock of a new diagnosis and **92** through the sadness of a life ending due to MND

Our support team had **3168** face-to-face contacts and **7108** contacts by phone, email, text

General Manager's report

Dear members and supporters of MND New Zealand,

The 2017/18 financial year was the second year of MND New Zealand's current three-year strategic plan (see www.mnd.org.nz/our-organisation). This plan has four priority dimensions: Value, Clients, Internal Processes, and People (see page 2). This report highlights progress made during this financial year in each dimension.

Value

This year saw the organisation hitting the \$1 million income mark for the first time in its 33-year history. This has allowed a growth in the provision of core services – providing information and support, advocating for our community, raising awareness, and encouraging research – and is mainly due to the success of 2017 Walk 2 D'Feet MND in November which raised a net income of \$307,000, a growth of 55% from 2016.

Walks took place in 17 locations with around 6000 attendees. A first for 2017 was the Extreme Walk 2 D'Feet MND in which a small group of firefighters walked the 170km from Palmerston North to Wellington in full uniform, collecting donations and raising awareness along the way.

This Walk income allowed us to appoint an eighth Support Team member (our second in the South Island) and increase the hours of three others, adding 51 additional support hours per week.

Walk fundraisers also raised the money to launch and fund the New Zealand MND Research Network in November 2017 (www.mndresearch.auckland.ac.nz) and allowed us to co-commission a 'Review of Current Research Regarding the use of Medicinal Cannabis for MS and MND Symptom Management', which we submitted to the Parliamentary Select Committee considering medicinal cannabis reform in March 2018.

From July 2017 to June 2018 the New Zealand MND Registry enrolled 118 participants and facilitated enrolment into in four research studies. As at 30 June 2018, there were 142 people enrolled in the Registry.

Work has started on a research funding policy to ensure income from the Walk 2 D'Feet MND 2018 continues to contribute to research in a meaningful way in the New Zealand context.

Work has also begun on a fundraising strategy to ensure long-term sustainable income to successfully meet the needs of our community and meet strategic priorities. New strategies were introduced to improve our communication, both internally and externally. Internally we introduced a cloudbased organisational tool,



Basecamp, and an internal newsletter.

Externally we reviewed and updated our InfoPack for people newly diagnosed with MND, added to the content on our website and made some website navigation improvements. We added an 'unsubscribe' link to emails to our database to ensure we maintain contact with only those who wish to continue to hear from us. We continue to consider Facebook an important daily broadcast communication tool to those with both tight and loose connections to MND and have worked throughout the year to convert people from Facebook followers to newsletter subscribers, to develop a deeper connection with our social media followers.

Clients

Client numbers remained relatively stable during the year, ranging from 310 to 335 clients at any one time. There is huge variability in the amount and type of support needed by different clients, and by individual clients over time. Ensuring we provide the necessary support to the right people at the right time remains a continual challenge for the MND Support Team.

In order to get a better understanding of our clients' needs, an external researcher was commissioned in early 2018 to conduct a survey to all MND New Zealand stakeholders – the 'MND Community Survey'. Five surveys were created so that we captured feedback from all stakeholder groups – people living with MND, their carers (current and previous), healthcare professionals and supporters/volunteers. Survey results are due in late 2018 and will form the basis of our strategic planning and direction for 2019 and into the future.

Work has also started on developing a community group framework which aims to encourage peer-to-peer support via regional support groups and connections. Survey findings will contribute to the development and direction of this work once we get a clearer idea of what is required in each region.

Internal processes

To provide clear guidelines and consistent processes, in August 2017 Council signed off the Policy and Procedures Manual. The Support Service Manual is under review and development, the induction procedure for new staff was reviewed and upgraded, and health and safety documentation for the National Office updated.

To ensure due diligence and transparency, an external HR advisor was consulted in employment matters, including the recruitment of new staff and establishing a successful relationship between Council and National Office.

Considerable work has been done at governance level with the establishment of two sub-committees: Risk, Audit, Finance & Investment, and HR/Remuneration. Working groups were also created during the year to assist in the development of the research strategy and the MND Community Survey.

Several items of equipment were upgraded, including three vehicles and three laptops for the Support Team. The National Office IT system was also upgraded to better suit staffing levels.

The four remaining regional branches were closed in early 2018 due to the results of the 2017 consultation that found they were struggling to recruit and retain branch members. A new community and volunteer framework will be developed using the MND Community Survey results to help establish current community needs.

Mid-year we changed accountant to Jamie Nicolas at Gofi8ure in Wellington.

People

There were several personnel changes over the year. We welcomed Greg Horton and Steve Green to Council in October, and as part of the change management process, a full-time General Manager was appointed in April. Other new additions to the team were Toni Foster (Support Team Leader), Hayley Watkinson (National Office Administration & Accounts) and Carol Matthews, Jacqui Drinkwater and Julie Hooper (Support Team Members). At year end there were 12 employees with a FTE of 8.35.

Role clarity and performance expectations of all positions have been a continued focus and I want to congratulate our team on the quality of their work. New position descriptions were created for the General Manager, Support Team Leader and National Office Administration & Accounts. All roles encouraged higher levels of leadership, autonomy, initiative, and personal and professional growth than previously required.

To ensure we are adequately resourced now and in the future, as we continue to grow, a role review was conducted for the Fundraising Development Manager and Communications & Engagement Advisor to establish greater role clarity. New position descriptions were created and these will be introduced later in 2018. The Support Service in the South Island was reviewed, and a second staff member was appointed in June.

Staff training and professional development opportunities included attendance of the Fight MND Research Symposium in Melbourne and a three-day Support Team workshop in June. Improvements were made to the induction processes for all new staff, involving all members of the national office team.

All Support Team staff were required to participate in professional supervision at least every two months, and an Employee Assistance Programme (EAP) was introduced in September.

Our amazing volunteers have continued to add a huge value within the MND community, being involved in a broad range of regional activities throughout the year. There were 17 Walk 2 D'Feet MND committees, a growing number of support groups, and a variety of fundraising events including 45 Cuppa Tea for MND events during 2018 Awareness Month.

I would like to take this opportunity to thank and acknowledge our volunteers, without whom we could not provide the level of service and activities we do in the community.

Thank you for your continued support. I look forward to working hard for 'team MND' in the year ahead, helping our organisation grow, unite and empower our community.

Carl Sunderland General Manager

Our Clients

We now have more than four years of client data recorded in our secure online database. The below figures show statistics based on information collected since late 2013

We support an average of 315 clients every year. For every client, we estimate we offer support and information to at least 12 additional people.





Our impact: **ADVOCACY**



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We were proud to make submissions on two Bills highly relevant to people with MND when they came before Select Committee in Parliament this year.

The **End of Life Choice Bill** proposes to make it legal in New Zealand for people with terminal illness to request medical aid to hasten their death ('assisted dying'). The **Misuse of Drugs (Medicinal Cannabis) Amendment Bill** proposes to make it legal for terminally ill people to possess and use cannabis and cannabidiol (CBD) products.

We felt it was best to neither support nor oppose each Bill, due to their controversial nature and the variety of beliefs held by our community. However, we felt it crucial to ensure that any rights these Bills may create do not discriminate against people with MND.

Regarding cannabis, should the Bill be passed, we advocated for the legal protection of carers who may need to procure, prepare or temporarily possess cannabis on behalf of a person with MND. We shared our report, 'Review of Current Research Regarding the use of Medicinal Cannabis for MS and MND Symptom Management', which found benefit in using cannabis for the treatment of several symptoms of MND (see mnd. org.nz/cannabis). We also recommended the 12-month time frame in which people are considered terminally ill be removed, to be fairer to people with MND who may experience uncomfortable symptoms for several years. Finally, we recommended that Government provides funding for ongoing research into the use of cannabis to treat the symptoms of MND and other neuromuscular and neurodegenerative diseases.

Regarding assisted dying, should the Bill be passed, we requested that the word 'talk' and 'tell' used several times in the Bill be specifically defined to include users of assistive speech technology. We also advocated for a substantial increase in funding for and improved access to palliative care services all over New Zealand, particularly to outreach services to rural areas, respite beds in hospices, inpatient services in small towns, and overnight nursing care.

We also continued with our core client advocacy work. Our Support Team members often work with clients to help them apply for vehicle and bathroom modifications, and help them identify the benefits they are entitled to.

Read our full submissions at mnd.org.nz/EOLCsub and mnd.org.nz/cannabis

Our impact: **RESEARCH**

In March, MND New Zealand staff attended the first ever Australasian MND Symposium in Melbourne. The conference brought together some of the world's best MND researchers, and we were encouraged and excited by their positivity. "I'm really optimistic for the future for the next five to 15 years," said Professor Paul Talman, director of the Australian MND Registry. "It will lead to a cure."

We summarised three full days of presentations in two conference streams into six documents containing up-to-date information about developments in research towards a cure and understanding the causes of MND, the drug development pipeline, key global and Australian clinical trials, and advances in our understanding of the importance of multidisciplinary clinics and palliative care to improve life expectancy and quality of life.

These research updates have been shared on our website and with the health professionals in our database.

We funded the development and November 2017 launch of the New Zealand Research Network (www.mndresearch.auckland.ac.nz), which connects all MND-related researchers in New Zealand. We continued to fund the New Zealand MND Registry (www.mnd.org. nz/registry) for its first full year. We maintain a reserve of funds to ensure the long-term sustainability of these two important initiatives.

Our Australasian MND Symposium summaries are available on our website under mnd.org.nz/research/research-resources

The New Zealand MND Registry enrolled **118** participants and facilitated enrolment into **4** research studies this year



Our impact: AWARENESS

Awareness Month media reached an audience of **2,640,000** Our Walk 2 D'Feet MND ad was seen or heard **8,913,000** times

Awareness matters. As a newly diagnosed person, sharing your MND diagnosis is difficult – and it's much worse when you must repeatedly explain the effects of MND to loved ones. Greater public awareness of MND lessens this burden, so we were thrilled that MND Awareness Month, June 2018, was a huge success for us this year. Media stories generated by our activities reached an audience of over 2.5 million.

In June we issued a press release alerting media to research published in January 2018 by the Centre for Brain Research (CBR) at the University of Auckland. Dr Emma Scotter, head of the MND Lab at the CBR, and her team had uncovered a surprisingly high mortality rate due to MND, showing that New Zealanders have the highest known rate of MND of any country in the world. The story was covered by One News, the *Sunday Star-Times*, the *New Zealand Herald* and The Project on TV3.

Thank you to Graeme Smith, Kirsty Gerlach and Greg Horton, for so generously sharing insight into their lives with MND during Awareness Month. Thanks also to Emma Scotter, for fielding media enquiries and taking interviews while on holiday. *Times, The Weekend Sun,* and *Whanganui Chronicle.* The Extreme Walk 2 D'Feet MND also featured on Seven Sharp, 3 News, and Prime News.

We really appreciate the bravery of Eric Beardmore, Wayne Cotton, David Seymour, Peter Macklow, Lana Hook, Nicola Galloway, Rob Smith, Fiona Butcher, Kevin Manning, Kirsty Gerlach, Tanya Gilchrist and Greg Horton, in sharing their experiences with MND with media, to raise awareness of MND and encourage attendance at the Walks.

Our TV commercial this year reached an audience of almost 9 million. We received generous support from media networks, with airplay donated across TV, radio and online to a value of \$564,000, for an investment of just over \$40,000. Over the two years since we created the TVC, it has returned over 1000% on our investment. Thank you to our pro bono creative agency, Hound & Steed (www.houndandsteed.co.nz), for so generously donating so much of their time to this project over the past two years. Thanks also to volunteer Alicia Newton.



Our impact: INFORMATION

This year we updated the information pack given to people when they're newly diagnosed with MND. We replaced nine brochures, all written over a decade ago, with one short booklet. We distributed about 90 of these new InfoPacks this year, along with 75 of the older InfoPacks, 840 'About MND' pamphlets, and 230 copies of our booklet 'A Problem Solving Approach for GPs and Health Professionals'.

Our support team members led 84 educational presentations to health professionals, community groups and service providers.

Over 28,000 people visited our website for information, with 4350 returning multiple times. The most-read information on our website was the Walk 2 D'Feet MND information, the 'About MND' section, and the page of information about the medication edaravone, approved in the US in May 2017 (mnd.org.nz/edaravone).

We posted 311 times on Facebook. The number of people who 'like' our Facebook page grew by 902, to 4539. Each of our posts was seen by an average of 1438 people who like our page. Over the year, all our Facebook posts were seen a total of 904,000 times and received a total of 70,864 comments, likes, shares and clicks.

We redesigned MND News, our 20-page newsletter sent twice per year, to create a warmer, brighter and more visually engaging publication. Thank you to Sue Hobbs of minimum graphics for her creativity, attention to detail, and the time she volunteers to design our newsletters. We posted the Spring and Autumn issues of MND News to around 500 people and organisations, and emailed each newsletter to a further 1400 people.

We sent **4835** publications to people affected by MND

We shared information that reached an audience of **938,000**



Our impact: FUNDRAISING

The 2017 Walk 2 D'Feet MND was our best-ever fundraiser, generating a net profit of \$307,000. This was an increase of 55% over the 2016 net result, and represents a fundraising return on investment of 300%, or cost per dollar raised of \$0.25.

Walks took place in 17 towns and cities throughout the country. A total of 3209 online registrations were received, a 28% increase on 2016, and a further 1469 adults registered on the day. Including children, attendance nationwide was approximately 6000. The move from September to November was successful and most places saw fine weather.

Aside from sponsorship, all income streams increased, with entries and merchandise increasing by 20% and 37% respectively. Direct donations accounted for over a quarter of revenue raised, largely thanks to one significant group of donors, the We Walk with Greg

team, who contributed \$79,000 in direct donations (as well as a further \$25,000 through peer-peer fundraising).

For every dollar invested in Everyday Hero, \$8 was returned. The number of active fundraisers increased 17% from 156 to 183. The average total raised was \$795 per page compared to \$783 per page the previous year.

We were also pleased with the results of our first Cuppa Tea for MND campaign, held throughout June 2018. Over 45 morning and afternoon teas were held all over the



country – including in the Beehive! The campaign raised over \$27,000 and was well-received by volunteers as a simple fundraising and awareness-raising activity.

Event attendee Tania Balzat described the Cuppa Tea event as "cathartic for all who are involved in running in these types of fundraisers. Friends and family feel that there is something they can tangibly do to show their support."

\$158,000 was raised for the Walk 2 D'Feet MND through Everyday Hero peer-to-peer fundraising, an increase of **20%** over 2016

The average Walk 2 D'Feet MND donation increased **21%** from \$62 in 2016 to **\$75** in 2017

Treasurer's report

The 2017/18 year saw the Association settle in after a number of changes from the previous year. The result for the year is a surplus of \$127K against a surplus of \$64K last year. Overall the Association continues to experience increasing demand for services and that is reflected in increasing costs. This is offset somewhat by greater success in grant applications and fundraising efforts.

Fundraising yielded \$986K of revenue compared to \$804K last year. Much of this relates to the Walk 2 D'Feet annual fundraising event which has become the flagship fundraiser for the Association.

Employee related costs increased by \$81K as we invest in growing capability in key roles including leadership and communication. These roles help the Association build awareness and generate the funds for a financially sustainable future.

Lucy Haberfield Secretary/Treasurer

Overall revenue increased by 17.5% and costs only increased by 11.5%

The Association has total assets of \$1.233M and total liabilities of \$212K. Cash and term deposits increased by \$67K, whilst the term investment portfolio increased in value by \$59K. Working capital ratio at 30 June 2018 was 3.29:1 compared to 3.02:1 at the same time last year. Treasury recommends that working capital should be between 4 and 6 months of operating expenditure. The Association has 6 months of cover, however the term investment portfolio provides a further 7 months of cover ensuring the Association is in a healthy financial position. Overall accumulated funds increased by \$179K.

The Association continues to build a strong position allowing us to develop our services and remain highly client focused

"I'm much more optimistic than I was 10 years ago. Researchers are intensely interested in MND."

PROF KEVIN TALBOT, HEAD OF CLINICAL NEUROLOGY, UNIVERSITY OF OXFORD UK, SPEAKING AT THE AUSTRALASIAN MND SYMPOSIUM, MARCH 2018

TEAM MND 2017/18

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

President Beth Watson president@mnda.org.nz

Vice President Andrew Pardoe-Burnett

Secretary / Treasurer Lucy Haberfield

Council Anna Chalmers, Fiona Hewerdine, Tony Treloar, Greg Horton, Steve Green **General Manager** Carl Sunderland carl.sunderland@mnd.org.nz

Office & Accounts Administrator Hayley Watkinson admin@mnda.org.nz

Support Team Leader Toni Foster

Communications and Engagement Manager Annabel McAleer

Fundraising Development Manager Claire Reilly

Grants Administrator Noelann Davis

Support Team Gilly Noon, Linda Oliver, Carol Matthews, Jacqui Drinkwater, Moira Young, Kate Moulson

Life Members Reima Casey, Robina Davies, Graham East, Dennis Hall. Edith McCarthy. Helen Palmer. Mary Pa

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

ANZ Staff FoundationBayTrust The Bill Brown Trust Blue Waters Community Trust Community Organisation Grants Scheme E M Pharazyn Trust F H Muter Trust Foundation North Iris & Eric Wilfred Nankivell Charitable Trust The Guy Anson Waddel Charitable Trust

Silicon Valley Community Foundation on behalf of Liquid Sky Vineyards Charitable Fund

Lottery Grants Board

Louisa & Patrick Emmett Murphy Foundation

Ministry of Health

North & South Trust Ltd

NZ Post

Oxford Sports Trust Pelorus Trust Phillip Verry Charitable Foundation Pub Charity Limited Thomas George Macarthy Trust Trillian Trust

Performance Report

The Motor Neurone Disease Association of New Zealand Inc

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Compilation Report

The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2018

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 2018.

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.

Neiholen

Go Figure 2005 Limited Level 4 85 Ghuznee Street Wellington Dated: 19 August 2018

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IntegrityReview

Entity Information

The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2018

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

269718

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.

IntegrityReview

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 2018

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 2018.

APPROVED

Rett Wal-Beth Watson President Date 10 - 2018.

Statement of Service Performance

The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2018

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.

	2018	2017
Description and Quantification of the Entity's Outputs		
Average number of clients and families during the year	315	326
Walk 2 D'Feet MND	18	14

INTEGRITYAUDIT

Statement of Financial Performance

The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2018

, , , , , , , , , , , , , , , , , , , ,	NOTES	2018	2017
Revenue			
Donations, fundraising and other similar revenue	1	985,657	803,564
Fees, subscriptions and other revenue from members	1	1,522	2,374
Revenue from providing goods or services	1	78,652	79,322
Interest, dividends and other investment revenue	1	27,111	32,903
Other revenue		(773)	11,458
Total Revenue		1,092,168	929,621
Expenses			
Expenses related to public fundraising	2	100,269	121,419
Volunteer and employee related costs	2	567,992	487,156
Costs related to providing goods or service	2	191,094	176,194
Grants and donations made	2	5,510	7,693
Research Expenses	2	59,968	39,500
Other expenses	2	40,552	33,290
Total Expenses		965,385	865,251
Surplus/(Deficit) for the Year		126,783	64,370

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 2018

	NOTES	30 JUN 2018	30 JUN 201
Assets			
Current Assets			
Bank accounts and cash		530,960	345,485
Debtors and accrued income	3	8,715	8,256
Inventory		8,431	12,110
Other Current Assets	3	22,023	4,583
Craig & Co Managed Portfolio (Current)	3	126,545	133,100
Term Deposits			118,810
Total Current Assets		696,674	622,364
Non-Current Assets			
Property, Plant and Equipment	5	96,434	61,952
Craig & Co Managed Portfolio	3	439,786	380,854
Total Non-Current Assets		536,220	442,810
Total Assets		1,232,893	1,065,174
Liabilities			
Current Liabilities			
Creditors and accrued expenses	4	70,182	47,763
Employee costs payable	4	23,405	44,996
Unused donations and grants with conditions		118,363	113,456
Total Current Liabilities		211,951	205,215
Total Liabilities		211,951	206,235
rotal Assets less Total Liabilities (Net Assets)		1,020,942	858,960
Accumulated Funds			
Capital contributed by owners or members	6	353,905	353,905
Accumulated surpluses or (deficits)	6	363,728	329,379
Reserves	6	303,310	175,676
Total Accumulated Funds		1,020,942	858,960

APPROVED

Bith Wal

Beth Watson

President Date 11-10-2018

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

Performance Report The Stotor Neurone Disease Association of New Zealand Inc.

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Statement of Cash Flows

The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2018

	2018	2017
Cash flows from operating activities		
Cash was received from:		
Donations, fundraising	984,657	776,275
Fees, subscriptions and other receipts from members	1,522	2,374
Receipts from providing goods or services	78,606	77,608
Intetest and dividends	25,816	3,017
Net GST	(8,391)	7,258
Cash was applied to:		
Payments to suppliers and employees	966,976	826,745
Donations or grants paid	5,510	7,679
Net GST	-	
Net cash flows from operating activities	110,725	32,108
Cash flows from investing & financing activities		
Cash was received from:		
Receipts from the sale of property, plant and equipment	•	•
Receipts from the sale of investments	35,200	315,326
Receipts from term deposits matured	118,816	260,414
Cash was applied to:		
Payments to acquire property, plant and equipment	42,849	30,272
Payments to purchase investments	47,101	375,368
Payments to reinvest term desposits	-	119,150
Net cash flows from investing & financing activities	64,066	50,950
Net increase/(decrease) in cash	174,790	83,058
Opening bank accounts and cash	356,170	273,112
Closing bank accounts and cash	530,960	356,170
This is represented by:		
Bank accounts & Cash	530,960	356,170

TEGRITYAUDIT

Statement of Accounting Policies

The Motor Neurone Disease Association of New Zealand Inc For the year ended 30 June 2018

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 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.

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 2018

	2018	2017
1. Analysis of Revenue		
Donations, fundraising and other similar revenue		
Grant monies received	329,596	260,507
Tagged Donations	22,035	16,102
Donations and bequests	347,320	262,447
Walk Registrations	53,164	53,813
Sponsorship and fundraising	187,503	181,571
Other	46,039	29,124
Total Donations, fundraising and other similar revenue	985,657	803,564
Fees, subscriptions and other revenue from members		
Subscriptions from members	1,522	2,374
Total Fees, subscriptions and other revenue from members	1,522	2,374
Revenue from providing goods or services		
Ministry of Health Contract	73,957	72,864
Merchandise sales	1,349	3,637
Other	3,345	2,821
Total Revenue from providing goods or services	78,652	79,322
Interest, dividends and other investment revenue		
Interest -Westpac	2,334	5,310
Interest Received - Craigs Managed Portfolio	11,271	6,548
Dividends Received - Craigs Managed Portfolio	11,698	12,048
Foreign Currency Gains/Losses	1,291	1,854
Profit/(Loss) on disposal of investment	517	6,440
FIF and PIE Income		703
Total Interest, dividends and other investment revenue	27,111	32,903
	2018	2017
2. Analysis of Expenses		
Expenses related to public fundraising		
Hope Puppy Purchases		41
Stock movement - Hope Puppies	3,685	4,840
Walk Merchandise	9,685	806
Advertising	44,495	47,341
Other	23,205	30,419
Walk Co-Ordinator	19,200	37,971
Total Expenses related to public fundraising	100,269	121,419
Volunteer and employee related costs		
Field Worker Salary	234,728	224,732
National Office Salaries	193,309	192,272

INTEGRITY

1,263 9,763 34,150 3,051 85,143 567,992	1,03 14,22 16,97 10,00 14,32
34,150 3,051 85,143	16,97 10,00
3,051 85,143	10,00
85,143	
	14,32
567,992	
	487,15
45,866	44,00
23,638	21,03
8,485	9,04
30,709	29,40
12,538	7,55
69,857	65,11
191,094	176,19
5,510	7,65
5,510	7,65
the second se	39,50
59,968	39,50
2.500	2.61
	3,69
	2,08
	4,21
	4,2
	33,29
40,552	33,25
2018	201
7,088	7,92
1,627	33
8,715	8,25
	_
14,606	2,72
7,417	1,08
22,023	3,81
25,014	10,68
101,531	122,42 133,10
	23,638 8,485 30,709 12,538 69,857 191,094 5,510 5,510 5,510 5,510 5,510 3,500 25,527 - 5,490 6,035 40,552 2018 7,088 1,627 8,715 14,606 7,417 22,023



Analysis of Liabilities		
	2018	201
Total Investments - Craig & Co Managed Portfolio (Non-Current)	439,786	380,85
International Shares - Equities	71,071	51,60
AU Shares - Property	13,025	13,77
AU Shares - Equities	85,875	72,78
NZ Shares - Property	15,685	14,10
NZ Shares - Equities	129,850	105,83
Fixed Interest Bonds	124,280	122,75

32,258	6,352
37,925	41,411
70,182	47,763
7,146	9,091
	10,000
16,259	25,905
23,405	44,996
	37,925 70,182 7,146 - 16,259



5. Property, Plant & Equipment

This 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
Total	146,552	61,953	61,231	1,222	25,527	96,435

Last Year	Cost	Opening Carrying Amount	Purchases	Sales/Disposals	Current Year Depreciation	Closing Carrying Amount
Motor Vehicles	94,571	44,308	20,580		12,244	52,644
Website	4,850	468	3,000		1,607	1,862
Advertising Display	3,043	569		569		.0
Computer Equipment	14,804	2,679	7,832	1,512	3,436	5,563
Office Furniture	6,123	2,741			856	1,885
Total	123,391	50,765	31,412	2,081	18,143	61,953

INTEGRITYAUDIT

6. Accumulated Funds

This Year	Capital Contributed by Members	Accumulated Surlpuses of 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)		125,301		125,301
Transfer to Reserves		(92,434)	92,434	
Closing Balance	353,905	362,246	303,310	1,019,461

Name	Actual This Year	Actual Last Year	
Research Reserve	204,491	112,057	
Investment Revaluation Reserve	98,819	63,619	
Total	303,310	175,676	

Last Year	Capital Contributed by Members	Accumulated Surlpuses of Deficits	Reserves	Total
Opening Balance	353,905	343,307	87,969	785,181
Gain on investments for the year			17,921	17,921
Surplus/(Deficit)		64,370		64,370
Transfer to Reserves		(78,298)	78,298	
Registry costs			(8,512)	(8,512)
Closing Balance	353,905	329,379	175,676	858,960

2017

2018

. 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	72,479	23,96
Everyday Hero fundraising suite has been contracted for 3 years from June 2016 at \$375 per month.	4,500	7,80
Total Commitments to lease or rent assets	76,979	31,76

8. Contingent Liabilities and Guarantees

There are no contingent liabilities or guarantees as at 30 June 2018 Last year - nil).

9. Goods or Services Provided to the Entity in Kind

Description	Amount
Hound & Steed - Pro-bono advertising and discounted TV/Radio	\$11,558
Walton Railton - Accounting Fees discounted by 50%	\$23,007
Sue Hobbs - Gifted design work for newsletters	\$3,040
Duncan Cotterill - Pro-bono legal advice	\$3,977
Media Works/TV3/Bravo - Advertising airtime gifted	\$104,590
Media Works - Radio airtime gifted	\$169,250
TVNZ - Advertising airtime gifted	\$76,401
NZME - Radio airtime gifted	\$44,319
Sky TV - Advertising airtime gifted	\$50,000
Total	\$486,142

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).





INDEPENDENT ACCOUNTANT'S REPORT TO THE MEMBERS OF THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC.

We have reviewed the Entity Information and Statement of Service Performance included in the performance report of the MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC, for the year ended 30 June 2018, on pages 4 - 7.

Review Conclusion

Based on our review, nothing material has come to our attention that requires reporting to you. In our opinion we believe that for the year ended 30 June 2018, the reviewed non-financial information of the MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC on pages 4 to 7 do present fairly, in all material respects:

- a) the reported outcomes and outputs, and quantification of the outputs to the extent practicable, are suitable in the statement of service performance;
- b) and the entity information,

in accordance with the PBE SFR T 3 NZASB standards, and the EG A1 Explanatory Guide.

Restriction on responsibility

This report is made solely to the governance, in accordance with section 42F of the Charities Act 2005, and the constitution of the entity. Our limited assurance work has been undertaken so that we might state to the governance those matters we are required to state to them in an accountant'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 assurance work, for this report, or for the opinions we have formed.

Responsibilities of the Governance

The Governance of the MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC are responsible on behalf of the entity –

- 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 & fair presentation of the entity information and statement of service performance

in accordance with the PBE SFR T 3 NZASB standards, and along with such internal control as the governance determine is necessary, to enable the preparation and fair presentation for the year ended 30 June 2018, that is free from material misstatement, whether due to fraud or error.

Reviewer's responsibilities

Our responsibility is to express a conclusion on the accompanying non-financial information that are required to be prepared by the governance in accordance with the Public Benefit Entity Simple Format Reporting tier 3 [PBE SFR T3] accrual accounting standards issued in NZ by the NZ Accounting Standards Board [NZASB], under the Financial Reporting Act 2013.

We conducted our review in accordance with the International Standard on Assurance Engagements ISAE (NZ) 3000, Assurance Engagements other than the Audits or Reviews of Historical Financial Information. ISAE (NZ) 3000 requires us to conclude whether anything has come to our attention that causes us to believe that the non-financial information, taken as a whole, are not prepared in all material respects, in accordance with the applicable financial reporting framework. These standards also requires us to comply with the relevant ethical requirements of PES 1 *Code of Ethics for Assurance Practitioners*.

We are also required to apply the explanatory guides EG Au 1&9.

A review of the non-financial Entity Information and Statement of Service Performance in accordance with ISAE (NZ) 3000 is a limited assurance engagement. The assurance practitioner performs procedures, primarily consisting of making enquiries of management and others within the entity, as appropriate, and applying analytical procedures, and evaluates the evidence obtained.

The procedures performed in a review are substantially less than those performed in an audit conducted in accordance with ISAE (NZ) 3000. Accordingly we do not express an audit opinion on the entity information and service performance statement.

Other than in our capacity as assurance practitioner we have no other relationship with, or interests in, the MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND INC.

Integrity Audit

Integrity Audit Chartered Accountants East Tamaki, Auckland 11 October 2018

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INTEGRITY AUDIT



INDEPENDENT AUDITOR'S REPORT

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

Report on the Financial Statements

Qualified Opinion

We have audited the financial statements contained in the performance report of THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND (INCORPORATED) on pages 4 to 15 which comprise the statement of financial position as at 30 June 2018, the statement of financial performance and 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 the basis for a qualified opinion, the financial statements on page 4 to 15 present fairly the financial position of THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND (INCORPORATED) as at 30 June 2018 and its financial performance and cash flows for the year ended on that date in accordance with the requirements of Public Benefit Entity Simple Format Reporting – Accrual [PBE-SFR-A] (Not-For-Profit) [NFP] issued in New Zealand (NZ) by the NZ Accounting Standards Board relevant to reporting financial position, financial performance and cash flows.

Basis for Qualified Opinion

We obtained sufficient and appropriate audit evidence on which to base our opinion, except that our audit work has been limited in the -

 verifying of the completeness of recording for cash sources of income such as cash from Sponsorship and fundraising revenue of \$187,503 where accounting control was weak because of limited segregation of duties prior to the cash being banked.

Other than in our capacity as auditor we have no other relationship with, or interests in, THE MOTOR NEURONE DISEASE ASSOCIATION OF NEW ZEALAND (INCORPORATED).

We conducted our audit in accordance with

International Standards on Auditing (NZ ISAs). Our responsibilities under those standards are further described below in the Auditor's Responsibilities for the Audit of the Financial Statements section of our report. We are independent of the organisation 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.

Restriction on responsibility

This report is made solely to the members, as a body, in accordance with section 42F of the Charities Act 2005, and the entity's constitutional requirements. Our audit work has been undertaken so that we might state to the members 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 members as a body, for our audit work, for this report, or for the opinions we have formed.

Other Information

The governance board is responsible for the other information being the entity information and statement of service performance. Assurances on the other information, if required, are engaged under a separate assurance engagement.

Our audit opinion on the financial statements does not cover any assurance on the other information.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If based, on the work we have performed, we conclude that there is a material misstatement of this other information, we are

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INTEGRITY AUDIT

required to report that fact. We have nothing to report in this regard.

Governance Board Responsibility for the Financial Statements

The governance board is responsible for determining that the PBE-SFR-A NFP framework is acceptable in the entity's circumstances, for the preparation of financial statements, and for such internal control as the governance board determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the governance board 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.

Auditor's Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are 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) will 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 these financial statements.

We are also required to apply the explanatory guides (EG) A 1 & EG Au 9.

As part of an audit in accordance with ISAs (NZ), we exercise professional judgement and maintain professional skepticism throughout the audit. We also:

identify and assess the risks of material misstatement of the financial statements, 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.
- □ conclude on the appropriateness of the use of the going concern basis of accounting by the board. Based on the audit evidence obtained, no material uncertainty exists related to events or conditions that may cast significant doubt on the entity's ability to continue as a going concern. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report, and no assurances are provided for any future events or conditions that may cause the entity to cease to continue as a going concern.
- evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by governance.

We communicate with the board 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.

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Integrity Audit Chartered Accountants East Tamaki, Auckland 11 October 2018

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