

Genomic DNA Test FAQs (Frequently Asked Questions)

Information About the Genomic DNA Test

1. How do I know if I am eligible to have this testing?

You are eligible if:

- You are at least 18 years old.
- You receive your primary care from a UVM Health Network Family Medicine provider.
- You or your partner are *not* currently pregnant. Other tests are more appropriate for screening during pregnancy. This test is not designed for screening during pregnancy. There are more appropriate genetic screening tests to choose when you are pregnant. Talk to your health care provider about tests designed to screen for recessive disease risk during pregnancy.
- You are part of the OneCare Vermont Accountable Care Organization (ACO), a care coordination and quality improvement organization. You can find out if you are part of OneCare Vermont ACO by asking your primary care Family Medicine provider.

2. My friend, who is not part of the OneCare Vermont ACO, is interested. Can they get the test?

This initial testing phase is open only to adults who are part of the OneCare Vermont ACO. We hope to expand testing in the future.

3. What is the cost to be tested?

The Genomic DNA Test is free of charge. There is also no charge for genetic counseling visits at the UVM Health Network Genomic Medicine Resource Center. If you need to have any follow-up testing, specialist visits, or you need to use genetic counselors not employed by the Genomic Medicine Resource Center, your insurance will be charged and you may have an insurance copay.

4. What are the benefits of this test for me and my family?

The Genomic DNA Test results will only include DNA differences that we know are medically important. Potential benefits include:

- This test may identify genetic causes of a health problem, or show increased risk of certain diseases for you that also could be a risk for your family members. This may help your health care provider recommend certain approaches that will keep you as healthy as possible. Some examples are:
 - Results might show a genetic cause for high cholesterol; your provider may prescribe cholesterol-lowering medicine that decreases your chance of an early heart attack or stroke.
 - Results might show a risk of heart and liver damage due to abnormal iron storage in your body; your provider can help you lower your iron levels.
 - Results might show an increased risk for certain cancers; your provider can plan for early detection and more successful treatment, and suggest other options to lower your risk.
- If a genetic health risk is identified, testing will be offered to family members who may also have inherited the risk.

- The test results may empower you to take steps to lower your chances of developing or passing on a serious disease.
- You may use this information to help make informed choices about your future family. This test can detect if you are a “carrier” of certain genetic conditions that could affect your children or other family members. The risk to your children depends on whether your partner is also a carrier of the same genetic condition. The test does not identify all carriers, but a negative test lowers the chances that you are a carrier.
- You may also learn you have decreased risks for some genetic disorders.

5. What information is not available with this test?

- This test cannot tell you everything about inherited diseases.
- A positive result does not always mean you will develop a disease. Additionally, because genetic testing cannot identify all the potential causes for changes to genes, a negative test does **not** mean that you have no risk of developing a genetic condition.
- This test cannot be used to determine your ancestry.

6. How will I be tested?

This test uses a small blood sample, about two teaspoons. The blood can be drawn at the same time you are having other blood tests, or by itself.

7. What are the risks of this test? How will my privacy be protected?

You should weigh the risks and the benefits before agreeing to have this test. Risks include:

- Unexpected information may be uncovered by your Genomic DNA Test. We will focus on what is most useful to you. However, situations such as non-paternity, adoption, and unexpected risks or diagnoses could be revealed when your information is reviewed in combination with genetic information from other family members.
- Genetic testing can have an emotional impact on you and your family, especially when a DNA difference predicting a serious disease is revealed. Genetic counselors are here to help you process your emotions and understand your options.
- Some people are concerned about the privacy of their genetic information. Since this test is a clinical test, the results will be stored in your health record and are protected by health information privacy laws including the Health Insurance Portability and Accountability Act (HIPAA).
- During the consent process, you will have the opportunity to discuss the risks of having your genetic information stored in your health record, the laws that currently prohibit genetic discrimination, and their limitations.

8. Can my insurance company or my employer use my genetic test results against me?

- The Genetic Information Nondiscrimination Act (GINA) is a federal law that protects you from discrimination in employment and health insurance decisions. GINA does not apply to long-term care, disability, or life insurance, so there are no Federal protections for those types of insurance. Also, if you have or have had medical diagnoses, health insurers can use that information in their decisions regardless of genetic test results. For more information, see <https://www.genome.gov/about-genomics/policy-issues/Genetic-Discrimination> and <http://ginahelp.org/>.
- If you are a service member in the military, the protections in GINA do not apply. You have protections other than GINA that focus on ensuring readiness. See <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5685294/> for more information.
- Vermont laws also prohibit the use of genetic information in employment [even small employers], membership in a labor organization, professional licensure, certification, or registration. See <https://legislature.vermont.gov/statutes/chapter/18/217> for more information. If you move to another state, that state's protections may differ.

9. Will you call me to request that I have this test done?

No, UVM Health Network will never call you to ask you to get this test. Testing is only arranged through your primary care provider. (Robo-calls or unannounced visits asking you to do a genetic test and stating it is covered by Medicare are a **scam**. See https://www.consumer.ftc.gov/blog/2019/07/medicare-does-not-give-out-dna-kits?utm_source=govdelivery

10. If I change my mind after the testing process has started can I withdraw?

After your blood has been drawn and sent for testing, it is not possible to stop the process. However, if you have concerns or questions after the testing process has started, please contact us at DNAtest@uvmhealth.org

11. What if I decide I don't want to have the test done?

UVM Health Network and your primary care providers will continue to provide you with high-quality care, whether or not you decide to have this test.

12. What if I still have questions about this test?

If you have questions at any time in the process, please contact UVM Health Network Genomic Medicine Resource Center by phone at **(802) 847-8135** or by email at DNAtest@uvmhealth.org

13. What is the informed consent process for, and why is it important?

The informed consent process helps you learn about the Genomic DNA Test and our program so you have the information you need to make a decision about having the test. If you decide to have the test, you will be asked to sign a form describing the test to confirm that you understand the education and genetic counseling provided and that you agree to proceed.

The signed consent form will go into your medical record. You should not sign the form if you do not understand the test education, if you do not agree to be tested, or if you do not want the test results.

Receiving Results and Genetic Counseling

14. How long after I give my blood will my results be available?

In most cases, portions of the results will be available within a month. However, we do not promise to have your results available within a specific time period. Portions of the results may be reported on different dates.

In addition, as our knowledge in this field grows, we may update your test results in the future. From time to time, you and your health care provider may request updates that may be important for your medical care.

15. How will I receive my tests results and what will happen next?

The UVM Medical Center genetics experts will receive your test reports when they are available. They will add the DNA test results to your medical record, so all providers who participate in your care will be able to read the report. We will notify your primary care provider and help them plan next steps.

Your primary care provider will contact you when your results are ready to review. You will meet with your primary care provider, speak with a genetic counselor, and/or possibly be referred to a specialist to learn more.

Genetic counselors from the UVM Health Network Genomic Medicine Resource Center will be available to meet with you by phone, by secure video (like online or smartphone video chat) or in person. The genetic counselor will add a summary of your conversation and recommendations to your medical record.

To clarify the current importance of any positive results, your primary care provider may recommend further medical testing for you. Genetics experts will guide your PCP in the appropriate steps.

If you have additional testing or are seen by a specialist following a positive result, your insurance will be billed and you may have a copay.

16. What does a negative test result mean?

A negative test result means that no DNA change was found that is known to be important for your health in the parts of your genome that we looked at. This can happen for several reasons, including:

- It is unlikely you have a risk for any of the genetic conditions detectable with this test.
- You could have a DNA change in a gene that was tested, but the change cannot be seen with the testing method used. No one form of genetic testing can find all changes in a gene.
- You could have a DNA change in a gene that was not tested. See the DNA Test Information Sheet for information about genes tested at this time.
- You could have a change in a gene that has not yet been discovered, or in one that is rarely changed in disease. We hope to increase the number of genes analyzed at a later date.

We cannot tell which of the above reasons explains your negative result. The most common reason is that you don't have a risk for the condition.

Only certain genes will be looked at in this test, so a negative test does *not* mean that you do not have any genetic risks or diseases. If you have a family history or medical symptoms of a genetic condition, please talk to the genetic counselor about it, and ask your provider if you should be seen by a genetic professional for further genetic counseling and testing.

17. What are genetic counselors and what are their roles in this Genomic DNA Test?

Genetic counselors are specially trained and certified genetic health professionals. They help you understand the genetic testing process, your genetic test results, and what they mean for you and possibly for your family members, including your children. For more information, see:

<https://www.nsgc.org/page/aboutgeneticcounselors>

- Before testing, genetic counselors can help you understand the test and its uses, and discuss the benefits, risks, and limitations of the Genomic DNA Test. They can walk you through the informed consent process.
- After testing, genetic counselors can explain your Genomic DNA Test results, answer your questions, suggest additional resources, and help you interpret your results in the context of your family health history. Their records also help your primary care provider and specialists take better care of you.

18. How do I meet with a genetic counselor?

- Genetic counselors at the UVM Health Network Genomic Medicine Resource Center can meet with you by telephone, video chat, or in person. This service is included with the free testing. Contact the Genomic Medicine Resource Center by phone at **(802) 847-8135** or by email at DNAtest@uvmhealth.org to arrange an appointment.
- If your Genomic DNA Test results identify a disease risk, your primary care provider may refer you to specialists at the UVM Medical Center, which may include in-person genetic counseling. Your insurance will be charged for these referral visits and you may have an insurance copay.

19. Can my genetic sequence be re-analyzed in the future when there is more knowledge about its medical value?

As we learn more information that helps us understand how your DNA differences may cause disease or disease risks, reviewing your DNA for new meaning over time might reveal new information about your health. We expect to do such a review about every two years after the initial result.

Contributing and Controlling My Health and Genomic Information for Research

20. Can I help medical researchers by sharing my DNA sequence and health information?

The DNA test discussed here is a clinical test, NOT a research test. That said, you may choose to share your information to support scientific research. Doing so can help grow the knowledge of how DNA differences relate to health and disease.

We have partnered with a patient-centered research database company, LunaDNA, which allows you to control the sharing of your genetic and health information and its use. LunaDNA will contact you to ask if you want to share your information securely. Deciding to share information with the LunaDNA database involves a separate consent process. Whether or not you participate in research is your choice.

To learn more, visit <https://learn.lunadna.com/uvmhn/>

Resources for More Information

21. Where else can I learn more about genomic tests, genetic diseases, research, and related topics?

Here are a few key online resources.

Genetic Home Reference:

<https://ghr.nlm.nih.gov/>

National Human Genome Research Institute:

<https://www.genome.gov/health/Genomics-and-Medicine>

National Society of Genetic Counselors:

<https://www.nsgc.org/>

Genetic Discrimination:

<https://www.eeoc.gov//laws/types/genetic.cfm>

<http://ginahelp.org/GINAhelp.pdf>

<https://www.genome.gov/about-genomics/policy-issues/Genetic-Discrimination>

<http://geneticalliance.org/advocacy/policyissues/geneticdiscrimination>

Genetic Alliance and LunaDNA partnership to engage everyone responsibly in research:

<http://geneticalliance.org/programs/biotrust/lunapeer>

Importance of Diversity in Human Genomic Medicine Research:

<https://www.genome.gov/news/news-release/Putting-diversity-front-and-center>