Support and education

SoulMates
Nancy Levitan Porrua, PhD, LICSW

A peer mentor support program providing guidance and support. If you are newly diagnosed and want to be matched to a survivor, or if you are a survivor looking to be a mentor, contact Nancy Levitan Porrua at 617-632-6501.

Young Women’s Telephone Support Group
Robin Swartz Raider, LICSW

For young women who are within the first year of diagnosis looking to connect with others who understand the impact of living with and beyond breast cancer. Sessions offered year-round. For more information, call Jenn McNutt at 617-632-3916 or email youngandstrong@partners.org.

 Facing Forward
Julie Salinger, LICSW

A six-session series held twice yearly for patients who have recently completed treatment for early stage breast cancer. For more information, call Julie Salinger at 617-582-8081.

Metastatic Breast Cancer Support Group
Liz Farrell, LICSW, and Fremont Mager, MD Monthly, 11 a.m. - 12:30 p.m.

For women of all ages with metastatic breast cancer. For more information or to register, call Liz Farrell at 617-632-5606.

Cancer and Careers

A program sponsored by Cosmetic Executive Women, Inc. a non-profit based in New York. Listen to webinars on changing careers, managing finances, working through treatment, and more. To listen or register, visit www.cancerandcareers.org.

Upcoming events

Breast Cancer in Younger Women: A Forum for Patients and Survivors
Friday, Oct. 16 | Joseph B. Martin Conference Center, Harvard Medical School

This annual full-day event includes a patient and survivor panel, an “Ask the Experts” panel including many prominent providers from the Susan F. Smith Center for Women’s Cancers, and small group sessions with our breast oncology social workers. For information or to register, call Jenn McNutt at 617-632-3916 or email youngandstrong@partners.org.

Sexual Health and Intimacy: Couples Workshop
Sharon Berson, PhD | Thursday, Nov. 12, 5:30 - 7 p.m.

Join Dr. Berson as she discusses common sexual challenges after treatment such as communication difficulties with your partner. To register, call Jenn McNutt at 617-632-3916 or email youngandstrong@partners.org.

Facing Our Risk of Cancer Empowerment (FORCE)
Anna Muriel, MD, MPH | Wednesday, Dec. 2, 5:30 - 7 p.m.

Join us for an informational session and discussion about parenting before, during, and after breast cancer treatment. For more information, call Jenn McNutt at 617-632-3916 or email youngandstrong@partners.org.

Researcher spotlight

Support and education

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What does genetic testing mean for you?

Genetic testing looks for mutations in one's genes. Some mutations may lead to an increased risk of cancer, while others may not. Your test results can help your doctor recommend cancer screening or advise on preventative measures beyond the treatment of your initial breast cancer.

What mutations increase the risk of developing breast cancer?

The two most widely studied and well-known breast cancer genes are BRCA1 and BRCA2. Mutations in either BRCA1 or BRCA2 can cause Hereditary Breast and Ovarian Cancer Syndrome (HBOC) and can lead to an increased risk of breast and ovarian (or similar) cancer as well as male breast cancer, pancreatic cancer, prostate cancer, melanoma, and others. Women with a BRCA1 or BRCA2 mutation have about a 50-85 percent lifetime risk of developing breast cancer, compared to the general population risk of 2 percent. Women with a BRCA1 mutation have about a 20-40 percent lifetime risk of developing ovarian cancer, and those with a BRCA2 mutation have about a 10-20 percent lifetime risk, compared to the general population risk of 1.2 percent. Despite those elevated risks, mutations in these genes are fairly rare, accounting for only 5-10 percent of breast and 10-15 percent of ovarian cancers.

A mutation in the TP53 gene— which causes Li-Fraumeni Syndrome— increases the risk of breast cancer as well as several other cancers including leukemia, brain tumors, and sarcomas. This, however, is a rare cause of breast cancer.

Mutations in the CDH1, PTEN, and PALB2 genes, among others, may also confer relatively high increases in the risk of breast cancer as well as some other cancers. The ATM and CHEK2 genes seem to be associated with a more modest increase in breast cancer risk. Other genes associated with an increased risk of breast cancer continue to be studied.

What are the available tests for genetic testing?

See page 3 for some of the tests currently available that analyze genes related to the development of breast cancer.

What types of results could I get?

Positive: A positive result may also be called pathogenic, likely pathogenic, deleterious, suspected deleterious, or clinically actionable. This result means that a mutation was discovered in one or more of the genes tested, conferring an increased risk of developing certain cancers. It is important to note, however, that a positive result does not indicate whether or not an individual will actually develop cancer or a new cancer.

Negative: A negative result means that no clinically actionable mutation was identified in the testing.

Variant, Favor polymorphism (or likely benign): This result means that a variant was discovered [a variant is a variation from the typical sequence of a gene, but it is not necessarily harmful]. Available data indicate or strongly indicate that it most likely does not cause increased cancer risk. The specific variants may or may not be reported.

Variant of Uncertain Clinical Significance (or unknown): This result means that a variant was discovered, but there is currently insufficient data to determine if it causes increased cancer risk. These specific variants will be reported to you, and you will be notified if your variant is upgraded to clinically actionable (all labs) or downgraded to a polymorphism (most labs).

What does a positive result mean for me?

Your risk of a new cancer and options for screening recommendations and prophylactic-risk-reducing measures will vary depending on the gene mutation you tested positive for, and prior breast cancer risks and treatment if you are a breast cancer survivor.

For women with a BRCA1 or BRCA2 mutation, specific recommendations will vary, but may include clinical breast exams, mammograms, and/or MRIs beginning at age 25 to 30. You may also consider prophylactic surgery, such as bilateral mastectomy (both breasts removed) and/or bilateral salpingo-oophorectomy (both ovaries and fallopian tubes removed). Additionally, chemoprevention (the use of drugs, vitamins, or other agents to reduce the risk of, or delay the recurrence of, cancer) may have a role. Currently two chemopreventive drugs (tamoxifen and raloxifene) have been approved by the FDA to reduce the risk of breast cancer in high-risk women, although their role in relation to BRCA mutations is not yet clear.

In addition to these options, you can help reduce your cancer risk by following a healthy lifestyle. Getting sufficient exercise, eating a nutritious diet, limiting alcohol consumption, using sun protection, and quitting smoking are some of the ways you may be able to help reduce your risk of developing cancer.

How do my results affect my family?

Both men and women can inherit and pass on BRCA1 and BRCA2 mutations. The chance of passing it onto a child is 50 percent, whether or not the parent developed cancer. If you have a mutation, the chance of each of your parents having the mutation is also about 50 percent. If one of your parents has the mutation, then each of your siblings also has a 50 percent chance of inheriting the mutation.

More distant relatives such as aunts, uncles, cousins, nieces, and nephews may also have inherited the mutation depending on where they are in the family tree. For more information about the risks for extended family members, please talk to a genetic counselor or someone from your healthcare team.

When you talk with your family about your results, you should take into account how informed they want to be. Knowing about a negative result may provide relief while knowing about a positive result might be unwelcome information for some, or could help them take steps to manage their own cancer risk.

To learn more about genetic testing, please talk to a genetic counselor. Dana-Farber offers a comprehensive program in Cancer Genetics and Prevention and counselors can try to provide referral information to services in your area. Visit www.dana-farber.org/cancergenetics or call 617-632-3915.