NEW ZEALAND MND REGISTRY

Te Whatu Ora Health New Zealand

# New Zealand Motor Neurone Disease Registry

# Consent Form

**Requesting an interpreter**

| | | | |
|---|---|---|---|
| English | I wish to have an interpreter | Yes | No |
| Maori | E hia hia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero | Ae | Kao |
| Cook Island | Ka inangaro au i tetai tangata uri reo | Ae | Kare |
| Fijian | Au gadreva me dua e vakadewa vosa vei au | Io | Sega |
| Niuean | Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu | E | Nakai |
| Samoan | Ou te mana'omia se tasi e auai e fa'amatalaina upu I le gagana Samoa | Ioe | Leai |
| Tokelaun | Ko au e fofou ki he tino ke fakaliliu te gagana Peletania kin a gagana o na motu o te Pahefika | Ioe | Leai |
| Tongan | Oku ou fiema'u ha fakatonulea | Io | Ikai |
| Other | Interpreter required | Yes | No |

**Please tick to indicate you consent to the following**

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.

I have been given sufficient time to consider whether or not to participate in this Registry.

I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the Registry.

I am satisfied with the answers I have been given regarding this Registry and I have a copy of this consent form and information sheet.

I understand that taking part in this Registry is voluntary (my choice) and that I may withdraw from the Registry at any time without this affecting my medical care.

I consent to the research staff collecting and storing and sharing my information, in the manner described above, including information about my health from my medical records held by my GP and the hospital system.

Where relevant I specifically give permission to collection regarding genetic tests that I have had

I agree to an approved auditor appointed by the New Zealand Health and Disability Ethic Committees, or any relevant regulatory authority or their approved representative reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for this Registry.

I understand that my participation in this Registry is confidential and that no material, which could identify me personally, will be used in any reports on this Registry.

| | | |
|---|---|---|
| I know who to contact if I have any questions about the Registry in general. | | |
| I understand my responsibilities as a participant. | | |
| **Optional questions:** | | |
| If I decide to withdraw from the Registry, I agree that the information collected about me up to the point when I withdraw may continue to be processed. | Yes ☐ | No ☐ |
| I would like my GP to be informed of my participation in this Registry | Yes ☐ | No ☐ |

**Declaration by participant:**

I hereby consent to take part in this Registry.

Participant's name:

| | |
|---|---|
| Signature: | Date: |

**Declaration by member of research team:**

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the Registry and has given informed consent to participate.

Researcher's name:

| | |
|---|---|
| Signature: | Date: |

Please return to the Registry Curator:

Email: mndregistry@otago.ac.nz

Post: NZ MND Registry
Otago Medical School
Department of Medicine
PO Box 56
Dunedin 9054
New Zealand

# Participant Contact Details

Please complete the form below to help us to locate your medical information. Please return this form along with your signed consent form.

**I am: (please tick as appropriate)**

☐ The participant

☐ The participant's representative

**Participant's personal details:**

| | | | |
|---|---|---|---|
| First Name: | | | |
| Middle Name(s): | | | |
| Surname: | | | |
| Date of Birth: | | | |
| Sex (please circle): | Male | Female | |
| Ethnicity (circle as many as required): | New Zealand European | Maori | Cook Island Maori |
| | Tongan | Niuean | Chinese |
| | Indian | Other (please state): | |
| Address: | | | |
| | | | |
| | | | |
| | | | |
| Email Address: | | | |
| Home Phone: | | | |
| Mobile Phone: | | | |
| NHI Number (if known): | | | |
| GP Name: | | | |
| GP Practice Name: | | | |

Please turn over

**Please choose one of the following:**

- ☐ I have been diagnosed with MND
- ☐ I have a family member with MND
- ☐ I have had a positive genetic test for an MND related gene, but have not been diagnosed
- ☐ Other (please specify): _____

_____

**Do you see a neurologist or other specialist privately or publicly? (please tick)**

- ☐ Privately
- ☐ Publicly

| | |
|---|---|
| Type of specialist seen: | |
| Name of specialist or location of neurology department: | |

**How did you hear about the NZ MND Registry?**

- ☐ From my neurologist
- ☐ From my MND New Zealand Support Advisor
- ☐ From information MND New Zealand supplied
- ☐ Other (please specify): _____

_____

**Are you also a client of the MND New Zealand Support Team Service?**

- ☐ Yes
- ☐ No

**If you are the participant's representative and completing this form on their behalf, please provide your full details:**

| | |
|---|---|
| Full Name: | |
| Address: | |
| | |
| | |
| Email: | |
| Phone: | |
| Relationship to participant: | |