



FACTS FOR LIFE

Genetics and Breast Cancer

What are genes?

Every cell in your body contains genes. Genes contain the blueprints (genetic code) for your body. For instance, they contain the code that decides the color of your eyes. They also affect other functions of your body, such as when cells grow, divide and die. Changes in the genetic code are called mutations. Mutations are rare. Some can be passed on from parent to child (inherited).

Genes and breast cancer

The best-known genes linked to breast cancer are *BRCA1* and *BRCA2* (Breast Cancer genes 1 and 2). While everyone has these genes, some have an inherited mutation in one or both. Having a *BRCA1/2* gene mutation increases the risk of breast and ovarian cancer. However, having a *BRCA1/2* mutation does not mean you will get breast cancer. Some people with a mutation will never get breast cancer. And, people without a mutation are still at risk.

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

Who should consider *genetic testing*?

A doctor or genetic counselor can help you decide if a genetic test is right for you. Genetic testing is only recommended for certain people, such as those with:

- A personal history of breast cancer at age 45 or younger;
- A personal history of breast cancer at any age and a family member diagnosed with breast cancer at age 50 or younger;
- A personal or family history of ovarian cancer.

What about men?

Men can also carry *BRCA1/2* and other inherited gene mutations and can pass them on to their children. Men with a *BRCA2* mutation have an increased risk of breast cancer and prostate cancer.

Men who have a *BRCA1* 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* mutation. However, about 1 in 40 Ashkenazi Jewish men and women have one of these mutations.

About 10 percent of Ashkenazi Jewish women in the U.S. diagnosed with breast cancer have a *BRCA1/2* mutation.

Testing for multiple gene mutations (panel testing)

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

The steps to genetic testing

STEP 1: If you have questions about mutations or genetic testing, talk with your doctor. It is strongly recommended you speak with a genetic counselor before being tested.

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.

STEP 2: Pre-test counseling will be done to help you decide whether testing is right for you. This includes discussing:

- risks and benefits, such as cost, privacy and the potential knowledge that you carry a gene mutation
- what you will do with the information once you know the test result
- the emotional impact of this information and how it may affect your family

STEP 3: A sample of your blood will be drawn for the test if you decide to proceed.

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

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

Cost of genetic tests

Check with your health insurance to find out if counseling and testing are covered. If you have an insurance plan that began on or after August 1, 2012, the Affordable Care Act (ACA) requires the test be covered when recommended by a doctor. It also requires coverage of genetic counseling before testing.

If you have a gene mutation that increases breast cancer risk, the ACA also requires coverage of counseling on risk reduction options. This can help you decide if taking medications to lower your risk is right for you.

At-home genetic testing

You may have seen ads for at-home genetic testing kits. These kits are not recommended to assess breast cancer risk and the U.S. Federal Trade Commission cautions against their use.

The results of any genetic test should be reviewed by a trained doctor or genetic counselor.

Protection from discrimination

Some people may be concerned about being treated unfairly based on the result of a genetic test. State and federal laws 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 breast cancer. It also protects employees from unfair treatment at work.

Where can I get genetic testing?

If you would like to learn more about genetic tests, talk with a doctor. A 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. They can refer you to a center near you with counselors on staff. They can also provide more detail about *BRCA1*, *BRCA2* and genetic testing.

Resources

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

Facing Our Risk of Cancer Empowered, Inc. (FORCE)
1-866-824-7475

National Cancer Institute
1-800-4-CANCER

National Society of Genetic Counselors, Inc.
1-312-321-6834

Related fact sheets in this series:

- Breast Cancer & Risk
- Types of Breast Cancer Tumors

The above list of resources is only a suggested resource and is not a complete listing of breast cancer materials or information. The information contained herein is not meant to be used for self-diagnosis or to replace the services of a medical professional. Komen does not endorse, recommend or make any warranties or representations regarding the accuracy, completeness, timeliness, quality or non-infringement of any of the materials, products or information provided by the organizations referenced herein.

The Running Ribbon is a registered trademark of Susan G. Komen®. © 2017 Susan G. Komen® Item No. KO0091 11/17