What is Invasive (or Infiltrating) Lobular Carcinoma (ILC)?

ILC is the second most common histological type of breast cancer comprising 10% to 15% of all breast cancers. Histology refers to the cellular structure of the cancer. Typically ILC cells grow in single file like a string and do not form a lump, though some less common cellular variants of ILC can have different cellular growth patterns. There is growing evidence that some molecular features of ILC are distinct from invasive ductal cancer (IDC), the most common histological subtype of breast cancer. (Cirello et al, Cell 2015).

How Common is Invasive Lobular Breast Cancer (ILC)?

Invasive Lobular Breast Cancer is the 6th most frequently diagnosed cancer of women in the US. An estimated 39,000 new cases of ILC are diagnosed each year in the US, and approximately 450,000 patients in the US are either currently receiving treatment or have completed treatment for invasive lobular breast cancer. While ILC is often thought of as a “rare” cancer, it impacts more women than cancers of the kidney, brain, pancreas, liver, or ovaries as well as melanomas, leukemias and Non-Hodgkin lymphoma. (Adapted 2018 ACS Surveillance Research, SEER)

Are there Different Sub-Types and Variants of ILC?

Yes. While classic ILC is the most common subtype of lobular breast cancer, there are other histological (cellular) subtypes of ILC that have different cellular structures and variants. Find basic information on ILC subtypes. A more comprehensive explanation Pathology and Genetics of ILC and their Pre-curser was presented at the ILC mini-symposium at the 2017 San Antonio Breast Cancer Symposium.

There is no current research about how or if different molecular and/or histological subtypes of ILC might respond differently to treatments. Patients who want to know their subtype of ILC should consult their pathology report and their health care provider.

What is Lobular Hyperplasia and Lobular Carcinoma In-Situ (LCIS)?

Lobular hyperplasia and LCIS are not considered to be cancer, however both convey a higher risk of developing breast cancer.
Hyperplasia is an overgrowth of cells. “Atypical” hyperplasia means that the cells look distorted when examined. The American Cancer Society offers a comprehensive summary of Hyperplasia and cancer risks.

**Lobular Carcinoma in Situ (LCIS)** means that cells that look like cancer cells are growing in the lobules (milk glands) of the breast but they are not growing through the wall of the lobules (invasive). LCIS typically does not become invasive, however it does convey a higher risk of developing breast cancer in either breast. The pleomorphic variant of LCIS, however, is a more aggressive variant of LCIS that can often lead to treatment recommendations similar to those for Ductal Carcinoma In Situ (DCIS), or stage zero non-invasive breast cancer. Pleomorphic variants of LCIS have more atypical cells than other types of LCIS.

**How is ILC Different than the more Common IDC?**

Invasive Ductal Carcinoma (IDC) is the most common histological (cellular) type of breast cancer and comprises approximately 80% of all breast cancers. IDC has a cell structure that forms a lump in the breast. When it spreads (metastasizes) it tends to spread to the bones, liver, lungs and brain.

Invasive Lobular Carcinoma (ILC) makes up 10 – 15 percent of all breast cancers and is the second most common histological (cellular) subtype of breast cancer. Classic ILC rarely forms a lump – instead ILC typically causes a thickening of the breast tissue due to cells that spread in single file patterns. ILC is usually (but not always) very strongly Estrogen positive, Progesterone positive and HER2-negative (ER+ PR+ HER2-). ILC is typically considered a slower growing cancer, and has a tendency to recur later than IDC. *(Pestalozzi et al, JCO, 2008; Engstrom et al, Histopathology, 2015; Adachi et al, BMC Cancer, 2016; Chen et al, PLoS 2017)*

**What is Unique about Invasive Lobular Breast Cancer?**

ILC cells frequently experience a loss of the protein E-cadherin. This loss reduces the ability of ILC cells to bond together to form a lump and instead the ILC cells grow in a single-file pattern. *(Cirello et al, Cell 2015)*

**What are the Physical Symptoms of ILC?**

Monthly breast self-exam is recommended self-care for all women, but is not always a reliable way for women to detect their own cancers. Routine self-exams can provide patients an awareness of the feel and shape of their breasts so that to more readily recognize changes and report them.

On self-exam ILC may cause a visual puckering or pulling of the skin or the nipple, unexplained skin hardening, a visual dimpling or dent in the breast, one breast that appears larger or a different shape than the other, or hard areas in the breast that are not easy to move. ILC can, but does not necessarily form a lump. Breast pain can be a symptom. ILC often may not be detectable on self-exams at all, particularly when tumors are small.
Why is ILC Harder to See on Mammograms?

ILC often grows in a single-file pattern through the breast tissue without always forming a lump that can more easily be seen on mammography. ILC is more likely to be missed on screening mammograms than ductal breast cancer. (Christgen M, et al. Pathol Res Pract. 2016; Berg WA, Gutierrez L, Ness Aiver MS, et al., Radiology. 2004; Lopez JK, Bassett LW. Radiographics. 2009.)

Are there Alternate Breast Cancer Screening Tools to Mammograms?

General population breast cancer screening is intended to broadly screen the majority of healthy women who have never been diagnosed with breast cancer. Mammograms are not a perfect screening tool, and ILC can be particularly challenging to detect on a mammogram. The annual mammogram is currently the only recommended general population screening test broadly available for the routine screening of all healthy women. Breast cancer screening recommendations for women who have not had a cancer diagnosis should be based on personal risk factors, such as family history, and patient preference, after a discussion of the pros and cons of screening with their health care provider.

What Imaging is Recommended after Cancer Treatment is Completed?

Tomosynthesis (also known as 3D Mammograms) and/or Screening Ultrasound (SU) increase the detection of all breast cancers. Breast MRI is gaining acceptance as a screening option for breast cancer survivors and women with an elevated lifetime risk of breast cancer due to abnormal biopsies, hereditary mutations, and/or significant family history of breast cancer. (NCCN.org) Patients may want to discuss the pros and cons of these mammogram alternatives with their providers.

How does Dense Breast Tissue Impact Detection and Imaging for ILC?

Women who have been found to have dense breast tissue on their radiology reports may choose to discuss alternatives to screening and imaging with mammograms with their health providers. Dense breast tissue itself is a risk factor for breast cancer. For women with a history of lobular breast cancer, having dense breast tissue can make finding a recurrence more difficult. Screening Ultrasound and Tomosynthesis (3-D mammography) are both imaging alternatives that increase cancer detection in all women with dense breasts. The American College of Radiology has a fact sheet on dense breasts and imaging (not lobular specific) and issued recommendations for MRI in particular cases for women with dense breast tissue.

Can Breast MRI before Surgery be Helpful?

Breast MRI can be useful for many women with newly diagnosed ILC before surgery to better define the extent of disease in their breast (Ha, et al. 2018 Radiology) Patients can discuss whether Breast MRI pre-surgery might benefit them with their surgeon.
What Imaging/Scans are used to look for Metastatic ILC (ILC that has spread)?

Imaging and scans available for metastatic ILC are currently the same as imaging for ductal breast cancers, including FDG PET scans, CT scans and bone scans. FDG-PET provides information about glucose metabolism in the body and is a sensitive method for detecting, staging, and monitoring the effects of therapy for many cancers. Computed tomography (CT) uses an external source of radiation to produce 3-D images that demonstrate the size, shape, and composition of organs and abnormalities within the body. Additionally, sentinel lymph node biopsy can indicate whether breast cancer may have spread beyond the breast and metastasized. The American College of Radiology (ACR) issues guidelines for imaging and offers patient oriented educational information about different types of imaging.

The impact of PET/CT on metastatic staging may be lower for ILC patients than for IDC patients. Hogan MP, Ulaner GA. J Nucl Med. 2015 Nov;56 (11):1674-80) Some patients may find it helpful to send their radiology records and scans to an NCI Designated Cancer Center for second opinions. Referrals should clearly specify “lobular breast cancer”.

What is the Current Standard of Care for the Treatment of Early Stage (stage 1 -3) Lobular Breast Cancer?

The treatment a patient receives is dependent on many factors, including the size of the tumor, genetic factors, lymph node involvement and the patient’s general health and preferences. The standard of care for treatment of hormone receptor positive ILC is typically no different as for hormone receptor positive ductal carcinoma. The National Comprehensive Cancer Network (NCCN) publishes and updates regularly, guidelines and clinical resources that outline standard of care for treatment of all cancers.

More research and clinical trials are needed to understand if refinements in treatment (surgery, endocrine therapy, chemotherapy, imaging, potential future targeted therapies or immunotherapy) might result in better outcomes for ILC patients. Learn more about ILC Research.

When can Lobular Breast Cancer Recur or Spread?

Like ductal breast cancer, lobular breast cancer can recur anytime after initial treatment ends. However, research shows that ILC can often recur years after initial diagnosis. Given the potential for later recurrence, patients may consider discussing with their health provider whether this potential for later recurrence should be considered when weighing the pros and cons of extending the number of years they receive adjuvant endocrine therapy such as Tamoxifen or an aromatase inhibitor. (Pestalozzi et al, JCO, 2008; Engstrom et al, Histopathology, 2015; Adachi et al, BMC Cancer, 2016; Chen et al, PLoS 2017)

What is Metastatic Lobular Breast Cancer (Stage 4)?

When any breast cancer spreads to distant tissue and organs outside of the breast (or metastasizes) it is considered metastatic breast cancer. All metastatic breast cancer is treatable, but considered incurable.
Where can ILC spread when it Metastasizes?

The bones are a common metastatic site for all breast cancers, including ILC. ILC can spread to unusual sites, including the GI tract (stomach, intestines), pleura (lining of the lungs), peritoneum (lining of the abdomen) and ovaries. ILC can also spread to other organs common for IDC breast cancer metastasis such as the lung, liver and brain. (Arpino et al, Breast Cancer Research, 2004; Mathew A et al GebFra 2017)

*More research and clinical trials are needed* to understand if refinements in treatment (surgery, endocrine therapy, chemotherapy, imaging, potential future targeted therapies or immunotherapy) might result in better outcomes for ILC patients. Learn more about ILC Research.

What are some Potential Symptoms of ILC Metastatic Disease that should be reported to a Doctor?

Bone pain, abdominal pain, abdominal distention and/or bloating, unexplained shortness of breath, unusual pelvic bleeding and unexplained weight loss would be some concerning symptoms to report to a doctor.

What is the Current Standard of Care for the Treatment of Metastatic ILC (Stage 4)?

There is no unique standard of care for the treatment of metastatic ILC. It is treated in the same manner as other types of metastatic breast cancer. For example, Hormone Receptor Positive (ER+ PR+) ILC metastatic breast cancer receives the same treatment as (ER+ PR+) IDC metastatic breast cancer. The National Comprehensive Cancer Network (NCCN) publishes and regularly updates, guidelines and clinical resources that outline standard of care for treatment of all cancers.

Are there Hereditary Genetic Risks for ILC?

A germline (hereditary) mutation in the CDH-1 gene can cause a hereditary syndrome of diffuse gastric cancer and lobular breast cancer. Most patients with ILC will not test positive for this rare mutation. The National Comprehensive Care Network (NCCN) has specific criteria to determine if testing is indicated.

What Tests of the Tumor (somatic testing) might be helpful for ILC?

Somatic testing of metastatic tumors to look for tumor-specific mutations has gained popularity as an attempt to tailor treatment to individual patients. It has limited applicability thus far in breast cancer generally. Somatic testing should be discussed with a health care provider.
**Are there any Steps Patients with ILC can Take or try to Avoid to Reduce their Risk of a Recurrence?**

ILC is typically an estrogen sensitive disease. Patients with ILC should consult with their oncologist before taking prescription or homeopathic medications or supplements that contain or mimic the hormone estrogen, including hormonal replacement therapies to relieve menopausal symptoms, supplements or other products that contain or mimic estrogen.

General healthy lifestyle recommendations also apply to patients with ILC, including a healthy diet, avoidance of weight gain (estrogen is made in fat after menopause), exercise, and stress reduction. Alcohol moderation or avoidance is advisable, as alcohol has been shown to increase estrogen levels in some studies.

**Are there Clinical Trials and Research Studies to learn more about ILC?**

Yes. Find information about ILC trials and studies and links to clinical trial search tools and information to determine whether a trial is a good option.

Lobular Breast Cancer is an understudied, unique subtype of breast cancer. Clinical trials are needed to better understand this disease and refine treatments. Pre-clinical research is critical to better understand the disease biology and behavior and potentially to identify targeted therapies. Patients can help advance research by participating in studies as appropriate and working with their doctors. Patients can also become a research advocate to advance research, raise awareness and educate others about ILC.

**Are there Clinical Specialists in Lobular Breast Cancer?**

LBCA does not recommend health providers or treatment facilities. However second opinions are always recommended, particularly for cancers like ILC that are less frequently treated at smaller hospitals. A second opinion can be sought for treatment advice, and consults are generally available for radiology and pathology. The National Cancer Institute (NCI) has a network of NCI-Designated Cancer Centers around the country. These Cancer Centers treat larger volumes of patients, see more lobular breast cancer patients, and serve as centers for research and cutting-edge cancer treatments. Find an NCI Designated Cancer Center.

**Where Can I Learn More?**

LobularBreastCancer.org has a resource library and other information and links out webinars, research and resources on lobular breast cancer. LBCA has compiled a resource list of educational and support resources for patients.

This FAQ is for informational and educational purposes only. Information found on this page or links should never replace professional medical advice.