

Young and Strong®

A PROGRAM FOR YOUNG WOMEN WITH BREAST CANCER

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SUSAN F. SMITH
CENTER FOR
WOMEN'S CANCERS



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 3,000 young women have been enrolled to date.

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

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THE SURVIVORSHIP STAGE of care can be a time of hope and empowerment, but can also bring physical and psychological challenges to survivors and caregivers. Cancer can have a profound effect on your physical and emotional health and well-being, and in many cases may affect your job, health insurance, finances, and other personal matters. There is a growing focus on meaningful and effective survivorship care to address these important issues.

What is cancer survivorship?

According to the National Cancer Institute, cancer survivorship addresses the physical, psychosocial, and economic issues of cancer, from diagnosis until the end of life. Survivorship care includes the ability to get follow-up treatment, understand the late effects of treatment and risk for second cancers, and enhance quality of life. Practically, however, the survivorship phase is generally the time when a patient is through early active treatment and trying to adjust. By this definition, there are approximately 14 million cancer survivors in the United States.

Many survivors report the need to define or develop a "new normal" after treatment. Some common challenges include:

- Long-term and late side effects of the cancer and its treatment
- Need to improve health behaviors such as diet and exercise, and smoking cessation
- Anxiety, depression, and fear of recurrence
- Relationship, social, employment, and financial concerns

What is a cancer survivor program?

A cancer survivor program is designed to maximize the quality of life of survivors and their caregivers. Strong programs include a comprehensive set of services in which medical professionals, social workers, physical therapists, and others work together

to address your needs. At the end of your treatment, some survivor programs and/or your medical oncologist offer a visit which includes developing and reviewing a treatment summary and survivorship care plan to outline potential late effects and medical information related to your past treatment and recommendations for future care. This plan can be a useful guide for you and your primary care doctor.



Young cancer survivors Amanda Skyepeck (left) and Judy Rosenbaum

Dana-Farber Adult Survivorship Program

The Adult Survivorship Program at Dana-Farber provides clinical services and care, including treatment summaries and survivorship care plans, educational programs, support services, and informational resources. It helps cancer survivors understand what they went through, and learn how to move forward after cancer. Through this unique program, survivors have access to medical and psychosocial experts as well as healthy living and resource specialists.

"It's important to acknowledge that life is different after a cancer diagnosis," says Patricia Nutting, NP, MSN. "It is okay to ask for

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What is precision medicine?

YOU MAY HAVE HEARD THE TERM “PRECISION MEDICINE” and wondered what it means, or wanted more information about this area of medicine. Precision medicine, also called personalized medicine, describes tailoring medical treatment for a person and his or her disease in order to give the most effective care possible. Precision medicine uses information such as inherited genes, lifestyle and environmental factors, and molecular characteristics of the disease.

Recently, there has been an increased attention to this area of science. President Obama announced the launch of the Precision Medicine Initiative, a bold research effort focused on the development of individualized care. This call was further supported and linked specifically to cancer care and research by Vice President Biden who, after losing his son to brain cancer, introduced his “moonshot” initiative to fight cancer in the U.S.

Why is precision medicine important in oncology?

Cancer is a disease of the genome. Everyone has a genome; it is your complete set of DNA, which includes all of your genes. Some genes help regulate or control cell growth and division. Cancer occurs when there is a change in normal cell growth and division. If the change is significant, such as many cells dividing in a disorderly pattern, genetic defects can happen, which may lead to cancer. The goal of precision medicine in oncology is to understand the genetic changes underlying the cancer and to find the most effective treatment for each person's unique cancer and genetic makeup.

We now know that cancer is not one disease, but many, even within a type of disease, such as breast cancer. Targeted therapies are an important part of precision medicine. These cancer treatments, which are often drugs, target the particular genetic or molecular characteristics of the cancerous cells, while minimizing damage to normal, healthy cells.

However, not all tumors behave in the same way, so these drugs are not equally helpful to everyone. Identifying who will benefit from targeted therapies is one of the main goals of precision medicine. To this end, scientists at Dana-Farber Cancer Institute, Brigham and Women's Hospital, and Boston Children's Hospital are building one of the largest databases of genetic abnormalities in cancer called “Profile.”

This genotyping study began in 2011 and currently holds genetic information of more than 15,000 patients. Every patient at the partnering hospitals can participate and have gene sequencing, which scans several hundred cancer-related genes to look for abnormalities. Group data is also reviewed so that researchers can study patterns between mutations and clinical outcomes to design therapies for the future.

How is precision medicine advancing the treatment of breast cancer?

Standard treatments in breast cancer care today are an early and simple form of precision medicine, called stratified medicine. Stratified medicine involves grouping patients based on the type of disease and the potential response to therapies. In breast cancer, patients are grouped by hormone receptor status; patients who test positive for estrogen receptors and/or progesterone receptors usually receive anti-hormone therapy, such as tamoxifen, aromatase inhibitors, or ovarian suppression. Similarly, patients who show receptors for the Her2 protein traditionally receive Her2 targeted therapies, such as trastuzumab or pertuzumab.

Finding the “best” treatment means finding a treatment that will work well against one's cancer, but also ensuring that unnecessary or



ineffective treatments are not given. Some breast cancer survivors may have had a tumor profiling assay called Oncotype Dx®. This can help clinical teams decide if chemotherapy is needed. This is an early example of using tumor characteristics to determine the potential benefit of a therapy, helping some low-risk patients avoid the side effects and health risks that come along with chemotherapy.

While breast cancer has led the way among other disease groups in using these stratifying techniques and tumor profiling tests to develop and deliver treatments, additional individualized treatments are still needed.

Next steps

The field of oncology is ripe for discoveries with life-saving potential. While key advances in precision medicine have been made, there is still a lot of work to be done. Continued patient participation and funding is essential to advancing this area of research which has such promise to improve the health and well-being of patients with cancer. **Y&S**

To learn more about Precision Cancer Medicine at Dana-Farber, visit: **www.precisioncancermedicine.org**.

To learn more about precision medicine in general, visit: **<https://ghr.nlm.nih.gov/handbook>**

You can also view the NIH Precision Medicine Initiative Channel on YouTube.



Spotlight

Meet Stephanie Cram



Stephanie Cram is the new program coordinator for the Young and Strong Program. Stephanie previously worked in Human Resources at Dana-Farber where she supported the needs of Dana-Farber staff and faculty. She looks forward to bringing her passion for helping others to the Young and Strong Program and is honored to be working on behalf of young women with breast cancer.

Stephanie can help answer questions about the program and all the resources available to you.

You can contact her at **617-632-3916** or

stephanie_cram@dfci.harvard.edu



Examples of precision medicine in breast cancer

Drug	Target	Approved for
Tamoxifen and Aromatase Inhibitors	Starve cancer cells of the estrogen they need to grow. Tamoxifen attaches to hormone receptors on cancer cells, blocking estrogen from “feeding” the cancer cell. Aromatase inhibitors lower the amount of circulating estrogen in the body by blocking aromatase, an enzyme that converts other hormones into estrogen.	ER+ and/or PR+ breast cancers. Tamoxifen can be used in all women, while aromatase inhibitors have traditionally been used only in postmenopausal women. However, recent research has shown that aromatase inhibitors, in combination with ovarian suppression, are also beneficial in premenopausal women.
Trastuzumab (Herceptin) and Pertuzumab (Perjeta)	Block Her2 receptors. Trastuzumab, a specifically made antibody, targets and attaches to the Her2 protein on the surface of cancer cells and can stop or slow their growth. Pertuzumab is another antibody that blocks a pathway of Her2 growth with the intent of preventing drug resistance to trastuzumab.	Her2+ breast cancers* *Pertuzumab is currently only approved in the metastatic and neoadjuvant (presurgery) setting given in combination with trastuzumab. Clinical trials are investigating its further value in early breast cancers.
CDK4/6 inhibitors, ex. palbociclin (Ibrance®)	Interrupt the growth of cancer cells by inhibiting function of CDK4 and CDK6 enzymes which are important in cell division.	ER+ Her2- metastatic breast cancers Clinical trials ongoing for early stage breast cancer.
Tyrosine-kinase inhibitors, ex. lapatinib (Tykerb®)	Block tyrosine-kinase enzymes , which are important for cell functions, at many points along the cancer growth pathway.	Her2+ metastatic breast cancer in women who have already had chemotherapy and trastuzumab.
PARP inhibitors	Block the PARP enzyme , which is involved in DNA repair, to decrease chances that the cancer cells become resistant to chemotherapy.	Still under study and only available in a clinical trial; early evidence suggests most benefit is for those who have a BRCA 1/2 mutation.

Living beyond cancer

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help. We work with you to create a treatment summary, support you as you transition to life moving forward and identify what your individual needs are. Getting support in a timely manner is so important.”

What resources are available?

It is important to know that no matter what your concerns are, there are resources available to support you to live well beyond cancer. Dana-Farber’s Adult Survivorship Program offers an array of services for adult cancer survivors.

To learn more about the Adult Survivorship Program at Dana-Farber, visit www.dana-farber.org/survivor. Here you can also find teaching sheets on various topics.

To make an appointment, please call the clinic facilitator at **617-632-4523** or email DFCI_adultsurvivors@dfci.harvard.edu.

Other trusted resources with Survivorship Care programs and toolkits include:

- The Young Survival Coalition (YSC) www.youngsurvival.org
- The Cancer Survivor Network csn.cancer.org
- Journey Forward www.journeyforward.org
- LIVESTRONG www.livestrongcareplan.org

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**.

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**.

Upcoming events

Young and Strong Walk Team Formed

A Young and Strong Walk Team will once again participate in the Boston Marathon® Jimmy Fund Walk on September 25, with Dr. Ann Partridge as team captain.

To prepare, we will continue the tradition of Long Walk Sundays this summer. The group is a great way for young survivors to meet one another and get exercise. We are looking for volunteers to lead these walks, so please be in touch if you are interested. You do not have to be a member of the Walk Team to participate in Long Walk Sundays; all are welcome.

To learn more or get involved, please visit www.jimmyfundwalk.org/2016/youngandstrong or email youngandstrong@partners.org.

Third annual Celebrating Young and Strong Gala

Friday, Oct. 14 | Boston Harbor Hotel

This fun-filled fundraiser, established and run by young survivors, celebrates the courage and strength of all young women who are faced with breast cancer. Proceeds benefit Young and Strong, the Program for Young Women with Breast Cancer at The Susan F. Smith Center for Women's Cancers at Dana-Farber.

In addition to a joyful night of food, cocktails, and dancing, this evening event provides a unique opportunity for young women who have been diagnosed with breast cancer to gather for support, love, and encouragement. For more information or to buy tickets, please visit the gala website <http://www.celebratingyoungandstrong.com/> or email the planning committee coordinators (Meghan or Maggie) at celebratingyoungandstrong@gmail.com.



Planning committee members (left to right) Carie Capossela, Margaret Loucks, Kelley Tuthill, and Meghan Martin

Breast Cancer in Younger Women: A Forum for Patients and Survivors

Friday Oct. 14 | Joseph B. Martin Conference Center, Harvard Medical School

This annual full-day event for our patients includes a patient and survivor panel, an "Ask the Expert" panel including many prominent providers from the Susan F. Smith Center, and small group sessions with our social workers. For information or to register, call Stephanie Cram at **617-632-3916** or email youngandstrong@partners.org.