Introduction
The Lobular Breast Cancer Alliance was founded in 2017 by patient advocates working with a Scientific Advisory Board of breast cancer researchers and clinicians. LBCA’s goals are to advance research and educate about ILC.

An early action of the LBCA was to launch a website: lobularbreastcancer.org to address the need for a central source of quality information about lobular breast cancer.

Objectives
Conduct a survey of users to determine the value of the website and identify potential ways to improve it.

✓ Understand who was visiting the site
✓ Identify the information sought
✓ Obtain feedback on the usefulness of content
✓ Seek input on content and navigation

Methods and Cohort
May 1 – June 3 2019
Online anonymous survey – recruitment via Newsletter, Website, Social Media (Facebook, Twitter)
950 Responders

71.5% Age 46 - 65
25% Responders resided outside of the United States

Results
Who Visits the LBCA Website?
Stage at Diagnosis
Frequency of Visits
94.7% Current or former ILC patients
83.7% Found the information they were seeking

Where Do Users Go For Information About ILC?
What Resources Do You Use for Information on ILC?

ILC Research/Clinical Trials
ILC Specific Treatment Information
General Information about ILC
What are LBCA Visitors Looking For?

Conclusions
• Patients most frequently reported frustration seeking quality in-depth information about ILC and best courses of treatment from their providers and the current state of knowledge among practitioners about ILC.
• The survey shows high levels of interest in more ILC research.
• LBCA is driving awareness of lobular breast cancer by sponsoring a website providing research-based information about ILC.

Future Direction
• The LBCA will continue to provide a central online resource for information about lobular breast cancer to educate the community and enable patients to advocate for their self-care.
• The LBCA will integrate more research findings into the website.
• The survey shows that lobular breast cancer is under-researched. LBCA will continue to advocate for additional studies and clinical trials to refine treatments, imaging and follow up care for patients.
• The LBCA is interested in the 2nd International Invasive Lobular Breast Cancer Symposium in May 2020, ILCsymposium2020.com #lobular2020