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 PERSON RESPONSIBLE

(To be completed by the Health Care Professional)

(name of patient) confirm that _________________________ because:

- he/she cannot understand the nature and effect of the testing
- 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: “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 Person Responsible 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 _______ / _______ / _______

PERSON RESPONSIBLE CONSENT

(To be completed by Person Responsible)

I understand that:

- The patient’s blood/tissue sample will be used to test the patient’s DNA for a gene fault involved in this condition;
- The patient’s 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 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
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**SUBSTITUTE CONSENT: DIAGNOSTIC, PREDICTIVE AND GENETIC CARRIER DNA TESTING**  
Guardianship Act 1987 (For patients 16 years and above where consent is provided by a person responsible)  

(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 insert name of condition insert name of patient 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

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NO WRITING