



Annual Letter 2007

2007 has been another exciting year for the inflammatory breast cancer (IBC) community. In this letter you'll read about the highlights from the perspective of the **IBC Research Foundation** (ibcRF).

With great sadness we said goodbye to **Debbie McKinney**, ibcRF Board Vice President, on February 6. 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 7 years, Debbie worked diligently to enhance the awareness and research of IBC, the principal goals of ibcRF. Debbie remains an inspiration and is sorely missed.

Also in February, 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 ibcRF 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 ibcRF has played an integral part in the **GlaxoSmithKline** (GSK) clinical trials for lapatinib/Tykerb. In March 2007, 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.

<http://www.fda.gov/bbs/topics/NEWS/2007/NEW01586.html>

Owen Johnson, ibcRF President, and Ginny Mason, Executive Director, participated in the **American Association for Cancer Research** (AACR) Annual Meeting in Los Angeles in April. Ginny was part of the Scientist ↔ Survivor Program offered for cancer advocates. This international gathering of researchers allows 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. www.aacr.org

ibcRF had a visible presence at the **Advocacy Training Conference**, a yearly meeting offered by the **National Breast Cancer Coalition Fund** (NBCCF). We reported in last year's letter that ibcRF received one of the Best Practices in Breast Cancer Advocacy Awards in 2006. Through a poster and workshop session, ibcRF shared information on the award winning 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's always good to put faces with names, as well as make new friends. In December ibcRF was notified of our selection to the **National Breast Cancer Coalition (NBCC/F) Board** for a 3 yr. term beginning in 2008. NBCC is actually two organizations under one Board, having different IRS tax status. NBCCF is a 501 c 3 and NBCC is a 501 c 4 per IRS guidelines. NBCC/F consists of member organizations (like ibcRF) who share the common goal of eradicating breast cancer. The nominating committee is responsible for identifying member organizations to serve on the Board, which serves as the guiding body for the broader organization. We are honored to be a part of the Board for this important breast cancer organization. Kathleen Livingston, ibcRF volunteer, will be representing ibcRF on the NBCC/F Board with Ginny Mason serving as the alternate. We hope to meet many of you at NBCCF's Annual Advocacy Training Conference in Washington D.C. April 26-29. www.stopbreastcancer.org

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

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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 announced toward the end of the year, expected to be open in 2008. 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.

For the past few years, Ginny 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 to the updated collection, following Ginny's repeated presentations to the committee about this need! The IBC treatment guideline can be printed and used by patients and caregivers in discussions with their treatment team. Patients can also search for NCCN medical facilities (on the NCCN website) when seeking treatment in an effort to locate those practitioners skilled in the treatment of IBC. We were encouraged to learn that these guidelines are used in the education of new physicians, which means they'll be learning about IBC as a specific type of breast cancer, no longer just listed as a subset of locally advanced breast cancer! www.nccn.org
<http://www.nccn.org/about/news/newsinfo.asp?NewsID=127> (news release on the new breast cancer guidelines)
http://www.nccn.org/professionals/physician_gls/recently_updated.asp (breast cancer treatment guidelines)

It's 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, MD, long time friend of ibcRF and Richard Love, MD. In addition, there is an IBC initiative of the **International Breast Cancer Research Foundation**.
<http://www.ibcrf.org/InflammatoryBreastCancerIBC.html> (note: not our website)

In June, ibcRF had an active presence at the annual meeting of the **American Society of Clinical Oncology (ASCO)**. More than 33,500 participants attended this important international oncology meeting. This was the third year ibcRF had a booth in the dedicated patient advocacy section in the exhibit hall. Thanks to our dedicated volunteers; Charlotte Bryant, Bonnie Gray, Gayla Little, Pam Haschke and Ginny Mason, conference goers received information about IBC and the IBC Research Foundation. Our volunteers were also able to attend educational sessions, daily mentor programs and network with other patient advocates. www.asco.org

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 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. <http://nihroadmap.nih.gov/faq.asp>
<http://ctep.info.nih.gov/>

A booth at the **Sister's Network Annual Meeting**, in the Chicago area during September, provided ibcRF a venue to increase awareness in the African American breast cancer community. Thanks to volunteer, Pam Haschke for representing ibcRF at the event exhibit. 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 'our cause'. Two IBC'ers served as advocate guides at the **California Breast Cancer Research Program's Symposium** in Los Angeles. ibcRF 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 ibcRF.
www.fda.gov/oc/advisory/default.htm

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Two highlights come to mind from the **San Antonio Breast Cancer Symposium** in December. 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 lots of interest in the poster. The poster can be viewed on the symposium website. In addition, San Antonio is a great venue for connecting with others in the breast cancer community. We were able to talk with a variety of researchers from around the world who were presenting research of interest that could benefit the IBC community.
www.sabcs.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. The brochure can also be printed from the website. You'll 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 and development of our website. With the aid of a computer development company and thousands of hours by a dedicated and tireless group of volunteers, the site went live in January 2008. Our website renovation and email listservs are supported by the tireless efforts of Becky Rosen, website volunteer. (thanks Becky!) Please bear with us as we work to provide a user-friendly, informative site. www.ibcresearch.org

Look for the **IBC Research Foundation e-Newsletter** to appear in your inbox on a regular basis in the new year. Editor Laurie Isenman debuted with her first issue in the fall of 2007 and will endeavor to get an issue out each month highlighting items of interest to the ibcRF community. We realize the e-newsletter is an important point of contact for those who do not participate in either of our email discussion lists. If you haven't signed up, do so on the website newsletter link, found at: www.ibcresearch.org

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, unlike many other tissue banks. If you'd like to participate or want additional information contact: biobank@ibcresearch.org

PREVIEW FOR 2008 ...

Over the past few years, ibcRF has been involved in conversations with thought leaders in the field of IBC to provide for collaborative efforts for IBC research. Those conversations focused on the need for a global network of individuals committed to providing improved diagnostic procedures for IBC and to move IBC research from bench to bedside in a timely manner. From those conversations the **IBC Consortium** (IBCC) has emerged. While still in the development 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 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

Our annual letter would not be complete without extending **our most sincere thanks** to the many people who make up the ibcRF community. Without your support, encouragement, and dedication, the work of the IBC Research Foundation could not move forward. 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 ibcRF to continue and grow.

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

Ginny Mason BSN, RN
Executive Director

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