



Muscular Dystrophy New Zealand



2023 ANNUAL REPORT

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MDANZ National Office
PO Box 12063, Penrose
Auckland 1642



419 Church Street East,
Penrose, Auckland



0800 800 337



info@mda.org.nz



facebook.com/MDANationaloffice



www.mda.org.nz

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.



Muscular Dystrophy
New Zealand

Vision

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

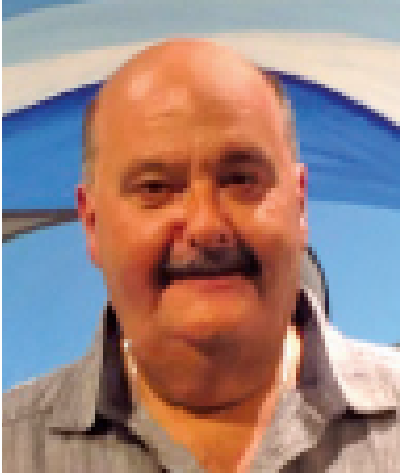
Mission

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 was a challenging year as we continued to make progress on our annual operating plan, while operating within a health sector under pressure and cost-of-living challenges widely impacting New Zealanders.

New Zealand's communities reopened after the pandemic response settings were largely removed and our branches were able to reignite member events such as coffee group meetings and swimming groups. It's always heart warming to see members together & enjoying themselves.

Through great teamwork, and some new faces to the team, our Fieldworkers continually adapted their services and learnings to ensure essential services remained. We are proud that we could welcome 211 new members and their families into our community.

It was great to welcome a new ambassador to the MDA, Callum Hedge. Callum's relationship with the MDA started last year with the Roll 1k annual appeal after his two nephews, Tommy & Noah, were diagnosed with DMD. Callum is an inspiring and energetic young professional race car driver who will bring great awareness of the association and neuromuscular conditions through his rising profile. We are thrilled to have him as part of our community.

In 2023, we had another successful annual appeal, Roll 1k for MDA, raising funds for the region they were collected in to contribute towards continued access to MDA's wellbeing services. We haven't only seen a rise in the need for our Fieldwork services but for counselling and support groups too.

Our members are continuously supported by our branches and staff and I would like to thank all branch, National Office staff and the NRFT for their continued service, positive commitment and hard work to deliver our services. I also wish to thank the many volunteers who have sacrificed many unpaid hours, particularly in the governance structures of our organisation. As a member-led organisation we ask a lot of our members, and I truly wish to honour and thank all who have stepped up to give time and resource to our organisation this year. I am humbled by your efforts and could not do my job without you.

Thank you for all of your support over the past year. Please stay with us on the next exciting step of our journey.

A handwritten signature in blue ink, appearing to read 'T. Jenkin'.

Trevor Jenkin
National Executive Chairperson

Our People

National Council



Trevor Jenkin
**National Executive
Chairperson**



Rebecca Poad
Vice Chairperson



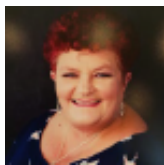
Jessica Anderson
Councillor



Francesca Herdahl-Thorsing
Councillor



John Hawkins
Councillor



Joy Jenkin
Councillor



Kim Russell
Councillor



Yaz Dolbell-Neville
Branch Rep

Patrons



Callum Hedge

2023 Annual Appeal Ambassadors



Noah & Tommy Fearnley

A snapshot of the year



Our branch reports



Northern Branch

It gives me great pleasure to present this report at the AGM of Muscular Dystrophy Northern Inc. (MDN) for 2023. After a steady year with all the financial hardship a lot of charities are currently facing, I am pleased to say that MDN has had another good year, thanks to all the very hard work the staff and the committee has put in to making this happen.

A special thanks to our members who got involved with our annual campaign Roll1k for MDA at Hampton Downs; what a huge success the event was!

In 2023, MDN made 553 face-to-face member contacts, 2,832 other contacts which could be by text, digital means or phone calls, 153 face-to-face contacts with Health or Education professionals, government agencies or caregivers and also Whanau of members living with Neuromuscular conditions, and 1,088 contacts with the same group by other means (phone, text or digital). Plus, 365 face-to-face contacts at community and network meetings. MDN also attended adult neuromuscular clinics at Auckland & Whangarei hospitals, and Pediatric clinics at Starship and transition clinics at Starship.

Some of the events held in 2023 included: Hamilton Coffee Groups, AGM held via Zoom, mid-winter lunches in Auckland and Hamilton, the Roll1k Event in Hampton Downs, Family Camp in Ngaruawahia in November and lectures to Nursing students at Auckland University.

I would like to conclude this report by noting my thanks to the MDN committee who are all volunteers and give their time freely; thank you for the support you all give to me. Also, thanks to our pro bono supporters, IT Outsource, and Raema Inglis, our accountant. Raema has been with us for many years giving hours of her time.

Plus, thank you to the Auckland HOGS & our many supporters that donate and give so much to keep MDN running.

I would like to acknowledge the significant contribution of our staff Denise Ganley, Lynn Williams, and Rachel Woodworth, who was with us for a short time. The staff have worked diligently over the year to ensure that MDN continues to support our community and stakeholders.

As I enter my thirteenth year as Chair of MDN, I continue to appreciate the opportunities this role offers me to know our community more closely, and where I can, to ensure that MDN continues to support the many people we come across everyday who work hard to make it a better place to live and work.

Trevor Jenkin - Chairperson

Thank you...

Bodmin Charitable Trust, COGS, Lottery Grants Board, Foundation North, The Trusts Community Foundation, Trust Waikato, CR Stead Trust, James Searle Say Trust, JM Thompson Trust, Lion Foundation, Pub Charity, JM Thompson Trust, The Trusts.



MDN Committee

Joy Jenkin – Secretary, Andrea Clive – Treasurer, Lew Pulman, Debbie Schneider, Yaz Dolbel-Neville, Chloe Schneider, Chloe Hovell, and Jessica Anderson.



Our branch reports



Central Branch

Well here we are wondering how to approach this, and procrastinating is not going to help at all! I came into the role as Chairperson of the Central branch with some misgivings and doubts but looking at the team we had, I was confident that things would be okay. Sadly, Fieldworker Phillipa McLean decided things were not going to work for her, but stayed on to get the wonderful cyclone payments distributed to members affected by last year's cyclone. Thank you Phillipa.

Then on 19th August 2023, Alison Risborough passed away suddenly, having only just come back on to the committee after retiring from regular employment. Alison, you are sadly missed. A memorial service was held for Alison on 6th November 2023.

Then in November 2023, Liz Church, our amazing Treasurer, found she had health and living condition problems and needed to stand down. Liz left a great financial guide that she had written for us, thanks Liz. Committee Member, Monique Tawhiri, put her hand up to take on the Treasurer role on a temporary basis, thanks Monique.

We also sadly lost Francesca Herdahl-Thorsing, our fantastic Secretary, who decided to stand down after getting married. Francesca has kept looking after the monthly swimming meetings at Kilbirnie pool, thanks Francesca. Lydia Wilson took over as Secretary and has been doing a great job, many thanks Lydia.

2023 was a big learning curve for all of us! We also co-opted Felicity van der Linde and Annelize Steyn to help with dwindling numbers on the committee and I thank you both for making yourselves available. I would also like to thank Joel Latimer for his amazing tech support knowledge and professional support.

Last year we advertised for Fieldworkers for the Wellington area (Wellington up to Otaki and including Wairarapa) and another fieldworker for Hawkes Bay/Tairāwhiti area. Well we struck lucky with a lovely lady named Debbie Hoskins for the Hawkes Bay/Tairāwhiti area. This is great for Hawkes Bay and East Coast! Debbie is doing an awesome job establishing herself and becoming Known to our members in the Bay. Talitha Vial has since extended her coverage area to now include the Wellington region.

My thanks to our Talitha Vial, Palmerston North Fieldworker, for continuing to look after Taranaki through to Manawatu, and more lately Wairarapa. Thankyou Talitha for all you do for the membership through that part of the Central Branch area.

I also want to thank Trevor Jenkin, and the National Support Office team, for their support and encouragement during this past year.

Although this year has been topsy-turvy to say the least and I know I haven't kept everyone well informed, I trust we have turned a corner and can look forward to a much more settled year ahead.

John Hawkins - Chairperson



Our branch reports



South Island Branch

2023 saw tremendous growth for our branch. We started the year down a fieldworker after Ross Paterson leaving in December 2022 and Jackie Stewart retiring in May 2023. Jane Hazlett (Upper South fieldworker) and I bridged the gap until Lisa Mora joined us in July 2023. Lisa's territory covers Canterbury, Otago and Southland. Lisa had a fair bit of catch up to do, but hit the ground running and has made contact with every member already. I would like to thank both Lisa and Jane for all their dedication and hard work.

Our small team of three made a significant impact on the South Island through attending expo's, running events and coffee groups. We are proud to boast that we held 54 coffee groups and 11 events during 2023 with a reach of over 500 members. The most popular event was the family day out at Willowbank.

We wish to thank our volunteer coffee group facilitators – Bruce Dodd, Kevin Page, Denise Martin, Emma Shewan, Emma Checketts, Chanel Sluys and Kim Russell. Without your help and support we would not be able to host groups and events. We would also like to thank the National Councillors for their governance throughout the year, especially Trevor Jenkin for his unwavering support and guidance.

We had another well supported Roll 1K for MDA campaign in 2023, raising \$10,000 for our branch. We held two Roll 1K events, including one in Christchurch and one in Nelson, we also had Little Oaks Preschool, Leithfield Primary School – Te Kura o Kōwai, Fairlie Primary School and the Rangiora Scout Group (Kia and Cub section) run events for us.

We also wish to thank all the trusts, foundations and individuals who have supported us and special thanks to BRONZ for their wonderful donation.

We look forward to continued growth and engagement in 2024.

Vivienne Fitzgerald - South Island Branch Manager

Thank you - Lottery Grants Board, COGS, Healthcare Otago Charitable Trust, DIA (COVID -19 Provider Fund), MOH (DIAS), Kiwi Gaming Trust, Guy Anson Waddell Charitable Trust, A & R Edgar Trust, Rata Foundation, Pub Charity, Blogg Charitable Trust, The Rehabilitation Welfare Trust, Four Winds Foundation, The Lion Foundation, Mainland Foundation and The Trusts Community Foundation.



Top L-R: Willowbank Family Day Out, Leithfield School - Te Kura o Kōwai Roll 1K event, Little Oaks Preschool Roll 1K event, Nelson Roll1k event.

Top: Christchurch Christmas Luncheon
Bottom: Invercargill Coffee Group

Annual Appeal



Highlights from 2023

For the third year running, MDANZ's annual fundraising and awareness campaign 'Roll 1k for MDA', took place between 18 September – 01 October 2023. Over 42 fundraisers, made up of members, families, staff, schools, and supporters signed up to roll during the official challenge week and together raised over \$25,062.



Using their social media platforms, participants reached out to family and friends to support them in rolling 1KM in distance on any kind of wheels.

A highlight this year was having New Zealand motorsport champion, Callum Hedge, on board as our new ambassador. Callum not only fundraised \$3,433 for the Association, but also gave three lucky prize winners the roll of their lives as they zoomed around Hampton Downs in a Lamborghini.



It was also great to see supporter organisations taking part for the first time. Allied Medical, Harley's Owners Group (HOGs), and Te Kura Whakaora Ngangahau (School of Occupational Therapy), all fundraised and did the challenge. And we can't forget the five amazing schools who held 'wheels days' and who all did a brilliant job of supporting their school mate.

Rolling his way to the top of the leaderboard was Mads Harrison, aged 7, from the South Island Branch. Mads received an overwhelming response from his supporters and raised \$4,797!

All of the funds raised by our amazing supporters went back to the region they were collected in to contribute towards continued access to MDA's wellbeing services.

2023 at a glance



Our Fieldworkers have driven more than 68,500kms to visit members



20 members utilised our free counselling support



211 new members joined for support



16,105 donations received



7 of our members took part in the Duke of Edinburgh programme



\$57,538 of research funded



7,750 *In Touch* magazines sent to our members, GPs, and specialists



28 members received funding from the Bradley Jenkin Memorial Fund



\$25,062 raised by our Annual Appeal

Our Stories

My own advocate

Prior to being diagnosed with Hereditary spastic paraplegia (HSP), Jason spent many years at sea commercial fishing until his health deteriorated and he could no longer keep up with the physical demands of the job. Jason's symptoms are worsening, and he can sadly no longer work at all. Jason's ability to walk far is also declining and he now uses a wheelchair most days.

"Before my diagnosis I was struggling to keep up with the demands of my job but had to work to pay bills & the mortgage. Now, I feel some relief with not being able to work as it takes the pressure off having to make ends meet each week", Jason said.



Jason praises his Fieldworker, Rachel Woodworth, and the support he has received from her. "Rachel has been tremendous to deal with and has really helped me", Jason says.

Rachel advocated on Jason's behalf after he was turned down for a health insurance claim, after taking out health insurance more than 12 years ago. The first time Jason was assessed, he received a low score from the assessor so had his claim denied. However, once he met with Rachel for the first time and explained the situation, Rachel got to work advocating on his behalf for a review and reassessment. "Thanks to Rachel, they came back to reassess me, and my assessment score was at the highest level on the threshold, meaning my claim was accepted. This has taken huge financial strain off me and my partner", Jason says.

"Without Rachel advocating for me this would have never happened", he said.

My smile hasn't been this big in a long time!

The last time I rode a bike was 29 years ago, when I was still at University. With my legs getting weaker over time due to Charcot-Marie-Tooth disease (CMT), I could eventually only cycle on the stationary bike in the gym.

I remember when e-bikes came out. A friend said surely I'd be able to ride an e-bike. But I knew I'd need a bike that would not only assist in the cycling, but also one that would allow me to be seated and remain seated before starting and after stopping, plus something to hold my feet in place.

Then last year, my husband decided to investigate options for me. We travelled up to Levin, where he found a company that makes adaptive bikes. At first, I was too scared to even get on the bike, but once on and cycling, you couldn't wipe the smile off my face.

Brian at NZ Trikes agreed to hold a bike for me for a deposit, and I could then seek funding and he'd finish the build once I was able to make final payment. My wonderful parents gave me a generous contribution and I applied to the Bradley Jenkin Memorial fund which I thankfully got - thank you MDA.

My e-trike arrived late Oct and we had a wonderful summer holiday, going for a number of cycles around our neighbourhood. Now I can also be out and about, having more active fun.

It's so good to be able to be active again, get out with my husband and enjoy life more - especially when I can cycle faster than him!

Roedeen Atkinson



Our Stories

Padding to gold

When Gary Sin joined a corporate team-building dragon boating team in 2011, he had no idea how much impact the sport would have on him. Gary joined The Zombies, a corporate team of 22 members as a fit and healthy 27-year-old and managed the weekly races and practices with ease. His condition, Miyoshi Myopathy, had no effect on him when he started, and it has only been in the past few years that symptoms of his condition are starting to take hold. "My condition is deteriorating each year, but I am still able to walk around the house, although I rely on crutches when I am outside. Primarily, my legs are affected, but I have noticed weakness in my upper body," he says.

Now 39-years-old, Auckland based Gary has been The Zombies' team manager for around 8 years and credits the sport for keeping him active. "Dragon boating is ideal for me as it's predominantly an upper body workout" he said. Gary spends about 15 hours a week exercising at home to keep his upper body strength in shape along with 1 training sessions on the water each week when the dragon boat season starts at the beginning of summer. "Along with our dragonboat training, I also participate in Waka-ama on the weekends and visit the local pools for a few aqua-jogging sessions each week. Not only can I still engage in these activities, but they also help me stay socially connected with my friends and provide a reason to get out of the house." he said.

The Zombies are an Auckland based team which predominately attend all the events in Auckland. Once a year, they travel to Wellington for the Wellington Dragon Boat Festival.

For over 15 years they have competed in the corporate division and for the first time in 2023, competed in the open grade.



Held on Saturday 4th March 2023, Gary & his team ended up in the B Grade Final and won it, earning them a gold medal!

For Gary & his teammates, this was an incredible result and a testament to their inclusive and supportive spirit.

Stepping out of my comfort zone!

Hi, I am Samantha Lenik, and I have the rare disorder Pompe Disease.

I might not like to think that Pompe defines me, but like it or not, it has shaped me and put me on a different course, one where I have been tested to push boundaries, go above my comfort zone and also on a more positive aspect, I have met amazing people who are also on the same journey as me.

Thanks to the Muscular Dystrophy Association, and financial support from the Bradley Jenkin Memorial Fund, last month I was able to attend and speak at the Australian Pompe Association & NZ Pompe Network Conference in Adelaide, Australia.

It was a first to see one of our NZ Specialists, Dr Richard Roxborough, Neurologist, Auckland City Hospital, and Dr Drago Bratkovic present together on "How to encourage Drug Trials in Australia & NZ".



I also presented at the Conference, a little out of my comfort zone, but important to share my patient journey with others.

I talked about my 7 years to diagnosis, originally being told it was possibly Muscular Dystrophy. My coming to terms with the Pompe diagnosis, but also knowing there was a treatment that could slow down progression, but that NZ did not fund it, and then my patient advocating for the last, nearly 10 years, to push for better medicine access.

These Conferences are invaluable for us as patients to attend. It is hearing about the latest developments in treatment, learning about any new recommendations in diet and exercise, as well as hearing the patient stories, knowing that someone gets what you are going through, this all helps you on your patient journey.

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.

2023 was a quietly productive year for the Research Trust. The Trustees reviewed and approved two grant applications for projects commencing in 2023:

1. Professor Richard Roxborough - Neurogenetic Research Group

Providing diagnostic closure for people with undiagnosed Ataxia in Aotearoa-New Zealand.

The proposed research will improve standards of care for people with neuromuscular disorders by providing a new diagnostic pathway that facilitates molecular genetic diagnoses for tangata whaiora and families living with ataxia, who have not yet been able to access a diagnosis. The potential discovery of new variants or genes that cause neuromuscular disorders or simply a diagnosis for an as yet undiagnosed patient addresses the MDANZ research priority of treatments and cures by providing diagnostic certainty for the patient and allows the clinician to identify targeted current and future therapies and trials for tangata whaiora.

2. Professor Richard Roxborough - Neurogenetic Research Group

Centre for Brain Research Neurogenetic Clinic for patients with Inherited Ataxia and Hereditary Spastic Paraparesis.

Inherited ataxia and hereditary spastic paraparesis (HSP) are rare and there is still much to find out about their natural history, which in turn informs clinical care and rehabilitation. The Centre for Brain Research Neurogenetics Research Clinic (CBR-NRC) aims to record longitudinal assessments of patients with rare neurogenetic diseases to understand better the natural history of these diseases. The assessments used will themselves be studied in order to develop sensitive tools for monitoring disease progression.

Information obtained from the assessments will be used to develop and advise patients and their treating clinicians on the best treatments in keeping with the current literature or from first principals or be used to define the patients' individual phenotypes in order to define the clinical manifestations of neurogenetic diseases.



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
NZ Post
One Technology
Spark NZ
The Access Group Foundation

A + R Edgar Charitable Trust
ANZ Bank Staff Fund
Aoraki Foundation
Aotearoa Gaming Trust
ARA Lodge No. 348
Bendigo Valley Sports
Blogg Charitable Trust
Bodmin Charitable Trust
Central Lakes Trust
Charles Rupert Stead Trust
Christchurch City Council
Community Organisation Grants Scheme
Community Trust Mid and South Canterbury
DIA Ethnic Communities Development Fund
Dunedin City Council
Eastern & Central Charitable Trust
Eastland Community Trust
Foundation North
Four Winds Foundation
Hawke's Bay Foundation
Healthcare Otago Charitable Trust
Independant Living Services
Invercargill Licencing Trust
J M Thompson Trust
Jack Jeffs Charitable Trust
James Searle Say Trust
JBS Dudding Trust
Kingdom Foundation
Kiwi Gaming – Cert
L W Nelson Trust

Mainland Foundation
Marlborough District Council
Merrilees Family Charitable Trust
Ministry of Health
Ministry of Social Development
Napier City Council
Network Tasman Charitable Trust
Nick Lingard Foundation
Nikau Foundation
NZ Lottery Grants Board
NZFGW Otago
One Foundation
Pub Charity
R J Doyle Estate
Rata Foundation
Redwood Trust
Rehabilitation Welfare Trust
Richdale Trust
Rothbury Insurance Brokers
South Canterbury Trust
Southern Trust
Stern Foundation
Te Pou Ltd
Te Whatu Ora
T G Macarthy Trust
The Community Trust South
The Guy Ansel Waddel Charitable Trust
The Lion Foundation Grant
The Trusts Community Foundation
Tiaho Trust
Trust Waikato
Tuia Legal Ltd
Walsh Trust
Wellington Methodist Charitable
Education Endowment Trust
Whanganui Community Foundation
Wilson Home Trust

