



Board of Trustees

Chair's Report – Annual Report 2022/23

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

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

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

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

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

In terms of our purpose and strategic direction, the year was also full of progress, not the least of which was the delivery of a hui in the Grand Hall of Parliament in July – supported and hosted by MP and supporter Tamati Coffey. The hui was the vehicle for the announcement of our Best Practice Recommendations for the Care of People with Motor Neurone Disease. Our goal is to have this document reside within the wider recommendations and support materials across the health and disabilities sector, being a blend of real-world, experience-based information and clinically relevant care and treatment aspects. The clinical working group that supported and drafted the document worked tirelessly to produce the document that is now in play nationally.

Our colleague and MND NZ Trustee, Alan Stanley, delivered a highly successful webinar in September outlining the current and future states of the Lighthouse 2 Clinical Trial. He highlighted the challenge of New Zealand's small population and the need for more participants, which in turn will assist in attracting additional research funding.

Motor Neurone Disease New Zealand Charitable Trust

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The Motor Neurone Disease Awareness Month in June 2023 raised around \$116,000 and this was fully due to the extraordinary work done around the country by supporters, clients, family, whanau, colleagues and the team at MND NZ. The new funds provided support the ongoing research and service delivery projects through MND NZ.

Our clients and their families also continue to benefit from the generosity of the Fulton Hogan fund, which provides for support and equipment not funded from other sources. In this last year, we reviewed and responded to 59 applications. The fund works within clear criteria, and we are confident that the recipients of support saw real, practical benefit delivered in a timely manner – this is one of those few areas where application and response work relatively seamlessly, and we do thank our benefactors, Fulton Hogan, for that ability.

We look forward to the next year with an eye on improving how we work and building resiliency in the organisation and within our stakeholder relationships, given recent significant changes in the health and disability sectors. With our new Research Adviser, Dr Natalie Gauld, we will be looking at the client journey – and our approach will lean on co-design with our client groups, so these next steps are shaping up to be of high value all round.

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

Lucy Haberfield,

Chair
Board of Trustees
Motor Neurone Disease NZ Charitable Trust