



# Focus on IBC

March 2009

## IBC Research Foundation Newsletter

### *IBCRF*

*Awarded \$15,000 Grant  
from NBCCF*

#### **(Press Release)**

Washington, D.C, March 12, 2009-The National Breast Cancer Coalition Fund (NBCCF) is pleased to announce the recipients of the 2009 Programmatic Capacity Building grants totaling \$190,000. Awardees were selected among invited membership organizations by a competitive process. These grants, which are generously made possible by the Breast Cancer Fund of National Philanthropic Trust, will be utilized by the 14 organizations to advance current Award-winning programs, or to aid in the development of previously nominated programs that have been identified as innovative, unique and able to bring about systematic change in the breast cancer advocacy community.

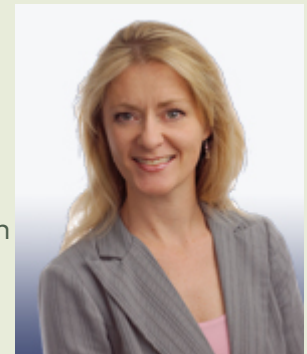
"We are excited to make this opportunity available to NBCCF member organizations that are doing difficult and important work to help in our mission to end

### Focus on Research

#### An Interview with Heather Cunliffe, Ph.D.

*By, Ginny Mason  
Executive Director, ibcRF*

Have you ever wondered what drives a scientist, why they are willing to spend day after day trying to understand a complex disease like inflammatory breast cancer? I posed this and other questions to Dr. Heather Cunliffe of The Translational Genomics Research Institute (TGen) during a recent telephone interview. Here is what I learned.



**What led you to a career in science?** "I was a math major studying at a university in New Zealand. When I was just six months from finishing, I walked into a wrong random hall one day to sit down to eat a sandwich. The lecture happened to be on recombinant DNA technology, and I was completely and utterly blown away by the lecture and the promise of genetic engineering to cure patients of horrible diseases." Dr. Cunliffe admits that she had become somewhat bored with math, so a switch to the study of DNA was a welcome one. Given the math and statistics involved in microarray technology, those years focusing on math were not wasted! The technology was captivating and led her to a Ph.D. from the Department of Biochemistry from the [University of Otago](#) in Dunedin, New Zealand. Before moving into the area of breast cancer, she spent one and one-half years studying kidney cancer. An opportunity to meet Dr. Jeff Trent a visiting scientist from the National Institutes of Health (NIH), led to an invitation to come to the U.S. and join the Cancer Genetics Branch at the National Human Genome Research Institute at the National Institutes of Health. Following her time at NIH, Dr. Cunliffe was recruited to join the Faculty at [Translational Genomics Research Institute](#) (TGen) in Phoenix where she serves as the head of the Breast and Ovarian Cancer Research Unit. TGen is a non-profit biomedical research institute founded in 2002.

breast cancer," said Frances M. Visco, president of NBCCF. "These grants will provide organizations with the capability to create or continue programs that will have a lasting impact on systems of research, access and/or public policy. All recipients are grassroots organizations that are managed by, and reflect the voices of, the people most affected by breast cancer."

The winning organizations receiving grants are: Alamo Breast Cancer Foundation (San Antonio, TX); The Annie Appleseed Project (Delray Beach, FL); Breast Cancer Alliance of Greater Cincinnati (Cincinnati, OH); Delaware Breast Cancer Coalition (Wilmington, DE); Family Services Center of Coffee County (Enterprise, AL); Georgia Breast Cancer Coalition Fund (Woodstock, GA); **Inflammatory Breast Cancer Research Foundation** (Bainbridge Island, WA); Linda Creed Breast Cancer Foundation (Philadelphia, PA); Nueva Vida (Washington, DC); Rhode Island Breast Cancer Coalition (Coventry, RI); SHARE (New York, NY); Virginia Breast Cancer Foundation (Richmond, VA); Wisconsin Breast Cancer Coalition (Whitefish Bay, WI); and the Women of Color Breast Cancer Survivors' Support Project (Inglewood, CA.)

### *Upcoming Events*

**March 31** - FDA Oncologic Drug Advisory Committee, Silver Spring, MD

[Click here.](#)

### **How did you become interested in inflammatory breast cancer (IBC)?**

"I've always had a passion for studying late stage, aggressive forms of breast cancer. I want to leverage technology to improve treatment for this group of patients who are so often neglected by the research community." In early 2006, three survivors from the local Phoenix IBC group arranged to meet with Dr. Cunliffe. "I was shocked when these women told me there was little research being done on IBC," said Dr. Cunliffe. As they talked and she heard their individual stories and concerns, Dr. Cunliffe was moved to ask how she could help. The Phoenix IBC group raised some "seed money" to begin an inflammatory breast cancer project in Dr. Cunliffe's lab. One of the Phoenix IBC survivors put Dr. Cunliffe in touch with us (Owen Johnson & Ginny Mason) and we began discussing how we might work together. A few months later Dr. Cunliffe submitted a research proposal outlining a plan to use the materials in the Inflammatory Breast Cancer Research Foundation BioBank and Clinical Data Base. That proposal was approved by the Medical Advisory Board and our collaboration began.

### **Tell us (in lay terms) more about your IBC project:**

"We're conducting whole genome profiling in an effort to capture a comprehensive molecular view of IBC... to identify unique characteristics that might be useful molecular therapeutic targets." Dr. Cunliffe is assisted in this work by Research Associate, [Catherine Mancini, B.S.](#) Preliminary work focused on IBC cell lines and has now moved on to using the IBC tissue samples from the Inflammatory Breast Cancer Research Foundation BioBank. Dr. Cunliffe's early findings in the first group of BioBank samples have been encouraging, and she is anxious to have additional samples available to continue and validate the work.

**What do you see as your "next steps?"** Dr. Cunliffe hopes "molecularly guided therapy....true personalized treatment....that allows each patient to receive treatment that is unique and specific to their cancer," will come from her work. The Molecular Profiling Institute, a part of the TGen group, is already heavily involved in clinical trials using this new treatment paradigm. Dr. Cunliffe is also exploring various drivers of breast cancer metastasis to better understand how it might be prevented. Typically localized disease can be controlled. Metastatic disease presents the biggest treatment challenge.

**What drives you....provides the passion for your work?** Dr. Cunliffe shared that her family has experienced first hand the pain, suffering, and loss that comes from both breast and ovarian cancer. "That's what prompted me to ultimately jump at the chance to head the Breast and Ovarian Cancer Research Unit and focus heavily on women who truly are running out of options." "We can do this," stated Dr. Cunliffe. "We have the technology now, we just need to translate the complicated laboratory information into the design of smart clinical trials and get these discoveries into the hands of clinicians to help save lives." "We need to treat based on measurable biology, and be really smart about patient recruitment into the right trial."

**April 3-5 - 10th**  
Anniversary Annual National African  
American Breast Cancer Conference  
and Day of Wellness, Houston, TX

[Click here.](#)

**April 18-19 - 3rd**  
Annual Conference for Women  
Living with Advanced Breast  
Cancer, Philadelphia, PA

[Click here.](#)

**April 18-22 -American Association**  
for Cancer Research (AACR) Annual  
Meeting, Denver, CO

[Click here.](#)

**April 21 - Triple-Negative Breast**  
Cancer: Treatment Update and  
Tools for Healthy Living.  
Teleconference

[Click here.](#)

**April 21 - NCI Community Cancer**  
Centers Program (NCCCP):  
Translating Scientific Advances into  
the Community. Teleconference

[Click here.](#)

Save The Date!

National Breast Cancer Coalition  
Fund  
Annual Advocacy Training  
Conference

May 2 - 5, 2009  
Omni Shoreham Hotel  
Washington DC

The National Breast Cancer Coalition  
Fund (NBCCF) works to ensure that  
advocates have a voice everywhere  
breast cancer decisions are made.  
Join your voice to ours in the fight  
to end breast cancer!

[www.stopbreastcancer.org](http://www.stopbreastcancer.org)

Register today!  
1-866-640-0969

We are grateful to have talented, motivated, caring scientists like Dr. Cunliffe focusing their efforts on the challenges of inflammatory breast cancer. The collaboration of Dr. Cunliffe and the Inflammatory Breast Cancer Research Foundation is already producing exciting results and more discoveries are anticipated.

## 9th Annual Conference for Young Women Affected by Breast Cancer

*By, Becky Rosen*

*Volunteer, ibcRF*

The IBC Research Foundation was honored to be an exhibitor at the 9th Annual Conference for Young Women Affected by Breast Cancer in Dallas, Texas, February 27 - March 1, 2009. This conference is presented by [Living Beyond Breast Cancer](#), [Susan B. Komen Breast Cancer Foundation](#), and the [Young Survival Coalition](#). The Young Women Affected by Breast Cancer Conference is the only international event focused on the unique needs and issues faced by young women who are diagnosed with breast cancer.

This was the second year that the IBC Research Foundation attended this conference for young women affected with breast cancer. I, Becky Rosen, and my dear friend and volunteer, Harriet Rathbun, were exhibitors for the IBC Research Foundation in Dallas this year and last year in Jacksonville, Florida. Next year the 10th Annual Conference will be held in Atlanta, Georgia.

This year's conference included many topics of concern for young women. Topics included fertility and pregnancy, adoption, single and dating, triple-negative breast cancer, advanced breast cancer, early stage breast cancer, managing side effects, chemo brain, careers and breast cancer, bone health, sex and intimacy, diet and nutrition, and reconstruction options to name a few. "Medical Update for Young Women" was presented by Eric Winer, M.D. from Boston's [Dana-Farber Cancer Institute](#). "Happiness in a Storm: Embracing Life Through and After Cancer" was presented by Wendy S. Harpham, M.D., FACP, doctor of internal medicine, best-selling author, long-term cancer survivor and mother of three who authored Happiness in a Storm.

Once again, we were happy to renew acquaintances with IBC survivors that we had met in Jacksonville last year. It was interesting to see some with hair again and doing so well. We also made some new friends with some courageous young women that were also IBC survivors. We educated everyone that stopped by our table about IBC. We distributed IBC brochures and IBC symptom bookmarks. These young women affected by IBC, as well as any breast cancer, know that they are now considered breast cancer

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

[www.ibcresearch.org](http://www.ibcresearch.org)  
email: [info@ibcresearch.org](mailto:info@ibcresearch.org)

"experts" and probable breast cancer resources for their friends and family with any breast symptoms. While some knew about IBC, because they already knew someone with IBC, too many were shocked to learn the symptoms of IBC. These young women thanked us over and over for providing them with information that they considered essential. We also met family members and caregivers that were angry that they did not know about IBC before their child, friend, or spouse was diagnosed. As this conference is international, we interacted with young women from all over the world including Kenya, South Africa, Australia, and Canada.



The IBC Research Foundation is committed to finding the cause and cure for IBC as well as awareness that there is a breast cancer that does not always include a lump. This Awareness of IBC and the symptoms of this most aggressive and deadly breast cancer is, for me, very rewarding and such a valuable resource that the IBC Research Foundation supports. It was three years after my IBC diagnosis before I met another IBC survivor in person. I met a young woman from the Dallas area that was diagnosed with IBC in January. She met me, an eight-year survivor, and also a 14-year survivor that was coincidentally exhibiting for NBCC next to our exhibit table. She was encouraged to learn that long-term survival is an option.

I look forward to representing the IBC Research Foundation again April 3rd - April 4th in Houston, Texas, at the [10th Anniversary Annual National African American Breast Cancer Conference](#). If you are in attendance, please stop by the IBC Research Foundation's exhibitor table. We are honored to be invited to this conference.