ADDITIONAL RESOURCES AND INFORMATION

Susan G. Komen
www.komen.org

Susan G. Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists working together to save lives.

Young Survival Coalition
www.youngsurvival.org

The Young Survival Coalition (YSC) is an international, nonprofit network of breast cancer survivors and supporters dedicated to the issues unique to young women with breast cancer.

Living Beyond Breast Cancer
www.lbbc.org

Living Beyond Breast Cancer (LBBC) is a national organization whose goal is to improve quality of life and help women in their recovery or management of the disease.

LIVESTRONG Fertility
www.livestrong.org

LIVESTRONG Fertility, a program of the LIVESTRONG Foundation, provides information and support to cancer patients and survivors whose medical treatments present the risk of infertility.

Bright Pink
www.brightpink.org

Bright Pink is the only national non-profit organization focusing on the prevention and early detection of breast and ovarian cancer in young women, while providing support for high-risk individuals.

FORCE
www.facingourrisk.org

Facing Our Risk of Cancer Empowered (FORCE) is the only national nonprofit organization devoted to hereditary breast and ovarian cancer. Programs serve anyone with a BRCA mutation or a family history of cancer.

Support and education

SoulMates
Nancy Levitan Poorvu, 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 Poorvu 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 Fremonta Meyer, 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 Bober, PhD | Thursday, Nov. 12, 5:30 - 7 p.m.
Join Dr. Bober 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**.

Parenting Workshop
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**.

Young and Strong®
A PROGRAM FOR YOUNG WOMEN WITH BREAST CANCER
Volume 7. Issue 2: Fall 2015

SUSAN F. SMITH CENTER FOR WOMEN'S CANCERS
DANA-FARBER CANCER INSTITUTE

A program just for you

Established in 2005, Young and Strong, the Program for Young Women with Breast Cancer at Dana-Farber's Susan F. Smith Center for Women's Cancers, provides comprehensive care and support to young women confronting the challenges of living with and beyond breast cancer. Our mission is to enhance care and education for patients and their families, as well as to advance understanding of the biology of breast cancer and the experience of the disease through ongoing research focused on younger women. More than 2,600 young women have been enrolled to date.

For more information about Young and Strong, please contact Jenn McNutt at 617-632-3916, or visit www.danafarber.org/YoungWomenBreastCancer.
You can also follow us on Twitter @YoungStrongDFCI.

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Babies after breast cancer

ABOUT 15 PERCENT OF PATIENTS with breast cancer are diagnosed during their reproductive years. Many of these young survivors are interested in having children after treatment ends and often have questions about this topic. Below, breast oncologists in the Susan F. Smith Center for Women's Cancers provide answers to some common questions.

Is it safe for me to become pregnant after breast cancer?

Yes, we believe it is safe for many women. Studies show that pregnancy after treatment for early stage disease does not increase the risk of recurrence (breast cancer coming back in the breast area or elsewhere in the body) or dying of breast cancer. However, studies are limited and some experts remain concerned. Women with a history of breast cancer continue to be at risk of recurrence both during and after a pregnancy.

Is it safe for my child if I become pregnant after breast cancer?

Yes. Your history of breast cancer treatment should not increase the risk of birth defects in your child, and birth outcomes after breast cancer appear to be the same as in the general population. This is true as long as treatment medications are out of your system before you become pregnant.

What research is being done?

For premenopausal women between ages 18 and 42 who have hormone responsive early breast cancer, there is a clinical trial looking at pregnancy outcomes and the safety of interrupting hormone therapy for those who wish to become pregnant. This international study, called the POSITIVE study (**P**regnancy **O**utcome and **S**afety of **I**nterrupting **T**herapy for women with endocrine respons**IVE** breast cancer) is currently enrolling women, and is slated to open in the United States later this year.

The study will track women who temporarily stop hormone therapy for up to two years to attempt to conceive. Investigators will assess the risk of breast cancer relapse and factors associated with positive or negative pregnancy success, such as menstruation pattern and pregnancy outcomes (full-term, cesarean section, miscarriage, etc.). The study hopes to provide information for survivors who want to get pregnant without waiting until hormone therapy is complete, which is sometimes as long as 10 years.

The study plans to recruit 500 patients worldwide over four years. Women will be followed for at least 10 years. The researchers hope to share results regarding safety within five to six years after the study begins. Y&S

We strongly recommend that you avoid getting pregnant while undergoing chemotherapy and/or hormonal therapy such as tamoxifen. Both can cause birth defects to a fetus, especially during the first trimester. To avoid pregnancy, speak with your doctor about contraception methods that are considered safe for young women with a history of breast cancer.

What does genetic testing mean for you?

YOUNG BREAST CANCER SURVIVORS ARE AT RISK of harboring a genetic predisposition to breast cancer. Among young women, about 10 percent of breast cancers are due to inherited mutations (a mutation is an abnormal change in a gene), which means that the majority of young women with breast cancer will not have a clear inherited mutation. Another 20% of breast cancers are thought to be familial, where genes may play a more limited role in the development of cancer.

Due to the complexity of genetics and genetic testing, many young survivors have questions about their risk and what type of testing is right for them. Below are answers to some common questions.

What is genetic testing?

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 12 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 these elevated risks, mutations in these genes are fairly rare, accounting for only 5-10 percent of breast cancers 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 tests are available to me?

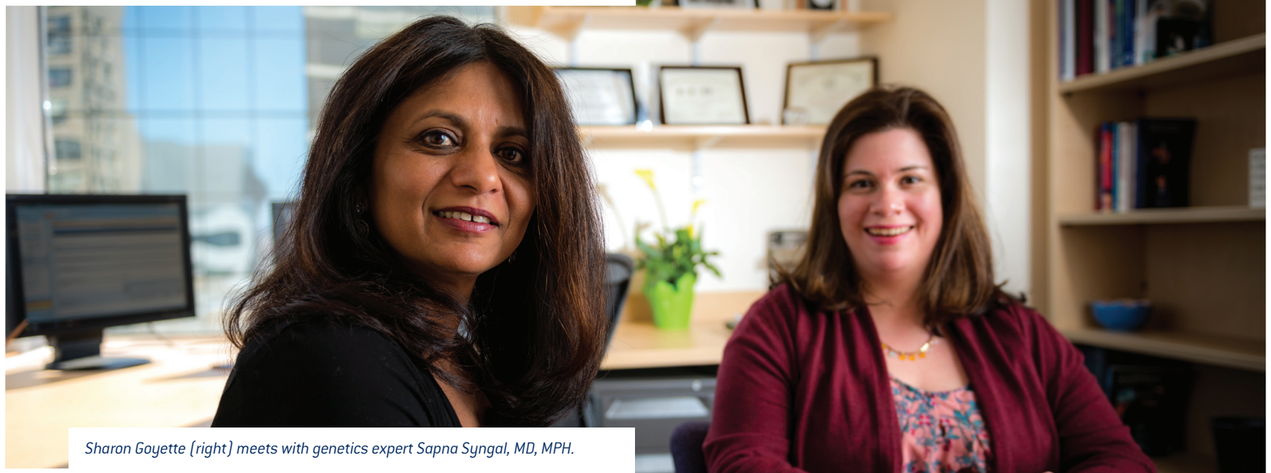
See page 3 for some of the tests currently available that analyze genes related to the development of breast cancer.

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), but 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.



Sharon Goyette (right) meets with genetics expert Sapna Syngal, MD, MPH.

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 have also 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.

Meet Shoshana Rosenberg, ScD, MPH

Shoshana Rosenberg, ScD, MPH, is helping us grow research in Young and Strong. Shoshana started with us as a graduate student in Epidemiology at the Harvard T.H. Chan School of Public Health and joined the Dana-Farber Cancer Institute and Harvard Medical School faculty in July 2014.

Shoshana has worked on projects in the Helping Ourselves, Helping Others: The Young Women's Breast Cancer Study, including studying how treatment affects quality of life for survivors, and decision-making about treatment. She recently received a five-year grant from the Agency for Healthcare Research and Quality to learn more about how young women make decisions about their breast cancer surgery. Her findings will be used to design and test a decision aid (a tool that shows the pros and cons of different treatment choices) to improve the surgical decision-making process for young women.

The first part of her research will include focus groups open to young women who are one to three years post-diagnosis. Additional details will be available soon; if you want to know more or participate, contact the study team at **617-632-3916** or **youngandstrong@partners.org**.

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 **617-632-2178**. Y&S

Test	Description	Lab(s)	Genes analyzed	Typical processing time
Typical BRCA testing	Testing for BRCA1 and BRCA2 usually includes comprehensive gene sequencing and deletion/duplication (i.e. large rearrangement) analysis. For those with known mutations in their family, specific site analysis is available which looks at the location of the mutation present in the relative. For those of Ashkenazi Jewish descent, there is a 3-site mutation panel which looks specifically at sites where mutations are common in this population.	Myriad Genetics, Ambry Genetics	BRCA1 and BRCA2	2 weeks
BRCAplus	This panel analyzes 5 high-risk breast cancer susceptibility genes and provides management guidelines.	Ambry Genetics	BRCA1, BRCA2, CDH1, PTEN, and TP53	3 weeks
BreastNext	This panel analyzes 17 genes associated with increased risk for breast cancer.	Ambry Genetics	ATM, BARD1, BRCA1, BRCA2, BRIP1, CDH1, CHEK2, MRE11A, MUTYH, NBN, NF1, PALB2, PTEN, RAD50, RAD51C, RAD51D, and TP53	1 month
myRisk	This is a 25-gene panel that identifies elevated risk for eight cancers (breast, ovarian, gastric, colorectal, pancreatic, melanoma, prostate, endometrial). This assessment utilizes genetic testing status as well as personal and family cancer history into a risk assessment and plan for follow-up.	Myriad Genetics	BRCA1, BRCA2, MLH1, MSH2, MSH6, PMS2, EPCAM, APC, MUTYH, CDKN2A, CDK4, TP53, PTEN, STK11, CDH1, BMPR1A, SMAD4, PALB2, CHEK2, ATM, NBN, BARD1, BRIP1, RAD51C, and RAD51D	3-6 weeks