Inflammatory Breast Cancer Research Foundation: patient information, and support, research collaboration and IBC BioBank

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TYPICAL SYMPTOMS
- Rapid, unusual increase in breast size
- Redness, rash, blotschiness of breast skin
- A ‘bug bite’ or ‘bruise’ that doesn’t go away
- Persistent itching of breast or nipple
- Lump or thickening of breast tissue
- Stabbing pain, soreness, heaviness or aching of the breast
- Feverish breast (increased warmth)
- Dimpling or ridging of the breast
- Flattening or retraction of nipple
- Nipple discharge or change in pigmented area around nipple
- Swelling of lymph nodes under the arm or above the collar bone

These symptoms may indicate a benign breast disorder, however any breast change should be investigated by a healthcare provider promptly, if not resolved within 2 weeks on its own.

WHAT IS IT?
- Inflammatory breast cancer (IBC) is the most aggressive form of breast cancer.
- Is poorly understood and research is fragmented and under-funded
- The median age at the time of diagnosis for IBC is 52, while the median age for all other breast cancer is 62.
- Symptoms appear and develop rapidly
- Higher incidence of Her2/neu positivity and triple negative cases

DIAGNOSIS
- Current 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 (i.e.: erythema, skin edema, and peau d’orange) and pathologic characteristics (i.e.: dermal invasion of breast lymphatics).
- Some patients have both breast inflammation and dermal invasion, while others have only one or the other making diagnosis difficult.
- IBC is not usually detected by mammogram or ultrasound without a defined tumor. Symptoms are often mistaken for mastitis and a short course of antibiotic is given. A biopsy is typically needed to obtain a definitive diagnosis.

Inflammatory Breast Cancer Research Foundation

WHO WE ARE:
- Incorporated in 1999, the Inflammatory Breast Cancer Research Foundation (ibcRF) is a web-based, non-profit organization dedicated to inflammatory breast cancer (IBC) research and education. Through a network of volunteers, ibcRF is able to be a voice for those with IBC in the research community.

SERVICES:
- ibcRF provides an extensive website containing journal articles, patient stories, IBC educational materials, photos, clinical trials and much more
- An email discussion list provides a place for sharing & education.
- Through an e-newsletter subscribers learn information relevant to IBC and the work of the Inflammatory Breast Cancer Research Foundation.
- The toll-free phone line provides one-on-one counseling and support by trained volunteers.
- Educational tri-fold brochure & bookmark
- The ibcRF BioBank & Clinical Data Base, a robust tool for research.

RESEARCH GRANT FUNDING
Since 2009, grants totaling close to $300,000 have been awarded to outstanding IBC projects. Those receiving grants include:

DIANE PALMIERI, PHD: National Cancer Institute
BRYAN SCHNEIDER, MD: Indiana University Simon Cancer Center
HEATHER CUNLIFFE, PHD: Translational Genomics (TGen)
ROBERT SCHNEIDER, PHD: NYU Medical Center
BETH OVERMOYER, MD: Dana Farber Cancer Institute
DEBORAH SILVERA, PHD: NYU Medical Center
MILAN RADOVICH, MD: Indiana University Simon Cancer Center

http://www.ibcresearch.org/research-grants-awarded/

OUR GOALS.....
--To ignite interest in the study of inflammatory breast cancer
--Facilitate research leading to better methods of detection, treatment and survival
--Education of the medical community and public about inflammatory breast cancer

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