GENETICS AND BREAST CANCER

Who should consider genetic testing?

Talk to a doctor or genetic counselor to see if a genetic test is right for you. Genetic testing is only recommended for people at high risk, including those with:

- A family member with a *BRCA1/2* gene mutation (or other mutation linked to breast cancer)
- A personal or family history of breast cancer at age 45 or younger
- A personal history of breast cancer at any age and a close family member with breast cancer at age 50 or younger
- A personal or family history of ovarian cancer, pancreatic or metastatic prostate cancer at any age

Go to komen.org/genetictesting for more information on genetic counseling, testing and test results.

What are genes?

Every cell in your body is made up of genes. Genes contain the blueprints (genetic code) for your body. Genes have the code that decides things like the color of your eyes. They also affect other functions, such as how the cells in your body grow, divide and die.

Changes in the genetic code are called 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.

Genes and breast cancer

The best-known genes linked to breast cancer are *BRCA1 and BRCA2* (Breast Cancer genes 1 and 2). Everyone has these genes.

Some people have an inherited mutation in one or both of these genes though. Having a *BRCA1/2* gene mutation increases the risk of breast and ovarian cancer. But, having a *BRCA1/2* mutation doesn't mean you'll get breast cancer. Some people with a mutation never get breast cancer. And, people without a mutation are still at risk.

Most breast cancers in the U.S. are not caused by inherited mutations. About 5-10 percent of breast cancers in these women are due to inherited mutations.

What about men?

Men can also carry *BRCA1/2* and other inherited mutations. They can pass them on to their children.

Men with a *BRCA2* mutation have an increased risk of breast cancer. Up to 40 percent of breast cancers in men may be related to *BRCA2* mutations.

Men who have a B*RCA1* mutation may also have an increased risk of breast cancer.

Are you of Ashkenazi Jewish descent?

In the U.S., about 1 in 400 people in the general population have a *BRCA1/2* gene mutation.

- However, about 1 in 40 Ashkenazi Jewish people have one of these mutations.
- About 10 percent of Ashkenazi Jewish women in the U.S. with breast cancer have a *BRCA1/2* mutation.

For more information, visit komen.org or call Susan G. Komen's breast care helpline at 1-877 GO KOMEN (1-877-465-6636) Monday through Friday, 9 AM to 10 PM ET.

Resources

Susan G. Komen®
1-877 GO KOMEN
(1-877-465-6636)
komen.org/genetictesting

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

Related educational resources:

- Breast Cancer & Risk
- Types of Breast Cancer Tumors
- Clinical Trials
- Risk-Lowering Options for Women at Higher Risk of Breast Cancer
- Questions to Ask Your Doctor: Inherited Genes & Breast Cancer Risk

Testing for multiple gene mutations (expanded panel testing)

In the past, breast cancer genetic tests only checked for mutations in *BRCA1/2* genes. Now, it's common to check for other gene mutations. This is called expanded panel or multi-gene testing.

Direct-to-consumer genetic testing (at-home genetic testing)

Direct-to-consumer (DTC) genetic testing allows a person to get tested at home. This means they don't have to involve a doctor or insurance company.

There are concerns about DTC tests:

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

Wait to act on any results from a DTC test. Have the findings confirmed by genetic testing in an approved lab certified by the Clinical Laboratory Improvement Amendments (CLIA).

Cost of genetic tests

Check with your health insurance to find out if you're 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 have a mutation that increases breast cancer risk, the ACA also requires coverage of counseling on risk reduction options. This can help you decide if things like taking medications to lower your risk are right for you.

If you can't afford testing, there are programs that may help.

Protection from discrimination

Some people may worry about being treated unfairly based on the results of a genetic test. State and federal laws help protect you. The Genetic Information Nondiscrimination Act (GINA) prevents health 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.

Where can I get genetic testing?

If you want to learn more about your breast cancer risk and genetic testing, talk with your doctor. Your doctor can refer you to a genetic counselor. If your doctor is not aware of one close to you, contact the National Cancer Institute or the National Society of Genetic Counselors (see resources links). They can refer you to a center near you with counselors on staff. They can also provide more detail about *BRCA1/2* and genetic testing.