

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 (Version 3.0). 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 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 consent to my medical record being accessed for the purpose of this study 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>I wish to have an interpreter.</i>	Yes	No
Maori	<i>E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero.</i>	Ae	Kao
Cook Island	<i>Ka inangaro au i tetai tangata uri reo.</i>	Ae	Kare
Fijian	<i>Au gadreva me dua e vakadewa vosa vei au</i>	lo	Sega
Niuean	<i>Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.</i>	E	Nakai
Samoan	<i>Ou te mana'omia se tasi e auai e fa'amatalaina upu i le gagana Samoa</i>	loe	Leai
Tokelaun	<i>Ko au e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika</i>	loe	Leai
Tongan	<i>Oku ou fiema'u ha fakatonulea.</i>	lo	Ikai
Other	<i>Interpreter required</i>	Yes	No



Signature of participant

Date

Signature of parent/guardian

Date

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

Participant's

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 Neuromuscular 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 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)

	The participant
	The participant's representative (parent/ guardian)

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

1. Participant's personal details:

First name(s):			
Family name:			
Date of birth:	/	/	(dd / mm / yyyy)
Sex:	male / female		
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 the participant's diagnosis? If you have had a genetic test please include a copy of your genetic test result.

	Duchenne or Becker muscular dystrophy
	Spinal muscular atrophy
	Limb-Girdle Muscular Dystrophy
	Facioscapulohumeral Muscular Dystrophy
	Myotonic Dystrophy
	Congenital Muscular Dystrophy
	Charcot-Marie-Tooth Disease
	Myasthenia Gravis
	Friedreich's Ataxia
	Spinocerebellar Ataxia
	Hereditary Spastic Paraplegias
	Other (please specify):

Checklist – please ensure the following items are returned in the pre-paid envelope provided 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 in calling the Curator of the registry on 0800 800 337 or **815 0247** if you live in the Auckland area or email registry@mda.org.nz.