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 example, they contain the information that determines 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 that affect the function of the gene are called mutations. Some mutations occur during our lifetime and we don't know what causes them. Some mutations can be passed on from a parent to a child (inherited). Many inherited gene mutations have little or no effect on health (good or bad). Yet others can increase the risk of certain diseases, like breast cancer.

Who has mutations in BRCA1 and BRCA2?

Most women who get breast cancer do not have an inherited BRCA1 or BRCA2 gene mutation. The chance that you have a gene mutation is greater if one or more of the following are true:

- You had breast cancer at an early age
- Your mother, sister or daughter had breast cancer at an early age or ovarian cancer at any age
- A woman in your family has had breast and ovarian cancer
- A woman in your family has had breast cancer in both breasts
- Your family is of Ashkenazi Jewish descent
- A man in your family has had breast cancer

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, but some people have an inherited mutation in one or both of them. Having a BRCA1 or BRCA2 gene mutation increases a woman's risk of breast and ovarian cancer.

Most breast cancers are not linked to inherited gene mutations. Only about five to 10 percent of breast cancers in the U.S. are due to inherited gene mutations.

What about men?

BRCA gene mutations are not only found in women. Men can also carry these mutations and can pass them on to their children. Men with a BRCA2 mutation have an increased risk of breast cancer and may also have an increased risk of prostate cancer.

Can I find out if I have an inherited gene mutation?

Genetic testing for BRCA1 and BRCA2 mutations is widely available. Testing is recommended for certain people who have a high chance of carrying a mutation. This includes those with a strong family history of breast cancer. Your doctor or a genetic counselor (a trained expert who can gather your family health history) can help you decide if a genetic test is right for you. After the test, he or she can also explain the results. In most cases, the test is done first on the person with breast cancer. If no mutation is found, the cancer was not likely due to a mutation. So other family members do not need to be tested.

The process:

STEP 1: You will provide a thorough family health history. The counselor will explain how this history may impact your personal risk.

STEP 2: Pre-test counseling will be done to help you decide whether or not to proceed with the genetic test. This counseling includes:

- An overview of the procedure
- A review of the risks and benefits of genetic testing, such as cost, privacy and the potential knowledge that you carry a gene mutation
- A discussion of what you will do with the information once you know the test result
- A discussion of the emotional impact of this information and how this can 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 three weeks to get results.

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

Cost of genetic tests

Check with your health insurance provider to find out if the costs of genetic counseling and testing are covered in your plan. If you have an insurance plan that began on or after August 1, 2012, the Affordable Care Act (ACA) requires coverage of these costs (when prescribed by a doctor). If you have a BRCA1 or BRCA2 gene mutation, the ACA also requires coverage of counseling to help you decide if taking medications to lower the risk of breast cancer 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. The U.S. Food and Drug Administration, U.S. Federal Trade Commission and Centers for Disease Control and Prevention all caution against the use of at-home testing kits. The results of any genetic test should be reviewed by a trained health care provider or genetic counselor.

Protection from discrimination

Some people are 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 to 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. 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. These organizations may be able to provide additional information:

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

American Cancer Society
1-800-ACS-2345
www.cancer.org

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

National Cancer Institute
1-800-4-CANCER
www.cancer.gov

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

Related fact sheets in this series:

- Breast Cancer Risk Factors
- Types of Breast Cancer Tumors
- What is Breast Cancer?