

Conditions covered

MDANZ provides support for people living with a wide range of neuromuscular conditions.

The following is a summary of conditions covered. Please contact us to discuss other neuromuscular conditions not listed here.

Muscular Dystrophies – all types, including **myotonic dystrophy**

Spinal muscular atrophies – all types, including **Kennedy's disease**

Hereditary Spastic Paraplegias (HSP)

Leucodystrophies – all types

Metabolic muscle diseases including **mitochondrial myopathy**

Hereditary motor and sensory neuropathies including all types of **Charcot-Marie-Tooth disease**

Myopathies – all types

Inherited ataxias including **CANVAS**, **Friedreich Ataxia** and **spinocerebellar ataxia**

Neurocutaneous syndromes – conditions affecting the brain and skin such as **neurofibromatosis type 1**

Myasthenia Gravis

Inflammatory myopathies

Support us

MDANZ is a registered charity (number 31123). We rely almost entirely on voluntary donations to continue our work in the community.

You can help us continue our work and join our mission to support the thousands of New Zealanders with neuromuscular conditions by donating securely online at www.mda.org.nz

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

Please donate. Your generosity helps us to provide vital services and support for our members and their whānau.

Thank you for your support.



www.mda.org.nz



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Muscular Dystrophy
New Zealand

About us

www.mda.org.nz



About us

The Muscular Dystrophy Association of New Zealand Inc. (MDANZ) is a member-led organisation established in 1959 by New Zealanders with lived experience of neuromuscular conditions, and those who support them.

The umbrella term "neuromuscular conditions" covers a wide range of progressive conditions. 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, sometimes difficult to diagnose, and there are limited treatment options.

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. Our governance structure ensures leadership of the organisation by individuals or family members with lived experience of a neuromuscular condition.

We are a trusted source of specialist information and provide advocacy and a range of free services to benefit individuals, families and whānau. We have three regional branches that are supported by the National Support Office based in Auckland.

What we do

We are the leading source of information and support for people with neuromuscular conditions. To achieve this mission, we provide:

- Information and advice, through our website, an 0800 info line, and printed resources
- A nationwide fieldworker service meeting members and whānau in the community, and connecting them to support and services
- In Touch magazine published three times a year, with inspiring stories, information on condition management and latest research
- Research funding and support for New Zealanders to access clinical trials and new treatments
- Education workshops for members, health professionals, schools and others
- Advocacy and lobbying at a community and national level
- Discretionary funding for life-enhancing resources not covered by government
- Funded support for counselling
- A platform for peer-to-peer networking and support groups
- Loan of resources, including cough assist machines, equipment, books and DVDs.

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

