

What is TREAT NMD?

The NZ NMD Registry is part of TREAT NMD, which is a network for the neuromuscular field that provides an infrastructure to ensure that the most promising therapies reach patients as quickly as possible.

Since its launch in 2007, the network's focus has been on the development of tools that industry, clinicians and scientists need to bring novel therapeutic approaches through preclinical development, into the clinic and on establishing best-practice care for neuromuscular patients worldwide.

Contact us:

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The NZ NMD Registry is an MDANZ initiative. It is generously supported by Neuromuscular Research New Zealand and the Richdale Charitable Trust. MDANZ publishes updates on the activities of the NZNMD Registry in its quarterly magazine *In Touch*.

The NZ NMD Registry has Health and Disability Ethics Committee approval # NTX/11/02/003

The NZ Neuromuscular Disease Registry



NZNMD
REGISTRY



**Providing opportunities for
people with neuromuscular
conditions to participate in
research since 2011**



Neuromuscular Research
New Zealand



If you have one of these conditions, then you can enrol with the NZ NMD Registry:

- Muscular dystrophies and myopathies, including congenital, inflammatory and metabolic myopathies
- Spinal muscular atrophy (all types)
- Hereditary neuropathies including Charcot-Marie-Tooth disease and hereditary sensory neuropathies
- Myasthenia Gravis, Lambert Eaton syndrome and congenital myasthenic syndromes
- Inherited ataxias including spinocerebellar ataxia and Friedreich's Ataxia
- Hereditary Spastic Paraparesis
- Leucodystrophies
- Neurofibromatosis or other Neurocutaneous Syndromes, including tuberous sclerosis

If you have a neuromuscular condition that isn't included here and you think it should be, please contact the Registry Curator NZNMDRegistry@adhb.govt.nz

What is a patient registry?

A patient registry collects information about people who are affected by particular conditions. In an anonymous form, valuable medical data from the registry will be made available to researchers whose work is ethical and has been approved, thereby accelerating the research into neuromuscular conditions and their possible treatments.

With the advent of clinical trials for many neuromuscular conditions, patient registries mean that people who may be eligible for certain clinical trials are readily identifiable and can be contacted quickly.

Neuromuscular conditions are rare conditions, so without a patient registry to gather patient details in one place, finding enough patients for a meaningful trial can take years, delaying the testing of potential therapies.

How do I enrol?

Enrolment is voluntary and people residing in New Zealand with a neuromuscular condition are encouraged to contact the Registry Curator or their local MDA fieldworker, who will provide information about the NZ NMD Registry. If you decide to participate you will need to sign a consent form and Registry staff may contact you for additional information.

Once you have been informed about the Registry and have consented to participate, information about your neuromuscular condition and, if applicable, genetic mutation is provided to the registry both by yourself and by the professionals involved in your care. This information is stored securely and while it is used to identify patients for clinical trials or for research, your personal details are protected and only known to registry staff.

If a clinical trial is being planned for which you may be eligible, the NZ NMD Registry will contact you with information about the clinical trial and contact details for the trial coordinator.

What information do I need to provide and what happens to it?

The NZ NMD Registry collects personal details such as your name, address, date of birth and gender so that you can be identified and contacted by the Registry staff where appropriate. For some neuromuscular conditions it also contains certain items of clinical and genetic information. All the data is stored securely and confidentially and is accessible only to NZ NMD Registry staff. For neuromuscular conditions that have a global database eg. the TREAT NMD global databases, anonymised data is transferred. Your information will be updated at least annually.