As we enter the final days of the summer, I want to update you on what we have been up to. Our 5th Annual (Virtual) Forum was a lively event attended by participants from all over the world. You can find some of the questions raised by the audience addressed in the IBC FAQ section of this newsletter and watch recordings of the forum sessions on Dana-Farber’s YouTube channel.

Our program continues to grow and we now have a dedicated clinical research coordinator. Read more about Elizabeth Troll and her role in the IBC Program at the end of this newsletter. This year we have been focused on launching two new clinical trials, and we will share more information about the trials in the next newsletter. We have also published important data related to the detection and incidence of brain metastases, the potential role of on-treatment biopsies, and HER2-low IBC. You can read more about some of these publications in this newsletter.

Finally, we are starting to prepare for the Boston Marathon® Jimmy Fund Walk coming up on Sunday, October 2. It will be so nice to walk together again, and we are all making sure we have the right shoes to do so! As usual Mariesa will be our Team Captain and you can sign up to be part of the team here. Thank you all for partnering with us and being such an important component of all the work we do.

I look forward to seeing you in person!

Best,
Filipa

Filipa Lynce, MD
Director, Inflammatory Breast Cancer Program
IBC Program 5th Annual Patient Forum Recap

In April, the IBC program virtually hosted our 5th Annual IBC Patient Forum. It was a special day of collaboration and education where sharing the latest in IBC research, treatment, and care with researchers, physicians, nurses, patients, and their loved ones. There were 75 participants from 8 different countries who attended a series of lectures by our Dana-Farber experts discussing bench-to-bedside research and patient-care-focused comprehensive treatment strategies.

- Filipa Lynce, MD, shared the latest in IBC research, including the validation process of a new diagnostic criteria, open and upcoming IBC clinical trials, and insights into our ongoing collaboration with MD Anderson Cancer Center’s IBC Program.
- Nikhil Wagle, MD, discussed the importance of patient-centered research initiatives such as Count Me In to drive forward progress in rare diseases like IBC.
- Focusing more on direct patient care, Antonio Giordano, MD, PhD, gave attendees a better understanding of biomarkers and how they are used to guide treatments and develop novel therapies.
- Jennifer Bellon, MD, shared her expertise in radiation therapy for IBC.

Finally, all in attendance had the opportunity to hear from experts in acupuncture, social work, and physical therapy as well as patients who shared their firsthand experiences with these supportive care resources. In the afternoon our wonderful social worker Julie Salinger, LICSW, MSW, led a social work and support group session.

We look forward to what next year will bring as we continue gaining a deeper understanding of and developing better treatments for IBC. For those who were unable to attend, recordings of some of the sessions on Dana-Farber's YouTube channel.
IBC FAQ: Scalp Cooling

What is scalp cooling?
Scalp cooling is a process that attempts to prevent or minimize hair loss for patients actively receiving certain types of chemotherapy, including taxanes. Depending on the type of chemotherapy a patient receives, their doctor may present scalp cooling as an option to limit hair loss. It works by placing a tight-fitting cooled cap on a patient’s head while they receive chemotherapy for the purpose of restricting blood flow to the patient’s scalp. A machine spreads cooled liquid throughout the cap to continuously lower the temperature of the patient’s head. By restricting the blood flow to the scalp, the dose of chemotherapy drugs that reach the cells that keep hair healthy is also reduced.

What is the Dana-Farber scalp cooling procedure?
The scalp cooling system used at Dana-Farber is made by a company called Paxman® and is approved by the U.S. Food and Drug Administration (FDA). If you are considering whether to use scalp cooling, be sure to first talk with your care team about its pros and cons. Scalp cooling isn't yet covered by insurance, so the entire cost of the kit and supplies is paid by the patient.

Will it work?
Studies show that patients using scalp cooling are more likely to keep more of their hair, but there is no guarantee as to what extent scalp cooling will prevent hair loss. Most users will still experience at least some hair thinning. Scalp cooling success depends on many factors, such as the fit of the cap, the state of a patient’s hair before treatment, the kind of chemotherapy received, and the dose administered. Patients should ask their provider what the likelihood of success for their individual case is. Learn more in this Dana-Farber blog post.

Are there any scalp cooling clinical trials available at Dana-Farber?
21-169: Assessing the Impact of Scalp Cooling in Patients with Metastatic Breast Cancer
This research is being done to compare rates of hair loss of people with metastatic breast who use scalp cooling versus those who do not use scalp cooling after receiving standard of care treatment with either sacituzumab govitacan, trastuzumab deruxtecan, or eribulin. More information about this clinical trial can be found here.

IBC FAQ: Alternative Therapies for Symptom Management

Exercise
Exercise is an important part of cancer care at every stage of treatment, and beyond. Studies show that staying active through treatment can help patients maintain strength and energy, reduce fatigue, reduce nausea, and combat insomnia and depression.
Are there exercise classes at Dana-Farber?
Yes. Our Zakim Center for Integrative Therapies and Healthy Living offers many free, virtual exercise programs and classes for patients of all levels of fitness. Visit the Zakim Center's program calendar to find a full listing. To learn more, talk with your cancer care team or call the Zakim Center at 617-632-3322.

Exercise consults: If you need help getting started or want to discuss a special need, contact Dana-Farber’s exercise physiologist for a free personalized exercise consult. Your session will include an exercise program and a list of resources to help you reach your goals.

Gym access: Dana-Farber patients have free access to the nearby BodyScapes® fitness center at 77 Avenue Louis Pasteur (two blocks from Dana-Farber). To learn more and check that the fitness center is open, call 617-738-9229.

Oncology Massage
Oncology massage is a type of massage therapy that is adjusted to provide a safe and helpful session for any patient with a cancer diagnosis. It must be performed by a massage therapist specifically trained in this kind of massage.

How can it help?
Oncology massage has been used to improve quality of life throughout cancer treatment by providing comfort and alleviating symptoms. It can be used to ease pain, anxiety, depression, fatigue, insomnia, and nausea. Oncology massage may be used before, during, and/or after cancer treatment.

Is oncology massage available at Dana-Farber?
The Zakim Center’s trained oncology massage therapists, in collaboration with your care team, will work to best meet your need for symptom management. To schedule an oncology massage appointment, call 617-632-3006.

Acupuncture
Acupuncture involves having hair-thin needles gently inserted into the skin at specific points, called acupoints. When stimulated in this way, as well as with heat, acupoints can help us correct and rebalance physical, mental, spiritual, and emotional energy.

How can it help?
Acupuncture may be used for patients with symptoms including chronic pain, nausea, vomiting, insomnia, depression, anxiety, and fatigue. It can be used at any stage of treatment in collaboration with a patient’s medical team.

Is acupuncture available at Dana-Farber?
Acupuncture services are available to Dana-Farber patients at the Zakim Center. To
schedule an appointment, call 617-632-3006.

IBC in the Media

Susan G. Komen® Grant Helps Advance Diagnosis of IBC

In 2019, the Komen IBC Task Force proposed common diagnostic criteria and a new scoring system that could be used by physicians to accurately identify IBC. This scoring system is based on clinical and pathologic characteristics, giving a weighted score to each characteristic of the disease. The score is then totaled and, based on that score, the diagnosing physician can determine whether a patient has IBC.

Dana-Farber and MD Anderson, which have the two largest IBC programs in the nation, are now collaborating to validate this new diagnostic system. The Susan G. Komen breast cancer foundation this year awarded a 2-year research grant to fund this process. This grant will allow the two institutions to work together and retrospectively apply the scoring system to their databases, allowing for validation and further refinement of the scoring system.

The validation and use of this diagnostic system have multiple implications for patients with IBC. A more standard approach to the diagnosis of IBC will allow patients to be treated sooner and properly. “This tool will help to define IBC, increase diagnostic accuracy, and provide data to standardize how we diagnose and treat inflammatory breast cancer,” said Dr. Lynce.

Read the media release here.

Research Updates

*Early on-treatment transcriptional profiling as a tool for improving pathological response prediction in HER2-positive inflammatory breast cancer* - Sonia Pernas, MD, PhD, et al. *Therapeutic Advances in Medical Oncology* 2022

Dana-Farber’s IBC program recently published results from a Phase II study that examined the role of trastuzumab, pertuzumab, and paclitaxel in patients with HER2-positive IBC. Biopsies were collected from each patient on day 1 and day 8 with the goal of predicting pathological response to neoadjuvant treatment. Using next-generation
sequencing technologies, including RNA sequencing, researchers were able to examine the molecular makeup of the tumors and subsequent changes in response to therapy. This study concluded that the biopsy taken at day 8 of treatment not only provided different biological information, but was a superior predictor of pathological complete response compared to the day 1 biopsy. Identifying changes in gene expression in early on-treatment tumor biopsies may aid in identifying new biomarkers of disease response and resistance. This would allow doctors to make earlier modifications to treatment plans for individual patients and could open the doors for the development of more targeted therapies.


The purpose of this study was to retrospectively quantify the risk of brain metastasis in patients with IBC who have been evaluated in the IBC program at Dana-Farber. Utilizing data from our registry it was concluded that the risk of developing brain metastasis was highest in certain subpopulations. These subpopulations include those with metastatic disease outside the brain, those with “triple negative” (estrogen receptor negative, HER2-negative) tumors, and patients who are younger when diagnosed with metastatic IBC. There is currently a trial open at Dana-Farber (NCT04030507) studying the usefulness of magnetic resonance imaging (MRI) to screen for brain metastases (spread of the breast cancer to the brain). This trial is open to patients with inflammatory breast cancer. See more info [here](#).

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**Walk With Us on Sunday, Oct. 2!**

**Team IBC** is walking for the sixth year in a row! Help us make it the best year yet. All Proceeds from our walk go toward Dana-Farber’s Inflammatory Breast Cancer Research Fund. We can't succeed without your help!

- **Join our Walk team** back on the Boston Marathon® course or walk your way (virtually in your own community)! Register [here](#).
- **Spread the word.** Support IBC by sharing our [fundraising page](#) with your friends, family, and social media networks.

For more information, including fundraising tips, walker stories, FAQs, and walk-day logistics, visit our [Walk team’s page](#) or email our team captain Mariesa Powell at [DFCI_IBC@dfci.harvard.edu](mailto:DFCI_IBC@dfci.harvard.edu).
A warm welcome to Elizabeth Troll, IBC clinical research coordinator and newest member of the IBC program. Elizabeth is responsible for meeting with new patients and introducing them to the research and clinical aspects of the program, acting as their first point of contact to available Dana-Farber resources.

Elizabeth graduated in December 2021 from UMass Amherst, where she studied biochemistry and molecular biology. Since 2014, she has worked in a variety of health care roles — as a candy-striper, a certified nursing assistant in hospitals and nursing homes, a hospice volunteer, and now as our clinical research coordinator. Elizabeth’s dedication, curiosity and kindness has led her to quickly become a valued member of our team.

As an aspiring oncologist, it is Elizabeth’s goal to always advocate for accessible, equitable healthcare for all people. Many of her loved ones have been diagnosed with cancer igniting a passion for cancer research, treatment, and, most especially, patient care.

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