



## Focus on IBC

February 2008

### IBC Research Foundation Newsletter

*NBCC Board Meeting  
January 27-28, 2008  
Washington DC*



For the first time, effective January 2008, the IBC Research Foundation has a position on the Board of the National Breast Cancer Coalition (NBCC.) Kathleen Livingston, an ibcRF volunteer and ibc patient, represents the ibcRF on the NBCC Board of Directors. Ginny Mason, Executive Director of the IBC Research Foundation, will serve as the alternate.

Both Kathleen Livingston and Ginny Mason attended the first

#### 2007 Annual Letter

2007 has been another exciting year for the inflammatory breast cancer (IBC) community.

It was with great sadness that we said goodbye to **Debbie McKinney**, ibcRF Board Vice President, on February 6, 2007. Debbie was diagnosed with IBC while nursing her second child at the age of 36. In spite of continuing treatment over the course of nearly seven years, Debbie worked diligently to enhance the awareness and the research of IBC, the principal goals of the ibcRF. Debbie remains an inspiration and is sorely missed.

Also in February, the ibcRF participated in the **Amelia Project**, an Indiana based breast cancer research consortium which meets annually. This meeting provides the unique opportunity to meet with two members of the Medical Advisory Board on staff at Indiana University, as well as network with the various researchers, clinicians, and advocates in attendance.

For the past few years the ibcRF has played an integral part in the GlaxoSmithKline (GSK) clinical trials for lapatinib/Tykerb. In March, lapatinib/Tykerb received FDA approval for use in metastatic breast cancer. We anxiously await the publication of data from the IBC specific clinical trials, while we continue to work with GSK on the next generation of IBC specific clinical trials using this compound. [Click here for more information.](#)

meeting of the year, as this was an Orientation meeting for all board members and their alternate in conjunction with the regular board meeting.

There are many organizations on the Board representing diverse groups across the USA, such as Y-Me National Breast Cancer Organization, SHARE from New York City and the Rhode Island Cancer Coalition, to name just a few. In total, there are approximately twenty-four organizations, all interested in eradicating breast cancer. Ginny and Kathleen met a lot of interesting advocates and believe that the IBC Research Foundation is in good company.

The IBC Research Foundation is very pleased to serve on the Board. Our representation on the Board will help raise the profile of inflammatory breast cancer in the breast cancer community. Also, for those of you who do not realize, the IBC Research Foundation was awarded a Best Practices in Breast Cancer Award in 2006 by NBCC.

The orientation meeting gave Kathleen and Ginny a lot of background on the organization: history, roles and responsibilities, conflict of interest, the grassroots structure, and an outline of government relations and NBCC programs such as Project Lead.

The official meeting involved some administrative activities

Owen Johnson, ibcRF President, and Ginny Mason, Executive Director, participated in the **American Association for Cancer Research (AACR)** Annual Meeting in Los Angeles held in April. Ginny was part of the Scientist-Survivor Program offered for cancer advocates. This international gathering of researchers allows the ibcRF to raise awareness of IBC in the midst of hearing outstanding presentations, networking with researcher friends, and meeting new leaders in the field of cancer research. [Visit AACR.](#)

The ibcRF had a visible presence at the **Annual Advocacy Training Conference of the National Breast Cancer Coalition** as a result of receiving one of the Best Practices in Breast Cancer Advocacy Awards in 2006 (reported in the 2006 Wrap-up letter.) Through a poster and workshop session, the ibcRF shared information on the IBC Research Foundation BioBank and Clinical Data Base. As in years past, IBC'ers attending the conference joined those living in the DC area for an evening of food and sharing. It is always good to put faces with names, as well as make new friends. [Visit NBCC.](#)

Patients continue to have more options when seeking medical advice from an IBC specific clinic. The **Odette Cancer Center at Sunnybrook Health Sciences Centre** in Toronto began a clinic for IBC and locally advanced breast cancer in 2004. This was followed by the opening of **the M.D. Anderson IBC Clinic** in the fall of 2006. Most recently the **University of Michigan** announced their new IBC Clinic in October of 2007. An additional IBC clinic at the **Arizona Cancer Center** was launched toward the end of the year. While these clinics offer one option, there are numerous outstanding physicians for the diagnosis and treatment of IBC across the country; not just in the specialty clinics.

It is exciting to know that various researchers continue to focus on the challenge of IBC. Ohio State University has an IBC Working Group, which includes Sanford Barsky, M.D, long-time friend of the ibcRF and Richard Love, M.D. In addition, there is an IBC initiative of the International Breast Cancer Research Foundation. [Click here.](#)

In June, once again the ibcRF had an active presence at the annual meeting of the **American Society of Clinical Oncology (ASCO.)** More than 33,500 participants attended this international oncology meeting. This was the third year the ibcRF had a booth in the dedicated patient advocacy section of the exhibit hall. Thanks to dedicated volunteers staffing the booth, conference goers were provided information about IBC, and volunteers were able to attend educational sessions and daily mentor sessions. [Visit ASCO.](#)

Ginny Mason, Executive Director, was invited to represent the breast cancer advocacy community at a **National Institutes of Health (NIH) Roadmap** conference in July. The conference focused on how to bring research from

such as the Treasurer's report. Like most non-profit organizations, NBCC is running on a shoestring. They have achieved a great deal over the years, despite a small budget.

The most interesting and meaningful part of the meeting was the discussion about current legislative priorities. A political consultant outlined the current political landscape which is very difficult, since it is an election year. Most of the legislative priorities have not changed much year over year. Again, the first priority is Guaranteed Access to Quality Care for All, with the DOD funding, enactment of the Breast Cancer and Environmental Research Act and Preservation of the Medicaid Breast and Cervical Cancer Treatment Program also included.

In April the NBCC Annual Advocacy Training Conference will be held in Washington, DC. Hopefully, many of those involved with the ibcRF will be able to attend and learn more about current breast cancer issues and become even more effective advocates.

*Kathleen Livingston  
ibcRF Volunteer*

### **The IBC-Consortium**

For the past few years ibcRF has been involved in conversations with leaders in the field of IBC about how to jump-start IBC research. Those conversations focused on the need for a global network of

bench to bedside more efficiently. Ginny also had her first experience as a member of the **Cancer Therapy Evaluation Program** (CTEP) a part of the National Cancer Institute programs. [Click here](#) for FAQ's on the NIH Roadmap. [Click here](#) to read more about CTEP.

A booth at the **Sister's Network Annual Meeting** in the Chicago area during September provided the ibcRF a venue to increase awareness in the African American breast cancer community. This conference was attended by the national leadership of this organization who took materials back to their local groups to share. With the higher incidence of IBC in African American women, this educational effort is vital.

Fall brought lots of activity and attention to "the cause." Two IBC'ers served as advocate guides at the **California Breast Cancer Research Program's Symposium** in Los Angeles. Brochures were made available, and one of the research posters focused on IBC research. The fall issue of **Women & Cancer** magazine featured two articles on IBC. One was a general educational piece; while the second focused on IBC advocacy work, featuring the IBC Research Foundation BioBank and Clinical Data Base.

In November, Executive Director Ginny Mason was named to fill the position of Consumer Representative on the **Oncologic Drugs Advisory Committee** (ODAC) for the **Food & Drug Administration** (FDA.) After an orientation meeting in November, she took her place as a voting member of the committee in December. While Ginny represents the broader cancer community on this committee, her participation increases visibility of IBC and the ibcRF. [Click here.](#)

Two highlights come to mind from the **San Antonio Breast Cancer Symposium** (SABCS) in December. The ibcRF presented a poster focusing on the collaborative efforts made possible by the BioBank. Thanks to a good location (near the coffee station!) there was a lot of interest in the poster.

For the past few years, Ginny Mason has served as an advocate on the breast cancer committee for the **National Comprehensive Cancer Network** (NCCN.) This group develops the cancer treatment guidelines used by oncologists across the country. This year, the committee chair announced an IBC specific guideline would be added following Ginny's repeated presentations to the committee about this need! It was exciting to know that these guidelines are used in the education of new physicians, which means they will be learning about IBC as a specific type of breast cancer; no longer just listed as a subset of locally advanced breast cancer!

[www.sabcs.org](http://www.sabcs.org)

[www.nccn.org](http://www.nccn.org)

Two major projects were "in process" throughout the year. A new edition of the **IBC Research Foundation brochure** was completed and is now available for order and can also

individuals committed to moving IBC research from bench to bedside in a timely manner. What has developed from those conversations is the **IBC Consortium** (IBCC.) While still in the developmental stage, a website homepage was launched at the end of 2007 and provides a listing of those who have signed on to the project to date. The IBCC has received a grant to provide "start-up" funds. It is hoped that additional capital will follow to build the Consortium. The beautiful Phoenix logo represents the hope that can rise out of the flames of IBC through the combined efforts of those dedicated to working together through the IBC Consortium.

[www.ibc-consortium.org](http://www.ibc-consortium.org)

*IBC Research  
Foundation Activities  
and Activities of  
Interest to the IBC  
Community*

**Feb. 20-23** 25<sup>th</sup>  
Annual Miami Breast  
Cancer Conference,  
Orlando, FL [Click here.](#)

**Feb. 22-24** Annual  
Conference for Young  
Women Affected by Breast  
Cancer, Jacksonville, FL  
[Click here.](#)

be printed from the website. You will note just a few changes to the brochure, most notably the addition of quotes from members of the IBC community. The other much larger project was the redesign, development, and deployment of the IBC Research Foundation website. With the technical support of a computer consulting company and many, many hours of volunteer hours; the new site was launched in January 2008. As with any major renovation, there can be glitches that may need attention. Please bear with us as we attend to any problems as we strive to provide a user-friendly, informative site.

The **IBC Research Foundation BioBank and Clinical Data Base** continues to grow and is gaining recognition in the breast cancer research community. While it is a time and capital intensive project, it is essential to have an independent biorepository to meet the needs of individual researchers interested in studying IBC. Having the associated medical record and the ability to consent deceased patients makes the BioBank a unique and very valuable resource. If you would like to participate or want additional information contact:

[biobank@ibcresearch.org](mailto:biobank@ibcresearch.org)

Thank you to the many people who make up the ibcRF community. Without your support, encouragement, and dedication; the work of the Foundation could not continue. Additionally, we offer our deepest gratitude to all those who have provided financial support in an amazing variety of ways, to allow the work of the ibcRF to continue.

We begin another year "**COMMITTED TO FINDING THE CAUSE**" with your continued help.

*Ginny Mason  
Executive Director, ibcRF*

**Feb. 28-29** Institute of Medicine Public Meeting on Evidence Based Medicine: Clinical Data as Health Learning, Washington, DC [Click here.](#)

**March 1** Current Trends in Breast Cancer, Pasadena, CA [Click here.](#)

**March 8** Current Trends in Breast Cancer, Minneapolis, MN [Click here.](#)

**March 12-13** Meeting: Oncologic Drugs Advisory Committee, Gaithersburg, MD [Click here.](#)

**April 4-5** Eight Annual New Strategies in Breast Cancer, Philadelphia, PA [Click here.](#)

**April 26-29** NBCC Annual Advocacy Training Conference, Washington, DC [Click here.](#)

*Quick Links for IBC Patients and Caregivers*



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1-877-786-7422

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