

## INFORMED CONSENT/ASSENT FOR MOLECULAR GENETIC TESTING OF A MINOR FOR AN ADULT ONSET DISORDER

**Patient Name** \_\_\_\_\_ **Date of Birth** \_\_\_\_/\_\_\_\_/\_\_\_\_ **Sex**  F  M  
**Condition/Gene** \_\_\_\_\_  
**Symptoms**  No  Unknown  Yes (please describe) \_\_\_\_\_

- The National Society of Genetic Counselors and the American College of Medical Genetics and Genomics encourage deferring predictive genetic testing of minors for adult-onset conditions when results would not impact the child's medical management or significantly benefit the child. Predictive testing should be offered after age 18 to allow individuals to consider their circumstances, preferences and beliefs and to preserve their autonomy and right to an open future.
- Parental anxiety or desire to know a child's genetic status does not outweigh a child's right to make his/her decision in adulthood when fully informed of the risks and benefits.
- Participation in genetic testing is completely voluntary. Genetic counseling is recommended prior to and following genetic testing. See [www.nsgc.org](http://www.nsgc.org) or [www.acmg.net](http://www.acmg.net) to find a medical genetics professional.
- There may be psychological responses to receiving genetic test results. Positive results may cause feelings of depression or anxiety. Inconclusive results may cause frustration. Negative results may provide relief.
- Results from genetic testing may be positive, negative or inconclusive.
  - A positive result may confirm whether a person is affected with, a carrier of, or at risk for developing a genetic condition.
  - A negative result does not exclude the possibility of being affected with or a carrier of a genetic condition. Genetic conditions may have many causes, some of which may not be completely known or testable.
  - An inconclusive result may occur due to limitations of laboratory methods, limitations in knowledge of the meaning of identified variant(s), or poor sample quality.
- Identified genetic variants are interpreted using current information in the medical literature and scientific databases. Since this information can change, ARUP Laboratories may issue a revised report if the meaning of a variant changes. Individuals with a variant of uncertain significance should contact their healthcare provider periodically to determine whether new information is available.
- Genetic testing may provide information that was not anticipated, such as:
  - Identifying a genetic risk unrelated to the original reason for testing.
  - Predicting another family member has, is at risk for, or is a carrier of a genetic condition.
  - Revealing non-paternity (the person stated to be the biological father is not, in fact, the biological father).
- Although DNA testing usually yields precise information, several sources of error are possible. These include, but are not limited to, clinical misdiagnosis of the condition, sample misidentification, and inaccurate information regarding family relationships.
- If a genetic variant is identified, insurance rates, the ability to obtain disability and life insurance, and employability could be affected. The Genetic Information Nondiscrimination Act of 2008 extends some protections against genetic discrimination (<http://www.genome.gov/10002328>). All test results are released to the ordering healthcare provider and those parties entitled to them by state and local laws.
- Because ARUP Laboratories is not a storage facility, most samples are discarded after testing is completed. Some samples may be stored indefinitely for test validation or education purposes after personal identifiers are removed. All New York samples are discarded 60 days following test completion. You may request disposal of your sample by calling ARUP at (800) 242-2787 ext. 3301.
- In cooperation with the National Institutes of Health's effort to improve the understanding of specific genetic variants, ARUP submits HIPAA-compliant, de-identified (cannot be traced back to the patient) genetic test results and health information to public databases. Confidentiality of each sample is maintained. You may choose not to share your test result by calling ARUP Laboratories at (800) 242-2787 x3301. Your de-identified information will not be shared with public databases after the request is made, but a separate request is required for each genetic test. For more information, see [www.aruplab.com/genetics](http://www.aruplab.com/genetics).

**Patient/Legal Guardian** My signature below indicates that a qualified health professional explained the benefits, risks, and limitations of genetic testing to my satisfaction and I desire predictive genetic testing for myself (or my minor child).

Minor's Printed Name	Signature	Date
Legal Guardian's Printed Name	Signature	Date

**Physician/Genetic Counselor** I have explained DNA testing and its risks, benefits and limitations to this minor child and his/her legal guardian and believe he/she desires testing.

Physician/Genetic Counselor Printed Name	Signature	Date
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