

Learning from each other

DFCI HELD ITS THIRD ANNUAL METASTATIC BREAST Cancer (MBC) Forum on October 18, 2014. More than 150 people attended the event, which focused on the latest advances in MBC trials, integrative medicine, and resources for caregivers.

A panel of four patients shared personal strategies for coping with MBC in a session created in response to requests from attendees at previous forums.

"We flock to our peers, we've done that forever, so it's not surprising that we want to hear from other people with MBC. Our histories are different, our struggles are different, our coping mechanisms are different, but we all have a desire to meet the challenges."

—Julie Salinger, MSW, LICSW
Panel discussion moderator

Each panelist shared insights about how she meets the challenges of MBC. "Our paths are all similar," a panelist affirmed, but each one has found her own solutions and coping strategies. Some of their insights are highlighted in this issue.

Read what they had to say on page 2.

Letter from Dr. Lin

After a long, snowy winter, it's so wonderful to feel a change in the air and the hope that comes with spring.

Thanks to all who participated in the third annual Metastatic Breast Cancer Forum last October, as well as all who gave feedback on the forum and this newsletter. Several of you suggested to include patient profiles and stories, and we have done a bit of that in this issue. We also have a few webcasts planned in the next year, in direct response to topic suggestions. I'm excited to announce a partnership with the Metastatic Breast Cancer Network to co-host this fall's fourth annual Metastatic Breast Cancer Forum with us. We have an exciting program planned, in large part due to your feedback, and hope you will find it useful.

In this issue, you'll hear about what Dana-Farber researchers are doing to better understand a specific type of breast cancer (HER2-positive) and the work being done to translate findings into new treatments. We will cover other breast cancer types and treatments in future issues. On the last page, you'll find a brief guide to some resources available to you.

Thank you again for your feedback and your willingness to take time out of your busy lives to help the EMBRACE team serve all of our patients better. You make the world a better place.

Warm regards,
Nancy Lin



| | |
|--------------------------------------|---|
| Metastatic Breast Cancer Forum | 2 |
| Research update: HER2 progress | 3 |
| Meet: Susan Moody, MD | 3 |
| Resources | 4 |

Patient panel: Coping with advanced cancer

FOUR PATIENTS SHARED THEIR STORIES AND INSIGHTS INTO HOW THEY MEET THE CHALLENGES OF LIVING WITH METASTATIC BREAST CANCER IN A PANEL DISCUSSION THAT WAS PART OF THE 2014 METASTATIC BREAST CANCER FORUM. EACH PERSON'S JOURNEY WAS UNIQUE, BUT "OUR PATHS ARE ALL SIMILAR," ONE NOTED. "OUR COMMONALITY AMAZES ME," ANOTHER OBSERVED. HERE ARE SOME OF THE STRATEGIES THEY SHARED, IN THEIR OWN WORDS.

My decision to continue to work gives me a great sense of gratitude. I had a career that I loved, and I wanted to continue what I was doing, although I've had to make some modifications. Because

WORKING

I work in the State Dept., after I was diagnosed I couldn't live overseas anymore. But I can travel and I can telecommute, so I still work full-time. I miss my colleagues and I talk to my dog, but it has been a big benefit to continue to pursue the dreams I've always had. —Lyn

I'm not working, though I still carry my union carpenter card. The Big Dig was my first carpenter job, and it was really hard work. I used to do home energy audits too, but then I couldn't carry the equipment anymore. I'm exhausted a lot of the time—I have to nap, sleep in the morning...I just can't work. I'm scraping by on Social Security and I take money out of the bank too much. That was my decision. —Meg

My daughter is my life. She keeps me looking forward and keeps me out of that black hole. Having a child forces you outside of yourself, to not think about how bad you feel, because there is someone who is more important. She wants to color and ride bikes and play. Maybe I can't ride bikes but I can color, I can read books, and help her with her homework. I spend as much time as I can with Sophie and that's the best thing. —Gail

FAMILY

Next MBC Forum: October 17, 2015

View the 2014 Forum webcast:

<http://video.dfcionline.org/accordent/mbcforum101814/>

I come to DFCI every 3 months and I've fallen in love with many of the people here, so having the opportunity to get that reinforcement from them is really positive. But because I'm only here every 3 months, there's that in-between time when I'm sitting up

SUPPORT FROM OTHERS

there in Maine and I get scared. So I communicate through Patient Gateway...and my doctor always answers me. My social worker gets the same thing now and then, when I need to check in. I've also set

up support with a counselor at home—once a month, someone other than family who I can talk with honestly. —Susan

At times I've gotten support by taking an anti-anxiety medication. I had a hard time accepting that at first. But I took my diagnosis fairly hard and got really anxious and that wasn't good. My husband

MEDICATION

had a conversation with DFCI for me. So I have used medication at times. —Susan

I had to learn how to support myself. At the beginning I did a lot of reading—the entire High Heel mystery series. Now I'm into knitting dishcloths and watching Bollywood. I cannot live with being in cancer and the uncertainty all the time, sometimes I need to get out. —Susan

SELF SUPPORT

Diet, exercise, relaxation to keep myself in the best possible health. Probably 2% of my body has cancer. The rest of me is healthy. I need DFCI's help for that 2% but I want to take responsibility for the other 98%. I have no idea if it makes any difference but it gives me a focus that helps me deal with the uncertainty. —Susan

LIFESTYLE

I am committed to reducing stress. As a single mother, I worried about managing money, debt consolidation, estate planning—things most people do, but I felt a sense of urgency. It was awkward talking with my investment advisor about the disease aspect of long-term planning. So

FUTURE PLANNING

I called DFCI and got a recommendation of a firm that counsels patients. I felt so comfortable with them. My daughter is my life and I need to make sure things are in place for her. That's an example of reducing worry and being able to move forward. —Lyn

I just try to have a good attitude. I like to travel, get in my convertible, her name is Tootie because we've got attitude and it's all in the 'tude! I'm going to hop in my car and drive to Maryland after this and live my life and see my friends. The diagnosis is sucky and I don't know how long I have, so let's keep up the attitude and no "woe is me." —Meg

ATTITUDE

Meet:

Susan Moody, MD, PhD

INSTRUCTOR IN MEDICINE

Susan Moody traces her interest in cancer back to her high school biology teacher, a breast cancer survivor who introduced the concept of metastatic disease to Moody. Moody's interest was sparked to understand how cancer works—and how it can be stopped.

As an undergrad at the University of Virginia, Moody worked in a lab and became interested in research. She completed a combined MD/PhD program at the University of Pennsylvania, followed by a residency and fellowship at Brigham and Women's Hospital before joining Dana-Farber.

Moody calls the balance of seeing patients and working in the lab "great...I see patients in clinic with the exact problems I'm addressing in the lab. This helps identify the important questions," she says. "Patients are the motivation behind everything. I love seeing them and getting to know them as people. It's easy to get absorbed in the lab; patient care helps bring me back to the why." In turn, her research "provides hope for new treatments that could be brought to patients through clinical trials, and it is such trials that can ultimately lead to changes in the standard of care."

Moody's research focuses on how HER2-positive breast cancer becomes resistant to treatment and on finding new ways to target cancer. Patients who participate in clinical trials and allow their tissue samples to be used for research play a crucial, "courageous" role, she says. "Tissue biopsies provide valuable information that researchers use to guide their hypotheses and design their experiments."

One of Moody's projects includes some EMBRACE participants. Conducted in collaboration with researchers at the Broad Institute and MIT, it involves the circulating tumor cells found in some patients' bloodstreams. Its exciting potential—though still experimental—comes from the possibility of a "liquid biopsy" from a blood draw that could provide the same information as a tissue biopsy. If this proves to be the case, this means a biopsy could be repeated "serially," such as every three months, and could provide a means for more easily tracking changes in cancer cells as they evolve during therapy.

Progress against HER2-positive breast cancer

Teamwork makes the difference

BY NANCY LIN, MD

Approximately 15-20% of breast cancers are HER2-positive, meaning that they produce excessive amounts of a protein called HER2 that sits on the surface of the cell. The extra HER2 produces signals for the cell to divide, grow, and survive. Medications such as trastuzumab (Herceptin) attach to HER2 and attack cancer cells in several different ways, including shutting down the growth and survival signals, and flagging cancer cells to activate the body's immune system. Since Herceptin was approved by the FDA in 1998, several other medications that target HER2 signaling have also been shown to be effective for metastatic breast cancer (MBC), including lapatinib (Tykerb), pertuzumab (Perjeta), and TDM1 (Kadcyla).

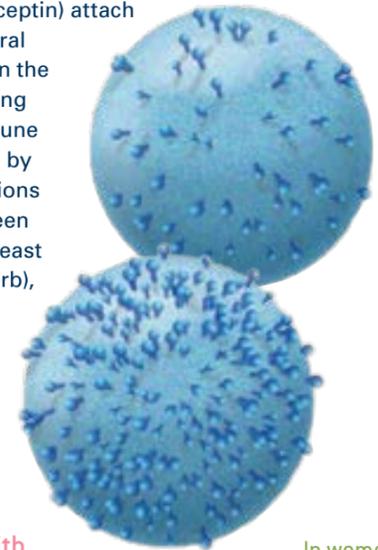
So how do we continue to make progress? Here are just a few examples of how researchers and patients are teaming up together to make a difference.

Pairing tissue and blood samples with information about a disease's course

Despite widespread use of medicines like Herceptin, we still don't understand all the ways that cancers can become resistant to (grow in spite of) treatment. To help us learn, we have collected breast cancer tissue from more than 100 patients (with their permission) with HER2-positive MBC at the time of cancer recurrence and/or at the time of tumor growth while the person was taking Herceptin. (Many of these 100 patients are EMBRACE participants!) By studying the genes in these tumor biopsies, we have found mutations ("spelling mistakes") in a number of genes, only some of which are present in the primary tumor (breast tumor tissue collected at the time of the first breast cancer diagnosis). We are now trying to understand whether these mutations affect tumor response to different types of treatments.

On the flip side, we have seen treatments work remarkably well for many years in some patients with MBC. We have identified a few patients whose breast cancer is still under control on their first treatment regimen, now more than five years after they first started Herceptin for MBC. We are studying the DNA of these patients' tumors to see if we can find differences that explain their long responses, and we hope to also explore whether there are any differences in how their immune systems work that may be important.

We are also studying ways to track changes in tumors through changes in the blood—which would be an easier process on patients than repeated tumor biopsies. In the EMBRACE



In women with HER2-positive breast cancer, tumor cells produce too much of a protein called HER2.

Continued on page 4

Progress against HER2-positive breast cancer

Continued from page 3

study, this includes studying circulating tumor cells, in collaboration with Dr. Susan Moody, in addition to a new project to study changes in tumor DNA that we can capture in blood samples, in collaboration with Dr. Rinath Jeselsohn and others.

Developing new models to test breast cancer treatments in the laboratory

Across all tumor types, Dana-Farber researchers are actively working on creating new animal models to study breast cancer. One example of this work is in patients undergoing either a biopsy or surgery for MBC who consent to have their tissue used for research. During the procedure, a small piece of the tumor that is removed is implanted into mice, and then different combinations of treatments can be tested against that specific tumor. We hope this approach may allow us to more accurately predict which treatments will be effective in patients with MBC and to prioritize the types of treatments we bring forward into clinical trials.

Testing new treatments in clinical trials

Based on data from the laboratory, researchers prioritize which treatments to take forward into clinical trials. In a clinical trial, new treatments are tested for safety and effectiveness in patients. Clinical trials require a lot of teamwork—between patients and their support network, physicians, scientists, nurses, research coordinators, pharmacists, schedulers, and more. This team approach is our best hope to make progress and to develop better and more effective treatments for MBC.



ENDING METASTATIC BREAST CANCER FOR EVERYONE



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questions, and suggestions!
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Produced by Health Communication Core
www.HealthCommCore.org

Resources

PRACTICAL AND SUPPORTIVE RESOURCES

Resource specialists

One-on-one help with local transportation, short-term accommodations during treatment, applications for financial assistance programs (including pharmacy programs), and other special needs (food pantry information, fuel assistance programs). Contact a resource specialist at 617-632-3301.

Financial counselors

One-on-one assistance with financial and insurance issues for patients and families. For more information, please call 617-632-3455.

Support groups, including for caregivers

Support groups are available for people with metastatic breast cancer (MBC), and for caregivers of people with MBC. For more information about support groups and seminars for DFCI patients and families, including new and updated offerings, please call 617-632-3301.

One-to-One program for support by phone

A free program connecting people and families dealing with a cancer diagnosis (before, during, and after treatment has finished) with volunteers who “have been there”—cancer survivors, caregivers, and family members who have completed specialized training and can offer comfort and support by phone. Ask your care team about the program, or contact 617-632-4020; onetooone@dfci.harvard.edu.

Family Connections Program (resources for parents with cancer)

Supportive resources to patients who are parents, including how to talk to children about cancer, advice for the well partner, and creating a support network. To access the program’s resources, visit www.dana-farber.org and search for “Family Connections Program.”

Palliative care for pain and symptom management

An extra layer of help and support for DFCI patients who are experiencing pain, challenging symptoms, and other quality-of-life concerns. For more information, ask your care team or call 617-632-6464. You can also request a copy of *Coping with Cancer Pain: A Handbook for Patients*.

RESEARCH OPPORTUNITIES

Clinical trials for people living with metastatic breast cancer

Clinical trials are scientific studies in which new treatments—drugs, diagnostic procedures, and other therapies—are tested in patients to determine if they are safe and effective. Such trials help researchers answer questions about new cancer therapies. Nearly all cancer drugs in use today were tested and made available to patients through clinical trials. To learn more, speak with your care team or visit www.dana-farber.org/Research/About-Clinical-Trials.aspx, click on “Search Dana-Farber clinical trials”; under “Adult,” see “Breast: Metastatic.”

OncoPanel research study (molecular characteristics of metastatic breast cancer)

Launched by DFCI and Brigham and Women’s researchers in 2011, OncoPanel is part of the Profile research study—one of the nation’s most comprehensive personalized cancer medicine initiatives. Profile researchers have been analyzing the DNA in tumor tissue from more than 31,000 patients coming for treatment of all types of cancers. OncoPanel, a new phase of Profile begun in 2013, is an advanced sequencing platform that can detect genetic mutations and other critical types of cancer-related DNA alterations. For more information, ask your care team or visit <http://www.dana-farber.org/Research/Featured-Research/Profile-Somatic-Genotyping-Study.aspx>.