LIVE LIFE EMPOWERED

What you should know about genes and cancer

FORCE
Facing Our Risk of Cancer Empowered

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People with cancer often wonder what caused the disease. Relatives of people with cancer often are concerned that they may be at increased risk for getting cancer too. Inherited gene changes can cause cancer to run in families.

This brochure can help you learn if your cancer or the cancer in your family could be caused by an inherited gene change and what you can do about it.

FORCE is the only national nonprofit organization devoted to individuals and families affected by hereditary breast, ovarian, and related cancers. By providing research, support, education, and awareness specific to hereditary cancer and those affected by it, we ensure that no one travels this journey alone.

What causes hereditary cancer? What is HBOC?

Hereditary cancers occur because of an inherited change called a mutation in certain genes that normally protect the body from developing cancer. This change increases a person's risk for one or more types of cancer and can be passed from generation to generation. BRCA1 and BRCA2 are the names of the two most common genes associated with hereditary breast and ovarian cancer (HBOC). Women with mutations in one of these genes have an elevated risk for breast, ovarian, and other cancers. Men with a BRCA mutation have an increased chance of developing breast and prostate cancers. Men and women with a BRCA gene mutation also have a slightly higher lifetime risk for pancreatic cancer and melanoma.

Mutations in other genes, such as those that cause Lynch syndrome and Cowden syndrome, and mutations in genes such as PALB2 can also increase risk of breast and/or ovarian cancers, and in some cases, other cancers too. Medical experts called genetic counselors can help you understand your cancer risk and make recommendations to help you stay healthy.

Warning Signs of Hereditary Breast and Ovarian Cancer

You or any family member has had:

- ovarian or fallopian tube cancer at any age
- breast cancer at age 50 or younger
- more than one breast cancer diagnosis
- both breast and ovarian cancer
- triple negative breast cancer
- Eastern European (Ashkenazi) Jewish ancestry and a history of breast or ovarian cancer
- male breast cancer

More than one family member on the same side of the family has had any of these cancers:

- breast cancer
- ovarian or fallopian tube cancer
- prostate cancer
- pancreatic cancer

Other hereditary cancers, such as those associated with Lynch and Cowden syndromes, have additional warning signs.

Mothers and fathers can pass cancer-causing mutations down to their daughters and sons.

For more information on hereditary cancer and gene mutations, visit FORCE at facingourrisk.org/genes.

How can I learn if I have an inherited mutation?

There are blood or saliva laboratory tests that can tell if you have an inherited mutation. Most people do not inherit cancer-causing gene mutations, so genetic testing is not recommended for everyone. Medical experts known as genetic counselors can provide you and your family with information about genetic testing, cancer risk, and medical options to help you stay healthy.

A genetic counselor will:

- help you understand hereditary cancer
- review your family medical history to assess and explain your risk for cancer
- describe the benefits and limitations of genetic testing and discuss whether it is right for you
- order the appropriate test if you choose to proceed with genetic testing
- interpret and explain what genetic test results mean for you and your family
- discuss how to manage your cancer risk and refer you to experts for follow-up care

There are many different types of genetic tests, so it's important to speak with a genetic counselor before genetic testing. Test results may affect your health care decisions, so it's equally important to speak with a genetics expert after testing. Your test results may also make you eligible to participate in clinical trials of new therapies. Sharing your test results with relatives can increase their access to genetic testing and medical services, helping them learn more about their own cancer risk and how they might reduce it.

For more information on finding specialists, visit FORCE at facingourrisk.org/specialists.

You should consider genetic counseling if...

You were diagnosed with ovarian, fallopian tube, or primary peritoneal cancer.

Women of any age diagnosed with these cancers meet national guidelines for genetic counseling and genetic testing.

You were diagnosed with breast cancer in both breasts, breast cancer before age 50, or triple negative (ER-/PR-/Her2-) breast cancer.

Having a diagnosis of any of the above types of breast cancer increases the likelihood that you have an inherited mutation.

You are a man who has been diagnosed with breast cancer.

Male breast cancers are rare and are often linked to inherited mutations in genes that increase cancer risk.

Your family has had multiple cancers.

Multiple relatives on the same side of the family with cancers such as breast, ovarian, pancreatic, prostate, and/or melanoma may signal an inherited family mutation.

You are Jewish.

One in every 40 people of Eastern European (Ashkenazi) Jewish ancestry carries a BRCA mutation. If you are Jewish, and you or a close relative has had breast, ovarian, pancreatic, melanoma or prostate cancer, a genetics expert can help you decide if genetic testing is right for you.

One or more relatives tested positive for a mutation in a BRCA or other gene that is associated with increased cancer risk.

The more closely related you are to a blood relative who tests positive for a gene mutation, the greater your chance of having the same mutation.

Although cancer-causing mutations may be more common in certain populations, mutations have been found in people of every race and ethnicity.

What happens after genetic testing?

Test results

There are several types of genetic tests, and interpretation of the results depends on which test was ordered. Your blood relatives may have the same mutation and may also have a high risk for cancer, so it is important to share information about your genetic counseling and testing result.

A positive BRCA test means that your risk for breast and ovarian cancers is very high, and your risk for prostate and pancreatic cancers, as well as melanoma, also is increased. A positive result for other mutations such as PALB2, PTEN, and the genes that cause Lynch syndrome is associated with different cancer risks.

Negative genetic test results do not always provide clear information on cancer risk, which is one reason that genetic counseling before and after genetic testing is so important. If you test negative for a mutation, your risk for cancer will vary depending on several factors, including family history of cancer.

"FORCE is such a blessing. I am so grateful to benefit from the work of hereditary cancer pioneers like the people of FORCE who planted trees so the rest of us could sit in the shade—and so we could feel empowered enough to plant a few trees ourselves."
Frances Ratner, FORCE Constituent

BRCA test results may affect your options for cancer treatment if you have been diagnosed with breast, ovarian, pancreatic, or prostate cancer.

You have options for managing your cancer risk

There are three medical options to manage cancer risk: surveillance (screening), chemoprevention (medication to lower risk for cancer), and risk-reducing surgery to remove healthy organs that are most likely to develop cancer. These strategies are not equally effective for all cancers, and each option carries benefits and risks. Your choice may differ from someone else's, and your approach to managing risk may change over time. Your health care team can help you develop a long-term risk management plan that is right for you. Visit facingourrisk.org/options for more information about options for managing risk.

Insurance, privacy, and discrimination

Does insurance cover genetic counseling and genetic testing?

The Affordable Care Act (ACA) requires that private health insurance covers the cost of genetic counseling and BRCA genetic testing without co-payment or deductible for individuals without cancer who meet specific guidelines. A genetic counselor can help determine whether you qualify for genetic testing under your health insurance.

Will you lose your health insurance if you test positive for a gene mutation?

The Genetic Information Nondiscrimination Act (GINA) prohibits health insurance companies and employers from discriminating based on an individual's genetic information. GINA does not apply to life, disability, or long-term care insurance.

For more information on these protections, visit FORCE at facingourrisk.org/laws.

"Ever since I found out I was BRCA1 positive and I had passed along the gene mutation to my daughter, FORCE has become an important part of my life. The information on the FORCE website and the support of FORCE members is invaluable to both me and my daughter."
Dave Bushman, FORCE Volunteer

For people facing hereditary breast or ovarian cancer

You don't need to face this journey alone. FORCE is here for you!

Website
Facingourrisk.org

Our website is the largest single repository of expert-reviewed information and resources about hereditary breast and ovarian cancer.

Educational Materials

E-newsletters, webinars, and printed materials provide information and news to individuals and families concerned about hereditary cancer.

Peer Support Groups

Local peer support groups meet regularly and, led by trained volunteers, provide unbiased support and expert-reviewed resources.

Joining FORCEs Against Hereditary Cancer Annual Conference

The largest gathering of its kind, our conference attracts BRCA mutation carriers, those with a strong family history of cancer, and medical professionals who treat members of the hereditary cancer community.

Toll-free Helpline
1-866-288-RISK (7475)

Trained volunteers answer helpline calls in English and Spanish, providing one-on-one support, referrals to resources, and connections to other volunteers who have had similar experiences.

Message Boards

Our online message boards reflect a large database of personal experiences, created and maintained by an active community of people affected by hereditary cancer.

Participate in research to help find better detection, prevention, and treatment options

Researchers are studying new options for detection and prevention of cancer in high-risk people. Everything we know about hereditary cancer treatment and managing cancer risk results from research. Participating in research studies or clinical trials helps to assure that this important research progresses. To accelerate HBOC research, FORCE has built the ABOUT Network Research Registry (facingourrisk.org/registry), the only national registry by and for the HBOC community. The registry will conduct research specifically designed to answer patient questions about the decisions they face and the medical options available, as well as connect individuals to appropriate HBOC research studies.

Who should read this brochure?

This brochure is for you if any of the following apply to you or to a close relative:

- ovarian, fallopian tube, or primary peritoneal cancer at any age
- breast cancer by age 50
- more than one breast cancer diagnosis
- triple negative breast cancer
- male breast cancer
- cancer of the breast, ovaries, pancreas, uterus, colon, prostate, or melanoma in multiple relatives on the same side of the family
- Jewish heritage and any of the above cancers at any age

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Fighting Hereditary Breast and Ovarian Cancer

www.facingourrisk.org

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