As we enter the heart of summer, we look forward to sunny days and more progress against our challenge of overcoming inflammatory breast cancer. The success of our 3rd annual IBC Patient Forum this year brought a great start to the season. The questions generated by those attending have prompted a new section in this newsletter. The “IBC FAQ” section will provide answers to some of the questions that we were not able to address during the May 2019 forum. Of course, we are already planning next year’s forum, tentatively scheduled for April 25, 2020. Mark your calendars – it should be a fantastic event!

This year, we have been designing research projects that allow greater access to IBC tumor and blood specimens for our scientists to investigate mechanisms that support the growth of IBC and to identify therapeutic targets that we can pursue in the clinic. We are expanding our IBC-focused clinical trials to include metastatic IBC as well as several studies for those individuals who have completed their chemotherapy and surgery and may benefit from additional treatment during and after radiation. The goal is to optimize therapy at every point in the treatment of IBC.

I am always so thankful when this time of year arrives, allowing us to focus on the growth of summer and more opportunities to target our efforts against IBC. Enjoy the sun – but don’t forget the sunscreen!

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

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Jimmy Fund Walk

Sunday, September 22, 2019: Walk with Us!

Team IBC is walking for the third year in a row! Help us make it the best year yet. All proceeds from our walk go towards raising funds for the Dana Farber’s Inflammatory Breast Cancer Research Fund. We can’t succeed without your help!

How to Participate:

- **Join the Team.** Get a “DFCI Team IBC” T-shirt! Walk along the Boston Marathon route in a length of your choice: 5k, 10k, half marathon (13.1 miles) or a full marathon (26.2 miles). All walk routes end in Copley Square, where we’ll celebrate with music and refreshments. Register [here](#).

- **Can’t make it on Walk day? Register as a Virtual Walker.** This is an option for individuals who want to join the team but cannot walk at the event.

- **Spread the word.** Support IBC by sharing our [fundraising page](#) with your friends, family, and social media networks.

For more information on the Boston Marathon Jimmy Fund Walk, including fundraising tips, walker stories, FAQs, and walk-day logistics, please visit jimmyfundwalk.org or contact our team captains, Ashley Narvaez and Jean Landry, at [DFCI_IBC@dfci.harvard.edu](mailto:DFCI_IBC@dfci.harvard.edu).

3rd IBC Patient Forum Highlights

This past May 4th we held our Third Annual Inflammatory Breast Cancer Patient Forum! We are so happy with the positive feedback we've received from everyone who was able to attend.

In addition to Dr. Overmoyer, we had two keynote speakers: Sharon Bober, PhD, of the Department of Psychology and Huma Rana, MD, of Cancer Genetics and Prevention, both at Dana-Farber. Dr. Bober spoke about the importance of sexual health during and after cancer treatment. She pointed out that sexual complications are among the first side effects of treatment, with most women reporting vaginal, vulvar, and urinary changes. She also discussed helpful tips for managing vaginal dryness and maintaining a healthy pelvic floor. Our other
keynote speaker, Dr. Rana, explained the role of inherited genetic risk in a cancer diagnosis. Ten percent of all breast cancers are due to an inherited genetic risk, with up to 15% risk associated with IBC.

With a field as fast-paced and ever-changing as genetics, she noted the importance of continued genetic testing, optimally every five years. For IBC patients tested before 2012, she strongly recommends being retested, as there is new technology today that was not available previously, and your results may change.

Dr. Overmoyer reviewed updates in IBC, including current epidemiology data that supports a greater risk of developing IBC in African American and Arab American women. There is also a unique association with being overweight (BMI > 25) and developing IBC regardless of whether the woman is premenopausal or postmenopausal. This has definite implications for IBC risk in the USA where 60% of people are overweight or obese. She also reviewed upcoming clinical trials for IBC that will be highlighted on our website once they are open at Dana-Farber.

Unique to this year, we offered two break-out sessions: a support group and the opportunity to participate in genetic testing. Numerous attendees took advantage of these services, and we hope to keep offering similar activities in the future.

Your input is very valuable to us. If you didn't get the chance to submit your survey, please email us with observations or suggestions for our next forum. Also, if you were unable to attend our forum, the presentations were recorded and should be available on our website in early August.

**IBC FAQ: Questions from the IBC Patient Forum**

As always, we received excellent questions from our forum attendees. While we answered many of them during our Q&A panel, we were unable to answer all of them. We’ve chosen a few questions to cover in this edition of our newsletter.

1. **Should I have a prophylactic mastectomy now that my IBC treatment has been completed?**

   Several patients have asked if the removal of the contralateral breast, meaning the removal of the cancer-free breast, is something they should consider post-treatment. This is a very personal decision and should be discussed at length with your treatment team. Currently, there are no data to suggest that there is a survival benefit to contralateral prophylactic mastectomy. However, while a contralateral prophylactic mastectomy does not reduce the risk of death, it would reduce the risk of developing a new primary breast cancer; though that risk may be so small that surgery is not indicated. Also, like reconstruction, if you desire a contralateral prophylactic mastectomy, we recommend this surgery later, rather than at the time of surgical treatment for IBC, so as not to delay any of the important timing of treating this disease.

2. **Is it possible to have no mutations in my genetic testing while also having a family history of breast cancer and other cancers?**

   Yes. Not all inherited risk for cancer is detectable, even with current state-of-the-art multi-gene panel testing. Some of this may be due to genes that are not yet discovered or to limitations with our current
laboratory testing methods. In some families, inherited risk to cancer is complex, not because of one powerful gene, but rather due to the cumulative effects of multiple genes acting together. The type of testing needed to measure this type of inherited risk will soon be available, which will allow us to identify people at increased risk who could benefit from opportunities for prevention.

Also, it’s important to remember that most cancers do not have a strong inherited component. In fact, the development of cancer involves a combination of many risk factors: genes, lifestyle, and the environment.

If a family history is significant, meaning there is more cancer present than we would expect due to chance alone, or there is early onset cancer, we recommend contacting the DFCI Genetics and Prevention Center at (617-632-2178) and consider additional genetic testing opportunities as they become available.

3. During chemotherapy, are drugs present in bodily fluids? Should intercourse be avoided?

Specific questions related to sexual activity should be openly discussed with your physician. In general, sexual intercourse while undergoing chemotherapy is safe. Many factors can influence decisions about chemotherapy and sex. Two important questions to keep in mind include:

a. What type of chemotherapy are you receiving? Some types of chemotherapy can lead to changes in the lining of the vagina, which may make sexual intercourse more difficult.

b. Could you become pregnant? Chemotherapy does not always prevent pregnancy; however, pregnancy is strongly discouraged during chemotherapy, due to the detrimental effects on the developing baby. If pregnancy is possible, a reliable method of birth control is recommended. Oral hormonal contraception (“birth control pill”) is not recommended for people with IBC or other types of breast cancer. Therefore, a barrier method (condoms, diaphragm) or non-hormonal IUD are the best strategies.

Annual Susan M. Donelan “Hope for the Future” Lecture

Every year, as part of the Breast Oncology Seminar Series (BOSS), the IBC Program invites a keynote speaker for the Susan M. Donelan Hope for the Future Inflammatory Breast Cancer lecture. This year on May 1st, our speaker was Gayathri Devi, PhD from Duke University. Her talk was entitled From Rare to Care: Models, Discovery and Therapeutics for Inflammatory Breast Cancer.

Through the annual endowed lecture, highly respected specialists are able to share information related to inflammatory breast cancer with a broad audience. We are very grateful for the vision and generosity that makes these efforts possible. The Donelan fund was created by James Boggs in memory of his wife Susan E. Donelan, who passed away from inflammatory breast cancer in 2006.
**Staff Spotlight**

Jennifer M. Rosenbluth, MD, PhD

Dr. Rosenbluth is a medical oncologist specializing in IBC and practicing in the Susan F. Smith Center for Women’s Cancer at Dana-Farber Cancer. She received her undergraduate degree from Princeton University, and her MD and PhD from Vanderbilt University School of Medicine. She then completed her residency in Internal Medicine at Massachusetts General Hospital, and her oncology fellowship at Dana-Farber. It was during her fellowship that Dr. Rosenbluth was introduced to patients with IBC and decided to devote her research focus on understanding this disease.

Dr. Rosenbluth’s research project is located within Dr. Joan Brugge’s laboratory, housed at Harvard Medical School. Dr. Rosenbluth uses advanced culturing methods to grow miniature IBC tumors.

Very few laboratory models of IBC exist for scientific exploration. By using this model system, Dr. Rosenbluth can gain insight into how IBC cells evolve and adapt both within and outside of the breast. Going forward, these tools allow researchers to test various combinations of drugs in the lab, allowing new potential therapies for IBC to be identified. In addition to her research, Dr. Rosenbluth enjoys traveling across the United States. She’s visited 40 state capitols thus far!

**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.