

Patient Genetic Testing Information for After Visit Summary

Genetic testing was discussed with you today, so you may find this background information helpful.

What is genetic testing?

- Genes are made up of DNA and provide the instructions for our body to function.
- Sometimes a person can have a variant in their DNA (also called a “mutation”) that increases their chance to develop a medical condition.
- Genetic testing, done on a blood or saliva sample, can look for these DNA mutations.

Why have genetic testing? Genetic testing may:

- Help your doctors make a diagnosis, understand your diagnosis better, and provide prevention, early diagnosis or treatment options based on *your* genes and DNA.
- Give you or your family members information about the chances of developing a medical condition, information that they may be able to act on to improve their health.

The results of genetic testing could be:

- **Positive:** A genetic variant or mutation was found which may increase your risk for a medical condition. This information may help determine a course of treatment or way to monitor your health.
- **Negative:** No genetic variant or mutation that affects your health was found in the genes that were tested.
- **Uncertain:** A genetic variant was found that the lab is not sure causes an increased chance of having a medical condition. This result is not used to guide clinical decision making at this time but may be if scientific developments discover more about the variant.

Risks and limits of genetic testing:

- There is a small risk for errors, such as incorrectly labeling a sample and technical problems.
- Even if a genetic diagnosis is not found, we cannot completely rule the diagnosis out. You might have a condition that was not tested for, not discovered yet, or that cannot be found with current technology. Not all genes are tested.

Privacy and protections for genetic test results:

- Genetic testing results will be made part of your medical record and are protected health information subject to privacy protections under HIPAA. For services provided in New Jersey, state law further limits disclosures that are permitted without patient consent.
The federal Genetic Information Non-discrimination Act (GINA) provides some protections against employment and health insurance discrimination based on genetic information but does not cover life, long-term care or disability insurance. The Affordable Care Act (ACA) protects against health insurance denial or premium increase based on pre-existing conditions.

Cost of testing:

- Genetic testing is usually billed to your insurance, just like any other medical lab or procedure.
- In many cases insurance fully covers the test. If there is a cost, it is usually less than \$100.
- You can contact the lab’s billing department if you have questions about billing and cost. The office ordering your genetic testing can let you know what lab to contact.

How will I get my results?

- In most cases your results will be delivered to you once available through the patient portal, unless you agreed to hold them until your provider has first reviewed. You may also hear from your provider directly about the results.