

EMBRACE

ENDING
METASTATIC
BREAST
CANCER
FOR EVERYONE

Fall 2011

Letter from Dr. Lin

WELCOME TO THE FIRST EMBRACE NEWSLETTER!

EMBRACE—Ending Metastatic Breast Cancer for Everyone—is the new name of the Metastatic Cohort Study. The word “embrace” reflects the study’s spirit and intent in many ways. The study embraces its participants as collaborative research partners. By learning from patients’ experiences, we hope to better understand how to provide treatment and support.

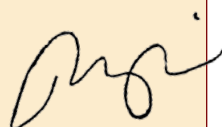
EMBRACE also has the connotation of family. Dana-Farber Cancer Institute has grown impressively over the years but we haven’t lost our unique sense of family. This study is based on human connection, and we thank you all for connecting with us.

EMBRACE is an acronym too—Ending Metastatic Breast Cancer for Everyone. Each person involved in the study shares that goal. Scientifically, we can see a light at the end of the tunnel. Though we can’t say exactly how close or far away it is, the light is there. By participating in this study, you are making an invaluable contribution to the future of science.

The EMBRACE newsletter is one way in which we hope to give something back to you—study news, a sense of the EMBRACE community, resources, updates on new metastatic cancer research, and information about clinical trials.

Please let us know what you would like to see in future issues! What would you like to learn more about? We eagerly await your feedback and suggestions! Please feel free to send all comments and questions to embrace@partners.org.

Warm regards,
Nancy Lin



Hidden Treasures

THE YAWKEY CENTER PROVIDES DFCI PATIENTS AND PROVIDERS WITH THIRTEEN STORIES OF STATE-OF-THE-ART FACILITIES. IT ALSO OFFERS AN INNOVATIVE HEALING ENVIRONMENT COLLABORATIVELY CREATED BY PATIENTS, PROVIDERS, ARCHITECTS, ARTISTS, AND MANY OTHERS.

Here are some highlights that we encourage you to explore and enjoy.

YAWKEY 1

Hundreds of golden leaves cascade in the air above visitors who enter the Yawkey Center from Brookline Avenue. When viewed from below, the **kinetic sculpture**, titled Human Nature, forms a three-dimensional mandala, which is an Eastern spiritual art form.

Entering from Jimmy Fund Way, a quick detour to the left takes you to a stairwell that exposes the **signed steel beams** upon which the Yawkey Center is built. The “Every Beam Tells a Story” display commemorates the beam signing by ironworkers, patients, and staff.

If you arrive via the Parking Elevators, exit on level P2 to experience the **Gene Display**, where thousands of glowing tiles that represent genes cover the walls of the curved connector to the Dana Building. Many genes have been personally inscribed (learn more at www.namegene.org).

Borrow an iPad or use one of the self-service stations in the **Shapiro Center for Patients and Families** to find out about events or where to eat, then

print out the information you find. 617-632-3750

Next door, the **Blum Resource Center** offers computer stations, a library of cancer-related resources, and staff who are happy to help you find what you need. Ask about the Creative Arts Program’s knitting program (they even provide the yarn). 617-632-5570

Experienced, sensitive staff in **Friends’ Place** consult with cancer patients experiencing changes in physical

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Gene Display.

Photo by Sam Ogden, DFCI Communications

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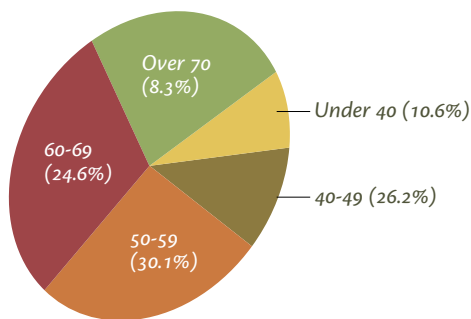
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EMBRACE at-a-glance

PARTICIPANTS IN THE EMBRACE STUDY ARE AN IMPORTANT AND EVER-GROWING COMMUNITY OF PEOPLE FROM ALL WALKS OF LIFE—TEACHERS, BUS DRIVERS, HEALTH CARE PROFESSIONALS, LAWYERS, PARENTS, AND RETIREES. HERE'S A SNAPSHOT OF OUR COMMUNITY.

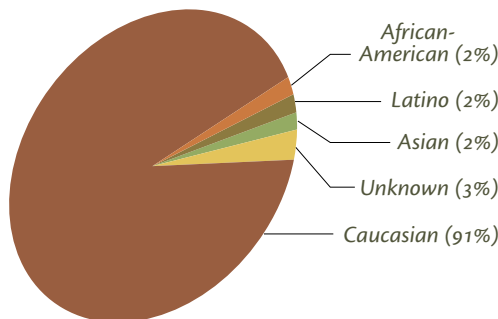
GENDER

Participants are primarily female but breast cancer also occurs in men and we are pleased that our first male participant has enrolled.



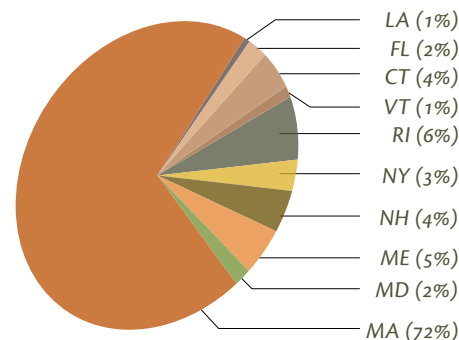
AGE

People of all ages participate, from twenty-somethings to octogenarians.



RACE

Participants currently are primarily Caucasian but we are committed to enrolling as diverse a cohort as possible.



LOCATION

Most participants live in Massachusetts but over one-fourth come from out of state.

Questions & Answers

WHO IS ELIGIBLE TO BE PART OF THE EMBRACE STUDY?

Men and women who are 18 years or older with metastatic or recurrent breast cancer are eligible if they have consented to 93-085, the breast cancer data and tissue banking study at DFCl.

WHAT ARE THE EMBRACE STUDY'S GOALS?

Many of Dr. Lin's patients told her they wanted to contribute to new medical knowledge and that research was not learning as much from them as it could. Unless they were part of a clinical trial, their data was not being collected and if they were in a trial, the data only benefited that specific study.

The EMBRACE Study is changing that by mobilizing the information collected every day as part of a patient's routine clinical care, integrating it with the latest science, and exploring what can be learned for the next generation.

Another goal is to learn directly from participants how patient care can be improved. Patients are the

experts on what it feels like to live with a disease—they experience the side effects of treatment and they know whether particular resources are helpful or not.

WHAT ARE THE CURRENT STUDY ACTIVITIES?

The study team is analyzing results of a small survey conducted among 30 participants. Results of the survey analysis will be shared in upcoming issues of this newsletter.

Another survey is being developed to collect information about which services people find useful and what's missing, to increase our understanding of areas that would benefit from more attention and resources.

A quality-of-life questionnaire is also being developed to follow patients over time and learn how the experience of metastatic cancer affects their lives, as well as how clinicians and others can make a positive difference.



Meet:

Carolyn Curley *Research coordinator*

Carolyn Curley introduces the EMBRACE study to potential participants and, if they volunteer to participate, guides them through the informed consent process. But the interactions don't end there. "We see each other at the clinic, on the sidewalk, in the elevator—everywhere!" she notes. "We say hello and catch up. I love those little moments."

Carolyn grew up in Wellesley, MA, playing the flute and planning a musical career until tendonitis from too much practicing forced her to choose a new direction. She majored in Spanish with a minor in history specializing in race and ethnic relations at Clark University in Worcester. Her current position feels like a great fit. "I always had an interest in working with health care and I love people," she says.

She interacts with dozens of people each day, including patients, physicians, and other members of the study team. "I enjoy the variety of what I do," she notes. "But my favorite part of the job is interacting with patients."

To identify potential study participants, Carolyn reviews the breast clinic patient database, then contacts physicians of patients she thinks meet the EMBRACE study criteria. If the physician agrees, she approaches the patient and introduces the study.

"I begin by explaining that the study doesn't require any medications, procedures, or extra visits," she explains. "When I mention that the data will help researchers learn more about metastatic cancer, people start nodding their heads. Just about everyone wants to volunteer and their primary motivation is wanting to help other people. They say things like, 'I don't want this happen to another 27-year-old' or 'I hope this will help my daughter.'"

Getting to know the participants in the study has been, according to Carolyn, "life changing. They come in with smiles on their faces. They're living life to the fullest. I learn so much from them every day."

Beyond statistics: Voices from around the world

GLOBALLY, ONE IN THREE PEOPLE DIAGNOSED WITH BREAST CANCER DEVELOPS METASTATIC DISEASE. THIS AMOUNTS TO NEARLY HALF A MILLION PEOPLE EACH YEAR, MANY OF WHOM ARE LIVING LONGER THAN EVER BEFORE BECAUSE OF TREATMENT ADVANCES.

But though they constitute a sizable global community, patients with metastatic breast cancer often report feeling ignored by public awareness efforts, underserved by available resources, and under-represented in research. Even their friends and families often have misconceptions about MBC, which can add to their sense of isolation and invisibility.

BRIDGING GAPS, EXPANDING OUTREACH

BRIDGE (Bridging Gaps, Expanding Outreach) is an unusual international research project exploring the effects of metastatic breast cancer on patients' lives and identifying gaps in resources and support.

More than 1,300 women diagnosed with metastatic breast cancer, were recruited in 13 countries (Argentina, Australia, Belgium, Brazil, Canada, Egypt, France, Mexico, Poland, Spain, United Kingdom, United States, and Venezuela).

Participants completed a survey developed by an international team of researchers. Their responses were analyzed and the results were recently published in an article titled "Living with metastatic breast cancer: a global patient survey" in *Community Oncology* (Commun Oncol 2010;7:406–412). If you'd like to receive a copy by mail or email, please let us know. It's also online at: <http://www.communityoncology.net/co/journal/articles/0709406.pdf>

BRIDGE Survey Responses

ATTITUDE

75% enjoy life

67% feel generally optimistic

61% consider themselves "cancer survivors"

SUPPORT

98% get sufficient support from at least one family member or friend

83% get sufficient emotional support from their oncologist

RELATIONSHIPS

48% report that friends are uneasy talking about MBC

38% are anxious about being open with their friends and family

EMPOWERMENT

76% take an active role in searching for information on MBC

81% are actively involved in making decisions about their treatment

SOURCES OF INFORMATION

50% look online

44% turn to therapists

46% get information from support groups

WHAT THEY'D LIKE MORE INFORMATION ABOUT

67%: talking to other people about MBC

70%: paying for medical care and treatments

PARTICIPATION IN CLINICAL TRIALS

34% of women who looked for information about clinical trials ultimately participated in one or more.

Hidden Treasures

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appearance as a result of treatment, provide fittings for compression garments or prostheses, and help with wigs, head coverings, and make-up. They also sell great organic makeup and skin-care products, athletic wear, and swimsuits. 617-632-2211

Save time and energy in the Friends' **Gift Shop**, where products range from the practical to luxurious.



Healing Garden.

Photo by Sam Ogden, DFCI Communications

YAWKEY 2

On your way to your appointment, take a minute to look at the leaves of the **mandala sculpture** up close. Relax on a comfy couch and listen to a **grand piano** concert by a visiting musician.

Soaring stained glass panels representing the elements of earth, water, fire, and air provide an inspiring backdrop to activities in the Chapel, like the Multi-Faith Chanting Series. The Chapel's doors are always open, welcoming everyone to enjoy its calm setting.

YAWKEY 3

The **Healing Garden** is an airy, peaceful space filled with seasonal flowers, river stones, and natural light. Patients, family, and staff come here to stroll, reflect, meditate, or simply take a break.

If you enjoy or are curious about art, wander through the **Cutler Art Gallery** in the 3rd floor Conference

Center or check out the latest exhibit in the **Rotating Art Exhibition** outside the gallery. The current exhibit features fashion drawings by Kenneth Paul Block and is on loan from Frederic and Jean Sharf and the Museum of Fine Arts, Boston.

In the **Dining Pavilion**, walls of windows fill the large space with light. Selections change every day and vegan, vegetarian, and healthful options are always available.

Do you have any favorite spots or resources in the new Yawkey Center? Let us know and we'll share them with others in future issues.

Resources

SUPPORT

Licensed social workers offer emotional support. Visits can be coordinated with doctor's visits and/or chemotherapy appointments. Talk to your doctor if you are interested in meeting a social worker.

PERSONALIZED EXERCISE PROGRAM

An exercise physiologist can help you develop a personalized exercise program tailored to your needs. DFCI Lance Armstrong Foundation Adult Survivorship Program (617-632-4523) or email nancy_campbell@dfci.harvard.edu.

INTEGRATIVE THERAPIES

Integrative therapies like acupuncture, massage, meditation, and other modalities are available from DFCI's Zakim Center for Integrative Medicine. Physicians, therapists, nurses, and other staff can guide you in choosing services. 617-632-3322

WEB RESOURCES

Some of these web addresses have been shortened and will take you to the most relevant section of the website.

SUPPORT AND INFORMATION

Susan G. Komen for the Cure: Up-to-date information on breast cancer diagnosis, treatment, and support. <http://bit.ly/p8LguL>

ASCO (American Society of Clinical Oncology): Oncologist-approved cancer information. <http://bit.ly/n1VqQu>

Living Beyond Breast Cancer: Information about treatments, research, and clinical trials. <http://bit.ly/gcOOhq>

Metastatic Breast Cancer Network: Patient-led advocacy group dedicated to women and men living with metastatic breast cancer. <http://mbcn.org/>

National Comprehensive Cancer Network: Information on cancer treatment guidelines for patients, caregivers, and families. <http://bit.ly/qx4wml>

Young Survival Coalition: A website focused on issues facing young women with breast cancer. <http://youngsurvival.org/> or <http://bit.ly/q7u1u6>.

WORK, SCHOOL, AND FAMILY

Kids Connected: Cancer support and education to help the whole family cope when a parent has cancer. <http://www.kidsconnected.org/>

Americans with Disabilities Act (ADA): Information on the Americans with Disabilities Act. <http://www.ada.gov>

Family Medical Leave Act (FMLA): Information about the Family Medical Leave Act of 1993. <http://www.dol.gov/whd/fmla>

Social Security Administration (SSA): Information about Social Security, including disability benefits. <http://www.ssa.gov/>

ACCOMMODATIONS

Hope Lodge: State-of-the-art facility providing a "home away from home" for patients traveling more than 40 miles to their outpatient treatments (no charge to stay at Hope Lodge for patients and their caregivers) <http://bit.ly/uLM5xT>

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