



Lobular Breast Cancer Alliance – Advocates Advancing Research, Screening, Treatment and Follow-up Care for Lobular Breast Disease



Petitti L¹, Axelrod J¹, Bittinger J¹, Campbell-Kotler M¹, Frank E², Jaremek J¹, Levine J¹, McWilliams M¹, Migyanka F¹, Ryan N³, Stiles H¹, Viggiano E¹, Oesterreich S⁴, Metzger-Filho O², Pate L¹
¹Lobular Breast Cancer Alliance (LBCA), United States; ²Dana-Farber Cancer Institute, Harvard University, Boston, Massachusetts; ³New Hampshire Breast Cancer Coalition, Lee, New Hampshire; ⁴Women's Cancer Research Center, University of Pittsburgh Cancer Institute, Pittsburgh, Pennsylvania

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.

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

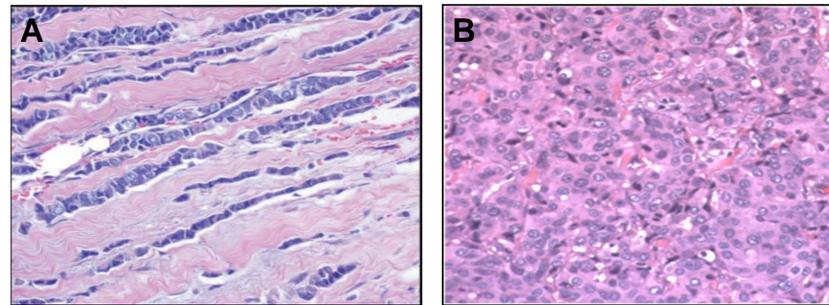
Breast (Ductal)	226,730	26%
Lung & bronchus	112,350	12%
Colon & rectum	64,640	7%
Uterine corpus	62,230	7%
Thyroid	40,900	5%
Breast (Lobular)	39,390	4%
Melanoma of the skin	36,120	4%
Non-Hodgkin lymphoma	32,950	4%
Pancreas	26,240	3%
Leukemia	25,270	3%
Kidney & renal pelvis	22,660	3%
All Sites	878,980	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 2018 ACS Surveillance Research, SEER

Challenges with ILC

Figure 2: ILC is a Unique Subtype of Breast Cancer



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.

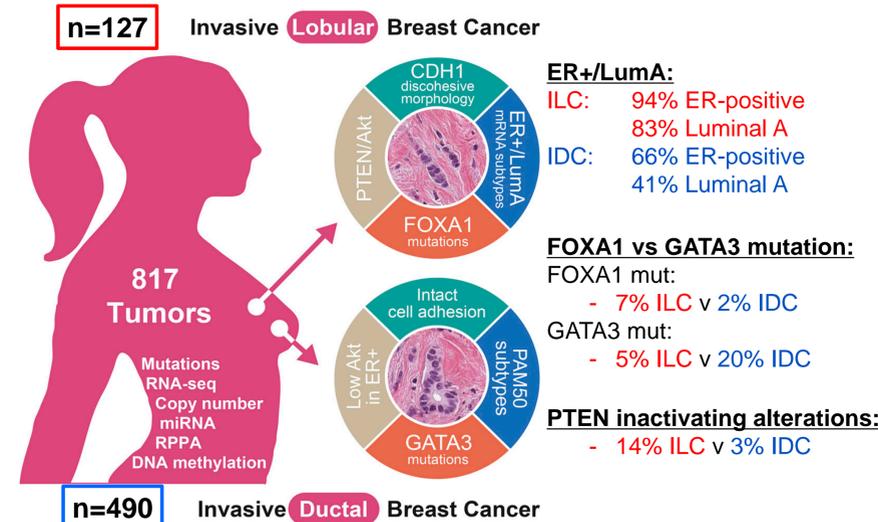
Images obtained from Oesterreich S

- 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.

Growing Interest in ILC

- 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. Encouraging opportunities to share ILC research as agenda topics and fostering collaborations between researchers, clinicians and advocates can accelerate progress.

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. Ciriello et al, (TCGA), Cell 2015

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:

- Build a website devoted to lobular breast cancer at www.LobularBreastCancer.org.
- 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.

Updated 2018 from the San Antonio Breast Cancer Symposium 2017

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