This form is accompanied by an Information Booklet: "Diagnostic, predictive and genetic carrier DNA 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: "Diagnostic, predictive and genetic carrier DNA testing".

For ______________________________________________________________________________________________

I have discussed:

- Diagnostic testing: when a gene fault has not yet been found in any other family member.
- Predictive testing: when a gene fault has already been found in another family member.
- Genetic Carrier testing: to identify individuals who carry a gene fault that will usually not have health implications for their health.

I confirm that I have discussed the likely results, risks and procedures involved in genetic 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 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 depending on the test type that is being done (see Information Booklet for explanation):
  a) Diagnostic Test - when a gene fault has not yet been found in any other family member
     - A positive result
     - An uninformative result
     - Results of uncertain significance where one or more gene changes are found, but it is not clear what they mean.
  b) Predictive test: when a gene fault has already been found in another family member
     - A positive result
     - A negative result
  c) Genetic Carrier test: to identify individuals who carry a gene fault that will usually not have implications for their health
     - A positive result
     - A negative result
Facility:

<table>
<thead>
<tr>
<th>FAMILY NAME</th>
<th>MRN</th>
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<tr>
<td>GIVEN NAME</td>
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<td>M.O.</td>
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<td>ADDRESS</td>
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**CONSENT:**
DIAGNOSTIC, PREDICTIVE AND GENETIC CARRIER DNA TESTING
(For parent/guardian of patients less than 16 years)

Complete all details or affix patient label here

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**(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.

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**(C) CONFIDENTIALITY**

1. My child’s 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, this consent is no longer valid and a new consent will be obtained from my child’s legal guardian.

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**(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

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**(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.

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Signature of Parent/Guardian __________________________ Print name of Parent/Guardian __________________________ Date ______/_____/______