Muscular Dystrophy Association of NZ Inc

"We offer support, information and advocacy to people living with Motor Neurone Disease, their families/whanau and carers and the health professionals and service providers involved in their care."



The Muscular Dystrophy Association of New Zealand Inc. (MDANZ) began in the late 1950's as a support group for families affected by muscular dystrophy. Since then, MDANZ has broadened its scope to include many other neuromuscular conditions.

We have four regional branches - Northern, Central, Canterbury and Southern - that are supported by the national office based in Auckland. MDANZ supports individuals, families and whānau by providing specialist information, practical resources, personalised support and Fieldworker services, social networks, campaigns for public awareness and advocacy. And through our research trust, we work to improve care standards and facilitate access to potential treatments for neuromuscular conditions.

Our organisation 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.

What are Neuromuscular Conditions?

Neuromuscular condition is a broad umbrella term that describes a variety of muscle disorders. The conditions covered by MDANZ are rare and mostly genetic. Progressive muscle wasting leads to loss of mobility and independence, and there are often major impacts on organ systems, which can result in early loss of life. Symptoms can appear at birth or for others not until much later in life. These conditions can be unpredictable and there are limited treatment options.

Key Northland Contact

Muscular Dystrophy Association of New Zealand PO Box 300429, Albany, Auckland 0752 09 415 5682 | www.mda.org.nz

Or Contact MDANZ National Branch 0800 800 337

Free phone 0800 636 787 (Muscular Dystrophy Northern Support)

Email <u>info@mda.org.nz</u>

Website http://www.mda.org.nz

Facebook

www.facebook.com/muscular.northern

Fieldwork Service

Our fieldworkers work in the community to provide personalised support and education, in the area of rare neuromuscular conditions covered by MDANZ. 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, 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 progressive neuromuscular conditions, which enables them to provide even better services and supports for our members.