



Focus on IBC

News and Updates from the IBC
Research Foundation

October 2007

Changes at ibcRF

Rita Kate VanOrsdal has accepted the position of Vice President of the ibcRF Board of Directors.

In the summer of 1997, Rita Kate's friend was diagnosed with IBC. Immersed in helping her, she turned to the Internet and found Owen Johnson, who in his quest to answer questions about IBC, founded the ibcRF. Rita Kate joined the discussion list. In her earliest involvement with the ibcRF, she and two others (The original Tissue Queens) asked women who were facing mastectomies to consider donating their tissue to research.

Rita Kate is the In-School Suspension Coordinator in a rural North Georgia school system where she dodges deer and bear on the way to school every day. She is also an accomplished fiberartist and photographer.

We also welcomed Laurie Isenman, a new member, who took over the Treasurer and Secretary positions this past spring. Laurie's background includes over 15 years of medical office management. She now has her own transcription and medical billing company she runs out of her home on Bainbridge Island, where she lives with her husband and two children.

ASCO Annual Meeting 2007

The American Society of Clinical Oncology (ASCO) Annual Meeting is truly a unique experience. The size of the meeting is overwhelming with people from all over the world in attendance. With multiple sessions going on at the same time in various places in the convention center, we struggled to find our way around McCormick Center amid a sea of people. ASCO covers all types of cancer with an emphasis on the more common forms of cancer.



This was the third year that ibcRF had an exhibit in the Patient Advocacy Booth area. This area is set up by ASCO to allow organizations (like ours) to have a presence at the meeting without the high cost of an individual exhibit booth. We had a great location, near the entrance to the exhibit hall and next to the Young Survival Coalition. The exhibit is to be staffed during the hours the exhibit hall is open. We were blessed to have a number of volunteers help in the booth this year. Our thanks to Charlotte Bryant and Bonnie Gray from North Carolina, Pam Haschke from Illinois and Gayla Little from Indiana who took turns staffing the booth area. I also worked in the booth when not attending educational sessions. As people walked by our volunteers would ask them, "Are you familiar with inflammatory breast cancer?" or "Do you know about inflammatory breast cancer?" or something like that. We got quite a variety of answers and sometimes people would stop and take some of the brochures, bookmarks or fireballs we had on the counter.

Over the course of the week we met a lot of interesting people, made some great contacts, and didn't have a single fireball left to take back home! When we weren't covering the booth, we would stroll around the exhibit area with a handful of brochures and bookmarks to make sure we "spread the word"! Also, each of the volunteers had the opportunity to use the educational passes to attend sessions of interest to them. There were lots of sessions specific to breast cancer as well as thousands of posters on various aspects of breast cancer research.

At the close of the exhibit hall each day advocate attendees could participate in mentor sessions in the advocate lounge. This was a new

Laurie is excited to join our team and looks forward to learning more about ibcRF and the BioBank. She will also be taking over the duties of editor for our online Newsletter and welcomes any stories, articles, or pictures that anyone would like to be considered for inclusion in one of our upcoming newsletters. Laurie can be reached at Laurie@ibcresearch.org.

Our sincere gratitude for all the hours of work that Anne Abate has put into her job as Editor of our Newsletter. We could not accomplish our goals at ibcRF without the hard work and dedication of all our volunteers.

*Owen Johnson
President, ibcRF*

ibcRF Executive Director Named to FDA Post

Ginny Mason, Executive Director of the IBC Research Foundation, was recently named to the Oncology Drugs Advisory Committee of the Food and Drug Administration (FDA.) This is a four-year term as a voting member on the committee, serving as the consumer representative. After extensive interviews and a back-ground check, Ginny was chosen for this position from a group of qualified candidates. She was nominated by ibcRF.

"The Oncologic Drugs Advisory Committee (ODAC) advises the Commissioner or designee in discharging responsibilities as they relate to helping to ensure safe and effective drugs for human use and, as required, any other product for which the Food and Drug Administration has regulatory responsibility."
(from the CDER website)

Quick Links for ibc Patients and

addition this year thanks to the Research Advocacy Network (www.researchadvocacy.org). Three additional IBC'ers were attending ASCO as guests of the Research Advocacy Network's Genomic Training Program. Kathleen Livingston, Carol McWilliams and Krysti Hughett had already been through a lot of training in the program prior to ASCO and had specific sessions to attend and papers to write. While it was a lot of work, I think each of them felt it was an excellent program and would highly recommend it. Those of us representing ibcRF at the meeting enjoyed the opportunity to get together with other IBC'ers for some time to network and share, as well as a photo-op!!

Hopefully ibcRF will be invited back to participate in the Advocacy Booth section at ASCO again in 2008. The meeting will be returning to McCormick Place in Chicago so it will be a bit easier to find our way around! The ASCO Patient Advocacy Office is doing a great job of providing a link to the patient advocate community by offering the exhibit area booths, patient advocate lounge and new resources on their website.

To read about the 2007 ASCO Annual Meeting, search the abstracts and explore the virtual meeting site go to: www.asco.org, then follow the links on the home page for the Annual Meeting 2007. On the home page you will also see a link to ASCO's patient oriented website People Living With Cancer (www.plwc.org) Be sure to explore that site as well. There is a wealth of information there that has been prepared to meet the needs of the lay community. Much of the material presented at ASCO can be found there in an easy to understand format.

*Ginny Mason RN, BSN
Executive Director*

Reflections From Our Volunteers

One great opportunity we have, at ASCO, is to take turns going to the sessions the doctors attend. I was able to attend a session, which discussed the results of a clinical study examining the efficiency of lapatinib (Tykerb) crossing the blood/brain barrier. It was exciting to hear the report and see the scans of breast cancer patients' brains, which

showed shrinking brain mets when lapatinib was used. While the treatment is not 100% effective for everyone, it is wonderful to know that doctors now have something effective to offer us if brain mets develop.

The highlight of the week was a dinner given for advocates by Genentech. They take the opportunity each year to wine us and dine us and tell us about their program for getting chemo into the veins of those without insurance. This is the second year I have attended, and both years I have been impressed; because I think they have a realistic income limit of \$75,000 rather than the poverty level limit used in many programs. What I enjoyed most, though, was the breakout session afterwards. We split up into tables according to cancer types and heard about research that is being done by Genentech. The researchers who spoke to us were working on targeted therapies and eagerly answered our questions and listened to our concerns. We didn't want to stop talking to them when the time was up.

The primary reason we attend ASCO, of course, is to represent ibcRF. I believe it is especially important for us to do this now that we have the BioBank and Clinical Database. The researchers need to know that we have blood and tissue samples available if they submit an acceptable study to research IBC. We have a special BioBank brochure available with all the contact information.

We are required to have an advocate present at the booth from 9 a.m. to 5 p.m. on the days the area is open. We are very serious about complying with this requirement. There are only about 20 advocate organizations invited to participate with a booth at ASCO, and we have

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been allowed to participate the last three years. Last year, because of our faithfulness staffing the booth; we were awarded a grant, which paid for the hotel bills of the participants. Of course, that positive reinforcement spurs us on to work even harder to do a good job representing the Inflammatory Breast Cancer Research Foundation.

Working as a team to fight this horrible disease is fulfilling and exhausting. We all return home expecting to crash until the realities of life force us to get out of bed. We have a lot to learn and we have a lot to teach. It is vital that we participate in ASCO so that researchers will learn that IBC is a viable option for research, because the BioBank is available to provide them with the tumor samples they need in a timely manner. If you have not sent in your samples, I urge you to DO SO. The decision on whether or not to do research on IBC is often based on how hard it is to get tissue samples to study. We want to make it convenient for them to do research, and we need to have enough samples available to meet the researchers' needs.

Gayla Little
Board Member & Volunteer, ibcRF

I would sum up ASCO in one word: **HOPE**. I think the posters tell such a story of immense progress in the fight against cancer, and for all of us, against metastatic breast cancers. Yes, the researchers are trying to find cures, but in absence of finding cures; they are trying to give us all the ability to live with our cancers as chronic disease and still have quality of life. The studies from all over the world were amazing to see. Observing the individuals who were the professionals reading those studies, you felt as though we truly have Hope.

Pam Haschke
Volunteer, ibcRF

The experience was wonderful this year. Being the "veteran" while Bonnie was the "newbie" felt good. We were both eager to do everything we could to make The Foundation proud. I enjoyed getting out to the other booths and talking to the people who could not leave their areas. When I saw someone who was not busy, I would approach them with "Did you know you do not have to have a lump to have breast cancer?" That question was a surprise to more than half the people I spoke to. Since we were at an oncology conference, more people were aware of IBC than in the general public. However, I think the fact that they were talking to a six-year survivor surprised them. I truly believe the IBC booth is very important at these conferences, because there are still people who have never heard of IBC. Education is my prime goal. ASCO gave me the opportunity to speak to the uninformed, meet the researchers, such as Dr. Massimo Cristofanilli, talk to the reps from companies who are developing drugs that will help IBC patients, and talk to other patients to compare treatment regimens.

Charlotte Bryant
Volunteer, ibcRF

While attending ASCO, I attended sessions on research and breast cancer. The important thing to remember is that one positive study is only a beginning. It needs to be replicated, often more than once, and needs to have a larger sample size before the results can effect clinical practice. Here are bits and pieces that particularly struck home for me: There has been a decrease in breast cancer incidence in 2003 and 2004, possibly due to lower use of hormone replacement therapy; but this has not been confirmed. Note that the decrease was 14.7% in ER+ patients, but only 1.7% in ER- patients.

A gene expression profile can predict response to neoadjuvant therapy (but most IBCers have neoadjuvant therapy.) What was studied was the combination of capecitabine/docetaxel with/without Herceptin. There was a 20% response rate in basal type breast cancers (triple negative types), but virtually no response in luminal type (ER+ .) The best response was in ER-/Her2+ types, but that might be attributable to the Herceptin.

More study is needed.

For breast cancer liver mets, adding surgery (anatomical liver resection) to patients with a small number of chemotherapy stable liver mets appears to increase overall survival to 41% at five years and 22% at ten years. Disease free survival was 21% at five years and 14% at ten years. The best response were in those patients without other types of mets. This was a retrospective study, with 460 patients.

A study of Taxol + Herceptin vs. Taxol + Carboplatin + Herceptin showed no difference in time to progression or overall survival. The Taxol + Carboplatin + Herceptin had slightly more adverse events.

In a very heavily pretreated population of patients, ixabepilone and capecitabine vs. capecitabine alone progression free survival was significant, 1.6 months more. However, the survival data is not ready. One-fourth of patients were triple negatives (ER-, PR-, Her2), and there was a good response in triple negatives as well. Minimal detectable disease (disseminated tumor cells) in blood and bone marrow is being studied for prognostic value, for markers to monitor the effectiveness of therapy, and to understand the biology of metastatic development. Detectable micromets in bone marrow or blood are neither necessary nor sufficient for macromets to develop. Not all disseminated tumor cells are the same. There is a need to better characterize them. ER+ cells have a greater tendency towards tumor dormancy.

*Carol McWilliams
Volunteer, ibcRF*

(Carol was part of a program sponsored by Research Advocacy Network. She, along with Kathleen Livingston and Krysti Hughett were part of the same program that was under the Indiana University Breast Cancer Center of Excellence program. They studied genomics via teleconference and participated in a two-day on site program at IU in mid-May.)

ibcRF Represented at "Pink Ice" Event in Anchorage Alaska



The Anchorage Aces (Hockey Team) played on pink ice Thursday, October 11th. The Aces wore pink jerseys (their team color is blue) and auctioned off the jerseys after Thursday night's game; all part of the team's "Paint The Rink Pink" promotion, designed to focus attention on cancer awareness and raise as much as \$75,000.

Owen Johnson, President of ibcRF, was at the event in Anchorage and handed out almost 1000 brochures; spreading the word and educating fans about the Foundation as well as our BioBank.

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