Welcome to our Spring 2020 Newsletter! I am happy to introduce our new IBC Program Coordinator, Mariesa Powell (see page 5). Mariesa comes from Dana-Farber’s Breast Oncology Clinic, where she worked closely with patients receiving treatment for IBC. For this reason, Mariesa brings a keen understanding of the impact that IBC has on patients and their friends and families. Mariesa and IBC Program Nurse Coordinator Jean Landry, NP, make a strong team, focusing on the care and education of our IBC patients.

Several exciting new developments in research were presented at our annual San Antonio Breast Cancer Conference in December 2019. Justin Balko, PhD, from Vanderbilt University presented a technique for isolating IBC tumor cells from within the lymphatics of the skin (dermal lymphatic involvement) using samples from Dana-Farber’s IBC tissue bank. This may give us a greater understanding of why IBC tends to recur on the chest wall after surgery and radiation.

Ginny Mason, RN, the president and executive director of the Inflammatory Research Foundation, presented a proposal outlining new diagnostic criteria for the diagnosis of IBC (see page 3-4). This concept was developed through a collaboration with the Komen Foundation, the IBC Research Foundation, and the Milburn Foundation. This proposal still needs to be validated and accepted by the medical community, but it is a step forward in the quest to avoid a misdiagnosis of IBC.

Lastly, I’d like to thank everyone who supported Team IBC in the Jimmy Fund Walk this year. The funds raised are used to support our clinical program and support our scientists who focus on IBC research. In addition, the funds raised through Team IBC are used to support our upcoming 4th Annual IBC Patient and Family Forum scheduled for June 13, from 9:30 a.m. – 1 p.m., in Yawkey 306. Like past events, this year’s Forum will be both educational and offer support for everyone involved with IBC. Don’t forget to register on our Eventbrite site! For now, the Forum will occur as planned, however, given the current COVID-19 crisis, we will inform everyone about the potential for cancellation by May 11, 2020.

Have a safe and healthy New Year! I am looking forward to achieving much success in the understanding and treatment of IBC during this new decade.

Sincerely,
Beth Overmoyer, MD, FACP, Director, Inflammatory Breast Cancer Program

In This Issue:
• 4th Annual IBC Patient Forum: Save the Date!
• IBC FAQ: Mastectomy, Delayed Reconstruction and Why
• Jimmy Fund Walk Recap
• IBC in the Media
• Research Update: San Antonio Breast Cancer Symposium
• Upcoming Fundraising Events
• Spotlight on IBC Program Staff: Mariesa Powell
IBC FAQ: Mastectomy, Delayed Reconstruction, and Why?

The recommended breast surgery for IBC patients is a mastectomy, which is non skin sparing. The following discussion only relates to the breast, and does not address the treatment of axillary lymph nodes which are also removed at the time of surgery for IBC.

**Why Mastectomy vs. Breast Conservation?**

Inflammatory Breast Cancer gets its name because the breast often appears red and swollen at time of diagnosis. This appearance is due to “tumor emboli” or individual cells/clusters of IBC tumor cells present in the lymphatic vessels of the skin covering the breast. The lymphatic vessels within the breast also contain IBC tumor cells. As a result of the lymphatic involvement with tumor in the skin and breast, it is necessary to remove all of the breast tissue and overlying skin in order to minimize the amount of disease remaining to prior to starting radiation. Removing the breast with its skin and nipple is known as a mastectomy. Breast conservation is generally referred to as a “lumpectomy”: removing only the tumor “lump” within the breast, leaving the remainder of the breast and skin intact. Breast conservation is not appropriate for IBC because all of the tumor throughout the breast and skin needs to be removed at the time of surgery.

**Why Is Delayed Reconstruction Necessary?**

Immediate reconstruction which occurs at the time of mastectomy requires a technique known as “skin sparing” mastectomy. This means that some of the skin overlying the breast is kept to form a new breast mound through reconstruction. The goal of mastectomy for IBC is to remove as much skin as possible, therefore immediate reconstruction is not appropriate for patients with IBC.
For IBC patients seeking breast reconstruction, it is recommended that those individuals wait at least six months to one year after completing radiation before beginning reconstruction. Radiation treatment usually occurs one to two months after surgery. Patients with IBC who have a shorter interval between surgery and starting radiation have better outcomes, therefore, the goal is to ensure a quick recovery time after surgery. Immediate reconstruction and the possibility of complications could delay a patient’s ability to receive radiation within the recommended timeline, thus possibly increasing the risk of IBC recurrence in the chest wall.

Lastly, delayed breast reconstruction is recommended to allow enough time for the patient’s body, and most especially the skin overlying the chest wall, to fully recover from surgery and subsequent radiation. The delay to allow healing of the skin increases the chance that the eventual reconstructed breast will heal well and look beautiful.

**I am interested in reconstruction. What options are available to me?**

Breast reconstruction methods fall into two categories: autologous reconstruction or implant-based methods. Autologous reconstruction methods use your own tissue and include procedures such as the DIEP flap or the TRAM flap. For IBC patients seeking breast reconstruction, autologous reconstruction methods are recommended and preferred.

While implant-based methods might sound like a more appealing strategy, it is not recommended for patients with IBC because of the damage to the skin from the intensive radiation needed to kill any remaining tumor cells within the skin. In addition, implant-based methods require the placement of a temporary implant known as a tissue expander at the time of mastectomy. This added dimension to the chest wall may compromise the radiation field, making the radiation less effective.

Breast reconstruction can be done after treatment for IBC! A plastic surgeon will work with you to determine the best type of reconstructive procedure specifically for you. It will be worth the wait!

**Jimmy Fund Walk & Team IBC**

Thank you to everyone who participated in or donated to this year’s Boston Marathon Jimmy Fund Walk! Our 21 team members raised a total of $36,400, performing even better than last year.

We’d like to highlight the generous contributions made by the IBC Network Foundation who provided us with a matched gift of $5,000 and we thank everyone who helped make that possible. We’d also like to mention other Jimmy Fund Walk teams that contributed to our IBC research fund. Team Annie G. and Liz’s Crew, with hard work from their respective team captains David Gacioch and Liz Cummins, raised a total of $29,465 and $4,555, to date. Our work would not be possible without their wonderful support.

Thank you to everyone who walked and/or contributed any amount. ALL contributions are appreciated and needed to accomplish our goal of understanding, treating and finding a cure for IBC. Remember to sign up for the 2020 Jimmy Fund Walk on October 4! Sign up [here](#) today. Hope to see you there!
IBC in the Media

Dana Farber’s online Health Library at www.dana-farber.org/health-library is a free resource with comprehensive information for patients and families. The library includes several pieces dedicated to IBC, including videos, patient stories, FAQs, and more. To find them, visit the Health Library and enter “inflammatory breast cancer” in the keyword search.

Research Update

San Antonio Breast Cancer Symposium

In April 2018, Susan G. Komen, the Inflammatory Breast Cancer Foundation, and Milburn Foundation invited patient advocates, breast cancer researchers, and clinicians to form an IBC Focus Group, with the goal of assessing what is currently happening in the field of IBC treatment and research. They wanted to use this information to determine what is needed to propel both research and treatment for IBC forward. Initially they focused on the definition and diagnosis of inflammatory breast cancer.

The current diagnostic criteria are vague and haven’t been updated since 1974. As a result, a diagnosis of IBC is subject to the examining physician’s interpretation. Due to the subjective nature of the current diagnostic criteria, patient treatment is variable, and the implications of current research is made less clear. For these reasons, it was decided by the group of experts and patient advocates that there is a critical need to create a more formal definition of IBC.

The Komen IBC Task Force proposed common diagnostic criteria and 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.

This scoring system was presented by Ginny Mason, RN, at the annual San Antonio Breast Cancer Symposium in December 2019. The next step is the validation of this system at large academic institutions and community centers. The goal of the project is to be able to identify IBC more specifically, resulting in more effective treatment and scientific investigation.

Upcoming Fundraising Events

The 5th annual Nancy Strong Memorial Golf Tournament will be held on Sunday, June 7, 2020. The event will be held at the Cranston Country Club in Cranston, RI. Registration will begin at 12:30 p.m., with a shotgun start to the tournament at 1:30 p.m. Win or lose, dinner is at 6:30 p.m! 100% of the proceeds made from this tournament go toward funding research for the Inflammatory Breast Cancer Program at Dana Farber. If you’re interested in signing up for a day of fun, food, and golf, register here!
Staff Spotlight

Mariesa Powell

A warm welcome to Mariesa Powell, our program coordinator and the newest member of the IBC program. For the past two years, Mariesa has been working with IBC patients as Dr. Beth Overmoyer’s clinical administrator. In her current role, Mariesa manages the day-to-day operations of the IBC Program. She is also responsible for meeting with patients, introducing them to the IBC Program, and acting as their liaison to resources available within Dana-Farber. In the coming months, she is eager to assist in the planning of the 4th Annual IBC Patient Forum.

Stay in touch!

We welcome feedback, questions, or suggestions of topics you would like to learn more about. Contact us at DFCI_IBC@partners.edu or 617-632-2311.