

Welcome!

This newsletter is the first from the **Program for Young Women with Breast Cancer at Dana-Farber Cancer Institute**. We hope to use this forum to keep you up to date on the latest developments in breast cancer care that are relevant for young women. We will also present you with results of research conducted through the Program and elsewhere, and promote opportunities to participate in ongoing studies to improve the information available for you and other young women. There will be some regular sections to expect each issue including a Q and A, a recommended resources section, in addition to a column covering recent happenings and personal stories. The question and answer section is inspired by your questions and will be answered by doctors and researchers with expertise in the area of concern. All articles are researched, written and checked, although you should always check with your own health care provider to confirm whether general recommendations are right for you.

For more information, we have included a section dedicated to recommended resources. Look to this section for reliable books, Web sites and other sources for support and information on anything from nutrition to how best to tell your friends and family you have cancer. And the calendar section highlights upcoming events in our area.

We would love to hear your feedback: what you liked, would like to see or would like to see changed, and any questions you might have. If you do not feel comfortable receiving this mailing please contact us to discontinue delivery.

Best wishes,
Ann Partridge and The Program for Young Women Team

Survivor Panel Inspires at Annual Forum

On a Saturday afternoon in July, there was a hush in the packed conference room as Magnolia Contreras described her initial reaction to learning she had breast cancer. "I asked the doctor to double check the medical record to be sure that it was mine because I couldn't believe what he was saying to me," she said. She went on to explain to the bewildered crowd of survivors, family and friends, advocates, staff and providers that it took a few days for her to acknowledge her denial. "Once I was ready to face the fact that I had breast cancer, I was able to fully engage in my care." Contreras, the director of community benefits at Dana-Farber, kicked off the patient panel with this dramatic admission at the annual Forum for Young Women with Breast Cancer held on July 12 at the Fairmont Copley Plaza Hotel in Boston. Contreras, now out 6 years from her diagnosis, along with 4 other women with a history of breast cancer, shared their stories and advice for those who are earlier on in their diagnoses. Carie Capossela, a 7 year survivor and contributor to the program, gave helpful tips and reassured the patients and loved ones in the audience that, "believe it or not, one day you will wake up and breast cancer won't be the first thing you think about."

This year's symposium was the 4th annual forum focused on younger women. In addition to the inspiring patient panel, attendees heard lectures focused on genetic testing, new directions in chemotherapy, and the role of hormonal agents in breast cancer treatment. Many Dana-Farber medical, radiation, and surgical oncologists as well as nurses, psychologists, social workers, and patients provided the latest information regarding treatment and living well with and after breast cancer. Information was also presented regarding the latest food facts by registered dietitians, and various therapists addressed areas of sexual health and wellness, exercise, and personal growth after breast cancer.

The Forum provided not only information, but also social outlets for young women. Between talks, Forum participants had the opportunity to choose between various breakout sessions, as well as participate in crafts and a group quilt-making exercise. Hala Moddelmog, president and CEO of Susan G. Komen for the Cure, attended the morning session and remarked: "This has been one of the most inspiring events I have attended in my time at Komen." For those who missed this year's Forum, planning for next year's is already underway. Stay tuned!

A Word About the Program

Established in 2005, the **Program for Young Women with Breast Cancer at Dana-Farber Cancer Institute** provides comprehensive care and support to young women confronting the challenge of living with and beyond breast cancer. Our mission is to provide optimal care and education for patients and their families, and to advance our understanding of both the biology of breast cancer and the experience of the disease for younger women through ongoing research focused on young women. Nearly 700 young women have been enrolled in the Program to date.

For further information about the Program, please call Jamie Isaacson at: 617-632-3916.



Participants in the forum enjoyed an artistic opportunity to create a quilt of expression

Fertility in Young Survivors: Recent Research Improves Understanding

We recognize that some young women are interested in having children after breast cancer. Balancing the desire to have a biologic child and the desire to get the best breast cancer treatment can be challenging. Treatments can affect future fertility: chemotherapy can damage ovaries to some degree, and tamoxifen or other hormonal agents are generally taken for several years, during which time fertility is declining with age. In the Program, we are conducting several studies to improve our understanding of ovarian function and fertility potential for breast cancer survivors. Recently, we completed an evaluation of ovarian reserve (i.e., fertility potential) in survivors who received chemotherapy compared to women without a history of breast cancer. The research revealed that fertility may be compromised, even in women who continue to menstruate regularly after breast cancer. While further research is clearly needed, women should consider this with their health care providers when thinking about their treatment and subsequent family planning decisions. While some women have impaired fertility, other young women can and do have biologic children after breast cancer, and a number of the survivor participants in this study have already contacted us to tell us they are pregnant.

We are currently looking for volunteers for a new study called: **Project FACE (Fertility and Cancer Education)**. This research aims to characterize the decision-making needs of young breast cancer patients (aged 21-45) when considering fertility and, in particular, thinking about available ways to try to preserve fertility through treatment. We will conduct focus groups in which women will be asked to share their thoughts and experiences regarding fertility in a small group setting (5-7 women). We aim to use this information to develop tools to improve communication about this important issue and the quality of decisions women make regarding fertility after a cancer diagnosis. Participating in the focus groups may also help women feel less alone in their experiences, while talking with others and gaining support may improve their quality of life. This study is being funded by the National Cancer Institute and is led by investigators at Brown University and Dana-Farber Cancer Institute. Young women who have been diagnosed with Stage I-III breast cancer within the past three years are eligible to participate. All participants will receive \$25. If you are interested, please contact Meghan Meyer at: 617-632-4983 or by email at mmeyer1@partners.org



Helping Ourselves, Helping Others: The Young Women's Breast Cancer Study

Doctors and nurses at Dana-Farber/Brigham and Women's Cancer Center often hear the following question from patients: "Are you learning anything from me and my cancer?" Over the past two years, researchers in the Program for Young Women with Breast Cancer have been trying to do just that - learn from every young patient. Through Helping Ourselves, Helping Others: The Young Women's Breast Cancer Study, we identify all women age 40 and younger at diagnosis seen at participating sites and ask them to participate in this novel study, designed to answer many of the unanswered questions facing young survivors.

Helping Ourselves, Helping Others, or HOHO, opened at Dana-Farber/Brigham and Women's Cancer Center, Faulkner Hospital, and Massachusetts General Hospital in late 2006, and spread to Beth Israel Deaconess Medical Center, North Shore Medical Center, Newton-Wellesley Hospital, South Shore Hospital, Cape Cod Hospital, Lowell General Hospital, and Caritas Saint Elizabeth's Medical Center. We anticipate that several other sites will open the study in the coming year, including sites in Italy and Switzerland. To date, more than 200 young women have joined the study, and we are actively recruiting additional participants. Women are identified through pathology records and contacted by invitation to participate. This mechanism allows us to identify and invite all young women with a new diagnosis.

Women on the study are asked to answer periodic surveys about their health and quality of life, share a blood sample, allow researchers to review their medical records, and use a piece of their removed tumor specimens to study the biology of breast cancer in young women. The blood and tumor specimens collected are being used to determine if tumors in young women are different than those found in older women. We will explore factors associated with side-effects of treatment in young women. The surveys will also help us to more fully understand the experience of young women with breast cancer, from a physical, emotional, and social standpoint. Questions such as the often-asked, "Will I be able to work through this treatment?", will be addressed including the experience of this diverse, large group of women. This type of information will ultimately help doctors develop more effective, personalized care for younger patients, including symptom and support interventions during early and long-term survivorship.

We are thrilled by the response to this study so far and hopeful that women will continue to participate. We look forward to providing early findings from the research as they become available in future newsletters from the Program. Please call Meghan Meyer at 617-632-4983 if you have any questions or would like to respond to an invitation to join the study.

Exercise Program Will Kick You Into Shape!

Regular exercise has many benefits for breast cancer patients during and after treatment. Most importantly, preliminary evidence suggests that women who exercise after being diagnosed with breast cancer may have lower rates of cancer recurrence as compared to less active women. Several studies have shown that recurrence rates are up to 50 percent lower in women who exercise moderately for three or more hours per week.

Although these studies are preliminary and we do not yet know for sure that increasing your exercise after cancer will improve your odds of remaining cancer free, there are several other good reasons why breast cancer survivors should include exercise as a part of their health routines. Women who exercise following diagnosis feel better and have more energy compared to women who do not exercise. Exercise also helps to improve mood and self-esteem, and prevents weight gain, which many breast cancer patients experience during chemotherapy and other treatments.

Before starting an exercise program, be sure to check with your physician or nurse practitioner. Remember that building up energy during and after treatment can be a slow process. Each woman is different, and each will regain her normal level of energy at her own pace. Be patient!

Cardiovascular exercise, weight-bearing exercise, and stretching are all important components of an exercise program. Walking is a very popular form of cardiovascular activity because the only equipment required is a good pair of walking shoes. Other good activities include biking, swimming, aerobics, and tennis. It is also important that you try to exercise up to at least a moderate pace where you break into a light sweat and your breathing increases.

In order to jump start you into an exercise routine and learn more about the value of exercise, we have a number of exercise studies available for breast cancer survivors. Two ongoing programs are listed below. If you are interested in participating in these studies or would like to learn more about future exercise programs at Dana-Farber, please contact Laura Shockro at 617-632-2122 or lshockro@partners.org.

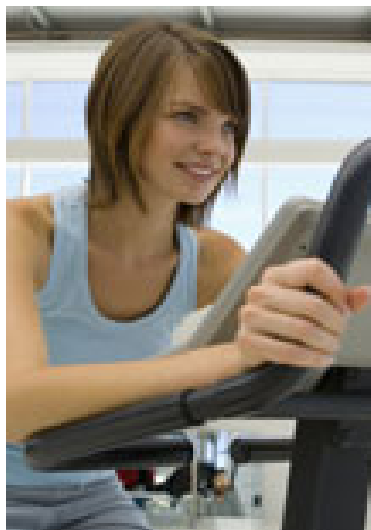
The Active after Cancer Trial is a telephone-based exercise study that is currently enrolling patients who have recently finished treatment. The study is being done to determine whether women who are not currently exercising can begin and stick to an exercise program with the help of telephone coaches. The study will also examine whether women who participate in the program lose weight and become more fit.

The Pilot Study of Exercise in Women with Metastatic Breast Cancer is a clinical trial to examine the effects of exercise on endurance, mood, and quality of life. Participants will work with an exercise physiologist to set goals and design an individualized exercise program. Women will receive a four-month membership to a local YMCA, a heart-rate monitor, and a pedometer.

Tips for getting started and sticking to an exercise program:

- 1. Wear comfortable clothes and sneakers***
- 2. Start slowly and gradually increase your duration***
- 3. Set short-term, achievable goals***
- 4. Exercise with a friend***
- 5. Don't get discouraged if you stop***

Try to make exercise a part of your daily routine!



Additional Resources and Information



Thrive Together, Inc.

Provides support, services and education to young women in the Greater Boston area who have been diagnosed with breast cancer.

www.thrivetogether.org



Susan G. Komen for the Cure

Susan G. Komen for the Cure, the global leader of the breast cancer movement, is the world's largest grassroots network of breast cancer survivors and activists, working together to save lives, empower people, ensure quality care for all and energize science to find cures.

www.komen.org



Young Survivors Coalition

The Young Survival Coalition (YSC) is the premier international, nonprofit network of breast cancer survivors and supporters dedicated to the concerns and issues that are unique to young women and breast cancer. The YSC also serves as a point of contact for young women living with breast cancer

www.youngsurvival.org

Q & A: "What's all this about Vitamin D? Should I take it and why?"

"Vitamin D" is actually a hormone that the body uses to regulate calcium absorption. Since calcium and vitamin D are important for bone health, it is important that you have adequate levels of both to avoid bone loss and fractures. There is also preliminary evidence that women with inadequate vitamin D levels may be at increased risk of breast cancer and breast cancer recurrence, although there has been no direct proof that taking vitamin D supplements can decrease the risk of developing breast cancer or recurrent disease.

Vitamin D is made by the body in response to sunlight and ingested as food or supplements. A few minutes of direct sunlight produces significant amounts of vitamin D, but women who are receiving chemotherapy and some other breast cancer treatments may be more sensitive to the sun. Always check with your doctor before getting direct sun exposure. And, of course, significant lifetime sun exposure increases risk of skin cancer.

The major dietary sources of vitamin D are dairy products (milk, yogurt, cheese, and egg yolks), liver, and saltwater fish such as salmon, tuna, and mackerel. There is currently a lot of debate about how much vitamin D supplementation the average woman should be taking. In the past, 400 IU (international units) was the recommended dosage for most women. Now, some experts suggest 800 IU or even more, although there is not much evidence to suggest that these higher doses are more beneficial, and there are some potential risks of too much vitamin D. Until more information is available, a daily Vitamin D dose of 400-800 IU is reasonable.

Harnessing the Power of Hormones

The effectiveness of most medications depends upon maintaining a therapeutic amount of a drug in the body for a minimum duration of time. Often a medication needs to be taken consistently for a specific period of time to even begin being effective, and the full benefit can only be achieved through regular use. The extent to which a person follows a prescribed regimen has been termed "adherence".

Research has recently revealed that adherence with hormonal therapy may not be as good as it could be in some women. Large clinical trials have revealed the substantial benefits in reducing risk of breast cancer recurrence from hormonal therapy (e.g., primarily tamoxifen for premenopausal women) for women with a history of hormone receptor-positive breast cancer. However, in the "real world", not all women take their tamoxifen or other medications as directed. Some women have difficulty incorporating regular medication use into their busy lives. Others have trouble with side effects which may affect the ability or desire to take hormonal therapy. Still, others may forget to refill their prescriptions or may not be able to afford them, and some women may not believe that the medications will do anything for them.

Whatever the reason, health care providers may be able to help women who are having difficulty sticking to their medication regimen. Sometimes, information to clarify the importance and goals of treatment or reinforcement may be all that women need. Information about managing side effects, affording medication, and alternative treatments can also be provided. Practical tips for maintaining adherence are often helpful as well. If women do not think of taking tamoxifen or other hormonal therapy as a chore but rather something empowering and hopeful, adherence may be easier and more satisfying. It is also important to make taking medication as convenient as possible.

Helpful Tips to Enhance Adherence to Hormonal Therapy:

**Put your medications in your make up bag, next to your tooth brush or your coffee pot, or another place that you go everyday, so taking your medication is not an out-of-the-way activity.*

**Use a decorative pill box or pill organizer with days of the week*

**Taking the pills out of their generic bottle might help to make them less threatening and more comfortable*

**If you are taking different pills multiple times a day for different reasons, speak to your*

doctor to see if you can simplify your medications and reduce to fewer pills and fewer dose times so that taking them is more manageable.

What your healthcare provider should be doing for you: Communication is the best way to help patients. Your doctor should clearly explain the importance of taking a specific medication, what its purpose is, and what the negative side effects might be. And when side effects occur, clinicians can help you to deal with them. Your team is on your side in the battle against breast cancer and good communication about how you feel and what you are doing may be critical to your overall health and well-being.

"Drugs don't work if people don't take them" – C. Everett Koop, Former US Surgeon General

*Save
the Date*

Facing Forward After Breast Cancer

Jane Bausch, LICSW

November 13, 20 and December 11, 2008

Shields Warren 300

5:30p – 7:00p

Young Survivors' Evening

Geralyn Lucas and Ann Partridge, MD

Wednesday, November 19, 2008

7:00 – 9:00 p.m.

Dana Building 1620

*Information and discussion geared toward young women who are at least one year out from diagnosis

Young Women's Support Group

Dana-Farber Cancer Institute

Genevieve Mason, LICSW

Dates and Location: TBD

Winter Young Women with Breast Cancer Telephone Support Group

Patricia Sheehan, LICSW

Wednesday, January 14, 21 and 28,

2009 and February 4, 11, and 18, 2009

7:30 p.m. – 9:00 p.m.

Coping Skills and Mindfulness Workshop

Sharon Bober, Ph.d, Karen Fasciano,

Psy.D, Amy Gross, LICSW, Genevieve

Mason, LICSW

Monday, January 26, 2009

9:00 a.m. – 1:30 p.m., Location: TBD