

ADVANCING LOBULAR BREAST CANCER RESEARCH, SCREENING, TREATMENT, AND FOLLOW-UP CARE

The First International Invasive Lobular Breast Cancer Symposium was held in September 2016 at the University of Pittsburgh Cancer Center. The symposium was chaired by Dr. Steffi Oesterreich and Dr. Nancy Davidson of the University of Pittsburgh Cancer Institute and Dr. Otto Metzger of Dana-Farber Cancer Institute and attended by over 130 researchers, clinicians and included lobular breast cancer patients from around the country.



*As the Lobular Breast Cancer Patient Advocates who attended this conference, we are writing this white paper to share the main findings of the meeting and **ask you to join us in promoting invasive lobular breast cancer as a *distinct cancer* that requires refinements in screening, patient care, enhancements in patient and provider education and substantive measures to accelerate research.***

This conference underscored that invasive lobular breast cancer (ILC) and other lobular breast pathologies (such as lobular carcinoma in situ, LCIS) are understudied and that current standard-of-care breast cancer treatments and protocols may not always be the best option for patients with lobular disease. Specifically:

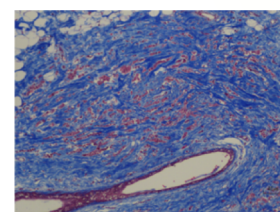
- A) Invasive lobular breast cancer is the **6th most frequently diagnosed cancer of women in the U.S.** with 26,000 to 34,000 new cases diagnosed a year. It is the second most common histological subtype of breast cancer, comprising 10% to 15% of all breast cancers, and impacts more women than cancers of the kidney, brain, pancreas, liver, or ovaries as well as leukemia or lymphoma. (2013 ACS Surveillance Research)
- B) While ILC is frequently associated with a good initial prognosis, recent retrospective analyses suggests that overall ***long-term outcomes of ILC may be worse*** than those stage-matched to ductal breast cancer (Pestalozzi, JCO, 2008; Engstrom, Histopathology, 2015; Adachi, BMC Cancer, 2016).
- C) ILC has **specific molecular features** distinct from ductal breast cancer with unique subtypes and variants (McCart Reed, Breast Cancer Research 2015; Dabbs D, Breast Pathology, Elsevier). The hallmark of ILC is E-cadherin loss. (Ciriello, Cell 2015) Histologically, ILC often forms a distinct single-file pattern.
- D) ILC has **differences in presentation and behavior**, including physical findings of thickening compared to the more common “lump” felt in ductal cancers, and a tendency to metastasize to unique locations including gastrointestinal, peritoneal and ovarian tissues. (Arpino et al, Breast Cancer Research, 2004)



E) **Current imaging tools are less reliable for early diagnosis of ILC and detection of lobular metastatic disease.** Given its anatomical growth pattern in breast tissue, it is often occult in routine mammogram or other screening, resulting in later stage diagnosis. Imaging protocols to diagnose local or distant recurrence of ILC can also be inadequate. (Pestalozzi, JCO, 2008; Engstrom, Histopathology, 2015; Adachi, BMC Cancer, 2016)

F) There is increasing evidence that **standard of care chemotherapy and endocrine therapy treatments currently equally applied to lobular and ductal breast cancers may have different effectiveness.** (Metzger-Filho et al, JCO 2015; Delpech, et al. Br J Cancer 2013 23299541; Barroso-Sousa R, Metzger-Filho O. Ther Adv Med Oncol. 2016)

Despite these fundamental differences in disease traits, invasive lobular breast cancer and Invasive Ductal Breast Cancer are often treated with similar protocols. *We believe that increasing our knowledge about this unique breast cancer subtype presents an opportunity to improve all aspects of this disease, from diagnosis through treatment to follow-up care.*



As such, we as patients are interested in working to improve the following aspects of ILC research and patient care:

- **Explore reliable screening and imaging tools** to identify early stage and metastatic ILC.
- Encourage collaboration among researchers from different institutions with different expertise to **better understand the unique metastatic behavior of ILC**, characterize ILC metastasis and better identify the subtle signs of recurrence.
- **Accelerate research into the molecular alterations and genomic differences** of ILC that might enable future targeted therapies.
- **Improve patient education** to provide better, more comprehensive support for patients with ILC.
- **Re-analyze existing clinical trial data sets** that combine all estrogen positive cancers to evaluate differences between Ductal and Lobular breast cancers.
- **Conduct clinical trials** to better identify differences in standard of care treatment between ILC and Ductal cancers, and assure inclusion of patients with ILC into all trials.
- **Integrate a designation for ILC within medical records and educate medical professionals** on the unique presentations of ILC compared to ductal, *especially at conferences and professional meetings.*

The First International Invasive Lobular Cancer Symposium highlighted the need to make substantive changes in diagnosis and follow-up care for the thousands of patients living with lobular breast cancer. The conference also suggested there are opportunities to research refinements in treatments to better address the unique traits of ILC given the differences in biology, pathology and etiology of lobular breast cancers. We strongly support more research and clinical trials to improve our understanding of this unique breast cancer subtype to better inform treatment and support positive outcomes for patients.

Review abstracts, slides, a patient Q & A video and other resource material from the First International Lobular Breast Cancer Symposium at
<https://upci.upmc.edu/wcrc/ilcsymposium-info.cfm>



This paper, **Advancing Lobular Breast Cancer Research, Screening, Treatment and Follow-up Care** was developed by patient advocates attending the ILC Symposium and released in February, 2017.

Patients formed a lobular patient advocacy group steering committee, and are working to create opportunities to improve lobular breast cancer screening, patient care, patient and provider education and substantive measures to accelerate research.

*Invasive Lobular Breast Cancer Patient Advocate Group Steering Committee Member
First International Invasive Lobular Breast Cancer Symposium Attendee*

Leigh Pate
Seattle, Washington

Meg Campbell-Kotler
Kensington, Maryland

Marilyn McWilliams
Hillsboro, Oregon

Nancy Ryan
Lee, New Hampshire

Lori Petitti
Santa Monica, California

John Liechty (Co-Survivor)
Santa Cruz, California

Elizabeth Frank
Lexington, Massachusetts

First International Invasive Lobular Breast Cancer Symposium Attendee

Orina Hodgson
Snowflake, Arizona

Elizabeth Viggiano
Portland, Oregon

Susan S. Sickler
Dayton, Ohio

Julia K Levine
Los Angeles, California

Joan C. Stevens
Merion Station, Pennsylvania

Elaine Eigeman
Seattle, Washington

Janice Axelrod MD
Pittsburgh, Pennsylvania

Contact the Invasive Lobular Breast Cancer Patient Advocacy Group at
ilcpatientadvocacy@gmail.com