



SPECIAL EDITION--MINI SYMPOSIUM
REPORTS

News and Updates from the IBC Research Foundation

Focus on IBC

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IBC Advocates and Experts Meet in the Nation's Capital

On the afternoon of Friday, April 30th, we had a GREAT ibc Mini Symposium! We were able to put faces with many names on the discussion lists, and wish everyone could have been there. There were about 75 people there, including our speakers.

George Washington University (GW)

Greetings!

Welcome to this special issue of Focus on IBC! Late last month, friends of the ibcRF met in Washington DC at George Washington University to hear about the latest developments in the research that is partially funded by the Foundation. This event immediately proceeded the Annual Training Conference of the National Breast Cancer Coalition Fund (NBCCF).

We asked several participants to share their impressions of both the Mini Symposium and the NBCCF Training Conference with you in this special edition. There is a lot to read--but we think you will enjoy these first-hand accounts.

The next regular edition of Focus on IBC will be coming soon. Please send your contributions and thoughts to [the editor by email](#).

Focus on IBC is [archived](#) on the ibcRF site. Feel free to point others to this link so that they can be updated with developments at the Foundation. If you would like to keep up with the ibcRF between issues of the newsletter, sign up for the [ibcrlist](#).

Anne

hosted the Symposium, and the GW Cancer Institute co-sponsored the event with the IBC Research Foundation. The lecture hall they provided was perfect! We heard from Dr. Paul Levine, Principal Investigator of the IBC Registry, then from Dr. Bill Anderson of the National Cancer Institute (NCI). Following that, ibcRF provided cheese, crackers, fruit, tea, coffee, soft drinks, and water for a 15 minute break. Following the break, we heard from Dr. Sandra Swain, Principal Investigator of the IBC Clinical Trial and the NCI. Finally we heard from Dr. Laszlo Boros of UCLA.

The Foundation could not have accomplished what it has without the support and help from hundreds and thousands of people just like you! Thanks.

Dr. Petierno, the Executive Director of the GW Cancer Institute, told me at the close of the session that anytime we want to plan for the 2nd ibc Symposium, he's ready to co-sponsor it, and that was very welcome.

Thanks to everyone who helped to make this inaugural event a success.

Owen Johnson President IBC
Research Foundation

[Read more about the ibcRF on our website . . .](#)

Thanks To Our Speakers

The ibcRF would like to publically thank each of the presenters for the Mini Symposium in April. When the seeds for this event were planted, back in February, we didn't expect such a large 'plant' to grow! The idea began as a small group of patients and their families having the opportunity to hear from a few folks in the ibc medical/research community. By early April, the event had taken on a life of its own and the final tally for attendance was somewhere around 75 people!

It was wonderful to have such variety in the presentations, exploring the topic of ibc from four different perspectives. Each of the speakers brought their specific expertise and data, making for a well rounded program. As the speakers learned from the Q & A time, many ibc patients are well informed about their disease and ask challenging questions. The audience appreciated the opportunity to ask questions and hear first hand from the medical research community.

At the dinner following the symposium, we heard over and over again how much people enjoyed the Symposium and they were already asking when we would schedule an event again!

Thanks again, to our speakers, for sharing your time, expertise, and passion to find answers to the unending questions about ibc. Thanks also to the ibc community- - patients, family, and friends--for coming together to be part of the process to understand this disease better, to facilitate improved treatment, and ultimately put an end to ibc.

Sincerely, Ginny

Ginny Mason BSN, RN Executive Director Inflammatory
Breast Cancer Research Foundation

Quick Links for IBC Patients and Caregivers ...

- [The IBC Research Foundation Website](#)
- [Previous Newsletter](#)
- [History of the IBC Research Foundation](#)
- [Mission and Goals of the Foundation](#)
- [Order your own ibcRF Cookbook](#)
- [Consider making a donation](#)

Debbie McKinney Enjoyed the Event



Boy, was I tired! I got back from the ibc Symposium and NBCC conference on a Tuesday night at 9:30 pm. what a whirlwind trip it was!

On Friday afternoon, we went to George Washington University for the IBC Mini Symposium. There were four speakers who filled us in on the latest in research in ibc. There were differing opinions on whether ibc should be considered a rare disease, but all agreed that it is unusual.

We heard an historical perspective of ibc, how it is diagnosed, and the differing opinions of what constitutes a diagnosis! The last presenter was a basic scientist, Dr. Lazlo Boros from UCLA, who spoke of his work with ibc cells and how they differ in many ways from any other cancer cells. The conclusion was that more research needs to be done, in order to duplicate Dr. Boros' results, and with different ibc cell lines.

Saturday was the start of the National Breast Cancer Coalition's (NBCC) Annual Advocacy Training Conference. This was a two and a half day conference. There was a lot of energy. The NBCC focuses on evidence-based research and pursuing a very specific agenda for eradicating breast cancer through research.

This was not a ground-breaking year. No Dr. Larry Norton saying breast cancer would be eradicated in 10 years; no hot topics like the mammography debate; no new drug breakthroughs. All in all, it was a bit disappointing to realize that we have so much yet to learn and do before we can cure cancer. But, we had fun and learned all about NBCC's legislative priorities.

On Tuesday, we boarded buses to Capitol Hill where we broke into groups by state and visited our Representatives and Senators (mostly their healthcare legislative aides). We pushed for funding of the DOD breast cancer research program. We worked to get signatures on a bill that would study a link between breast cancer and the environment. All good stuff. I made some new friends, and got to spend time with some old ones.

This is one time of year when I actually feel like I am doing something in the fight against breast cancer. I feel that I am an important role model for my children, and will encourage them to take action as well. I encourage you to look into joining us next year. Start socking money away a little at a time, and next May you'll be ready.

A special thanks to Ginny and Owen for their steadfast devotion and efforts with the IBC Research Foundation. We are no longer a complete unknown. I believe the message is getting out there. Keep it up!

Richard Smith Joined the Group



In conjunction with the National Breast Cancer Coalition Conference held in early May, the IBC Research Foundation held a Mini Symposium, on April 30. I took the trip down from New Jersey to attend the IBC Symposium. I wanted to add a few personal comments about the event.

The general feeling I walked away from the meeting with is that this "orphan disease" of ours is not as orphaned as it appears. The medical community has been getting the message that it isn't "just another case of cancer."

We were addressed by three doctors / researchers on IBC. They went over past, current, and planned future projects. The presentations were detailed and very interesting. What impressed me on a personal level, however, were the presenters themselves. They did not seem to be following a casual academic interest in a "rare" disease. I sensed that they are personally dedicated to finding the cause, and cure, of this disease in the interest of those suffering from it now, and to help avoid future suffering. They are real people, caring for real people through research.

All successful organizations need a good organizer at the helm. This was my first contact with Owen Johnson, and I will tell you that IBCRF is in good hands. Owen is driven and dedicated.

At the close of the meeting, Ginny Mason asked for a moment of silence to remember those IBC Sisters who are no longer with us. It was one of the most touching moments I have experienced in the eight months I have spent without my wife, Doracina. To be there with so many of her IBC Sisters and, together with doctors dedicated to help us, I felt the presence of all the pathfinders watching over us, nodding in approval. Their faces passed in front of me: Donna . . . Lee . . . Menya . . . Marianne . . . all of them and, of course, my Doracina.

After the meeting, many of us had dinner together. There were over thirty of us and spending that evening with so many of my IBC sisters confirmed what I have known all along. I was honored to be with so many beautiful and courageous women.

Those are my personal impressions. Know that the fight continues: in test tubes, labs, clinical trials, and data banks as well as in your own personal battlefield. We will beat this thing!! As always, you are in my thoughts and prayers.

Linda Rush Tells Her Story About the Symposium



The NBCCF and the IBC Mini Symposium could not have come for me (as a teacher with two publication deadlines the day after I got home!) at a worse time, but the IBC Mini Symposium made it all worth the effort!!! It was fabulous!

At the NBCC Conference, I heard four presenters talk about bio-banks, each of the two founders of a specific bio-bank and two lawyers. The main presenters were Sharon Terry, who had been a chaplain at a university, and her husband, Patrick Terry, who had been an engineer and project manager of major building projects. Separately they told of their experience that propelled them into action to establish bio-banks in various places in the world (including the U.S., South Africa, and Europe) with 57 support offices worldwide. Within the first year and a half they had 2700 individuals in their own disease registry.

Why did they do this? And what does this have to do with the ibcRF? In December of 1994, they were told their two small children (now 16 & 14) had a rare, serious genetic condition called PXE (pseudoxanthoma elasticum). They didn't know anything about this disease, and they certainly didn't know anyone else who suffered with it.

Sound familiar so far?

Out of love for their children and a desire to get to the bottom of this disease, they began to meet with scientists who had written papers on the disease. They also got in touch with other patients who had the disease and their families. They decided that in order to facilitate the work of the scientists and researchers, they would gather the precious commodity of DNA samples, without which there could not be effective research. In one year and a half, as I said, they had 2700 individuals in their registry. They put their heads together with the researchers to determine what type of research needed to be made and exactly what steps should be taken to reach the goals they had set to combat this "new" and awful disease. Although PXE was new to them, it wasn't new to medicine.

Sound familiar again? In short, they became their own best advocates to finding the cause, leading to treatment, of this disease.

The ibc Research Foundation is excited about this effective example of "scientist/researcher"- "lay people/advocate" teamwork. Neither party without the other could have found, at least in the time span it took them, an effective means of gathering large numbers of DNA and doing research to "unlock" this disease. This task not only required great communication between these two groups, but it also required the willingness of strangers with the disease to pool their genetic information. The result is that they found the gene that caused the disease. They have even patented that gene.

Now what are they going to do with the efficient machinery they have created? They formed a non- profit group named the Genetic Alliance BioBank , a membership organization with non-profit disease advocacy groups eligible to be members. The ibc Research Foundation is one of the first members and will soon be starting the ibc Research Foundation BioBank and Clinical Data Base to collect tissue samples from ibc patients and store them in our own BioBank. We hope the research that will follow will mean great progress made toward understanding the molecular makeup and

behavior of the inflammatory breast cancer cell. Once that is accomplished, then finding a cure can be tackled, but it must be done in sequential order.

Sound far-fetched? It's already been done by this family, and they have made a huge difference in the lives of individuals around the world. If we want to follow their example, why should we reinvent the wheel? They've already got the entire vehicle!! But we have to provide the gas that will make it run ... the tissue needed to unlock OUR disease. There are many small, grassroots organizations like ours who have already joined on and who are in the process of joining on to find the keys to unlock their own riddles. I also think that in the not-too-distant future, BioBanks could become morassed in legal and ethical red tape. That's why I'm excited to know that we could possibly fly in under the radar now and get our project underway. So, I learned that bio-banks take care of one component needed ... the storage facility, as it were. We also have to have a team to be in charge of contacting individuals and gathering their samples. That's where the ibc Research Foundation and each of us come in. We can contact others, and we can all gladly give them that which will no longer do us any good ... ibc cells from real live people. What about the other component needed? The researchers and scientists?

It was thrilling to hear from the researchers who are doing work with ibc. We heard a report from Dr. Paul Levine. Dr. Levine, with the help of the ibc Research Foundation, started the IBC registry with tissue samples from nearly 150 women.

Dr. Levine told about the eight different categories they divided the disease samples into, some with pathological only symptoms, others with clinical only symptoms, and some with both. He talked about the Tunisian study that he had previously done and we heard reports about his findings in that work.

We heard from Dr. Sandra Swain, who gave reports on her work with ibc patients and showed graphs about survival rates and the different factors that seemed to affect them.

Dr. William Anderson from the National Cancer Institute reported on SEER data and presented charts regarding survival rates, ethnicity of ibc patients, ages, and er+ v. er- curves. He seemed intrigued by the ibc curves for different data as compared to regular breast cancer.

Most exciting to me, we heard from Dr. Laszlo Boros from

UCLA who has been working on the metabolic profile of ibc in order to facilitate diagnosis and treatment some day. It was exciting to hear his findings and hear the words that the ibc cancer cell seems to be different from all other tumor cells. With his mass spectrometer and radioisotope glucose media, he found that the ibc cell releases or produces two molecules that are not supposed to be present. He also found spikings with these two molecules and only small amounts of glucose which is normally present in the media. In summary, he said that ibc cells produce something that the body cannot even use and which he's not found in any other cell or tumor cell ... which spells big metabolic trouble for the host of these cells. To do further study, however, he needs more cell lines, more tissue samples, more genetic material.

Why did I get off into all these other areas when talking about bio banks? Because, of course, the other component needed to duplicate what the Terry Family did to isolate and patent the PXE gene from DNA is the research arm of this team effort. From what I saw at George Washington University as I heard these researchers present their data is that we who make up the ibc Research Foundation are a group of people who can bring all the necessary components together to accelerate the study of Inflammatory Breast Cancer.

Who better? Owen Johnson, President, and Ginny Mason, Executive Director, were truly professional in their presentation of these speakers and in the very coordination of this Mini Symposium with the George Washington University Medical School.

I think it is only a matter of time until all of these components, including you and I, come together to help the ibcRF reach their stated goal of Finding the Cause of IBC. Others may talk about racing for the cure ... but we have to find the cause of our disease before we can race toward any cure!

I wish I better understood all that I heard during the 4 days spent in Washington, DC, but I'm not a scientist. Even so, I know that in the hearts of these scientists there is a desire to unlock the ibc mystery. They can have all my tissue they want for biobanking and researching!! The ibc cell sure never did me any favors!

How about you? Are you going to hang on to your ibc tissue or would you consider donating it to the IBCRF BioBank for research? Details are expected to follow in the next couple of months.

The IBC RF is committed to finding the cause. Together we can.

[Find out more about ibcRF activities . . . »](#)