

Ending Metastatic Breast Cancer for Everyone Summer 2017

SUSAN F. SMITH **CENTER** FOR WOMEN'S CANCERS

DANA-FARBER/BRIGHAM AND WOMEN'S 📂 CANCER CENTER 😽

Extending metastatic breast cancer care

THE BREAST ONCOLOGY PROGRAM AT DANA-FARBER'S SUSAN F. SMITH CENTER FOR WOMEN'S CANCERS CARES FOR MANY

All of them are now able to benefit from a new clinical program, EMBRACE (Ending Metastatic Breast Cancer for Everyone), launched in August 2016. Since then, about 1,500 people have received the program's support, which is

available at no charge throughout their MBC journeys.

"The EMBRACE clinical program extends our ability to help people by offering education and support, and by allowing us to partner with oncologists in the community," says Nancy Lin, MD, clinical director of the Breast Oncology Program and director of the Metastatic Breast Cancer Program. The EMBRACE clinical program grew out of Lin's research study (also called EMBRACE), which focuses on developing a better understanding of metastatic breast cancer, with the hope of

PEOPLE LIVING WITH METASTATIC **BREAST CANCER (MBC). PATIENTS** RANGE FROM NEWLY DIAGNOSED TO OTHERS WHO HAVE BEEN LIVING WITH METASTATIC DISEASE FOR MANY YEARS.

> Nancy Lin, MD (right), clinical director of the Breast Oncology Program and director of the EMBRACE Metastatic Breast Cancer Program at Dana-Farber, with a patient.

improving treatment options now and in the future. The clinical program and the research study are separate, although they share the same name. People can be part of the research study, part of the clinical program, both, or neither.

Invitation to participate

At their first visit, patients meet with their assigned EMBRACE coordinator, who introduces resources-such as social work, nutrition, and integrative therapies-and

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ecent events around the world remind me how precious life is, how fragile it can be, and how much every day is a gift. In contrast to these events, I recently returned from our annual American Society of Clinical Oncology meeting—a truly international

Letter from Dr. Lin

gathering of almost 40,000 people focused on advances in cancer research. Groundbreaking research across many cancer types was presented, including new approaches for treatment of ER-positive, HER2-positive, and triple-negative breast cancer-some of which will likely gain FDA approval in the near future. I came away re-inspired by the enormously

talented individuals who dedicate their lives to making the world a better place now and into the future. As patients, you teach us more than you will ever know, and you inspire us to do better. Thank you.

In this issue, you will hear from other people

living with metastatic breast cancer, receive an update about our EMBRACE clinical program, and learn about a promising new technology—circulating tumor

DNA-that you have helped to develop. I would like to extend a special thanks to Drs. Heather Parsons and Daniel Stover, who guest-edited this issue of the EMBRACE newsletter, and who have been at the forefront of this exciting new approach.

We look forward to seeing many of you in person at our 6th annual Metastatic Breast

Cancer Forum in October.

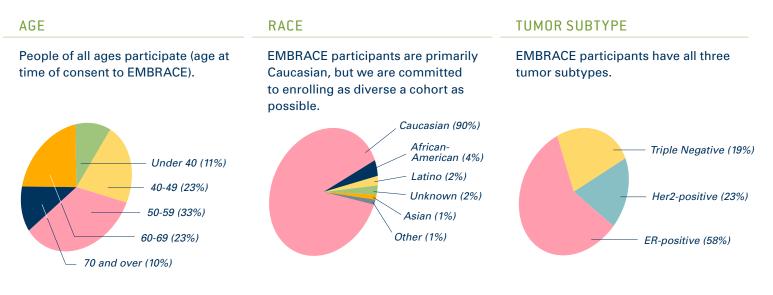
As always, we are open to your feedback. Many of our articles, webcasts, and annual forum sessions are a direct result of your suggestions. Please send your comments and questions to embrace@partners.org.

Warm regards, Nancy Lin, MD

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EMBRACE at a glance

The following information gives a snapshot of the people who make up the EMBRACE community.



GENDER

EMBRACE participants are primarily female, but men participate as well.

• Female 99%

• Male 1%

PATIENT PROFILE

hen I first came to Dana-Farber, I couldn't believe / was in a major cancer center; it was terrifying. But I've come to associate different things with the place now. I've found the beautiful areas—the birds on the walls in a DFCI hallway, the third-floor garden, the light in Yawkey from all the windows—these things really make a difference."

Susan was diagnosed with metastatic breast cancer nearly six years ago, in her early 50s, after 10 years of thoracic back pain and kidney bleeding that doctors were unable to find a cause for. After finally getting a long askedfor thoracic MRI, doctors knew it was cancer but not the point of origin. An ultrasound revealed breast cancer that had metastasized to her bones. She describes the shock—with no family history and negative mammograms: "I never would've guessed in a million years and to be diagnosed with metastatic breast cancer-I still can't believe it. It makes no sense."

Susan

After a negative experience with a local oncologist, Susan learned about Dana-Farber from a neighbor and made the drive from Maine. Susan describes her first visit as "such an unbelievable contrast" from her prior oncology care. She says it was very clear that she'd made the right choice, from her first appointment when Michael Hassett, MD, MPH, and staff spent an entire afternoon with her, to ongoing support from her social worker, Julie Salinger, MSW, LICSW. While facing a monthly drive of at least three-and-a-half hours each way during her first year of treatment, and every three months since, Susan says that the personal, high-quality care has always made it worthwhile.

Another life-changing aspect of her care was that "from the beginning, Dana-Farber promoted the concept of metastatic breast cancer as a chronic disease. My whole first year I kept asking Julie, 'Is Dr. Hassett lying to me?' I had to build my confidence before accepting the idea that this is something I could



live with," Susan says. "The largest challenge is psychological, keeping my mind in the right place. I've been very stable for five-and-a-half years with tamoxifen and an aromatase inhibitor. This is a totally different view of cancer.

"My health is not a random act—maybe it never was, but I recognize it now," she says. "At the beginning, I said to Dr. Hassett, maybe 5 percent of my body has cancer, and for that percent, I really need Dana-Farber's help. The other 95 percent of my body I'm really trying to take care of and keep as healthy as I can to stack the deck."

An invaluable combination: New technology and EMBRACE data

THANKS TO A NEW TECHNOLOGY THAT HAS ADVANCED RAPIDLY IN RECENT YEARS, EMBRACE PARTICIPANTS' CONTRIBUTIONS, PAST AND PRESENT, ARE PROVING INVALUABLE FOR CURRENT RESEARCH. EMBRACE BLOOD SAMPLES AND OTHER DATA ARE PLAYING A CRITICAL ROLE IN THE SEARCH FOR GREATER UNDERSTANDING OF METASTATIC BREAST CANCER AND NEW OPTIONS FOR PEOPLE WHOSE CANCER IS RESISTANT TO STANDARD TREATMENT.

The technology

The new technology uses what is called circulating tumor DNA, DNA is a code inside our cells that tells them how to work. Cancer cells have small changes in their DNA (mutations) that make the DNA different and unique to the cancer cell, like a fingerprint. Heather Parsons, MD, MPH, a physician and researcher in breast oncology at Dana-Farber, says, "We think all cells release little bits of their code into circulation. Because of the difference in cancer cells' DNA, we can use it to identify the cancer DNA floating around in the blood (or, circulating tumor DNA) that's different than regular cell DNA."

Easier than biopsy

Identifying cancer DNA in the blood is significant because the current way to get a "fingerprint" of cancer DNA is with a biopsy, which can be painful or risky for some people. Daniel Stover, MD, a physician and researcher in breast oncology at Dana-Farber, explains, "There is growing evidence we can study circulating tumor DNA that's in the blood and gain a proxy for the mutations in the tumor. That is great for patients, and it allows us to take multiple snapshots over time. We can't do a biopsy on a tumor six times a year, but we could take six blood draws." While we aren't quite at that point, he adds, identifying cancer

DNA in the blood holds one of the most exciting potentials for circulating tumor DNA.

The role of EMBRACE

Parsons and Stover, in collaboration with the Broad Institute of MIT and Harvard, have been using blood samples donated by EMBRACE study patients to research the ways cancer cell mutations might evolve in metastatic breast cancer and why a particular person's cancer stops responding to treatment. "If we could use circulating tumor DNA to understand how that resistance happens, we may be able to develop better treatments for the cancer. This is what we're most excited about," Parsons says. Stover adds, "We have a very poor understanding of why patients respond to a particular therapy for a while and then stop responding." A greater understanding might help researchers learn how to prevent it, such as with certain drug combinations or sequences of drugs.

As part of EMBRACE

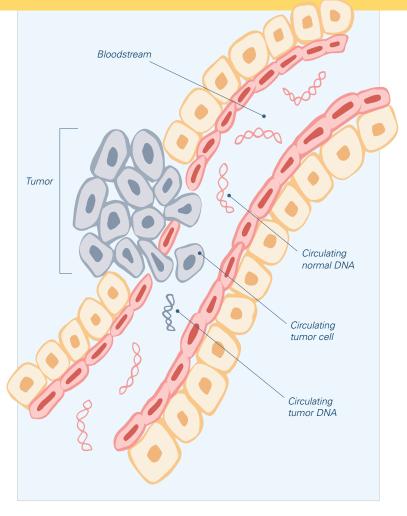
research, participants sign a consent for blood to be drawn. Stover says, "It's a credit to Dr. Lin that she's carefully saved all those blood samples over the many years of the EMBRACE cohort. And now the technology has developed to a point that we can take that blood out of the freezer and do these analyses that weren't possible three, five even two years ago."

A powerful opportunity

Having the blood samples provides an opportunity to study metastatic breast cancer in a way that wouldn't have been possible otherwise, or that would take many years to be able to do, Stover says. "The fact that patients have participated in the EMBRACE study over many years and have been willing to give blood samples is an incredible gift to the community," he says.

Parsons says that newly obtained samples from EMBRACE participants are equally valuable to the stored samples: "As samples are coming in now, we are processing them to analyze, not quite in real time, but very quickly. It's important to both look back but also to make sure that we're studying patients on modern therapies as well."

Circulating tumor DNA



Extending care

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invites them to participate in the clinical program. Existing Dana-Farber patients are also invited to participate.

Patients may share their email address to receive periodic communications about new resources, educational materials, and support groups. Program participants also receive a yearly newsletter and are invited to an annual education and support forum.

Patients can also choose a "collaborative care" model in which care is shared between their local oncologist and Dana-Farber oncologist.

At the initial visit, EMBRACE coordinators also work with patients' oncologists to determine if there are appropriate research studies and discuss these with the patient. Before each subsequent clinic visit, a coordinator reviews results of tumor testing and possible clinical trial options with the patient's oncologist, who can then review these with the patient.

"A win-win-win"

The program's benefits are as varied as its participants. Marie, who is newly diagnosed, consented to genetic testing during her first visit. Louisa learned about a promising clinical trial. Stan has been living with MBC for eight years; he "loves the program" and attends EMBRACE's educational events.

Marie and Louisa receive their ongoing care from oncologists at other institutions. Under the collaborative care part of the program, their providers receive updates on their tumor testing results and can discuss their patients with their DFCI colleagues when considering all possible approaches to treatment.

"I think the program is wonderful," says Rachel Freedman, MD, MPH, associate clinical director of the Breast Oncology Program. "For our patients with metastatic disease, EMBRACE provides ongoing engagement with Dana-Farber, which translates to more support, being part of a patient community, and enhanced communication with referring physicians. It's great for the patients, their providers, and us—a win-win-win."

The best possible care

Nicole Kuhnly, an EMBRACE coordinator, affirms the program's benefits. "There can be a lot going on with MBC patients, and we are here to help streamline everything," she says. "Patients can call us whenever they have a question or concern—we're always available. We help them get the information, support, or resources they need. For the patients who receive care

ENDING METASTATIC BREAST CANCER FOR EVERYONE

> Principal Investigator Nancy Lin, MD

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Please send us your comments, questions, and suggestions! Email: embrace@partners.org Phone: 617-632-5510

Resources

New webcast: Role of Radiation in Metastatic Breast Cancer

Jennifer Bellon, MD, describes different types of radiation and how they are used to treat and alleviate symptoms in metastatic breast cancer. The presentation includes four patient scenarios. To view the webcast, visit www.dana-farber.org/metsbc, click on the Support and Education tab, and scroll down.

Past newsletters available

You can read and download previous issues of the EMBRACE newsletter by visiting www.dana-farber.org/metsbc, then scrolling down the right-hand column.

Neuro-oncology collaboration

People with metastatic breast cancer that has spread to the brain can benefit from the Brain Metastases Program (BMP) at Dana-Farber/Brigham and Women's Cancer Center. BMP is one of the most comprehensive programs in the U.S. for people whose cancer has metastasized to the brain. With the most advanced treatment options available—including surgery, radiation therapy, chemotherapy, immunotherapy, and targeted therapies, and extensive clinical trial options—the BMP is in a unique position to treat people whose cancer has spread to the brain. For more information, visit www.dana-farber.org/mbcbrain.

2017 Metastatic Breast Cancer Forum

The next Annual Metastatic Breast Cancer Forum will be Saturday, October 21, 2017, at Dana-Farber Cancer Institute.

elsewhere, we are piloting a program to call them every three months to check in. They appreciate this and have said it makes them feel valued."

Kuhnly and the other four coordinators "huddle" with the oncologists every morning to review a summary report for each patient being seen that day, identify any appropriate clinical trial opportunities, and ensure that everything to do with a patient's care is covered and communicated.

Kuhnly says, "We can be a point person, making sure everyone is in the loop. Patients who come to Dana-Farber for second opinions can return to their local oncologists for ongoing care. They and their providers can reach out whenever necessary to discuss ways to improve their treatment or consider clinical trial opportunities. Even if the provider is in Oklahoma, everyone knows what's going on and that the care is the best it possibly can be."

"We hope that this program can expand the number of patients we reach," says Lin. "While we cannot care for people without seeing them in person, we hope that the program will make it easier for patients and their local oncologists to reach out to us when there is a potential change in treatment, to make the process of re-consultation smoother and more meaningful, to provide patients with clinical trial opportunities over time, and to allow us to be effective partners in patients' care. The program also allows us to optimally care for patients receiving their treatment at Dana-Farber."