



Annual Report 2011

By, Ginny Mason, RN, BSN
Executive Director, ibcRF

*The mission of the **Inflammatory Breast Cancer Research Foundation (ibcRF)** is to assist scientists and researchers in their quest to determine the definitive causes of inflammatory breast cancer. The Inflammatory Breast Cancer Research Foundation seeks to assist them in their work so effective and meaningful detection and diagnosis, prevention and treatment can be pursued and achieved.*

While **Research** continues to be the primary goal of the ibcRF, until that research ends the disease we must continue to educate the public as to the signs and symptoms of *Inflammatory Breast Cancer*.

RESEARCH

Through collaboration once again with the **Milburn Foundation** (www.milburngift.org) the Inflammatory Breast Cancer Research Foundation was able to award two research grants in 2011. A select group of researchers were invited to submit proposals. Five proposals were received. Following review by both the Medical Advisory Board and the Board of Directors, two awardees were chosen. **Heather Cunliffe, PhD of Translational Genomics Research Institute** (TGen) in Phoenix, AZ, received a grant of \$50,000 to pursue work on the molecular underpinnings of triple negative inflammatory breast cancer. The ultimate outcome is to identify new therapeutic targets for treatment and better understand the disease. Dr. Cunliffe is Head of the Breast and Ovarian Cancer Research Unit at TGen. <http://www.tgen.org/research/index.cfm?pageid=77&peopleid=62>

A second \$50,000 grant was awarded to **Dr. Beth Overmoyer of Dana Farber Cancer Institute**, Boston, MA, to pursue her research project, "Validation of Jak2 as Novel Therapeutic Target in Triple Negative Inflammatory Breast Cancer." Dr. Overmoyer, a medical oncologist is Assistant Professor of Medicine at Harvard Medical School and heads the team of specialists for the Dana-Farber/Brigham and Women's cancer Center's IBC Program. <http://www.dana-farber.org/Adult-Care/Treatment-and-Support/Treatment-Centers-and-Clinical-Services/Breast-Cancer-Treatment-Center/Inflammatory-Breast-Cancer-Program.aspx>

Diane Palmieri, PhD and Bryan P. Schneider, MD, grant recipients in 2009, have been submitting reports of their work. As soon as data is available for publication we'll be sharing that information. **Robert Schneider, PhD**, continues his pre-clinical work, funded by a grant in 2010. His project should move forward to clinical trial in the near future. The generous support of our donors allows us to continue to fund high quality, high reward research to benefit those dealing with inflammatory breast cancer. These projects are possible thanks to your generosity.

Representatives from the Inflammatory Breast Cancer Research Foundation were part of the annual **Amelia Project** research meeting in Indianapolis, IN. This one day conference brings together clinicians, researchers and advocates from Indiana University, Purdue, and Notre Dame. It's an outstanding opportunity to hear quality speakers and network.

Executive Director, Ginny Mason, continues to serve as an ad hoc reviewer on the Integration Panel of the **Congressionally Directed Medical Research Program (CDMRP) for Breast Cancer Research** through the Department of Defense. <http://cdmrp.army.mil/bcrp/default.shtml> As a part of this program Ginny participated in the **Era of Hope** conference in August co-moderating one of the sessions. The Era of Hope meeting brings together the breast cancer community so those researchers funded through the CDMRP can showcase their work.

The **Inflammatory Breast Cancer Research Foundation BioBank and Clinical Data Base** continues to grow, and awareness of this valuable resource is also growing in the research community. More samples are necessary for researchers to have adequate tissue for study. It is vital that those enrolled complete the process by banking their tissue samples and submitting copies of their medical records. Those records make the samples even more valuable for research. As always, we respect and protect your confidentiality in the research process. For more information contact: biobank@ibcresearch.org

In October, Executive Director Ginny Mason, participated in **Advances in Breast Cancer Research: Genetics, Biology, and Clinical Applications**, a conference sponsored by the **American Association for Cancer Research (AACR)**. As one of just three registered patient advocates it was important to bring the patient voice to this highly technical meeting and interact with others in attendance. The conference provided an opportunity to encourage some young investigators to explore IBC. www.aacr.org

The **34th Annual San Antonio Breast Cancer Symposium** is a highlight for all in the breast cancer community. Unfortunately there were no program presentations on IBC this year but there were a number of posters and more IBC advocates in attendance. This conference provides important "one on one" opportunities to talk with researchers, clinicians, and others who are involved in the broader IBC community. Once again a wrap-up session at the close of the meeting provided the highlights of the year in breast cancer. This session is available on-line and worth viewing. www.sabcs.org

With research as our primary focus, ibcRF is involved in a variety of research projects. Ginny Mason is part of a Multi-Team Award grant with New York University (NYU) and UCLA. A number of grant proposals that will make use of ibcRF expertise are in the review process. This year relationships have been developed with Purdue University and an ongoing relationship with Duke University should result in some exciting news for the IBC community.

AWARENESS

The Inflammatory Breast Cancer Research Foundation is no longer on the Board of Directors for the **National Breast Cancer Coalition** but as a member organization our involvement continues. Ginny Mason presented a *workshop on tissue banking*, along with Dr. Sue Clare of Indiana University, at the spring Advocacy Training Conference. She is also part of the **Artemis Project**, a multi-disciplinary team exploring the development of a preventive vaccine for breast cancer. www.breastcancerdeadline2020.org

For the fourth year ibcRF exhibited at the **Young Survivors (C4YW) Conference**. The 11th Annual conference was held in Orlando with Board Member, Carol McWilliams, staffing the exhibit. Many conference attendees stopped by the table to talk and pick up literature. A special IBC workshop brought together attendees dealing with the disease. This conference provides an opportunity to enroll participants in the ibcRF BioBank. www.youngsurvivorsconference.org

The Inflammatory Breast Cancer Research Foundation did not exhibit in the Advocacy Exhibit area at the annual meeting of the **American Society of Clinical Oncology (ASCO)** this year, however Ginny Mason and Gayla Little attended thanks to scholarships provided by the Conquer Cancer Foundation. While not exhibiting, they still had ample opportunities to provide IBC information to countless conference attendees and interact with clinicians, researchers, and other advocates. This huge international conference brings together over 25,000 participants to the McCormick Center in Chicago, to learn the latest in cancer treatment. www.asco.org

ibcRF continues to be an active presence on **Facebook** with both a **Cause Page and Fan Page**. There are over 5000 members (Cause Page) now joining us in the cause to raise awareness and striving for quality research. Social media has presented an opportunity to engage people in our cause in new ways and we will continue to explore how we might enhance those options. Join us on **Facebook** by searching for "Inflammatory Breast Cancer (IBC) Research Foundation."

For 12 years now the **Inflammatory Breast Cancer Research Foundation** has been an active voice for the inflammatory breast cancer community. Through the efforts of countless volunteers more and more people know "**YOU DON'T HAVE TO HAVE A LUMP TO HAVE BREAST CANCER!**". Thanks to Board member and webmaster, Carol McWilliams, the website is undergoing updating, adding features to encourage people to return to the site. Be sure to visit the "One Woman's Journey" in the expanded photo section. We continue to provide two e-mail discussion lists, monthly e-newsletter, personally responding to questions/comments by e-mail and phone, and remain an active presence in the breast cancer community and broader oncology community. **The Inflammatory Breast Cancer Research Foundation** is here to represent **YOU**, our loyal supporters, to see that quality research on IBC receives funding and attention, while raising awareness of this disease in both the lay and medical communities.

Looking ahead....what does 2012 hold for ibcRF? The more samples are needed if the **BioBank** is to be a truly useful resource for research. Hopefully there will be adequate funds to support more research. As plans solidify, we promise to remain committed to the mission and goals of ibcRF and strive for an end to inflammatory breast cancer. We sincerely thank those who have given of their time and resources to join us on this journey, especially in these tough economic times. Together we celebrate survivors, yet mourn the loss of our pathfinders, all the while remaining...**COMMITTED TO FINDING THE CAUSE.**

Inflammatory Breast Cancer Research Foundation Board of Directors