



What do genes have to do with breast cancer?

Why are genes important?

Our genes have a role in everything from the shape of our eyebrows to the way we laugh. They also affect other functions of our bodies, like when our cells grow, divide and die.

Every now and then, our genetic code changes. Sometimes these rare changes, known as mutations, happen during a person's lifetime. Sometimes they pass from parent to child (called an [inherited mutation](#)). Inheriting a gene mutation can also mean inheriting a higher risk of a disease like breast cancer.

The best-known genes linked to breast cancer are BRCA1 and BRCA2 (short for BReast CAncer genes 1 and 2). We all have these genes, but very few of us (about 1 in 400 people in the U.S.) have an inherited mutation in one or both. Women and men with a BRCA mutation have a higher risk of breast, ovarian and prostate cancer.

Having a BRCA mutation does not necessarily mean you'll get cancer. In fact, only 5 to 10 percent of breast cancers in the U.S. are due to inherited gene mutations. And not having a BRCA mutation does not guarantee you won't get breast cancer. Anyone is at risk.

So why worry about mutations? Because if you're one of those 1 in 400 people with a BRCA mutation, you have [a much higher risk of getting breast cancer](#). If you know you have a mutation, there are things you can do to take extra care of your breast health and reduce your risk of cancer.

Should I get tested for BRCA1 and BRCA2?

[Genetic testing isn't recommended for everyone](#). For example, if only one person in your family has had breast cancer and they were over 50 when they were diagnosed, you probably don't need testing.

If you have doubts about whether to get tested for a BRCA mutation, a doctor or genetic counselor can help you decide. You can use the [Know:BRCA tool](#) first to assess your risk and prepare to talk with your doctor. You can also answer these questions.

- Has someone in your family tested positive for a BRCA1/2 gene mutation, or any other inherited gene mutation that's linked to breast cancer?
- Have you had breast cancer and, if so, were you 45 or younger when you found out?

- If you have had breast cancer yourself (at any age), has anyone else in your family found out they had breast cancer at age 50 or younger?
- If you have had breast cancer yourself (at any age), have 2 or more members of your family had breast, pancreatic and/or aggressive prostate cancer?
- If you've had breast or pancreatic cancer, is there anyone of Ashkenazi Jewish descent in your family?
- Have you had triple negative breast cancer and, if so, were you 60 or younger?
- Have you or anyone in your family had ovarian cancer?
- Has a man in your family ever had breast cancer?
- Has anyone in your family found out they had breast cancer at age 45 or younger?

If you answered yes to one or more of these questions, your family could have a higher risk of a BRCA mutation. Talk to your doctor or a genetic counselor about next steps.

How does genetic testing work?

If you're thinking about getting tested for BRCA1/2, the first step is to meet with a genetic counselor. The counselor can help you decide if it makes sense for you to get tested right now.

If possible, the person with cancer should get tested first. If they test negative for the mutation, other family members don't need testing. If they test positive, a genetic counselor can help figure out who else in the family should be tested.

Here's a step-by-step preview of how genetic testing works:

STEP 1: You meet with a genetic counselor and provide personal health information, including your [family health history](#).

STEP 2: The counselor explains how your family health history and other factors may affect your risk. You'll be able to discuss things like:

- the risks and benefits of genetic testing
- your rights relating to privacy and discrimination
- costs and resources for financial assistance
- how to deal with the potential knowledge that you carry a gene mutation and how it can affect your family
- what you will do with the information once you know the test result

STEP 3: If you decide to proceed, a sample of blood or saliva will be taken.

STEP 4: The sample will be sent for testing. It usually takes 3 weeks to get results.

STEP 5: The genetic counselor will review and explain the results.

FAQs about genetic testing

1. How much does genetic testing cost?

If you have health insurance and your doctor recommends genetic counseling and testing, the Affordable Care Act requires your plan to cover it. However, insurance providers have different policies about which tests they cover. If you plan to get genetic testing covered by your insurance, [get in touch with your insurance provider](#) first to confirm what's covered.

If you have to pay out of pocket, genetic testing can cost hundreds or even thousands of dollars. The good news? Genetic testing companies and labs often have programs to help with cost based on income. A genetic counselor should be able to help you find an affordable way to get tested.

2. Where can I get genetic testing?

If you're interested in testing, the first thing to do is meet with a genetic counselor. Your doctor should be able to refer you to one. You can also search the directories of the [National Cancer Institute](#) or the [National Society of Genetic Counselors](#) for a counselor in your area.

3. Can I use one of those at-home genetic testing kits?

Genetic testing in the privacy of your own home? Interest in at-home (a.k.a. direct-to-consumer) genetic testing is growing.

The pros: It's simple. A test kit is mailed to you and usually involves collecting a saliva sample from the inside of your cheek. You send the sample back for analysis and will get the results by mail, phone or online. At-home testing may be the most affordable option if you don't have insurance or don't want to involve your insurance company.

The cons: The process of genetic testing is complex. Without guidance from a doctor or genetic counselor, at-home testing can result in incomplete testing or incorrect information.

If you want to try direct-to-consumer genetic testing, [the Federal Trade Commission \(FTC\) recommends you:](#)

- Talk with a doctor or genetic counselor about whether it would be useful—and, if so, which test is best for you. You should also discuss the benefits and limits of this type of testing.
- Discuss your results with a doctor or genetic counselor. They can help you make informed decisions about screening tests and any risk-lowering options that may be right for you.
- Understand how your personal information is protected. Make sure you know how the company uses your information, how it protects the information it collects and whether it shares your information with others.

4. Could my test results be used to discriminate against me?

It's totally reasonable to have concerns about fair treatment based on the results of a genetic test. There are state and federal laws that protect you. The Genetic Information Nondiscrimination Act (GINA) prevents health insurers from denying someone coverage or charging them more

money because of genetic testing results. It also protects employees from unfair treatment at work. GINA doesn't guard against all discrimination, but it means the law is on your side when it comes to insurance and employment. It doesn't affect life insurance or disability insurance providers.

5. How can I learn more about this?

The [National Cancer Institute](#), the [National Society of Genetic Counselors](#), and [Know:BRCA](#) all provide more detail about BRCA1/2 and genetic testing in general. Facing Our Risk of Cancer Empowered (FORCE) has [information on their website](#) and gives personalized guidance through [their free Helpline](#) (1-866-288-7475). You can [call Susan G. Komen's free Helpline](#) 1-877 GO KOMEN (1-877-465-6636) if you have questions or concerns about breast cancer. You can also email them at helpline@komen.org.



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