What you should know about genes and cancer

FORCE
Facing Our Risk of Cancer Empowered

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 called mutations 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. FORCE research, support, education, advocacy and awareness efforts ensure that no one has to face hereditary cancer 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. An inherited mutation increases a person's risk for one or more types of cancer and can be passed from fathers and mothers to their sons or daughters. BRCA1 and BRCA2 are 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, ATM, CHEK2 and others, 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 personal cancer risk and make recommendations to help you stay healthy.

Signs of Hereditary Breast, Ovarian and Related Cancers

You or any family member has had:

- ovarian, fallopian tube or primary peritoneal cancer
- breast cancer at age 50 or younger
- two separate breast cancers
- a type of breast cancer called "triple-negative breast cancer"
- pancreatic cancer
- male breast cancer
- prostate cancer at age 55 or younger or metastatic prostate cancer
- Eastern European Jewish ancestry and any of the above cancers at any age

OR

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

- breast cancer
- ovarian, fallopian tube or primary peritoneal cancer
- prostate cancer
- pancreatic cancer
- melanoma

Other hereditary cancers, such as colon, uterine or thyroid cancer, may be associated with Lynch and Cowden syndromes. A genetics expert can help you understand if the cancers in your family may be caused by an inherited mutation.

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

How can I learn if I have an inherited mutation?

Blood or saliva laboratory tests 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 to 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 health care decisions about cancer screening, prevention and treatment, 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. Sharing your test results with relatives can help them learn more about their own cancer risk and provide them with more medical options for staying healthy.

For more information on finding specialists, visit www.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 before age 50, triple-negative breast cancer, breast cancer in both breasts or breast cancer more than once.

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 prostate cancer before age 55 or younger or metastatic prostate cancer.

Men with young-onset prostate cancer or metastatic prostate cancer are more likely to have an inherited mutation.

You were diagnosed with pancreatic cancer.

Pancreatic cancer is a rare cancer that can be associated with a genetic mutation.

You have one or more blood relatives with any of the cancers above or multiple cancers.

Having a blood relative with any of the cancers mentioned above may make you eligible for genetic counseling and testing. Multiple relatives on the same side of the family with cancer may also 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 gene that is associated with increased cancer risk.

If you have a blood relative who has tested positive for a mutation, you may also share the same mutation.

If you're not sure if you need genetic counseling or you need help finding an expert, visit www.facingourrisk.org/pnp or call our toll-free genetic counselor helpline at 866-288-7475, ext. 704.

What do my genetic test results mean?

Different genetic tests look for mutations in different genes, and different gene mutations are associated with different cancer risks. The meaning of your test results depends on which test was ordered and whether or not a mutation was found in any of your genes. This is why speaking with a genetics expert before and after genetic testing is so important.

A positive test result means that an inherited gene mutation was found in one of your genes. Your cancer risk depends on which gene has the mutation, your gender, your age, your family history of cancer and other factors.

A negative genetic test result means that no mutation was found in any of the genes included in your test. Although this is good news, a negative genetic test may not provide clear information on your cancer risk. If you test negative for a mutation, your risk for cancer will vary depending on several factors, including your personal and family medical history.

Your genetic test results may provide your relatives with important information about their risk for cancer. Therefore, it is important to share information about your genetic counseling and testing result with your family members.

"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

You have options!

Your genetic test results may affect your options for detecting, preventing and treating hereditary cancer.

There are three ways to manage increased cancer risk: screening, chemoprevention (medication to lower risk for cancer) and risk-reducing surgery to remove healthy organs before cancer can develop. 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.

For people with a diagnosis of cancer, genetic test results may affect treatment options, including decisions about surgery, chemotherapy, radiation, immunotherapy or targeted therapy.

Visit www.facingourrisk.org/options for more information about managing increased cancer risk. Visit www.facingourrisk.org/treatment for more information about options for treating hereditary cancer.

Insurance, privacy and discrimination

Does insurance cover genetic counseling and genetic testing?

Most insurance companies will cover the cost for genetic counseling and testing for people who meet the national guidelines. A genetic counselor can help determine whether you qualify for genetic services under your health insurance plan. FORCE has sample letters to help you appeal if your insurance company refuses to cover services for which you qualify. There are also low-cost options for genetic testing if you need to pay out-of-pocket.

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 access to genetic services and insurance appeals, visit www.facingourrisk.org/access.
For more information on protections against discrimination, visit www.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

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

Everything we know about hereditary cancer treatment and managing cancer risk results from research. Researchers are studying new options for detecting, preventing and treating hereditary cancers. Participating in research studies or clinical trials helps assure that this important research progresses. To accelerate HBOC research, FORCE has built the first HBOC Research Study Search Tool to match people to research studies enrolling patients affected by hereditary cancer.

To search for research studies enrolling patients like you, visit www.facingourrisk.org/research.

For people facing hereditary breast, ovarian and related cancers

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

Educational Information

Our website is the largest repository of expert-reviewed hereditary cancer information.

www.facingourrisk.org

Joining FORCEs Conference

The largest gathering of its kind, our conference attracts cancer survivors; high-risk people; people who have tested positive for a BRCA, PALB2, ATM, CHEK2 or other mutation associated with inherited cancer risk; those with a strong family history of cancer; researchers; and medical professionals who treat members of the hereditary cancer community.

www.facingourrisk.org/conference

Personalized Peer Support

FORCE's Peer Navigation Program matches individuals to trained volunteers who share a similar experience and provide confidential phone support and a free personalized guide.

www.facingourrisk.org/pnp

Hereditary Cancer Research

FORCE's research program matches people affected by hereditary cancer with prevention, detection, treatment and other research studies enrolling people like them.

www.facingourrisk.org/research

XRAYS—Making Sense of Cancer Headlines

Funded by the CDC, XRAYS helps breast cancer survivors and people at high risk more easily understand breast cancer-related news and information.

www.facingourrisk.org/XRAYS

Local Support

Trained volunteers provide nonjudgmental support to individuals in local communities.

www.facingourrisk.org/support

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
- pancreatic cancer
- prostate cancer by age 55 or metastatic prostate cancer
- multiple family members diagnosed with cancer, especially breast, ovarian, pancreatic, melanoma or prostate cancer
- Jewish heritage and any of the above cancers at any age

To learn more about hereditary cancer, visit www.facingourrisk.org. To receive support, call our peer support helpline at 866-288-RISK (7475) or visit www.facingourrisk.org/pnp.

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www.facingourrisk.org

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To reorder this brochure, visit www.facingourrisk.org/brochure.