



Focus on IBC

June 2008

IBC Research Foundation Newsletter

REMEMBERING A FRIEND

The Inflammatory Breast Cancer Research Foundation lost a dear friend this month. Elaine Julian, mother of Nancy Johnson past Board member, "passed peacefully into the presence of the Lord on Tuesday, June 3rd, in Kitsap Hospice Care Center. She was 91."

Elaine took delight in volunteering her time in a variety of ways to benefit the IBC Research Foundation. She especially enjoyed assisting with donation related correspondence and for some time did the 'thank-you' letters to donors. Elaine's warm, caring and encouraging attitude came across in all that she did.

Our warm thoughts and condolences go out to Nancy and all Elaine's

ASCO Annual Meeting 2008

May 30 through June 3, 2008, over 33,000 oncology physicians, nurses, researchers and others associated with the field met together in Chicago for the 44th Annual Meeting of the American Society of Clinical Oncology (ASCO.) McCormick Center was filled with people hurrying from one session to another clutching their program booklets, trying to find a given room. It was helpful that this was the second consecutive year for the meeting in the same location. This was the fourth year that the Inflammatory Breast Cancer Research Foundation was invited to exhibit in the ASCO Patient Advocacy Booth. The booth is divided into twenty sections, each filled by a different non-profit cancer advocacy organization. We had a great location this year, on one of the corners; so we had people coming past from two directions. The group "Cancer 101" was on one side of us and around the corner, on the other side of an opening, was the "Her 2 Support Group" booth. We knew many of the exhibitors from previous years and enjoyed catching up during slow times throughout the day. While many people attending this conference are familiar with inflammatory breast cancer, we learned that many were not; allowing us to share information. In fact, I think we had more interaction with the conference attendees this year than in previous years at the booth. I credit some of that attention to a wonderful poster, prepared by our webmaster Becky Rosen, with pictures depicting a variety of IBC breasts. You can be sure the poster got people's attention, and I think that encouraged people to stop and learn more.

The exhibit hall was an amazing array of large, elaborate pharmaceutical company displays, laboratory equipment sales booths, individual cancer center exhibits, and much

extended family during this time of loss yet celebration for a life well lived.

Upcoming Events

June 23-25 caBIG: Harnessing the Power of Connectivity, Washington, DC

[Click here.](#)

June 24 Survivors Too: Family Friends and Loved Ones, Telephone Education Workshop: Cancer Care. Register at 1-800-813-HOPE (4673)

June 25-28 Department of Defense (DOD) Breast Cancer Research Program (BCRP), Era of Hope; Baltimore, MD [Click here.](#)

June 28 National Breast Cancer Coalition Fund Board Meeting, Baltimore, MD

July 14-16 The Latest Advances in Breast Cancer Research; Hyogo, Japan

[Click here.](#)

July 20-23 AACR (American Association for

more. Each time I would decide to take a break and explore the various exhibits, I would take along a handful of brochures and give them to folks as I went up and down the aisles.

ASCO sessions cover a wide variety of oncology topics, not just breast cancer. This is the meeting where clinical trial results are often showcased and publicly announced for the first time. Of interest to the IBC community was the data from the "Tykerb as monotherapy in Her2-positive refractory inflammatory breast cancer" trial. Lead investigator, Bella Kauffman from Israel, reported data on the largest prospective trial ever conducted in Her-2 positive inflammatory breast cancer. This international group of 126 patients with Her2-positive refractory inflammatory breast cancer had an overall response rate of nearly 39% and 36% of Herceptin-refractory patients achieved a response to Tykerb (lapatinib) Overall progression-free survival was 14.6 weeks. This is exciting news for the IBC community. Previous trials had shown the value of Tykerb in combination with Xeloda (capecitabine) but this trial validated the efficacy of Tykerb monotherapy (Abstract #636.)

A number of abstracts were devoted to the use of Avastin (bevacizumab). Results of the AVADO trial were of particular interest (Abstract #1011.) Early data correlated with the preliminary results given last year on the E2100 trial. A dose-dense regimen including bevacizumab was presented by the Eastern Cooperative Oncology Group (ECOG) (Abstract #520.) These are just a sampling of trials using Avastin.

Biomarkers continue to be an area of interest, and the NOAH trial of neoadjuvant trastuzumab (Herceptin) in Her2 positive locally advanced breast cancer looked at potential predictors of pathologic complete response (pCR) (Abstract #504.)

Molecular changes in primary breast cancer versus the relapsed/metastatic lesion, looking at a large database and tissue microarray series was quite interesting. Data showed that the primary disease and metastatic disease may differ molecularly; raising the question, "Is a biopsy of metastatic disease necessary to properly treat recurrent disease?" (Abstract #1000.)

There were a couple abstracts dealing with Vitamin D deficiency and breast cancer. Vit D deficiency at diagnosis

Cancer Research)
Centennial Conference
Translational Cancer
Medicine 2008: Cancer
Clinical Trials and
Personalized Medicine,
Monterey, CA

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and its potential impact on distant recurrence received a lot of pre-conference media; and I found the session where this was presented interesting, but certainly not conclusive in its findings. Clearly Vit D is an area deserving more study and attention. (Abstract #511.)

A high profile topic this year was "triple negative breast cancer." An early morning educational session was devoted to the topic, followed by an in-depth look at the use of Platinum agents in the treatment of this unique subset of patients. Unfortunately, there were no 'practice changing' presentations in this area, but it is encouraging to note that more attention is being focused on the "triple negative" group.

These are just a few highlights from the educational sessions at the meeting. A conference of this size provides the opportunity to meet new people, connect with old friends, and expand the ever-growing network of the IBC Research Foundation. Special thanks to Gayla Little, Pam Haschke, and Bonnie Gray (all IBC survivors) who helped staff our booth. We worked together to answer questions, give accurate information and printed materials to those who stopped by our booth.

Go to www.asco.org and under "Highlights" click on the link to view abstracts of the meeting. You can search the abstracts by number, author, topic. The abstracts are available to anyone.

*Ginny Mason
Executive Director, iBCRF*

Reflections From Our Volunteers

This was my third year at ASCO and, as usual, it was a lot of work and a lot of fun. One thing that was different for me this year is that I had the opportunity to participate in a program through the Research Advocacy Network called Focus On Research. I was particularly pleased, because this

year's topic was Genomics with a section on BioBanking. We did a lot of study prior to ASCO and then while there, I went to many more sessions than I normally do. I learned more about how clinical trials are developed and what researchers do to make sure that they are clear about any conflicts of interest that they might have concerning the drugs that they study.

One session I went to was very exciting. They showed a picture of a mouse with a huge lump on its breast and a normal looking breast on the other side. The side with the lump had been injected with breast cancer cells and about 200 cells made up the lump. The side that looked normal had been injected with "Breast Cancer Initiating Cells." (Some called these "breast cancer stem cells.") That side had about 20,000 cancer cells; but, there was no lump! Sound familiar? I spoke to the researcher after his presentation and they are definitely going to study whether these cancer initiating cells are what make inflammatory breast cancer so aggressive.

Ginny Mason, Executive Director of the IBC Research Foundation, brought a poster displaying pictures of IBC breasts. It was certainly an attention getter. Not only did we have more doctors and researchers stop by to talk to us about IBC, there were some non-medical folk present who were concerned about their own IBC symptoms.

It was a great week with a great team. I need to thank Ginny Mason, Pam Haschke, and Bonnie Gray for the extra work they put in so that I could attend my required Focus on Research sessions. We all enjoyed being at the booth. I felt like we got a lot of good work done and "a good time was had by all."

Gayla Little
Volunteer, ibcRF

This year at the Patient Advocacy booth, we displayed a small poster that shows how Inflammatory Breast Cancer looks in the skin tissue, the inflammation, and the other outward symptoms. The poster sat on a counter that was about chest-high for most participants, and given our booth was in a high-traffic area, many people walked by. It was amazing to see the reactions on people's faces or in their body language. Some were visibly intrigued, and it created more discussion at the booth as they asked about the photos. Others were familiar with IBC and appreciated that we were demonstrating, quite graphically, its appearance. But there were a fair majority who would glance over at the photos and wince, grimace, turn away. This was ASCO - an internationally attended conference of oncologists! Not

lay people, these are doctors, medical professionals, nurses, researchers. In the four years since my diagnosis, we have come so far to raise awareness and get more information out about IBC. However, we still have a ways to go. Moral of the story? We all know the phrase - "A picture is worth a thousand words." We need to continue to educate and demonstrate what this disease is like for the women who are diagnosed with it. Others need to visibly see what we lived with, or are living with, as patients and survivors of this cancer.

*Pam Haschke
Volunteer, ibcRF*

It was great fun to watch the passersby, and fun to share our stories with all who would stop by our booth to chat. One European physician who practices breast surgery, oncology, and obstetrics (that's right -- he delivers babies too) explained that that he saw his patients through the entire breast cancer journey. He stated that European women would never tolerate going from physician to physician for care, because they would view it as fragmented and impersonal. We conversed about how specialized American medicine has become, and the pros and cons of the American way. He was very familiar with IBC and wished us the best in our quest for more research about this awful disease.

We were thrilled when earlier in 2008, the National Comprehensive Cancer Network (NCCN) published a guideline for the treatment of inflammatory breast cancer. I visited the NCCN booth and picked up a copy of their guidelines and quickly flipped through the pages to make sure inflammatory breast cancer held its rightful place -- and there it was! I also picked up a copy of Highlights of the NCCN 13th Annual Conference that was held in March 2008. Robert W. Carlson, M.D., of Stanford Comprehensive Cancer Center and Chair of the NCCN Breast Cancer Guidelines Panel, was quoted as saying "Clinically, this looks like cellulitis of the breast, and any cellulitis of the breast that occurs in a non gravid, non lactating woman should be assumed to be inflammatory breast cancer" until proven otherwise (p. 28.) My sentiments exactly!

It was such an honor to be among the greatest minds in the cancer world. The energy and enthusiasm for cancer research was amazing. Genomics and targeted therapies are the hot topics, and rightly so. It was a pleasure to meet Dr. Sanford Barsky, Chair of the Department of Pathology at Ohio State University, who developed the mouse model of



IBC, Mary-X; and who has devoted much of his career to studying inflammatory breast cancer. I was wearing the Foundation's pink breast cancer ribbon with the cluster of IBC cells in the middle of the loop when I met him. He recognized the cluster as a symbol of his work, and I thanked him for his dedication to our cause.

There seems to be growing interest in our BioBank as evidenced by several researchers and pharmaceutical company representatives who wanted to speak with Ginny, and numerous others who took our BioBank brochures. We even recruited some participants for the BioBank from visitors to our booth who were IBC survivors or had family members with IBC. I am more convinced than ever that our repository of tissue and DNA with the associated medical records will be instrumental for the breast cancer research community to increase knowledge about IBC. I am reminded that I need to complete my medical records for the BioBank now that I have finished my treatment, and I hope you will do likewise if you have not already done so. Research drives the future of health care, and research will provide the answers we need to better diagnosis and treatment of IBC. I am so thankful for the undying spirit and tireless dedication of Owen Johnson, Ginny Mason, and the entire IBC Research Foundation Board and volunteers who advocate for us every day. We have a voice at ASCO and beyond!

Bonnie Gray
Volunteer, ibcRF