



# Focus on IBC

October 2008

## IBC Research Foundation Newsletter

***Advocate  
Involvement in  
Research at M.D.  
Anderson***

*By Gayla Little  
ibcRF Volunteer*

Most readers of this newsletter will remember the celebration when the Komen Promise Grant was approved for the cooperative work of patient/advocates and researchers at M.D. Anderson Cancer Center. I am very excited to represent the Inflammatory Breast Cancer Research Foundation as a member of that team. The IBC Team includes IBC Researchers, Clinical (those who treat patients) Members, Patient Advocates, and External Advisors. They will meet a minimum of

### The Bigoski's Annual IBC Bowling Day

*By Ginny Mason RN, BSN*

*Executive Director, ibcRF*

In August 2003, Julie Bigoski was diagnosed with inflammatory breast cancer. Like most folks neither she, nor her husband Jack, had heard of inflammatory breast cancer. Being healthcare professionals, they wanted information and went searching the internet. Jack became the "resource person" and combed the internet looking for things that would help him be the best advocate and caregiver he could be for his "dear Julie." Those internet searches lead him to the Inflammatory Breast Cancer Research Foundation website ([www.ibcresearch.org](http://www.ibcresearch.org)) and a call to the organization asking to speak with a volunteer. When I returned that call, shared my story and answered questions, a special friendship began with the Bigoski family.

The next year was filled with the usual chemotherapy, surgery, and radiation treatments; and life went on as much like normal as possible. Julie was blessed with the support and encouragement of her husband, three adult children, as well as countless other family and friends. Jack joined the Inflammatory Breast Cancer Research Foundation e-mail discussion list and continued phone contact when questions arose, taking his role as caregiver and advocate for his wife seriously.

As Julie approached the first anniversary of her diagnosis, her oldest son Tom suggested the family do something to financially support the Inflammatory Breast Cancer

three times a year for a minimum of five years to discuss the pre-clinical studies, which are going on at MDA; and the potential for new agents to be tested in clinical trials as a result of the pre-clinical studies. We plan to discuss the ongoing clinical trials specific to inflammatory breast cancer and what is being learned from them. In addition, at our first meeting, which will be held December 5-7, 2008, during the First International IBC Conference in Houston; we will be putting together a vision statement and forming a strategic plan to identify the most pressing areas for research.

I am grateful to Fredika Robertson, Ph.D., for inviting me to be part of the IBC Team. Dr. Robertson is Director of the Department of Translational Research at the Morgan Welch Inflammatory Breast Cancer Research Program at M.D. Anderson. Good dialogue between IBC patients and researchers is vital to move the process of finding the cause, treatments, and cure for IBC forward. This grant makes that dialogue possible.

Research Foundation as a "thank you" for the support and encouragement they received since Julie's diagnosis. After some long and spirited family discussions, they settled on the idea of a bowl-a-thon. Steve, the youngest of the Bigoski siblings, designed a website and logo; while other family members and friends worked on sponsors and raffle items. Daughter Amy has even enlisted help from her husband's family in supporting the event. In spite of their lack of fundraising experience, things fell into place; and the first event in 2004 raised \$9,656 for the Inflammatory Breast Cancer Research Foundation.

Unlike many other fundraising events that require participants to solicit donations for participation, here teams of four or five bowlers pay \$25 each for three hours of bowling fun. In addition to the bowling, there is the raffle, quickly becoming a major attraction! Bowlers and others attending the event purchase raffle tickets (six for \$5) and carefully plan their strategy to secure their favorite items. A couple of specific, higher-priced raffle items go for \$5 per ticket; like a weekend vacation or special sports tickets. Family members contact local businesses for raffle items and are asked to sponsor the event. Prior to "IBC Bowling Day" the Bigoski's dining and living rooms are filled with sports memorabilia, specialty gift baskets, and awesome prizes; not to mention stacks of gift certificates/cards to local businesses. It is a sight to behold!

In 2006, I accepted the Bigoski's invitation to come and witness first hand the "IBC Bowling Day" phenomenon. By this time, they had the event working like a well-oiled machine. Everyone had their job, knew what to do, and did it. It was an impressive sight! At the close of the day's events, Tom handed me one of those oversize checks for \$27,306, which I accepted on behalf of the Inflammatory Breast Cancer Research Foundation. A photo of the exchange, showing our smiling faces, made the front page of the local paper the next day.

Again this year, 2008, I had the opportunity to join the Bigoski family for the special 5th Annual IBC Bowling Day. In the first four years they were able to raise \$80,328, a feat that still amazes everyone. However, the family set a goal to bring the five-year total over \$100,000. Things got off to a slower start than in previous years, and the family worried they



To read more about Gayla Little and the work she is doing for Inflammatory Breast Cancer, [click here](#).

**Press Release:**

WASHINGTON, D.C. - September 9, 2008 - [The Coalition for Genetic Fairness](#) today announced the launch of an interactive, online guide to the landmark Genetic Information Nondiscrimination Act (GINA). The resource, "[What Does GINA Mean? A Guide to the Genetic Information Nondiscrimination Act](#)", summarizes the protections of the first civil rights legislation passed in the new millennium and outlines its impact on the future of health in America.

**Upcoming Events**

**Oct. 18** Living Proof: The Story of Herceptin; Lifetime TV movie  
(Check your local listing for time)

**Oct 23-26** 10th

might not make their goal; but kept working none the less.

Words can't adequately describe the air of excitement and goodwill that permeated the bowling alley on August 16th. Long before the official start of the event, people were lining up to purchase raffle tickets. So many people were checking out the raffle items, it was hard to get close enough to put the tickets into the containers in front of each item. Reminders to "keep one half of your ticket" were frequently heard since that half had to be shown to win! I stood back in amazement watching from my post between the ticket sales and the chocolate cakes. Julie is known for the delicious chocolate cakes she makes to share with the participants as a thank-you. In spite of being back in treatment for a recurrence, Julie managed to provide her signature cakes as usual.

As this year's event came to a close and the proceeds were counted, Tom was able to present a check in the amount of \$28,712, bringing the five-year total to \$109,094!! Tom and I posed for a picture; and there were lots of hugs, smiles, and cheers as the totals were announced. In spite of some challenges and disappointments, the Bigoski family not only made their goal, they did one better! Way to go Bigoski family!!

Not only is IBC Bowling Day a fundraiser, it is also an awareness raising event with participants receiving information about inflammatory breast cancer. The parasol with Julie's ribbon proudly displayed has a prominent place on one of the tables not far from the cake. The Inflammatory Breast Cancer Research Foundation extends our most sincere gratitude to the Bigoski family for all they have done to further the mission and goals of the organization. Their contributions continue to support important projects and initiatives of the Inflammatory Breast Cancer Research Foundation. It is important to note that this event is planned and implemented solely by the Bigoski family. While the Inflammatory Breast Cancer Research Foundation is the beneficiary of the proceeds, it is in no way involved in planning or putting on the event. I have had the pleasure of attending the event and representing the Inflammatory Breast Cancer Research Foundation thanks to services donated by area businesses.

Annual Lynn Sage  
Breast Cancer  
Symposium, Chicago,  
IL [Click here.](#)

**Oct. 29** Part 2:  
Advanced Breast  
Cancer: Treatment and  
Quality-of-Life Update:  
Living Beyond Breast  
Cancer teleconference  
[Click here.](#)

**Oct. 29** National  
Cancer Institute  
Teleconference for  
advocates: NCI's  
Cancer Information  
Service: Reaching the  
Community with  
Evidence-Based  
Resources [Click here.](#)

**Nov. 1** News You Can  
Use: Breast Cancer  
Updates & Insights.  
Living Beyond Breast  
Cancer Annual Fall  
Conference [Click here.](#)

**Nov. 6-8** Life in  
Balance: Breast Cancer  
Survivorship Forum;  
Breast Cancer Network  
of Strength, Chicago,  
IL [Click here.](#)

**Nov. 7-9** National  
Cancer Institute  
Translational Science  
Meeting, Washington,  
DC [Click here.](#)

**Nov. 13-16** Clinical  
Trials Project I FAD.



For more details, plus great photos from this and previous year's events go to: [www.ibcbowling.com](http://www.ibcbowling.com). You will see the Bigoski family is already planning for 2009 with a countdown clock running! If you are in the general Philadelphia/Norristown area, plan on attending this awesome event!

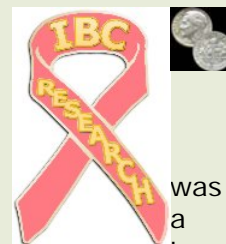
## A Story About Dimes

*By Jo Pabon, LaGrange, Illinois*

My mother, Harriet Cimock, grew up in Corning, a small farming town in southwest Iowa. She raised five kids and married to my dad for 58 years. She was farm wife, helpmate, and spent much of her time making rosaries and small blankets for hospitals and nursing homes. She loved to read and loved garage sales. She had a lifetime collection of butterflies; pictures, statues, butterflies in every shape and size. She was very active in her church; a small country church she and my dad attended for more than fifty years. She went on many fishing trips with my dad and became very good at cleaning fish! She was kind hearted, soft spoken, dependable, patient, humble, and good spirited.

My mom had a normal mammogram and physical in April 2007. As part of her physical, her doctor recommended she get a shingles vaccine. My dad had had a bad bout with shingles, so my mom got the shot. (The CDC now recommends it to all over the age of 60.) Shortly after the vaccine, she started getting a rash on her chest. The doctor diagnosed it as shingles - she was one who happened to get shingles from the shot, she was told.

My mom visited me in Illinois the end of June 2007. She showed me her "spots." I could tell that they were troubling her. She was not a complainer, and she seemed



National Breast Cancer Coalition  
Program, Dulles, VA  
[Click here.](#)

**Nov. 16** National Breast Cancer Coalition Board Meeting, Washington, DC

*Quick Links for IBC Patients and Caregivers*

[Previous Newsletters](#)

[ibcRF BioBank](#)

[Donate to ibcRF](#)

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

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

distracted by them. After her return home the spots were not getting any better. She had a biopsy, and it tested positive for Inflammatory Breast Cancer. Treatment for my mom began immediately; chemotherapy, with hopes of radiation and a mastectomy.

Back in Illinois with my family and still trying to accept the news, a strange occurrence started happening. I started finding dimes. Dimes - too many to ignore. Not quarters, nickels, or pennies ... but dimes. Dimes in unusual places - peeking out from under a baseboard, in the back of a dusty broom closet, washer, dryer, when making the bed, in the shower(?), in driveways - dimes and more dimes. It became almost comical. After about a month of finding too many to be a coincidence, I told my good friend, Vicki, about it. She started finding dimes too! We would joke about where we had found one, and somehow it would make it a good day.

In October I returned to Iowa to be with my mom. She was not doing well. No amount of chemo seemed to keep up with this rapidly spreading cancer. She kept her good spirits and attitude of "It will either get better or get worse." One day I went to chemo with her and after the session was over she stood up from the chair and under her was .... a dime.

I returned home and the dime finding continued - in an old forgotten coat pocket, a windowsill, taxi cab, store parking lots. My three kids and husband were finding dimes too. We were amassing quite a collection. Unfortunately, my mom's decline continued. She never did make it to the point of radiation or mastectomy. She fought the disease with gentle, but courageous suffering, faith and acceptance and passed away on December 18, 2007 - just five months after her diagnosis.

Her service at their country church was beautiful. She had planned everything in advance, from the music to her obituary. She loved butterflies and her memorial was filled with butterflies and beautiful picture boards of her life. After her service we were returning funeral flowers back to the house. I lifted up a big vase and underneath it was .... a dime.

I had another surprise at her house. My siblings and I were starting to sort through her things. (She loved those garage sales.) I opened a cabinet and was shocked at what I saw. A clear, plastic piggy bank right before my eyes. You could see every coin in the bank and there was one kind of coin in there - it was packed with only dimes! My brother mentioned that he had given my mom a bank

several years earlier and he went to the bedroom to find it. He returned and turned it over on the table top. We could not believe our eyes as the dimes started pouring out!

I returned home after the funeral trying to accept the suddenness of all of this. My mom was always so healthy. She exercised, did not drink or smoke, loved her fruits and vegetables, stayed out of the sun, and followed her doctor's orders - all the right things. Her mother and grandmother had lived well into their nineties. My mother was only 76 - still so much life ahead of her. My dad and mom had been married for 58 years and he was lost. He came for a visit and in sharing stories with him and my four siblings, they were starting to have dime stories of their own. It was comforting for us - made us all laugh and smile.

One day I was searching for breast cancer awareness items on the internet. I came across a picture of a pink breast cancer pin and next to it in the photo was a dime! The ad said the dime was in the picture to show the size of the pin. That was a light bulb moment for me. It was not right that we would save all our dimes and sit around and look at the pile.

We were to pass them on for a good cause and what better cause than breast cancer research and awareness. I knew the dimes would really multiply once we started passing them on.

We have a special jar in the kitchen, and my family knows right where to put their "found" dimes. As the jar fills, we will keep donating towards finding a cure. My nine-year old son even cashed in his \$25 savings, converted them to dimes, and added them to the jar. Our friends are saving their dimes too. Everyone can spare a dime, right?

I have two beautiful reminders of my mom - every time I see a butterfly and every time I find a dime. (Or should I say - a dime finds me?!) On my first Mother's Day without my mom, I found two dimes - one for me and one for her? On her birthday, May 30th, we counted our dimes and sent in a donation in her memory to the Inflammatory Breast Cancer Research Foundation. We are saving our dimes once again and know there will be more coming our way.

Thanks, Mom!