

# 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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"Most Private Insurers Cover Genetic Testing for Inherited Mutations." Private Insurance Coverage of Genetic Services, <https://www.facingourrisk.org/support/insurance-paying-for-care/genetic-services/private-insurance.>

"Questions to Ask a Certified Genetic Counselor." American Board of Genetic Counseling, [https://www.abgc.net/about-genetic-counseling/questions-to-ask-your-counselor/.](https://www.abgc.net/about-genetic-counseling/questions-to-ask-your-counselor/)

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