**Pūnaha Io Neuro-genetic Research Bank**

**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 |
| Tokulauan | Ko u 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 |

**Declaration by participant / parent/guardian:**

I, \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ have read and I have understood the Pūnaha Io New Zealand Neuro-genetic Research Bank participant / parent/guardian information sheet (September 2020 v1).

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 Pūnaha Io New Zealand Neuro-genetic Research Bankat 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 New Zealand Neuro-genetic Research Bank.

I consent to my / my child’s information being transferred in a form identifiable only by a code to the relevant global registry.

I consent to my / my child’s genetic test results being held with my clinical and personal information in the registry at the Auckland DHB 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 study coordinator once a year to ensure my / my child’s clinical details and contact details remain up to date.

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

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

|  |  |  |
| --- | --- | --- |
| 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. | Yes | No |
| 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 |
| I would like to nominate the following person to consider consent on my behalf in the eventuality that I’m unable to do so: | | |
| I am willing to be contacted to discuss muscle / nerve / skin tissue donation | Yes | No |
| I am willing to be contacted, in the future, to discuss post mortem tissue (brain) donation | Yes | No |
| I consent to give blood samples that may be processed and  stored for future research and shared with other researchers for the  purpose of biomedical research | Yes | No |
| I consent to give urine samples that may be processed and  stored for future research and shared with other researchers for the  purpose of biomedical research | Yes | No |
| I consent to give cerebrospinal fluid (CSF) samples that may be processed and stored for future research and shared with other researchers for the  purpose of biomedical research | Yes | No |
| I consent to give samples of previously collected muscle / nerve / skin tissue so that they may be processed and stored for future research and shared with other researchers for the purpose of biomedical research | Yes | No |

Participant’s NHI: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Participant’s name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Participant’s signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Print Name of parent / guardian: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature of parent / guardian: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Relationship to patient: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**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: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_