



Contact us:

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New Zealand
Motor Neurone
Disease Registry



Facilitating research
and clinical trials
for people with
Motor Neurone Disease



What is a patient registry?

A patient registry collects information about people who are affected by particular conditions. The NZ Motor Neurone Disease Registry collects information about people who have motor neurone disease (MND). It collects health and contact information about the people who decide to participate.

What does the registry aim to do?

The aim of the registry is to help those people in New Zealand with MND to participate in national and international clinical trials and research about MND, if they would like to.

The registry also aims to help researchers by assisting them to plan their research and helping to find people who may be interested in participating.

Because MND is not common, and New Zealand only has a small population, finding enough participants for a study about MND can be difficult. Without a registry to gather details in one place, finding enough patients for a meaningful study can take years, potentially delaying the testing of new treatments or the advancement of knowledge of MND.

Am I eligible to participate?

If you have been diagnosed with motor neurone disease (also called ALS), or have a genetic form of motor neurone disease in your family, you are eligible to register with the NZ Motor Neurone Disease Registry. People with family members who have an expansion in the specific gene that can cause motor neurone disease or frontotemporal dementia, C9orf72, can also participate even if their affected family members have only had dementia symptoms.

What does it involve?

If you decide to participate in the registry, we will collect information about your clinical condition and any genetic testing results, if you have them. We will also ask for your contact information and some demographic information.

The registry curator will contact you every so often to ensure that this information is up to date.

What are the benefits for me?

The Registry Curator will contact you if there is any research or clinical trial available for which you may be eligible. The curator will pass on information about this study so that you can make a decision about whether you would like to participate or not. You can say yes or no to any of these opportunities as you wish.

What happens to my information?

Your data is stored securely at Auckland DHB and also anonymously in an online database maintained by the Australian Motor Neurone Disease Registry (AMNDR) at Geelong Hospital, Barwon Health, Victoria, Australia. Only the NZ Motor Neurone Disease Registry staff will be able to link your personal details with your health information.

