Muscular Dystrophy
New Zealand

2024

ANNUAL REPORT

Contents

Our Association

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About Us

The Muscular Dystrophy Association of New Zealand (MDANZ) is a member-led organisation established by New Zealanders with lived experience of neuromuscular conditions and those who support them. We began in the late 1950s as a support group for families affected by muscular dystrophy. Since then we have broadened our scope to include many other neuromuscular conditions and have become a leading source of information and support to our community.

Our logo is a person shown in the form of DNA. The double helix represents the genetic component to many of our conditions and acknowledges the whakapapa or family histories, which are woven through the stories of our members.

Neuromuscular conditions
We provide support for people with all types of; muscular dystrophy, spinal muscular atrophies, myotonic dystrophy, inherited ataxias and spastic paraparesis, metabolic muscle disorders including mitochondrial disorders, Charcot-Marie-Tooth disease and all types of hereditary motor and sensory neuropathies as well as neurocutaneous conditions such as neurofibromatosis.

Our members are of all ages and backgrounds, as symptoms can appear at birth or, for others, not until much later in life. Neuromuscular conditions are unpredictable, with limited treatment options.

What we offer
We have three regional branches that are supported by the national office based in Auckland. Together, we support individuals, families and whānau by providing information, practical resources, a fieldwork service, advocacy and peer-to-peer networks. We campaign to improve public awareness of rare neuromuscular conditions and work with clinicians and researchers to improve pathways to diagnosis and care standards for our members. Through our research trust, we offer hope for the future by funding research and facilitating access to clinical trials and potential new treatments.

Vision

To promote and enhance the well-being of people affected by neuromuscular conditions – fostering an inclusive and supportive community.

Mission

As the leading source of information and support for people affected by one of over 60 neuromuscular conditions, we advocate for their care and provide services that address the unique needs of our members and their families.

Values

Sustainable *Toitūtanga*
Empowering *Whakamanatanga*
Proactive *Kōkiritanga*
Connected *Tūhonotanga*

Chairperson Report

It has been another year of resilience and progress as we continued to advance our annual operating plan while navigating the ongoing pressures within the health sector and the rising cost-of-living challenges affecting many New Zealanders.

Our branches have continued to foster meaningful connections through member events such as coffee groups, swimming sessions, and other social gatherings. It is always heartwarming to see our members come together, building friendships and support networks.

Thanks to the dedication of our team, including some new faces, our Fieldworkers have remained agile, adapting their services to meet the growing needs of our community. We are proud to have welcomed 157 new members and their families this year, reinforcing our commitment to providing essential support.

We were also thrilled to see our ambassador, Callum Hedge, continue his inspiring journey with MDA. Callum’s passion and dedication to raising awareness of neuromuscular conditions. As his profile in professional motorsport continues to rise, so does awareness of our cause, and we are incredibly grateful for his support.

In 2024, our annual appeal, Miles for Muscles, once again made a meaningful impact, raising funds within local regions to ensure continued access to MDA’s services. Alongside the increased demand for Fieldwork services, we have also seen a rise in the need for counselling and peer support, reinforcing the importance of our work.

I would like to extend my heartfelt thanks to our dedicated branch teams, National Support Office staff, the Board and the NRFT, and the many volunteers who give their time and expertise so generously, particularly those involved in the governance of our organisation. As a member-led organisation, we rely on the passion and commitment of our community, and I am deeply humbled by your efforts.

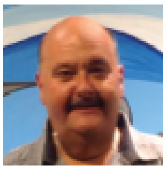
Thank you for standing with us over the past year. Your support fuels our work, and I look forward to taking the next steps together in 2025.

T. J

Trevor Jenkin
National Executive Chairperson

Our People

National Council

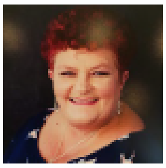


Trevor Jenkin
National Executive Chairperson

Rebecca Poad
Vice Chairperson

Jessica Anderson
Councillor

Scott Boyle
Councillor



Joy Jenkin
Councillor

Kim Russell
Councillor

Yaz Dolbell-Neville
Branch Rep

John Hawkins
Branch Rep

Patrons

Callum Hedge

2024 Annual Appeal Ambassadors

Mads and Harper Harrison

A snapshot of the year

Our branch reports

Northern Branch

It is with great pleasure that I present my report as Chairperson of Muscular Dystrophy Northern Inc. for another year. I am also honored to announce my intention to stand for re-election for a further two-year term, which would mark my 15th year as Chairperson of MDN, should I be re-elected.

While 2024 presented its own unique set of challenges, I would like to extend special thanks to Denise Ganley, who has been with MDN since its inception. Denise continues to play a crucial role in securing grants and supporting the organization in numerous other ways. Her dedication is invaluable, and we are fortunate to have her with us.

In 2024, we made significant strides in connecting with our community. We engaged directly with 676 members through face-to-face meetings, while also making 4,385 additional contacts through various channels, including text, digital means, and phone calls. Furthermore, we reached out to 2,234 other contacts who are involved in supporting our members.

Throughout the year, we organised a number of important events, including Coffee Groups in Hamilton, North Shore, South Auckland, and East Auckland, as well as our AGM via Zoom. We also held mid-winter lunches in Auckland and Tauranga, and a memorable 65th Birthday Party to celebrate MDANZ's milestone. This event was a tremendous success, thanks in no small part to Joy Jenkin, our Committee Secretary, who worked tirelessly to organize it and secure sponsorship. We also had the privilege of lecturing nursing students at Auckland University, a valuable initiative led by Denise.

I would also like to extend my deepest gratitude to the MDN Committee for their unwavering support and commitment to the organization. Yaz Dobel-Neville (Vice Chairperson), Andrea Clive (Treasurer), Joy Jenkin (Secretary), Jessica Anderson, Meagan Ballam, and Nia Fredrickson are all volunteers who generously give their time to ensure the success of MDN. I am truly grateful for the support they provide, which allows me to continue leading the branch.

A special acknowledgment is due to our staff: Denise Ganley, Mike Schneider, and Lynn Williams. Their hard work and dedication are the backbone of MDN, ensuring we continue to provide exceptional support to our community and stakeholders.

I would also like to thank Raema Inglis, our pro bono accountant, who has been volunteering her time and expertise for many years. I would also like to thank the Harley owners Group Auckland Chapter (HOGs) for their continued support and donations over the year, HOGs have been long time supporters of MDN.

As I enter my 15th year as Chairperson, I remain deeply grateful for the opportunity to serve in this role. It has allowed me to connect more closely with our community and further understand the challenges faced by those we support. I remain committed to ensuring that MDN continues to thrive and provide the necessary support to improve the lives of the people we serve.

Trevor Jenkin - Chairperson

Thank you...
Community Organisation Grant Scheme, Lotteries Grants Board, Lion Foundation, Foundation North, L.W. Nelson Trust, Trust Waikato, James Searle Say Trust, The Trusts Community Foundation (TTCF), Lister Presbyterian Health Trust, Bodmin Charitable Trust & Charles Rupert Stead Trust.

Our branch reports

Central Branch

I would just like to offer condolences to anyone who has had someone close to them pass away or having been inflicted with a bout of ill health in the past year our thoughts and prayers are with you all.

2024 was a year of taking a great plunge into the unknown in some ways as we wrestled with whether to play it safe and work with what we had, or knowing we would be going into deficit for the year. We as a committee decided we needed to cover the Wellington area with an active field work service, as there had been a lot of discontent with not having one for some time. We advertised towards the end of 2023 but never got anyone suitable, so we decided to extend Talitha's hours to make her a full-time employee and so she now covers the Wellington region added on to her area of responsibility. Talitha has been looking after Taranaki across to Manawatu and Wairarapa for many years. This has proved to be a good move with members happy to know they have support when they need it and or someone they can contact when they need to. Thanks to Talitha and her ever present personal assistant Cherie.

Debbie our Hawkes Bay and Tairawhiti field worker has now settled in and doing a great job in that region. We are now having to look for another car, as towards the end of last year Debbie's MDA car was stolen and taken for a joy ride and then backed with some force into a tree which caused sufficient damage as to have it written off, something we could have done completely without and upset Debbie very much, sorry Debbie but we will get another maybe soon!

We are still having a private session at the Kilbirnie Aquatic Centre hydrotherapy pool once a month thanks mostly to Francesca who has once again made herself available, our hope is that more people will take advantage of this facility in Wellington City.

I just want to thank the Executive Committee for all they have done this year, particularly Lydia who spends quite a few hours a week keeping things happening, such a massive support for the region.

We are also looking for people to step up to help with our minimum sized committee, come on give it a go, do some volunteer time to help the Central branch to support others with a Neuromuscular condition they didn't ask for either.

John Hawkins - Chairperson

Our branch reports

South Island Branch

2024 was another fantastic year of growth and member engagement for our branch. We have experienced a significant increase in demand for fieldwork services and attendance in coffee groups has also seen a big increase in numbers.

Between Lisa, Jane and Vivienne we have completed over 1000 face to face meetings with members and travelled nearly 19000 kilometers to ensure all our members who wish to see us have had the opportunity to do so. We held 76 coffee groups across the motu and 11 member events throughout the year.

Jane held some fantastic Miles for Muscles events in Nelson, Blenheim and on the West Coast where our members raised awareness of the conditions we cover and also raised some money along the way. The South Island branch again rose to the annual appeal challenge and raised $10,000 for the branch.

We welcomed 66 new members to our branch during 2024.

I wish to thank Lisa, Jane and Vivienne for their work during 2024 and wish them a great year ahead.

Trevor Jenkin - National Executive Chairperson

Annual Appeal

Highlights from 2024

New-look Miles for Muscles is MDA’s annual fundraising and awareness campaign, where participants rally support from family and friends before hitting the pavement to log miles.

Whether by bike, scooter, or walking, over 45 fundraisers, including members, families, schools, and staff, raised $17,705 to boost awareness and funds for those living with muscle-wasting conditions.

This year’s event saw strong participation despite tough economic times, with people across New Zealand taking part from Greymouth to Orewa Beach. Fieldworkers Jane Hazlett and Debbie Hoskins organized 'Walk and Wheel' events, creating an inclusive atmosphere. Schools such as Orewa Beach Primary and Broadgreen Intermediate also held "Wheels Days" in support of students living with muscular dystrophy.

National Executive Chairperson Trevor Jenkin praised the efforts, noting the heartwarming commitment shown during challenging times. Zoe Ellery led the fundraising efforts, raising $4,535 in support of others with muscular dystrophy. The top team, Team Roth Shank, raised $2,100 in honour of young Eden, diagnosed with Duchenne Muscular Dystrophy.

The funds raised directly supported essential services for MDA members, ensuring they receive the support they need to meet their unique challenges. Even from across the globe, our Ambassador, Callum Hedge, lent his support by dedicating his Music City Grand Prix race in Tennessee to the appeal.

Special thanks were given to sponsors One Technology, Datam, and Rothbury Insurance, whose support was crucial, as well as campaign faces Mads and Harper Harrison for their efforts in promoting the appeal.

2024 at a glance

52 members utilised our free counselling support

157 new members joined for support

13,901 donations received

$23,330 of research funded

6,054 *In Touch* magazines sent to our members, GPs, and specialists

$17,705 raised by our Annual Appeal

Our Stories

A Journey of Resilience

Life doesn't always follow the path we expect. For me, the challenges began early with multiple surgeries during school that were later linked to Charcot-Marie-Tooth disease (CMT), a neurological condition affecting peripheral nerves.

At the time, CMT wasn't well understood, and complications, including a serious infection that nearly led to amputation, kept me out of school for long stretches, disrupting my education and shaping my early years.

Despite these setbacks, I was determined to move forward. At 16, I began working for Jack Laing at Laing Shoe Repairs in Dunedin. Jack became a mentor, teaching me the value of hard work and community. When he retired, he offered me the business. I took a leap of faith at 22 and I've been running the shop ever since, now serving generations of loyal customers.

Living with CMT makes running a hands-on business physically challenging, but the joy I get from helping people makes it all worthwhile. I've since expanded into key cutting, growing the business while staying true to its roots. Without family in New Zealand, the Muscular Dystrophy Association (MDA) has become a vital support network. Their care, connection, and community mean the world to me.

My journey has been one of resilience—marked by hardship, yes, but also by purpose, growth, and pride in the life I've built.

Jodie is continuing to ride the wave of success

For Jodie Thorne, horse riding isn't just a passion—it's a vital part of her life. "Life just wouldn't be the same without it. It would be incredibly boring, that's for sure!" she says.

Jodi began riding at age 10. At the time, her facioscapulohumeral muscular dystrophy (FSHD) had little impact—she only needed a mounting block to get on her horse. But after stopping at 15 and returning at 26, everything had changed. Her strength and balance had deteriorated so much that she needed to be lifted onto the horse and supported during a brief five-minute ride. "My legs felt like jelly when I got off," she recalls. But that short ride reignited her love for the sport.

Over the next year, she rode weekly with the Riding for the Disabled Association, steadily rebuilding her stamina and balance. Eventually, she began riding independently at a walk and discovered Para Equestrian competition in New Zealand in 2010—"the rest is history," she says.

As her FSHD progressed, Jodi found her current saddle flaps no longer supported her weakening leg muscles, causing pain and increasing her risk of falling. To address this, she applied to the Bradley Jenkin Memorial Fund for new saddle flaps with built-in leg support, significantly improving her comfort and safety in the saddle.

Jodi is deeply grateful for the support, noting that riding has helped slow the decline of her posture and stamina despite her condition worsening over the years. And beyond the physical benefits, she emphasizes the emotional rewards: "Horses are good for the soul."

Our Stories

My trip on the 'Wish for Fish' boat

Recently, I was lucky enough to go on a fishing trip with Wish for Fish, a charitable trust offering accessible boat experiences. I'd only signed up shortly before Christmas, so I was surprised and thrilled when Tony called just two weeks later to offer me a spot. My husband Steve and I caught the bus into town, grabbed lunch, and headed to the Viaduct where the boat was docked. There were about eight participants, most in wheelchairs, along with caregivers. The boat was incredibly well-equipped with a hoist for boarding, a lift to the wheelhouse, and an accessible bathroom with a hoist and bed — all designed with disabled people in mind.

The crew, made up of volunteers and sponsors, were welcoming, helpful, and full of laughs. Our first stop was near Rangitoto, and although I'd never fished before, I've always loved being out on the water. With very limited arm movement, I was thrilled to use a fully automatic reel designed for someone like me, allowing me to fish using just my thumb and forefinger! The crew baited the hooks and before long, fish were being pulled in left and right — snapper, gurnard, trevally, and even a baby shark. Each catch was met with cheers and excitement, and the whole trip was filmed for an upcoming episode of Fishy Business with Adam Clancy.

We moved to another great fishing spot before heading back, where the crew cleaned and filleted the catch to share among us. The entire experience was joyful, empowering, and beautifully accessible — a perfect day on the water. If you're interested in learning more or signing up for a trip, visit wish4fish.co.nz. There's no cost to join, but donations are always welcome to support their fantastic work.

Denise Ganley

Lydia's full life

Diagnosed at age 9 with Friedreich's Ataxia (FA), Lydia Wilson once feared her future was uncertain. Her mum, Ruth, a nurse, noticed early signs - stumbling, falls, and bedwetting, and pushed for answers, leading to a diagnosis of FA, a progressive condition that affects the nervous system and muscle coordination.

"At school, it was hard accepting I had a disability when others didn't," Lydia recalls. Support from the Muscular Dystrophy Association of NZ helped her school understand her condition, providing much-needed awareness and inclusion.

Now 28, Lydia lives with her family in Inglewood. Despite needing a wheelchair full-time and daily assistance from her carers and family, staying mobile is a priority. "Thanks to my carers, I walk with my frame every day," she says. A recent surgery on her toes and Achilles tendons improved her mobility but made independent living difficult.

Previously employed at Powerco, Lydia stepped back due to fatigue but now channels her energy into volunteering. She serves as Vice-Chairperson of the Central Region branch committee and finds purpose in giving back.

Lydia's outlook remains positive: "Take life one step at a time. Things can be hard, but there's always light at the end of the tunnel—you never know how much joy life can bring until you get there."

Neuromuscular Research Foundation Trust

The Neuromuscular Research Foundation Trust (NRFT)* is the entity primarily responsible for supporting the achievement of MDANZ strategic goals in research. These research priorities are updated periodically in response to member needs and feedback, and are currently as follows:

- To advance research into effective treatments: Research that facilitates and/or contributes to clinical research aimed at developing effective treatments for neuromuscular conditions.

- To improve health outcomes or quality of life: Research that encompasses standards of care, innovative practice in supporting people with neuromuscular conditions, and/or evaluation of therapy approaches, service delivery modes and interventions.

- To improve the diagnostic journey: Research that aims to reduce diagnostic timeframe and improve experience of receiving a diagnosis. The trust accepts funding applications for research relevant to New Zealanders living with neuromuscular conditions annually and monitors the progress of the research to ensure accountability.

2024 was a quietly productive year for the Research Trust. The Trustees reviewed and approved one grant application for a project commencing in 2024:

1. Dr Angus Lindsay - PhD in Biochemistry, Sir Charles Hercus Health Research Fellow (Health Research Council), and Principal Investigator at the University of Canterbury

Understanding the role of the adrenal gland in Duchenne muscular dystrophy

Duchenne muscular dystrophy (DMD) is a severe genetic condition that causes muscles to weaken over time. It mainly affects boys and leads to the gradual loss of mobility, followed by serious heart and breathing problems in early adulthood. Although there is no cure, doctors often use medications called glucocorticoids to slow the disease. These drugs can help maintain muscle and heart function, but they also cause significant side effects, including problems with the adrenal glands—organs that help the body respond to stress.

Recent research suggests the adrenal glands may play a more important role in DMD than previously recognised. Studies in a common DMD mouse model show that the adrenal glands react too strongly during stressful situations. This overreaction may prevent the body from using energy properly, making the animals more vulnerable to stress and worsening their symptoms.

This project will be the first to directly examine how the adrenal glands contribute to DMD. Understanding this connection could reshape how we think about stress in the disease and point to new ways to better support individuals with DMD, including treatments that specifically address adrenal function.

Supporters

The Muscular Dystrophy Association of New Zealand is grateful for the support received from individuals, sponsors, trusts and foundations, and government this year.

Harley Owners Group – Auckland Chapter
Auckland Harley Davidson
Hyundai
The Access Group Foundation

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Community Organisation Grants Scheme
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