



## N. Z. Cardiac Inherited Diseases Registry Consent Form Blood Test / Storage

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English:	I wish to have an interpreter.	Yes	No
Maori:	E hiahia ana ahau kitetahi tangata hei korero Maori ki ahau.	Ae	Kao
Samoan:	Oute mana'o e iai se fa'amatala upu.	loe	Leai
Tongan:	'Oku fiema'u ha fakatonulea.	lo	Ikai
Cook Island:	Ka inangaro au I tetai tangata uri reo.	Ae	Kare
Niuean:	Fia manko au ke fakaaoga e tagata fakahokohoko vagahau.	E	Nakai

- i. I / we understand the Cardiac Inherited Disease Registry may collect a **blood sample** and this sample may be **stored and or used** for diagnostic/research analyses aimed at gene identification/diagnosis of **my / our or our child/spouse/parents'**, specific Cardiac Inherited disease.
- ii. I / we understand that the Cardiac Inherited Disease Registry **may send my/our or our child/spouse/parents'** sample to an International Research or Diagnostic facility in order that it may conduct research/ or attempt to provide a diagnoses on **my/our or our child/spouse/parents'** behalf into the cardiac inherited disease that specifically affects myself or my/our family member.
- iii. I / we understand that it may take many months/or years to establish a diagnosis.
- iv. When the blood sample is no longer required for the specific testing or research it was intended for, I / we would like it to be **either**:  destroyed **or**  returned to me / us **or**  retained in storage for up to 20 years in case further diagnostic testing or research based analysis is required. (**Tick one box only**)

**If testing cannot be undertaken at this time a sample may be stored until such time as testing is available to you/your family member.**

- v. If testing is not currently available for my / our or our child/spouse/parents' condition we choose to have a DNA sample stored for up to 20 years. The sample will not be tested until I / we consent to it being tested. I / we understand that we can request this sample be returned / destroyed.  (**Tick if you choose to store a sample at this time.**)

**Test Results:**

- 1) I / we choose to be **informed** of the results of my/our or our child/spouse/parent tests when and if they become available.  
 (**Tick the box if you wish to be informed of the results when they are available**)
- (Or)**
- 2) I / we choose **not to be informed** of the results of my/our or our child/spouse/parent tests if and when they become available.  
 (**Tick the box if you do not wish to be informed of the results when they are available.**)
- 3) I nominate the following person to be advised of my results if anything should happen to me before my test results become available (*applies only to living adults consenting for genetic testing or long term storage of DNA*).  
Name: \_\_\_\_\_ DOB: \_\_\_\_\_ Relationship: \_\_\_\_\_
- 4) I / we would like the following health care providers to be informed of the results of my tests when and if they become available. (**tick those who you wish the results to be sent to**): *Note this can be decided at the time the results are given to the family*  
General Practitioner    Specialist Cardiologist/Paediatrician: \_\_\_\_\_

**After considering the information provided and taking my /our time to make the decision, I / we agree to take part in the Cardiac Inherited Disease Registry.**

Participant Name (print): \_\_\_\_\_ Sign \_\_\_\_\_ Date: \_\_\_\_\_  
(Participant is the person who is being tested for the condition. If the participant is deceased their name is still printed in this column.)

Parent / Guardian (if under 16yrs) or NOK: \_\_\_\_\_ Sign: \_\_\_\_\_ Date: \_\_\_\_\_  
(Next of kin must provide consent if the participant is deceased)

Lead Clinician/Registry Co-ordinator  
Name \_\_\_\_\_ Role: \_\_\_\_\_ Date \_\_\_\_\_

**The N.Z Cardiac Inherited Disease Registry has received Ethical Approval from the N.Z. Multi-centre Ethics Committee: AKX/02/00/107**