CONSENT: GENETIC/GENOMIC TESTING
(For patients 14 years and above - not for Guardianship Act purposes)

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 PATIENT To be completed by the Health Care Professional

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

I confirm the patient has been provided 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.
I confirm that I have discussed the likely results, risks and procedures involved in genetic/genomic testing and the storage and use of blood/tissue/DNA for approved medical research.
The patient 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 _______ / _______ / _______

PATIENT CONSENT To be completed by Patient

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

A) TESTING AND RESULTS

I understand that:

- My blood/tissue sample will be used to test my DNA for a gene fault involved in this condition;
- My test result may have implications for the health care of my 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 my 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 patients.
- I understand that a clinically significant incidental finding may have implications for my/my genetic relatives’ health.

a) I wish to be informed about clinically significant incidental findings due to gene faults that cause or make me/my 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; OR
  - None at all regardless of whether the genetic condition is potentially treatable/ preventable.

b) I wish to be informed about genetic carrier results (see Information Booklet for explanation):
  - Yes ☐ No ☐
**CONSENT:**

**GENETIC/GENOMIC TESTING**

(For patients 14 years and above - not for Guardianship Act purposes)

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(Where required please indicate by a tick in the [ ])

**B) STORAGE**

I understand that my 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.

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**C) CONFIDENTIALITY**

1. My genetic health information can be released to relevant health professionals involved in the care of my 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 test results may be made known to:

   a) Relevant health professionals involved in my care and the care of genetic relatives

      - [ ] Yes  [ ] No;

   b) A nominated individual

      - [ ] Yes  [ ] No;

      If yes please provide contact details of nominated individual:

      Name: __________________________ Address: ______________________________________________________

      Telephone/mobile: ___________ Email: ________________________

**D) RESEARCH**

1. My 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, my family and my genetic relatives;
- I understand that I can withdraw my consent at any stage by contacting my 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.

___________________________  ____________________________  _______ / _____ / ______
Signature of Patient                                               Print name of Patient                                                Date