



## Annual Report 2013

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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

This year's federal sequester had a huge impact on the field of medical research. As a result we have received many requests for grant money. We have started a file of those who have interest in studying IBC. The Board decided to do something a bit different this year and offered a research grant in memory of a special IBC volunteer, Kathleen Livingston. This grant was made possible thanks to the generous memorial donations received in Kathleen's name. Ms. Livingston was a tireless advocate for IBC. Over the more than eleven-year course of her disease, she participated in numerous clinical trials, lobbied Congress for the National Breast Cancer Coalition, and started the Michigan Breast Cancer Coalition. Her dedication to research and her struggle with skin metastasis from IBC led us to formulate the Request for Applications (RFA) focusing on research that would improve understanding and treatment of this manifestation of IBC. Skin metastasis is particularly difficult to treat and poorly understood. Our Medical Advisory Board reviewed each application, guiding the Board's decision. 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 the Gustavo S. Montana Professor of Radiation Oncology in the School of Medicine, **Duke University Medical Center** in Durham, NC. Dr. Dewhirst's proposal is titled, "HIF-1 driven therapeutic resistance mechanisms in chest wall recurrences of inflammatory breast cancer (IBC)". Dr. Dewhirst has been working on this IBC issue in the past and brings a wealth of knowledge and experience to the project. <https://www.dtmi.duke.edu/directory/Dewhi001>

Last year we reported on a seed grant to **Heather Cunliffe, PhD** for her work on triple negative IBC. Heather has moved back to her native New Zealand to teach and continue her work. She will soon publish results from this project. Our website will be updated with links when that information is available.

Executive Director, Ginny Mason, continued to serve as a peer reviewer for the **Congressionally Directed Medical Research Program (CDMRP) for Breast Cancer Research** through the Department of Defense. <http://cdmrp.army.mil/bcrp/default.shtml> .

The **Inflammatory Breast Cancer Research Foundation BioBank and Clinical Data Base** continues to slowly increase in size, and awareness of this valuable resource is also growing in the research community. However, changes are in the works for this project. It has become necessary to move the archival tissue to a new location, once a contract site can be established. To make the BioBank more valuable to the research community more samples are necessary. *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. As always, we respect and protect your confidentiality in the research process. For more information contact: [biobank@ibcresearch.org](mailto:biobank@ibcresearch.org)

To remain in touch with current research and treatment in the breast cancer community, representatives from ibcRF participated in the **Annual Meeting for the American Association for Cancer Research (AACR)**; <http://www.aacr.org> in April at the Washington, DC Convention Center and the **Annual Meeting of the American Society of Clinical**

**Oncology** (ASCO; <http://www.asco.org>) in June, at McCormick Center in Chicago. A highlight of the AACR meeting was having our abstract "**Characterization of the neuroinflammatory response in a mouse model of brain metastatic inflammatory breast cancer**"

([http://cancerres.aacrjournals.org/cgi/content/meeting\\_abstract/73/8\\_MeetingAbstracts/4976](http://cancerres.aacrjournals.org/cgi/content/meeting_abstract/73/8_MeetingAbstracts/4976)) presented by Tiffany Reed of the National Cancer Institute. This work was supported by a grant from ibcRF, building on Dr. Palmieri's supported research. Attending these meetings allows ibcRF to make valuable contacts, meet with clinicians and researchers involved in IBC, as well as educate practitioners and advocates in attendance.

We closed the year with two notable conferences. In November, our Executive Director was invited to present an educational poster detailing IBC and the work of the Foundation, at the **Second Advanced Breast Cancer Consensus Conference (ABC 2)** in Lisbon, Portugal. A generous scholarship covered registration and travel expenses for this conference. This was an extraordinary opportunity, participating in an international meeting of breast cancer experts gathered to develop consensus guidelines for the treatment of advanced breast cancer. Ginny was invited to the podium to speak about reconstruction in IBC. It's essential that IBC be included in these guidelines to improve treatment.

The **36<sup>th</sup> Annual San Antonio Breast Cancer Symposium** is a December highlight for all in the breast cancer community. Again this year there were no program presentations on IBC but there were posters and quite a few IBC advocates in attendance (including our ED!). This conference provides important "one on one" opportunities with researchers, clinicians, and others who are involved in the broader IBC community. A wrap-up session at the close of the meeting provided highlights of the year in breast cancer. This session is available on-line and worth viewing. (<http://www.sabcs.org>)

Our research activities often spread beyond just the narrow focus of IBC. Ginny Mason continues her work on a Multi-Team Award grant with New York University (NYU) and University of California, Los Angeles (UCLA). Board members are often involved in grant reviews for various organizations. Ginny was appointed to the **Translational Breast Cancer Research Consortium (TBCRC)** representing Indiana University, joining other advocates to provide a patient voice to research projects. She is also a member of the Steering Committee for the Genentech sponsored **SystHERs Registry**. This registry enrolls patients with Her2 positive metastatic breast cancer and collects data on them for up to eight years, providing valuable day to day information on side effects, financial issues, job and family concerns, general health and more. It's hoped that a significant number of IBC patients will enroll since we know so little about the long-term issues facing these patients. 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. Costs associated with these projects 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. Given the cost of exhibiting and providing staffing, we only exhibited at **C4YW (Conference for Young Women with Breast Cancer)** this year. This conference was held in Bellevue, WA in mid-February. Due to distance only Ginny staffed the exhibit. She also shared in a workshop on IBC. This conference provides a great opportunity to educate and network with others with IBC.

We continue as a member 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 Leadership Conference** in the spring, bringing together advocates committed to the NBCC goal of ending breast cancer by 2020. Patricia's leadership in NBCC includes involvement in the **Artemis Project** exploring the development of a preventive vaccine for breast cancer. To learn more about NBCC and their work visit <http://www.breastcancerdeadline2020.org>

Our Board members and others across the IBC community look for local opportunities to raise awareness. Ginny has become involved with the YWCA Women's Cancer Program in Lafayette, IN. As a result she was able to share the Foundation's bookmarks at the Ultimate Pink Party, a YWCA program fundraiser reaching over 400 people. It's through events like this that we are able to educate people about IBC. Phyllis Johnson, Board member, writes a regular breast health column for a health oriented website. Board members R.K. VanOrsdal and Carol McWilliams work diligently to help 'spread the word' by managing literature orders and keeping the website up to date and working well. Each Board member is essential to keep the work of the organization moving forward.

It has become increasingly clear that social media tools can help us reach a broader audience for education and as a source of funding. To keep doing what we do takes money. Changes in **Facebook** have made the cause page somewhat obsolete. We

now direct people to our **Organization Page** <https://www.facebook.com/pages/Inflammatory-Breast-Cancer-IBC-Research-Foundation/446772405646> and hope you'll join the over 1,100 people who are already following us there. We're now active on Twitter (@IBCRResearch) and invite you to follow us, and we're in the process of developing a Pinterest page as well. It's a huge job to manage all these outlets, but we're finding it to be an important part of our work.

Another important area of outreach is our **toll-free phone line** and **e-mail response team**. We typically received about 20 messages a month to our website with questions about worrisome symptoms, IBC physicians, treatment and other things. Calls to the toll-free phone line cover much of the same topics, along with a few business calls each month. Even in this technological age, many people prefer to contact us via phone and appreciate talking to a "real" person as opposed to electronic communication. It's expensive to provide these services, but we feel they are important services. 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.

### **WHERE WE ARE.....WHERE WE'RE GOING**

It's been said that the only thing that's constant is change. We've added two new members to the Board of Directors, Patricia Haugen and Phyllis Johnson. With these additions the majority of our working Board are IBC survivors. Our long-term secretary treasurer, Laurie, tendered her resignation at the end of the year, so we'll be starting the new year with the search for a new treasurer. Yes, change is constant, yet the cause remains and still calls us to keep pushing ahead to find answers that will improve the diagnosis, treatment and survival of those facing IBC.

Where would we be without our amazing volunteers, generous donors, and dedicated supporters? We're not a membership organization but consider each person that's been touched by this disease to be an advocate, educating the people in their circles about IBC. It might not seem like much, but together we're making a huge difference, one person at a time.

When you're sharing about IBC, be sure to have a brochure or bookmark handy so people will come to the website to learn more. Be sure YOU visit the website regularly. We're always working to update it and meet the needs of our visitors. Sign-up for our e-mail newsletter so you can keep up with IBC happenings and information. The email discussion remains active. Use it; it's private and a useful tool for this journey. (<http://www.ibcresearch.org/newsletter-and-discussion-list/>)

In 2014 we'll celebrate our 15th birthday! Surely something to celebrate but a sobering reminder that there is still so much to do. When we started this work back in 1999, we didn't anticipate the complexities of cancer and the challenges ahead. As the breast cancer advocacy landscape changes, it's tempting to change our focus, yet we're reminded that no one else is doing what we do, so we must continue.

We offer our heartfelt thanks to all those who have shared their time and talents, resources and dedication to this cause. Money is tight, people are busy, but the need remains. We MUST remain the voice for IBC in the research community if mortality and survival are to change. 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*