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
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 ki na gagana o na motu o te Pahefika	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai
Other	Interpreter required	Yes	No

First name: ______________________________ **NHI:** _ _ _ _ _ _ _

Family name: ______________________________ **Date of birth**:_ _ / _ _ / _ _ _ _

Address: ______________________________

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Telephone: ______________________________

Email: ______________________________

Signature of participant Date

______________________________________ ____________________

Signature of parent/guardian Date
(Required if the participant is a child 15 years old or younger)

______________________________________ ____________________

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

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. The information you provide on this registration form will help us to complete your enrolment. If you have any questions please do not hesitate to contact the Registry Curator email NZNMDRegistry@adhb.govt.nz or ph / txt 0274688044

I am: (please tick as appropriate)

	The participant
	The participant's representative

All of the following questions relate to the participant with the neuromuscular 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:	

NZNMD REGISTRY

TREAT-NMD Neuromuscular Network

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.

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

Checklist – please ensure the following items are returned to the registry curator.
Scan and email to nznmdregistry@adhb.govt.nz or
Post to NZ NMD Registry, Neurology, Auckland City Hospital, Private Bag 92024, Auckland 1142

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