

# A NEW PARADIGM



**ibcRF BioBank**  
[www.ibcresearch.org/biobank](http://www.ibcresearch.org/biobank)

# Inflammatory Breast Cancer Research Foundation

- Incorporated in 1999, the Inflammatory Breast Cancer Research Foundation (ibcRF) is the only non-profit organization dedicated solely to the support of research and public awareness of inflammatory breast cancer (IBC).
- Our mission is to assist the scientific community to learn more about IBC and improve detection and treatment.
- Through a network of volunteers, ibcRF is able to be a voice for the IBC community.

# *“There is more than one kind of breast cancer”*

- Inflammatory breast cancer (IBC) is the most aggressive form of breast cancer affecting younger women disproportionately: the median age at the time of diagnosis for IBC is 52, whereas the median age for all other breast cancer is 62.
- Diagnosis of IBC is not based on histopathological characteristics, as it is for other types of breast cancer, but on a combination of clinical symptoms (ie: erythema, skin edema, and peau d'orange) and pathologic characteristics (ie: dermal invasion of breast lymphatics).

# *Problems....*

- Research has been hampered by the lack of an easily accessible, well documented IBC cohort.
- Remains fragmented, competitive and under-funded.
- The current clinical/pathological definition of IBC is ambiguous and controversial.
- IBC cell lines are limited.

# ....*What's being done*

- The Inflammatory Breast Cancer Research Foundation (ibcRF) has established a BioBank and Clinical Database.
- The BioBank will contain non-tumor RNA and DNA, tumor RNA and DNA, blocks and slides from diagnostic pathology, and medical records describing clinical and pathologic findings at diagnosis providing an invaluable resource.
- A unique characteristic of this BioBank is the inclusion of specimens and records from deceased patients who had rapid disease progression and resistance to treatment. This data will provide valuable comparison for study.

# *The model*

- The Genetic Alliance BioBank (GAB) is a collaboration of disease specific advocacy groups providing the infrastructure. (ibcRF is a founding member)
- Standardized collection, storage and distribution of samples and data.
- Secure sample storage and attention to confidentiality issues.
- Standardized model documents designed and approved by GAB Institutional Review Board.

# *Value of an Advocacy Owned Blood and Tissue Bank*

- Established relationship with patient cohort improves recruitment for samples
- Brings patients and researchers into a new collaboration model
- Broadens scope of advocacy beyond awareness, lobbying and fundraising
- Provides a robust disease specific database
- Allows patients/advocates to help define the focus for research

# *Proposed Results from ibcRF BioBank Research*

- Identify a pattern (genetic, molecular, metabolic and/or protein) that will diagnose IBC with high sensitivity and specificity
- Phenotype/genotype correlations
- Allows safe and ethical re-contact and follow-up for natural history and longitudinal studies
- Keeps research coordinated and focused on affected individuals
- Identify IBC family clusters for additional study
- Determine sub-groups of IBC which impact prognosis and treatment
- Increased “bench to bedside” research that will improve treatment and outcomes

# Access

- Researcher contacts ibcRF for proposal guidelines
- Submit proposal
- Evaluation process of proposal by ibcRF Medical Advisory Board and Board of Directors
- Discussion/negotiation of transfer agreement and applicable fees
- If approved, ibcRF authorizes release of coded samples from the contract lab



**For more information:**

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