

Focus on IBC

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BioBank News



ibcRF BioBank
www.ibcresearch.org/biobank

IBC Angels Still Available



Do you have your IBC Angel yet? This fall, the ibcRF commissioned a pewter artist to produce a special pewter

The ibcRF BioBank has been "in business" now for about 20 months. In that time period we have enrolled 110 participants. While it may appear that not much is happening, since the initial kick-off of the project is behind us, nothing could be further from the truth!

We are actively working on the next steps of the project which includes sending out an update letter and medical questionnaire to all those who have enrolled in the project. If you are enrolled in the BioBank and have changed your email address or mailing address, please let us know by sending a message to biobank@ibcresearch.org, so that we can update your records and you don't miss any important updates to the participants.

As we have reported over and over, the BioBank is a patient-driven project. ibcRF does not have a well staffed office that can do the

ornament just for us. The design was inspired by a drawing done by the niece of an IBC survivor. Each angel is hand cast, creating a unique collectors item.

The angels are being generously donated to ibcRF to be used to generate financial support for the various programs and projects of the organization. The angels are being sent as a thank you gift to those contributors who donate \$300 or more to ibcRF, either in a single donation or installments over a year beginning November 1, 2006. There is a limited supply of the angels, so they will be available on a first come first served basis.

Click on the link at the bottom of this column to find out more about making a donation and receiving your own ibc Angel.

Editors' Notes

It's been a very busy year at the ibcRF. The BioBank is starting to be used by the research community; the ibcRF had a presence at a number of national research meetings including American Association for Cancer Research, American Society of Clinical Oncology (we had a booth!), National Breast Cancer Coalition Fund, San Antonio Breast Cancer Symposium; much more research is being done specifically focused on IBC thanks to the persistent encouragement from ibcRF; and the ibcRF won an award!

We would like to report about everything going on throughout the IBC community. Please send your ideas to [the editor by email](#). Your announcements about local community events will be reviewed and included in Focus as appropriate.

intensive "leg work" of collecting medical records. We are counting on patients, or their representatives, to do this part. The update letter includes a list of the materials to be collected for the BioBank. Once you have this list, please begin working on this part of the process. We know it will take some time and effort but believe it is worth it for the benefits that will come from these banked materials.

For those who have not yet enrolled in the BioBank . . . what are you waiting for? The BioBank is open to anyone who has been diagnosed with IBC. If you are a family member of a pathfinder, you can enroll your loved one in the BioBank by having the legal representative of the pathfinder complete the consent form.

If you would like to have a consent packet sent to you, send the following information to: biobank@ibcresearch.org:

1. Full name
2. Mailing address
3. Preferred email address
4. Preferred phone number
5. Indicate if you have participated in the George Washington Univ. IBC Registry with Dr. Levine.

While we are not at liberty to disclose the specific research projects using BioBank materials, we can say that we are receiving proposals to use the materials from researchers and anticipate more proposals in the near future. As the researchers are able to share information and results of their studies with us, we will share that information with the BioBank participants so that you can truly feel part of the research process. This novel project is being recognized in the breast cancer

We hope to have enough news to send out more regular issues this year as well. All article submissions may be edited for grammar, spelling, and, in some cases, content. Each issue of Focus on IBC is [archived](#) on the ibcRF site. Please spread the word and let others know about this website so that they can be kept up with all the latest developments at the ibc Research Foundation! If you would like to keep up with the ibcRF between issues of the newsletter, please sign up for the [ibcResearch Discussion List](#).

Thanks for reading.

Anne Abate & Jayne Collie
Co-Editors

[Read More About ibcRF on our Website](#)

Quick Links for ibc Patients and Caregivers ...

- [Read Previous Newsletters](#)
- [Learn the History of the ibcRF](#)
- [Learn more about the ibcRF BioBank](#)
- [Donate to the ibcRF](#)

We are creating a new collaborative model of patients and researchers working together to move research forward!

Thanks to all who have already enrolled in the BioBank. Thanks to you critical research of IBC will move forward.

[Read More About the BioBank on our Website](#) »
ibcRF Wins Award

As reported previously, the National Breast Cancer Coalition Fund (NBCCF) has chosen the Inflammatory Breast Cancer Research Foundation (IBC Research Foundation) as one of the recipients of the 2006 Best Practices in Breast Cancer Advocacy Awards. The IBC Research Foundation is being recognized for its strategic, high-impact work in breast cancer research, and can serve as a model for other organizations. A total of \$25,000 was awarded to the IBC Research Foundation.

[Read the Full Press Release Explaining the Award](#) »
M.D. Anderson Opens IBC Center

The University of Texas M. D. Anderson Cancer Center announced in October that they were opening the first clinic in the world dedicated to the treatment and research of inflammatory breast cancer.

Under the co-direction of Massimo Cristofanilli, M.D., associate professor in the Department of Breast Medical Oncology, and Thomas Buchholz, M.D., professor in the Department of Radiation Oncology, the clinic will be housed in M. D. Anderson's Nellie B. Connally Breast Center. The clinic was opened to patients on October 25.

M. D. Anderson sees approximately thirty new cases of IBC a year, more than any other institution in this country. With the new clinic, Cristofanilli and his team hope to see 60-80 new cases annually. Exploring new treatments for IBC will be a priority of the clinic. Along with Cristofanilli, the clinic will be staffed with a

multidisciplinary team experienced in caring for women with IBC. Faculty include: Thomas Buchholz, M.D., professor, Department of Radiation Oncology and the center's co-director; Anthony Lucci, M.D., associate professor, Department of Surgical Oncology; Gildy Babiera, M.D., assistant professor, Department of Surgical Oncology, Shaheena Dawood, M.D., Susan G. Komen Interdisciplinary Breast Fellow.

Tykerb® Effective in Inflammatory Breast Cancer

According to results recently presented at the 2006 annual San Antonio Breast Cancer Symposium (SABCS), Tykerb (lapatinib), either alone or in combination with Taxol® (paclitaxel) provides activity in inflammatory breast cancer. More information on this research can be found [here](#).

[Read the Full Press Release from M.D. Anderson »](#)

Raise the Awareness Level



IBC Survivors Meet at Livestrong Summit

Three IBC survivors met for the first time while attending the Lance Armstrong Foundation LIVESTRONG

Summit held in Austin, Texas October 27- 29. This inaugural LIVESTRONG Summit was a three- day event to organize, inspire, and direct the efforts of cancer survivors from across the country to change the face of cancer survivorship. Through the Summit, the Lance Armstrong Foundation hopes to broaden awareness and impact the unmet physical, emotional and practical needs of people living with cancer.

Pam Haschke, Eva Lafferty, and Anne Abate all attended the Summit and were able to share their experiences of ibc and survival. Thanks to Pam for providing the following perspective of the event.

"Of course, Lance Armstrong was there. And with medical speakers such as Dr. Lasalle Leffall, Chairman of the President's Cancer Panel, and Dr. Antonia Novello, the first female Surgeon General, and dynamic speakers such as author Jim Collins and Senator John Kerry, one could not help but be in awe of the power and knowledge in the room to promote cancer survivorship and awareness. One of the Armstrong Foundation's mission statements is "Unity is Strength", and the unity, love, compassion, and fervor that was part of this summit and its 1000 participants, representing 44 different cancers, and 49 different states was amazing.

The energy of all of these individuals brainstorming to find ways to further cancer awareness, increase resources available to cancer survivors and their caregivers, and think creatively "out of the box" was amazing. I think Senator Kerry put it eloquently when he said, "Survivorship is not a state of grace, it is a state of responsibility."

Each and every delegate embraced the responsibility to strengthen survivorship for others in the cancer community. I was honored not only to participate, with my IBC sisters, Anne and Eva, but to meet so many individuals who want to aide others to Livestrong!"

[Be an IBC Advocate and Help Raise Awareness](#)

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