National Cancer Institute

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Genetic Testing for Breast and Ovarian Cancer Risk

It's Your Choice

Genetic Testing for Breast and Ovarian Cancer Risk

Breast cancer is the second most common form of cancer and the second leading cause of cancer deaths for American women. Each year, more than 210,000 women in the United States learn that they have breast cancer.

It's your choice.

Some kinds of cancer, such as breast and ovarian cancer, seem to run in families. There is a test that may tell some people if they are at risk for breast, ovarian, and other cancers. Before getting tested, though, there are many factors you should consider.

This booklet will give you an overview of testing for breast and ovarian cancer risk. This information may also apply to risk of other cancers. It describes the advantages and disadvantages of this kind of testing. It also gives basic medical terms to help as you talk with your doctor or other health care professionals trained in genetics.

Who is at higher risk of breast and ovarian cancer?

A woman with a **significant family history** of breast and/or ovarian cancer has a higher risk of getting these cancers. You have a significant family history if:

- You have two or more close family members who have had breast and/or ovarian cancer, **and/or**
- The breast cancer in the family members has been found before the age of 50.

Talk with your doctor or other health care professional trained in genetics about your family history. He or she can help you know if you have a significant family history of breast and/or ovarian cancer. This information may help you learn about your cancer risk and help you decide if genetic testing is right for you.

A Note About Family History

A close family member can be your:

- Mother
- Father
- Sister
- Brother
- Grandparent (on your mother's or father's side)
- Mother's sister and/or brother
- Father's sister and/or brother

Having a family history of cancer does not mean you are going to get cancer. Many things, such as family history and age, may increase a person's chance (or risk) of getting cancer. But family history alone is not the only reason people get cancer. Scientists do not know all the reasons why people get cancer.

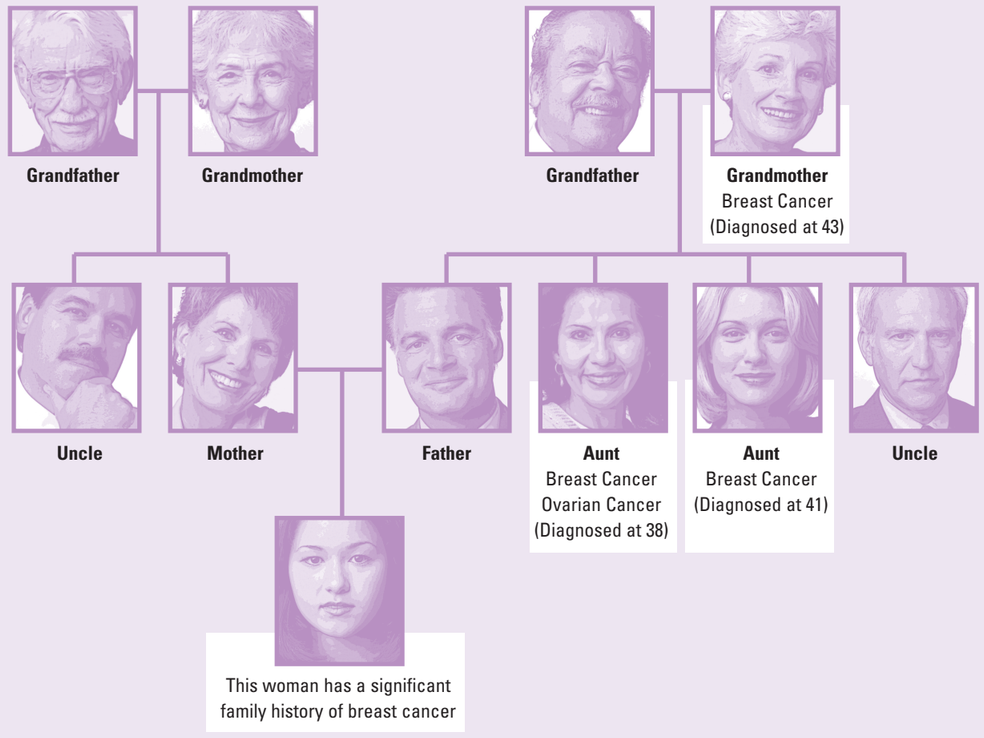
How do genes affect breast and ovarian cancer risk?

Genes are nature's blueprints for every living thing. Most genes come in pairs: one set of genes is passed down (or inherited) from your mother and the other set from your father. Genes determine how your body will function and grow, as well as the color of your hair and eyes.

Sometimes genes do not function properly because there is a mistake in them. If a gene has a mistake, it is said to be mutated or altered. When a gene with a mistake is passed along in family members, it is called an **inherited altered gene**. All people have altered forms of some genes. Certain altered genes can increase your risk of illnesses such as cancer. Gene alterations have been found in many families with a history of breast cancer. Some women in these families have also had ovarian cancer.

These alterations are most often found in genes named BRCA1 and BRCA2 **(BR**east **CA**ncer Gene **1** and **BR**east **CA**ncer Gene **2)**. Both men and women have BRCA1 and BRCA2 genes, so alterations in these genes can be passed down from either the mother or the father. More genes like these may be discovered in the future.

Who is at increased risk for breast and ovarian cancer?



Does every woman with an inherited altered BRCA gene get cancer?

A woman with a BRCA1 or BRCA2 alteration is at higher risk for developing breast, ovarian, and other cancers than a woman without an alteration. However, not every woman who has an altered BRCA1 or BRCA2 gene will get cancer, because genes are not the only factor that affects cancer risk.

Most cases of breast cancer do not involve altered genes that are inherited. At most, about 1 in 10 breast cancer cases can be explained by inherited alterations in BRCA1 and 2 genes.

What about men with an inherited altered BRCA gene?

Although breast cancer in men is rare, men with altered BRCA1 and BRCA2 genes have higher rates of breast cancer than men without an altered gene. Men with an altered BRCA1 or 2 gene may also have a slightly higher risk of other cancers. Even if a man never develops cancer, he can pass the altered gene to his sons and daughters.

What is genetic testing for inherited cancer risk?

Genetic testing is a process that looks for inherited genetic alterations that may increase your risk of certain cancers. This type of testing may show whether the risk in a family is passed through their genes.

Although the lab test itself is quite complex, only a blood sample is needed. For breast and ovarian cancer risk, the testing involves looking for altered genes such as BRCA1 and BRCA2. Finding an altered gene can take several weeks. So your test results may not be ready right away.

The price of testing varies and, in some cases, may not be covered by health insurance. Ask your doctor or other health professionals for more information on genetic testing, privacy issues, and insurance coverage.

What should I think about before getting tested?

- The limits of the test
- The advantages and disadvantages of the test
- Would knowing this information cause me to make changes in my medical care?

What are the limits of the test?

Testing for breast and ovarian cancer risk will not give you a simple "yes" or "no" answer. If a gene alteration is found, this will tell that you have an increased risk of getting cancer, but it will not tell if or when cancer will develop. If an alteration is not found, it still is no guarantee that cancer won't develop.

What are the advantages and disadvantages of testing?

Genetic testing can affect relationships with family members. Think about who in your family might want to know your test results, and who you'd like to tell.

If you are thinking about being tested, you should decide what the advantages and disadvantages of testing are for you. What is right for one person is not always right for another.

What is informed consent?

If you are thinking about genetic testing, you should be informed, both verbally and in writing, about the risks of getting tested, as well as what the test can and cannot tell you. You can decide if testing is or is not right for you. You may also choose to delay the decision, if this is not the best time for you to be tested.

Advantages and Disadvantages

Having a genetic test may help you to:

- Make medical and lifestyle choices
- Clarify your cancer risk
- Decide whether or not to have risk-reducing surgery (see next page)
- Give other family members useful information (if you choose to share your results)
- May explain why you or other family members have developed cancer

The disadvantages to testing:

- There is no guarantee that your test results will remain private
- Although rare, you may face discrimination for health, life, disability, and other insurance
- You may find it harder to cope with your cancer risk when you know your test results
- If you find that you do not have an inherited altered gene, you may think that you have no chance of getting cancer. People who are found not to have an inherited cancer gene can still get cancer.

What can I do if I find out that I have an inherited altered gene?

You can make choices that help lower your risk of getting cancer or help find cancer early. You do not need to be tested to consider these options.

- **Increased monitoring.** You may choose to be watched more closely for any sign of cancer. This can include more frequent breast and pelvic exams, mammograms, breast MRI, breast self-exams, ultrasound of the ovaries and breasts, and blood tests.
- **Risk-reducing surgery.** Called prophylactic (PROH-fuh-LAK-tik) surgery, this is when women choose to have healthy ovaries and/or breasts removed to reduce their chance of getting cancer. You may want to talk with your doctor and other health care professionals to learn more about this.

Who can I call?

A person who is considering genetic testing should talk with a professional trained in genetics before deciding whether to be tested. For more information on genetic testing or for a referral to centers that have health care professionals trained in genetics, call the National Cancer Institute's Cancer Information Service toll-free at 1-800-4-CANCER (1-800-422-6237), or visit online at www.cancer.gov. The Cancer Information Service can also provide information about clinical trials, other research studies, and current risk management information.

What are the main questions I should ask?

If you are thinking about genetic testing, be sure to talk with your doctor, nurse, genetic counselor, or other health professionals, and take some time to answer these questions together. You may want to get more than one opinion.

- ☐ What are the chances that an inherited gene alteration is involved in the cancer in me or my family?
- ☐ What are my chances of having an inherited altered gene?
- ☐ Besides having altered genes, what are my other risk factors for breast and ovarian cancer?
- ☐ Are all genetic tests the same? How much does the test cost? How long will it take to get my results?
- ☐ What are the possible results of the test?
- ☐ What would a positive result mean for me?
- ☐ What would a negative result mean for me?
- ☐ How might a positive test result affect my health, life, and disability insurance options?
- ☐ How might a positive test result affect my employment?
- ☐ Do I want to ask my insurance company to pay for my test?
- ☐ Where will my test results be placed/recorded? Who will have access to them?
- ☐ Would knowing this information cause me to make changes in my medical care?
- ☐ What are my reasons for wanting to be tested?
- ☐ What type of cancer screening is recommended if I don't get tested?

Other questions to think about and discuss with your family:

- ☐ What effect will the test results have on me and my relationship with my family members if I have an inherited altered gene? If I don't have an altered gene?
- ☐ Should I share my test results with my spouse or partner? Parents? Children? Friends? Others? How will they react to the news, which may also affect them?
- ☐ Are my children ready to learn new information that may one day affect their own health?