

EMBRACE

SUMMER 2014

SUSAN F. SMITH
CENTER FOR
WOMEN'S CANCERS

DANA-FARBER
CANCER INSTITUTE

ENDING
METASTATIC
BREAST
CANCER
FOR EVERYONE



Letter from Dr. Lin

MORE THAN 600 WOMEN AND MEN WITH metastatic breast cancer have enrolled in the EMBRACE study since it started. Your feedback has helped improve the resources we offer, such as the second annual Metastatic Breast Cancer Forum and a new addition to our series of webcasts. We have shared your thoughts (for example, results from the survey at the end of last October's forum) with doctors, nurses, and social workers in our program, and we will continue to use them to improve the care we provide at Dana-Farber. The entire EMBRACE team is so grateful to you, and we consider you part of our team!

In this issue you will read about the work Dana-Farber investigators are doing to understand the underpinnings of drug resistance in estrogen receptor-positive breast cancer. You'll also learn strategies for managing some common side effects of cancer and its treatment, such as fatigue and, in our newest webcast, difficulties with intimacy and sexual functioning. Feedback from last fall's Forum and relevant links are also included.

These topics may seem unrelated, but they illustrate the complexity of breast cancer and the diversity of our research and clinical care efforts. Dr. Jennifer Ligibel is a pioneer in studying the roles of exercise, diet, and other lifestyle factors among patients with breast cancer. Dr. Rinath Jeselsohn has uncovered one of the ways in which estrogen receptor-positive breast cancers may become resistant to hormonal therapies over time. Dr. Sharon Bober is the founder and director of the sexual health program at Dana-Farber.

I hope you will be inspired by their passion and commitment as much as we are, every day, by you, our patients.

What you can do about fatigue

FATIGUE. THE WORD MIGHT MAKE YOU SIGH WITH FAMILIARITY, AND THERE'S GOOD REASON FOR THAT, ACCORDING TO JENNIFER LIGIBEL, MD, SENIOR PHYSICIAN IN MEDICINE AT DANA-FARBER CANCER INSTITUTE. FATIGUE IS "EXTREMELY COMMON" AMONG PEOPLE WITH CANCER. SOME PEOPLE FIND THAT FATIGUE CAN BE THEIR MOST LIMITING CANCER SYMPTOM.

CAUSES

Fatigue can result from cancer itself, from treatment, and from the psychological effects of having cancer. "There is not a lot of information on the exact cause," Ligibel says, "But research is ongoing."

FROM MISCONCEPTION TO MANAGEMENT

Research has shown that exercise decreases fatigue and builds endurance in people with cancer. Ligibel acknowledges that it's a difficult concept to grasp: "It seems counterintuitive, but exercise is actually the most effective fatigue management strategy. People think, 'I'm tired, so I should rest' but it's a vicious cycle," she explains. A better strategy, she advocates, is "Try to stay active, but

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2013 Metastatic Breast Cancer Forum

“ Thank you so much for sharing your knowledge. I truly appreciate your efforts to educate patients and communicate the availability of services and trials. Your dedication brings me hope. ”
 —Sara, 60

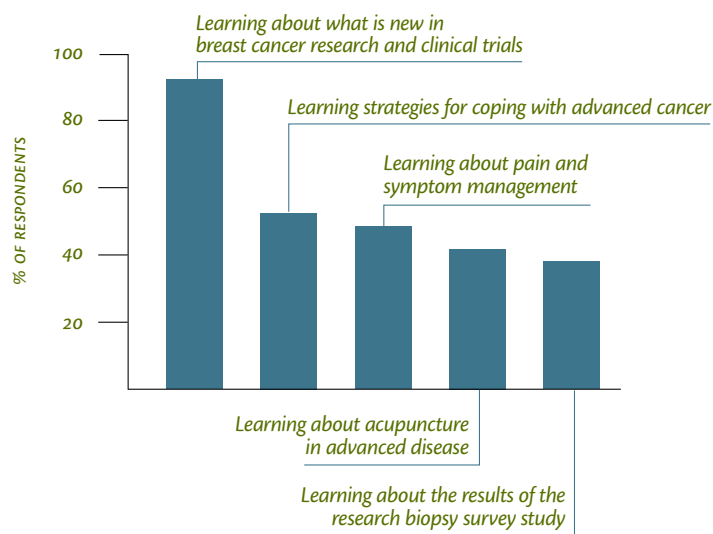
THANK YOU TO ALL WHO ATTENDED OUR METASTATIC BREAST CANCER FORUM ON OCTOBER 5, 2013! WE HAD 106 ATTENDEES, AND FEEDBACK INDICATES THAT IT WAS A SUCCESS: 100% OF PARTICIPANTS WHO COMPLETED SURVEYS (59) SAID THEY WOULD RECOMMEND THE FORUM TO OTHER PEOPLE WITH ADVANCED BREAST CANCER. ALSO, 100% FOUND THE FORUM USEFUL, WITH 73% FINDING IT VERY USEFUL.

Speakers and topics included:

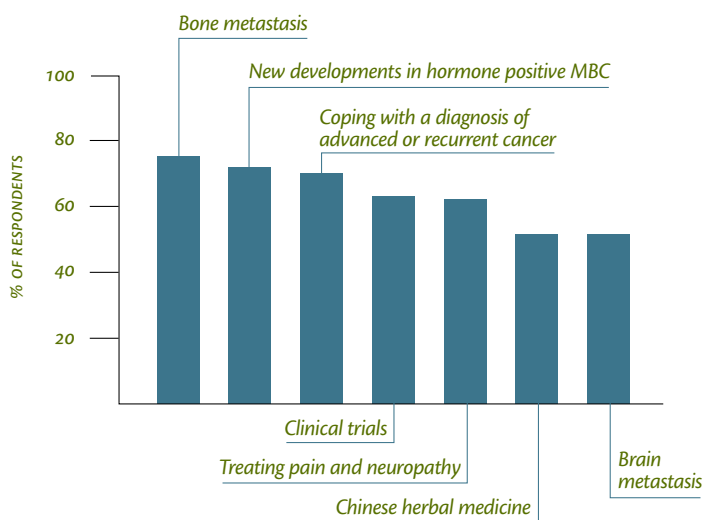
- Dr. Davinia Seah on Return of Results of Research Biopsy Survey
- Dr. Nancy Lin, Dr. Ian Krop, and Dr. Sara Toloney on What's New in Metastatic Breast Cancer Clinical Trials
- Dr. Lida Nabati on Pain and Symptom Management: Planning for the Future
- Elizabeth Farrell, LICSW, on Coping with Advanced Cancer
- Dr. Weidong Lu on Integrative Therapies: Acupuncture

“ This was my first Forum and I *really* enjoyed it. So much good information. Well delivered. ”
 —Rachel, 49

WHAT DID YOU FIND VALUABLE AT TODAY'S FORUM?



WHAT DO YOU WANT TO LEARN ABOUT AT THE NEXT FORUM?



“ Each speaker was articulate, organized, and informative. Thanks to all who made today work so well. Your efforts were successful and very much appreciated. ”
 —Jessie, 53

IF YOU WEREN'T ABLE TO ATTEND

Watch the webcast: <http://bit.ly/1eLL2fU>

SAVE THE DATE

Our next Metastatic Breast Cancer Forum will be October 18, 2014



Meet:

Jennifer Ligibel, MD

Senior Physician in Medicine

JENNIFER LIGIBEL, MD, HAS FULFILLED THE VISION of her four-year-old self who drew a self-portrait showing a lab coat. An Ohio native, she came to Boston after medical school to work as a resident in medicine at Massachusetts General Hospital. Ligibel was interested in women's health and a primary care path. "But I was drawn to complex medical needs and felt I could be of greater help to patients in more difficult times than in primary care," she says. When her aunt was diagnosed with ovarian cancer at a young age, Ligibel "saw a need to help people with serious illness navigate their care. It brought me to oncology."

Ligibel came to DFCI through a joint oncology fellowship with MGH and DFCI and stayed on staff at DFCI afterward. "I was initially hired as the first Dana-Farber oncologist working at the Faulkner Hospital," she says. Over time, she realized she needed research to balance clinical work. "I am always asked by patients, 'What can I do to help myself feel better?' There were no answers, and it was frustrating. Patients are often debilitated after treatment, and there's a real need to figure out how to help them regain their strength, and how to impact cancer risk." In 2004, she got her first grant and has received nine grants to date, all supporting interventions that investigate the effects of diet, weight, and exercise on cancer.

Ligibel's research interests were sparked by research linking lifestyle factors and cancer risk. She explains, "There was a lot of population-based evidence that with a healthier lifestyle, cancer risk was decreased. I wondered whether behavior change could be incorporated into treatment? Could regular exercise after a cancer diagnosis improve outcomes? An enormous volume of data indicated it could. It was very compelling."

Asked what she likes most about her work, Ligibel says, "Seeing patients is very important; it's why I came into medicine. It also helps ground me in what's important for research." About research, she says, "After 13 years of patient care, it was important to feel I'm working to combat cancer on a broader scale."

Research Update: ER Mutations

by Nancy Lin, MD

IN THE UNITED STATES, MORE THAN 60% OF ALL PATIENTS WITH breast cancer have estrogen receptor (ER)-positive and HER2-negative breast cancer. The most common anti-hormonal treatments for these types of cancers currently include tamoxifen, letrozole (Femara), anastrozole (Arimidex), and exemestane (Aromasin).

For more than 100 years, it has been known that ER-positive tumors can respond to anti-hormonal treatments, but a critical unanswered question is why these treatments don't work in all patients. Some patients with ER-positive metastatic cancer get little to no benefit from anti-hormonal treatments and need to transition to chemotherapy relatively early, while other patients can stay on hormonal treatments for many years.

Until recently, almost all research on breast cancer tissue has been done on the "primary tumor" (tissue collected at the time of the first breast cancer diagnosis, for example, at the time of a lumpectomy). Very little has been done on biopsies of patients after they have developed metastatic disease. Research on primary ER-positive tumors has turned up disappointingly little, with the exception of mutations in a gene called PIK3CA (numerous clinical trials are ongoing to test promising medicines that target this gene).

A VERY STRONG LEAD

In new research led by DFCI investigators Dr. Rinath Jeselsohn and Dr. Myles Brown, changes in the estrogen receptor gene have been found in metastatic tissue but not in the primary tumor. "With advanced sequencing technologies and an international effort to put together a large cohort of metastatic breast cancer samples, we have found functional ER mutations in approximately 15% of patients," reports Dr. Jeselsohn. When tested in the lab, the changes to the estrogen receptor made it overactive, resulting in cancer cells that were able to grow, despite exposure to commonly prescribed anti-hormonal treatments. These changes may explain why and how hormonal treatments stop working.

More research is needed to understand whether we should routinely test patients for this estrogen receptor change or whether the results should influence recommendations for treatment. However, we believe that this is a very strong lead. Based on these results, investigators at DFCI are working together to study these and other molecular changes in DFCI patients, and we hope to have a study open within the next 6–12 months.

In the future, this information may allow us to develop new and better drugs to treat ER-positive breast cancer and to personalize the treatment regimens we prescribe to patients.

This research is an important example of the power of cooperation between patients, pathologists, oncologists, statistical experts, and laboratory scientists—without any one of these partners, the research could not have been done.

Fatigue

Continued from page 1

be realistic." For example, walk around the block rather than for an hour. Your endurance will build. "You may be surprised," says Ligibel. "It becomes easier."

PRACTICAL TIPS

Ligibel offers a few tips to optimize energy and help manage fatigue:

- Conserve energy. Try to structure your activities around the times of day when you have the most energy.
- Delegate responsibility. What's on your plate that others could help with?
- Try labor-saving devices, for example, a bedside commode, a raised toilet seat, grabbing tools, or a walker.

RESOURCES

Resources at DFCI and in the community can help with fatigue.

EXERCISE. For help incorporating exercise into your life, free consults are available with Nancy Campbell, MS, through DFCI's Adult Survivorship Program (617-632-4523). Nancy also offers a free women's exercise class twice a week, and DFCI's Zakim Center for Integrative Therapies offers qigong and yoga classes (617-632-3322).

Outside of DFCI, the LiveStrong Foundation and YMCA created a 12-week exercise program called LiveStrong that's available free of charge for all cancer patients and survivors. The program is appropriate for people at any stage of cancer, Ligibel says, although you should talk to your doctor before beginning any new activity. LiveStrong offers small group classes that build strength, introduce aerobic exercise, and help establish a personalized program.

Info and map: LiveStrong.org (search for YMCA or scroll to the bottom of the page for a link).

COMPLEMENTARY THERAPIES. The Zakim Center for Integrative Therapies offers acupuncture, massage, meditation, reiki, and other therapies that may help with fatigue. Several future projects are planned to test the effect of these programs on fatigue in cancer patients.

PALLIATIVE CARE. DFCI's Adult Palliative Care Program (617-632-6464) offers symptom management services, including for fatigue. These services are often more pharmacologically based.

DO WE HAVE YOUR EMAIL ADDRESS?

If we don't already have your email address, please share it to receive updates via email. Email us at embrace@partners.org.

EMBRACE

ENDING METASTATIC BREAST CANCER FOR EVERYONE

Nancy Lin, MD *Principal Investigator*

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Please send us your comments, questions, and suggestions!
Email: embrace@partners.org Phone: 617-632-4915



Produced by DF/HCC Health Communication Core
www.healthcommcore.org

RECIPE FROM THE DANA-FARBER NUTRITIONISTS



Blueberry frozen yogurt

INGREDIENTS

- 2 cups of non-fat Greek yogurt
- 2 cups of fresh or frozen blueberries (or strawberries, blackberries, or raspberries)
- 1/4 cup of honey (or sugar)
- 1 tablespoon of lemon juice

DIRECTIONS

Blend blueberries, honey, and lemon juice in a blender or food processor until smooth.

Add yogurt to blueberry mixture in blender or food processor and mix until combined.

Pour blueberry and yogurt mixture into ice cream maker and freeze according to manufacturer's instructions.

If you do not have an ice cream maker, pour mixture into a freezer-proof container (shallow metal pan or glass container). For soft-serve consistency, freeze 30 to 60 minutes, stirring every 15 minutes. For solid ice cream consistency, freeze for 1 to 2 hours, stirring every 30 minutes.

Serve immediately or store in a container in the freezer. If frozen yogurt becomes too solid in freezer, place in refrigerator for 30 minutes until desired consistency is met.

YIELD: 4-6 servings

Dana-Farber offers a free iPhone app to help you find recipes and advice. Find it in the iTunes App Store or at www.dana-farber.org/nutritionapp.

Resources

NEW EMBRACE WEBCAST

We're pleased to share our second webcast: Intimacy and Sexuality for Women Living with Metastatic Breast Cancer, featuring Dr. Sharen Bober, founder and director of the sexual health program at DFCI.

Watch it: <http://video.dfcionline.org/accordent/Metastatic012214/>

STAGE IV BREAST CANCER SUPPORT GROUP

DFCI has a monthly support group to discuss the challenges of a stage IV breast cancer diagnosis. To participate, call Liz Farrell, LICSW, at 617-632-5606.