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
My decision to continue to work gives me a great deal 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 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 seeing 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 of a lot of the time—I have to nap, sleep in the morning. I just can’t work. I’m snapping 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

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 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 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 disclths and watching Bollywood. I cannot live with being in cancer and the uncertainty all the time, sometimes I need to get out. — Susan

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

I am committed to reducing stress. As a single mother, I worry 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 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 ‘ude’. 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 lucky and I don’t know how long I have, so let’s keep up the attitude and no “woe is me.” — Meg
Progress against HER2-positive breast cancer

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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.

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; onetone@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.