



## 2006 Wrap-Up Letter

2006 will be remembered as a year of important advances for the inflammatory breast cancer (IBC) community. This letter will take you through the year's highlights, month by month, from the perspective of the IBC Research Foundation (ibcRF).

In January, the Foundation mourned the loss of a dynamic and dedicated supporter and IBC patient. This loss reminded us all of the crucial need for more research to improve the diagnosis and treatment of IBC. Too many women continue to die of IBC. We must keep being the "squeaky wheel" to create change.

The **Amelia Project**, an Indiana based breast cancer research consortium which meets annually in February, provided the perfect opportunity to touch base with two members of the Medical Advisory Board on staff at Indiana University. A dynamic computerized database for tracking breast cancer patients was demonstrated by one of the Indiana University physician/researchers during the meeting and privately to ibcRF. Talks with other researchers on the IU campus will hopefully result in new IBC specific projects.

Ginny Mason, Executive Director, represented ibcRF as a consumer reviewer for the **California Breast Cancer Research Program** in March. This was her third year to participate in the program. This unique California funded breast cancer research program provides monies for breast cancer research carried out by California based scientists. Consumer reviewers participate fully in the grant review process.

<http://www.cbcrp.org/about/>

Participating in the **American Association for Cancer Research (AACR)** Annual Meeting in April provided numerous opportunities to increase awareness of IBC. New brochures about the BioBank project were shared with researchers and others attending the event. Important meetings such as this provide networking opportunities that extend the reach of ibcRF beyond the breast cancer community.

<http://www.aacr.org>

ibcRF remains one of the active member organizations of the National Breast Cancer Coalition. The **NBCC Annual Advocacy Training Conference**, held each spring in Washington DC, has become a venue for a gathering of those in the IBC community. Getting together, apart from the conference, over a meal, is a great way to make new friends. The new ibcRF educational/informational DVD was debuted to this assembled group and received rave reviews. Copies of the DVD have been limited with a distribution plan to be launched in 2007. [www.stopbreastcancer.org](http://www.stopbreastcancer.org)

IBC gained attention as a result of media exposure starting in the spring and carrying through into summer. A circulating e-mail, containing a link to a television report on IBC, caused such a surge of interest that the ibcRF website was overwhelmed with visitors (requiring the purchase of additional bandwidth) and the way

phone calls were being handled required evaluation. Increased awareness is a good thing and taking a good, hard look at how things are done is also a good thing. Now, when the toll-free phone number (1-877 stop ibc) is accessed, the caller chooses from a menu of options to meet their needs. Should the caller not have access to the internet or still need to speak with a volunteer, a toll number is available. The toll number is answered 24/7 by a professional answering service and the messages are then handled by ibcRF volunteers. Questions posed via the website have increased significantly as a result of the change. Increasingly, people with worrisome symptoms or questions are using the internet to seek help. As a result ibcRF receives about 100+ questions per month through the website. Thanks to the volunteers who help respond to these questions. Overall the new system is working well.

For a second year ibcRF exhibited at the **American Society of Clinical Oncology (ASCO)** annual meeting in early June, held this time in Atlanta. Volunteers from Georgia, North Carolina and Indiana helped staff the booth, answer questions and hand out thousands of brochures and bookmarks. In addition to the booth, attendees participated in poster sessions, educational presentations and focus groups.

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

Also in June, ibcRF representatives traveled to **Phoenix** to meet with a researcher who expressed a strong interest in studying IBC. A local group of IBC patients, who meet on a regular basis, was able to provide "seed money" for this researcher to begin with the plan to submit a proposal for additional grant funds to expand the project. Talks continue with the researcher who will be submitting a proposal for use of IBC Research Foundation BioBank and Clinical Data Base materials. The Phoenix IBC group is a dynamic combination of patients, survivors, friends, and family who are anxious to assist in the mission of ibcRF.

After months of preparation and planning, **ibcRF partnered with Living Beyond Breast Cancer (LBBC)** of Pennsylvania to host a **Teleconference on IBC**. Dr. DeMichele, of the University of Pennsylvania, was the guest speaker and did an outstanding job of providing basic information and answering a host of questions from the participants. Ginny Mason of ibcRF served as moderator of the event and Elyse Caplan of LBBC acted as host for the teleconference. The positive response to this teleconference encouraged LBBC to plan a session on IBC at their 2007 Annual Young Survivor's Conference. ibcRF assisted in securing a speaker for that session and will participate in the conference. For the transcript go to:

<http://www.lbbc.org/event-detail.asp?c=educational&t=participate&sn=teleconferences&id=110>

Another group that uses consumers/patient advocates in the grant review process is the **Congressionally Directed Medical Research Program**. This is typically referred to as the **Department of Defense (DoD) Breast Cancer Research Fund** since the monies are administered by the DoD. Since 2002 a number of IBC patients/survivors have participated in this process. Ginny Mason was part of the Era of Hope Scholars review in early September. Monies for breast cancer and other cancer research are determined each year by Congress. <http://cdmrp.army.mil/bcrp/default.htm>

The first annual **American Association for Cancer Research (AACR) Special Conference on Molecular Diagnostics and Therapeutics** was attended by representatives of ibcRF. Hearing presentations on the cutting edge of molecular research brings hope to all in the cancer community. The networking opportunities at these meetings broadens IBC awareness and increases interest in research of IBC.

The October opening of the **M.D. Anderson Cancer Center IBC Clinic**, in Houston, TX, attracted national media attention. ibcRF founder and President Owen Johnson was invited to speak at the opening ceremonies. The new clinic builds upon established relationships the Foundation has built with M.D.A. physicians. A meeting with IBC Clinic staff and ibcRF is planned for 2007 to explore how to maximize use of this resource.

An application/nomination for the first "**Best Practices in Breast Cancer Advocacy Awards**" given by the National Breast Cancer Coalition Fund (awards made possible by a generous grant from the Breast Cancer Fund of the National Philanthropic Trust) was submitted in August. Imagine our excitement when in November we learned the ibcRF BioBank project had been selected to receive one of the seven awards! This is exciting for all the IBC community to have the work of ibcRF acknowledged by the larger breast cancer community. The BioBank was recognized as a program of best practices in advocacy.

For the ibcRF specific press release:

[www.ibcresearch.org/biobank/bestpracticespressrelease.pdf](http://www.ibcresearch.org/biobank/bestpracticespressrelease.pdf)

For the NBCCF general press release about all the recipients:

<http://www.stopbreastcancer.org/bin/index.asp?strid=876&btnid=2&depid=20>

A highlight in the breast cancer community is the annual **San Antonio Breast Cancer Symposium** each December. This year's meeting opened with a presentation on the clinical trial for newly diagnosed IBC patients using **Lapatinib (Tykerb)**. The results of the trial were very encouraging. ibcRF has been involved with the development and patient recruitment of IBC specific clinical trials for this new tyrosine kinase inhibitor since 2004. The early success of this new compound will encourage GlaxoSmithKline to continue their focus on IBC in the coming months and ibcRF will be there as part of that process. It was particularly exciting to see ibcRF mentioned in the acknowledgement slide that accompanied the platform presentation at the conference. For more on Lapatinib and the trial see:

[http://professional.cancerconsultants.com/oncology\\_main\\_news.aspx?id=38805](http://professional.cancerconsultants.com/oncology_main_news.aspx?id=38805)

The **ibcRF BioBank and Clinical Data Base** has been a focus for the organization this year with enrollment at year's end totaling 110. Initial blood and cheek cell samples have been banked on the majority of those enrolled. All participants were re-contacted in November and received an update letter and asked to complete a medical questionnaire. A list of the requested tissue samples and associated medical records was included in the letter so patients can work on collecting those materials for banking. Recognition of the BioBank via the NBCCF Best Practices in Breast Cancer Advocacy Award, articles on tissue banking mentioning the project and growing awareness in the research community are making a difference. Our greatest research resource is the committed and dedicated IBC community. Together we will make research history.

Over the past few years, ibcRF has provided financial support for the **metabolic study of various IBC cell lines** and their reaction to a variety of therapeutics. Early research reported by **Dr. Boros of SiDMap** in 2004 was exciting and lead to additional grant money from ibcRF to explore these unusual findings in more detail as well as expand the study to additional new therapeutics. It was learned that the cell line used in 2004 was probably infected with a bacteria when received by Dr. Boros, and trying to replicate the results of the 2004 experiments with the uninfected cell line proved not possible, even after multiple attempts. <http://www.sidmap.com/>

The Foundation continues to use an e-newsletter, website and two email discussion lists for communication. We're pleased to report that the number of subscribers to the newsletter has increased over the year. Should you miss an issue, the newsletters are archived on the website. In the fall a weekly ibcRF Bulletin was started in an effort to draw attention to research of interest to the IBC community. Be watching the **website** for a "**new look**" coming in 2007 as well as a **revamped brochure**. With the aid of a professional web development company and dedicated volunteers things are coming together. Content will be added and updated, areas devoted specifically to research and awareness as well as new survivor stories will all be a part of the plans for the website. As a true 21<sup>st</sup> century "virtual community" it is important that our communication tools keep pace with technological changes and reflect the growth and change of the organization.

This year end report would not be complete without offering **thanks** to the many people who make up the ibcRF community. Without your support, encouragement, and dedication, the work of the Foundation could not continue. For the amazing ingenuity and enthusiasm of those who held events to benefit ibcRF, to those who have made individual contributions and the tireless efforts of those involved in raising awareness and facilitating research of IBC, we offer our deepest gratitude.

Here's to another great year as we remain, "COMMITTED TO FINDING THE CAUSE"!

*Ginny Mason BSN, RN*  
*Executive Director*