Welcome to the second issue of the DFCI Inflammatory Breast Cancer Program’s Newsletter. There has been a great deal of excitement in the IBC world since our last newsletter. Team IBC was a successful presence at the Jimmy Fund Walk in September, and the IBC Program presented research data at two well-attended poster sessions at the San Antonio Breast Cancer Symposium in December. We are getting the word out that IBC research is needed and productive!

In 2018, we plan to focus on our mission to increase education about IBC by hosting the 2nd Annual IBC Patient Forum this spring and speaking at the 6th International IBC Symposium in Spain this fall. Our research focus continues through our collaboration with basic science colleagues at the Dana-Farber and other academic institutions, and providing much needed funding for our IBC specific clinical trials at the Dana-Farber. Finally, we have recruited several outstanding surgical and medical oncology faculty members who will devote more time to improving the treatment of IBC at Dana-Farber/Brigham and Women’s Cancer Center.

We hope 2018 provides the resources for us to continue optimizing the treatment and understanding of IBC. Exciting times indeed!

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

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IBC FAQ: Lymphedema

Lymph is a fluid that circulates throughout the body to help fight infection and remove waste and bacteria. “Edema” means the buildup of excess fluid in one part of the body, so lymphedema is the accumulation of lymph fluid that can cause swelling, a feeling of heaviness or tightness, discomfort, and restricted range of motion. For people going through treatment for IBC, this most commonly happens in the arm or hand on the side that surgery was performed on. Removal of underarm (axillary) lymph nodes as part of mastectomy surgery requires lymph fluids from the arm to be rerouted and filtered through other areas. Like Boston traffic when major roads are closed, the remaining nodes and vessels can get overwhelmed, causing lymph fluid to build up.

Why are people with IBC at risk of developing lymphedema?

With an axillary dissection (removal of underarm lymph nodes) or radiation to the axilla, risk of developing lymphedema for all breast cancer patients is up to 20% over a patient’s lifetime. This risk increases with the number of axillary lymph nodes removed. Radiation therapy to that area can also add to risk. Because standard of care for IBC includes a modified radical mastectomy (which removes most of the underarm lymph nodes) and post-mastectomy radiation therapy, patients with IBC are more likely than the general breast cancer population to develop this condition.
Prevention
Unfortunately, we do not currently have medical evidence that lymphedema can be prevented, and we can’t always explain why one person gets lymphedema and another doesn’t. Another frustrating factor is that there is so much conflicting advice available. It is important to remember that tips from the internet or word-of-mouth are often not evidence based and may not be helpful.

What we do know:
- **Maintain a healthy weight.** This has been shown to reduce the risk of lymphedema. Check out Dana-Farber's Nutrition ([dana-farber.org/nutrition](http://dana-farber.org/nutrition)) and Healthy Living ([dana-farber.org/Zakim](http://dana-farber.org/Zakim)) resources for information, classes, and more.
- **Exercise is OK!** There is strong evidence that exercise does not cause or worsen lymphedema. Strengthening the affected arm may even be beneficial. Remember to start gently with light weights and progress gradually.
- **Avoid cuts and infections.** The buildup of lymph fluid increases the risk of some infections, so it is important to avoid damaging the skin. You can do most normal activities – just take a few precautions. For example, if you want to get a manicure, ask them not to cut your cuticles; if you garden, wear gloves; wash cuts and scrapes right away with soap and water.

Myths about prevention:
- "**You can't have blood pressure measurements, injections, or blood draws from your affected arm.**" There is no evidence that any of these procedures cause lymphedema. Until we know more, it is sensible to ask for these to be done on the other arm. However, if needed it is safe to have blood pressure and needle sticks on the affected arm.
- "**You need to wear a medical alert bracelet.**" As explained above, we do not know that common medical procedures trigger lymphedema, and if it is an emergency, then life-saving procedures should be performed.
- "**Always wear a compression sleeve while flying.**" Because air pressure is lower at higher altitudes, it is commonly believed that this can trigger lymphedema. There is no evidence that air travel increases lymphedema risk or that wearing a compression sleeve when you have no signs of lymphedema will prevent it.

More research on preventing lymphedema is needed. Until then, most advice on risk reduction will be based on existing medical knowledge and common sense. It is best to seek advice from a reputable online source (such as [dana-farber.org](http://dana-farber.org) or [breastcancer.org](http://breastcancer.org)) or from a medical professional who is experienced in treating patients with lymphedema.

Treatment:
Although there is no permanent cure for lymphedema, it is possible to reduce symptoms and make it easier to manage. Seek medical attention at the first signs of swelling in the hand or arm, feelings of heaviness, or noticing that a sleeve, watch, or jewelry feels tight. Mild lymphedema can be reversed with treatment. If you notice these symptoms, contact your healthcare provider and ask for a referral to a physical therapist or occupational therapist who specializes in lymphedema care. A variety of treatments are available; some are still experimental, so consult with an experienced health care provider to find the best fit for you.
Jimmy Fund Walk & Team IBC

On September 24th, Team IBC participated in the Boston Marathon Jimmy Fund Walk for the first time and raised over $24,000! More than doubling our initial goal, Team IBC was recognized as the "Rookie of the Year" team for doing so well on our first walk. Most importantly, the money we raised will be going directly to our IBC Research Fund. Our team was comprised of 27 patients, staff, and family members who walked along the Boston Marathon route; we also had “virtual” walkers lending support throughout the US and beyond.

We also want to acknowledge the contributions to the IBC Program by the teams "Annie G" and "Liz's Crew". Help from everyone is so appreciated and so needed!

Thank you to everyone who participated and mark your calendars for September 23, 2018 because we are already preparing for next year!

IBC in the Media

As part of the WEEI/NESN Jimmy Fund Radio-Telethon in August 2017, Dr. Overmoyer and Jennifer Millar spoke about the difficulties of diagnosing IBC and balancing family life during treatment.


NBC Boston featured Dr. Overmoyer and the Thomas Family during Breast Cancer Awareness Month, October 2017. The Thomases are also the driving force behind the declaration of October 1-7 as "Inflammatory Breast Cancer Awareness Week" in Massachusetts for the past two years.

**Research Update**

**San Antonio Breast Cancer Symposium**

Every year in early December, researchers and physicians from over 90 countries gather in San Antonio, Texas to share information on the biology, causes, prevention, diagnosis, and therapy of breast cancer.

This year, Dr. Overmoyer and other members of the IBC International Consortium met and discussed ways to increase collaboration among international colleagues on clinical trials and basic science research for IBC. They discussed the upcoming 6th International IBC Symposium, to be held in September 2018 in Segovia, Spain. If the 5th International IBC Symposium held in Boston in 2016 is any example, this year's event should be an exciting opportunity for learning and collaboration. More information to come!

Our IBC Program was represented by two successful posters, one discussing preliminary results of our pre-operative clinical trial for HER2+ IBC and another presenting our newly opened multicenter clinical trial for triple negative IBC sponsored by the Translational Breast Cancer Research Consortium (TBCRC).

**Staff Spotlight**

Jennifer Bellon, MD, FASTRO

After earning her MD at Case Western Reserve University and completing her residency at University of Washington Medical Center, Dr. Bellon joined Radiation Oncology at Dana-Farber in 2000. She is currently the Director of Breast Radiation Oncology at DFCI and has served as the Radiation Oncology Leader for the DFCI IBC Program since its creation in 2009.

In this role, Dr. Bellon provides care to many women with IBC and is our resident expert on the latest research and treatment options for radiation therapy for IBC. Not only does she provide critical input as part of our multidisciplinary group, but has led several specialized studies to better understand IBC and outcomes of radiation therapy.

Dr. Bellon is also an avid photographer - when not busy with research, teaching, and clinical care, she is likely to be out capturing stunning shots of wildlife.

**Stay in touch!**

We welcome feedback, questions, or suggestions of topics you would like to learn more about. Contact us at:
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