

# Is Your Pancreatitis Genetic?

Your Family History is Important. Here's What You Should Know.

## WHAT CAN I DO WITH THIS TOOLKIT?

Certain people are at **higher risk of developing pancreatitis** and pancreas disease or **having their disease progress faster** based on their family medical history and/or ancestry. Use this toolkit to assess whether or not you might be at risk for pancreatitis or pancreas disease.

Your gastroenterologist or pancreas specialist might not be aware of all of the genetic drivers of pancreatitis. Use this **toolkit as a jumping off point** with your GI doctor. Talk to them about your family history and risk of pancreatitis using this toolkit, and discuss whether **ordering a genetic test** is the right option for you.

### Possible Risk Factors For Pancreatitis



**Check each box that applies to you and your family**, going back **three generations**. This means your parents, siblings, parent's parents (your grandparents), your parent's siblings (your aunts and uncles), and your parent's sibling's children (your first cousins)

- |   |  |
|---|--|
| <input type="checkbox"/> History of pancreatitis**  | <input type="checkbox"/> History of sinusitis                                    |
| <input type="checkbox"/> History of pancreatic cancer**   | <input type="checkbox"/> History of high triglycerides                           |
| <input type="checkbox"/> History of cystic fibrosis**   | <input type="checkbox"/> Ashkenazi Jewish ancestry                               |
| <input type="checkbox"/> History of male infertility**  | <input type="checkbox"/> Shared ancestry or family intermarriage                 |
| <input type="checkbox"/> History of other cancers   | <input type="checkbox"/> Sudden or unexplained death before old age              |
| <input type="checkbox"/> History of diabetes  | <input type="checkbox"/> History of high cholesterol                             |
| <input type="checkbox"/> History of autoimmune conditions (i.e. Hashimoto's, lupus, rheumatoid arthritis) | <input type="checkbox"/> History of chronic obstructive pulmonary disease (COPD) |

**\*\*The asterisked items are the most important risk factors when considering genetic pancreatitis.**



**Talk to your doctor** about a referral to a genetics provider

**Talk with your family:** Has anyone had genetic testing done? What were their results?

### Why Focus On Genetics?

In some cases, **pancreatitis is a genetic condition**, which means that a gene change or abnormality (also known as a mutation) occurs that increases the risk of disease.

Mutations in certain genes, like **PRSS1, CTRC, CPA1, CTSB, CEL, CFTR**, and **SPINK1**, may increase your risk of pancreatitis. Other genes might also play a role, but they are still being researched.

If your standard hereditary pancreatitis panel is negative, **there are other rare genetic disorders** (such as lipid metabolism disorders) that **increase the risk for pancreatitis**. Talk to your genetics provider about other possible causes for pancreatitis.

# 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 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.

## WHAT SHOULD I EXPECT?

### Genetic Counselors



Genetic counselors are certified medical professionals trained to assess the risk of inherited conditions, educate families about genetic disorders, and plan genetic testing.

### Geneticists



Geneticists are physicians who specialize in genetics, and can perform a medical evaluation and order genetic testing.

### When you meet with a genetic counselor, they will:

- Assess your risk
- Go through your family history with you
- Give you general information about the disease
- 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 can **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 for 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.

# What You Should Know About Genetic Testing

## HOW CAN I GET GENETIC TESTING?

Your primary care provider, gastroenterologist, or pancreas specialist 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 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**.

Learn about **financial assistance programs** at [mission-cure.org/pancreatitis-financial-assistance-resources/](https://mission-cure.org/pancreatitis-financial-assistance-resources/)

## 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

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

- [Genetic and Rare Diseases Information Center's](#) guide to finding specialists in genetic and rare conditions
- [National Society of Genetic Counselors's](#) searchable directory of genetic counselors (US 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 US