

YSC Fact sheet: Frequently asked questions about hereditary breast cancer

All cancer involves changes in genes called mutations. However, in most people, these changes occur after birth, usually later in life and only in a limited number of the body's cells.

Hereditary cancer refers to cancer that is caused by a mutation that is present at birth and in all cells of the body. This gene change makes individuals more likely to develop cancer in their lifetime but doesn't mean they will definitely develop the disease. Certain cancers, including those of the breast, ovary, and colon, are more likely than others to be hereditary.

This fact sheet will answer questions on hereditary breast cancer. It might not answer all of your questions because the issue of hereditary breast cancer is very complex. We have provided a listing of helpful resources at the end of this sheet where you can get more information. If you are concerned that you are at increased risk for breast cancer due to your family history, please contact a genetic counselor in your community.

How common is hereditary breast cancer?

Approximately 10% of breast cancer is considered "hereditary." The majority of breast cancers, however, are called "sporadic," meaning we don't know why they happened.

How can I determine if the breast cancer in my family is hereditary?

Important factors in determining if the breast cancer in a family is hereditary include: the age of onset of breast cancer; the presence of certain other types of cancer in a family; and the number of relatives with cancer and their relationship to you. A genetic counselor will look at your family's medical information (called a pedigree) including the medical information on first-degree relatives (parents, siblings, and children), second-degree relatives, (grandparents, aunts, and uncles), and third-degree relatives (cousins).

Two of my close relatives have had breast cancer. Does that mean that I will get breast cancer too?

Having two relatives on the same side of the family with breast cancer can be significant. However, even if your mother, sister, or daughter has had breast cancer, this does not mean that you will definitely get breast cancer. In addition, it's important to remember that hereditary cancer risk can be passed down from your mother or your father. When looking at your family medical history, you need to look at both sides of the family.

What are some signs that I may be at greater risk for hereditary breast cancer?

Factors that can increase the likelihood of hereditary breast cancer in a family include breast cancer before age 45, cancer in both breasts, male breast cancer, and several cases of breast and/or ovarian cancer on the same side of a family.

Can I still get breast cancer even without a family history of the disease?

A woman with no family history of cancer can still develop breast cancer. In the United States every year more than 210,000 women will be diagnosed with breast cancer; five percent of these cases (11,000 women) will be in women age 40 and under.

Genetic testing

What is genetic testing?

Some hereditary mutations or gene changes linked to breast cancer have already been identified. The two most common are BRCA1 and BRCA2 (for breast cancer 1 and breast cancer 2). Blood tests are now available to determine if someone carries one or both of these two gene changes.

What are the benefits and limitations of genetic testing for a BRCA mutation?

The benefits of genetic testing can vary depending on individual circumstances. Knowing your BRCA genetic status can be very empowering. Should you test positive for a known mutation, genetic testing can allow you to choose medical options to lower your risk for cancer or detect the disease at an early stage. It may also qualify you to participate in research studies that are looking for better ways to detect cancer early or to prevent cancer. However, not everyone views the knowledge of cancer risk as a benefit.

The limitations of the test are complex. Genetic testing impacts both the individual undergoing testing and other members of the family. Some people may find the information and uncertainty associated with risk overwhelming, especially at first. And since the test itself can only identify the two most common genes involved in hereditary breast cancer, under certain circumstances, a negative test may not rule out hereditary breast cancer in your family.

Because not every person who carries a mutation will get cancer, it is very important to remember that genetic testing cannot detect breast cancer nor can it tell you with certainty if you will get breast cancer at some point in your life.

Should I have genetic testing?

The decision to undergo genetic testing is a very personal one. There is no right or wrong choice. However, genetics is an area of cancer research where knowledge is growing rapidly. It is important to get the most up-to-date information from health care providers who are specially trained in cancer genetics when you are making the decision whether or not to have genetic testing.

What can be done to decrease my risk for breast cancer if I test positive for a gene mutation?

There are several options available for breast cancer risk reduction in high-risk women. Chemoprevention involves taking a medication to lower the risk for cancer. Tamoxifen is a medication that has been approved to lower breast cancer risk in certain high-risk women and appears to lower risk by up to 50%. Other medications are being researched. Surgical removal of healthy breasts and/or ovaries, known as prophylactic surgery, can effectively lower the risk for breast cancer in high-risk women as much as 95%.

In addition to risk reduction options, increased surveillance tools such as Magnetic Resonance Imaging (MRI) and ultrasound can be used in conjunction with mammography to assist in detecting breast cancer at its earliest and most treatable stage. These tools and others, such as ductal lavage, are currently being studied to see if they improve outcome for high-risk women who choose surveillance.

None of these options eliminate the risk for breast cancer. In addition, each option has its own benefits and risks. It is important to choose a health care team that is trained in managing high-risk women and discuss each option thoroughly with them.

I have already been diagnosed with breast cancer. Is genetic testing still worthwhile for me?

Genetic test results can provide information that affects treatment choices and follow-up care for breast cancer patients and survivors. Further, if a cancer survivor is the first person to have a genetic test in a family, that test result may help identify the cause of hereditary cancer in a family. This information can help other family members make decisions about genetic counseling and testing.

Should my young children have genetic testing for the BRCA mutation?

The high-risk cancers that occur in carriers of a BRCA1 or BRCA2 mutation do not occur in childhood. Because there are no beneficial medical options to offer children who carry a BRCA mutation, medical professional societies recommend against BRCA testing for minors. This also allows individuals to make their own informed decisions, as adults, about whether they want to undergo genetic testing. Further, because tremendous strides are being made in cancer genetic research, it is likely that more effective surveillance and risk reduction strategies will be available by the time they reach adulthood.

Are there other cancers associated with BRCA mutations?

The BRCA1 and BRCA2 gene mutations are linked primarily to breast and ovarian cancer, but BRCA2 mutations also carry a somewhat higher risk for other cancers, including melanoma and prostate cancer in men.

Where can I go for support and more information?

If you are a young woman with breast cancer, Young Survival Coalition (YSC) is the only international, non-profit network of breast cancer survivors and supporters dedicated to the concerns and issues that are unique to young women and breast cancer. If you are concerned about your risk for breast cancer, FORCE: Facing Our Risk of Cancer Empowered is the only international, non-profit organization specifically for individuals and families affected by hereditary breast and ovarian cancer or hereditary cancer risk.

Hereditary cancer resources

- ***How can I find a specialist in cancer genetics?***

The National Cancer Institute has a list of cancer genetics specialists and risk assessment counselors. You can find a specialist in your area through their website at: www.cancer.gov/search/genetics_services or by calling (800) 4-CANCER.

The National Society of Genetic Counselors has a list of board certified genetic counselors. You can find a counselor in your area through their website at www.nsgc.org.

- ***How can I find a clinical trial or other research for hereditary breast cancer?***

A way to be involved in research including future research studies is to enroll in a hereditary breast cancer registry. Some national registries focusing on hereditary cancer include:

Cooperative Family Registry for Breast and Ovarian Cancer at www.epi.grants.cancer.gov/CFR
Family Cancer Genetics Network You can enroll in this registry online, and they will keep you apprised of new research opportunities: www.fcgn.org or (800) 456-3434 Ext. 4990

FORCE: Facing Our Risk of Cancer Empowered has links to research opportunities in breast cancer surveillance and prevention at www.facingourrisk.org/finding_health_care/clinical_trials_and_research.html
Salud en Accion has links to research on Hispanic populations and hereditary cancer at www.saludenaccion.org/Projects/genetics.html

- ***Where can I go for information on genetic testing and discrimination?***

FORCE and the National Society of Genetic Counselors have information and a brochure on genetic testing and genetic discrimination that is available online at www.facingourrisk.org/finding_health_care/genetic_info_and_discrimination.html

The National Conference of State Legislatures has a state-by-state guide to laws regarding genetics at www.ncsl.org/programs/health/genetics/charts.htm

The United States Department of Health and Human Services has a website with in-depth information about HIPAA at www.hhs.gov/ocr/hipaa

 Breast Cancer Legacy
Directed and produced by Beth Murphy (Principle Pictures and Young Survival Coalition, DVD, 2004)
www.youngsurvival.org or (877) YSC-1011

This video focuses on the role that genetics and family history play in young women affected by breast cancer. The documentary tells the story of four young women and their families while illustrating the psychological, medical, ethical and interpersonal issues these women face as they confront their family histories of cancer and make life-altering decisions about their futures.

Facing Our Risk of Cancer Empowered (FORCE)

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www.facingourrisk.org

FORCE is the only international, non-profit organization specifically for individuals and families affected by hereditary breast and ovarian cancer or hereditary cancer risk.

Understanding Gene Testing

(National Cancer Institute, 1997)

www.cancer.gov or (800) 4-CANCER

This comprehensive overview of genetics and genetic testing is reminiscent of high school biology. It offers important and in-depth information about genetics and cancer as well as genetic testing.