



WHAT YOU SHOULD KNOW ABOUT GENES AND CANCER



SHOULD YOU BE CONCERNED ABOUT HEREDITARY CANCER?

People with cancer often wonder what caused the disease. Relatives of those with cancer are often concerned that they may also be at increased risk for getting cancer. Hereditary cancers occur because of an inherited change (mutation) in certain genes that normally protect the body from developing cancer. This change increases a person's risk for one or more cancers and can be passed down from mothers or fathers to daughters and sons.

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

Facing Our Risk of Cancer Empowered (FORCE) is a national nonprofit organization devoted to improving the lives of the millions of individuals and families facing hereditary breast, ovarian, pancreatic, prostate, colorectal and endometrial cancers. Our community includes people with a BRCA, ATM, PALB2, CHEK2, PTEN or other inherited gene mutation and those diagnosed with Lynch syndrome. We accomplish this through our education, support, advocacy and research efforts.

SIGNS OF AN INHERITED MUTATION OR HEREDITARY CANCER

You have a blood relative who has tested positive for an inherited mutation

—OR—

You or any family member has had:

- Pancreatic, ovarian, fallopian tube, primary peritoneal or male breast cancer at any age
- Breast, colorectal or endometrial cancer at age 50 or younger
- Two separate cancer diagnoses
- A type of breast cancer called “triple-negative breast cancer” at age 60 or younger
- Prostate cancer at age 55 or younger or metastatic prostate cancer
- Colorectal cancer at any age with tumor testing that shows microsatellite instability (MSI-High) or other tumor test results that are suggestive of Lynch syndrome
- Endometrial cancer at any age with tumor testing that shows microsatellite instability (MSI-High) or other tumor test results that are suggestive of Lynch syndrome
- More than 10 colon polyps
- Rare or young-onset cancers
- Tumor testing that shows a mutation in a gene associated with hereditary cancer
- Eastern European Jewish ancestry and breast, ovarian or pancreatic cancer at any age

—OR—

More than one family member on the same side of the family has had a combination of the following cancers:

- Breast cancer
- Ovarian, fallopian tube or primary peritoneal cancer
- Prostate cancer
- Pancreatic cancer
- Melanoma
- Colorectal cancer
- Endometrial cancer
- Stomach cancer
- Rare or young-onset cancers

Speak with your doctor about a referral to an expert known as a genetic counselor if you or a family member have any of the conditions listed above. This list is not comprehensive; other cancers may be hereditary, too.



“Ever since I found out I was BRCA1 positive and passed the genetic mutation to my daughter, FORCE has become an important part of my life. The information I receive from FORCE and the support of all its members is invaluable to both me and my daughter. ”

—Dave Bushman

WHAT IS GENETIC TESTING AND HOW MIGHT IT AFFECT YOU?

Genetic tests that use a sample of your blood or saliva can show if you have an inherited mutation in a cancer-related gene. Most people do not have an inherited mutation, so genetic testing is not recommended for everyone.

When someone is diagnosed with cancer, their tumor may be tested to discover if they might benefit from a type of treatment known as a “targeted therapy.” These tumor tests can sometimes find inherited mutations, although they cannot detect all types of inherited mutations. It is important to speak with your doctor to learn which tests can be performed on your cancer and to understand the meaning of your tumor test results.

A genetic counselor will:

- review your family medical history to assess and explain your risk for cancer
- describe the benefits and limitations of genetic testing to help you decide if testing is right for you
- discuss insurance coverage, the cost of testing, legal protections and privacy issues
- order the appropriate genetic test if you choose to proceed
- interpret and explain what genetic test results mean for you and your family
- discuss how to manage your cancer risk and refer you to specialists to make recommendations for screening, prevention and other medical options

“Thankfully I found FORCE after my CHEK2 breast cancer diagnosis. The information I received from the website has been invaluable and the incredibly supportive people who support one another every day has helped me take something terrible and turn it into something positive. ”

—Chelsea Gregory



INFORMATION IS POWER!

Your genetic test results may affect your options for detecting, preventing and treating hereditary cancer. Sharing your test results with relatives can help them learn more about their own cancer risk and provide them with medical options for staying healthy.

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

Genetic test results may also provide you with more options for lowering your risk for cancer or detecting it at its earliest, most treatable stage through:

- intensive screening
- chemoprevention (taking medication to lower risk for cancer)
- risk-reducing surgery to remove organs before cancer can develop

INSURANCE, PRIVACY AND DISCRIMINATION

Most insurance companies 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 provides sample letters to help you appeal if your insurance company refuses to cover services for which you qualify. Low-cost options for genetic testing are also available if you need to pay out-of-pocket.

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.



“FORCE plays an important role for those with hereditary cancer or the risk of it. When I was diagnosed with Lynch syndrome related colon and endometrial cancer, it was the FORCE website I stalked for information, and it was the FORCE community that provided me with the support I needed.”
—Wenora Johnson

YOU DON'T NEED TO FACE HEREDITARY CANCER ALONE. FORCE IS HERE FOR YOU!

We are dedicated to providing up-to-date, expert-reviewed information and resources that help people make informed medical decisions. Our strong, supportive community of peers and professionals ensures no one must face hereditary cancer alone. FORCE serves as a champion, unifying the community and advocating for awareness, access to care and better treatment and prevention options.

Educational Information

Our website has one of the largest collections of expert-reviewed hereditary cancer information.

Hereditary Cancer Research

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

Joining FORCEs Conference

The largest gathering of its kind, our conference attracts cancer survivors; individuals who are at high-risk for cancer; 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; and researchers and medical professionals who treat members of the hereditary cancer community.

Networking

Connect with other members of the hereditary cancer community online or face-to-face and meet new friends.

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 expert-reviewed resource guide.

XRAY: Behind the Cancer Headlines

The XRAY program helps people who are diagnosed with or at high risk for cancer to more easily understand cancer-related news, information and research that is covered by the media.



Facing Hereditary Cancer **EMPOWERED**

As a not-for-profit organization, FORCE relies on and deeply appreciates contributions from friends, corporations, foundations and partners. All contributions to FORCE are tax-deductible to the fullest extent allowed by law.

FacingOurRisk.org