



Annual Report 2010

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 is accomplished we must continue to educate the public as to the signs and symptoms of Inflammatory Breast Cancer.

RESEARCH

A February highlight is the **Amelia Project** meeting, bringing together researchers, clinicians and advocates from across the state of Indiana. This unique one day meeting combines networking opportunities with outstanding speakers on the campus of Indiana University in Indianapolis. ibcRF was well represented by Ginny Mason and Gayla Little and her husband, Michael.

Owen Johnson, President, and Ginny Mason had the opportunity to represent ibcRF at the **American Association for Cancer Research (AACR) Annual Meeting** in April. This international gathering of scientists was held in the Washington Convention Center in the nation's capitol. Both Owen and Ginny were a part of the Scientist->Survivor Program, offered by the Survivor and Patient Advocacy department of AACR. Through this conference we had the opportunity to interact with a wide variety of scientists as well as other advocates providing IBC education and making valuable contacts. www.aacr.org

While in Silver Spring, MD for an Oncology Drug Advisory Committee Meeting, Ginny Mason had the opportunity to spend a day in the National Cancer Institute lab of **Diane Palmieri, Ph.D.** She received some 'hands-on' experience while getting an update on the research being funded by a grant from the Inflammatory Breast Cancer Research Foundation and The Milburn Foundation, as noted in our 2009 letter.

In October, Ginny Mason was given the opportunity to attend the **Second Annual International IBC Conference** in Marseille, France, thanks to a travel grant. As the only IBC patient in attendance she felt compelled to speak on behalf of patient needs and concerns. The setting was lovely and the French were warm hosts but given the location the size of the conference was small. There were interesting presentations and it was good to interact with the international IBC community. www.2ibc-conference.com

The **Inflammatory Breast Cancer Research Foundation**, in collaboration with the **Milburn Foundation**, awarded a \$50,000 grant to Bryan Schneider, MD of Indiana University Simon Cancer Center, to do Next Generation Sequencing on 10 samples of triple negative IBC. Obtaining 10 triple negative IBC samples will be challenging but ibcRF is helping Dr. Schneider obtain the samples so work can begin. To learn more about this technology: <http://www.wellcome.ac.uk/News/2009/Features/WTX056032.htm>

Executive Director, Ginny Mason, continues her term on the **Food and Drug Administration (FDA) Oncologic Drugs Advisory Committee**. Serving on this committee has provided the opportunity to better understand the drug development and approval process and opened the door to work with a wide variety of people in the broader oncology community. While it is time consuming, it remains a unique opportunity to raise awareness of inflammatory breast cancer and the organization. www.fda.gov

This year we were fortunate to receive yet another gift from the **Milburn Foundation** and are nearing the completion of the granting process. The **Milburn Foundation** has requested that the funds go to support research that will benefit those patients currently diagnosed with triple negative inflammatory breast cancer. Researchers were invited to submit proposals and those have been reviewed by the ibcRF Board and Medical Advisory Board. The recipient of the grant will be announced early in 2011. We are excited that this continued collaboration is allowing us to fund important research initiatives that advance understanding of the disease and impact patients.

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. 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

AWARENESS

Serving on the Board of Directors for the **National Breast Cancer Coalition/ Fund (NBCC)** has been an honor. The last year of our 3 yr term began in 2010 with a Board meeting and orientation. *Kathleen Livingston* has been the official ibcRF representative with Executive Director, Ginny Mason, providing back-up. NBCC is a strong voice for breast cancer in both the media and with policy makers. ibcRF is a member organization and joins with many other organizations to comprise this group. www.breastcancerdeadline2020.org

Once again ibcRF exhibited at the Young Survivors conference. The 10th Annual conference was held in Atlanta with Ginny Mason and RK Van Orsdal staffing the exhibit. Many conference attendees stopped by the table to talk and pick up literature. It was also a good opportunity to enroll participants in the ibcRF BioBank. www.youngsurvivorsconference.org

Each May volunteers from ibcRF attend the **National Breast Cancer Coalition Annual Advocacy Training Conference** in Washington, DC. This conference provides a wide variety of plenary sessions, workshops and networking opportunities bringing together breast cancer advocates who share a common passion. Executive Director, Ginny Mason, provided leadership for a workshop on the Food and Drug Administration's Accelerated Approval Process. www.stopbreastcancer.org

For the 6th year, the Inflammatory Breast Cancer Research Foundation was invited to participate in the Advocacy Exhibit area at the annual meeting of the **American Society of Clinical Oncology (ASCO)**. Volunteers Gayla Little, Carol McWilliams, Pam Haschke and Ginny Mason staffed the booth while providing IBC information to countless conference attendees. This huge international conference brought together over 25,000 participants to the McCormick Center in Chicago, to hear the latest in cancer treatment. www.asco.org

Also in June, inflammatory breast cancer was the topic of the day on **Dr. Radio**. Executive Director, Ginny Mason, was interviewed on this satellite radio production that originates from New York University's Langone Medical Center. Dr. Silvia Formenti, professor of Medicine, Chair, Department of Radiation Oncology is co-host of the program and involved in research to benefit IBC patients.

Our thanks to the Bigoski family for hosting the **7th Annual Bowling Day** to benefit the Inflammatory Breast Cancer Research Foundation in August. Once again this was an amazing event to honor and remember Julie Bigoski. This family has raised over \$100,000 with these events. We appreciate their generosity and wish them all well as they move on to other endeavors. A special thanks to all our donors!

The **33rd Annual San Antonio Breast Cancer Symposium** is a highlight for all in the breast cancer community. ibcRF Medical Advisory Board member and ASCO President, George Sledge Jr. MD, gave a wonderfully energizing presentation for the William L. McGuire Memorial Lecture. 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

As announced last year, ibcRF continues to be an active presence on **Facebook** with both a **Cause Page and Fan Page**. We have close to 5000 members now joining us in the cause to raise awareness and striving for quality research. Join us on **Facebook** by searching for "Inflammatory Breast Cancer (IBC) Research Foundation."

In 2009 the **Inflammatory Breast Cancer Research Foundation marked 10 years** as a voice for the inflammatory breast cancer community. Through the efforts of our organization and countless volunteers, more and more people know "**YOU DON'T HAVE TO HAVE A LUMP TO HAVE BREAST CANCER**". With the help of a new web person, Carol McWilliams, we are updating the website and making it more user friendly and providing content that will bring people back to the site. We continue to provide two e-mail discussion lists, continue a 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. We are here to represent YOU, our loyal supporters, to see that quality research on IBC is funded and accomplished while raising awareness of this disease in both the lay and medical communities.

What's ahead? When ibcRF began in 1999, we expected our work to be finished by now so there would be no need for this organization anymore. Unfortunately, we were wrong. We've made some important progress but the work is NOT done. We will continue, committed to the mission and goals of the organization and remain focused on the prize....no more 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.**