



Annual Letter 2008

Each year we take the opportunity to review the *Inflammatory Breast Cancer Research Foundation's* activities for the year. In this letter we'll highlight some of those things and mention a few hopes for the new year.

As mentioned in the 2007 review letter, the *National Comprehensive Cancer Network* (NCCN) added an inflammatory breast cancer specific treatment guideline to their Breast Cancer Clinical Practice Guidelines. This new guideline was added to the 2008 version and published on-line and announced via the NCCN journal and conference. While it is a bit challenging to access the guideline from the internet (it requires a free registration) the guideline is an important tool to have available for discussions with medical professionals. An NCCN spokesperson indicated that the guidelines are used in training new physicians, this means those physicians-in-training will learn that inflammatory breast cancer should not be considered a subset of locally advanced breast cancer and be aware of the specific treatment needs. For more information visit: www.nccn.org and click on "NCCN Clinical Practice Guidelines in Oncology". To go further you'll need to register.

January 25, Owen Johnson (President) and Ginny Mason (Exec. Director) served as guest speakers at an *Inflammatory Breast Cancer Educational Symposium* in Phoenix, AZ. The event was held at the Translational Genomics Research Institute (TGen). This meeting, planned and implemented by members of the Phoenix IBC group, included a tour of TGen's research facilities, talks by various physicians, researchers and survivors and time to mingle over refreshments. It was a good opportunity to share the work of the Inflammatory Breast Cancer Research Foundation and meet others interested in inflammatory breast cancer research and treatment.

Also in January, the *National Breast Cancer Coalition/Fund* held its first Board meeting of the year. This was our first meeting since the Inflammatory Breast Cancer Research Foundation was voted onto the Board in 2007. Kathleen Livingston (ibcrf volunteer) serves as our official representative and Ginny Mason (Exec. Director) is the alternate. Both attended the orientation and Board meeting in Washington, DC. Being a part of this organization's Board gives us the opportunity to be involved more closely in the work of this important breast cancer organization. Kathleen and/or Ginny attended additional Board meetings during the course of the year. www.stopbreastcancer.org

Once again the Inflammatory Breast Cancer Research Foundation participated in the Indiana based breast cancer research consortium, the *Amelia Project*. This one day meeting brings together clinicians, researchers and advocates to focus on important topics in breast cancer research. A lunchtime poster session encourages one on one discussion and networking. Touching base with two of our Medical Advisory Board members while at Indiana University was an added bonus.

Owen Johnson (President) participated in the Scientist ↔ Survivor Program during the *American Association for Cancer Research* (AACR) Annual Meeting in San Diego, CA. This international gathering of researchers allows our organization to raise awareness of IBC while at the same time learning about cutting edge cancer research. Ginny also attended this conference. www.aacr.org

Each spring representatives from the Inflammatory Breast Cancer Research Foundation attend *the National Breast Cancer Coalition Fund Advocacy Training Conference* in Washington, DC. This conference provides good

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opportunities for networking with other advocates and hearing from a variety of excellent speakers. We had the opportunity to interact with a group of college students who were attending the conference with one of their professors. They received an education about inflammatory breast cancer when they joined us during breakfast! In keeping with tradition, IBC'ers in the DC area and those attending the conference were invited to share in an evening of food and conversation. It was a small group this year but that didn't impact the spirit of the group! www.stopbreastcancer.org

The *American Society of Clinical Oncology* (ASCO) annual meeting was held in Chicago again in 2008. For the fourth year the Inflammatory Breast Cancer Research Foundation was invited to participate in the Advocacy Exhibit area. Dedicated volunteers Pam Haschke, Bonnie Gray, Gayla Little and Ginny Mason staffed the booth and provided IBC information to all those who visited the booth. The ASCO annual meeting brings together over 30,000 participants from around the world to learn about cutting edge oncology research and clinical trial data. It's a wonderful opportunity for advocates to learn as well as meet people involved in the broader cancer community. www.asco.org

Ginny Mason (Exec. Director) served as the advocate moderator for an inflammatory breast cancer special session at the *Era of Hope* breast cancer conference the end of June in Baltimore, MD. The Era of Hope meeting showcases the work of those researchers who have received funding from the Department of Defense Congressionally Directed Medical Research Program. This was the first year that a session was devoted specifically to inflammatory breast cancer. Advocates who have served on grant review panels are invited to attend the conference. <http://cdmnp.army.mil/bcrp/default.htm>

In August, Owen Johnson (President) and Ginny Mason (Exec. Director) participated in the *American Association for Cancer Research (AACR) Metastasis Conference* in Vancouver, BC. Few advocates were in attendance at this conference focusing on mechanisms of cancer metastasis. Outstanding work by the Brain Metastasis Center of Excellence grant group, also presenters at the Era of Hope conference, was a highlight of the meeting. www.aacr.org

Due to the ravages of hurricane Ike, the *Sisters Network Annual Meeting*, scheduled for Houston, TX, had to be cancelled. This would have been the second year for the Inflammatory Breast Cancer Research Foundation to exhibit at this meeting. The conference is to be rescheduled for 2009. It is important to have information on IBC available at this conference with the higher incidence of the disease in African American women.

The National Cancer Institute (NCI) *Translational Science Meeting*, held in early November, brought together forty-plus invited advocates and hundreds of select scientists to participate in a ground-breaking conference. The conference was "designed to accelerate early translational cancer research and to encourage collaboration and enhancement of knowledge across NCI-funded research programs." The Inflammatory Breast Cancer Research Foundation was honored to have Ginny Mason (Exec. Director) invited to participate and serve as an advocate moderator for one of the meeting sessions. <http://ncitranslates.nci.nih.gov/>

December brought multiple opportunities for IBC. *The First International Inflammatory Breast Cancer Conference* was held in Houston, TX the beginning of the month. Advocates, patients, clinicians, researchers and other interested parties joined together for a weekend of information and networking. Sanford Barsky, MD, researcher and long-time friend of ibcRF, provided the opening key-note address giving an overview of his work on IBC. The first full day was devoted to laboratory based research and the conference closed with presentations on treatment. Specialty sessions were held for advocates and nurses. Advocates were given brief opportunities to share their story throughout the conference. Inflammatory Breast Cancer Research Foundation's Ginny Mason provided one of these vignettes and also served as a guest speaker in the nurses specialty session. Gayla Little (Board member) also participated in this conference. Another conference is planned for 2010 in France.

The *31st Annual San Antonio Breast Cancer Symposium* brought together thousands of people from the breast cancer community. While no exciting new IBC material was presented, there were some interesting posters on the subject. Two researchers from Egypt expressed interest in working with our organization as they move forward in their study of IBC. Four people, representing ibcRF, attended the symposium. A highlight of the conference was the Brinker Award lecture by Patricia Steeg, PhD of the National Cancer Institute. Her topic, "Molecular insights into breast cancer metastasis" was intriguing and insightful. To learn more about the conference visit: www.sabcs.org

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Ginny Mason (Exec. Director) continues her work with the *Food and Drug Administration (FDA) Oncologic Drugs Advisory Committee*. Having completed the first year of this four year appointment has been a learning experience. The process of drug development and approval is complex involving many people and processes. The FDA involvement provides new insights and understanding that benefit the Inflammatory Breast Cancer Research Foundation.

In 2008, the *Inflammatory Breast Cancer Research Foundation BioBank and Clinical Data Base* completed its first 3 yr. IRB (Institutional Review Board) review. We're delighted to report that the only problem was a typographical error! This project continues to be a time and capital intensive project but we continue to believe this independent biorepository is essential to meet the needs of the research community. Enrollment remains open with close to 150 currently participating. Only a subset of participants have banked their medical records and archival tissue samples. That will be a focus for 2009 to make the BioBank a more robust resource. For more information on this project contact: biobank@mail.ibcresearch.org

PREVIEW FOR 2009.....

As noted above, the BioBank continues to be an important focus for our organization. In the coming year we want to help participants get their tissue and records banked. Having these materials will enhance the value of this important resource. Researchers need to study human tissue to unlock the secrets to this insidious disease.

As an organization we are continuing to develop our relationship with an international group of clinicians/researchers interested in inflammatory breast cancer. Watch the e-newsletter for more on this subject as we move forward with research collaborations and clinical trials. It is important to keep inflammatory breast cancer in the spotlight.

In 2009 the Inflammatory Breast Cancer Research Foundation will turn 10 years old! While it is important to look back over the past 10 years and acknowledge all that has been accomplished it is perhaps more important to look to the future. How can we, together, work to accomplish the mission and goals of the Inflammatory Breast Cancer Research Foundation? We appreciate your input and hope you will share your thoughts and ideas as we shape plans.

Of course, an annual letter is the perfect time to extend *our most heartfelt thanks* to all those who comprise the Inflammatory Breast Cancer Research Foundation community. Through an amazing network of volunteers the work of this organization moves forward. Your dedication, support and encouragement lift our spirits and your continued financial support allows the Inflammatory Breast Cancer Research Foundation to be an active and integral part of the breast cancer research and advocacy community.

We remain, "*COMMITTED TO FINDING THE CAUSE*" with your help.

Ginny Mason RN, BSN
Executive Director

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