

The New Zealand Neuromuscular Disease Registry CONSENT FORM

- I have read and I have understood the New Zealand Neuromuscular Disease Registry 'Participant / parent Information Sheet dated Nov. 2012 (v4)'. I have had the opportunity to discuss this information and I am satisfied with the answers I have been given.
- I understand that taking part in this registry is voluntary (my choice) and that I / my child may withdraw from the registry at any time and this will in no way affect my medical care.
- I understand that my participation / my child's participation in this registry is confidential and that no material which could identify me / my child will be used in any subsequent reports.
- I consent to my / my child's registration in the New Zealand Neuromuscular Disease Registry. Yes No
- I consent to my / my child's information being transferred in a form identifiable only by a code to the relevant global registry. Yes No
- I consent to my / my child's genetic test results being held with my clinical and personal information in the registry for the purpose of research and planning of clinical trials. Yes No
- I consent to the registry curator reviewing my / my child's medical notes to obtain information relevant to this registry Yes No
- I would like to be informed about a clinical trial for which I / my child would be eligible. Yes No
- I consent to my GP being informed of my participation in this registry. Yes No
- I agree to be contacted by the curator once a year to ensure my / my child's clinical details and contact details remain up to date. Yes No

REQUESTING AN INTERPRETER

English	I wish to have an interpreter.	Yes	No
Maori	E hiahia 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
Samoaan	Ou te mana'omia se tasi e auai e fa'amatalaina upu i le gagana Samoa	loe	Leai
Tokelaun	Ko au e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika	loe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai
Other	Interpreter required	Yes	No



Signature of participant

Date

Signature of parent/guardian

Date

(Required if the participant is a child 15 years old or younger)

First name:

Family name:

Address:

Telephone:

Email:

Project explained by _____

Title (e.g MDA fieldworker, GP, Neurologist etc)

Signature _____ Date _____

Interpreter

I _____ translated the project to the participant

Signature _____ Date _____

Registration form for the NZ NMD Disease Registry

[Generic Data]

Thank you for agreeing to participate in the New Zealand Neuromuscular Disease Registry. Please ensure you have read the participant information sheet and signed the consent form. To complete your registration you will need to fill in this form and return this form. You may like to complete it with the assistance of your doctor or MDA fieldworker. Alternatively, if you are not certain about the answer to any question please discuss this with the registry curator.

I am: (please tick as appropriate)

<input type="checkbox"/>	The participant
<input type="checkbox"/>	The participant's representative

All of the following questions relate to the participant's with the condition

1. Participant's personal details:

First name (s):			
Family Name:			
Sex:	Male / female		
Date of birth:	/ / (dd / mm / yyyy)		
Ethnicity (Do you identify yourself as – please circle the one that is most appropriate)	NZ European	Maori	Samoan
	Cook Island Maori	Tongan	Niuean
	Chinese	Indian	Other
NHI number:			
Address			
Postcode:			
Email:			
Home Phone:			
Mobile:			

2. Please provide the name of your GP below giving us permission to contact your GP directly if we require further information to complete your registration.

GPs Full name:	
Medical Practice Address	
Email:	
Medical Practice Phone:	

3. If you are the participant's representative (parent/guardian), please provide your details:

Full name:	
Address	
Email:	
Phone:	
Relationship to participant	

4. What is your diagnosis, according to your doctor? If you have had a genetic test please include a copy of your test result.

	Charcot-Marie-Tooth disease
	Congenital muscular dystrophy or myopathy
	Facioscapulohumeral Muscular Dystrophy
	Friedrich's Ataxia
	Limb-Girdle Muscular Dystrophy
	Myasthenia Gravis
	Myotonic Dystrophy
	Spinocerebellar Ataxia
	Hereditary Spastic Paraplegias
	Other (please specify):

Checklist – please ensure the following items are returned to the registry curator

	Signed consent form
	Copy of genetic test result or
	Name and address of doctor who ordered genetic test
	Registration form (this form)

Thank you for completing this form if you have any questions please do not hesitate to contact the Registry Curator email NZNMDRegistry@adhb.govt.nz or ph / txt 0274688044