A Message from Ann Partridge, MD, MPH

Welcome to the Fall 2016 edition of the Young and Strong newsletter.

Fall is an exciting time for the Young and Strong Program. We have our Annual Forum on October 14th, held at the Joseph B. Martin Conference Center at Harvard Medical School, in the Longwood Medical Area in Boston, MA. This special event brings together experts who focus on the array of issues that are important to the care of young women with breast cancer and the Young and Strong community. During this season we will continue to offer educational seminars and workshops developed just for young women; we hope you can join us for our in-person and web-based programming. We share these opportunities in our monthly emails. If you do not receive these emails and would like to, please contact the Young and Strong team at youngandstrong@partners.org.

In this issue of our newsletter, we are highlighting new research opportunities as well as the exciting progress made since our last research update, particularly in the research that we have conducted in Helping Ourselves, Helping Others: The Young Women’s Breast Cancer Study. Many of you have participated in the research and I am extremely grateful for your contributions. You have helped advance science in the area of breast cancer in young women- thank you!

You will also find a spotlight on members of our wonderful walk team, Team Young and Strong. This year we raised over $35,000. Funds will go directly to support the Young and Strong Program. A very special thank you to our walk members and supporters! It was an honor to be this year’s team captain and walk with you. We hope current and new members will join us next September when we walk again.

Finally, we are asking for your feedback. This program is meant for you, so we would love to hear from you. On the enclosed comment card please let us know all the things you appreciate about the program as well as areas in which you would like to see changes or have questions.

In closing, a patient of mine recently shared the quote below. It speaks to me and I hope you too find that it resonates.

"Life isn’t about waiting for the storm to pass…it’s about learning to dance in the rain.”
—Vivian Greene

Best wishes, on behalf of the Young and Strong team,

Ann Partridge, MD, MPH
Founder and Director, Young and Strong
Director, Adult Survivorship Program
Associate Professor of Medicine
The Young Women’s Breast Cancer Study (Helping Ourselves Helping Others or HOHO) Update

We have enrolled 1302 women diagnosed with breast cancer at age 40 and younger to this study; we have closed accrual this year. Through surveys, blood and tissue collection, and review of medical records, we have gathered a wealth of information regarding breast cancer in young women which will help many women in the future. We are grateful for the continued participation of all women in the cohort and are pleased to give an update about findings based on the data collected.

BRCA Testing

The frequency of BRCA testing among women enrolled in the cohort increased over the last several years. Among women diagnosed in 2006, 77 percent reported having a BRCA test. Among women diagnosed in 2013, 95 percent reported testing. Additionally, about 30 percent of respondents said that knowledge or concern about genetic risk affected treatment decisions in some way. Of these women, 86 percent of BRCA mutation carriers and 51 percent of non-carriers said they chose bilateral mastectomy.¹

Perceptions toward Endocrine Therapy and Adherence

For young women with hormone sensitive tumors, views about endocrine therapy, such as tamoxifen or an aromatase inhibitor, may play an important role in their adherence to this treatment. Adjuvant endocrine therapy has been shown to substantially reduce the risk of breast cancer recurrence and mortality in women with hormone sensitive breast cancer. However, in a survey of a subset of women enrolled in the cohort, only 48 percent of respondents believed that endocrine therapy was essential.

Women who reported a greater degree of financial comfort as well as those who had more positive emotions toward endocrine therapy were more adherent with their endocrine treatment. Findings from this study may inform the design of interventions intended to modify young women’s perceptions of endocrine therapy, with the goal of improving adherence and ultimately outcomes.²

Local Therapy Decision-Making

As rates of bilateral mastectomy have dramatically increased in the U.S. over the past several years, we sought to examine the surgical decisions made by young women enrolled in the cohort. In this study, we found that 43 percent of women had a bilateral mastectomy, 30 percent had a lumpectomy, and 27 percent a unilateral mastectomy. Women who said they made the decision about surgery mainly on their own [vs. shared the decision with their doctor] were more likely to have chosen bilateral mastectomy. Other factors that were associated with having a bilateral mastectomy included both clinical (e.g., larger tumor size, lower BMI) and emotional factors (e.g., anxiety). Findings from this study suggest enhancing psychosocial support as well as encouraging shared decision-making with providers might be helpful to newly diagnosed women who are making decisions about their treatment.³

Molecular Phenotype of Breast Cancer

According to Time Since Last Pregnancy in a Large Cohort of Young Women

There is a known increase in breast cancer risk during pregnancy and postpartum. However, the types of breast cancer that occur shortly after pregnancy have not been well studied. To better understand this, we looked at responses from both women who had not given birth and women who had given birth before their cancer diagnosis, documenting types of breast cancer in relation to time since pregnancy. Numerically, patients diagnosed more than five years after pregnancy and women who were never pregnant had more luminal A-like subtypes, a category that includes tumors that are hormone sensitive (“ER+” and/or “PR+”) and are also Her2 negative, compared to women with shorter times to pregnancy. However, there was no evidence of a relationship between time since pregnancy and subtype of breast cancer when important factors such as family history of breast cancer and age at diagnosis were considered.4

Did you know?...

- Women from **41 states** and **4 countries** are represented in HOHO
- We have recruited women from **13 different sites**, many of which are local to Boston, but as far away as Mayo Clinic in Rochester, MN, University of Colorado Denver and Sunnybrook Cancer Center in Toronto, Canada.
- The average age of the study participant at diagnosis was **35**
- The very first person who enrolled in the study still actively participates and she is now in her **10th year** with the study.

Partner Support and Anxiety

Perceptions of partner support were found to have a significant effect on anxiety in young women with breast cancer. Among women diagnosed with early stage breast cancer, findings showed that those who reported being in an unsupportive partnered relationship were more likely to have anxiety symptoms compared with women in a supported partnered relationship. Interestingly, unpartnered women did not have higher levels of anxiety compared with those who were partnered and supported. Interventions to enhance partner support and reduce anxiety might be beneficial to address challenges experienced as a couple in this setting.5
A Cancer Treatment in your Medicine Cabinet?

What if there was a medicine in your cabinet that could lower your risk of breast cancer recurrence and enhance overall survival? Researchers at Dana-Farber Cancer Institute and Brigham and Women's Hospital are investigating this question with the launch of a randomized study that will examine the therapeutic role of aspirin in breast cancer treatment.

Previous research has shown that breast cancer survivors who reported taking aspirin regularly had a 50 percent lower risk of breast cancer recurrence and death compared to those who did not use aspirin regularly. What does this mean for you?

The study will be the first in the U.S. to randomize breast cancer survivors to either aspirin or a placebo. It is supported by the Department of Defense and the National Cancer Institute. If the results of the trial show a reduction in recurrence and mortality rates associated with aspirin use, this could support the use of aspirin as an inexpensive, low side-effect addition to treatment plans.

“The results of this trial, if positive, could have a huge impact on the disease, as we have estimated that aspirin may save 10,000 lives a year in the U.S. and 75,000 lives in low-income countries," says Wendy Chen, MD, MPH, a senior physician at the Susan F. Smith Center for Women's Cancers at Dana-Farber and a co-investigator on this study.

This study will be open to enrollment in the near future. For more information, please contact your provider.

Dana-Farber Investigators
Put Breast Cancer on a Diet

Jennifer Ligibel, MD, a breast oncologist in the Susan F. Smith Center for Women’s Cancers at Dana-Farber, is investigating the impact of weight loss on breast cancer recurrence. The study, conducted with support of the National Cancer Institute and in partnership with several organizations including Fitbit, Susan G. Komen, and Nestle Health Science, will enroll 3,200 overweight or obese U.S. and Canadian women. Participants must have stage II or III breast cancer diagnosed within the last year and meet certain weight criteria at enrollment. Participants will be randomized either to a health education program (control group) or a health education program plus weight loss intervention program. Participants in the weight loss program will be paired with a health coach, who will work with them on the telephone to increase exercise and cut calories, and will receive tools like a Fitbit and protein shakes to help them meet weight loss goals. According to Dr. Ligibel, “If this study shows that losing weight through increasing physical activity and reducing calories improves survival rates in breast cancer, this could lead to weight loss and physical activity becoming a standard part of the treatment for millions of breast cancer patients around the world.” If you are interested in the study, please contact your physician and ask if the Breast Cancer Weight Loss (BWEL) study is open at your institution.

Support and Education

SoulMates
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 SoulMates 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 twice a year. For more information, contact Stephanie at 617-632-3916 or 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, 11-12:30pm
For women of all ages with metastatic breast cancer. For more information or to register, call Liz Farrell at 617-632-5606.

UPCOMING EVENTS

Parenting Workshop
Anna Muriel, MD, MPH, and Nancy Borstelmann, MPH, LICSW | November 16, 2016
Join us for an informational session and discussion about parenting before, during, and after breast cancer treatment. For more information, contact Stephanie Cram or email youngandstrong@partners.org.

Webcast on Local Therapy
December 13th 7:00 PM – 8:00 PM EST
Join us for our 4th webcast in the Young and Strong Webcast series as Shoshana Rosenberg, ScD and Laura Dominici, MD present on “Local therapy: surgical decision making to long-term side effects”. Email youngandstrong@partners.org for more information or to register.