CONSENT:
GENETIC/GENOMIC TESTING
(For parent/guardian of patients less than 16 years)

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 PARENT/GUARDIAN To be completed by the Health Care Professional
(where required please indicate by a tick in the )

I confirm the parent/guardian 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 insert name of condition 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 parent/guardian 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 ________/______/__________

PARENT/GUARDIAN CONSENT To be completed by Parent/Guardian
(where required please indicate by a tick in the )

(A) TESTING AND RESULTS

I understand that:

• My child’s blood/tissue sample will be used to test my child’s DNA for a gene fault involved in this condition;

• My child’s test result may have implications for the health care of my child’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 my child’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 parent/guardians of patients.

• I understand that a clinically significant incidental finding that is currently treatable or preventable in childhood will be reported to me.

• I understand that a clinically significant incidental finding may have implications for the health of my child’s genetic relatives.

Incidental findings involving adult onset conditions and genetic carrier results.

a) I wish to be informed about clinically significant incidental findings due to gene faults that cause or make my child/my child’s genetic relatives to be at increased risk for (please choose ONE option):

☐ All known genetic conditions that do not onset until adulthood (regardless of whether the condition is currently treatable or preventable); OR

☐ Only those genetic conditions that do not onset until adulthood 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
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(please indicate by a tick in the )

(B) STORAGE

I understand that my child'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. My child's genetic health information can be released to relevant health professionals involved in the care of my child'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, this consent is no longer valid and a new consent will be obtained from my child’s legal guardian.

(D) RESEARCH

1. My child'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, my child and my child’s genetic relatives;
✓ I understand that I can withdraw my consent at any stage by contacting my child’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.

___________________________     _____________________________________________
Signature of Parent/Guardian                                Print name of Parent/Guardian                                         Date