



## Focus on IBC

News and Updates from the IBC Research Foundation

December 2007

### *Give Thanks, Give Back*

'Twas a holiday eve  
(which one? doesn't matter)  
And a feast had been readied,  
platter upon platter  
The candles were placed throughout  
every room  
To warm human hearts  
and scare away gloom



The children were antsy, unable to sleep  
Imagining gifts near the top of the heap  
And Ma in Vicky's Secret, and I in BVDs  
Had just cuddled up to watch Letterman on TV

When out of our widescreen there arose  
so much chatter,  
We were snapped from

### **NEWS FROM THE SAN ANTONIO BREAST CANCER SYMPOSIUM**

*December 13-16, 2007*

The San Antonio Breast Cancer Symposium, SABCS, was held on December 13-16, 2007. This was the 30th year for this annual symposium and was attended by more than 8,000 physicians, researchers, and patient advocates; with 83 countries represented! There were many presentations and posters of interest, but one especially of value to the IBC community was the one presented on Saturday morning at Plenary Lecture 4 by Dr. Robert Carlson representing the National Comprehensive Cancer Network, [www.nccn.org](http://www.nccn.org).

The NCCN Guidelines are updated annually. In the latest update for 2008 Breast Cancer Guidelines, there is now a specific Guideline for Inflammatory Breast Cancer. At the SABCS it was announced that the updated Breast Cancer Guidelines would be online at [www.nccn.org](http://www.nccn.org) this week including that for IBC.

On behalf of ibcRF, our executive director Ginny Mason, has been working with the National Comprehensive Cancer Network for past two years impressing upon them the importance of a specific IBC guideline. Having NCCN develop a treatment guideline for IBC helps establish that IBC is an individual disease, not just a subset of locally advanced breast cancer (LABC.) This change will have impact beyond just treatment (although that is important.) We learned that this distinction for IBC will have positive impact for new drug development. For too long, IBC has been over-looked in clinical trials and lumped with locally advanced breast cancer. The NCCN guidelines are also used in the education of medical students, so this new guideline will have an impact on the education of those coming out of medical school now.

Ginny Mason and Owen Johnson, President of ibcRF, were invited to a private NCCN luncheon on Friday, December 14th, where the first announcement was about the new IBC guideline. Dr. Carlson gave Ginny a "Thank You,

our comfort by quite  
weighty matters  
For there on the set  
was "The Year in  
Review"

Events worldwide and  
at home, both happy  
and blue

The Middle East grew  
far more fractious each  
day

And we worried about  
crime in a very big way  
There was hunger and  
homelessness and  
worrisome gas prices  
Peacekeeping  
problems and nuclear  
crises

But there was also  
good news and  
generous souls  
Warren Buffet gave  
billions and set high  
giving goals

Education's improving;  
our kids need to know  
That we're all here to  
help them surpass  
status quo

Then onto our screen  
there appeared a wise  
soul

Who said, "Don't be  
daunted; set one  
simple goal:

Sit down with your  
family, hone in on one  
need,  
Then pick a pet project  
and do a good deed."

As Oprah reminds us,  
help others in need  
Be thoughtful, be  
generous, eliminate  
greed  
Matching passions to  
giving provides

Ginny" for her persistence.

A big thank you to the Breast Cancer Committee for NCCN for listening to the pleas of the advocacy community!!

The slide show for NCCN presentation at SABCS on the new 2008 Breast Cancer Guidelines may be viewed at:

<http://tinyurl.com/yqyfjf>

Click on Presentations, Day 3, Plenary Lecture 4

### *Reflections from our Volunteers*

Back nearly ten years ago, I met Lee Smith via the internet site. Along with Marilyn Kirschenbaum, the three of us became fast friends. In fact, we decided to spend part of the 2000 Christmas holiday with each other.

Lee and Marilyn met me at the airport with flashing red noses and reindeer ears. This was going to be a great three days.

Among other things we did, Lee took us to see the hospice she had chosen. It was a lovely place but very hard to know that Lee was planning for her death even as she valiantly fought to live. As part of our gift exchange, Lee gave us a pin from her hospice.

Fast forward to Thanksgiving 2002. Lee was desperately ill and in the hospital in Ottawa. I put her hospice pin on my coat and went shopping with my sister, Claire. It was Black Friday and we traditionally spend the day at the outlet mall.

I kept feeling for my pin, afraid that I might lose it and wanting to feel a connection with Lee. As Claire and I were leaving the bookstore, our last shopping site of the day, I reached up and felt for my pin. In that instant I knew Lee had died. It was 6:10.

Lee died at 6:10 on November 28, 2002

It was an amazing gift. I felt like she'd come to kiss me goodbye. I am thankful forever and thankful for it.

*Rita Kate VanOrsdal*  
*Vice-President, ibcRF*



*Kathleen Livingston, Volunteer*

personal pleasure  
Find joy in contributing  
time, talent, and  
treasure

We sat all a-tingle at  
our holiday feast  
And we prayed for  
good health 'fore we  
carved the roast beast  
Then we said "Thanks  
is good, AND we want  
to give back"  
And we spent most of  
the day plotting our  
attack

We picked a good  
cause that had  
meaning for all  
We searched on the  
Web and we made a  
few calls  
We found just the thing  
and then outlined our  
scheme  
Some less fortunate  
than us would soon  
realize a dream

We spoke not a word,  
but went straight to our  
work  
We filled out our  
checks, and then threw  
in some perks  
And driving along  
toward our charity of  
choice,  
There was joy in our  
hearts, a time to  
rejoice!

The folks we helped  
out were excited that  
day  
Their lives were  
improved, in not a  
small way  
As for us, we  
exclaimed 'fore retiring  
that night,

### *Named to NBCC Board*

The National Breast Cancer Coalition Board met and voted on new Board members. ibcRF received a unanimous favorable vote and will "have a seat at the table" on the NBCC Board starting in Jan. 2008!

Kathleen Livingston will serve as the primary Board member, with Ginny Mason serving as the alternate. Both will attend the first Board meeting of the year, Jan. 27 & 28 in Washington DC. Congratulations Kathleen and thank you for your hard work on behalf of the ibcRF!

### *Update of ibcRF Brochures*

Since its beginnings in August 1999, the IBC Research Foundation has relied upon its tri-fold brochure to help educate the public about IBC. With the help of volunteers all over the globe the brochure has found its way into a variety of settings. Folks enclose them when paying bills, leave them along with a tip in a restaurant, put a stack in their local gym or beauty shop, fill the brochure rack in their doctor's office or mammogram center;...and the list could go on and on!

Periodically the IBC Research Foundation Board reviews the brochure and makes changes to update the information and to address common questions. A number of changes are evident in Version 6, which arrived from the printer earlier this month. One panel contains "Thoughts from the IBC Community". Here you'll find comments from patients, a caregiver and various medical professionals. The "Frequently Asked Questions" page has been updated with a few minor changes for clarification.

We decided to go back to a white background with black and red print, using some shades of red for contrast. As before, the front panel shows the ibcRF logo and the reminder "You don't have to have a lump to have breast cancer", boldly printed at the top of the panel.

Becky, our web-wizard, is working to put the new brochure onto the website in place of the previous version so it can be printed on your home computer. Quantities of the brochure can be ordered from the website or by contacting our literature volunteer, Rita Kate. ([information@ibcresearch.org](mailto:information@ibcresearch.org)). While we don't sell the brochures, we do suggest a donation of 15 cents per brochure be made to help cover the cost of shipping and printing.

Thanks to all the volunteers who have helped raise awareness of IBC by sharing brochures and bookmarks. People ARE reading and learning!

"'Twas the best holiday  
ever; giving back suits  
us right."

A modern rendition reminiscent  
of The Night Before Christmas  
that Mary "Dubbie" Buckler,  
Executive Director of Y-ME  
Indiana modified from a version  
she received from the Central  
Indiana Community Foundation.

*The Inflammatory  
Breast Cancer Research  
Foundation would like to  
thank all of you who join  
in supporting the  
mission to provide  
information and support  
to those facing  
inflammatory breast  
cancer so that no one  
has to face this alone.  
Happy Holidays to ALL,  
and to all - You are  
**star-bright!***

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](#)

Donate to the ibcRF  
[http://www.ibcresearch.org/left-  
side/donations/](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)

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