

In the Genes: How Black Communities May Benefit From Genetic Counseling & Testing



Today, Black women are not offered genetic testing as often as white women. In fact, sometimes the tests are not offered at all to Black women. This is not ok.

It's important to know about genetic testing and how it may help you and your family. And that's where genetic counseling can help. Talk with your doctor if you feel you may be at high risk due to a personal or family history of breast or other cancers. Ask about genetic counseling. It's important to advocate for yourself.

Why? The results of genetic testing can help determine breast cancer risk and can help plan treatment if diagnosed. If you're at risk of breast cancer, there are options now that can help lower this risk.



What do genes have to do with breast cancer?

Let's go back to the basics. Every cell in your body is made up of genes. They contain the code for things like your eye color or skin color. They also affect how the cells in your body grow, divide and die. Changes in these genes are called genetic mutations. They can be harmful, helpful or have no effect. And they can be passed from parent to child. When this happens, it's called an inherited gene mutation.

Certain inherited gene mutations, like *BRCA1* or *BRCA2* gene mutations, increase the risk of breast, ovarian and other cancers. But having one doesn't mean you'll get breast cancer. Some people with a mutation never get breast cancer. Your doctor and a genetic counselor can help you decide if genetic testing is right for you based on your personal and family health history.

What is genetic testing?

Genetic testing looks for the most common changes, or mutations, in your genes linked to breast cancer using a blood or saliva sample. The most common tests look for *BRCA1/2* gene mutations. Other tests, called expanded panel or multi-gene testing, look for other less common gene mutations.

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Why should Black families consider genetic counseling and testing?

- People with a gene mutation are more likely to have triple negative breast cancer (TNBC), an aggressive breast cancer. Younger Black women and those with *BRCA1* gene mutations may be more at risk of TNBC.
- Men can pass gene mutations to their children. They can also get breast cancer themselves. So, that's why it's important to share information about inherited gene mutations with the men in your lives.

What is genetic counseling?

Genetic counseling is a discussion with an expert in genetics. It can help determine whether genetic testing could give you useful information about your risk of breast and other cancers.

A **genetic counselor** can:

- Help you decide if genetic testing is right for you.
- Discuss the benefits and risks of genetic testing for you.
- Help explain the results of the genetic test and help you make informed decisions on next steps.
- Help inform you of the risk of breast cancer so you and your doctor can talk about ways to reduce your risk or plan treatment if diagnosed with breast cancer.

If you and your doctor think a genetic counselor could help you decide if genetic testing is right for you, they can refer you to a genetic counselor. If there's not one close to you, contact the **National Cancer Institute** or the **National Society of Genetic Counselors**. They can refer you to a center near you with counselors on staff.

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Resources:

Susan G. Komen®

1-877 GO KOMEN
(1-877-465-6636)

komen.org/genetic-testing
[My Family Health History](#)



Facing Our Risk of Cancer Empowered, Inc. (FORCE)

1-866-824-7475
facingourrisk.org

National Cancer Institute

1-800-4-CANCER
cancer.gov

National Society of Genetic Counselors, Inc.

1-312-321-6834
nsgc.org



Am I protected from discrimination if I get genetic testing?

As you're probably aware, there's a history of discrimination, mistrust and injustices with the health care system negatively impacting the Black community. As a result, you may be fearful about getting tested. Fortunately, there are state and federal laws in place to protect you.

The [Genetic Information Nondiscrimination Act \(GINA\)](#) prevents insurers from denying coverage or charging higher premiums for a person with an increased genetic risk of cancer. It also protects people from unfair treatment by employers.



How much do genetic tests cost?

Check with your health insurance company to see if the test is covered. If you have a plan that began on or after August 1, 2012, the Affordable Care Act (ACA) requires genetic testing be covered when recommended by a doctor. It also requires coverage of genetic counseling before testing. If you don't have insurance, call the [Susan G. Komen Breast Care Helpline at 1-877 GO KOMEN \(1-877-465-6636\)](#) for information and resources.



Should I use an at-home genetic test?

At-home, or direct-to-consumer genetic tests, can be misleading. There are concerns about at-home tests because:

- There may be errors in the results.
- Testing can be incomplete.
- They often test only for a few of the many gene mutations related to breast cancer.

Before taking any action based on these test results, a genetic test at a certified lab is recommended. **Your doctor or a genetic counselor can arrange this testing for you.**