

New Zealand Motor Neurone Disease Registry

Participant Information Sheet and Informed Consent Form

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You are invited to take part in the New Zealand Motor Neurone Disease Registry. This Registry is an initiative of and sponsored by the Motor Neurone Disease Association of New Zealand, a non-profit registered charity dedicated to supporting people with motor neurone disease.

This information sheet is designed to help you to decide whether you would like to take part. Please take your time to read the information and feel free to ask any questions you might have.

Introduction

The NZ Motor Neurone Disease Registry is a database designed to help people diagnosed with motor neurone disease to participate in research.

The Registry holds participant data such as their contact details, date of birth and genetic information (if this is relevant) and key information about their disease. When research into MND is planned, the database can be searched for participants who would be eligible and these participants can be contacted about participating in studies or trials for which they may be eligible.

Am I eligible to participate?

All people in New Zealand diagnosed with motor neurone disease or who have a genetic form of motor neurone disease in their family are eligible to register with the NZ Motor Neurone Disease Registry. Families who have an expansion in the specific gene that causes motor neurone disease or frontotemporal dementia – *c9orf72*, can also participate even if their affected family members have only had dementia symptoms.

The Registry is sponsored by the Motor Neurone Disease (MND) Association of New Zealand, but any New Zealand resident can participate in the Registry, you do not have to be a member of MND New Zealand.

Whether you would like to take part or not is entirely your choice and your decision will not affect your future healthcare. If you do agree to take part, you can change your mind at any time and have your information removed from the Registry.

What do I have to do?

If you agree to participate, you will need to sign the consent form and return it to the registry curator, along with the registration questionnaire. In the questionnaire, you will be asked for some personal details, such as your age and ethnicity, and some information about your disease. The Registry will also collect some of your medical information and any genetic testing results, if they have been done.

You may wish to complete the questionnaire with the help of your doctor or MND support worker. If you are not sure of the answer to any question, please discuss with your doctor, MND support worker, or the registry curator. The registry curator can approach your doctor on your behalf to clarify the answer to any question, if required.

You will be requested by the registry curator to update your clinical records once per year. We also request that you contact the registry curator if your contact details change or there are major changes in your clinical condition.

What happens to the information I provide?

The information you provide will be stored securely and confidentially on computers at the New Zealand Motor Neurone Disease Registry office at Auckland City Hospital and the office of The Australian Motor Neuron Disease Registry, at Geelong Hospital, Barwon Health in Victoria, Australia.

Each participant's record is coded and their data is stored only under this code. Only the Principal Investigator, Registry Curator and co-investigators specifically employed to help with curation will be able to link your medical information to your personal information, using this code. No unauthorised people will be able to gain access to any information about you. Researchers worldwide who have been approved by their own local ethics committee and by the New Zealand Motor Neurone Disease Registry will only be given access to anonymised data.

Your data will never be made available to employers, governmental organisations, insurance companies, educational institutions or to a family member or doctor.

If a clinical trial, or other research study is identified for which you might be eligible, the registry will de-code the data to find your personal details and contact you directly. If you are interested in the research, you can contact the study organiser directly. Your name or other personal details will not be given to researchers. Belonging to the registry does not mean you have to participate in any research. You are free to make your own decision about whether or not to participate on a case by case basis, and you may wish to discuss this with your family/whānau or your doctor.

From time to time there will be international collaborations which include anonymised data from multiple international databases. These may include for example, collaborations where the factors that influence the progression of disease are explored, or responses to pharmaceutical companies wanting to know in general terms how many people are trial ready for their drugs. In these cases, amalgamated and anonymised data, including yours, may be shared internationally with overseas collaborators. All steps to preserve your anonymity will be taken.

In accordance with New Zealand law, you have the right to access the information collected and stored about you at any time. If you would like to access your information, please contact the registry curator, or Dr Roxburgh.

Who do I contact for further information?

If you would like to ask any questions about the Registry, please contact:

Dympna Mulroy
Curator
NZ Motor Neurone Disease Registry
Ph: 0800 MND REGISTRY (0800 663734)
Email: mndregistry@adhb.govt.nz

Dr Richard Roxburgh
Principal Investigator
NZ Motor Neurone Disease Registry
Ph: 021 896-662
Email: RichardR@adhb.govt.nz

If you want to talk to someone who isn't involved with the Registry, you can contact an independent health and disability advocate on:

Phone: 0800 555-050
Fax: 0800 2 SUPPORT (0800 2787-7678)
Email: advocacy@hdc.org.nz

If you require Māori cultural support, talk to your whānau in the first instance. Alternatively, you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning:
09 486-8324 ext 2324

If you have any questions or complaints about the Registry you may contact the Auckland and Waitematā District Health Boards Maori Research Committee or Maori Research Advisor by telephoning:
09 486-8920 ext 3204

This Registry has been approved by the New Zealand Health and Disability Ethics Committee (HDEC). Ethics reference number 17NTA28. You can contact the HDEC on:

Phone: 0800 4 ETHICS
Email: hdec@moh.govt.nz