

**GENETIC TESTING CONSENT FORM**

For the purposes of this form, "Provider" may reference a provider or genetic counselor.

After speaking with my provider, I understand the following:**Purpose of the test**

The purpose of this test (Test Name: _____) is to find genetic changes that might be associated with general health or these specific health problem(s): _____

Other documents provided: _____

The test results may not change anything about my current or future medical care. Or, the results may help to

- diagnose my disease
- make treatment decisions
- give me and my provider more information about my condition or health

About the testing:

- The test will look for genetic changes by using samples of my blood, saliva or other tissue(s).
- A special lab will focus on certain genes related to the reason for testing. There may be some genes that cannot be fully tested or tested at all. My provider explained how well this test will work for the reasons it is being done.
- There may be new discoveries in the future about the results of gene testing. So, what is known today about the test results may change over time.

Possible test results:

- The results may find these things related to the reason for the test:
 - Meaningful genetic changes. Some of these changes may indicate risk for additional medical problems that are part of a larger genetic condition.
 - No meaningful genetic changes.
 - Uncertain genetic changes.
- The results may also find meaningful genetic changes not related to the reason for testing.

Potential risks and limitations of genetic testing:

- No genetic test can look for all genetic conditions.
- There may be a genetic cause for a medical condition, even if testing doesn't find one.
- There are laws that help to protect against discrimination based on genetic information by employers and most health insurance companies. Some results may impact the ability to get life insurance, disability insurance, or long-term care insurance.
- Genetic testing can result in unanticipated findings such as:
 - Information about family relationships that were not known, like adoption or discovering that someone is not a biological relative.
 - Genetic changes that are believed to have medical importance but are unrelated to the original reason(s) for undergoing testing. These are often called 'incidental' or secondary findings. For some types of testing, you may be asked if you would like to know about these results.

Who has access to the results and my health information:

- My health care provider may share my health information with the testing laboratory to help the lab interpret my results.
- The results of my genetic testing will be in my health record, just like other medical tests. I understand that they may be shared now or in the future with healthcare providers involved in my care.
- The hospital may need to share information about this test and the results with health insurance companies for payment purposes.
- Genetic testing results with personal identifiers removed may be shared with external databases to improve our understanding of how genetic changes cause disease.

Access to genetic counseling:

- Genetic counseling services are available to talk with me about testing options, explain genetic findings and how these tests might affect me and my family. These services can be found within the Mass General Brigham’s system at: <https://tinyurl.com/PartnersGCs>. Your provider can assist you in identifying the appropriate counseling services for your needs.

My signature below means that:

- I read and understand the information on this form.
- The information on this form has been explained to me.
- All my questions and concerns have been addressed by my provider.
- I agree to provide blood or other samples for testing.
- If my samples are not at this hospital, I agree that the hospital can get them from other institutions for testing.
- I understand that I can have a copy of this form after signing.

Date: _____ Time: _____ AM/PM _____
Patient/Surrogate Decision Maker

Print Name: _____

For provider:

The following was used to assist in the consent process:

- Interpreter – Name/ Number: _____
- Decision Aid – Version: _____
- Genetic counseling assistant/other consenting provider – Name: _____

I attest that I discussed with the patient all relevant aspects of this testing, including the indications, risks, and benefits, as compared with alternative approaches, and answered any questions.

Date: _____ Time: _____ AM/PM _____
Signature Healthcare Provider

Print Name: _____