



Annual Report 2012

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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 cause(s) 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

It's been a tough year economically for everyone and that includes non-profits. In spite of those financial challenges *ibcRF* remains committed to funding quality research to improve diagnosis and treatment of inflammatory breast cancer (IBC). We've been impressed with the work of **Milan Radovich, PhD, at Indiana University's Simon Cancer Center**. Dr. Radovich has been involved with the Next Generation Sequencing project, funded by an *ibcRF* grant to Dr. Bryan Schneider in 2009, and is now established in his own lab. With the aid of the new Next Generation Sequencer in the Radovich lab, he is prepared to expand on the earlier work and sequence some untreated IBC tissue. *ibcRF* provided a grant of \$5000 to Dr. Radovich, thanks in part to a gift from the Milburn Foundation (www.milburngift.org) To learn more about Dr. Radovich and his research visit http://www.cancer.iu.edu/research/members/member_bio.php?id=3659

Two additional seed grants were given to researchers currently working on triple negative inflammatory breast cancer (TN IBC). These grants are to enable them to take their current work to the 'next phase', building on what they have already learned.

Heather Cunliffe, PhD, from Translational Genomics Institute (TGen) in Phoenix, AZ, received a \$50,000 grant last year to study the molecular underpinnings of TN IBC. Dr. Cunliffe plans to publish her initial findings in 2013 and will use the additional funds from the seed grant to further study the therapeutic targets she has identified through her earlier work.

<http://www.tgen.org/research/index.cfm?pageid=77&peopleid=62> The second seed grant went to **Deborah Silvera, PhD of New York University** has been working closely with Dr. Robert J. Schneider (grant recipient in 2009) and Dr. Silvia Formenti, both of NYU, to use radiation as a means to potentiate cell death in the treatment of TN IBC.

Diane Palmieri, PhD, 2009 grant recipient, is no longer in the Steeg lab at the National Cancer Institute but Dr. Patricia Steeg presented the findings of her IBC brain metastasis mouse work at the Third International IBC Conference in Dec. 2012. Another member of the Steeg lab will be presenting a poster at the 2013 AACR (American Association for Cancer Research) on this same project.

Executive Director, Ginny Mason, continues to serve as an ad hoc reviewer on the Integration Panel and as a peer reviewer for the **Congressionally Directed Medical Research Program (CDMRP) for Breast Cancer Research** through the Department of Defense. <http://cdmrip.army.mil/bcrp/default.shtml> .

The **Inflammatory Breast Cancer Research Foundation BioBank and Clinical Data Base** continues to slowly increase, 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 Ginny Mason has represented *ibcRF* on a **Tissue Think Tank**, a multi-disciplinary collaborative group exploring tissue banking and its value in the cancer research community. Two meetings were held in 2012 with at least one follow-up gathering and conference calls scheduled for 2013. The group discussed tissue collection, privacy, ethics, and public education efforts.

To remain in touch with current clinical and treatment in the breast cancer community representatives from ibcRF participated in the **Annual Meeting for the American Association for Cancer Research** (AACR; www.aacr.org) in April and the **Annual Meeting of the American Society of Clinical Oncology** (ASCO; www.asco.org) in June, both in Chicago in 2012. These meetings allow ibcRF to make valuable contacts, meet with clinicians and researchers involved in IBC, as well as educate practitioners and advocates in attendance. Thanks to a scholarship from the Conquer Cancer Foundation, Ginny Mason was able to represent ibcRF at the **ASCO Breast Cancer Conference** in October in San Francisco. This smaller conference focuses specifically on clinical and research studies related to breast cancer where the Annual Meeting is devoted to all types of cancer.

New this year ibcRF had the opportunity to attend the conference, **International Breast Cancer & Nutrition, Working Together for Prevention**, held on the campus of Purdue University. This was a unique conference covering a wide variety of topics. Presenters represented countries Ghana, Qatar, Uruguay, Canada, and Sweden. Talks focused on topics that included nutritional ways cancer might be controlled or prevented, providing breast cancer education in cultures that do not value women or their health, as well as computerized data bases to manage data collected in breast cancer studies.
<http://www.purdue.edu/discoverypark/oncological/ibcn/>

We closed the year with two conferences back to back. The **Third International IBC Conference** was held in Philadelphia. For 1 1/2 days attendees learned about research and clinical findings specific to IBC. A number of advocate groups were in attendance and each had the opportunity to give a brief presentation about their work. Executive Director, Ginny Mason and Board member, Gayla Little, attended this conference. The **35th 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 quite a few 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.

The Inflammatory Breast Cancer Research Foundation is proud to be a part of team **Registries4All**, winner of the Sanofi U.S. Collaborate/Activate challenge. Together with the Genetic Alliance, CFIDS Association of America, and National Psoriasis Foundation, ibcRF has developed a project that targets patients and their families with rare diseases to join a virtual research network using patient-generated information around rare diseases to accelerate development of clinical trials. The first prize of \$300,000 is already being put to use as the elements of the project are in development. www.collaborateactivate.com

AWARENESS

As reported last year ibcRF continues to be active in the programs of the **National Breast Cancer Coalition** although not serving on the Board of Directors. Board member Carol McWilliams and Ginny Mason participated in the Annual Advocacy Training Summit in May. In addition, Ginny served as moderator for a workshop session on Tumor Dormancy. Ginny's involvement with the NBCC **Artemis Project**, a multi-disciplinary team exploring the development of a preventive vaccine for breast cancer, came to an end this year and she hopes to be involved in the project focusing on tumor dormancy. www.breastcancerdeadline2020.org

Again this year ibcRF exhibited at the **Young Survivors (C4YW) Conference**. This was our 5th year to have a presence at the conference. The 12th Annual conference was held in New Orleans with Executive Director, Ginny Mason, staffing the exhibit. Many conference attendees stopped by the table to talk and pick up literature. A group of 8 IBCers and spouses met for a meal together on Saturday night, hosted by ibcRF. This is an important conference for reaching young women and providing information on the ibcRF BioBank. www.youngsurvivorsconference.org

Organizers of the July program **Breast Cancer New Horizons Current Controversies**, offered by Harvard Medical School Department of Continuing Education, invited Executive Director Ginny Mason to provide a patient voice as part of a panel discussion following Dr. Beth Overmoyer's presentation on inflammatory breast cancer. The panel, **Challenging Case Discussion on Locally Advanced and Inflammatory Breast Cancer**, provided an opportunity to share about the work of ibcRF as well as highlight the ibcRF's role in developing the National Comprehensive Cancer Network guidelines for diagnosis and treatment of inflammatory breast cancer.

Board member Gayla Little represented ibcRF with an educational exhibit at the **Lynn Sage Town Hall Meeting** in Chicago, sponsored by Northwestern University. We've been a regular exhibitor at this meeting for a number of years. There's no charge to exhibit and it helps to raise awareness of both the organization and educate the public about inflammatory breast cancer.

October usually brings opportunities to raise awareness and people posted messages about their advocacy efforts on our email discussion list and Facebook pages. Newspaper articles, TV interviews, and public speaking were just a few of the ways our broad network of volunteers helped educate the public about inflammatory breast cancer. Ginny Mason had the honor of speaking at the American Cancer Society's Making Strides Against Breast Cancer in Lafayette, IN. The talk focused on the need for women to be their own advocate if they have worrisome symptoms. Following the speech she joined community leaders in cutting the ribbon to begin the walk/run.

Social media is now the important way to convey information. 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. Over 700 people are now following our work on the Fan Page. 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. We haven't joined the **Twitter** world as yet but have discussed how this tool might also be useful. Join us on **Facebook** .
https://www.facebook.com/ginny.mason.92?ref=tn_tnmn#!/pages/Inflammatory-Breast-Cancer-IBC-Research-Foundation/446772405646

WHERE WE ARE.....WHERE WE'RE GOING

It's been a challenging year. We're trying to do more with less....just like many others. There have been losses as well as good news. It is with sadness that the Board accepted the resignation of our Founder, Owen Johnson, who had been serving as President of the Board for many years. It was his vision and dedication that brought the Inflammatory Breast Cancer Research Foundation into being and his leadership helped bring us to where we are today. Fortunately we have talented and capable leaders who will continue that vision, taking the organization forward.

You, our tireless volunteers keep spreading the word, "**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. The photo section continues to grow with visuals to help those with worrisome symptoms and those facing new treatments. We consolidated our e-mail discussion lists into one, are regular with the monthly e-newsletter, still 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.

While we were the **FIRST** inflammatory breast cancer non-profit group, started in August 1999, we are no longer in this crusade alone. **RESEARCH** will continue to be our focus and as long as we are able, thanks to our generous donors, we'll fund quality research that will bring us closer to understanding this dreadful disease and improving treatment and survival. We'll also continue our efforts to educate the medical community and public about inflammatory breast cancer using a wide variety of means. Ultimately, we remain committed to the mission and goals of ibcRF and strive for an end to inflammatory breast cancer.

We sincerely thank those who continue to give of their time and resources, joining with us in this uphill challenge. The going may become tough but we're committed to this cause. Let's celebrate those who are able to go with life in spite of IBC, mourn our pathfinders who give us the passion to keep going and keep our eyes on a future without inflammatory breast cancer!

Ginny Mason RN, BSN; Executive Director and the Inflammatory Breast Cancer Research Foundation Board of Directors

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