Introduction to the LBCA

Thirty patient advocates attended the First International Invasive Lobular Breast Cancer Symposium in 2016 at the University of Pittsburgh Cancer Center.

The conference underscored that invasive lobular breast cancer (ILC) and other lobular pathologies are understudied.

• Growing interest in ILC requires improved tools to link patients with ILC to clinical trials and studies, and match ILC patient advocates to research proposals and grant reviews.
• Patients, researchers and clinicians will benefit from a central on-line source of ILC information and educational resources.
• ILC is under represented in key meetings and literature.

Figure 1: Lobular Breast Cancer is a Leading Cause of Cancer for Women in the U.S.

Breast (Ductal) 226,730 26%  
Lung & bronchus 112,350 12%  
Colon & rectum 64,640 7%  
Uterine corpus 62,330 7%  
Thyroid 40,900 5%  
Melanoma of the skin 36,120 4%  
Non-Hodgkin lymphoma 32,950 4%  
Pancreas 26,240 3%  
Leukemia 25,270 3%  
Kidney & renal pelvis 22,660 3%  
All Sites 878,980 100%

ILC is the sixth most prevalent cancer of women and the second most frequently diagnosed histological subtype of breast cancer impacting over 39,000 patients a year in the US.

Adapted 2019 ACS Surveillance Research, SEER

Challenges with ILC

Clinical specimens from (A) ILC and (B) invasive ductal breast cancer (IDC) reveal distinct pathologies between the two diseases including a linear growth of ILC cells throughout tissue.

• ILC is a biologically distinct breast cancer with unique subtypes and variants with differences in presentation and behavior and a tendency to metastasize to unique locations.
• While ILC is frequently associated with a good initial prognosis, recent analysis suggests that long-term outcomes of ILC may be worse than those stage-matched to IDC.
• Current imaging tools are less reliable for early detection of lobular disease and detection of distant recurrence.
• Standard of care chemotherapy and endocrine therapies may have different effectiveness applied to ILC and IDC.

Figure 2: ILC is a Unique Subtype of Breast Cancer

• Growing interest in ILC requires improved tools to link patients with ILC to clinical trials and studies, and match ILC patient advocates to research proposals and grant reviews.
• Patients, researchers and clinicians will benefit from a central on-line source of ILC information and educational resources.
• ILC is under represented in key meetings and literature.

Figure 3: TCGA ILC Working Group Has Defined Basic Etiology of the Disease

The Cancer Genome Atlas (TCGA) ILC working group recently performed comprehensive analyses that revealed clues about the etiology of ILC. Some of their main conclusions described major mutations present in ILC clinical samples. Giri et al. (TCGA). Cell 2013

ILC: 94% ER-positive
- 14% ILC vs 3% IDC
- 7% ILC vs 2% IDC
- 5% ILC vs 20% IDC

PTEN inactivating alterations:
- 14% ILC vs 3% IDC

Formation of the LBCA

The Lobular Breast Cancer Alliance (LBCA) was formed by patient advocates who attended the First International ILC Symposium.

LBCA’s mission is to bridge patients, clinicians and researchers to increase our knowledge of lobular breast disease and promote research that leads to advances in prevention, diagnosis, treatment and patient follow-up care.

Conclusions

LBCA is driving an increased awareness of lobular breast cancer with specific goals:
• Elevate lobular research and foster opportunities for researcher, advocate and clinician collaborations at prominent meetings.
• Advance efficient new research and analysis to understand the behavior of ILC and refine treatments.
• Link patients and advocates to ILC tumor research and clinical trials and grants.
• Initiate a clinician outreach strategy through targeted literature, meetings and education services to share information on ILC presentation, metastatic patterns and screening and treatment challenges of patients with ILC.
• Build partnerships with existing breast cancer organizations to integrate ILC into existing resources.

This information is the intellectual property of the Lobular Breast Cancer Alliance. Contact them at info@lobularbreastcancer.org for permission to reprint and/or distribute.