



INFLAMMATORY
BREAST CANCER
Research Foundation

Focus on IBC

May 2008

IBC Research Foundation Newsletter

No, you did not miss an April Newsletter! It has been a busy spring for the Inflammatory Breast Cancer Research Foundation. My apologies for not getting an April Newsletter out to all of you. As always, we appreciate your continued support.

Laurie Isenman
Secretary/Treasurer
Editor, IBCRF Newsletter

Upcoming Events

May 15-18 Oncology
Nursing Society (ONS) 33rd
Annual Congress,
Philadelphia, PA

[Click here.](#)

May 20-23 Candidate
Pathways, Whole Genome
Scans: Reconciling Results,
Looking into The Future,
Carefree, AZ

[Click here.](#)

May 30 - June 3

44th American Society of
Clinical Oncology (ASCO)

NBCCF Annual Advocacy Training Conference

April 26-29, Washington DC

This was my seventh year attending the National Breast Cancer Coalition Fund Annual Advocacy Training Conference in Washington, DC. Over the years I've gotten to know a number of people active in breast cancer advocacy, so this conference often feels like a "family reunion." I had no sooner walked into the lobby of the hotel to register, when I ran into my good friend and mentor, Musa Mayer. Musa is known in the breast cancer community for her work with metastatic breast cancer patients and her outstanding journalism. She's been a wonderful model for me as I broadened my scope in advocacy work.

The very first workshop session of the conference focused on the Best Practices in Breast Cancer Advocacy Awards nomination process. It was a delightful surprise to see the Inflammatory Breast Cancer Research Foundation's BioBank and Clinical Data Base used as an example of a winning program focused on research advocacy in the workshop. Three previous winning groups/programs were used to illustrate the various types of projects that meet program criteria. It is exciting to have the National Breast Cancer Coalition Fund acknowledge our effort to produce a quality program like the IBC Research Foundation BioBank and Clinical Data Base.

Once again we were able to bring together folks from the IBC community to share over dinner at a local restaurant. While our numbers were down this year for a variety of reasons, we still had a great time. Seven of us feasted on gourmet Chinese food in an upstairs dining room in Chinatown. There was a lot of talking, laughing and eating going on while old friends reconnected and new friends were made. It was good to have two new folks join us this year and also attend the conference. We were sorry that Indiana IBC survivor, Krysti Hughett, didn't get to town in time to join us. Maybe next year, Krysti!!!

Annual Meeting,

Chicago, IL

[Click here.](#)

May 30 Food & Drug Administration (FDA) Oncologic Drugs Advisory Committee (ODAC), Chicago, IL

[Click here.](#)

June 4-7 5th World Conference on Breast Cancer, Winnipeg, Canada

[Click here.](#)

June 23-25 caBIG: Harnessing the Power of Connectivity, Washington, DC

NCI

cancer Biomedical Informatics Grid (caBIG)

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www.ibcresearch.org
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*Back Row Left to Right: Jeanne Calkins (Kansas City, MO) Pat Haugen (Sioux Falls, SD) Ginny Mason (Citronelle, AL) MP Jamison (Phoenix, AZ)
Front Row Left to Right: Tina Pecht (Montpelier, VA) Laurie Isenman (Bainbridge Island, WA) Kathleen Livingston (Waterford, MI)*

A new workshop offered this year was a session on breast cancer stem cell research with Dr. Max Wicha, director of the University of Michigan Comprehensive Cancer Center. Dr. Wicha has become one of the leading experts in this field, and University of Michigan researchers have teamed with Baylor University and Dana Farber to launch the first clinical trials in this new area of research.

I was particularly interested in Dr. Wicha's workshop, since I had attended one of his sessions in April at the American Association for Cancer Research conference and had some questions based on that presentation. Cancer stem cell theory suggests that traditional therapies, like surgery, chemotherapy and radiation are not able to kill all the cancer cells; and those that remain may actually be resistant to treatment and cause the cancer to grow. If these stem cells can be identified and targeted, there is the possibility of stopping the spread of cancer. Dr. Wicha's lab has been studying breast cancer cell lines to determine which ones contain an identified stem cell population. I was excited to see that at least one cell line studied represents IBC (SUM 149.) I had the opportunity to ask Dr. Wicha about his findings in the IBC cell line, SUM 149. He confirmed that there appears to be a stem cell population in this cell line, which could account for the aggressive and difficult to treat nature of IBC. His lab plans to continue to study other IBC cell lines as well as tumor tissue to determine if this hypothesis can be proven. This research remains somewhat controversial since it represents a very different view of cancer growth and metastasis, but it is certainly something worth following and learning more about. To read more about the University of Michigan stem cell research [click here.](#)

One morning, I found my breakfast table filled with college students who were attending the conference. I wondered what brought this group of young women and men to the conference. Read the following report from Shannon Talbott, one of the students in the group, to learn more about what brought them to DC.



I attended my first National Breast Cancer Coalition (NBCC) conference in April 2008. I was very blessed with having this opportunity come about because of one of my professors at Western Oregon University. Dr. Jessica Henderson is a 14-year breast cancer survivor and a true advocate. She has been attending the conference for four years, and each year she takes a group of students with her. This year she asked me to come as her assistant, and we brought seventeen undergraduate students with us

This conference has changed my thoughts and actions toward fighting breast cancer. I have always known it is one of the leading causes of death among women, but until I came to the conference; I had not seen it first hand. Every person at the conference had been effected by breast cancer, whether they had it themselves or a loved one had been diagnosed with breast cancer. It was very special to see so many different groups of women come together and fight for the same cause.

Although I personally have not been diagnosed with breast cancer, my grandmother was diagnosed about five months ago. The opportunity to attend the conference gave me the feeling that I could make a difference by talking to state representatives and being a true advocate for my grandmother. I met strong, powerful women who are standing up for a cause to save the lives of women. I was surprised at how much I learned at the conference. I did not know there were so many kinds of breast cancer, and I certainly did not know anything about Inflammatory Breast Cancer until I met Ginny Mason, the executive director of the Inflammatory Breast Cancer Research Foundation. Within five minutes of meeting Ginny, I knew what IBC was and how serious and scary it can be.

I am very thankful for this amazing experience and the opportunity to meet people from so many different places in our country fighting for the same cause. It is an experience I will never forget and one I will never stop fighting for.

*Shannon Talbott, 25
Graduate Student
Western Oregon University*

Needless to say, having this group of young people around the table as a "captive audience" gave me the perfect opportunity to educate them about IBC. Each one got a brochure and bookmark and learned that "You don't have to have a lump to have breast cancer"!

The IBC Research Foundation was invited to participate in the Best Practices in Breast Cancer Research poster session at the conference. We joined other 2006 winners and the 2007 winners exhibiting posters telling about our award winning projects. Lots of folks came by the poster and learned about the IBC Research Foundation BioBank and Clinical Data Base. A Nigerian survivor came by the poster and was very interested in what we are doing and wondered if such a project could be done in Nigeria. There was the 1st Annual Africa Breast Cancer Conference this past spring, and the 2nd conference is planned for March 2009. The IBC Research Foundation will remain in contact with African breast cancer survivors to determine how we can work together.

The NBCCF Annual Advocacy Training Conference is a great place for new advocates to "get their feet wet", to learn about the broader breast cancer community concerns, and a wonderful opportunity to meet other people passionate about ending breast cancer. It is a powerful experience to join 600-700 people all interested in conquering breast cancer. Consider attending next year!

For more information about NBCCF go to: www.stopbreastcancer.org

Ginny Mason
Executive Director, ibcRF