

Letter from Dr. Lin

The takeaway is hope

“Every patient is different.” You’ve probably heard this in your cancer journey and have recognized that others you know with breast cancer may have received different treatments, and cancer behaves differently in each person.

To me, though, these words also bring the focus back to the patient—that every person facing a cancer diagnosis comes to it with unique life experiences, goals, priorities, and worries, and that our real goal is to not only “treat the cancer” (though we want to do that, too), but to care for our patients, using all available resources, as best we possibly can.

In this issue, you will hear from a woman living with metastatic breast cancer and her experiences sharing her diagnosis with her children. And one of our social workers offers concrete advice on communicating with your children—something that many patients tell me is among the hardest things they have had to do.

From the treatment perspective, having accurate information about your cancer and your treatment options can help you feel more empowered, and we recommend key information to be aware of as you work with your oncologist as a partner in your care. We also provide updates on helpful resources, including the Zakim Center for Integrative Therapies and Healthy Living, and advocacy groups focused on metastatic breast cancer.

For those who attended our 6th annual Metastatic Breast Cancer Forum, we hope that the day was useful. For those unable to attend, the taped sessions are now available on the Dana-Farber website.

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




NEARLY 200 PATIENTS, FAMILY MEMBERS, AND FRIENDS ATTENDED DFCI'S METASTATIC BREAST CANCER FORUM

ON OCTOBER 21, 2017—DOUBLE THE NUMBER WHO ATTENDED OUR FIRST FORUM FOUR YEARS AGO.

“This is a pretty special event,” said Eric Winer, MD, in his welcome. “And there is a lot of good news. More treatments for metastatic breast cancer have been approved in the past five years than in the previous 20.”

“People are living longer and living better than ever before,” continued Dr. Winer, who is director of the Breast Oncology Program at Dana-Farber. “Although we still don’t have a cure for most metastatic breast cancer patients, there is good reason to be optimistic. It’s all about partnerships—between labs and clinical researchers and pharmaceutical companies, but most important, between doctors and nurses and our patients and their families.”

This was the second forum for Susan Rosen, who participated in the patient panel. “What I took away was hope. My treatment options are running out, but new treatments are on the horizon.”

Patients, clinicians, and researchers came together for presentations on topics ranging from exercise to genomics, informal lunches with forum faculty, facilitated discussions with social workers, and a simulated “Tumor Board.” Later, attendees were able to continue their discussions during a post-conference reception.

“The forum is an opportunity to talk with people who are going through the same thing as me,” Susan said, “And to meet people who have been living with this for many, many years!”

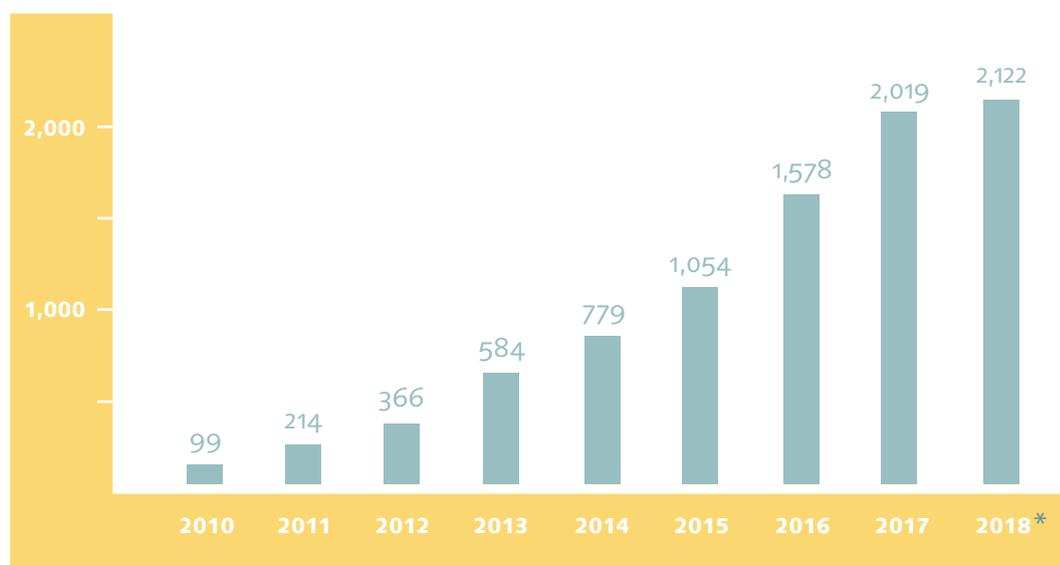
View the Forum online:
www.dana-farber.org/MBCforum

INSIDE

EMBRACE community.....	2
Q & A.....	2
Communicating with children.....	3
Patient profile.....	3
Resources.....	4

EMBRACE community

NUMBER OF EMBRACE PARTICIPANTS



*Numbers as of May 2018

What started as a small study with fewer than 100 participants has grown into a community of more than 2,000 people. Participants in the EMBRACE study come from across the US and they represent all walks of life—teachers, bus drivers, health care professionals, lawyers, parents, and retirees. Each participant is an important partner in research that is helping us better understand how to provide treatment and support for people with metastatic breast cancer.

QUESTIONS AND ANSWERS

Q: What should I know about my cancer?

A: Having accurate information about your cancer can help you feel more empowered, make informed decisions, and avoid unnecessary anxiety. People diagnosed with metastatic breast cancer (MBC) are often confronted with an enormous amount of information from their providers, the internet, friends, and others. Too much information can be overwhelming.

Here are some recommendations from the EMBRACE team on the key information to be aware of.

Tumor subtype

Increasingly, MBC is treated according to subtype. Subtypes are determined by testing a sample of your cancer for three key markers: estrogen receptor, progesterin receptor, and HER2. The combination of results determines your breast cancer subtype. The three breast cancer subtypes are:

- Triple negative
- HER2-positive
- ER-positive

Treatments for each subtype differ significantly. Patients often ask about a particular drug they've read about on the internet, not realizing that it's only useful for a cancer subtype that they don't have.

Knowing your tumor subtype can help you understand your treatment options—why something is being recommended, potential anticipated benefits, and side effects.

Side effects

Every drug, even aspirin, has a lengthy list of potential side effects--too many to remember, and so many it can be scary. Talk to your doctor about these things that are most important to know:

- Common side effects
- Symptoms to report so they can be addressed
- Symptoms that may be serious

It's not about location

Many people worry about the location of their metastatic cancer. For example, someone may be concerned if there is a spot in the liver and have an idea that different parts of the body are worse or better to have cancer than others.

Cancer location is actually much less important than knowing how the disease is responding to treatment. Understanding this can help reduce unnecessary anxiety.

Your personal preferences

One of the most important things to know is what works best for you in terms of receiving and processing information. Some people want to know all the options, do a lot of research on their own, and engage in extensive discussion. Others prefer to let the medical team guide their treatment decisions. And of course there are many preferences in between.

The best decisions about treatment result from a partnership between patient and physician. Let your doctor know how you'd like to receive information and describe your decision-making style. That will help strengthen your partnership.

Communicating with children

LIZ FARRELL, MSW, IS A DFCI SOCIAL WORKER WHO HELPS PATIENTS AND FAMILIES NAVIGATE THE COMPLEX ISSUES AND EMOTIONS THAT ACCOMPANY HAVING CANCER. ONE SUCH

issue is talking with children about a metastatic diagnosis. The following are her suggestions.

Do tell your kids

For kids ages two to five, tell them your diagnosis, sharing what's appropriate for their understanding. And make a plan to share more details when they are five so it doesn't get forgotten. For children five and older, have a more detailed conversation. Even though initial conversations are hard, kids do better when they have the truth upfront.

Be honest and accurate

Many parents think "cancer" is a scary word. But children are incredibly observant and much more worried when they don't know what's happening. If you haven't told your kids, you may think they have no clue, but maybe they overheard you saying "cancer," and are thinking—"There's something awful happening, and it's so bad you can't tell me." As soon as they know that you'll

share information when you have it, they can let go and trust that nothing is being kept from them.

Be clear that it's cancer, that it's not going to go away, that you'll always be on treatment. Explain that there are lots of treatment options and what they are/ what you'll be doing.

Try to avoid knee-jerk reassuring responses

If reassuring means being untruthful in some way, that can damage trust down the road. You can always buy time—"I don't know the answer; I'll find out" (then do get back to them).

Help alleviate long-term anxiety, such as a fear that you're dying, with concrete answers about the present: "That's not what's happening right now, and if at some point we do need to be worried about that, I'm going to let you know." This helps the child let go of the anxiety that at any moment things could change.



Liz Farrell, MSW

Validate

Validate your child's feelings and reassure them that they won't be left to worry alone: "We will deal with this as a family and get through it together. Anytime you have questions or are worried, ask me. If I don't have the answers, I'll ask my doctor."

[Continued on page 4](#)

PATIENT PROFILE

Kate

After treatment for Stage 3 breast cancer in 2012, Kate lost her hair and, choosing to wear hats instead of a wig, describes the experience and communication around it as "pretty public, with my hair gone."

Two years post-treatment, with ongoing hip pain, she learned the cancer had returned and was metastatic. This time, "Since I didn't have treatment that made me lose my hair, I was much choosier about who I told," she says.

"First and foremost, I have children, and I wanted to ensure that they were protected from anyone's fear and misunderstanding about the diagnosis."

In deciding who to share your diagnosis with, she recommends thinking about who you trust, who it would be helpful to tell for logistical and emotional support, and "go with your gut." "Avoid those who are likely to just ask a lot of probing questions that you don't want to answer," she says.

After the metastatic diagnosis, a new medication initially worked well. "Because it didn't change my outward appearance or function, I approached the communication differently this time," she says. "I had the luxury of being able to pick and choose. Then, almost a year ago, it stopped working. Now I need treatment that will impact my functioning forever, and I have lost my hair again. This time I chose to wear a wig so that I don't always have to share my diagnosis."

"My social worker and my support group helped me to think through how to approach this change with my children and how to create a space for them to dialog about it. The book, *Raising an Emotionally Healthy Child When a Parent is Sick*, has also been helpful."

She told her children when the cancer returned but didn't go into detail initially. With the change in treatment, "We

It feels good to have my kids know and be able to ask questions.

told our kids over dinner, 'Mom hasn't been feeling well, and this is what we're going to do. This means I'm going to need treatment on an ongoing basis.'"

"It feels good to have my kids know and be able to ask questions. They ask, 'Why can't they get rid of the cancer?' I respond, 'I don't know, but we're doing the best we can. I have great doctors, and I'm confident in them, and that's where we're at.' It's hard, but I've come to believe it's better to bring them in on what's going on. And if you have more than one child, you need to juggle how to approach each. You want to be fair and inclusive, but also sensitive to their individual responses and needs."



Healing and health at the Zakim Center

Acupuncture, mindfulness, and movement can often reduce cancer-related side effects. These therapies are among the many services DFCI patients can benefit from at the Leonard P. Zakim Center for Integrative Therapies and Healthy Living.

Patients using the Zakim Center's services often report reductions in cancer-related pain, less fatigue and nausea, and overall better quality of life. The Center features:

- Tranquil treatment rooms for acupuncture, massage, reiki, and reflexology
- A Mind Body Studio for yoga and group movement classes
- An airy workout area for exercise training
- Quiet, comfortable spaces for meditation and mindfulness
- Nutrition consultation rooms

Free activities, ranging from "Beginner Ukulele" to "Chair Hatha Yoga," are also available to patients. See what's happening at www.dana-farber.org/about-us/events-calendar/.

The Center is located on the first floor of the Shields Warren Building. You can find more information, including a calendar of events, at www.dana-farber.org/zakim. You can also call 617-632-3322, or email Zakim_Center@dfci.harvard.edu.

Communicating with children

Continued from page 3

Tell school staff

School staff may notice subtle shifts in behavior, whether social or academic. They'll be able to help your child or clue you in if more supports are needed.

Revisit the conversation periodically

Check back based on where your child is developmentally. Often people have the initial conversation but don't revisit it. You can say, "We haven't talked about this in a while, here's how I'm doing, and here's what's going on with my treatment. Do you have any questions?"

Access services and support

Other people have gone through this, and you can benefit from their collective wisdom—access that support, because it's here for you. Dana-Farber has social workers, support groups, and a Family Connections program to guide parents with cancer. To learn more, visit www.dana-farber.org, and type "Family Connections" into the search tool.

Resources

Immunotherapy and breast cancer article and Facebook Live chat (video)

Ian Krop, MD, PhD, chief of the Breast Oncology Center at Dana-Farber, explains the treatment of breast cancer with immunotherapy at blog.dana-farber.org/insight/2017/10/whats-new-immunotherapy-breast-cancer/.

Metastatic Breast Cancer Alliance

A national alliance of patient advocacy groups offering education, support, and research. Visit www.mbcalliance.org for information, including links to national organizations that offer patient support and financial resources, and a quarterly newsletter with educational events.

Metastatic Breast Cancer Network

Learn about patient advocacy through the Network at www.mbcn.org, including patient stories, advocacy tips, and a listing of state-by-state support groups.

To view the following webcasts, visit www.dana-farber.org/metsbc, click on the Support and Education tab, and scroll down.

New webcast: Clinical trials for metastatic HER2-positive breast cancer

Ian Krop, MD, PhD, discusses several clinical trials of new drugs, including kinase inhibitors, antibody drug conjugates, and immunotherapies.

New webcast: Clinical trials for metastatic triple negative breast cancer

Sara Tolaney, MD, MPH, covers several clinical trials of new drugs, including antibody drug conjugates and immunotherapy combinations.

New webcast: Designating a Health Care Proxy While Living with Advanced Breast Cancer

This new webcast covers issues when choosing a health care proxy. Stephen O'Neill, LICSW, BCD, JD, helps with terminology and commonly asked questions, and practical tips.

EMBRACE

ENDING METASTATIC BREAST CANCER FOR EVERYONE

Principal Investigator
Nancy Lin, MD

Susan F. Smith Center for Women's Cancers
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: 617-632-5510

Produced by Health Communication Core www.HealthCommCore.org