

EMBRACE

SPRING 2013

Letter from Dr. Lin

IT WAS WONDERFUL to see so many of you at the Metastatic Breast Cancer Forum in October. Special thanks to Liz Frank, Dr. Davinia Seah, Elizabeth Sewall, Peter Devereaux, Fran Smith, and the many volunteers for organizing and running this first-ever event. This newsletter highlights some of the event's topics.

If you missed the Forum, you can still see the webcast. Visit www.dana-farber.org and type "metastatic breast cancer forum" into the search tool.

Dr. Eric Winer, Director of the Breast Oncology Center at Dana-Farber, and I were moved by the energy in the room and struck by the obvious need for events like this, so we have committed to making it a yearly event. I'm especially grateful to

those of you who asked questions and provided feedback both during and after the Forum. The EMBRACE study team is already thinking of ways to use your feedback to improve the care for all of our breast cancer patients.

Since the last newsletter, Carolyn Curley, whom many of you have met, has left the study to take on a new role outside of Dana-Farber.

I still miss her dearly, as her boundless energy and dedication really helped to get the EMBRACE study off the ground. We have since hired two new research coordinators, Sairah Mahmud and Katie Cohen, and are continuing to improve and expand the EMBRACE study. You'll also read about three new faculty who have joined the Breast Oncology Center. Each brings complementary strengths to our program, and we are excited to welcome them to Dana-Farber.

In a very real way, you are the reason all of this is possible, and I want to thank you for your generosity and participation.

Warm regards,
Nancy Lin

EMBRACE survey results

"WHEN WE FIRST BECOME PATIENTS, WE RECEIVE AN ENCYCLOPEDIA OF RESOURCES THAT WE'RE NOT READY TO LOOK AT. HOW CAN WE GET THE RESOURCES WE NEED AT THE TIME WHEN WE NEED THEM?" – LIZ FRANK, PATIENT ADVOCATE

A survey conducted by the EMBRACE study is helping to identify the unique needs of metastatic breast cancer patients, with the goal of providing them with appropriate, accessible resources. Fifty females and two males within their first year after metastatic breast cancer diagnosis completed a questionnaire that explored informational needs, awareness and use of services, and quality of life issues. Some of the findings were presented at the Metastatic Breast Cancer Forum on October 13, 2012.

About 70% of those surveyed had high informational needs, according to Davinia Seah, MD, MPH, who analyzed the data. Print (brochures and books) and online materials like websites were found to be the most popular sources of information.

The survey also explored patients' awareness and use of 22 services currently available at DFCI (see list on page 2). "We learned that there are many resources people really want that are not being communicated," notes Dr. Lin. "As providers, we're not

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Dr. Lin and Dr. Seah present at the MBC Forum.



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Embracing DFCI resources

A SURVEY BY THE EMBRACE STUDY TEAM IDENTIFIED A WIDE RANGE of patient needs. DFCI's supportive resources offer financial, physical, emotional, and spiritual help to patients and their families. Find out what's available at the Shapiro Center for Patients and Families on Yawkey 1 or request a DFCI Supportive Resources brochure that describes available services and provides contact information so you can find what's right for you.

AWARENESS & USE OF DFCI RESOURCES

Findings from the EMBRACE survey about awareness and usage of supportive resources are presented in this chart. The EMBRACE study team is using this feedback to improve patient care.



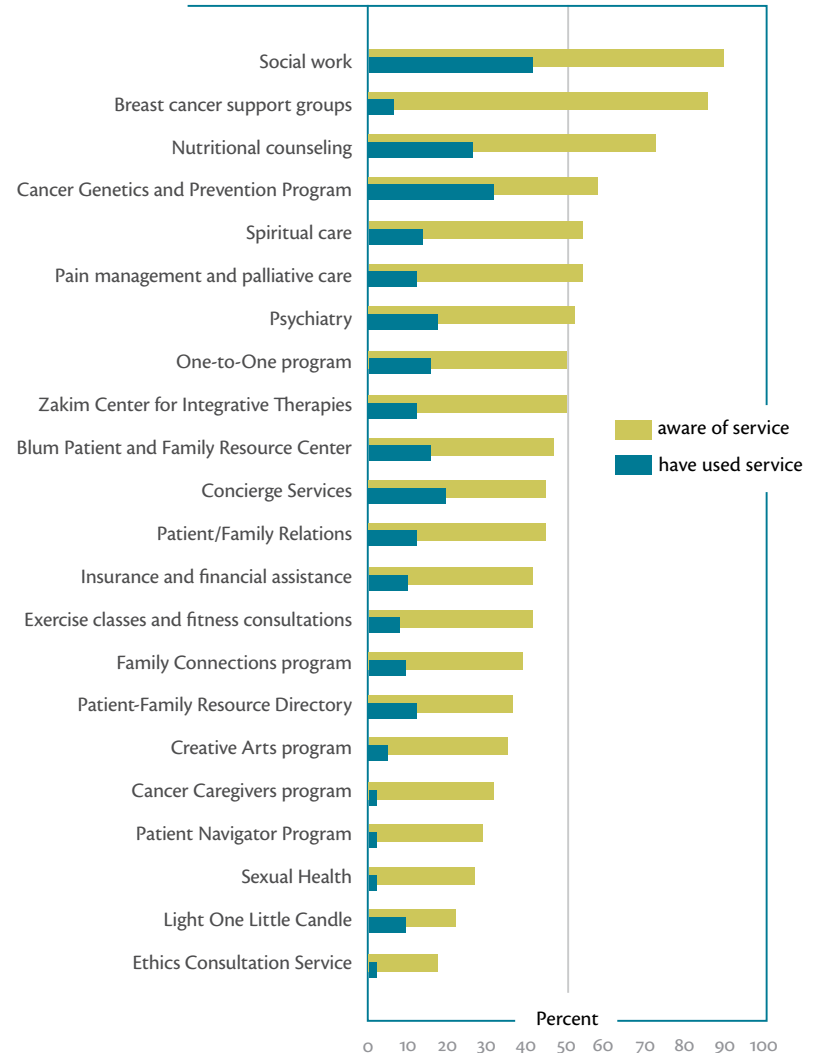
Sam Ogden

I STARTED TAKING DFCI'S women's exercise class, and it's the best thing I've ever done. Nancy Campbell, who leads the class, is an expert in the field. With exercise, you get the endorphins and feel so good about yourself, so alive. You may be a little sore, but you think, 'I got through class, I can do more.' And the class camaraderie is fabulous. We're all in the same boat, and there's such positive energy! It's a fabulous adjunct to treatment. I can't control my cancer; I can control my fitness.

Dana-Farber offers so many resources that are easily tapped. I really encourage other patients to go to the Shapiro Center on the first floor of the Yawkey Center and see what's available, or pick up a copy of DFCI's Supportive Resources brochure.

—Karen Yelin

DFCI exercise instructor Nancy Campbell leads a class through the Adult Survivorship Program (617-632-4523).



Sam Ogden

Rami Rones holds a Qi Gong class at the Zakim Center for Integrative Therapies (617-632-3322).

THE ZAKIM CENTER is an oasis of support and caring. Pain and chemo wear you down. You don't realize at first that it's not only your physical being that needs treatment, but your spiritual/emotional/mental being. This is where integrative therapies can help. The Zakim Center can help with side-effects, but it also rebuilds your spirit. It gives me the inspiration to go on.

—Susan Digiovanni

Meet:



Liz Farrell, MSW, LICSW *Clinical Social Worker*

LIZ FARRELL WAS A SPANISH TEACHER when a friend at a private oncology practice approached her about a Spanish-speaking patient advocate position. Liz accepted the job and discovered, “I loved oncology and working with oncology patients.” Wanting more counseling in her work, Liz pursued a social work degree and came to DFCI in 2008 as an intern and stayed as an employee.

She is one of 16 DFCI social workers, and one of three dedicated to breast cancer. A favorite aspect of her work is interacting with patients who have metastatic cancer, because she enjoys working with them and their families over longer periods of time.

Social workers are available to any DFCI patient in active treatment, and sessions aren’t billed—“they’re part of a patient’s total care.” Liz explains that social work can include anything from counseling on the emotional impact of illness, to connecting patients with resources, to helping with family issues, including bringing family members to a session. “We can also be an advocate for the patient with providers or care teams,” Liz says.

Support is based on what individuals want, and its frequency can be on a regular basis or “as needed.” For metastatic patients in particular, Liz says she can be “another support to help throughout their illness” if, over time, they start to feel like a burden to their families and friends. Liz also facilitates support groups for young women with metastatic breast cancer, metastatic cancer patients of all ages, and men with breast cancer. There are many other support groups, she notes, including one for caregivers. Some groups take place by phone, allowing participation from anywhere. Liz encourages becoming involved in a group early, pointing out that, “It’s easier to reach out when you’re not in crisis.”

“I want patients to know about the resources available to them and how important it is to get in touch,” she says. “Start the conversation early. There are many ways to connect with people who are going through the same thing.”

Eat to feel your best

Cancer and nutrition

“NUTRITION CROSSES ALL AREAS OF CANCER, FROM PREVENTION TO TREATMENT THROUGH SURVIVORSHIP,” SAYS STACY KENNEDY, MPH, RD, CSO, LDN, SENIOR CLINICAL NUTRITIONIST AT DFCI.

Whether it’s how you eat affecting how you feel or the other way around, nutrition and cancer are deeply intertwined.

You have likely received a wide range of well-meaning advice by now, from being told to avoid or eat certain foods or a specific diet (macrobiotic, raw, vegan, etc.), to being encouraged to eat anything you want. The challenge is if “anything” winds up being junk food, it can cause inflammation in the body, which, when eaten in excess, can often make a person feel worse. Eating some junk food can be fine, Stacy says, but as a “go to” solution for weight gain or more calories, it usually doesn’t work. Instead, a person can get the same calories in healthful ways with better nutrients, such as peanut, almond, or other nut butters, nuts, hummus, avocado, and other healthy, calorie-rich foods. Stacy doesn’t recommend that patients change their whole diet at once, but instead that they integrate small amounts of new foods. “Small changes do make a difference,” she says.

The good news is DFCI’s six nutritionists are on hand to help by setting up a customized, healthy eating plan that can work in a person’s

own context and culture. That means a balanced diet with favorite foods—“there’s room for all,” Stacy says. Anyone with a DFCI patient card can see a nutritionist, and visits are billed to insurance just like a doctor’s visit.

The nutritionists can also help put into context eating approaches you’ve encountered in your own research or that have been recommended. These well-intended recommendations may be fine and workable, but sometimes might make a person feel stressed, frustrated, or overloaded by information and confused about what to do.

While specific symptoms and side effects tied to eating vary with each individual, here are some approaches anyone can try:

- Do your best. Don’t beat yourself up for not eating perfectly.
- Know that you’re not alone if you feel confused about optimal nutrition or are having a hard time with food.
- Try small, frequent meals, and include fluids in the same way.
- Enjoy smoothies—they provide nutrients and also help keep you hydrated.
- Include protein and a fruit or vegetable with all snacks and meals—try a roasted sweet potato with chicken or fish, eggs with spinach and tomato, Greek yogurt with fresh fruit, or a quinoa and mixed veggie salad.





Avocado- berry smoothie

INGREDIENTS

- 1/2 cup ice cubes or crushed ice
- 1 (11.5-ounce) can peach nectar
- 1/2 teaspoon ground cinnamon
- 1 teaspoon vanilla extract
- 1/2 large, ripe avocado
- 1 (6-ounce) carton non-fat vanilla or peach yogurt
- 1 cup fresh blueberries, rinsed, picked over, completely drained
- 1 cup fresh strawberries, rinsed and sliced

GARNISH

- 1/4 ripe avocado, peeled, sliced lengthwise (optional)
- 6 plump blueberries (optional)

DIRECTIONS

Peel, seed, and cut avocado in small chunks. Place all ingredients in a blender with a lid. Blend on high speed for two minutes or until all of the ingredients are smooth and creamy. Pour into two tall glasses to serve. If desired, garnish with 1/4 slice of avocado and fresh plump blueberries.

YIELD 2 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.

IN MEMORIAM

Elizabeth Sewall passed away in September 2012 due to complications of breast cancer. In addition to her many other roles, she was instrumental in helping us plan the MBC Forum, for which we are very grateful. We will miss her dearly.

Breast Oncology Center welcomes...

RINATH JESELSON, MD, is a medical oncologist and an instructor in medicine at Harvard Medical School. Prior to joining DFCI, she held a faculty position at the Lester and Sue Smith Breast Center at Baylor College of Medicine, where she specialized in the care of breast cancer patients with hormone receptor positive disease. Dr. Jeselsohn's research focuses on understanding the genetic and epigenetic changes that lead to the development of hormone receptor positive metastatic disease and resistance to endocrine therapy.



NIKHIL WAGLE, MD, is a medical oncologist, an instructor in medicine at Harvard Medical School, and an associated researcher at the Broad Institute of MIT and Harvard. Dr. Wagle's research focuses on cancer genomics, resistance to targeted therapeutics, and the application of new technologies to personalized cancer medicine. He is currently leading an effort at DFCI to comprehensively characterize tumor samples from patients with breast cancer.

RACHEL YUNG, MD, is a medical oncologist and an instructor in medicine at Harvard Medical School. Dr. Yung focuses on clinical care of women with breast cancer and has an interest in geriatric oncology. Her research focuses on survivorship and quality-of-life issues and, in particular, psychosocial care for women with a diagnosis of breast cancer.



Resources

METASTATIC BREAST CANCER TELEPHONE SUPPORT GROUP

An opportunity to share with others who truly understand coping with the prognosis, living with the uncertainty, and interacting with loved ones. Registration is required for anyone interested in participating. Please call DFCI social workers at 617-632-3301 to register.

YOGA CLASSES The Zakim Center for Integrative Therapies offers yoga classes that encompass meditation, posture, and breathing. Call the Zakim Center at 617-632-3322 for more information.

DANA-FARBER CANCERCONNECT A new online cancer community that offers patients, families, survivors, and friends a safe place to connect with others in similar situations and share experiences and information. Registration is free and confidential. Safely express your thoughts, pose questions, voice concerns, or just read what others have to say. Visit www.dana-farber.org and type "CancerConnect" into the search tool.

EMBRACE survey

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always asking them what they need, and we may not even be aware of everything that's available."

From the results, it is clear to the EMBRACE team that awareness alone is not enough. For example, 90% of respondents knew about social work services, but only 40% had used them. Awareness and use were even lower for other services. Many respondents were unable to use available services because of their work schedules or because they do not live nearby.

From transportation to meditation, the survey revealed a broad spectrum of needs. Genetics and prevention services, social work, and nutrition were ranked most useful by people who had used them. "While we do not know what the ideal is, we suspect that a number of these services are not being used to their full potential," says Dr. Seah.

Patients completing the survey offered innovative ideas for meeting patient needs, including increased use of new technologies, such as online lectures and Skype support groups.

Based on the survey's findings, the EMBRACE team is working to increase awareness of services, and this issue of the EMBRACE newsletter highlights several.

EMBRACE

ENDING METASTATIC BREAST CANCER
FOR EVERYONE



Nancy Lin, MD
Principal Investigator
Breast Oncology Center
Dana-Farber Cancer Institute
450 Brookline Avenue
Boston, MA 02215

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

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