

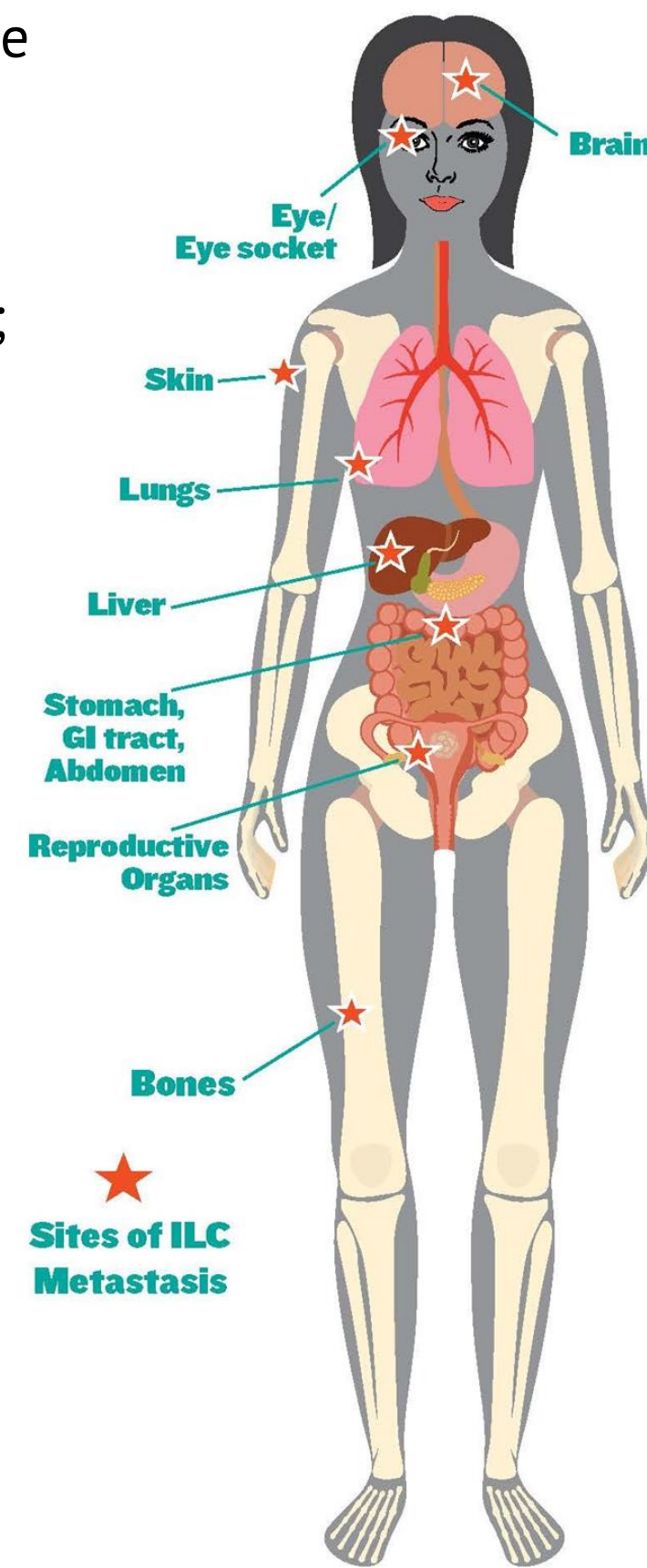


To learn more about LBCA and ILC, use this QR code to visit the LBCA website. Upon publication, the poster will be available on the LBCA website. Copies of this poster are for personal use only and may not be reproduced without permission from SABCS® and the author of this poster.

What we learned: Individuals with metastatic invasive lobular carcinoma (mILC) often present de novo, and mILC's metastatic sites can be challenging to detect/monitor

Background

- Invasive lobular carcinoma (ILC), representing 15% of breast cancer diagnoses in the US annually, is a relatively common but understudied breast cancer subtype
- ILC has some distinct characteristics including: 1) ILC typically does not form in lumps and is harder to detect with standard imaging; 2) ILC sometimes recurs later than breast cancer of no special type (NST, including invasive ductal breast cancer); and 3) ILC sometimes metastasizes to unique parts of the body
- Members of the Lobular Breast Cancer Alliance's (LBCA's) community have expressed frustration at the lack of sensitivity in imaging or laboratory techniques for detecting ILC and metastatic ILC, and in monitoring mILC progression
- Members of the LBCA community are concerned about the lack of access to clinical trials for patients with mILC, who are often excluded because it can be hard to observe measurable changes in mILC
- LBCA shares ILC issues and these survey results in keeping with the advocacy organization's commitment to raising awareness of the distinct, often troubling aspects of ILC, and to promoting the need for research on all ILC stages



Objective

Conduct a survey of LBCA community members with mILC about their experiences with diagnosis, treatment, and surveillance of mILC. Survey questions included:

- Were metastases diagnosed as de novo (DN) or as a distant recurrence (DR)?
- Where were the sites of metastases?
- How was the metastatic disease diagnosed and what surveillance modalities were used?
- What was patient experience with ongoing surveillance and diagnostic testing?
- Were individuals participating in or had they ever participated in a clinical trial?

Methods and Cohort

- Online, anonymous survey conducted in June 2022 – recruitment via newsletter, website, sister organizations, and social media
- 241 individual respondents submitted complete responses
- 77% of respondents were from the US and Canada
- Respondents reported having lived with metastatic ILC for between 1 and 30 years, with average of 3.9 years for DN mILC, and 3.3 years for DR mILC
- Average number of years to distant recurrence among respondents with DR was 5.5 years, with a maximum number of years to recurrence reported as 22 years

Results

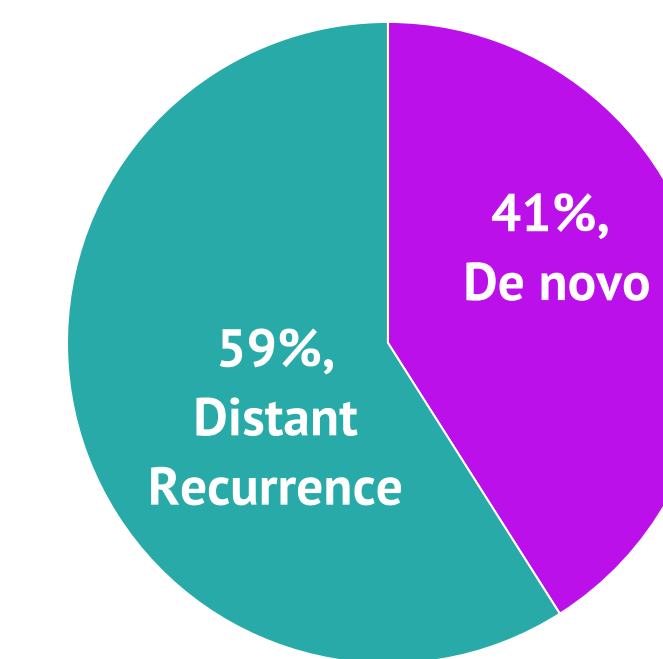
IMAGING IS OFTEN CHALLENGING WITH METASTATIC ILC

- 48% of respondents stated their mILC was an unexpected or an incidental finding during another medical procedure
- 36% of respondents reported that at least one imaging modality failed to visualize one or more of their metastatic sites at initial diagnosis of mILC
- 54% of respondents with bone metastases and 19% of those with GI metastases indicated their metastases had not been visualized by standard imaging modalities

PATIENT EXPERIENCE FINDINGS

- 58% of respondents reported feeling that non-oncologists caring for them (primarily PCPs, radiologists, and gastroenterologists) needed to be better informed about ILC
- Only 28 respondents reported they were in or had participated in a clinical trial

% Diagnosed with mILC as Distant Recurrence vs. De Novo



47% OF RESPONDENTS REPORTED METASTATIC PROGRESSION

- 36% of individuals with de novo mILC reported progression
- 54% of individuals with distant recurrence reported progression

14% REPORTED A CHANGE IN STATUS IN ONE OR MORE RECEPTOR

- For example, ER+/-, PR+/-, and/or HER2+/-

Discussion

- Surveyed individuals confirmed the perception that mILC can occur in unique locations and be difficult to diagnose, that mILC may be challenging to monitor, and standard surveillance methods may fail to visualize it
- Low clinical trial participation may be the result of limited access to trials for patients with mILC because treatment response can be hard to measure
- A large % of respondents reported their mILC diagnoses were unexpected or incidental findings during another medical procedure

Next Steps

- The large number of women who reported having been diagnosed de novo indicates that ILC remains difficult to detect early with routine screening and suggests that more sensitive ILC detection methods are needed
- Further study is warranted regarding receptor status change over time
- Study is also warranted to compare rates of progression in individuals diagnosed with DR mILC vs. those diagnosed with DN mILC
- Educational materials about the unique aspects of ILC should be developed and disseminated to clinicians
- New methods to determine treatment response in individuals with mILC should be developed to increase opportunities for clinical trial enrollment

Acknowledgements

- LBCA thanks all survey respondents for sharing their experiences, and all volunteers and LBCA Scientific Advisory Board members who contributed to the design and synthesis of the survey and results

Sites Reported of Metastatic ILC Disease at Diagnosis

