



December 31, 2005

### 2005 Year End Report Letter

The Foundation is “committed to finding the cause,” that is, the unique molecular and metabolic features that result in inflammatory breast cancer (IBC). One of those features is “you don’t have to have a lump to have breast cancer.” Not only is that feature not well known by the general population, but, sadly, neither is it broadly enough well known by clinicians. Advocates all over the country, including you, zealously work to promote awareness of the “typical” symptoms of IBC which may mimic benign breast disorders at presentation, often treated as mastitis. Several weeks ago we received an e-mail from a 42-year long friend of a lady who died of IBC; her friend had been diagnosed and treated for shingles for nearly one year before her friend learned about IBC by finding our web site herself. We rely on donations like yours to provide information about IBC via our web site, e-mail lists, an electronic newsletter, a toll-free telephone number (extending to Canada as well as the United States), brochures, bookmarks, and by other means.

“Research” is not just a word in the Foundation’s name, research is our primary mission. Several years ago, researchers across the country began advising us that the most critical resource they lacked in their research of IBC was not money; it was lack of an easily accessible patient cohort for study. After considerable preparation, we began accruing IBC patients to our IBC BioBank and Clinical Data Base in June 2005. A unique feature of the IBC BioBank includes the collection of samples and data from deceased patients as well as minors diagnosed with IBC, preserving important information that is often unavailable to researchers from these populations. As hard as it may be to believe, yes, minors have been diagnosed with IBC; an athletically active 16-year old high school junior in California was diagnosed with IBC in December 2002 and died at age 16 in September 2003. The pathology and records of my wife, Marilyn, who died of IBC in May 1998, are in the BioBank. If you or someone you know has been diagnosed with IBC, we welcome their participation in the BioBank by calling 1-877-stop-ibc (1-877-786-7422) or by sending an e-mail to [biobank@ibcresearch.org](mailto:biobank@ibcresearch.org).

The IBC BioBank is a patient driven model with involvement of the patient or patient representative from the consent process through to the actual research projects. The Medical Advisory Board, as well as the Board of Directors, is responsible for reviewing

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the research proposals received requesting access to the samples and database. Participants in the project receive regular updates from the IBC Research Foundation regarding IBC BioBank activity. Researchers using the samples and data are required to return their findings for inclusion in the database, thus increasing the IBC knowledge base.

The IBC BioBank is one way that the IBC advocacy community can not only be involved in the research process but drive it toward translatable results. By providing a biorepository of high quality, well documented samples and a robust database to accompany the specimens, the IBC Research Foundation will truly realize its mission to facilitate meaningful research.

We invite you to continue to partner with us to make a positive difference in the way IBC is diagnosed and treated.

Thank you for your partnership,

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