



**JULY 1, 2020 - JUNE 30, 2021**

# **YEAR IN REVIEW**

**LOBULAR BREAST CANCER ALLIANCE**



# LBCA's Mission

**As the only organization in the US dedicated to invasive lobular breast cancer (ILC), LBCA's mission is:**

To make all who are touched by ILC aware of its unique characteristics and the critical need for more ILC research; to be the go-to source for information on ILC studies, clinical trials and educational tools; to foster partnerships among patients, scientists, clinicians, and breast cancer organizations to increase dialogue about ILC and research advocacy; and to fund vital ILC research.

## LBCA's Vision

A world in which lobular breast cancer is found early, treated effectively, and eradicated permanently.

To accomplish our mission and vision, LBCA is guided by **five primary goals:**

1. Raise Awareness and Educate about ILC
2. Be the Go-to Source for ILC Research Findings and Information about ILC Treatment
3. Support ILC Patient Research Advocacy
4. Cultivate Alliances Among U.S. and International Breast Cancer Advocacy Organizations
5. Fund and Advance ILC Research



## MESSAGE FROM THE EXECUTIVE DIRECTOR

Dear LBCA Community,

What a year this has been for the Lobular Breast Cancer Alliance (LBCA), despite the pandemic! LBCA has made great strides toward becoming an independent, non-profit organization working with several staff and many volunteers. We also expanded our Scientific Advisory Board, and have attracted 870 new newsletter subscribers.

The following are some of the highlights of this past year in each of our major goal areas, about which we are quite proud. More about our goal areas follows in our report.

Over the year, many individuals with ILC responded to our invitation to tell their ILC story. We received many tales of frustrated searches for information about ILC until people found their way to LBCA and moving descriptions of the resilience of patients with ILC in the face of difficult treatment and incomplete information. These stories have become newsletter favorites.

In our aim to continue to be the go-to source for ILC research findings and information, we revamped our website to make it more user-friendly and added over 50 new publications to our online library. We also produced a scientific blog and several video interviews with our Scientific Advisory Board members on hot topics.

In support of ILC patient advocacy, this winter we launched a series we call Advocate Chat, which are opportunities for patient advocates to meet one another virtually and to learn about and share pointers on a variety of advocacy activities. These were well received and more are planned.

We continue to expand relationships with other breast cancer advocacy organizations, such as the MBC Alliance with which we collaborated to produce the July edition of their web-based *Here All Year* campaign providing key facts and issues about metastatic ILC. And in June, LBCA advocates and scientists collaborated with breast cancer advocate and scientific organizations in Europe to present the long awaited second ILC Symposium virtually.

But perhaps our biggest accomplishment this year, which propelled us one step closer to our vision of eradicating ILC, was our collaboration with AACR and ASCO that enabled us to fund two ILC research grants directly! There was a great response to these ILC research grant solicitations, and we plan to issue even more next year.

I am thankful for the engagement of our lively and supportive community of patients with lobular breast disease and their loved ones, whose input helps us to continually improve what LBCA is and does.

I am supremely grateful for the loyal support of all of our donors, including Kim and John Motschenbacher, whose cross-country bike ride to raise awareness of ILC and funds for LBCA has been so inspiring.

Without our donors, we would not continue to be the vibrant and growing entity that we are, and we would certainly not have been able to fund ILC research this past year and be planning for more in the next.

Thank you all!

A handwritten signature in blue ink that reads "Laurie Hutcheson".

Laurie Hutcheson





## RAISE AWARENESS AND EDUCATE ABOUT ILC

LBCA activities to raise awareness and educate about ILC through our website, through collaborations with other advocacy organizations, and through our presentations in webinars and at conferences have been numerous this year.

Early in 2020 we assessed our website for user-friendliness. With the input of many patient advocates, we upgraded it with many new improvements. We added a page specifically for patients that includes a metastatic ILC section, launched a calendar to provide information each month on important breast cancer conferences, and posted presentations with relevance for ILC or research advocacy opportunities all in one place so they are easier to access. We also initiated a quarterly scientific blog on varying topics written by our Scientific Advisory Board members and other guest scientists. Finally, we increased our social media presence by creating an LBCA profile on LinkedIn and a branded YouTube channel.

Members of LBCA's leadership and Scientific Advisory Board collaborated with partners to amplify voices and information about metastatic ILC. This included an interview for the *OurMBCLife* podcast and a collaboration with the Metastatic Breast Cancer Alliance to develop materials and videos focusing on various aspects of metastatic ILC for the organization's *Here All Year* campaign.

Throughout the year, LBCA patient advocates presented at many virtual conferences including the National Breast Cancer Consortium Leadership Summit, the Alamo Breast Cancer Foundation Advocates Program, and the Komen Metastatic Breast Cancer Conference. LBCA advocates and scientific advisors also developed lay summaries for the 13 ILC-focused posters at the virtual San Antonio Breast Cancer Symposium (SABCS) 2020 and worked with GRASP to provide mentors for many virtual poster sessions. These sessions gave advocates a deeper understanding in lay language of the science presented in the posters.

Finally, in June, LBCA helped conduct the long-awaited and previously canceled International ILC Virtual Symposium including developing and moderating a 90-minute advocate focused session featuring a panel of our Scientific Advisory Board members presenting highlights of the ILC symposium sessions.



# BE THE GO-TO SOURCE FOR ILC RESEARCH FINDINGS AND INFORMATION ABOUT ILC TREATMENT

Over the year, LBCA has continued to expand its library of ILC-specific publications and make it easier to navigate. Over 50 new, important ILC-focused publications were added to our library. Additionally, information regarding three clinical trials that include or focus on people with ILC were added to our website's clinical trials page.

Working with the Scientific Advisory Board, LBCA's volunteer advocate research committee created a timeline graphic and accompanying story in lay terms regarding milestones in the progress of ILC research between 2000 and 2020.

LBCA also continued its partnership with BreastCancerTrials.org. Their resource, Metastatic Trial Search, a clinical trial matching service developed specifically for people with advanced and metastatic breast cancer, was updated to better meet the needs of people with ILC. The tool added lobular as a subtype so that users can filter trials to see only the trials that allow enrollment of people with metastatic lobular breast cancer. It also added a checklist in their filter of unusual places where ILC can spread.





## SUPPORT ILC PATIENT ADVOCACY

LBCA is committed to helping individuals with ILC and their loved ones learn how to educate others about ILC. We describe this as education advocacy. We provide information and virtual training about advocacy and how to find or create this type of advocacy opportunity. We also strive to help individuals with ILC who are interested in the basic science of breast cancer and having some influence on decisions about breast cancer research to become “research advocates.” We do this by providing resources for learning more about research advocacy and links to organizations that provide training.

In the summer of 2020, LBCA sponsored two opportunities for patients with ILC around the world to meet one another via video conference. The consensus was that such get-togethers with other patient advocates to focus on patient advocacy was really important. At the suggestion of attendees, LBCA launched its Advocate Chat series in the winter of 2021.

The Advocate Chat series features invited guests presenting on various topics including advocacy and social media and how to get involved in research locally. Recordings of all of the presentations are on our website.

In the Spring of 2021, LBCA and Scientific Advisory Board members developed two ILC-focused grant solicitations and wrote in explicit requirements for applicants to utilize patient advocates in both the development of applications and grant implementation if awarded. LBCA members also participated in the grant application review process. Also this year, five advocates participated in research advocacy training and breast cancer grant review activities for the Department of Defense Breast Cancer Program.

In June, 2021 LBCA patient advocates conducted a survey on imaging and ILC among people with ILC in the LBCA community. Over 1,475 responses were received and the discussion of the survey process and analysis was developed into an abstract for submission to the San Antonio Breast Cancer Symposium (SABCS) 2021 for publication and an invitation, we hope, to prepare a corresponding research poster for presentation at the SABCS this December.

# CULTIVATE ALLIANCES AMONG U.S. AND INTERNATIONAL BREAST CANCER ADVOCACY ORGANIZATIONS

Early in the calendar year, LBCA began to host meetings with two European lobular breast cancer advocacy organizations with the intention of keeping one another apprised of our actions and identifying opportunities for collaboration in the promotion of ILC research.

LBCA, with these advocacy representatives, also helped members of the LBCA Scientific Advisory Board and of the European Lobular Breast Cancer Consortium implement the 2021 International ILC Virtual Symposium. LBCA and these same representatives also collaborated on a piece titled *How Researchers, Clinicians and Patient Advocates Can Accelerate Lobular Breast Cancer Research*. The article was published in June by *Cancers*, an online, peer-reviewed, open access journal of oncology published semimonthly.

## International Partners:





# FUND AND ADVANCE ILC RESEARCH

With the help of its Scientific Advisory Board, patient advocates, and very generous donors, LBCA has made huge strides in advancing ILC research this year. Five donors' significant gifts made it possible for LBCA to establish and fund two early investigator grants with the administrative support of the American Academy of Cancer Research (AACR) and Conquer Cancer/the American Society of Clinical Oncologists (ASCO) Foundation.

The one-year Conquer Cancer/ASCO Foundation grant will be awarded at the end of July 2021 and will be effective August 1. Applications for the AACR grant, which is a two-year research fellowship, are due in the fall. The review processes for both include LBCA Scientific Advisory Board members and other scientists and clinicians with ILC expertise, and LBCA research advocates. The two ILC grant solicitations generated a lot of excitement in the scientific community and, as we had hoped, interest in ILC research. Over 40 individuals submitted Letters of Interest to apply for the AACR grant alone!

LBCA was also approached by two intrepid individuals, one with ILC, who proposed a new way to increase awareness about ILC and to fund more ILC-sponsored research by riding across the continental United States on their bicycles. The couple are promoting their journey and fundraising effort via a blog called *Mo'ch Across America*. They left from Washington state in May and plan to reach Virginia by Labor Day. Not only have they already raised thousands of dollars for LBCA, but publicity about this ride and ILC and LBCA has already been shared in local newspapers and picked up by TV stations in two media markets - the first time ILC has appeared in general media!



# What Our Supporters Are Saying



"Women with lobular breast cancer, their caregivers, and their primary care physician need more education and insight! A lobular breast cancer patient in Nigeria has numerous challenges. One is understanding their diagnosis. A second is finding resources to navigate their way through their treatment continuum. I support my patients as best as I can with the available resources, such as those from the LBCA, but I look forward to being able to do even more as more is learned about best treatment methods through more research."

Olayinka, Patient Navigator, Nigeria

"As an ILC patient who has been fortunate to be able to help support LBCA, I'm very pleased with how LBCA has expanded their advocacy, their network of patient advocates, and now funds research grants. It's exciting to be a part of LBCA as the organizations grows, with the ultimate goal being that in the future, there will be little or no need for it to exist."

Sarah B., Loyal Supporter and Person with ILC



"I was diagnosed with lobular breast cancer at the age of 46. This ride is a time for personal growth and a time to reflect on the last 10 years and our cancer journey. Now, I'm just ready to make a difference and really bring awareness to the Lobular Breast Cancer Alliance."

Kim Motschenbacher reflecting on her cross country bike ride with husband, John.