

WHAT YOU SHOULD KNOW about **GENETIC TESTING**



WHY IS GENETIC TESTING IMPORTANT?

This Toolkit is designed to help you understand **how genetic testing and counseling work** and understand the **benefits, risks, and limitations of both**. Genetic testing can help your doctor establish a diagnosis and inform your treatment.

Genetic testing can better help you **understand the cause of your disease**, which can help **make more informed choices** about how to manage your disease. Some of the risks associated with genetic testing are emotional and financial.

Genetic counselors are **certified medical professionals** trained to **assess risk for** a variety of **inherited conditions**, **educate families** about genetic disorders, and **coordinate genetic testing**.

Geneticists are physicians who specialize in genetics, and may perform a medical evaluation and/or order genetic testing when an individual is suspected to have a genetic disorder.



WHAT SHOULD I EXPECT?

When you meet with a genetic counselor, they will **assess your risk**, go through your **family history** with you, provide you with **general information** about the disease in question, and give you **logistical information** about genetic testing. Your genetic counselor will explain and advise whether genetic testing is right for you. **A meeting with a geneticist might also happen**, depending on the medical institution.

When the results are ready, **your genetic counselor will explain** your results. If your results are abnormal, you will have the opportunity to **learn more** about the **gene, disease** and **inheritance/risks** to family members. Results of your genetic testing **should be shared with your pancreatitis provider to discuss possible options about a treatment plan**. Your genetics provider may provide a **family letter** to help explain a genetic diagnosis to your relatives who may also be at risk for the genetic condition in question.

Be patient. Receiving results may take some time.

HOW CAN I GET GENETIC TESTING?

Your primary care provider, gastroenterologist, or pancreas specialist (if you are a pancreatitis patient) may be able to give you **a medical referral** to a genetic counselor. If you are insured, you can **contact your health insurance** company and ask them if there are medical geneticists or genetic counselors who participate in your plan.

Most private health insurers cover genetic counseling and testing, but the coverage may vary. Ask your insurance provider whether prior authorization is required to receive genetic testing and counseling. If you need help paying for care, organizations like the [Patient Advocate Foundation](#) offers **case managers who help in identifying financial assistance programs**.

QUESTIONS TO ASK A GENETIC COUNSELOR

It is normal to have questions before you get genetic testing. To help you prepare, here are some questions you can ask a certified genetic counselor.



About Testing

- Can genetic testing tell me for sure whether or not I have a particular condition?
- How is genetic testing done?
- How long will it take for me to receive the results?
- Who will give me my results and how will I receive them?
- Should I share my results with my family?
- Are there any disadvantages to getting genetic testing done?

About Future Care

- Could I face discrimination based on genetic information?
- How will a diagnosis affect my insurance?
- Where can I go for a second opinion?
- Are there any organizations that can help connect me with people affected with my condition?
- How can I learn more about this condition?

FIND A GENETICS PROVIDER*

- [Genetic and Rare Diseases Information Center's guide to finding specialists in specific genetic and rare conditions](#)
- [National Society of Genetic Counselors's searchable directory of genetic counselors in the United States and Canada](#)
- [American Board of Genetic Counseling's searchable directory of certified genetic counselors worldwide](#)
- [Canadian Association of Genetic Counselors's searchable directory of genetic counselors in Canada](#)
- [American College of Medical Genetics and Genomics's searchable database of medical genetics clinic services in the United States](#)

****Make sure the genetic counselor you choose specializes or has relevant experience in the disease you are interested in learning more about.***

References

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