



## Focus on IBC

News and Updates from the IBC  
Research Foundation

November 2007

### **HAPPY THANKSGIVING**

The entire board of the IBC Research Foundation wishes you a very Happy Thanksgiving. We are so very thankful for all the wonderful people who have committed so much of their lives by volunteering their time on behalf of the Foundation; including the Email

Response Team: Gayla Little, Roberta Humphreys, Charlotte Bryant, Laney Cummings, Rita Kate VanOrsdal, Rich Smith, Bonnie Gray, and Ginny Mason.

We also appreciate all the work Becky Rosen does monitoring our discussion lists and work with our website.

We are so grateful for all you do.

*Owen Johnson  
President, ibcRF*



### **We Are So Thankful**

Saturday August 18th the Bigoski family of Eagleville, Pennsylvania, hosted the 4th Annual IBC Bowling Day. Started in 2004 by Tom Bigoski as a way to honor his mother, Julie; it has now become a yearly family event. With this year's \$27,307, the 4-year total monies raised is just over \$80,000. The event continues to grow each year and the Bigoskis look forward to Saturday, August 16, 2008 for the 5th Annual IBC Bowling Day.

For more information go to [www.ibcbowling.com](http://www.ibcbowling.com)

Each fall, more than 30 bikers join Steve Bermel (husband of Laurie Bermel of Elkton, Maryland) on their bikes to make the ten-mile ride to raise money and awareness for IBC and to help cancer patients and their families. The \$25 entry fee includes a barbeque and a t-shirt. Laurie and Steve recruit friends, colleagues, and family members to donate food, music and prizes. Various people donate items for the raffles and more than 200 people turn out for the celebration after the ride. This year's event raised almost \$6,000 for the IBC Research Foundation.

"Let us give thanks..."

How many of us say those words each year as we gather together family and friends to our tables? I wonder how many of us really take the time to reflect on the good things for which we are thankful each year.

In 2004, my chemotherapy ended in time for my surgery to occur in November. As it happened, my surgeon scheduled the mastectomy for the Monday before Thanksgiving. Scheduling surgery so close to the holiday was a bit frightening for us. So many "What ifs?"

Surgery was performed without incident, and by mid-afternoon on Tuesday I was released. On Thanksgiving Day, I put on my very best sweatpants outfit - the velour one - over the drains along with a button-down cotton shirt. My husband helped me with my socks and shoes, and together we tied up the turban on my head to cover what little peach fuzz had grown back. With a pillow tucked under the arm on my surgery side, and wedged in so the trip wouldn't jostle the drains, off we went. "Let us give thanks," my nieces and nephews began, "That Aunt Pam is able to be here with us today."

*Pam Haschke  
Volunteer, ibcRF*

[Quick Links for ibc Patients and Caregivers ...](#)

[Read Previous Newsletters  
Newsletter Archives](#)

[Learn the History of the ibcRF  
About Us](#)

[Learn more about the ibcRF  
BioBank  
IBC BioBank](#)

Laurie's 16-year old niece, Katie, was required to do a project for school and decided to have a soccer camp ("Kicks for Cancer") to benefit IBC. She had t-shirts printed, and she and her friends held a soccer camp for a few hours each day for a week. Congratulations to Katie and all her efforts. She raised almost \$400.00!

#### Reflections From Our Volunteers

I had the opportunity to attend The 9th Annual National African American Breast Cancer Conference sponsored by the Sisters' Network Sept 21-23 in Oak Brook, Illinois. The ibcRF staffed a booth in the exhibitors gallery to promote educational awareness of IBC for this group.

Each year close to 500 attendees come to the conference, and this year's event was justly represented. Most of the attendees are the chapter officers from each of the local affiliates around the country. Between conference agenda topics, these women congregate in the exhibitors gallery to get current information about breast cancer topics. In addition to the ibcRF, other exhibitors were the local affiliates of the American Cancer Society, Y-Me Illinois, Susan G. Komen, and Gilda's Club. In the spirit of helping these survivors to continue to feel good about themselves, other exhibitors were Warm Spirit (a consultant network that sells spa products) and Kingdom Klothes (an independent breast cancer entrepreneur who designs shirts for survivors and the people who care for them).

About 50% of the attendees were familiar with IBC, mostly through a chapter member who is a survivor, or because of the increased information from awareness campaigns and media across the country. All of the literature we displayed was taken, with many of the chapters asking how they could get more information to distribute to their membership, and could ibcRF potentially help them with speaking engagements and articles for their newsletters to continue to spread the word. Our exhibitor's table included bookmarks, brochures, BioBank brochures, and several copies of the "Women & Cancer" magazine (kindly donated) with the informational article about IBC. We offered fireballs, and they blazed off the table!!

For information about the Sisters' Network go to:  
[www.sistersnetworkinc.org](http://www.sistersnetworkinc.org)

*Pam Haschke  
Volunteer, ibcRF*

**A Message From Our Executive Director**

Donate to the ibcRF  
<http://www.ibcresearch.org/left-side/donations/>

**1-877-STOP-IBC**  
**1-877-786-7422**

[www.ibcresearch.org](http://www.ibcresearch.org)  
email: [info@ibcresearch.org](mailto:info@ibcresearch.org)

Things are moving along with the BioBank. Earlier this year we made some major changes in how we are handling our specimens and have been updating our paperwork.

Last fall ibcRF received a "Best Practices in Breast Cancer Advocacy Award" from the National Breast Cancer Coalition Fund in the amount of \$25,000. This money has allowed us to purchase a very sophisticated and high-tech computerized data base for storing the medical record information and tracking samples. It is an amazing system, and I am still learning all the "bells and whistles" as I work with the software.

With this new system in place, we can concentrate on getting tissue samples into the BioBank. Paraffin embedded tissues that are left over after diagnostic purposes are banked. These are from both biopsy and mastectomy. As with all items in the BioBank, they are coded with your unique identifier number and nothing leaves the BioBank with your name or other identifying information. We protect your confidentiality very carefully. Human tissue is essential for research and having tissue and its associated medical record is incredibly valuable to the research community. The BioBank is an amazing resource and gives patients an opportunity to be a part of cutting edge research without leaving the comforts of home!

It is important to enclose any pathology reports with the samples so that our contract pathologist knows what he/she is dealing with in terms of each block or slide. There will likely be multiple blocks from mastectomy and only a small amount of tissue from biopsy.

The tissue samples can be sent to: 321 High School Road NE, STE D3 #149, Bainbridge Island, WA 98110. The samples will be checked and verified before being sent to the pathologist and then banked. Samples can be sent USPS or any other carrier you prefer, just be sure there is some form of tracking used in case it doesn't arrive as planned. When you send something, please notify us ([biobank@ibcresearch.org](mailto:biobank@ibcresearch.org)) by email and provide the tracking number. We'll be watching for the package and let you know when it arrives.

We have a number of researchers anxiously awaiting tissue samples, so we are excited to get these samples into the BioBank. If there are additional medical records that have not already been collected, those can be sent along as well. We also need the completed medical questionnaire that was sent out last fall by email. It has come to my attention that we omitted an important question on that form. Please add 'date of birth' for our records. If you are enrolled and did not receive the questionnaire, please let us know and it will be sent again.

For those already enrolled in the BioBank, thank you for

your continued participation in this novel, patient driven research project. If you haven't yet enrolled or enrolled your loved one, contact us at [biobank@ibcresearch.org](mailto:biobank@ibcresearch.org) for more information.

**Together we are making a difference in the field of IBC Research.**

*Ginny Mason RN, BSN  
Executive Director, ibcRF*

[Forward email](#)

✉ [SafeUnsubscribe®](#)

This email was sent by [IBC Research Foundation](#)

Email Marketing by



IBC Research Foundation | 321 High School Road NE, Suite D3, #149 | Bainbridge Island | WA | 98110