

FY2022
July 1, 2021 - June 30, 2022

ANNUAL REPORT



Remembering Leigh Pate

November 30, 1966 - June 25, 2022



"Lobular breast cancer is a little breast cancer in a big breast cancer world. It is only by working together and working collaboratively that we can continue to make meaningful progress in the next decade so patients will finally benefit from personalized therapies that truly meet the challenges of this disease."

Leigh Pate, Founder, Lobular Breast Cancer Alliance

A Message from our Executive Director



Fiscal Year 2022 was a remarkable year and a year of firsts for the Lobular Breast Cancer Alliance (LBCA). Becoming, for the first time, a fully independent nonprofit organization in January, with significant support from of a growing number of generous donors, LBCA has catapulted forward towards achieving our goals to raise awareness of invasive lobular carcinoma (ILC), to support the worldwide ILC patient advocacy community, and to promote more, desperately needed ILC research.

This year we've been able to create important additions to the resources offered on our website. These include two movies about the unique challenges of ILC and the informative resources that LBCA offers, a new translation of ILC information into Spanish, and video presentations for individuals with lobular breast cancer seeking to learn more about ILC and how to advocate for more ILC research. Along with our work to optimize our website so that LBCA shows up earlier in internet searches, we have profoundly increased our visibility and the number of important ILC resources that we share each day with an everwidening audience.

LBCA also made history this year with the funding of two early investigator ILC research grants directly with the administrative help of two partner organizations. The awarded grants hold great promise for advancing ILC knowledge. They also fueled significant interest in ILC research among researchers early in their careers and have paved the way for more LBCA-funded ILC grants in the future.

Another first was the launch of LBCA's <u>Patient Advocate Advisory Board (PAAB)</u>. This important companion to our <u>Scientific Advisory Board (SAB)</u> in guiding all that we do is key to ensuring that the ILC patient voice is factored into all of LBCA's initiatives.

Finally, in June, LBCA helped conduct the first international, in person lobular breast cancer symposium in Europe. Thanks to the generosity of our many donors, we were also able to provide scholarships to patient advocates and our ILC researcher grantees to help them attend.

Sadly, just days after the symposium, we lost LBCA's visionary founder Leigh Pate. Leigh was an inspiration to all individuals with ILC. She so effectively transformed her anger and frustration about the lack of ILC knowledge and research into energy and action. This included launching LBCA as a platform for ILC information and advocacy. We are committed to helping this amazing organization that Leigh conceived continue to grow and thrive. Visit our <u>webpage</u> honoring Leigh.

We invite you to read more about our major accomplishments this fiscal year. On behalf of LBCA, I thank you for your continued support of this organization and for your belief in the work we are doing. We could not have the growing impact that we do without your help.

With Gratitude.

Laure Hutcheson

LOBULAR BREAST CANCER ALLIANCE INC.
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A Message From our Volunteer Leaders



As the chair of Lobular Breast Cancer Alliance (LBCA) Scientific Advisory Board (SAB), I had the privilege to work in close collaboration with renowned colleagues around the world with a clear goal of advancing outcomes for patients diagnosed with invasive lobular carcinoma.

Over the past year, the LBCA SAB continued to promote educational materials for patients facing an invasive lobular carcinoma diagnosis through its website. Webinars with invited experts answering important patient questions were incredibly informative and will most likely continue as a successful strategy for knowledge dissemination.

Importantly, the SAB embraced the challenge of funding research, overseeing two successful requests for applications conducted in close collaboration with the American Society of Clinical Oncology (ASCO) and the American Association for Cancer Research (AACR). SAB members joined as reviewers for ASCO and AACR grant applications and were instrumental in the allocation of research funds to critical projects dedicated to ILC.

Dr. Otto Metzger, Past Chair (FY2022) LBCA Scientific Advisory Board



The Patient Advocate Advisory Board (PAAB) was brought into existence to ensure patients and their loved ones always have a voice to share their perspective on LBCA initiatives.

As chair of the PAAB, I worked in tandem with fellow members and the Scientific Advisory Board to help initiate and implement annual strategic goals. This year a key strategy was to prioritize and focus on the unique differences this "sneaky" cancer has. Invasive lobular carcinoma has been both under studied and under funded. This must change. It is my privilege to be a contributing part of such a worthwhile and much needed organization.

Irene Jamieson, Chair LBCA Patient Advocate Advisory Board

Our Volunteer and Executive Leadership 2022

Board of Directors

















LBCA 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 Vision

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

LBCA Staff

Laurie Hutcheson, Executive Director Mason Mitchell-Daniels, COO/Volunteer Coordinator Karen Ferguson, Development Director Colleen Fitzwater, Communications Director

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LOBULAR BREAST CANCER ALLIANCE INC. **2022 ANNUAL REPORT**

LBCA Launches Groundbreaking ILC Research Grant Program



The Lobular Breast Cancer Alliance (LBCA) was proud to award the first research grant dedicated to ILC in July 2021.

The grant was funded by LBCA and the selection, award, and oversight processes conducted through a partnership with Conquer Cancer, the ASCO Foundation. The \$50,000, one-year grant was designed to support a physician-scientist focusing on ILC research during the transition from a fellowship program to a faculty appointment.

David W. Lim, MDCM, MEd, PhD, of Women's College Hospital in Toronto, Ontario, Canada, was the recipient of the 2021 Conquer Cancer/ASCO Foundation – Lobular Breast Cancer Alliance Young Investigator Award for Invasive Lobular Carcinoma Research.

For his population-based observational study, Dr. Lim used a healthcare database to determine incidence and survival rates of people with pure vs. mixed lobular breast cancer between 1990-2020 treated in the province of Ontario, Canada. This was one of the largest cohorts of people with lobular breast cancer ever studied. Leveraging this resource, he identified factors impacting survival of people with ILC, including patient factors (such as age, ethnicity, socioeconomic status) and tumor factors, variations in care and treatments received, and treatment center characteristics.

"I am profoundly honored to receive the inaugural Young Investigator Award for ILC Research," Dr. Lim said upon receiving his grant. "This early career development award will support my research interest in characterizing disparities in lobular breast cancer care and treatment and, importantly, how these disparities affect outcomes for ILC patients."

LBCA established another first with the Conquer Cancer/ASCO Foundation by requiring that two or more individuals with lobular breast cancer be a part of the grant application review committee as voting members and requiring that individual(s) with lobular breast cancer be included in any applicant's grant development and implementation activities in order to be successful.

Dr. Lim expressed his gratitude to LBCA Patient Advocate Advisory Board member and ILC patient advocate Christine McKay, with whom he collaborated on his research grant application. The grant period started on August 1, 2021.

A final report on the findings from Dr. Lim's research is due in early 2023.

LBCA Video Focuses on Cancer Moonshot



In June, the Lobular Breast Cancer Alliance (LBCA) created a video conveying ILC imaging issues. The five-minute piece was created in response to a Biden Administration call for input on what cancer research should be prioritized through its revived "Cancer Moonshot" initiative.

LBCA intended to raise awareness of the fact that while there has been great progress made in breast cancer research generally, as the White House press release about its Moonshot initiative proclaimed, lobular breast cancer has been left behind.

LBCA's "Moonshot" video emphasizes how little is known about ILC, its unique issues, and how so many people are still being diagnosed with ILC at later stages and/or when their tumors are larger or already metastatic because of inadequate ILC detection methods. It discusses the need for more ILC research to discover better imaging methods and obtain a better understanding of why ILC recurs and how to prevent metastasis. These points are highlighted by testimonies from seven women whose ILC tumors were initially missed with routine screening.

LBCA believes it is important that the Biden Administration and the public understand that breast cancer has subtypes and that ILC is one that has many troubling characteristics that are not yet garnering appropriate attention or research.

LBCA uploaded its Moonshot video to the administration's Cancer Moonshot webpage on June 7, 2022. LBCA hopes that the administration's Cancer Cabinet agencies will be moved by the movie's message that lobular breast cancer has been left behind and will support more subtype-specific research, especially ILC.

LBCA also shared the video with the Society of Nuclear Medicine and Molecular Imaging (SNMMI) to promote the message about ILC detection issues. SNMMI shared it with its 15,000 members by posting it in its breast cancer video collection on its website.

The recording was also shared across LBCA's digital channels, including YouTube where the piece has been viewed more than 1,600 times.

International ILC Symposium



In June 2022, ILC researchers, clinicians, and patient advocates came together in Utrecht, Netherlands, for the joint International ELBCC/Lobsterpot & LBCA ILC Symposium and Summer School. LBCA sponsored the event and co-planned its patient advocate session.

This was the first in-person ILC symposium since 2016 and the first ever in Europe. Sessions included one specifically for patient advocates from across Europe and from LBCA followed by a day and a half of sessions delving into ILC science. Topics included: ILC Histology/Pathology; Systems Biology Approaches for ILC; Risk Factors, Clinical Diagnosis, and Treatment of ILC; Hormone Receptor Function and Drug Responses; and Cell Adhesion and the ILC Microenvironment.

There were also sessions focusing on how patient advocates and researchers can work collaboratively to further ILC research. This included a session featuring LBCA's three ILC research grantees discussing how they worked with patient advocates. Everyone was thrilled with the energy in the meeting, how the current information on ILC was shared in such an accessible way, and with the opportunity for formal and informal dialogue among the researchers and patient advocates.

ILC patient advocate Nancy MacGillivray attended the symposium with her husband, Brian. Both received travel scholarships from LBCA to attend the conference. She described coming away with much more knowledge about ILC and its challenges. "I loved every minute of the Symposium," Nancy commented. "In addition to the presentations and posters, meeting the other advocates, doctors, clinicians, and researchers was also so rewarding."

In September, LBCA hosted a webinar summarizing the Symposium science in lay terms. Drs. George Sflomos, Karen Van Baelen, and Rita Mukhtar provided a summary of the basic science, translational, and clinical ILC research, respectively.

Links to recordings of most of the <u>ILC Symposium sessions</u> and the <u>Summary webinar</u> are available. Planning is already underway on the 2023 ILC symposium to be held in Pittsburgh, PA.

LBCA Survey Highlights

The Lobular Breast Cancer Alliance (LBCA) issued a performance survey asking how we have done relative to each of our five key goal areas and activities in support of our mission and vision. There were 291 respondents. Among the 240 people sharing demographic information, 96% have/have had ILC and 83% were over age 51. Most reside in North America (82%) followed by 12% in Europe. Following are survey result highlights.

In terms of questions about LBCA's effectiveness raising awareness and educating about ILC research:

93% agreed or strongly agreed that LBCA's website and materials were easy to understand and about the same number think LBCA provides useful information about the differences between ILC and invasive ductal carcinoma (IDC).

96% believe LBCA explains ILC and conveys the urgent need for more research and **88%** agreed they perceive LBCA as the "go to" website for ILC information.

82% of respondents who use the LBCA Publications Library on the website indicated that they can find what they are looking for and the information is useful. Similarly, **88%** of respondents who reported using LBCA's patient advocacy tools and materials agreed they found the information useful.

63% indicated being aware that LBCA collaborates with other breast cancer advocacy groups in the US and globally. A few commented that this collaboration is effective because together organizations are better able to raise awareness and educate about ILC. There were many suggestions in answer to our request for suggested organizations in the US and elsewhere with which to collaborate in the future.

We also received comments thanking LBCA:

"I'm incredibly grateful for the resources and advocacy provided by LBCA"

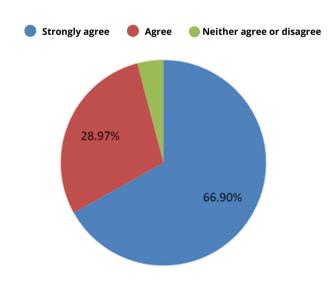
"I would have been totally lost without the information available on your website, thank you!"

"I appreciate reading other survivors' stories. I read them every month."

"Thank you for being there...I am grateful to LBCA for its work."

"I am encouraged your organization exists and provides current information and research... early in my ILC journey, I was often frustrated when trying to become more informed about my disease. This changed when I found LBCA."

The information on the website helps explain ILC and conveys the urgent need for more research to others.

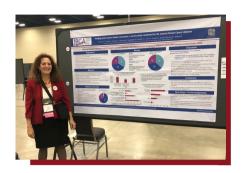


LOBULAR BREAST CANCER ALLIANCE INC. 2022 ANNUAL REPORT

LBCA Major Accomplishments By Goal Area

Fiscal Year 2022 (July 1, 2021 - June 30, 2022)

LBCA Goal: Raise Awareness and Educate about ILC



- LBCA surveyed individuals with ILC regarding issues with imaging.

 An abstract and a poster were developed conveying the results for presentation at the San Antonio Breast Cancer Symposium (SABCS21) and publication. Results included confirmation of patient experiences having ILC tumors missed by mammograms.
- Produced and distributed an ILC awareness raising video, audio PSAs, and a 3-minute interview with LPGA golfer Angela Stanford discussing her mother's battle with metastatic ILC and the need for more ILC research.
- Produced and posted an <u>educational webinar</u> on how FES/PET is used in imaging to help determine how well hormone positive cancer tumors respond to treatment. The webinar premiered on Facebook and was then shared on social media.
- Completed two movies about ILC: a <u>10-minute movie</u> promoting awareness of ILC and LBCA and the need for more ILC research featuring patient advocates, SAB members and other scientists and clinicians; and a <u>5-minute movie</u> on the issues of ILC and imaging.
- Increased newsletter subscribers by 17.1%. Increased newsletter open rate by 10.15%. (54.15% this year vs. 44% last year). Nearly 37,000 people visited LBCA website.
- Produced and posted three video interviews with LBCA Scientific Advisory Board (SAB) members and three LBCA-funded ILC researchers about their ILC research.
- Surveyed newsletter subscribers to better understand their needs and wants.

LBCA Goal: Be the Go-to Source for ILC Research/Clinical Trials and ILC Treatment Information

Posted blogs by LBCA SAB members on various aspects of ILC on the LBCA website and also shared on social media. Blog topics included:



- ILC treatment (two blogs by <u>Drs. Rita Mukhtar</u> and <u>Rachel Jankowitz</u>).
- <u>Dr. Raquel Nunes</u> blogged about the utility of BCI index for assessing ILC risk of recurrence.
- Executive Director Laurie Hutcheson and past LBCA SAB Board Chair Dr. Otto Metzger co-hosted a webinar on metastatic ILC for the Dana Farber Cancer Institute's program Ending Metastatic Breast Cancer for Everyone (EMBRACE).
- Created a <u>page</u> on the LBCA website highlighting the ILC research of our SAB members.

LBCA Goal: Cultivate Alliances Among US & International Breast Cancer Advocacy Organizations

- Launched a campaign with our European ILC advocate peers during Breast Cancer Awareness Month in October conveying how important it is to say explicitly "I have LOBULAR breast cancer" and not just "I have breast cancer."
- LBCA founder Leigh Pate and executive director Laurie Hutcheson interviewed LBCA scientific advisory board member Matt Sikora about his ILC research for a KOMEN Advocates In Science online "Coffee Chat" program.
- Planned, participated in and co-sponsored the <u>first international ILC Symposium</u> in Utrecht, Netherlands, hosted by the European Lobular Breast Cancer Coalition (ELBCC).
- Worked with LBCA partner organization the Metastatic Breast Cancer Alliance (MBCA):
 - on the creation of an LBCA-specific page on their relaunched website.
 - on content for MBCA's "Here All Year (HAY)" initiative. Each week in July featured a different metastatic ILC (mILC) issue and short video recordings of women with mILC sharing their stories.
- Collaborated with the Harvard/MIT Broad Institute's "Count Me In" program on their Amplifying Black Voices Across Cancer digital campaign.

LBCA Goal: Promote and Fund ILC Research



- Awarded and funded three ILC research grants via administrative partnerships with the American Society for Cancer Oncology (ASCO) and the American Academy for Cancer Research (AACR).
 - Awarded first ever ILC research grant for \$50K for one year and a two-year grant for \$100K plus administrative fees via ASCO.
 - Awarded first ever two-year ILC research grant for \$120K plus administrative fees with AACR.
- Hosted a recorded panel discussion moderated by past LBCA SAB Chair Dr. Otto Metzger and featuring SAB member Dr. Jorge Reis-Filho and ELBCC members Drs. Christine Desmedt and Anne Vincent-Salomon regarding the need for standardizing ILC. The <u>recording</u> was shared across social media.

LBCA Goal: Support ILC Patient Advocacy

- The LBCA SAB grew by two with the additions of Dr. Jason Mouabbi of MD Anderson and Dr. Rinath Jeselsohn of Dana Farber Cancer Institute who became the new chair in June.
- Provided travel scholarships to LBCA's three ILC grant awardees so they could attend and present their research at the ILC Symposium.
- Commenced quarterly meetings of LBCA's new 14-person ILC Patient Advocate Advisory Board.
- Conducted two informal Advocate Chat conversations with ILC patient advocates attending the San Antonio Breast Cancer Symposium (SABCS) in December 2021 to provide tips on how to make best use of this most important breast cancer conference.
- Shared summaries of select ILC poster presentations of ILC research presented at SABCS 21
- LBCA was invited to join the Society of Nuclear Medicine and Molecular Imaging (SNMMI) Patient Advocate Advisory Board.
- Held informative *Advocate Chats* including one on Telling Your ILC Story in June.



Fiscal Year 2022 Finances

This was truly a year of transition and exciting growth for LBCA Inc. With the receipt of thousands of dollars in donations by the end of December 2021, we were able to officially spin off from our fiscal sponsor in January and commence operations as our own free-standing charity. In the remaining six months of the fiscal year (which ended June30), we were fortunate, as a new independent and small non-profit organization, to have received sufficient funding from donors to enable us to commit to funding two new ILC research grants – one focusing on ILC imaging.

Judicious in our spending and strategic in our use of volunteers, we were also able to offer financial support to several ILC patient advocates and researchers to enable them to attend the first international, in-person ILC symposium in Utrecht, Netherlands, at fiscal year end.

We also expanded our awareness raising efforts to include the production of two short movies that provided information about ILC and LBCA resources. And with careful stewardship of our funds, we ended the fiscal year with funds available for producing additional educational webinars, short informational movies, and more ILC research grants in the coming fiscal year.

LBCA's First Financial Review as an Independent 501(c)3

Fiscal Year 2022 (FY22) was the first year LBCA had an independent CPA review of its financial statements as a free-standing organization, with statements reporting revenue and expenses for the year ended June 30, 2022. Revenue reported for the period included the transfer of net assets accrued by LBCA in its prior status as a project under a non-profit fiscal sponsorship, in addition to contributions that were made directly to LBCA. Expenditures reported do not include expenditures incurred by LBCA while under fiscal sponsorship (i.e., prior to January 2022). These expenditures include two (the second and third of three) ILC specific grant awards to early investigators that LBCA has instituted. The grant awards in the amounts of \$50,000 and \$60,000 were made by LBCA but conveyed through its fiscal sponsor at the beginning of FY22.

LBCA engaged the independent CPA firm Citrin Cooperman and Company, LLP, to conduct an independent review of LBCA's financial statements for its first fiscal year as an independent 501(c)(3) charitable organization. Based on their review, the certified public accountants concluded "we are not aware of any material modifications that should be made to the accompanying financial statements in order for them to be in accordance with accounting principles generally accepted in the United States of America."



Fiscal Year 2022 Finances

SUMMARY OF REVENUE & EXPENSES	FISCAL YEAR 2022
Contributions (Includes asset transfer from fiscal sponsor)	\$416, 315
In Kind Contributions	\$36,000
Grants Received	\$1,000
Payroll and related	\$131,316
Professional Fees	\$75,573
Scholarships and Sponsorships	\$11,500
Office and Other	\$7,483
Insurance	\$1,261

^{**}LBCA funded ILC Research Grants in FY22 (while under fiscal sponsorship) totaled \$110,000 and are not reflected in the expenses listed above.

ASSETTS, LIABILITIES & NET ASSETS	END OF YEAR 2022
Assets	\$236, 186
Liabilities	\$11, 273
Net Assets	\$224,913

Fiscal Year 2022 Donors

Everything we are able to accomplish is due to the generosity of our donors. We are grateful to each of them for their support.

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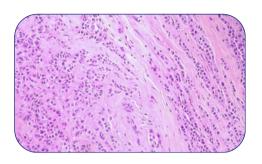
While every effort has been taken to ensure the accuracy of this list, we know mistakes may happen. We apologize for any omissions.



"Breast cancer is at epidemic proportions.
Lobular is the sneaky one, evading normal screening protocols making it difficult to detect, often caught so late that tumors are much more dangerous and life threatening. We know that with more attention and research, it doesn't have to be this way. As individuals we support the patients with lobular breast cancer, scientists, and medical professionals who are advocating for change and committed to finding answers. LBCA facilitates their collaborative efforts to do this important work. This is why we wholeheartedly support LBCA."

Judy and Bob McDevitt, Patient Advocate Advisory Board Member (Judy) and Loyal Donors

Thanks to You... We're Making a Difference



"LBCA introduced me to patient advocacy....It is a very efficient non-profit that delivers results... Through it, I've found community, understanding, and most importantly, an avenue to give some purpose to my diagnosis by working towards a world without lobular breast cancer." Sue. Patient Advocate



"If we don't have enough studies of ILC then we can't really say what is different between ILC and IDC. We truly can't treat ILC appropriately." Dr. Candace Frerich, AACR – LBCA Invasive Lobular Carcinoma Research Fellowship Recipient



"Lobular breast cancer is not well known, and yet, it affects a sizable number of women each year and merits more attention among the breast cancer community and the public. With funding for lobular breast cancer research, we can and will find better ways to screen it, detect it, and treat it—ultimately saving lives." Shirley Mertz, Metastatic Breast Cancer Network, Loyal Supporter



"I donate monthly in support of what LBCA does for researchers and patients; We need more research and to share the scientific facts about lobular breast cancer to better support us all. LBCA helps get this done." Donna, ILC Patient Advocate and Monthly Donor



"When I was diagnosed I had never heard of ILC. In my first google search I discovered LBCA. With the information I learned I was able to make decisive decisions with my surgeon on how "I" wanted to proceed.... Most of what I do know about ILC is due to LBCA."

Anonymous, ILC Survivor

"I feel incredibly grateful to the LBCA for providing funding which allowed me to attend the ILC symposium in Utrecht. This was the first time after my diagnosis that I had the opportunity to meet other ILC patient advocates, clinicians, and researchers in person and I was blown away by the various collaborations and the role of advocacy in the presented studies." Gitte, ILC Patient

Advocate



"I came across LBCA, and I learned so much. I loved that they were advocating for lobular cancer to be seen as the unique entity that it is. I loved how they promoted research that looks at targeting the unique qualities of lobular breast cancer to hopefully create treatments that are more effective for this type of cancer in the future." Julie, ILC Survivor



"I give to LBCA because as an ILC patient I believe building a knowledge base is very important. I am grateful for the state of the art website with all the resources, and am comforted by the fact that the Scientific Advisory Board works hard to help ensure the accuracy of information shared and are committed to their own ILC research to find a cure for this breast cancer." Jennifer, Professor, ILC Patient and Loyal Supporter



"As a breast cancer patient, it's important to me to give thoughtfully and with impact. Through my donation to LBCA, I'm able to make a difference not only in the breast cancer community in general, but within the ILC community specifically. I love that we are funding research into ILC."

Sarah, Loyal Supporter and ILC Survivor



"What appealed to me is this is an initiative from patients and patient advocates. It's from the LBCA together with the Conquer Cancer Foundation and it gives the award an extra dimension. There is a lot of focus with working together with patients and patient advocates. The patient advocates are also involved in reviewing the applications and that is important to me." Dr. Karen Van Baelen, 2022 Conquer Cancer – LBCA Young Investigator Award for ILC Research Recipient





The Lobular Breast Cancer Alliance Inc. is the go-to source for invasive lobular carcinoma (ILC) information and advocacy, and the only organization in the U.S. dedicated to raising awareness about ILC in a quest to eradicate lobular breast disease.

Our next step on the path to fulfilling our mission is to build our capacity to share more ILC information, publicize current and cutting edge research and clinical trials, grow and nourish a network of patient advocates, and fund more ILC research grants.

We continue to need your help:

- to ensure sorely needed research on methods of detecting ILC and preventing its recurrence, and identifying best treatment approaches for ILC distinct from that for ductal;
- to support our growing community of women collaborating to educate clinicians and help one another raise awareness about this understudied disease: and
- to keep LBCA moving forward to stop this deadly breast cancer subtype that afflicts tens of thousands of women each year.

Please support LBCA with a contribution now to help us succeed!

Lobular Breast Cancer Alliance Inc.

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