Department of Women's and Children's Health
Te Tari Hauora Wāhine me te Tamariki
Clinical Genetics Research Group

Genetics of Developmental Disorders

CONSENT FORM – NON-NEW ZEALAND PARTICIPANT

Full Name: _____

I have read and understood the information sheet about this study, and I understand what is involved. ..... **YES / NO**

I understand that I will be given a copy of the Information Sheet to keep. ..... **YES / NO**

I have been given the opportunity to discuss this study and to ask questions about it. I am satisfied with the answers I have been given. ..... **YES / NO**

I understand that taking part is voluntary and I am free to withdraw at any time and for any reason ..... **YES / NO**

I understand that my participation in this study is confidential and that if any information that could identify me will be used in any reports on this study, my consent for this step will be obtained separately. ..... **YES / NO**

I am aware that this study will involve potentially extensive analysis of my genetic makeup. ..... **YES / NO**

I am aware that this genetic analysis may produce unexpected results of potential health significance that are unrelated to the research into developmental disorders. ... **YES / NO**

I agree to being notified of any additional findings of health significance should they be identified ..... **YES / NO**

I consent to providing up to 20ml of blood/skin biopsy for this study ..... **YES / NO**

I am aware that the study will store and examine my DNA (genetic make-up) for this research project and I consent to such analysis being performed..... **YES / NO**

If yes, I consent to the samples being stored until the conclusion of Professor Robertson's research programme but only used for uses which I consent to..... .**YES / NO**

I understand that if I consent to such analysis, no rights will be created for the researcher to my genetic information..... **YES / NO**

I agree to complete questionnaires about my medical history and have my physician release relevant related details to the study investigators ..... **YES / NO**

I consent to being contacted in the future to ask about participating in related studies **YES / NO**

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I consent to my DNA sample and clinical data being retained for later use as part of research with other international research collaborators (subject to approval by a NZ Ethics Committee)..... **YES / NO**

I consent to my DNA sample being sent overseas for analysis ..... **YES / NO**

I understand that I can request to have my/my child's DNA sample destroyed at any time **YES / NO**

I, _____ (print full name), hereby consent to taking part in this study.

Signature: _____ Date: _____

Consent obtained by:

Staff signature: _____ Date: _____

Staff name: _____

Declaration by Referring Clinician

I am aware that this research has been authorised by the New Zealand Health and Disbility Ethics Committee. I am satisfied that the participation of this subject falls within the ethical standards required of my own locality. A copy of the ethics committee application and consent is available on request.

Signature of Consenting Geneticist.....

Date.....