



or reducing isolation by linking people to others with shared experience.

Community education may include talking with teachers, health professionals or disability support staff to improve their understanding of these conditions.

Counselling service

Living with a progressive neuromuscular condition sometimes raises feelings or issues that can be helpful to talk about. By partnering with a respected organisation that screens counsellors and matches them with clients nationwide, MDANZ is able to provide members with funded access to a private, close to home counselling option.

Discretionary funding

We make small discretionary grants to our members, to assist them to purchase life enhancing resources that are not met by government funding.

Support us

MDANZ is a registered charity and we rely almost entirely on voluntary donations from the general public, trusts and other businesses/organisations to continue our work in the community. Call 0900 426 98 to make an automatic \$15 donation, or donate online at www.mda.org.nz.

There are also many ways you can get involved, as a volunteer, or being part of our annual Freedom campaign in September.



www.mda.org.nz



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Muscular Dystrophy
New Zealand



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New Zealand

About us

Freedom beyond limits



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 1950's 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 parapareses, 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.



Vision

Freedom beyond limits

Mission

Promoting freedom of choice
and a responsive society

Values

Sustainable Toitūtanga
Empowering Whakamanatanga
Proactive Kōkiritanga
Connected Tūhonotanga

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 four 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.

Fieldwork service

Our fieldworkers work in the community to provide personalised support and education. Personalised support may include supporting through diagnosis, walking alongside during times of grief and change, offering information and advice about conditions, facilitating service access through referrals or advocacy,