SUBSTITUTE CONSENT: GENETIC/GENOMIC TESTING
Guardianship Act 1987 (For patients 16 years and above where consent is provided by a person responsible)

This form is accompanied by an Information Booklet: “Genetic/Genomic Testing”.
Please read the Information Booklet prior to completing this Consent Form. Genetic File No. ______________________

PROVISION OF INFORMATION TO PERSON RESPONSIBLE  To be completed by the Health Care Professional
(where required please indicate by a tick in the □)

I Dr. __________________________ confirm that __________________________ is incapable of consenting to genetic testing
because: □ he/she cannot understand the nature and effect of the testing or □ he/she cannot indicate whether he/she consents.
The patient’s condition that indicates the requirement for genetic testing is: __________________________
I have provided the Person Responsible with the Privacy Leaflet for Patients of NSW Health Genetics Services and the
Information Booklet: “Genetic/Genomic Testing”.
I have discussed testing for the gene fault for __________________________ using panel gene testing and/or genomic testing.
insert name of condition
I confirm that I have discussed the likely results, risks, benefits and procedures involved in genetic/genomic testing and the
storage and use of blood/tissue/DNA for approved medical research.
The Person Responsible has had an opportunity to seek further information regarding the genetic/genomic testing and
appropriate explanations have been provided.
Name of Health Care Professional __________________________ Designation __________________________
Signature of Health Care Professional __________________________________ Date ____/____/____
Interpreter present: □ Yes □ No
Name of Interpreter __________________________ Accreditation Number (where relevant) __________________________
Signature of Interpreter __________________________ Date ____/____/____

PERSON RESPONSIBLE CONSENT  To be completed by Person Responsible
(where required please indicate by a tick in the □)

(A) TESTING AND RESULTS
I understand that:
• The patient’s blood/tissue sample will be used to test DNA for a gene fault involved in this condition;
• The test result may have implications for the health care of the patient’s genetic (blood) relatives;
• There are a number of possible result outcomes from the testing (see Information Booklet for explanation):
  - A positive result
  - A result of uncertain significance
  - An uninformative result
  - A benign result
  - An incidental finding

In regard to incidental findings:
• I understand that the laboratory will report the incidental finding to the patient’s doctor who ordered the test and an
  assessment will be made of the clinical significance of the result. Only incidental findings which are assessed to be of clinical
  significance will be available to be returned to the Person Responsible.
• I understand that a clinically significant incidental finding may have implications for the patient’s genetic relatives’
  health.
  a) I wish to be informed about clinically significant incidental findings due to gene faults that cause or make the patient
  /the patient’s genetic relatives to be at increased risk for (please choose ONE option):
  □ All known genetic conditions (regardless of whether the condition is currently treatable or preventable); OR
  □ Only those genetic conditions that may be treated or prevented or where knowledge of the genetic condition can
  result in other health benefits;
  b) I wish to be informed about genetic carrier results (see Information Booklet for explanation):
□ Yes □ No

NO WRITING
**Facility:**

<table>
<thead>
<tr>
<th>FAMILY NAME</th>
<th>MRN</th>
<th>GIVEN NAME</th>
<th>□ MALE</th>
<th>□ FEMALE</th>
<th>D.O.B. / /</th>
<th>M.O.</th>
<th>ADDRESS</th>
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</thead>
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**SUBSTITUTE CONSENT:**

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(Complete all details or affix patient label here)

(Where required please indicate by a tick in the □)

**B) STORAGE**

I understand that the patient’s identified DNA or blood/tissue sample will remain the property of the laboratory and will be stored for a minimum period of time determined by laboratory practice, legal and ethical requirements. I understand that re-testing may occur without my further consent.

**C) CONFIDENTIALITY**

1. The patient’s genetic health information can be released to relevant health professionals involved in the care of the patient’s genetic relatives:
   - Yes
   - No

   Notwithstanding your response above, in accordance with the Health Records and Information Privacy Act 2002 (NSW), genetic information can be used and disclosed without consent in order to lessen or prevent a serious risk to the life, health or safety of a genetic relative no further removed than third degree; and, only where the disclosure is made in accordance with the guidelines issued by the Information and Privacy Commission NSW http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/IB2014_065.pdf.

2. In the event of my death, the next ‘Person Responsible’ for the purposes of the Guardianship Act will be notified of the test results.

**D) RESEARCH**

1. The patient’s identified DNA sample and health information may be used and stored for health and medical research approved by a recognised health research ethics committee:
   - Yes
   - No

2. My contact details may be shared with researchers for contact in regard to future approved research projects:
   - Yes
   - No

**E) CONFIRMATION**

- I have read the Information Booklet or someone has read it to me in a language that I understand;
- I understand the potential benefits, potential consequences and limitations involved in the testing and storage of this sample;
- I have had an opportunity to discuss the information, ask questions and have any concerns addressed and I am satisfied with the explanations and answers to my questions;
- I understand that genetic counselling will be available for me, the patient’s family and the patient’s genetic relatives;
- I understand that I can withdraw my consent at any stage by contacting the patient’s doctor;
- I understand that information from genetic testing can have implications for obtaining or renewing some forms of insurance such as life or income insurance.

**SUBSTITUTE CONSENT**

I consent to genetic testing for __________________________ I have considered the views of __________________________ and consider the testing should be provided to the patient. I am satisfied the testing will promote the health and wellbeing of the patient.

__________________________     _____________________________________________
Signature of Person Responsible     Print name of Person Responsible     Date

________________________________________________________________ (Relationship to Patient in terms of the Act)

________________________________________________________________
Address of Person Responsible