



Focus on IBC

October 2009

IBC Research Foundation Newsletter

NBCC Corner

By, Kathleen Livingston, IbcRF Volunteer

As most of you are aware, I represent the Inflammatory Breast Cancer Research Foundation on the Board of the National Breast Cancer Coalition (NBCC.) One of the NBCC initiatives is: "Guaranteed Access to Quality Healthcare for All." Sound familiar? As you know, this is currently a "hot topic" in Washington DC that affects everyone, but especially those of us who have been touched by cancer. Following the September 2009 Board meeting, a number of NBCC Board members lobbied on Capitol Hill regarding this issue.

Since we are such a powerful grassroots organization, which has been lobbying on this issue for many years, I believe that Congress and the Senate do listen to us.

Any organization needs to raise funds and NBCC is no exception.

Lee Denim Day is really longer than just one day, and you can form a team and/or donate until the end of 2009. The 14th annual New York Gala will be held November 5th and will be an amazing evening of entertainment. Sheryl Crow will be there! If you can support any of these initiatives, thank you in advance. Please refer

IBC Research Foundation Awards Grant to Study Brain Metastasis of IBC

*By, Ginny Mason, RN, BSN
Executive Director, IbcRF*

Diane Palmieri, Ph.D, National Cancer Institute staff scientist in the Laboratory of Molecular Pharmacology, Women's Cancers Section, has been chosen to receive a grant from the Inflammatory Breast Cancer Research Foundation. The award, in support of her proposal "Development of Mouse Models of Inflammatory Breast Cancer Brain Metastasis," will seek to further the understanding of progression of this unique, aggressive form of breast cancer.



Inflammatory breast cancer, a less common and potentially deadly form of breast cancer, remains a poorly understood disease. While general breast cancer research has provided some insight, specialized study of inflammatory breast cancer and its aggressive metastatic nature is essential. Dr. Palmieri's proposal was selected from a pool of outstanding submissions receiving high marks for its relevance and translational potential.

Dr. Palmieri is a Co-PI on a Department of Defense Center of

to www.stopbreastcancer.org for more details.

NBCC offers many training opportunities across the country. For example, the next SPEAK OUT to end Breast Cancer is November 14 in Minneapolis, MN. There are additional training opportunities listed on the website, and I encourage you to check them out (www.stopbreastcancer.org) Trained and informed advocates are more effective advocates!

Update on 6th Annual IBC Bowling Event!

Last month we reported on the incredibly successful bowling event hosted by the Bigoski Family. The article reported a grand total of \$29,555 raised. Since then, additional donations have been received, bringing the total for the event to:

\$30,045!!!

Needless to say, the Bigoski Family, and all those who helped make this such an amazing event, are ecstatic to have topped their all-time high total.

A huge "THANK YOU" from all who will benefit from your generosity and hard work!

Upcoming Events

Oct. 20-23 - National Cancer Institute Advocacy Board Meeting; Bethesda, MD

[Click here.](#)

Excellence Award entitled, "Studies Directed toward the Eradication of Brain Metastasis of Breast Cancer." A comprehensive website has been developed to disseminate research results from this exciting project (www.brainmetsbc.org.) Advocates are an integral part of this Center of Excellence (COE) project and are responsible for developing the website, providing a resource for those seeking information on brain metastasis of breast cancer. Dr. Patricia Steeg, Head of the Women's Cancer Section and long time friend and supporter of the Inflammatory Breast Cancer Research Foundation, has assembled an amazing group of researchers and advocates to escalate the development and implementation of new treatments for patients dealing with brain metastasis from breast cancer.

In addition to her research, Dr. Palmieri is a faculty member of the National Breast Cancer Coalition Fund's Project LEAD advocate science training program. She gave an outstanding presentation, entitled "Understanding Cell Signaling," to Project LEAD graduates attending the San Antonio Breast Cancer Symposium in 2008. ([Click here](#) to view this presentation.)

Dr. Palmieri received her B.S. in Biotechnology from Rochester Institute of Technology and her Ph.D. from the University of North Carolina. She began her career in the Women's Cancer Section in 2002 as a research fellow, moving into the position of staff scientist in 2005. Dr. Palmieri has numerous peer-reviewed publications to her credit and has given poster and other presentations at a variety of cancer venues.

This grant award is made possible through a partnership of the Inflammatory Breast Cancer Research Foundation (www.ibcresearch.org) and the Milburn Foundation (www.milburngift.org.) The Inflammatory Breast Cancer Research Foundation, a non-profit incorporated in 1999, is dedicated to facilitating research and raising awareness of inflammatory breast cancer. The Milburn Foundation, a private charitable foundation, was created to support leaders who are making a difference in the fight against critical health care challenges.

[Click here](#) to visit Dr. Palmieri's web page at the National Cancer Institute, Center for Cancer Research.

Oct. 21 - Advanced Breast Cancer: Living Well Through Information & Support; Part 2, Patricia Steeg Ph.D., Research & You: Understanding Clinical Trials; Teleconference - 8:15 pm ET

[Click here.](#)

Oct. 23-25 - Project LEAD Workshop; Los Angeles, CA

[Click here.](#)

Nov. 3 - FDA Transparency Task Force; Washington, DC

[Click here.](#)

Nov. 4-8 - Quality Care Project LEAD; National Breast Cancer Coalition; Northern Virginia

[Click here.](#)

Nov. 5 - Advanced Breast Cancer: Living Well Through Information & Support, Part 3, Lillie D. Shockney, RN, BS, MAS, Living Fully: Making Treatment Decisions; Teleconference 7-8:15 pm ET

[Click here.](#)

Nov. 5 - National Breast Cancer Coalition Fund 14th Annual New York

Who Is The Milburn Foundation

By, Ginny Mason, RN, BSN

Executive Director, ibcRF

Just a year ago, October 14, 2008, an interesting message came through the Inflammatory Breast Cancer Research Foundation's website with a subject line of "IBC Donation." The message was from Bryon Davis, a Board member of the Milburn Foundation, a family charitable foundation from San Luis Obispo, California. In that message, Mr. Davis indicated his organization was interested in partnering with the Inflammatory Breast Cancer Research Foundation to fund research benefiting inflammatory breast cancer patients. I responded to the message and made arrangements to speak with Mr. Davis about this opportunity.

Since that first contact, we have had many telephone and cyberspace communications. We are delighted that the Milburn Foundation has chosen to support the work of the Inflammatory Breast Cancer Research Foundation. Thanks to this partnership, we were able to award a research grant to Diane Palmieri, Ph.D, of the National Cancer Institute (see "IBC Research Foundation Awards Grant to Study Brain Metastasis of IBC above) and will soon announce another grant award as well.

A few months ago, I asked Mr. Davis to provide background about the Milburn Foundation to share with our readers. Hopefully, these questions and responses will help you get to know this group and their important role in supporting inflammatory breast cancer research and other areas of health care.

How did the Milburn Foundation start? *The Milburn Foundation (milburngift.org) was created to support leaders who are making a difference in the fight against critical health care challenges, like Inflammatory Breast Cancer. We believe in the importance of supporting and developing leadership, not just donating funds. We seek to support those who consistently cut through the road blocks that stop others from achieving results.*

The genesis of the Milburn Foundation is through a family-

Gala

[Click here.](#)

Nov. 14 - The Future of Breast Cancer Care; Living Beyond Breast Cancer Annual Fall Conference; Philadelphia, PA

[Click here.](#)

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backed private foundation. This is the right structure for us to begin working on our goals. We are positioning ourselves on many levels (i.e. professional associations, people, processes, finances, etc), to be a catalyst for action over the long term. We are building a network of international partners and volunteers to give our team greater scale as we plan for growth over the next 5, 10 and 20+ years.

Why start a private foundation? *A private charitable foundation, as opposed to an operating charitable foundation, is essentially one that does not engage directly in charitable work. Rather, a private foundation supports those who are already committed to worthy causes. There are compelling advantages to this structure given our objectives.*

The private foundation model makes sense for us, because we want to focus on supporting and developing leadership in solving health care issues. We have a fundamental belief that by helping to develop multiple leading organizations, we can affect the greatest amount of benefit from our work. Very simply, if we can assist in advancing and aligning the goals of leaders across separate like-minded charitable organizations, the chances for creating high-impact progress improves dramatically. Our donations and gifts always have this end goal in mind.

What do you hope to accomplish with the organization? *Our first priority is Inflammatory Breast Cancer. Our family has been touched by this disease in a very personal way, and we want to empower impactful work that will move the research community significantly closer to a cure. We see a continued association with the IBC Research Foundation as an important part of meeting this objective.*

Longer term, we are creating an organization that bridges different charities/researchers to solve critical health care issues. Broadly speaking, our objective will be to identify and support both leaders within organizations and leading organizations themselves. We define leaders as those who have passion, vision, and an ability to drive results. We believe effective leadership can be employed by those with the will to make a difference and an ability to act thoughtfully, yet decisively. This is true on both the individual and organizational level.

Who makes up your organization? *Our Board of Directors is comprised of two MBAs, two RNs, and a former Human Resources Professional and Salvation Army Board Member.*

Our complementary management expertise includes: Military Service (Retired Colonel USAF), Management Consulting (Deloitte), Start Up Ventures, Pediatric and General Nursing, as well as Corporate HR.

Our volunteers include those in the following fields: Management Consulting and Operations, Medical (Doctor), Marketing, Teaching, Student and Financial Planning/Wealth Management. We are also building alliances or associations with a number of charities, both in the USA and internationally.

What future plans do you have for the organization?

As mentioned above, our plan is to build both a robust volunteer and partner network to support our goals and objectives into the future. We are organizing our foundation much as one might structure a business. Our board provides high level strategic direction, then our volunteer executives implement the strategy and work together across different functional areas (i.e. Finance, Medical Advisory, Marketing/Sales/Fund Raising, HR, Legal, Operations, IT, etc) to achieve results.

Our plan is to assign a volunteer executive to each functional area. We are looking for people that are passionate and committed to making a change in health care, both locally and globally. We are also looking for folks who are open to a virtual volunteer environment, since this is how we often operate. In exchange for our volunteer's time, we are offering people a chance to build their resumes with what we hope are exciting projects. Additionally, we are testing the concept of listing volunteer's names and a brief outline of what they do on our website. We think this is "fun" recognition for a job well done, but we also respect people's privacy if they don't care for this type of publicity.

With a growing team of professional volunteers, we hope to be able to give ever increasing contributions to the IBC Research Foundation. We see the IBC Research Foundation as a valuable partner in the fight against Inflammatory Breast Cancer.

For those who might be interested, more information is available on the MilburnGift.org website. Kindly note we are a different organization from the one listed at Milburnfoundation.com and Milburnfoundation.org.

Thanks to Mr. Davis for his thoughtful responses to my

questions and giving us an opportunity to learn more about their mission, vision, and goals. We look forward to a long and productive relationship with the Milburn Foundation.

As noted above, you can find more information about the Milburn Foundation at: MilburnGift.org

Oprah.com

Inflammatory Breast Cancer gains coverage on Oprah.com!

Visitors to Oprah.com will now find information about inflammatory breast cancer, thanks to a recently posted article by Lynn Okura, Associate Producer. When Ms. Okura contacted the Inflammatory Breast Cancer Research Foundation asking to speak with an oncology professional, she was immediately referred to Medical Advisory Board member, George W. Sledge, Jr., M.D. We are grateful to have Dr. Sledge, Professor of Medicine and Pathology, Ballve'-Lantero Professor of Oncology and CoChair of the Breast Cancer Program at Indiana University School of Medicine, available to provide accurate and thoughtful responses for the article.

Ginny Mason, the Inflammatory Breast Cancer Research Foundation's own Executive Director, shared the story of her diagnosis in an attempt to help readers understand the challenges in obtaining an accurate and timely diagnosis. This personal story, combined with a list of symptoms and comments by Dr. Sledge, will help introduce inflammatory breast cancer to a wide audience raising awareness.

Please take a moment to read the full story and share a comment at: Oprah.com