Welcome to our Inflammatory Breast Cancer (IBC) Program’s Summer 2023 newsletter!

I always feel energized when the warm weather comes along with [SED1] days full of brightness. I hope you have been able to enjoy some time off and away from your daily routines. We all need to recharge from time to time!

As always, we have been busy at the IBC Program in recent months.

In May, we hosted our first IBC Virtual Gallery fundraising event, where our very own Jennifer Bellon, MD, joined with our Jimmy Fund walk “hero” and patient Stephanie Lafontaine to present their wildlife photos. It was a tremendous success with many of us joining for this inaugural event. You can learn more about it in this newsletter.

In the last few months, we launched new trials dedicated to patients with IBC, some with novel agents and others focused on local therapy. Every single patient who is newly diagnosed with stage III IBC now has a clinical trial available for consideration.

On a bittersweet note, we said goodbye to our valued social worker Julie Salinger, LICSW, MSW, who had been our social worker since 2012. We are so grateful for all that Julie did for our patients, but we are also pleased to welcome our new social worker Jess Mosey, LICSW, MSW, and we look forward to working with her to start a new chapter.

I hope you enjoy reading this newsletter and, as always, reach out to us if you have any comments, questions, or suggestions. We hope to see you on October 1st at the Jimmy Fund Walk. Please consider joining Team IBC, we would love to walk with you!

Sincerely,

Filipa Lynce, MD
Director, Inflammatory Breast Cancer Program
**Walk With Us on Sunday, Oct. 1!**

Team IBC is walking for the sixth year in a row! Since 2017, we have raised nearly $178,000 in support of IBC research and patient care. 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 Team IBC Walk team** on the Boston Marathon® course or walk your way (virtually in your own community)! Register at our [Team IBC page](#).
- **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 MariesaD_Powell@dfci.harvard.edu.

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**IBC Virtual Gallery Fundraiser: Event Recap**

In May 2023, our program hosted its first virtual gallery event featuring photography from Jennifer Bellon, MD, and Stephanie Lafontaine to launch fundraising for Team IBC. Dr. Bellon, one of our IBC radiation oncologists, loves to travel around the world to pursue her art, often resulting in stunning wildlife photos. Stephanie Lafontaine was diagnosed with IBC in 2019 and completed her treatment with the goal of getting back to her passion of scuba diving and underwater photography. For all who participated by buying tickets to this event, these artists shared their breathtaking photos and told the adventurous stories behind each work.

In addition to the art, the event also hosted a raffle. Prizes included a wall print from Dr. Bellon, a calendar of Stephanie’s underwater photography, and Red Sox tickets. We have received overwhelmingly positive feedback from everyone who attended, and we look forward to our next Virtual Gallery Event.
IBC FAQ: PT and Yoga for Lymphedema Management

What is lymphedema?

Lymphedema is the accumulation of lymphatic fluid that can cause swelling in the arm and/or hand, and it can be a common side effect of certain breast cancer treatments. Lymphatic fluid is normally filtered through the lymph nodes. Removal of lymph nodes requires lymph fluids from the arm to be rerouted and filtered through remaining axillary lymph nodes. Lymphedema occurs in many patients with IBC, and symptoms can range from hand swelling alone to total arm swelling.

Should you notice any swelling, please contact your surgeon’s office for instructions on appropriate follow-up care. Treatment includes physical or occupational therapy, manual lymphatic drainage, and compression bandaging and garments. New research suggests gradual, progressive strengthening, when cleared by your physician, may minimize the risk of lymphedema by dilating, or widening, remaining lymphatic channels around the shoulder and arm.

Where can I receive physical therapy for lymphedema?

Brigham and Women’s Hospital has a number of lymphedema physical therapists on staff and has a dedicated lymphedema clinic at their Faulkner location. If you choose to receive care closer to your home, please look for a physical therapist that specializes in lymphedema treatment.

Are there exercises for lymphedema management?

Yes! Therapists from Brigham and Women’s Hospital offer a 6-week yoga/lymphedema management program redesigned to offer relief, healing, and comfort to many patients with lymphedema. The yoga program is suitable for all levels, with a focus on education on how to better live with lymphedema. It provides guidance for safe and appropriate lymphatic yoga practice with breathing exercises, physical postures, meditation, and mindfulness techniques. The course also includes guidance for self-manual lymph drainage, compression garments, lymphedema risk reduction/flare reduction education, mental/physical/social wellness and other topics that may help you improve your quality of life.

Please note that there is a cost to enroll in this 6-week program. For more information, please visit the program’s website.
IBC Social Work Updates

Our IBC social work group meets monthly for a discussion lead by our social worker Jess Mosey, LICSW, MSW. We will be meeting every third Wednesday of the month at noon for a directed discussion on a topic unique to IBC patients.

Every quarter, these meetings will include expert speakers who lead a discussion on topics relevant to patients with IBC. These dates and times may vary depending on speaker availability. In June, we had the pleasure of hosting Justin Broyles, MD, to discuss reconstructive surgery options and eligibility criteria for IBC patients. Dr. Broyles emphasized that plastic surgery is integral to the comprehensive treatment of patients with IBC, therefore his team at Brigham and Women’s Hospital has made it a priority to see patients at the time of their initial diagnosis. Dr. Broyles emphasized that seeing patients early on in their treatment helps to ensure that patients are informed about the preventative strategies for lymphedema as well as reconstructive options and eligibility.

Earlier this spring, Shailesh Agarwal, MD, discussed lymphedema treatment options and interventions. He reminded us that the first line of treatment for lymphedema should always be occupational or physical therapy with a lymphedema specialist, and that for IBC patients it’s especially important to establish care early. Dr. Agarwal then introduced us to cutting-edge surgical options to re-establish lymphatic drainage, including lymphovenous bypass and vascularized lymph node transfer. These surgical interventions are available for patients with lymphedema who have already received optimal non-operative therapy and are still experiencing symptoms. Patients with long-standing lymphedema may also benefit from direct removal via liposuction.

If you are interested in joining our next meeting, you can join by zoom or call in at 1 929 205 6099 using meeting ID 983 8671 8379 and passcode 371107. Our next meeting will be held September 20th at 12noon.

IBC Selected As a ‘People’s Choice’ Educational Session at Major Breast Cancer Symposium

The San Antonio Breast Cancer Symposium (SABCS) is the largest annual breast cancer conference in the world and we are thrilled to announce that its attendees have voted to include a 2-hour educational session this year called Inflammatory Breast Cancer: Clinical challenges, evolving concepts and novel treatments. Some members of our IBC Program will be talking at or chairing this “People’s Choice” session and we look forward to learning about the latest in IBC research from around the world!

SABCS aims to provide state-of-the-art information on the experimental biology, etiology, prevention, diagnosis, and therapy of breast cancer and premalignant disease to an international audience of academic and private physicians and researchers. Attendees also include other health professionals, patient advocates, and others with a special interest in breast cancer.
Research Updates: Metastatic Registry and Newly Opened Clinical Trials

TRUDI: A phase II study of neoadjuvant Trastuzumab deruxtecan and Durvalumab for stage III, HER2-expressing Inflammatory Breast Cancer

The purpose of this study is to test the safety and effectiveness of an investigational drug combination (trastuzumab deruxtecan and durvalumab) to learn whether the intervention works in treating Human Epidermal growth factor Receptor-2 (HER2)-expressing inflammatory breast cancer. Participants must have a clinical diagnosis of stage III inflammatory breast cancer within the past 6 months and must be treatment-naïve. Participants must have HER2-positive status as determined locally by current ASCO/CAP guidelines or Her2-low tumor expression.

Longitudinal monitoring of quality of life in patients with de novo metastatic inflammatory breast cancer (mIBC)

Twenty-five to 30% of patients diagnosed with inflammatory breast cancer (IBC) present with de novo metastatic disease. Systemic therapy is the cornerstone of distant disease control in metastatic IBC (mIBC). The loco-regional disease presentation in IBC is characterized by diffuse involvement of the breast parenchyma and infiltration of the dermal lymphatics. If loco-regional disease in mIBC is untreated it is likely to progress, possibly leading to troublesome symptoms that could have an adverse impact on the patients’ quality of life (QOL) as well as presenting a therapeutic challenge for loco-regional disease control. The impact of loco-regional disease on QOL in patients with de novo mIBC is not known. Given the aggressive biology of mIBC and the known limited life expectancy associated with this diagnosis, it is important to systematically longitudinally assess the quality of life of this patient population. Upon completion of this study, we hope to gain knowledge of the impact of loco-regional disease on these patients’ QOL, with a specific focus on overall wellbeing, lymphedema risk and skin toxicity, to be able to better counsel future patients with the diagnosis of mIBC.

Primary objective of this metastatic registry:

To monitor quality of life in patients with de novo mIBC, using the following instruments:

- a. Lymphedema self-assessment
- b. Quality of life survey
- c. Skin toxicity assessment
- d. Decision regret assessment
Recent published studies from our Dana-Farber IBC doctors and Researchers

**Clinical Outcomes of de novo metastatic HER2 positive inflammatory breast cancer**


**Copy Number Variation in Inflammatory Breast Cancer**


**Tailoring Treatment for Patients with Inflammatory Breast Cancer**


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**Staff Spotlight: Jess Mosey, LICSW**

We extend a warm welcome to Jess Mosey, LICSW, MSW, who is our new IBC social worker and newest member of the IBC Program. She is excited to join us and looks forward to supporting, guiding, and connecting with our amazing patients and their families.

Jess has always had a passion for helping others and, as with many people, she has loved ones who have been impacted and affected by cancer. These experiences led her to work in the field of clinical social work, with particular interest in breast cancer.

After earning her master’s degree in social work from Bridgewater State University, Jess worked in hospice care before shifting her focus to oncology social work, which led her to Dana-Farber.

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**Stay in touch!**

We welcome your feedback, questions, or suggestions of topics you would like to learn more about. Contact us at DFCI_IBC@dfci.harvard.edu or 617-632-2311 or visit our web page.