

IBC Research Foundation Newsletter

NBCCF

Annual Advocacy Training Conference

By, Kathleen Livingston

Volunteer, *ibcRF*

Those of you who were lucky enough to attend the annual National Breast Cancer Coalition Fund (NBCC/F) Annual Advocacy Training Conference in Washington DC, May 2-5, 2009 will concur that it was another successful and inspiring event.

On Saturday night, a small group of IBC survivors met and shared their experiences and knowledge of life with IBC over dinner. Since we are spread out over the USA it is the only time we can meet "face to face". As always, it is very comforting to meet with others who have experienced this disease. Since we are a small number of breast cancer survivors, with this type of breast cancer, we need to stick together!

The conference covered many thought provoking topics, too numerous to recount. One concept though, that I thought was worth



Testing . . .

More is Not Always Better

By, Ginny Mason
Executive Director, *ibcRF*



We have all heard the mantra "Early Detection Saves Lives" a message that appears to have been over simplified. While it is wise to follow your physician's advice for the typical cancer screening tests, it is important to understand that testing is not infallible; something those of us in the inflammatory breast cancer community know far too well.

A recent article in the May/June issue of the *Annals of Family Medicine* reports that patients who have 14 or more cancer screening tests have at least a 50% chance of a false-positive result, which can lead to unnecessary invasive procedures.

Jennifer Miller Crosswell, M.D., of the [National Institutes of Health](#) in Bethesda, Maryland, and colleagues analyzed data from the Prostate, Lung, Colorectal, and Ovarian (PLCO) Cancer Screening Trial of 68,436 participants randomized to screening or usual care. They found that the cumulative risk of at least one false-positive test was 60.4% for men and 48.8% for women after 14 tests.

"The cumulative risk of an individual obtaining a false-positive result in a multimodal screening program increases with number of screening tests; by the 4th screening test-which in the PLCO trial would mean the end of day 1- the risk is about 37% for men and 26% for women. By the 14th test, the risk is approximately 60% and 49% for men and women. The risk of undergoing any false-positive-prompted invasive diagnostic procedure is about 17% for men and 12% for women after 4 tests, 29% for men and 22% for women after 14 screening tests." The study was not designed to evaluate mammograms, the authors wrote. There is a 1 in 5 risk of a false positive on the mammogram after three tests, previous estimates have shown.

While this article deals with cancer screening tests for cancers other than breast, in a Bloomberg Review Article, Dr. Crosswell was quoted as

mentioning, was a statistic quoted by a representative from the American Cancer Society. He showed a graph illustrating how the U.S. spends the most per capita in the world by far, on health care but is only 29th in the world, regarding life expectancy. Obviously, we are not getting good value for our health care dollar, especially considering that more than 40 million people in the U.S. do not have health insurance and many are underinsured.

This leads me to explain the National Breast Cancer Coalition Fund (NBCC/F) legislative priorities for which we lobbied on Capitol Hill. NBCC/F has been lobbying for a number of years for "Guaranteed access to quality health care for all". Without healthcare, a breast cancer diagnosis becomes an even scarier prospect than it already is. Most of the congressmen's and senator's offices are working on this issue, as the President has mandated that legislation be ready for the mark-up process by June '09 and final signing in the third quarter of '09. Let's see what happens as it is in all of our interests to have cost effective, available healthcare.

The other legislative priority was the allocation of \$150 million for FY 2010 for the Department of Defense Breast Cancer Research Program (part of the Congressionally Directed Medical Research Program/CDMRP). As a result of this program groundbreaking scientific advances, such as the development of Herceptin, have come about. This, of course, is a very important

saying, "This should serve as a reminder to both medical practitioners and the public that, like everything else in medicine, there's no free ride." She went on to talk about our current practice of medicine relying more on test results than patient symptoms and conversation.

The American Society of Clinical Oncology (ASCO) has recommended minimal testing for asymptomatic cancer patients post-treatment. There have been recent discussions about the cumulative risk of repeated imaging, especially using radiation and/or contrast agents. It can be tempting for cancer patients to "want it all" with frequent scans, blood tests, biopsies, etc., but such intensive management is not without risk. Risk-benefit issues should be examined by patients with their physicians and make decisions accordingly. Once cancer has metastasized, more frequent testing may be necessary to monitor treatment effectiveness; but it is still wise to consider risks and determine if the test will provide important treatment knowledge that outweighs those risks.

Whether looking at cancer screening or post-treatment surveillance, less may actually be better.

To read the full text article: Cumulative Incidence of False-Positive Results in Repeated, Multimodal Cancer Screening; Jennifer Miller Crosswell, MD, et al. [Click Here](#)

Patient Error: A Preliminary Taxonomy; Stephen Beutow, PhD, et al. [Click Here](#)

Question of the Month

How to Choose Your BioBank

By, Gayla Little

Volunteer, ibcRF

Recently, on one of the support lists, a lady asked to which BioBank she should contribute her tissue. Here are some questions to ask and have answered before you make your decision.

1. Who owns the tissue when you donate it to a BioBank?

About two years ago, I received a phone call from a well known university asking me to donate my tissue to a newly formed BioBank. I refused. The reason I refused was because they wanted PERMANENT OWNERSHIP of my tissue. This is going to be the case with any BioBank; but some will have a tighter grip on your tissue than others. As a general rule, the larger the institution, the tighter the grip. A good question to ask is, "Is there a protocol for the tissue to be returned to me should I need it in the future?"

2. Is the BioBank overseen by an Institutional Review Board (IRB)?

drug in the breast cancer community and particularly for inflammatory breast cancer patients, as approximately 50% of IBC patients are Her 2/neu positive.

The IBC Research Foundation received one of the "Best Practices in Breast Cancer Advocacy Awards" in 2006 as well as a "Capacity Building Grant" in 2009. Ginny Mason, Executive Director, represented the Inflammatory Breast Cancer Research Foundation by sharing our BioBank and Clinical Data Base work through a poster during the poster session and reception.

Overall, breast cancer advocacy issues effect inflammatory breast cancer issues, so it is important that the Inflammatory Breast Cancer Research Foundation has a presence at the NBCC/F Annual Advocacy Training Conference. We were there and I would encourage you each to attend next year, May 22-25, 2010 in Washington DC, so that your voice and the Inflammatory Breast Cancer Research Foundation's can join with others working to eradicate breast cancer.

Upcoming Events

May 29 - FDA: Oncology Drugs Advisory Committee, Orlando, FL

[Click here.](#)

May 29-June 2 - ASCO Annual Meeting, Orlando, FL

[Click here.](#)

June 11 - Breaking News from the 2009 Annual Meeting ASCO; teleconference; 12 - 1 pm EDT

If not, run away and do not give them access to your tissue. IRB oversight is REQUIRED of all BioBanks operating in the United States. The IRB is paid to make sure the BioBank is doing what it is supposed to do. (The IBC Research Foundation BioBank just passed its first three-year review, and the only fault was one misspelled word!) IRB oversight lets people know the BioBank is legitimate and follows all the necessary rules and regulations for tissue banking.

3. How long will they keep your tissue and what will happen to it after the time is up?

Different states have different rules about this. For example, in my own state of Indiana, tissue is kept by the hospital pathology department for ten years (Legally, the pathologist owns the tissue.) At the ten-year mark, the patient is to be given thirty days notice before the tissue is destroyed. However, this is not universally true for all states. The IBC Research Foundation BioBank will keep your tissue samples, indefinitely, in facilities contracted to store them in environmental conditions designed to keep the tissue usable for study as long as possible.

4. Can any scientist have access to your tissue?

Some research centers will give no scientist access to your tissue unless they work for that center. I like the IBC Research Foundation BioBank, because any researcher who submits a proposal to the Inflammatory Breast Cancer Research Foundation goes through a rigorous review process by the [BioBank Medical Advisory Board](#). Once approved, and the researcher agrees to the written policies, access is granted to a small sample of the tissue; the result being that each BioBank participant's tissue samples are available for use by many researchers, each with different goals and "scientific aims."

5. Who will benefit from the research done using your tissue?

A big problem in the research community is that scientists tend to keep the results of their research secret until publication. Often, the results of clinical studies are NEVER published. The result is that they keep researching a broken wheel. This is common when the research did not turn out the way the scientist expected it to turn out. When the scientific hypothesis and/or "scientific aims" do not turn out to the benefit of the research, the "negative" results are not published or shared.

Any scientist seeking access to the IBC Research Foundation BioBank and Clinical Database must sign an agreement stating that they will share with IBC Research Foundation the results of their work -- positive or negative. It is our goal to move the study of IBC along as quickly as possible. If a scientist approaches us with a proposal that we know has already been studied, we can let them know; and they won't waste their time, money, and your tissue.

6. Does the facility that has possession of your tissue have a financial interest in the results of the research?

This question is strongly tied to the question above. If a facility (either a medical, academic, or pharmaceutical company) has a policy of non-disclosure, the researchers' hands are tied. If they are not allowed to

[Click here.](#)

June 23 - 7th Annual Survivorship Series: Family, Friends and Loved Ones - Managing the Fatigue of Caregiving; teleconference; 1:30 - 2:30 pm EDT [Click here.](#)

June 25 - Understanding NCI: Cancer as a Model for Research; 1:00 - 2:00 pm EDT [Click here.](#)

Quick Links for IBC Patients and Caregivers

[Previous Newsletters](#)

[ibcRF BioBank](#)

[Donate to ibcRF](#)

1-877-STOP-IBC
1-877-786-7422

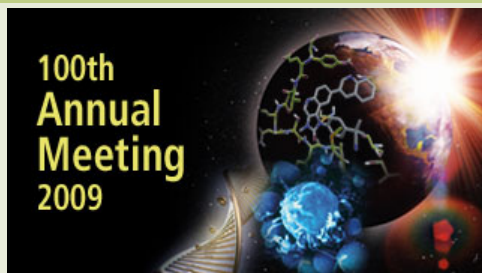
www.ibcresearch.org
email: info@ibcresearch.org

disclose the results of their research, because a potential treatment could mean huge financial gains or losses for the institution, they will not grant others access to the tissue or disclose the results of their research until they patent their research results. Many of the pharmaceutical companies now have huge biorepositories and are asking patients to donate tissue to them. Patients may have trouble getting tissue from large research hospitals, because the hospitals want it for their own projects. Read consent forms carefully when you are admitted to a hospital. Some hospitals embed in the consent that the hospital (not the patient) owns anything removed during surgery. It is extremely important to carefully read consents for clinical trials to know who will "own" any biopsy samples or imaging results.

Patient/advocacy owned BioBanks are vital, because patients are motivated by results rather than financial gain. We, as patients, do not care who finds the cause and resultant cure of IBC. We just want results. As stated above, researchers must agree to disclose the results of their research, whether it be positive or negative; so that scientists, as a group, can move forward as quickly as possible.

I hope this information will help you make your decision about where to store/donate your tissue. Donating your tissue is the most important step you can take in the quest to find the cause.

For more information go to: [ibcRF BioBank](#)



AACR Devotes Special Session to IBC

By, Ginny Mason

Executive Director, ibcRF

April 18-22, 2009 over 17,000 people from 89 countries came together in Denver for the Annual Meeting of the American Association for Cancer Research (AACR.) Denver greeted us with an unexpected spring snowstorm that left many stranded in airports en route and created lots of delays.

This year I had the opportunity to serve as an advocate mentor with the Scientist <-> Survivor Program through AACR. The Scientist <-> Survivor Program (SSP) brings together cancer advocates and scientists to bridge the gap that exists between the two. Through special educational sessions and impromptu discussions over meals, advocates have the chance to learn more about the science of cancer

and the scientists are introduced to an advocate perspective. It's a great program. As an advocate mentor, I was assigned to a group of 5-6 advocates along with two scientific mentors. I had the opportunity to work with two breast cancer advocates from Jordan and one from Sweden during the course of the meeting. There were a number of international advocates in the SSP giving us all a broader perspective.

This year's annual meeting included a special session dedicated to inflammatory breast cancer. Tuesday afternoon the "New Concepts in Organ Site Research" session was titled "Inflammatory Breast Cancer: A Global Perspective of Translation from the Laboratory to the Clinic." [Dr. Sofia D. Merajver](#) of the University of Michigan Comprehensive Cancer Center chaired the session.

Dr. Merajver opened the session with an overview of the current definition, clinical characteristics and translational challenges of inflammatory breast cancer. Unfortunately the medical community can't agree on a clinical presentation that constitutes inflammatory breast cancer. That continued ambiguity has caused problems for patients when seeking an appropriate diagnosis. The rapid onset of the disease is one of the few characteristics that most agree upon. It's unclear how we will come to a consensus on a clinical diagnosis.

Second, [Dr. Robert J. Schneider](#), from New York University School of Medicine, presented on the topic, "Regulation of translation in inflammatory breast cancer." Dr. Schneider's work has focused on inflammatory and locally advanced breast cancer. His work on translation initiation factors suggests that "eIF4GI (an initiation factor) in high levels might act to specifically increase proliferation (growth), prevent autophagy (cell destroying itself) and release tumor cells from control by nutrient sensing." This is research at a cellular level that once validated in cell lines, moves to animal models and then human study. Research of this nature seeks to find therapeutic targets that could be manipulated with pharmacologic compounds. Dr. Schneider has a new publication coming out soon that further explores these areas of study.

[Dr. Steven Van Laere](#) of the Translational Cancer Research Group in Antwerp, Belgium presented "Advances towards a molecular signature of IBC: How do we use what we know so far and how we can learn more?" This Belgian group has been studying inflammatory breast cancer for a number of years. They have access to fresh and paraffin inflammatory breast cancer tissues and have worked to identify a molecular signature specific to inflammatory breast cancer. This work and the work of others, has shown that inflammatory breast cancer has a higher incidence of Her 2/neu positivity and Estrogen receptor and Progesterone receptor negativity. Since not all inflammatory breast cancer fits this criteria it makes it more challenging to identify pharmacologic targets consistent in all patients. This research group has continued to find additional molecular targets that might prove to be amenable for treatment.

Inflammatory breast cancer is not confined to the United States and [Dr. Amr Soliman](#) of the University of Michigan presented "Global epidemiology of inflammatory breast cancer." Dr. Soliman compared the incidence of inflammatory breast cancer in a number of countries and pointed out the higher numbers of patients in northern Saharan countries. While it was thought that Tunisia had an abnormally high

incidence of inflammatory breast cancer, those cases have been categorized using the U.S. criteria for the disease; and the incidence numbers dropped by about half, still higher than the U.S. but not nearly as significant as thought. (This information was reported in [Seminars in Oncology](#), Feb. 2008.)

[Dr. Sanford Barsky](#) of The Ohio State University Medical Center presented his work "Expression of stem cell phenotype and stem cell signaling in inflammatory breast cancer." For quite some time Dr. Barsky has been actively studying inflammatory breast cancer and is known for developing MaryX, a mouse xenograft model to study inflammatory breast cancer. Dr. Barsky believes that there is a component of inflammatory breast cancer that behaves like a stem cell in that it can evade treatment and be involved in recurrence of the disease symptoms. Rather than the term "stem cell", Dr. Barsky often refers to these cells as progenitor cells for their tenacity and abilities. It is intriguing work.

To close the session, Dr. Merajver spoke on "The laboratory and the global clinic. IBC research as a model for science in the service of humankind." Recently Dr. Merajver has been involved in studying inflammatory breast cancer in Egypt and other areas of North Africa. She shared that this kind of global effort will be needed if we are to gain a better understanding of inflammatory breast cancer and find better ways to treat the disease. Dr. Merajver stressed the importance of researchers and clinicians around the world working together for a common cause for the greater good.

It was exciting to see the American Association for Cancer Research choose to devote an entire special interest session to inflammatory breast cancer. The session appeared to be well attended and a few of the speakers made reference to the important impact of advocates in their work and the increased awareness of inflammatory breast cancer.

To learn more about AACR and browse abstracts from the meeting, visit: www.aacr.org