

Focus on IBC

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Editors' Notes

Let us know what you would like to read about in Focus on IBC. Send your thoughts to [the editor by email](#). We also accept your article submissions as appropriate.

"Focus on IBC" newsletters are [archived](#) on the IBCRF site. Feel free to point others to this link so that they can be updated with developments at the Foundation. If you would like to keep up with the IBCRF between issues of the newsletter, sign up for [IBCresearch](#).

The Two-Week Rule by Gayla Little

IBC is a disease that stays with us for life. Even when we have reached that wonderful NED (no evidence of disease) status, there is always the little voice in the back of our minds that asks, "What if it comes back?" Many of us continue to deal with it when it comes back. I call it the IBC Dance. It comes, it goes, and it comes.

Currently, after fighting stage 4

NBCCF Annual Advocacy Conference: April 29 - May 2



Submitted by Ginny Mason, BSN, RN
Executive Director IBC Research
Foundation

Hundreds of women and men from around the United States and the world will gather in Washington, D.C. for the National Breast Cancer Coalition Fund's (NBCCF) Annual Advocacy Training Conference from April 29 - May 2, 2006. "Beyond Ribbons to Revolution" is the theme of this year's conference, marking the coalition's 15th anniversary.

Attendees will participate in three days of plenary sessions and interactive workshops on cutting edge breast cancer research, quality health care efforts, and public policy developments. The breast cancer advocates will hear from more than 70 dynamic and influential speakers who are among the leading researchers and policy makers in the country. Some of the plenary speakers include:

- Leslie Bernstein, Ph.D., on exercise, nutrition and breast cancer; professor of preventive medicine, Keck School of Medicine, University of Southern California
- Mauro Ferrari, Ph.D., on nanotechnology research; Edgar Hendrickson professor of biomedical engineering, Ohio State University
- George Askew, M.D., on access to quality health care; senior fellow, Center For American Progress, Washington, D.C.

Workshop sessions instruct attendees on how to work effectively with the media, use the Internet to engage others and be as influential as possible wherever breast cancer decisions are being made.

Each year we try to arrange some sort of formal gathering of the IBC community within the downtime

disease, I am in a good place . . . "NED again" (sing it to the tune of "On the Road Again"). My oncologist has always been supportive. He tells me to report any unusual symptom. But what is unusual? His answer has saved me many an anxious moment and I share it with you for the same purpose.

He wants me to report anything that lasts longer than two weeks. Infected hair? Wait two weeks. If it's gone, there's no reason to worry. If it isn't, I'll show my oncologist. A cough that wasn't there last spring? Two weeks. If it's gone, it was probably an allergy. If not - - to the oncologist. Itchy skin? You know the rule by now, if you can't get rid of it in two weeks, to the oncologist with it.

None of us like being anxious and we have more than our share with IBC. I find that this two-week rule allows me to put off the anxiety for a fortnight. So far, I've only had to report one case of what turned out to be contact dermatitis. His response? He gave me a topical cream and told me to let him know if it wasn't gone in -- you guessed it, two weeks. If it was still there, we would biopsy it. It wasn't and we didn't.

I would like to challenge those of you who are NED to try the two-week rule. Included, of course, is the stipulation that you cannot worry about the symptom for that period of time. If you can't stop worrying, your instinct may be guiding you more than the two-week rule. It never hurts to call your doctor.

The other important piece of information to remember is that I am not a doctor and we are all different. The above is not intended to be used in place of medical advice. It is intended to be combined with common sense as a tool to decrease anxiety in our unusual situation. If I had a swollen lymph node on my collar bone, I would call my oncologist immediately. But for symptoms that could easily be caused by benign circumstances I have learned to wait

of the NBCCF conference schedule. If you are planning to attend this conference let us know so you'll be sure to hear about any plans being made.

For more information on the conference, visit www.stopbreastcancer.org Those who register before April 17th get the low \$100 member or \$140 non-member rate.

BioBank Update



Submitted by Ginny Mason BSN, RN
Executive Director
IBC Research Foundation

In March 1995, one year after my IBC diagnosis, I began searching for someone interested in studying my case. I knew that IBC was not common and that my survival should be of interest. But I could not find anyone studying IBC. Year after year, I kept searching, but to no avail. The longer I survived the more frustrated I became.

When the IBC Research Foundation was started and we began envisioning ways to facilitate research, we dreamed of storing tissue and medical records to encourage IBC research. Here we are 6 years later and that dream is reality and my case can now be studied!!

Currently 69 people have enrolled in the BioBank with two-thirds of them having submitted blood samples and cheek cells for DNA extraction. Nearly double that number of consent packets have been mailed out. We continue to hope that at least some of those folks will decide to enroll and send back the consent form.

If you are looking for a way to be a part of research without leaving your home area or being in a clinical trial, consider participating in the IBC Research Foundation BioBank!

To receive a consent packet and learn more about the project, send the following information to biobank@IBCresearch.org:

1. Full Name

two weeks.

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[Read more about the IBCRF on our website . . .](#)

Quick Links for IBC Patients and Caregivers ...

- [Read Previous Newsletters](#)
- [Learn the History of the IBCRF](#)
- [Learn more about the IBCRF BioBank](#)
- [Donate to the IBCRF](#)

2. Mailing Address
3. Preferred Telephone Number
4. Preferred Email Address
5. Indicate if you participated in the George Washington University IBC Registry with Dr. Paul Levine.

The [IBCRF BioBank](#) is a novel, patient-driven research project dedicated to furthering the knowledge base of IBC. All materials and specimens are handled with care, confidentiality and security. Identifying data is not shared with researchers.

[For basic information on the BioBank project . . . ?](#)

The Impact of IBC: From the Eyes of an Onlooker



Editor's Note: This will be an on-going series for Focus on IBC. How did the diagnosis of IBC of your loved one impact your life? Please write to [Jayne](#) and share your thoughts, feelings, ways of coping, or activism that were sparked by the diagnosis of IBC in someone you care

about. We will share them with our readers in a future issue.

What follows here is story about a patient named Vicki that is written by an onlooker, a lady who takes her friend Cathy, who has IBC, to chemo each week. Obviously, Vicki has had quite an impact on the lives of these two women as they tread the path of a breast cancer journey.

Vicki is forthright and tenacious. She decided to keep a pack of cards and she gives away one a week, till she has completed her Herceptin chemotherapy, as a way of marking this journey. She hands me the 10 of diamonds and writes her email on it, asking that I send her a copy of what I'd written. I am pleased that she has put another week behind. Happy news: she has only a few remaining cards. My friend Cathy has the same type of cancer as Vicki; IBC it is called, an insidious cancer that doesn't show up on a mammogram, is a fast-spreading, invading the tissue. Observing Vicki's recovery process weekly, her amazing attitude and wealth of experience, she gives us hope, hearing her survival story.

The conversation in the chemo room moves along "to reconstruct or not to reconstruct, that is the question?" Whether it is nobler to suffer the operations (painful), placement of expanders (painful), insertion of implants (more pain), to end up

with what Vicki described as "square looking breasts with no feeling", and in a wink, Vicki whoops out her prosthesis, and tosses it across the room. The environment is intimate, and genuine. The prosthesis is the real deal: soft, squishy with a slight nipple. She explains that there are removable pads that wick away moisture on the back. She lifts her shirt and inserts it into a pocket in her bra. We marvel. "You'd never know," we say in unison. Vicki encourages Cathy to look at all her options and extols the benefits of these removable breasts. Vicki is slight in stature, petite and energetic; she was never big busted, and so the transition for her seems to have been eased by that fact.

My friend, on the other hand, isn't quite there yet. She is still literally smarting from her recent mastectomy, and removal of a number of lymph nodes. There is pooling of lymphatic fluid above her rib cage. They discuss lymphedema, which is a threat to IBC sufferers. Vicki is affected by this condition, and I know Cathy fears this fate as well. Where Cathy once had ample breasts, she is now concave. Her surgery has left her with indentations, as a great deal of tissue was removed. She takes in all the info. Today the Benadryl is making her "loopy and sleepy," she tells us. There's a whole lot to process, physically, and emotionally. She drifts off. We are women of menopausal age. With this surgery, being thrown into menopause is yet another hurdle these women face. We talk of our sleep-deprived states; Cathy gets a prescription for the latest and greatest sleep aid. Vicki's chemo bags are empty, she says, "I want every drop." This brave woman now jumps up from her chair, and leaves us, to go to her volunteer job at a thrift store; volunteering, direct from chemo, helping others. She's already helped all of us in ways she may never know.

*Submitted with love and respect,
Loril Maxine Paluzzi*

[Read More Stories ?](#)

Raise the Awareness Level



Broadcast Coverage in SF!

On February 27th, the Dr. Dean Edell segment of the ABC-7 news in San Francisco carried a great story on IBC!

Special thanks to Linda Sherif, Bay area local, for speaking out about her experience to educate others about IBC. Her doctors also did a great job. You can [read the transcript](#) and you can also watch the video of the newscast by clicking on a link on the transcript page. Please also [contact the station](#) and thank them for running a story on IBC and encourage them to do a follow-up story as well!

Meet Us In DC!

Do you live in the Washington, DC, area or plan to be there for the National Breast Cancer Coalition Fund Advocacy Training Conference in April? An informal time of sharing and dining together is being planned for Saturday, April 29, at a restaurant within walking distance of the Renaissance Hotel (conference location). If you are interested in participating or would like more information, please contact [Ginny Mason by email](#). As time gets closer, those interested will be notified of the specific time and place for the activity (meal is "Dutch Treat"). This activity is planned as an opportunity for those within the IBC community to meet face to face, network, and share together. An update will be provided on the BioBank and consent packets will be available for those who would like to start the enrollment process.

28th Annual San Antonio Breast Cancer Symposium 2005

One of the premier events in the breast cancer world is the San Antonio Breast Cancer Symposium (SABCS) each December. Nearly 7,000 clinicians, scientists, advocates and exhibitors attended the event this year that included five plenary lectures, four mini-symposia, 48 oral presentations, nearly 700 posters, a satellite symposium and four award lectures. There are also numerous breakfast, lunch, and dinner programs and forums. Needless to say there is little free time!

"Tools for Today, Ideas for Tomorrow" was the theme of this collaborative effort of the Cancer Therapy and Research Center and the University of Texas Health Science Center at San Antonio, along with Houston's Baylor College of Medicine. Lectures covered treatment, genetic testing, proteomics, lifestyle issues, Her2 research and many more topics. Of particular interest was the Sunday morning presentation by Elizabeth Rafferty, MD, of Massachusetts General Hospital Breast Imaging Center. She discussed her work on the development of breast tomosynthesis, a three-dimensional mammographic technique in which a series of breast images is obtained from multiple angles; the images are then digitally assembled to "synthesize" thin slices of the breast. Initial studies have shown

tomosynthesis can reveal 16% more cancer than conventional mammography and reduce false positives by 85%. Dr. Rafferty anticipates that tomosynthesis will be available for widespread use within the next five years.

It was exciting to see new posters from a group of Belgian researchers who have shown great interest in IBC. Gert Van den Eynden shared thoughts on the role of NF-kappaB in IBC as well as lymphangiogenesis in IBC and non-inflammatory breast cancers. Dr. Sandra Swain presented results from the small IBC specific Avastin trial done in newly diagnosed patients where response in gene expression was analyzed. A poster by a French group characterized 109 IBC patients with 25 proteins using tissue microarrays, while a Turkish poster looked at the presence of p53 in patients with metastatic IBC. Dr. Paul Levine's poster focused on data collected in the IBC Registry for improving the case definition of IBC. While IBC was evident in the posters as a research subject it would be great to see more interest.

While SABCS is an amazing educational experience it is also a great place to network, meet other advocates, talk with researchers, and spread the word "You don't have to have a lump to have breast cancer", which we did with each interaction! To view posters, streaming-video web casts and other information from SABCS, go to www.sabcs.org.

[Be an IBC Advocate and Help Raise Awareness ?](#)

**Comments or questions: Email information@IBCresearch.org
web: <http://www.IBCresearch.org>**