



## Annual Report 2014

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 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 about *Inflammatory Breast Cancer* and provide an educated resource for questions.

### RESEARCH

At the end of 2013 the Board awarded a research grant in memory of Kathleen Livingston. Kathleen was an amazing advocate willing to speak out about IBC, lobby congress, and facilitate research all the while struggling with skin metastasis encompassing her chest and back. The \$50,000 Kathleen Livingston Memorial Grant went to **Mark W. Dewhirst, DVM, PhD, FASTRO** (Fellow of the American Society for Therapeutic Radiology Oncology), **FAAAS** (Fellow of the American Association for the Advancement of Science). Dr. Dewhirst is a Professor of Radiation Oncology in the School of Medicine, **Duke University Medical Center** in Durham, NC. His research will hopefully result in a better understanding of skin metastasis. Improved treatment would make a difference for patients. <https://www.dtmi.duke.edu/directory/Dewhi001> Dr. Dewhirst received half of the grant money in 2013 and the remainder in 2014. This grant was made possible thanks to the generous memorial donations received in Kathleen's name.

Drs. Schneider and Radovich, at **Indiana University Simon Cancer Center** (recipients of grants in 2009 & 2012) continue to collect IBC samples for a sequencing project (BioBank samples are part of this research). Next Generation Sequencing will provide genomic data that could lead to new therapeutic targets, improving IBC treatment options.

The **Inflammatory Breast Cancer Research Foundation BioBank and Clinical Data Base** continues to slowly increase in size and changes are in the works for this project. It has become necessary to move the archival tissue to a new location. We are exploring options and want to continue to maintain this resource for research. We need your help... *It is vital that those enrolled complete the process by banking their tissue samples and submitting copies of their medical records to the BioBank.* The treatment and outcome data in the medical record add value to the samples. For more information contact: [biobank@ibcresearch.org](mailto:biobank@ibcresearch.org)

To remain in touch with current research and treatment we attended the **Annual Meeting of the American Society of Clinical Oncology** (ASCO; <http://www.asco.org>) in June, at McCormick Center in Chicago, IL.

Attendance at the **37th Annual San Antonio Breast Cancer Symposium** is a must for all in the breast cancer community. Sadly there were no platform presentations on IBC but there were posters and quite a few IBC advocates. We interact with researchers, clinicians, and others who are involved in the broader IBC community. The closing wrap-up session of the meeting provided highlights of the year in breast cancer. This session is available on-line and worth viewing. (<http://www.sabcs.org>)

Executive Director, Ginny Mason and Board members Carol McWilliams and Patricia Haugen served as grant reviewers for the **Congressionally Directed Medical Research Program (CDMRP) for Breast Cancer Research** through the Department of Defense, bringing the patient voice and perspective to breast cancer research. <http://cdmrp.army.mil/bcrp/default.shtml>

Many IBC patients have metastatic disease so *ibcRF* has joined the Metastatic Breast Cancer Alliance to help raise awareness of issues related to metastatic disease, support patients, and facilitate research to change the landscape

for those with advanced breast cancer. We were honored to participate in the press release on October 13, Metastatic Breast Cancer Day, in New York City. Learn more about the project: [www.mbcalliance.org](http://www.mbcalliance.org)

Through collaboration with other disease specific advocacy groups we are empowering patients to engage with investigators and move research forward. The **Community Engaged Network for All (CENA)** is funded by a grant from PCORI (Patient Centered Outcomes Research Institute). We are in phase I development and hope to launch the project sometime in 2015. Updates will be posted in our email newsletter and website.

Our research activities reach into the broader breast cancer community. Board members provide grant reviews, serve as advocate representatives on research projects, and provide advocate input on hospital IRBs. Ginny continues her work with the **Translational Breast Cancer Research Consortium (TBCRC)** representing Indiana University and providing a patient voice for research projects. As a member of the Steering Committee for the Genentech's **SystHERs Registry**, a project enrolling patients with Her2 positive metastatic breast cancer, she's helped develop and analyze instruments that capture 'real life' data on side effects, financial issues, job and family concerns, general health, etc. of those participating. A limited number of IBC patients have enrolled but we need more.

Each of these activities are extensions of the Foundation's work to enhance research and educate others about IBC and the needs of the IBC community. Working with a variety of clinicians, researchers and others in the oncology community helps raise awareness of IBC, ibcRF and our work. Costs associated with these projects typically are covered by the sponsoring agencies allowing the ibcRF to focus resources on our mission and goals.

## AWARENESS

An important way we educate and raise awareness of IBC is through conferences. However we are very selective in choosing which conferences to attend and when to exhibit. While useful, there are costs associated so we only exhibited at **C4YW (Conference for Young Women with Breast Cancer)** this year. This conference was held in Orlando, FL in mid-February. Board member, Carol McWilliams, helped staff the exhibit and provided housing a significant help. Being a part of this conference has extended our reach in the young survivors community allowing us to educate and network with others with IBC.

We are in our second year of our term on the Board of Directors of the **National Breast Cancer Coalition (NBCC)** with ibcRF Board member Patricia Haugen serving as our representative. Both Patricia and Ginny participated in the **NBCC Summit** in the April. NBCC remains focused on the goal of ending breast cancer by 2020. Patricia continues to provide leadership in the NBCC **Artemis Project**, dedicated to the developing a preventive vaccine for breast cancer. To learn more about NBCC and their work visit <http://www.breastcancerdeadline2020.org>

We encourage our Board members and all those involved in the IBC community to find ways to raise awareness. Ginny has become involved with the local YWCA Women's Cancer Program. Board member RK VanOrsdal has provided education in her community through local events. Phyllis Johnson, Board member, writes a regular breast cancer column for HealthCentral a health oriented website. Carol McWilliams, of our Board, manages our website and helps with bookkeeping. Each Board member plays an important role in providing the strong framework of our organization while reaching out and sharing the IBC message.

Social media is essential for reaching a broader audience. We use Facebook, Twitter and CrowdRise to engage people in our mission and support it financially. You can find us at <https://www.facebook.com/pages/Inflammatory-Breast-Cancer-IBC-Research-Foundation/446772405646>. Be sure to like our page and keep up with the posts. We're @IBCResearch and invite you to follow us. You'll even find us on Pinterest sharing photos and information. As a small organization and no real staff, it takes a lot of time to make sure we're "out there" where people can find us.

Not everyone has easy access to a computer so we continue offer our **Toll-free phone line**. Call numbers are down but those who call are anxious to talk to someone and appreciate that personal contact. Those wanting that one-on-one experience can also make contact from the website. We receive questions about physicians, treatment, worrisome symptoms, as well as some general messages. The subjects are much the same as those by phone. Board members share the responsibility of responding to messages and callers providing a listening ear as well as guidance, while making it clear that we cannot provide medical advice. These are costly and time intensive services, but important.

## 15 years: WHERE WE ARE.....WHERE WE'RE GOING

With the resignation of our treasurer last year we started the search for a new treasurer and did some restructuring to streamline our business practices. We have a strong and dedicated Board of Directors, all either long-term IBC survivors or closely connected to the disease. We've learned that change is challenging but can be an opportunity to

reevaluate things. When we started this organization in 1999 no one realized how difficult it would be to unravel the complexities of cancer. In spite of 15 years of work the need for improved diagnosis and treatment of IBC remains.

This report wouldn't be complete without a huge thanks to our amazing volunteers, generous donors, and dedicated supporters. As a small non-profit we can't possibly have the impact we'd like on our own. Each of you carry the message into your community, telling your story, making it personal. As you share about IBC, be sure to have a brochure or bookmark ready! Hopefully people will be motivated to visit the website and learn more. New content is added regularly, so visit often.

Don't forget to sign-up for our e-mail newsletter. The e-mail newsletter comes out early in each month and is filled with educational information, clinical trials and updates on our activities. While not as active as it used to be, we still operate the email discussion list. Make use of it, it's private (archives are private too) and a useful tool for this journey. (<http://www.ibcresearch.org/newsletter-and-discussion-list/>)

We offer our heartfelt thanks to all those who have shared their time and talents, resources and dedication to this cause. You do it because you care. You want to see an end to this disease. We must remain the voice for IBC in the research community if survival is to improve. It's in the memory of those we've lost that we strive to keep pushing for an end to IBC. Let's honor those amazing women and men by carrying the candle in their name.

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