

General Genetics, Family History and Risk Resources.....43



This symbol indicates resources specifically for
Young Women with Breast Cancer.



GENERAL GENETICS, FAMILY HISTORY AND RISK RESOURCES



Be Bright Pink
P.O. Box 10915
Chicago, IL 60610
www.bebrightpink.org

Bright Pink offers support and information to young women who are at high risk for breast and ovarian cancer. Bright Pink provides a network of high risk women armed with knowledge, options and a great attitude to offer companionship and empathy during their journey.



Breast Cancer Legacy
Directed and produced by Beth Murphy
(Principle Pictures and Young Survival Coalition,
2004)

This DVD 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.

Cancer Facts-Genetic Testing for BRCA1 and BRCA2: It's Your Choice

(2002)
(800) 4-CANCER or www.cancer.gov

This booklet defines the BRCA mutations and addresses how testing positive impacts a person's risk for cancer. It also discusses what a person with a mutation can do.

Facing Our Risk of Cancer Empowered (FORCE)

16057 Tampa Palms Blvd. W, PMB #373
Tampa, FL 33647
(866) 288-RISK or (954) 255-8732
info@facingourrisk.org or www.facingourrisk.org

FORCE is a non-profit organization for women with increased risk of cancer due to family history and genetic status, and is for members of families in which a BRCA mutation may be present.

Hereditary Breast Cancer

1800 30 90 40 (Helpline) or www.cancer.ie/action

This fact sheet from the Irish Cancer Society aims to give information on breast cancer that runs in a family. It provides an overview of what hereditary breast cancer is, how it is passed on, and the importance of family history in guiding the search for changes in genes that can lead to cancer.

If You Want to Find Ways to Prevent Cancer, Learn About Prevention Clinical Trials

(2004)
(800) 4-CANCER
www.cancer.gov/clinicaltrials/learning/about-prevention-trials

For people considering participation, this easy-to-read brochure explains the basics of cancer prevention trials.

Pretty Is What Changes: Impossible Choices, the Breast Cancer Gene, and How I Defied My Destiny

Jessica Queller (2008, \$24.95)
(212) 782-9000
www.randomhouse.com/spiegelandgrau

The author tells her personal story about the choices she was forced to make after discovering she was positive for the BRCA "breast cancer" gene mutation.

Understanding Gene Testing

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

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.

Women at Risk (W.A.R.)

601 West 168th Street, #7 and #8
New York, NY 10032
(212) 305-9525 or info@womenatrisknyc.org

Frequent lectures – recent topics have included genetic screening, hormone replacement therapy, breast reconstruction, menopause and breast cancer risk and the role of antioxidants and vitamin therapies in reducing risk.

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?

Less than 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. Current estimates indicate more than 180,000 new cases of female breast cancer annually. Of those cases approximately 10,000 will be age 40 or under and almost 23,000 will be age 45 or under. Again, less than 10% of these new cases are hereditary.

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. If you are interested in more information about genetic testing, contact your health care provider for a referral to a certified genetic counselor or consult the National Society of Genetic Counselors. (www.nsgc.org)

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 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.

Are there other genetic tests I should ask for?

There are other genetic mutations that can cause many different types of cancer within families. If you have a family history of numerous cancers, you should consult with a genetic counselor about the possibility of other mutations associated with multiple cancers.

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. Be Bright Pink is a network of young women genetically at high risk for breast and ovarian cancer.

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

Revised 2008, YSC - This information was originally developed and published as a collaboration between FORCE—Facing Our Risk of Cancer Empowered, Inc. and Young Survival Coalition © 2004

NOTES

**Genetics, Family
History and Risk**

4