

Pūnaha Io – the New Zealand Neuro-Genetic Registry & BioBank Consent Form

Request for interpreter:

English	I wish to have an interpreter.	Yes	No
Deaf	I wish to have a NZ sign language interpreter	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhakamāori/ kaiwhaka pākeha korero.	Ae	Kao
Cook Island	Ka inangaro au I tetai tangata rui reo.	Ae	Kare
Fijian	Au gadreava me dua e vakadewa vosa vei au.	Io	Sega
Niuean	Fia manako au ke fakaaoga e taha tagata kakahokohoko kupu.	E	Nakai
Samoan	Ou te mana’o ia I ai se fa’amatala upu.	Ioe	Leai
Tokelauan	Ko u e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika.	Io	Hēai
Tongan	Oku ou fiema’u ha fakatonulea.	Io	Ikai

Declaration by participant / parent/guardian:

I, _____ have read and I have understood the Pūnaha Io New Zealand Neuro-genetic Registry & BioBank participant / parent/guardian information sheet (v.5; October 2023).

I have had the opportunity to discuss this information and I am satisfied with the answers I have been given.

DATA

Core parts of this study:

I understand that taking part in this registry is voluntary (my choice) and that I / my child may withdraw from Pūnaha Io – the New Zealand Neuro-Genetic Registry BioBank at any time, and this will in no way affect my / my child’s medical care.

I understand that my / my child’s participation in this study 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 enrolment in Pūnaha Io - the New Zealand Neuro-Genetic Registry & BioBank.

I consent to my / my child’s genetic test results being held with my clinical and personal information in the Registry at Te Whatu Ora – Auckland City Hospital for the purpose of research and planning of clinical trials.

I consent to the study coordinator reviewing my / my child’s medical notes to obtain information relevant to this study.

I agree to be contacted by the Pūnaha Io study coordinator once a year to ensure my / my child’s clinical details and contact details remain up to date.

I consent to my / my child’s information being transferred anonymously or in a form identifiable only by a code, to NZ and international research studies including relevant global registries.

I consent to the study staff approaching me to inform me about clinical trials or research opportunities for which I / my child would be eligible.

I have been given a copy of the Participant Information Sheet and Consent Form to keep.

Optional parts of this study:

Please consider and understand each of the following before making your selection. You are able to change your mind and change your selection at any time.

I consent to my GP being informed of my / my child’s participation in this registry.	Yes	No
I consent to participate in the collection of my family history information	Yes	No

BIOSAMPLES

I / my child are willing to give biological samples.	Yes	No
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If Yes:

Core parts of this study:

I understand that my / my child's biological samples will be processed and stored at Te Ira Kāwai – the Auckland Regional Biobank.

I understand that the samples may be shared with researchers in a de-identified manner, for the purpose of future biomedical research.

I understand that such research will require separate ethics approval and that the decision whether to share de-identified samples rests with the Pūnaha Io Access Committee and the Te Ira Kāwai Scientific Advisory Board.

I consent to the study staff approaching me to inform me about research opportunities where my / my child's biological samples might be used in a potentially identifiable way and that I can choose at that time whether to take part in such a study.

Optional parts of this study:

Please consider and understand each of the following before making your selection. You are able to change your mind and change your selection at any time.

I consent to my / my child's samples being used for research overseas	Yes	No
Types of samples: I consent to give biological samples collected from me / my child in a non-invasive procedure (e.g. saliva, tears, urine and faeces)	Yes	No
I consent to give biological samples collected from me / my child in a minimally invasive procedure (e.g. blood draw, or cells collected by swab)	Yes	No
I consent to being contacted to discuss cerebrospinal fluid (CSF) / muscle / skin tissue donation)	Yes	No
I consent to share samples sourced from past clinical procedures that are currently stored and surplus to clinical requirements (e.g. DNA / CSF / muscle / nerve / skin) taken from me / my child	Yes	No
I consent to share samples sourced from future clinical procedures which are surplus to clinical requirements (e.g. DNA / CSF / muscle / nerve / skin) taken from me / my child	Yes	No

Participant's NHI: _____

Participant's birthdate: _____

Participant's name: _____

Participant's signature: _____

Date signed: _____

Print Name of parent / guardian: _____

Signature of parent / guardian: _____

Relationship to patient: _____

Date signed: _____

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant/ parent/guardian, and have answered the participant/ parent/guardian's questions about it.

I believe that the participant/ parent/guardian understands the study and has given informed consent to participate.

Researcher's name: _____

Signature: _____

Date signed: _____