

EMBRACE

Winter 2019
Ending Metastatic
Breast Cancer for Everyone

SUSAN F. SMITH
CENTER FOR
WOMEN'S CANCERS

DANA-FARBER/BRIGHAM AND WOMEN'S
CANCER CENTER



Dana-Farber Facebook Live chat highlights metastatic breast cancer

It's hard to believe that it has been 10 years since we started the EMBRACE program, which initially was a small-scale research study in which we hoped to learn from patients living with metastatic breast cancer. To date, we have reached over 2,200 women and men, and we have

care. We look forward to partnering with you on these important initiatives.

In this issue, two patients and one of our social workers will share their perspectives about communicating to family and friends about a diagnosis of metastatic breast cancer.

You will also read about advances in genetic testing, including the availability of "panel testing," which allows us to test for many inherited causes of breast cancer, not

just the BRCA1 and BRCA2 genes, with a single blood test.

Finally, we are excited to share with you an update on two PARP inhibitors: Olaparib and talazoparib were recently approved by the FDA for patients with inherited BRCA1 or BRCA2 mutations.

As always, we welcome 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

Letter from Dr. Lin

expanded beyond a research-only project into a clinical program aiming to improve the care we give to patients.

Over the next year, we are excited to be working on several large-scale projects to analyze the research blood samples many of you have contributed, to understand how cancers become resistant to treatment, and to use this information to develop better treatments. We will also be launching a series of surveys to understand the impact of metastatic breast cancer on patients' lives. We intend to share results of these surveys with you and to use the findings to improve our clinical

"LIVING WITH METASTATIC BREAST CANCER" WAS A DANA-FARBER FACEBOOK LIVE WEBCHAT ON JULY 19, 2018. IT FEATURED

Dana-Farber social worker Liz Farrell, LICSW, and Dana-Farber patients Hanna and Krista. The chat covered the importance of coping strategies and support, especially from other metastatic breast cancer patients. "It sure is great to have people who know what it means when you say, 'I'm living with something that is uncontrollable, with a life span that is unknowable—and how do you do that?' And then I get to see women who are doing that," said Krista.

Hanna agreed, pointing out, "It's hard to explain this disease to people who are not familiar with it. [With a support group, you're] just jumping over that hurdle because you're talking to people who are living it. It saves a lot of time and

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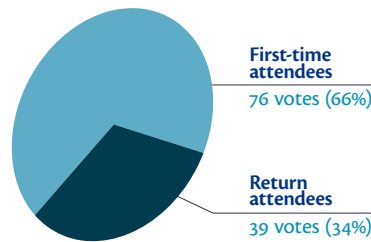
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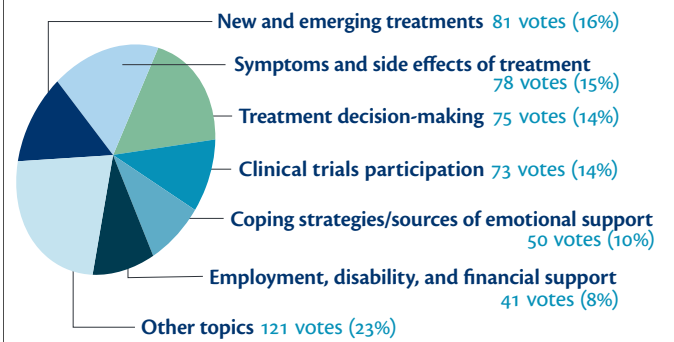
2018 MBC Forum: Attendees respond

At our 2018 MBC Forum, we tried out a technology called an audio response system (ARS) that allowed us to hear directly from attendees. Audience members were given small clickers that allowed them to respond to questions with a click. Here's a sample of what we learned.

NEW VS RETURNING ATTENDEES



TOPICS OF GREATEST INTEREST



Communicating about a metastatic breast cancer diagnosis

IN DANA-FARBER'S JULY 2018 FACEBOOK LIVE WEBCHAT, "LIVING with Metastatic Breast Cancer," Dana-Farber patients Hanna and Krista shared the initial shock of getting their metastatic breast cancer (MBC) diagnosis and how they learned to cope over time. Another challenge they discussed is how to communicate about this complicated disease to the people in their lives.

Dana-Farber social worker Liz Farrell, LICSW, shares her advice for communicating with someone diagnosed with MBC:

1. Offer specific ways to help. Saying "Call me if you need anything" is well-intentioned, but most people won't call to ask for help for fear of being a burden. One example is a friend calling to say, "I'm going to the grocery store. Give me three things to pick up for you."

2. Allow the person to share what they're feeling. A lot of the time people aren't going to be thrilled to be dealing with MBC. They may seem to be in a bad mood or negative about their prognosis, and it's important that they have the space to say that. The kneejerk reaction for a loved one is often to try and make it better, for example, saying, "No, no, you're going to be fine; you're going to be one of the people who live forever." Sometimes people just need you to listen, not to offer solutions, to hear that they're really afraid. You can say something like, "I really hope that's not what happens, but I want you to know you can talk to me about it."

3. For someone with MBC, when asked when you'll be done with treatment, base your answer on what your relationship with that person is. A basic answer you can give is, "I'll never be done with treatment; I'll always have to be on something for the rest of

my life." If the relationship matters to you, then take the time to explain that you're in treatment forever and give more education and explanation about what MBC is and how the process works. If it's not that kind of a relationship, then it's fine to leave it at a basic answer.

Patient perspective

"I am pretty straightforward..."

...in communicating about the diagnosis, and I do share information about it. I find that most people do not know about MBC and what it means. So I look at it as an opportunity to provide information, and advocate for funding, and for them to understand—both Hanna and I don't look sick. I have a hard time squaring it sometimes. For people that I meet, they see me and say, "Oh—are you in remission, are you better?" And I say, "No, I still have it. This is what MBC looks like, for me, right now."

—Krista, Dana-Farber MBC patient

"For me, the conversation..."

...about MBC is usually triggered by questions from friends and family. My close family gets updates from me all the time. As for friends, if they ask how much longer I have to have treatment, that's when I have to explain that this is a chronic disease where you're going to be treated for the rest of your life, and that you'll be on a certain treatment for as long as it's working. I think it takes people by surprise. And we often stop talking about it—there's no more follow-up questions. I think people feel sorry for me when we get to that point, when I say this is indefinite, whatever that means. But I don't shy away from telling people."

—Hanna, Dana-Farber MBC patient

For more information about communicating about MBC to children, see the Summer 2018 issue of the EMBRACE newsletter, available under "Support and Education" at www.dana-farber.org/metastatic-breast-cancer-program.

New genetic testing guidelines for metastatic breast cancer

THE FDA'S RECENT APPROVAL OF A DRUG TO TREAT GERMLINE BRCA-MUTATED METASTATIC BREAST CANCER (MBC) HAS INCREASED THE IMPORTANCE OF GERMLINE

genetic testing among MBC patients. Germline testing is done via a blood or saliva test to check the DNA a person is born with, present in all their cells and inherited from their parents. Tumor testing is done on a biopsy or surgical sample and specifically analyzes the tumor's DNA.

For the first time, a medication for MBC is available for use based on germline (blood or saliva) testing results.

DFCI's standard of care is that all MBC patients be considered for germline genetic testing, including people who have had limited testing before, because new tests are more comprehensive. While testing might not be right for every patient, the criteria to consider testing has expanded in recent years. The cost of genetic testing has also decreased significantly. Most insurance programs now cover testing, and many labs have programs to help cover the cost for people lacking coverage.

The test

Meeting with a genetic counselor is part of the testing process. Dana-Farber has 16 counselors who will help you understand the process, possible results, and discuss your results with you.

Testing is done with blood or saliva from which white blood cells are isolated and DNA is extracted. Three kinds of results, which are available in two to four weeks, are possible:

- Positive: A mutation was identified in the DNA that predisposes to disease (the least common result)
- Negative: No mutations were found (the most common result)
- Variant of uncertain significance (VUS): A change in the DNA was identified, but the change is not known to be consequential. Over time, most VUS results are reclassified, usually to a negative result.

Why test?

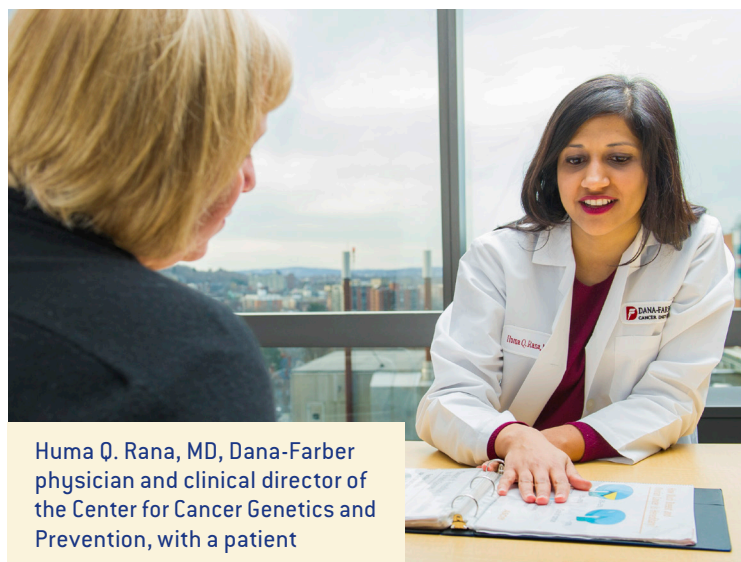
"A positive result opens a window of opportunity," says Huma Q. Rana, MD,

Dana-Farber physician and clinical director of the Center for Cancer Genetics and Prevention. "Someone may be eligible for new treatments, clinical trials, or precision therapeutics, based on their results."

Another reason to get tested is to share risk information with your family. First-degree relatives have a 50% chance of having the same mutation, and knowing their risk has important ramifications for their own care, such as more intensive cancer surveillance, screening for specific cancers, or getting preventive care they

wouldn't have otherwise.

"Some patients worry about the effect of this information on their relatives," says Dr. Rana. "It's good information for family members to have. Your results may alert them to their own need [Cont. on page 4](#)



Huma Q. Rana, MD, Dana-Farber physician and clinical director of the Center for Cancer Genetics and Prevention, with a patient

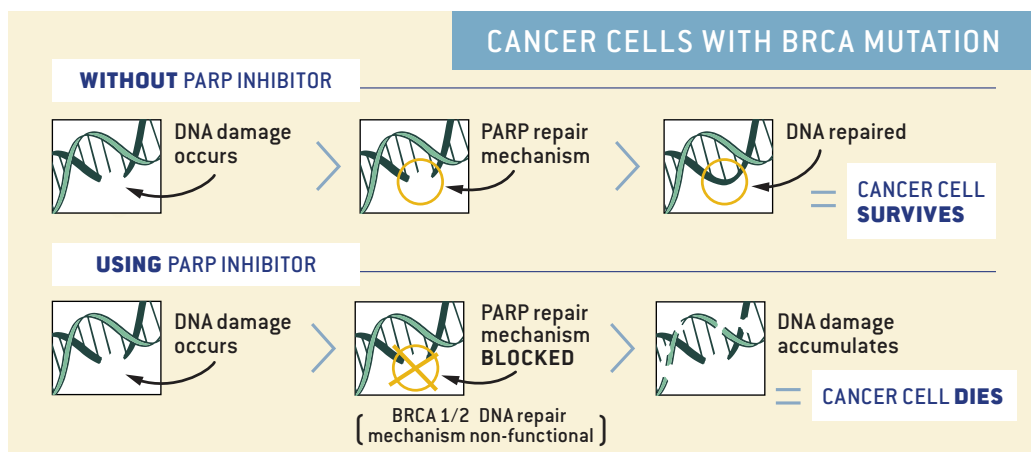
BRCA research yields new medication and hope

AROUND 5% OF PATIENTS WITH BREAST CANCER WILL HAVE INHERITED A version of the BRCA1 or BRCA2 gene that doesn't work properly (called a mutation). Mutations in the BRCA1 or BRCA2 gene can be found across all ethnic groups and can be passed through the mother's or father's side of the family.

BRCA function

Scientists at Dana-Farber were among the first in the world to discover the function

of BRCA1 and BRCA2, which help the body to repair DNA damage from everyday life. Because everyone inherits one copy of the BRCA gene from their mother and one copy from their father, for patients who have an inherited BRCA mutation, in most cells in the body, the "good" copy compensates for the "bad" copy. Over time, though, some breast cells can lose the "good" copy, and this allows mutations in the DNA to build up, which can lead to breast, ovarian, and other cancers. [Cont. on page 4](#)





Left to right are Dana-Farber patients Krista and Hanna, with Liz Farrell, LICSW, Dana-Farber social worker

Resources

MBC Alliance: Patient Info & Support Services

www.MBCalliance.org/support

A compilation of resources for people with MBC, including blogs, clinical trials, helplines, social media, webinars, and more.

MBCN (Metastatic Breast Cancer Network): Resources

www.mbcn.org/resources

A listing of resources by category, including complimentary & alternative medicine, legal resources, housing for appointments, free transportation, caregiver support, and more.

Metastatic Trial Talk website

MetastaticTrialTalk.org

A new portal that provides patients with carefully selected news and features about MBC research.

SHARE

www.sharecancersupport.org/about-us

SHARE is a national nonprofit that supports, educates, and empowers women affected by breast or ovarian cancer. Telephone support for patients living with MBC is available during day and evening hours.

DFCI's Metastatic Breast Cancer Forum

www.dana-farber.org/mbcforumhighlights

For those who attended our 7th annual Metastatic Breast Cancer Forum, we hope that the day was valuable to you. For those unable to attend, the taped sessions are available at the link above.

The 2019 8th Annual Metastatic Breast Cancer Forum will be Saturday, October 5, 2019.

Facebook Live chat Cont. from page 1

energy and emotions. We just go through the nitty-gritty of what's going on with you, what's going on with me. It's great. Just talking it through, sharing it, is hugely helpful for me."

The chat also touched on experiences with being diagnosed, tips for coping and support,

impact on children, communicating the diagnosis to friends and family (see page 2), and answers to audience questions.

Find the recorded chat on Dana-Farber's Facebook page (www.facebook.com/DanaFarberCancerInstitute) under "Videos" or at <http://bit.ly/mbclive2018>.

BRCA research Cont. from page 3

New medication approved

PARP inhibitors are a new type of oral medication that work by preventing cells from repairing DNA damage. In cancer cells that have lost the "good" copy of BRCA1 or BRCA2, treatment with a PARP inhibitor leads to so much DNA damage that the cancer cell cannot survive. However, normal, non-cancerous cells are much less affected, because they are still able to repair their DNA with the functioning version of the BRCA1 or BRCA2 gene.

Two recent phase 3 studies have compared PARP inhibitors vs. traditional chemotherapy in patients with metastatic breast cancer who also have an inherited BRCA1 or BRCA2 mutation. Both studies showed that patients treated with a PARP inhibitor were much more likely to see tumor shrinkage or stabilization, and for treatment to work longer than patients treated with chemotherapy. This was equally true for patients with triple-

negative breast cancer and for patients with estrogen receptor-positive breast cancer.

Patients treated with PARP inhibitors also experienced fewer side effects and better quality of life compared to those treated with chemotherapy. In January 2018, the FDA approved one of these PARP inhibitors, olaparib for use in breast cancer, and the second PARP inhibitor, talazoparib, was approved later in 2018.

Next steps

Now, Dana-Farber researchers are trying to build on the success of these two studies by testing new combinations of PARP inhibitors with other medicines. And an ongoing clinical trial is testing whether PARP inhibitors might work in patients with other (not BRCA1 or BRCA2) hereditary causes of breast cancer. We believe all of these advances are cause for hope and show the power of partnering with patients on basic and clinical research.

Genetic testing guidelines Cont. from page 3

for testing or, more commonly, reassure them about their genetic risk."

Dana-Farber patients interested in getting a genetic test can talk to their oncologist or call the Dana-Farber Center for Cancer Genetics

and Prevention at 617-632-2178. Appointments can usually be made for the same day as your next Dana-Farber appointment. Family members of Dana-Farber patients can also get genetic testing and can call the same number for more information.

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ENDING METASTATIC BREAST CANCER FOR EVERYONE

Please send us your comments, questions, and suggestions!

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