Letter from Dr. Lin

The Annual ASCO (American Society of Clinical Oncology) Meeting, held in June, always energizes me with the progress against metastatic breast cancer (MBC).

Highlights include updated results of immunotherapy for patients with triple-negative MBC, confirming an improvement in length of survival in patients whose tumors are positive for the marker PDL1.

In addition, we are all working hard to understand which other patients may benefit from immunotherapy and new therapeutic combinations.

We also heard promising results of phase 3 clinical trials demonstrating benefits of the regimen of neratinib (Nerlynx) + capecitabine (Xeloda) for patients with HER2-positive MBC, as well as a new type of HER2-targeted antibody called margetuximab in combination with chemotherapy. I anticipate that both regimens will be reviewed by the FDA within the next year, increasing treatment options for patients.

For estrogen receptor (ER)-positive breast cancer, we saw results of two randomized clinical trials in young women with MBC. One trial showed longer survival when patients received a CDK4/6 inhibitor together with hormonal therapy. The other showed that for most patients with ER-positive breast cancer, starting with hormonal therapy plus a CDK4/6 inhibitor...
From its start with just 99 people in 2010, the EMBRACE program continues to grow and thrive, thanks to each of you. Your participation in EMBRACE is an invaluable contribution to increasing our knowledge about metastatic breast cancer (MBC) and to helping us find additional ways to treat and support people with MBC.

Resources for MBC patients

with cancer and their children; the Creative Arts Program; and more.

Legal and financial assistance
617-632-3301

Limited, needs-based financial assistance may be available for basic needs and parking costs, and referrals to legal services related to care (for Massachusetts residents, not for emergencies, bankruptcy, divorce, child support, or contested guardianship) and financial coaching to help review your financial situation and provide advice and guidance. You must meet financial or other eligibility requirements to use this service. Please call the number above for eligibility information.

Ellie Fund

The fund provides need-blind support services for up to 6 months for metastatic breast cancer patients living in or getting care in Massachusetts. No financial information is required to apply. Applicants can pick up to 2 kinds of services to receive, including grocery gift cards, transportation to/from appointments, light housekeeping, childcare reimbursement, prepared meals, and new since 2018 for metastatic breast cancer patients: funding for acupuncture, acupressure, and oncology massage therapy. Apply for services through your cancer care provider (e.g., social worker, patient navigator/advocate/coordinator, resource specialist, or similar staff)—only oncology professionals have access to the application. Patients can apply more than once but are asked to take a 6-month break between requests.

www.elliefund.org; Anne Meisner, Patient Services Manager 781-449-0100

Metastatic breast cancer support groups
617-632-4235

Two monthly groups for metastatic breast cancer patients are co-facilitated by a psychiatrist and a social worker. Members vary from newly metastatic to people who have been living with metastatic breast cancer for years. Attendees report powerful benefits of getting to know and being able to process with people who “get it.”

Pharmacy Resource Program
DFCI Outpatient Pharmacy
617-632-3526

Medication access and co-pay assistance may be available for high chemotherapy and medication costs. Eligibility requirements may apply.

Resource specialists
617-632-5817
rgermano@partners.org

These specialists are able to help with concrete resource needs: short-term housing, transportation, food insecurity, and limited financial assistance for patients receiving treatment at Dana-Farber. Eligibility requirements may apply.
AFTER SUCCESSFUL TREATMENT AT DANA-FARBER IN 2008 FOR EARLY-STAGE TRIPLE NEGATIVE BREAST CANCER, JOYCE DIGIANTOMMASO THOUGHT SHE WAS DONE.

But 6 years later, a cold, a lingering cough, and a primary care visit led to news that cancer had returned.

Joyce remembers, “I panicked, and the first person who came to mind was my former Dana-Farber oncologist, Dr. Silver. I had the emergency number in my phone from years ago; I left a message, and he called back before I even made it home from the appointment.” His team then made arrangements over the weekend for Joyce to get appointments at Dana-Farber on Monday morning.

That morning, Joyce met with her care team, had several tests, a scan, and a lung biopsy. She learned that her cancer had metastasized to her lungs, and she was diagnosed with metastatic breast cancer (MBC). “What impressed me so much about my doctor was that he had returned to the laboratory at Dana-Farber over the weekend to review my previous tumor. I thought to myself—’How cool is that; he’s reviewing all of my records and treatments from back in ‘08.’ I never had a doubt; I fully trusted my team. I knew they would provide me with the best treatment plan.”

Joyce had weekly chemotherapy treatments for about 8 months. However, the side effects eventually became too much. Fortunately, her oncologists, Dr. Silver and Dr. Lin, had just returned from a conference in San Antonio with word of a new treatment for triple negative breast cancer called immunotherapy.

In December 2014, Joyce was asked if she wanted to participate in a clinical trial at Dana-Farber for triple negative breast cancer patients using immunotherapy, with Dr. Lin as her oncologist. “I was nervous because the consent form listed tons of side effects associated with immunotherapy, and there was not much research data to say what would happen or how MBC patients would respond to the treatment,” she says. “After talking with family and weighing the pros and cons, I took the leap of faith, trusting my oncologists and my team. From the first scan, I responded; the treatment was definitely working, and with each scan, I showed progress. I show up every 3 weeks for treatment, and I’ve been on this immunotherapy treatment for 4 years.”

Joyce began her yoga practice, attended a meditation clinic at Dana-Farber, became reiki certified to self-heal...I used every modality I could to help myself. In addition to the integrative therapies and my treatment, I reached out to my faith. I attended healing masses at my church, and I prayed every day.”

Since the trial’s start, Joyce’s twin daughters both were married, she took a yoga teacher training and became certified as an instructor, and she welcomed her first grandchild. She and her family have also put a team in the Boston Marathon Jimmy Fund walk and raised $38,000 over the few years they’ve participated.

Joyce says, “When you receive a diagnosis of MBC, you think the worst. You think, ‘OMG, I’m going to die,’ and you panic. I am forever thankful to my doctors and team at Dana-Farber. I’ve been so blessed to participate in this trial—a trial that has proven to work in many patients. I believe that patients can live long, happy lives when diagnosed with MBC.”

The 2019 Annual MBC Forum will be Saturday, October 5, 2019. Register for free at mbcforum2019.eventbrite.com

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EMBRACE patient survey project

Beginning in the late fall, the EMBRACE program will be asking patients who have recently been diagnosed with metastatic breast cancer (MBC) to complete a short survey. The goal of the survey project is to better understand our patients’ emotional, social, financial, and informational needs close to the time of their diagnosis, so that we can ensure that our program offerings are available to meet those needs.

The process of developing the surveys has integrated feedback from our EMBRACE Patient Advisory Group and will continue to evolve as we learn from patients who take the survey.

We will share the results of this first survey effort with you in our next newsletter, as well as in our email updates. We are planning future survey efforts to address the needs of patients who have been living with MBC for a longer time.

Resources for MBC patients

Social workers
617-632-3301
Licensed clinical social workers provide professional counseling, consultation, and advocacy for patients, couples, and family members. People reach out to social workers for many reasons, including adjusting to a new diagnosis, for help talking with kids or others about their diagnosis, or if something has changed in their cancer or their treatment. Social workers can also provide an opportunity for patients and their family members to process concerns or worries, and to make a connection in anticipation of future needs. Consultations and follow-up visits can be scheduled by calling the number above.

Shapiro Center for Patients and Families
Yawkey 1
617-632-3750
The Center provides a range of support for patients and families during the day of their clinic visit. Patients and family members can borrow an iPad, get appointment information, find help navigating Dana-Farber and the area around for yourself or your visitors, access ambassadors who can escort you to your appointment, use computers/get online, ask about occasional free tickets to sports and local events, and get information about more resources.