

# 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 6,000 young women have been enrolled to date.

For more information about Young and Strong, please contact the Young and Strong team at [youngandstrong@partners.org](mailto:youngandstrong@partners.org), or visit [www.danafarber.org/YoungAndStrong](http://www.danafarber.org/YoungAndStrong).

You can also follow us on Twitter @YoungStrongDFCI.

# A Letter From Young and Strong

## Where We Came From and Where We're Going

Dear Readers,

As many of you know, Young and Strong, the Program for Young Women with Breast Cancer at Dana-Farber/Brigham and Women's Cancer Center, is specially designed to meet the unique needs of you and your loved ones. A cancer diagnosis is life-altering for most people, and we recognize that young women with breast cancer often face other challenges. You're currently managing (or have recently managed) a serious illness and may also be:

- Dealing with concerns about being able to have children in the future
- Considering genetic risks in treatment and prevention decisions
- Parenting young children
- Finishing school
- Managing a career
- Building relationships

Young and Strong exists to guide you through this difficult time, offering comprehensive care, support, and programs tailored specifically for you.

What some may not realize is that all our offerings – our supports and resources – are born out of research. Young and Strong is Dana-Farber's clinical program that was launched in parallel with a robust research program focused on illuminating the unique biological, medical and psychosocial features of breast cancer in young women. From 2006-2016, our research team enrolled 1,302 women with newly diagnosed breast cancer at age 40 years or younger to Helping Ourselves, Helping Others: The Young Women's Breast Cancer Study at select centers in North America. The goal of this study was to gain a deeper knowledge of breast cancer in young women from diagnosis, through treatment, and into survivorship. Researchers have looked at how biologic differences and emotional factors impact both short- and long-term health and quality of life, and we also support clinical trials focused on young women.

Early research provided the evidence needed for our team to develop an education and support program for young women with newly diagnosed breast cancer. In an effort to make this program widely available, we recently tested the Young and Strong Intervention in a clinical trial at 54 sites across the US. We have revised our materials and [website](#) for more widespread patient access. We are now working on studies to unite these initiatives and ultimately expand our reach and impact for young women with breast cancer.

This issue of Young and Strong's newsletter series provides you with research updates from studies lead by our team and how these research findings are impacting breast cancer care at Dana-Farber. Thank you for tuning in, and thanks especially to those of you who have, are currently or will participate in our research studies to help young women!

Sincerely,  
Ann Partridge, MD, MPH, Founder and Director, and the Young and Strong Team

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# Young, Empowered, and Strong (YES) Study: From Observation to Intervention

Based on extensive prior research and clinical experience, we have designed, piloted, and refined a mobile self-monitoring and self-management tool: the Young, Empowered and Strong (YES) portal. YES builds upon our very own web and clinic-based Young and Strong Program, which engages newly diagnosed breast cancer patients and their clinicians. YES is a multi-part tool to enable and encourage

young women with breast cancer to self-monitor and self-manage their concerns and symptoms at home. Tailored information, resources and support are all provided. For additional emotional support, YES contains an expressive writing and journaling platform as well as a monitored discussion board for young women to connect with others as they cope with their new normal.

## For Newly Diagnosed Young Women and Young Women Living With Metastatic Breast Cancer (MBC)

Recruitment for this research study is currently for newly diagnosed young women with early stage disease and for young women living with metastatic breast cancer. YES is designed to help monitor cancer-related symptoms and share self-management information and resources about common issues. Specifically, acute symptoms (which often gradually resolve in the year following the end of primary treatment) and less acute symptoms (which can remain for many years post treatment) are targeted.

Examples of these symptoms include:

- **Acute symptoms:** fatigue, pain, hair loss, physical function changes
- **Less acute symptoms:** menopausal symptoms, cognitive complaints, mood disturbances, and sleep and exercise changes

YES is also designed to serve as a platform for joining future clinical studies and accessing additional supports.

## Eligibility Criteria:

### Stage 0-III

- Female
- Diagnosed with breast cancer between the ages of 18-39 years
- Less than 3 months post diagnosis date of new primary or local recurrence (prior history of other cancer is allowed if it was treated with curative intent and there is no evidence of disease from that cancer)
- Has not started treatment for breast cancer yet
- Is planning to get care at Dana-Farber
- Be fluent in and able to read English
- Have reliable internet access

### Stage IV (Metastatic)

- Female
- Initial diagnosis of breast cancer between the ages of 18-39 years
- Be fluent in and able to read English
- Have reliable internet access

If you are interested in participating in this trial, please email [YESportal@partners.org](mailto:YESportal@partners.org) with your name, date of birth, and phone number.

## For Young Breast Cancer Survivors

As we have seen among patients actively receiving care, there is an increasing need for self-management among survivors, particularly for lingering symptoms, health behaviors, and emotional concerns.

While many physical complaints resolve after initial treatment, the long-term physical and emotional impact on a young woman's life may become evident or worsen in survivorship. Our team and others have documented the burden of these unmet needs.

Unmet needs fall into two interconnected categories:

- **Symptoms** such as sexual problems, anxiety, fatigue, stress, depression, sleep problems, hot flashes, and musculoskeletal issues.
- **Young adult concerns** are defined as concerns unique to (or accentuated by) being young at the time of diagnosis. These concerns may include fertility and family planning, genetics, finding life partners, childrearing, body image and sexuality, fear of recurrence, as well as educational, occupational, and financial concerns.

Symptom monitoring using electronic systems has improved quality of life and survival in adults actively receiving chemotherapy. For this new ongoing study, we adapted this model to address the unmet needs of young breast cancer survivors, a demographic already comfortable with using technology as part of their everyday lives. We will conduct a randomized controlled trial of the YES intervention among 360 geographically and racial-ethnically diverse young breast cancer survivors. This means that some patients participating in the trial will be enrolled in the YES portal (in addition to traditional survivorship care), and others will receive traditional survivorship care until they are given access to the portal after the initial study period. Participants will be recruited from Dana-Farber Cancer Institute, Ohio State University, and the Columbia University Medical Center.

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# Exciting New Research Findings from the Young Women's Research Team

[Phil Poorvu, MD](#), led a study focusing on a specific "recurrence score" test done on hormone-receptor-positive tumors and showed that the score predicts recurrence in young women. Recurrence means that breast cancer has returned to the breast area or other parts of the body. Dr. Poorvu and his team found that the test was able to predict recurrence among young women with node-negative and limited node-positive breast cancer, and is a valuable tool even for very young women. [Read more about this study.](#)

In a related analysis, Tal Sella, MD studied women with early stage hormone-receptor positive breast cancer who were treated with chemotherapy prior to surgery. Researchers looked at the relationship between their recurrence score and their response to chemotherapy. Dr. Sella and his team found that the only patients who had no cancer found at surgery after chemotherapy were those whose tumors had the highest recurrence scores. These findings may help us to develop better, more tailored treatments for patients with lower recurrence scores. [Read more about this study.](#)

Given that many young women present with breast cancers that warrant treatment to shrink the tumor prior to surgery, researchers at Dana-Farber/Brigham and Women's

Cancer Center conducted an analysis among young women who used treatment to shrink the tumor prior to surgery, to evaluate their responses to treatment and surgical decisions. Led by Hee Jeong Kim, MD, PhD, we found that among the 50% of women for whom it appeared to be medically safe to keep their breast after neoadjuvant therapy, about 40% chose mastectomy anyway. The main reasons cited for having more extensive surgery were preference or a known hereditary predisposition or strong family history. While the proportion of young women eligible for breast preservation increased after neoadjuvant therapy, this suggests that surgical decisions are often driven by factors beyond extent of disease and treatment response. [Read more about this study.](#)

## Surgical Decision-Making in Young Women With Breast Cancer

With funding from a 5-year grant from the Agency for Healthcare Research and Quality, [Shoshana Rosenberg, ScD, MPH](#) led a multi-phase study to better understand and improve the surgical decision process in young women with breast cancer.

Dr. Rosenberg and her team assessed the experiences of young women around their surgical decisions. Four focus groups, with a

total of 20 participants, were conducted with women who were 1-3 years post diagnosis. Themes which emerged included the emotions/feelings about surgery, considerations that influenced the decision, communication and interaction with the clinical team, the post-surgical impact and recovery, and support. Reassuringly, most women were satisfied with their choices. However, some women indicated feelings of uncertainty about parts of their decision. [Read more about this study.](#)

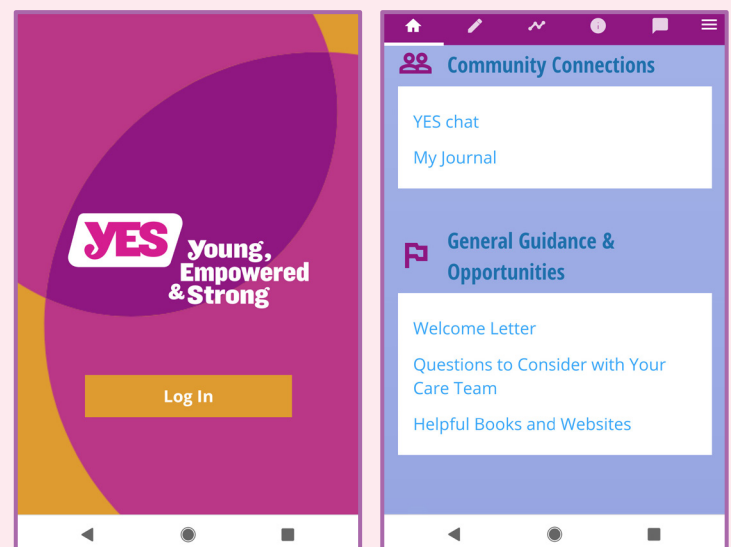
Dr. Rosenberg and her team also conducted 20 interviews with newly diagnosed women before surgery. In these interviews, women cited that a desire to breastfeed, concerns how recovery would affect caring for kids, and returning to work factored into their surgical decision and in some cases, resulted in feeling conflicted about the decision. Other factors/concerns included having cancer cells remain even after surgery and the necessity for surveillance. [Read more about this study.](#)

The team also explored the impact of different types of surgery on quality of life during the first 5 years after diagnosis. Findings showed improvement in emotional health during follow-up, though some differences by surgery remained even 5 years after diagnosis. Women who underwent bilateral mastectomy reported having more sexual and body image concerns

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## Eligibility Criteria:

- Female
- Age 15-39 years at diagnosis of stage 0-III breast cancer
- Within 3 years of breast cancer diagnosis
- No known evidence of breast cancer recurrence (local or distant) or second primary breast cancer
- No prior history of new other malignancy since their breast cancer diagnosis (other than non-melanoma skin cancer)
- Able to speak, understand, and read English
- Ability to access medical records from treating hospital
- Willing to provide cell phone number and/or email address, and willing to receive email and/or text messages from the study team
- Pregnant survivors are also eligible for this protocol, given that fertility and pregnancy are important young adult issues



If you are interested in participating in this trial, please email [YESportal@partners.org](mailto:YESportal@partners.org) with your name, date of birth, and phone number.

If you'd like to receive our monthly e-newsletter, please email [youngandstrong@partners.org](mailto:youngandstrong@partners.org).

compared to women who underwent less extensive surgery. [Read more about this study.](#)

The final phase of this project was to develop CONSYDER, a web-based decision aid tailored to the concerns of young women with breast cancer. In the small pilot study CONSYDER was sent to 50 newly diagnosed young women following their first surgical consult at Dana-Farber. Among the 20 women who used the decision aid and responded to a post-surgical consult survey, 100% said CONSYDER helped them understand the pros and cons of their surgical options and 90% said it helped them learn about resources to help better manage stress around diagnosis. Additionally, 100% of participants said it helped clarify what is important when choosing surgery and 85% said it helped them learn about other resources for young women with breast cancer.

### **Pregnancies Within the Young Women's Cohort, 5 Years After Diagnosis**

Dr. Poorvu led an analysis of 1,026 eligible participants, among whom 368 (36%) reported interest in future biologic children at least once within 5 years after diagnosis, including 16% at 5 years after diagnosis. Among 130 women who attempted to become pregnant, 90 (69.2%) conceived. Among 896 women who did not attempt to conceive, 18 (2%) became pregnant. A total of 152 pregnancies resulted in 91 live births. Factors associated with pregnancy included age at diagnosis and history of prior pregnancy(ies). Women who had received endocrine therapy for their breast cancer were less likely to become pregnant during the first five years. These findings suggest that many women remain interested in future fertility after a breast cancer diagnosis. While only a minority of those interested in having children attempted to become pregnant in the first 5 years, most who attempted to conceive did so and had live births.

[Read more about this study.](#)

### **Pregnancy After Breast Cancer in Patients with Germline *BRCA* Mutations**

Young women with inherited variants in the *BRCA1* and *BRCA2* genes often face unique reproductive challenges. Although pregnancy after breast cancer does not increase the risk of recurrence, only limited data have been available for patients with *BRCA* variants. Helping Ourselves, Helping Others: The Young Women's Breast Cancer Study was one of the largest participants in this international study, which is by far the most extensive to date to focus on young patients with *BRCA* variants. The main goal of this study was to evaluate the impact of pregnancy on breast cancer outcomes among patients with inherited *BRCA* variants. Of the 1,252 eligible patients, all of whom had *BRCA1* or *BRCA2* variants, 195 (19%) had at least 1 pregnancy within 10 years after breast cancer. Among the 150 women of the who gave birth (76.9%), pregnancy complications, such as preterm labor, occurred in 11.6% of pregnancies, and congenital abnormalities in 1.8% of the offspring. Breast cancer outcomes among patients who became pregnant after their breast cancer diagnosis were equivalent to outcomes among women who did not get pregnant. Based on the findings from this study, pregnancy after breast cancer in patients with germline *BRCA* mutations appears safe and without apparent increase in risk of recurrence for the mother. Furthermore maternal and fetal outcomes appear similar to the general population. These results provide reassurance for breast cancer survivors with *BRCA* variants who are interested in future fertility.

[Read more about this study.](#)

### **Clinical behavior and outcomes of breast cancer in young women with germline *BRCA* mutations**

Young breast cancer patients carrying inherited *BRCA* variants have similar breast cancer outcomes as patients who are non-carriers. Helping Ourselves, Helping Others: The Young Women's Breast Cancer Study was one of the largest participants in this international study, which investigated the impact of the gene variant (*BRCA1* vs. *BRCA2*) and breast cancer subtype (hormone receptor positive vs negative). Among 808 and 428 patients with *BRCA1* or *BRCA2* variants, 191 (23.6%) and 356 (83.2%) had hormone receptor positive tumors, respectively. Distant recurrences were uncommon in both groups, and less frequent among patients with *BRCA1* variants. New unrelated breast cancers and the development of other cancers (non-breast cancers) were less frequent among patients with *BRCA2* variants. No differences in breast cancer outcomes were observed according to hormone receptor status. These results provide reassuring information for patients with *BRCA1* or *BRCA2* variants that the type of mutation does not impact prognosis and additional important for treatment, prevention, and surveillance strategies. [Read more about this study.](#)



## ADDITIONAL RESOURCES AND INFORMATION



**Susan G. Komen**  
[www.komen.org](http://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](http://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](http://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**  
<http://bit.ly/2qxgceS>

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](http://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](http://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

## EMBRACing Young and Strong

A community for young women with **metastatic breast cancer**. Virtual social events are held twice monthly for young women with MBC to connect with each other. For more information, please email [youngandstrong@partners.org](mailto:youngandstrong@partners.org)

## Facing Forward

**Ashley Boyd Fermin, MSW, LCSW**

A six-session series held twice yearly for patients who have recently completed early-stage (0-III) breast cancer treatment. For more information, email [youngandstrong@partners.org](mailto:youngandstrong@partners.org).

## Young Women's Telephone Support Group

**Megan Donovan, MSW, LCSW**

These weekly group calls, facilitated by a breast oncology social worker, give young patients and survivors an opportunity to discuss topics relevant to young women with breast cancer. This group is best suited to women who were diagnosed with stage 0-III breast cancer before age 45 and are within 12 months of the diagnosis. If you're interested in registering for the next cohort, please e-mail [youngandstrong@partners.org](mailto:youngandstrong@partners.org) or call **617-632-3916** for more information.

# Join Team Young and Strong for The Jimmy Fund Walk October 3

To continue keeping our community safe, the 2021 Jimmy Fund Walk will not follow routes along the Boston Marathon® course. Instead, walkers will choose their own location to walk: your neighborhood, a local trail, a treadmill, your backyard—the options are endless! Join Team Young and Strong for a day of celebrating each other! Donations are also greatly appreciated. Please visit <http://danafarber.jimmyfund.org/goto/YoungAndStrong2021> to sign up.

