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 study.

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

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

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study 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 the study.

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

I know who to contact if I have any questions about the study in general.		
I understand my responsibilities as a study participant.		
Optional questions:		
If I decide to withdraw from the study, 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 study	Yes ☐	No ☐

Declaration by participant:

I hereby consent to take part in this study.

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 study and has given informed consent to participate.

Researcher's name:

Signature:	Date:

Please return to the Registry Curator:

Email: MNDRegistry@adhb.govt.nz

Post: Dympna Mulroy
NZ MND Registry
Neurology Department
Auckland City Hospital
Private Bag 92024
Auckland 1142

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 NZ Support Worker
- ☐ From information MND NZ 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:	