

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 the 22nd March 2011 (Version 2.0). 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 notes 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

Circle one

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 tetahi 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
Samoa	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 fiemaʻu 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 _____

Project role _____

Signature _____ Date _____

Interpreter

I _____ translated the project to the participant

Signature _____ Date _____