



# Focus on IBC

August 2009

## IBC Research Foundation Newsletter

*Dr. Francis  
Collins named  
Director, NIH*

**(Press Release)**

Secretary Sebelius Announces Senate Confirmation of Dr. Francis Collins as Director of the National Institutes of Health. HHS Secretary Kathleen Sebelius announced today that the United States Senate unanimously confirmed Dr. Francis Collins as the next Director of the National Institutes of Health. "Dr. Collins is one of our generation's great scientific leaders. A physician and geneticist, Dr. Collins served as Director of the National Human Genome Research Institute, where he led the Human Genome Project to completion," said Secretary Sebelius. "Dr. Collins will be an outstanding leader. Today is an exciting day for NIH and for science in this country." To read more about Dr. Collins [click here](#).

### Reflections from our Volunteers

*By, Kathleen Livingston  
NBCC Board Member & ibcRF  
Volunteer*

I am sure you are aware healthcare reform is currently a HUGE topic affecting every one of us. In a previous newsletter I outlined that "Quality Healthcare for All" is the #1 initiative



### IBC Research Foundation Marks 10th Anniversary!

August, 2009, marks the 10th Anniversary of the Inflammatory Breast Cancer Research Foundation, started in August 1999 by Owen Johnson and a small group of individuals "committed to finding the cause" of this deadly disease.

Having lost his wife to inflammatory breast cancer, Owen was determined to raise awareness of this disease especially in the research community. A search of current medical literature showed that only a very few people were actively studying inflammatory breast cancer. When he came across the definitive article, "Inflammatory carcinoma of the breast: a report of twenty-eight cases from the breast clinic of the Memorial Hospital" by B.J. Lee and N. E. Tannenbaum (<http://www.ibcresearch.org/research/what-we-know/what-we-know-1924-1937/>) from 1924 he was appalled at how little progress had been made in the understanding of inflammatory breast cancer.

Realizing there was also a need for public awareness of inflammatory breast cancer (IBC) the fledgling organization chose a two-fold mission, research advocacy and awareness, working together to eradicate the disease. A website was created to help those searching for information, an e-mail discussion list to connect those in the IBC community, and a phone line to facilitate "one-on-one" guidance between callers and a volunteer. Eventually, the first educational brochure was developed and volunteers began passing them out in a variety of places. A mini-symposium in 2004 brought researchers and members of the patient community together to share ideas and explore research needs in Washington, DC.

A special thanks to all those who have served and continue to serve on the Board of Directors. It has been particularly hard to say goodbye to those members whose lives were cut short by IBC. It is important that the Board always contain patients/survivors of IBC to keep the work of the organization patient focused and understand the needs of the IBC community.

for the National Breast Cancer Coalition (NBCC.) The staff, Board of Directors, and members of NBCC have all been following healthcare reform and inputting to the various committees of Congress and the Senate our position that NBCC WANTS QUALITY, AFFORDABLE HEALTHCARE THIS YEAR.

As you know, "Quality Healthcare for All" is very important for inflammatory breast cancer patients.

Because the disease is very aggressive and less is known about this form of breast cancer than standard breast cancer, we use the healthcare system extensively. If an IBC patient does not have insurance or is underinsured, that is a HUGE problem that can be ultimately life threatening.

Our Congress and Senate are now on summer recess. This is the perfect time to contact your representatives and express your position on healthcare reform. The status quo is not working. To find your representative and understand the issues better [click here](#).

If you have been following this issue in the media, you probably know it is confusing. There is a lot of misinformation, and many citizens are very emotional about the issue. I suggest you go to [www.healthreform.gov](http://www.healthreform.gov) where you can read the

The IBC Research Foundation is a dynamic organization, growing and changing to meet the needs of those seeking information and those dealing with IBC. In recent years the website has gone through a complete overhaul. If you haven't visited the website recently, take time to explore the site at [www.ibcresearch.org](http://www.ibcresearch.org) and give us your feedback. There is a lot of information on the site, including many valuable links and patient stories.

There are now two e-mail discussion lists. One list focuses on education, information and support while the other is designed to connect those interested in raising awareness of IBC. There are quite a few folks who belong to both lists and enjoy connecting via cyberspace. In fact, there have been some face-to-face meetings develop as a result of discussion list contacts. It is encouraging to those newly diagnosed or in the midst of treatment to meet survivors. That hope is invaluable in this difficult journey.

The e-mail newsletter is another connection tool. The newsletter comes out about once-a-month and includes a variety of articles contributed by Board members as well as others in the IBC community. The newsletter typically contains a calendar of activities of interest to the IBC community, research information, and articles about the IBC Research Foundation's involvement in a wide variety of areas. If you know someone who would like to receive the e-newsletter, ask them to go to the website ([www.ibcresearch.org](http://www.ibcresearch.org)) and sign-up. Newsletter archives are available on the website.

A new venture this year was the development of a Facebook cause page. Many organizations are using social media to connect with a broader constituency. You can now find the IBC Research Foundation two places on Facebook. The cause page, which now has almost 2,500 members, can be found at: <http://apps.facebook.com/causes/224383/45694757?m=8267094b>. From the cause page there is a link to the non-profit page. If you are a Facebook user, be sure to check us out, join the cause and invite your friends to join!

The IBC Research Foundation continues to be a visible and involved member of the breast cancer and broader cancer community. Contacts made through the American Association for Cancer Research and the American Society of Clinical Oncology have lead to exciting research collaborations.

As a member organization of the National Breast Cancer Coalition and also serving on the Board of Directors, the IBC Research Foundation is an integral part of a grassroots effort to drive change that has positive impact on the breast cancer patient community. Thanks to a generous gift from the National Philanthropic Trust, the IBC Research Foundation has been the recipient of two grants from the National Breast Cancer Coalition. The first grant, in 2006, recognized the unique value and design of the BioBank and Clinical Data Base. Then again, in 2009, an additional capacity building grant was received. This second grant is designed to grow and develop the BioBank and Clinical Data Base further to provide an even more valuable

official position of the government including many facts about healthcare issues in your state. I have received e-mails from people, including congress representatives in which information is taken out of context creating scare tactics. Try and see the forest for the trees and remember, even if you have good insurance and you are not currently on treatment, the current system is costing us all too much! The American healthcare system costs much more per person than most western countries, and we also have a lower life expectancy than these countries.

Through American ingenuity, I believe healthcare reform will make healthcare more functional for all!

### Upcoming Events

#### August 15 -

6th Annual IBC Bowling Day; Norristown, PA  
[Click here.](#)

#### August 25 -

Hormonal Therapy Update: Understanding Your Options; teleconference; 12:00-1:30 pm EDT [Click here.](#)

**August 26 - Coping with Nausea and Vomiting from Chemotherapy;** teleconference. [Click here](#) to register online or call 1-800-813-HOPE.

research resource.

In 2008 the National Comprehensive Cancer Network developed its first treatment guideline for inflammatory breast cancer, thanks to involvement of the IBC Research Foundation on the breast cancer treatment guideline panel. The implementation of this guideline will help assure all patients will receive the appropriate standard of care no matter where they are treated. The guideline also helps establish inflammatory breast cancer as a distinct disease entity, not just a subset of locally advanced breast cancer. This distinction will aid in the development of therapeutics and clinical trials.

As the IBC Research Foundation marks this "first decade" anniversary, it is important to restate our commitment to facilitating research that will benefit the IBC community while also raising awareness of the disease in both the lay and medical communities. The IBC Research Foundation is comprised of volunteers that span the globe. Through this network of volunteers who do things like distribute brochures and bookmarks, speak to local groups, and share their story with the media, more people are aware of IBC.

Many, many thanks to the dedicated supporters who, through their generous donations, have allowed the IBC Research Foundation to be a driving force and voice in the breast cancer community. Each donation is deeply appreciated and is used to further the important mission and goals. While much has been accomplished, there is much more to do to improve the diagnosis, treatment, and survival of IBC. We remain "committed to finding the cause."

For now, join in the celebration.....HAPPY 10TH ANNIVERSARY, IBC RESEARCH FOUNDATION!!!!

## 2009 Accelerating Anticancer Agent Development and Validation Workshop

*By, Ginny Mason, RN, BSN*

*Executive Director, ibcRF*

June 17-19, I was honored to be one of nine patient advocates invited to serve as faculty for this interesting conference held in North Bethesda, Maryland.

The development and validation of anticancer agents is a long and expensive process. Patient safety and drug efficacy must be established before making a compound available to the public or there can be serious consequences. Unfortunately the various people involved in bringing a compound from bench to the bedside may not be trained in all aspects of the process, hampering timely approval. How to expedite this process while maintaining quality and safety remain a challenge in

The poster for the 2009 Accelerating Anticancer Agent Development and Validation Workshop features a blue and white color scheme. At the top, the title "Accelerating Anticancer Agent Development and Validation Workshop" is displayed in blue. Below the title, the year "2009" is prominently shown in large orange numerals. The dates "June 17-19, 2009" and the location "National Cancer Institute & Charles Center, North Bethesda, Maryland" are listed in white text on a dark red background. A small note indicates "Webinar application available at www.acceleratingworkshop.org". The bottom of the poster contains logos for the FDA, ACS (American Association for Cancer Research), Duke Comprehensive Cancer Center, National Cancer Institute, and ASCO (American Society of Clinical Oncology).

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cancer drug development.

Duke Comprehensive Cancer Center, one of the workshop sponsors, explains the purpose of the meeting in the following words. "The Accelerating Anticancer Agent Development and Validation Workshop, established in 2004, is designed to bring academia and industry leaders together to focus specifically on understanding and improving the process for cancer drug development. The goal of the workshop is to expedite the development and validation process for new cancer treatments so that treatments can be made available to patients sooner."

A special thanks to [H. Kim Lyerly, M.D.](#), Director of the Duke Comprehensive Cancer Center and Program Chair of the Workshop, for assuring that patient advocates have a strong and involved role in the meeting. Patient advocates served as session moderators, on various discussion panels, and as resource members of small groups reviewing the development and approval of specific anticancer agents. This year's advocates, recruited by Program Committee member [Musa Mayer](#), were chosen from a variety of cancer groups and actively represented the patient perspective in all aspects of the meeting, often asking the most challenging and thought provoking questions.

From the start participants were challenged to break out of their usual groups and meet new people over meals and other networking opportunities. As a result new contacts were made and potential working collaborations developed over the course of the meeting. I went prepared with brochures, bookmarks and business cards in an effort to educate about inflammatory breast cancer and make new contacts.

Participants in the program, referred to as "learners" in the printed materials, heard presentations on Phase I Trials, Pharmacology/Toxicology, Biomarkers, Clinical Trial Development, Peri and Post Marketing Studies, Statistical Design Challenges as well as many other topics. Reviewing the step by step process of drug development and approval was intense but very informative. I now have a much better understanding of the overall process and the monumental challenges involved in developing anticancer therapies. The recent advent of biologics and vaccines bring with them new issues that must be addressed as cancer treatment moves in new directions.

Serving as invited faculty for this workshop was a unique opportunity to interact with scientists, regulatory agency personnel, industry and other advocates to review and re-think the process of cancer drug development. It was a great learning experience and I appreciate the opportunity to represent the patient advocate voice.

Other sponsors of the three day workshop include the American Association for Cancer Research (AACR), American Society of Clinical Oncology (ASCO), National Cancer Institute (NCI) and National Institutes of Health (NIH) as well as the U.S. Food and Drug Administration (FDA). To learn more [click here.](#)