



Focus on IBC

November 2008

IBC Research Foundation Newsletter

Reflections from our Volunteers

*By Pamela Haschke
ibcRF Volunteer*

I was honored to participate in this year's [Lynn Sage Breast Cancer Public Town Hall Meeting](#) this year, representing the IBC Research Foundation by staffing a table we had there. Each year the Comprehensive Cancer Center of Northwestern University hosts a breast cancer symposium for the medical profession. At the end of the conference, the public is invited in for a Sunday town hall meeting, led by a panel of doctors from the Cancer Center. This year's panel was Dr. William Gradishar, Director of Breast Medical Oncology; Dr. Kevin Bethke, Surgery; Nancy Davenport-Ennis, Founder and CEO Patient Advocate Foundation; Dr. Virginia Kaklamani, Cancer Genetics; Dr. Laura Millender, Radiation Oncology; and Dr. Judy Wolfman, Radiology.

The topic of discussion was "The Promises and Myths of

Clinical Trials Project LEAD

*By Gayla Little
ibcRF Volunteer*

I just returned from [Clinical Trials Project LEAD](#) in Leesburg, Virginia. It was amazing. Four days of intense study on the different designs of clinical trials - what makes a good trial, what makes a trial that tells you nothing?

The speakers were top experts in their fields. One of the world's foremost biostatisticians, Don Berry, spent several sessions patiently explaining statistical concepts such as "Confidence Interval," and "Hazard Ratio." He stepped us through the process of analyzing a clinical trial and told us why it is important that Patient Advocates, like ourselves, sit on Independent Review Boards that oversee clinical trials.

Dr. Susan Clare, of Indiana University School of Medicine, taught us the importance of Bio-Banking (a subject near to the heart of the Inflammatory Breast Cancer Research Foundation.) Dr. Steven Goodman explained the importance of ethics in research, and Dr. Janet Woodcock, the Director of the Center for Drug Evaluation and Research at the U.S. Food and Drug Administration (FDA), told us about their role and scope of authority in the drug approval process.

There were too many speakers to mention them all, Musa Mayer and Taddy Dickerson, M.D., come to mind, as well as others who are strongly involved in the patient advocate community.

The highlight of the week, for me, was watching the movie, [Living Proof](#), in a room filled with breast cancer survivors. Each of us knew what the ladies in the movie were feeling and having just learned about the clinical trial process, we knew that the steps of development were even more difficult than portrayed in the movie.

Breast Cancer Research." At this year's forum over 400 people were in attendance. I participated two years ago, and would say we were lucky to have half of that amount in attendance. A key difference this year is that the attendees (even the non-medical ones) were better educated about breast cancer, the differences in positive/negative/Her2 status, and what that means. Those who asked questions were deliberate and intelligent in their probes of the doctors on the panel. And, even better news, is that more people are familiar with Inflammatory Breast Cancer, although many found the photographs we displayed at the table disturbing to look at. Each person was grateful that we had pictures available demonstrating how this disease without a lump might look like. Because I was staffing the table, it was a bit challenging to take notes from the panel discussion; and from what I understand, transcripts or a podcast are not going to be made available (although I have advised the coordinator would be a good endeavor for them to undertake!) The following are just a few highlights I came away with.

Heredity: 12% lifetime risk of getting breast cancer. Primary relationship (Mother to daughter, as example), may be at greater risk of developing cancer; although they are still studying genetic correlations.

Regarding recurrence of breast cancer in the other breast that didn't have the primary cancer: Statistics show that the chances of getting BC in that non-BC breast are about 1/2% for each year that passes. So

The overriding message was the important role of patient advocates (and from our point of view, inflammatory breast cancer research advocates) in clinical trials.

It is the mission of the Inflammatory Breast Cancer Research Foundation to assist researchers in any way we can to find the cause of inflammatory breast cancer. The knowledge learned and the contacts made at CTPL will help us move forward as we work to find the cause.

UCSF Launches Nationwide Clinical Trial Matching Web Site for Breast Cancer

(Press Release) SAN FRANCISCO, CA, October 14, 2008 - The University of California, San Francisco (UCSF) Center of Excellence for Breast Cancer Care today launched BreastCancerTrials.org, a free, non-profit, clinical trial matching service that provides nationwide information for individuals diagnosed with or at risk for breast cancer. BreastCancerTrials.org is the only clinical trial matching service dedicated exclusively to breast cancer, with an online database that includes information about clinical trials taking place at more than 1100 medical facilities across the country. The site is an outgrowth of a successful regional pilot initiated by the UCSF [Carol Franc Buck Breast Care Center](http://CarolFrancBuckBreastCareCenter.org), the National Cancer Institute ([NCI](http://NCI.org)) and patient advocates. The nationwide launch of BreastCancerTrials.org is made possible by a grant from [The Safeway Foundation](http://TheSafewayFoundation.org), the philanthropic arm of Safeway, Inc.

"BreastCancerTrials.org is an exciting, win-win development for the breast cancer community," said Laura Esserman, M.D., Director of the UCSF Center of Excellence for Breast Cancer Care and the UCSF Carol Franc Buck Breast Care Center. "Every advance in our understanding and treatment of breast cancer has come from clinical trial results. The more we can empower our patients to find out about and participate in trials, the faster we will be able to complete trials, and the sooner this new knowledge will translate into better care and outcomes for all patients."

By making information about trials easy to find, BreastCancerTrials.org hopes to make consideration of clinical trial participation the norm rather than the exception. By helping patients find and evaluate trials for which they may be eligible, and by encouraging and facilitating patient enrollment in trials, BreastCancerTrials.org intends to increase the rate at which new treatments and procedures are made available to all breast cancer patients, as well as those at heightened risk for developing the disease. "I made the decision to enroll in a clinical trial, because I wanted to explore all of my treatment options," said

after 10 years, it is an 8% chance it may happen. If the patient tests positive for the BRCA gene, this percentage doubles to 1% year over year. So after 10 years, it would be a 16% chance. This came out of a discussion relative to voluntary removal of the non-cancerous breast to avoid recurrence. This panel stated that prophylactic removals have gone up 50% in the past several years, but that this is less to do with anxiety about recurrence, and more about plastic surgery. Younger women in particular want the breasts to look "even", and older women do not want one droopy and one perky. Also, the panel stated that survival is determined by the cancer you have, and NOT by whether or not you remove the other breast.

REALLY GOOD NEWS: For metastatic cancers (like ours) the incidences of recurrence is dropping significantly. Why? Because of the advanced monitoring of patients over a ten-year period. They are likely to catch a recurrence of cancer more quickly, and with the follow-up protocols of drug therapies, etc., they are able to keep the cancer away.

Lastly, there was a lot of talk about prevention. We all hear a lot about whether there are certain foods we should eat, drink less alcohol, etc. The panel advocates common sense practices to maintain general health and states there are two key elements to reducing breast cancer risk: control your weight and physical activity. Studies show that these two things are the most directly correlated to breast cancer risk and recurrence.

breast cancer survivor and BreastCancerTrials.org user Isabel Hemming of Los Angeles, California. "Through BreastCancerTrials.org, it was easy to find several trials that were seeking women with the type of breast cancer that I was diagnosed with, and -- after talking to my doctor -- I was able to identify one that I was eligible for. I hope that my participation in the trial may one day result in improved treatment for other women like me." BreastCancerTrials.org users enter a detailed health history, which matches them to trials that are specific to their personal health situation. Information on whom to contact for further discussion about a trial and additional criteria for enrollment is also provided. Individuals can use BreastCancerTrials.org on a one-time basis or store their health.

Social Security Administration: Compassionate Allowances

(Taken From The Social Security Website) Social Security has an obligation to provide benefits quickly to applicants whose medical conditions are so serious that their conditions obviously meet disability standards. [Compassionate allowances](#) are a way of quickly identifying diseases and other medical conditions that invariably qualify under the Listing of Impairments based on minimal objective medical information. Compassionate allowances will allow Social Security to quickly target the most obviously disabled individuals for allowances based on objective medical information that we can obtain quickly.

Commissioner Astrue has held two Compassionate Allowance public outreach hearings. The first was on rare diseases and the second was on cancers. A third hearing on brain injuries is planned for November 18, 2008.

The initial list of Compassionate Allowance conditions was developed as a result of information received at public outreach hearings, public comment on an Advance Notice of Proposed Rulemaking, comments received from the Social Security and Disability Determination Service communities, and the counsel of medical and scientific experts. Also, we considered which conditions are most likely to meet our current definition of disability.

A modest 50 conditions have been selected for the initiative's rollout. The list which follows may expand over time. NOTE: Inflammatory Breast Cancer is #24 on the alphabetical list of diseases.)

[Initial List of Compassionate Allowance Conditions](#)

[Additional information about how compassionate allowances are processed](#)

So ladies, get moving!

My thanks to the IBCRF for allowing me to represent the group at this wonderful event. For those of you in the greater Chicago area, if you have an opportunity to attend next year's town hall (it's usually at the end of October), I highly recommend it. The information both from the panel as well as those who have tables (Gilda's Club, American Cancer Society, many of the drug companies, Sisters Network, Susan B. Komen, Breast Cancer Network of Strength, etc), is quite good.

Upcoming Events

Dec. 3 Bridging the Gap: Communicating with Family and Friends; teleconference [Click here.](#)

Dec. 5-7 First Intl. Conference on IBC, University of Texas, M.D. Anderson Cancer Center, Houston [Click here.](#)

Dec. 10-14 CTCRC-AACR 31st Annual San Antonio Breast Cancer Symposium, San Antonio, TX [Click here.](#)

Feb. 3-6 Second AACR Conference on the Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved; Carefree A7 [Click here](#)

NCI Translational Science Meeting

*By Ginny Mason, RN, BSN
Executive Director, ibcRF*

The NCI (National Cancer Institute) [Translational Science Meeting](#) was held November 7-9, 2009 in Washington, DC. Forty-plus advocates were invited to join hundreds of scientists and participate in this ground-breaking conference "designed to accelerate early translational cancer research and to encourage collaboration and enhancement of knowledge across NCI-funded research programs."

The [TRWG](#) (Translational Research Working Group) was established in 2005 to discuss how the NCI could better facilitate translational research. Over a span of two years and numerous discussions with the broader cancer community, recommendations were presented by the committee. As part of Phase 3 of the plan, the TRWG put together six "developmental pathways" that "outline the processes through which fundamental scientific discoveries are transformed into clinical modalities."

Specific key activities and decision points on the diagram highlight essential elements along the research continuum. Similar in design to a "treatment tree" used to determine the best course of treatment for a cancer patient, these "developmental pathways" help researchers focus on the translational potential of a given project.

The conference webpage gives the following: "Format and Objective - This by-invitation-only meeting is designed to identify opportunities to accelerate the conversion of a basic science discovery to the point of early-stage clinical trials using a poster discussion format." Do you wonder just what that means? As the advocates gathered for an orientation session, prior to the start of the meeting, it was clear that everyone involved was a bit confused as to the purpose of our gathering together, in spite of a lengthy preparation teleconference! After some helpful presentations, the purpose of the meeting and the role of the advocates was more clear and we were ready to explore this new research paradigm.

I was assigned to co-chair the session "Biospecimens: Biomarkers for Breast Cancer." We had 37 posters in our session and just 2½ hours to view the posters, then discuss how the research presented might fit on the given TRWG pathway. In the first hour people mingled around the room viewing the variety of posters for the session and asked questions of the presenters. Two posters were used as models by the scientific co-chairs, leading the discussion of the pathway. The two scientific co-chairs did a great job of leading the discussion and helping those present to view research through this new model. Given the topic of this session, the importance and value of biospecimen banking was highlighted. In my closing statement I was able to share about the Inflammatory Breast Cancer Research Foundation BioBank and Clinical Data Base. It was a great opportunity to meet a variety of breast cancer researchers as well as some new advocates.

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All those who participated in the meeting, scientists and advocates, were invited to provide feedback on both the process and the pathways themselves. It will be up to the TRWG to review all the information and determine the next steps in this process. With research dollars dwindling, it is more important than ever to find ways to improve the process and move promising research from "bench to bedside" in a more timely fashion.

To learn more about advocate involvement in the National Cancer Institute and this meeting [click here.](#)