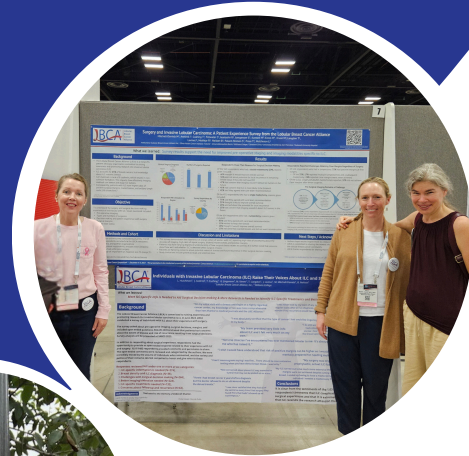
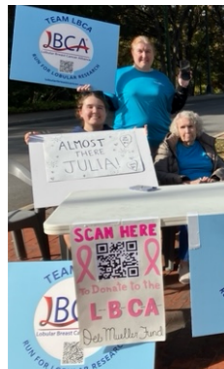
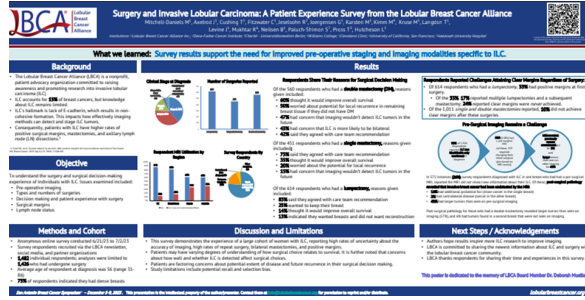
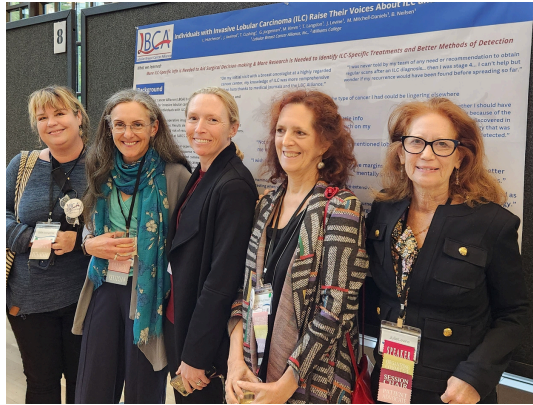


FY 2024 ANNUAL REPORT



JULY 1, 2023 - JUNE 30, 2024

YEAR IN PHOTOS



New Today! LBCA Launching Satellite Advocacy Groups

The Impetus: Regular inquiries from individuals w lobular breast cancer seeking local opportunities & peers with whom to advocate/meet researchers/raise funds for LBCA and ILC research in person

Examples of Satellite Advocacy Group Activities (pretty wide open):

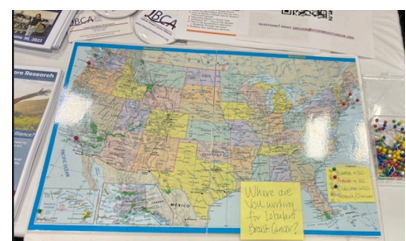
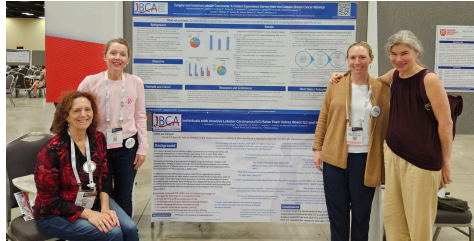
- In person outreach to breast cancer programs to get info to their ILC patients about ILC/LBCA
- Participate/provide patient voice in a lobular grand rounds presentation
- Meet/collaborate with local ILC researchers – visit labs, assist with ILC research grants
- Reach out to local media with information about ILC and LBCA – tell your story
- ID local businesses near you that might be interested in sponsoring LBCA activities
- Meet up routinely and brainstorm, plan, and implement additional advocacy actions

The Plan:

- LBCA Board developed and adopted charter to provide guidance and parameters
- LBCA team will provide resources and guidance and publicity for the groups
- Volunteer coordinator position - will join LBCA team/meet with each group virtually, regularly
- LBCA starting outreach (now) to ID interested ILC advocates by state
- Start small and evolve - future formation of LBCA chapters a possibility

Interested in hearing more? Email lauriehutcheson@lobularbreastcancer.org

Sign up Here to participate in or lead an LBCA Satellite Advocacy Group ->



A MESSAGE FROM OUR EXECUTIVE DIRECTOR

I am proud to share that our most recent fiscal year (FY24), which ended June 30, 2024, was another year of "firsts" and new achievements for LBCA in supporting patient advocates and promoting more lobular breast cancer research.

Our most significant "first" advocacy initiative was launched in the fall of 2023 during the LBCA-sponsored Invasive Lobular Carcinoma Symposium in Pittsburgh, where I announced LBCA's new initiative - Local Advocacy Teams (LATs). The intention of the LAT initiative is to promote local, in-person lobular breast cancer education and advocacy activities. We believe that it is the perfect and natural next step in the evolution of LBCA.



With the ideal volunteer leadership of Kathleen Moss to assist us in helping individuals interested to get started, we have convened a planning and brainstorming group that has so far produced two LATs. I am optimistic for the LAT initiative to help accelerate the pace at which we can penetrate many more breast cancer programs and persuade them to share lobular breast cancer information and our URL with their patients.

Our second "first" was hard earned. After two years of our messaging and outreach to President Biden's National Cancer Panel and Moonshot Initiative, in which we repeatedly conveyed information about lobular breast cancer and how it has been left behind in research, we were excited to be commended for our advocacy and to see the Panel promote awareness of our organization's mission. The President's Cancer Panel posted the commendation on LinkedIn and X, shared our URL and urged everyone to visit our website.

LBCA also was proud to be among the first members of the newly formed American Cancer Society National Breast Cancer Roundtable Meeting in Houston. It was an honor and a boost for our visibility. I left the two-day meeting with great hope and new connections that have already assisted us in influencing government breast cancer sites to add comprehensive information on lobular breast cancer. Another exciting aspect of FY24 was significant grant making activity. We were able to develop and issue a record number of lobular breast cancer research grant solicitations through our partnerships with AACR, ASCO and SNMMI. Our ability to offer so many grants this fiscal year was only possible because of the support and generosity of all our donors, including many who are new. It was a record year for LBCA, both in terms of fundraising, breaking \$1M for the first time, and in terms of expanding our reach.

In addition to these exciting new program activities, LBCA continues to be the go-to resource for vital information about lobular breast cancer. Our website with its extensive, scientifically vetted information, provided in multiple languages, received 41,000 visits during the fiscal year, and we now have 6500 subscribers to LBCA's informative newsletter. LBCA also proudly continues to sponsor patient advocate training and participation in breast cancer research symposiums.

I am truly humbled by and grateful to all our volunteers, including our scientific and patient advocate advisory board members without whose guidance, thoughtfulness, time and energy we would not be making such great strides in all our mission driven work. Please read about all we have achieved this year and thank you so much for continuing to believe in and support us as we strive to do even more towards achieving our vision of a world in which lobular breast cancer is detected earlier, treated effectively and eradicated permanently.

A handwritten signature in cursive script that reads "Laurie Hutcheson".

Laurie Hutcheson

MESSAGES FROM THE CHAIRS OF OUR SCIENTIFIC & PATIENT ADVOCATE ADVISORY BOARDS

"Serving as the Chair of the Scientific Advisory Board for the LBCA has been one of the most fulfilling and rewarding experiences of my career. Leading such a passionate and dedicated group of professionals has been a true privilege, and together, we have accomplished so much this year. Our success started with a well-received, LBCA-sponsored, educational session at SABCS, which was a significant step forward in increasing awareness and education around ILC. Furthermore, I'm particularly proud that we applied for what will be the first-ever dedicated session on ILC at ASCO, a milestone that underscores the growing recognition of this unique subtype of breast cancer within the broader oncology community. Moreover, we pioneered a new funding model by creating multiple ILC mini grants through the ASCO Conquer Cancer Foundation and AACR, specifically targeting both early and mid-career physicians. We are also collaborating with both the SABCS and AACR to sponsor Merit awards for the best ILC abstracts selected for presentation at SABCS 2024. Finally, we worked closely with colleagues around the world to establish October 15 as Lobular Breast Cancer Awareness Day. This effort is crucial in raising much-needed awareness and understanding of ILC, ensuring that this unique subtype receives the attention it deserves. It has been an honor to serve as Chair during such a transformative year, and I am excited about the continued progress we will make together in the fight against ILC."



Jason Mouabbi, MD
Chair, LBCA Scientific Advisory Board

We Patient Advocate Advisory Board (PAAB) members work together diligently to surface and express what matters most to invasive lobular breast cancer patients in all that LBCA does in raising awareness and promoting more research for lobular breast cancer. As ambassadors of LBCA, we are privy to the most current information from both the medical and scientific community focusing on ILC research, which is of great benefit in helping to prioritize LBCA's strategic programmatic goals each year. We strive to make the PAAB meetings always "actionable" with a focus on increasing awareness and pushing for advancements in the treatment protocols to identify those most effective for lobular - this distinctly different breast cancer. Progress is certainly being made, in fact this year we created a wonderful new brochure about lobular breast cancer and LBCA and translated it into 19 languages. We still have so much more to do. We remain committed and determined to keep pushing forward, so that people with lobular breast cancer can feel confident that their type of breast cancer is being addressed and treated accordingly. Invasive lobular breast cancer is not rare, accounting for 15% of all breast cancer diagnosed. There are a lot of us, but lobular breast cancer is still not getting the attention it needs, that we deserve. As proud chair of the PAAB, I continue to be committed to helping ensure that the lobular patient voice is a part of the planning to make this happen. This year we have helped to launch a movement to declare October 15th global lobular breast cancer awareness day as a step in this direction. I am excited to see the momentum growing.

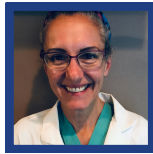


Irene Jamieson
Chair, LBCA Patient Advocate Advisory Board

OUR VOLUNTEER AND EXECUTIVE LEADERSHIP

FY 2024 - as of June 30, 2024

LBCA Board of Directors



Chair: Tracy Cushing, MD



Brenda Cunningham



Laurie Hutcheson, MS



Kathryn Krantz, MD



Tanya Martin



Judy McDevitt



Robert Oakes, JR. CPA, MBA

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 Team

Laurie Hutcheson, Executive Director
Mason Mitchell-Daniels, COO/Volunteer Coordinator
Amie Kolodziej, Communications Director
Suzie Cook Kinsellagh, Major Gifts Officer
Kathleen Moss, Local Advocacy Team Coordinator
Joe Hutcheson, General Counsel
Julia Katherine Levine, Lead Research Advocate and Publications/Clinical Trials Curator
Janice Axelrod, Research and Communication Officer

Patient Advocate Advisory Board

Irene A. Jamieson, Chair
Janice Axelrod, Vice Chair
Ann Camden, Vice Chair*
Brenda Cunningham
Shay Chawla
Karan Garrison
Gitte H. Joergensen
Julia Katherine Levine
Nancy MacGillivray
Diane Mapes
Judy McDevitt
Christine McKay
Flora Migyanka
Barbara Neilsen
Lori Petitti

Scientific Advisory Board

Jason A. Mouabbi, MD, Chair
Rinath Jeselsohn, MD
Patrick W.B. Derksen, PhD
Rachel C. Jankowitz, MD
Maxine Jochelson, MD
Megan Kruse, MD
Rebecca Shatsky, MD
Rita Mukhtar, MD
Shani Paluch-Shimon, MD
Fresia Pareja, MD
Rebecca B. Riggins, PhD
Mothaffar Rimawi, MD
George Sflomos, PhD
Matthew J. Sikora, PhD
Peter Simpson, PhD
Christos Sotiriou, MD, PhD
Gary A. Ulaner, MD, PhD

*deceased July, 2024

LOBULAR BREAST CANCER ALLIANCE

2016-2019

First survey conducted
Re: need for patient facing website on Lobular Breast Cancer (2016)

Founding Advocates

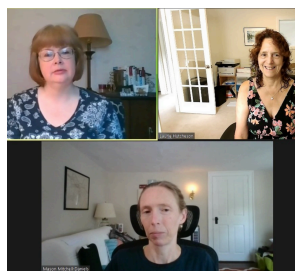


White paper written and LBCA website launched by Leigh Pate and patient advocates who formed the LBCA steering committee (Winter 2017)

2020

May 1, 2020
Laurie Hutcheson becomes Executive Director

First staff hired:
COO and volunteer deputy director (Mason Mitchell-Daniels)

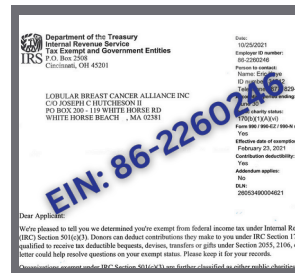


Communications Director (Colleen Fitzwater) and Volunteer general counsel (Joe Hutcheson) start Summer 2020

2021

Awarded first ILC research grants

First quarterly Patient Advocate Advisory Board (PAAB) convened



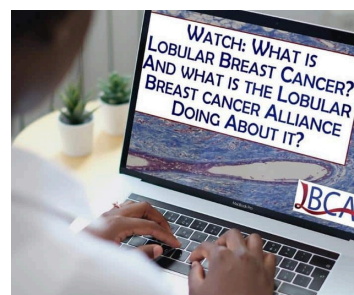
LBCA received tax-exempt status

Awarded second ILC research grants

2022

LBCA became independent nonprofit Lobular Breast Cancer Alliance Inc. (January)

Produced first Video about ILC and LBCA



Awarded third ILC research grant

2023

Created breast cancer types flyer with 21 breast cancer advocacy organizations and sent to congress



Funded first ILC Imaging research grant

LBCA joined the ACS National Breast Cancer Round Table and was Commended for advocacy by President's Cancer Council

2024

Funded and named for Deb Mueller and Sarah Bieze, two ILC research mini grants and a second ILC imaging grant (the 9th ILC grant)

Released ILC brochure, translated into 19 languages



Awarded AACR-LBCA- Deborah Mueller Foundation ILC Innovation and Discovery Grant

MAJOR MILESTONES TIMELINE

2016
-
2019

LBCA becomes fiscally sponsored nonprofit through Social and Environmental Entrepreneurs (SEE) (Winter 2018)

First LBCA newsletter published electronically

Strategic plan created calling for creation of formal organizational infrastructure (Summer 2019)



2020

Convened first quarterly Scientific Advisory Board (SAB) meeting via zoom.



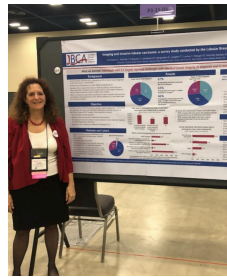
Added 50 new studies to the publication library

Created lay summaries of 13 posters on ILC research presented at virtual SABCS

2021

First major newspaper covers ILC and Motschenbacher's cross country bike ride

Presented LBCA poster on ILC at 1st post-COVID SABCS



Produced PSA with professional golfer Angela Stanford



Produced video recap of virtual ILC Symposium

2022

Produced video on ILC imaging challenges



Presented poster on metastatic ILC patient perspective at SABCS

Issued first Annual Report



2023

Co-sponsored ILC Symposium in PA and assisted 12 with scholarships to attend



Launched the Local Advocacy Team initiative



Co-sponsored first education session on ILC at SABCS

2024

Reached 6,500 newsletter subscribers Active on LinkedIn, Instagram, & Facebook

Drafted October 15th Declaration Letter



Achieved Gold Transparency Guidestar Candid rating

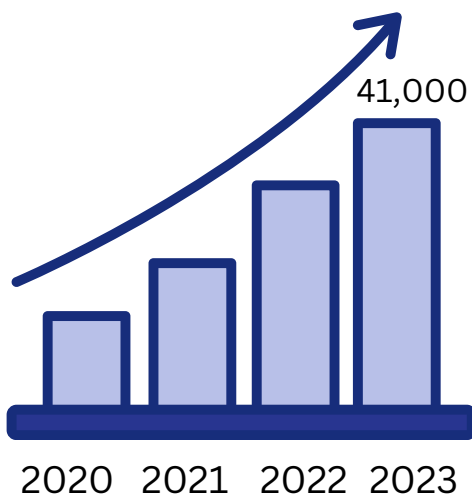
Gold Transparency 2024

Candid.

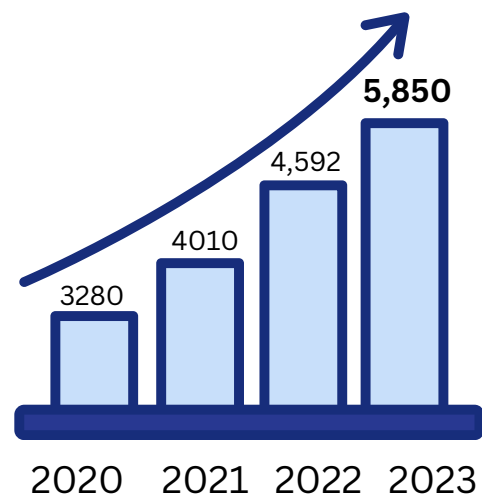
STAKEHOLDER ENGAGEMENT

LBCA has seen steady growth across all metrics including its volunteer participation, and in digital engagement across all channels including website views, newsletter subscribers and social media followers. We have now created benchmarks to track year over year growth beginning with FY23.

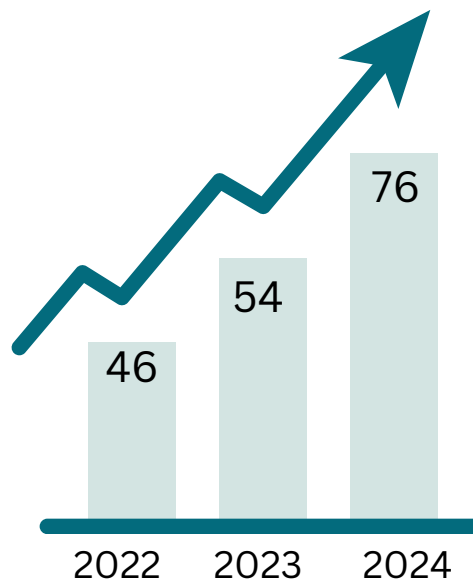
WEBSITE VISITS



NEWSLETTER SUBSCRIBERS



VOLUNTEER PARTICIPATION



LOBULAR BREAST CANCER FEATURED IN SABCS EDUCATION SESSION

The San Antonio Breast Cancer Symposium (SABCS) is the world's largest breast cancer conference and hosts clinicians and scientists from around the world.

In 2023, Invasive Lobular Carcinoma finally merited a full educational session.

LBCA proudly sponsored this session and assisted many ILC patient advocates to attend. The panel was moderated by LBCA Scientific Advisory Board (SAB) founder and ILC researcher Dr. Steffi Oesterrich, and included SAB Chair and oncologist Dr. Jason Mouabbi, translational researcher Dr. Christine Desmedt, breast cancer surgeon Dr. Tari King, and lobular breast cancer patient advocate Siobhan Freeney.

The ILC session covered the latest information on what is known of

- the biology of lobular breast cancer,
- genetic mutations in lobular
- certain proteins found in ILC more than in IDC and what that might mean for future targeted therapies.

Also shared were;

- the challenges of imaging due to the lack of the protein E-cadherin,
- challenges in surgery and obtaining negative margins,
- some of the peculiar sites that ILC can metastasize to
- updates on promising ILC clinical trials.



The nearly full ballroom of attendees included many LBCA travel scholarship awardees – the largest number of LBCA associated volunteers to ever attend.

The 2023 SABCS conference had another first for LBCA – an LBCA booth! The booth was stocked with printed materials and gave LBCA great new exposure to share resources.

LBCA presented another lobular breast cancer patient experience poster. Results from our survey about the challenges of lobular breast cancer and surgical decision included: high rates of women reported high rates repeat surgery and are factoring concerns about imaging accuracy and about potential extent of disease and future recurrence into surgical decisions.

Read more about our poster and a record number 20 other posters on lobular breast cancer presented throughout the weeklong conference here:

<https://lobularbreastcancer.org/a-collection-of-ilc-focused-poster-summaries-from-sabcs23/>

MAJOR ACCOMPLISHMENTS BY STRATEGIC GOAL AREA

1. Raise Awareness and Educate about ILC



Panel commends @LobularBCA for their commitment to raising awareness, promoting patient advocacy, & supporting lobular breast cancer research. We invite you all to learn more about their initiatives lobularbreastcancer.org #NationalCancerPlan #Every1HasARole



- LBCA commended for advocacy from President Biden's National Cancer Panel
- Presented patient experience posters at breast cancer conferences
- Published 12 ILC Stories and one tribute video
- Produced new trifold brochure on ILC/LBCA
- Produced and hosted on website 2 live webinars (1. ILC symposium recap / 2. what's new in screening/treatment)
- Developed FAQ resource on Tissue Donation
- Translated patient resources into 16 languages
- Conducted 3 "Advocate Chat" webinars with researchers SAB member Dr. Pete Simpson and Drs. Amy McCart Reed, Carlos Arteaga and Sana Shabbir

2. Be the Go-to Source for ILC Research/Clinical Trials and ILC Treatment Information

- Produced new video supporting clinical trial participation
<https://tinyurl.com/LBCAClinicalTrials>
- Conducted 3 video interviews with SAB members, Drs. Mouabbi, Sflomos Simpson & Shatsky, about their research
- Added 14 new additions to SAB member research page
- Provided lay summaries of 14 posters presented at SABCS23



MAJOR ACCOMPLISHMENTS BY STRATEGIC GOAL AREA

3. Cultivate Alliances Among US & International Breast Cancer Advocacy Organizations



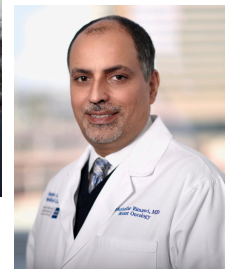
- LBCA participated as a member in inaugural meeting of the ACS National Breast Cancer Round Table
- Co-sponsored and helped plan ILC Symposiums in Pittsburgh and Belgium

4. Promote and Fund ILC Research

- Funded 2 more ILC research grants including 1 focused on imaging
- Co-authored study on how absence of ILC patients in clinical trials impedes finding ILC treatments
- Brought on 3 new Scientific Advisory Board members: Dr. Fresia Pareja, Dr. Mothaffar Rimawi and Dr. Rebecca Shatsky



Dr. Pareja



Dr. Rimawi



Dr. Shatsky

5. Support ILC Patient Advocacy



- Assisted a record number of individuals (Travel Grants) to attend SABCS23 and the ILC Symposium in Pittsburgh, PA.
- Launched Local Advocacy Team (LAT) initiative
- Supported Advocates to attend NBCC's Project Lead breast cancer training program

LAUNCH OF THE LOCAL ADVOCACY TEAM (LAT) INITIATIVE



LBCA launched the **Local Advocacy Team (LAT)** initiative to provide opportunities for individuals with lobular breast cancer living in the same geographic area in the US to connect with one another and engage in in-person ILC awareness raising activities.

LBCA worked with ILC patient advocate and volunteer, Kathleen Moss, who became LBCA's Local Advocacy Team (LAT) Coordinator and chairs monthly meetings of advocates interested in starting or who have started LATs to share tips and challenges. Two LATs (below) were initiated in FY24.

Lobular Awareness Network of South Carolina

led by LBCA Ambassadors Minnie Campolong and Melanie Trimble launched in April of 2024.



LAT DMV: DC, Maryland & Virginia

led by LAT Ambassadors, Brenda Sulick and Jeanette Brown launched in June of 2024.

A Message About LATs from our Volunteer Coordinator



It's been ten months since we began the Local Advocacy Teams (LAT) project in the fall of 2023. The LAT project was initiated to support individuals seeking to advocate in person together, to educate patients and community members as well as medical professionals and other service providers in the oncology community about the peculiarities of Lobular Breast Cancer from the perspective of the ILC patient.

We successfully launched two official Local Advocacy Teams in FY24. And we now have over fifty dedicated advocates from 25 of the 50 states interested in doing local advocacy and attending our monthly check-in meetings and who may one day form their own LAT. I am excited in anticipation of launching three or four more in FY25.

Stay tuned to hear more as we grow in knowledge, members and outreach efforts!

Kathleen Moss

Local Advocacy Team (LAT) Coordinator

RESEARCH GRANTS

LBCA Awarded the following research grants in partnership with the American Association for Cancer Research (AACR)

2023 AACR-LBCA Invasive Lobular Carcinoma (ILC) Research Fellowship

The 2023 AACR-LBCA Invasive Lobular Carcinoma (ILC) Research Fellowship was awarded to **Capucine Héraud, PhD**, in July of 2023. The two-year grant, totaling \$120,000, allows Dr. Héraud to continue her research on the differences between ILC and invasive ductal carcinoma (IDC) cells and on how those differences make ILC more resistant to traditional treatments.



AACR-LBCA – Deborah Mueller Foundation Invasive Lobular Carcinoma Innovation and Discovery Grant

LBCA awarded two new AACR-Lobular Breast Cancer Alliance – Deborah Mueller Foundation Invasive Lobular Carcinoma Innovation and Discovery Grant awards to:

Dr. Julia Houthuijzen from the Netherlands Cancer Institute-Antoni van Leeuwenhoek Hospital (NKI-AVL) and

Dr. Carolina Reduzzi from Weill Medical College of Cornell University.

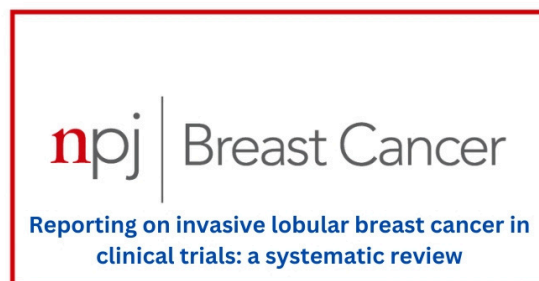
The two recipients of these one-year \$50,000 grants will focus one, on studying ex vivo human ILC cultures to develop personalized ILC treatments and the other on comprehensive liquid biopsies to decipher lobular breast cancer metastasis. These are the first two of three ILC research grants funded by the Deborah Mueller Foundation to support lobular breast cancer research in memory of LBCA board member Deborah Mueller who passed away in 2023 from metastatic lobular breast cancer.



LBCA MEMBERS CO-AUTHOR JOURNAL ARTICLES

LBCA Members Co-author npj Breast Cancer Journal Article Highlighting How Absence of Lobular Patients in Clinical Trials Impedes Finding Treatments

LBCA members including SAB Members Rachel Jankowitz and Patrick Derksen, ILC Grantee Karen Van Baelen, LBCA Executive Director Laurie Hutcheson, LBCA Patient Advocate Advisory Board members Ann Camden and Julia Levine, LBCA Travel Scholars Megan-Claire Chase and Valerie Fraser co-authored an article with sister organizations – the European Lobular Breast Cancer Consortium and Advocates.



The article, “Reporting on invasive lobular breast cancer in clinical trials: a systematic review” provides a review of the representation and documentation of ILC in phase III/IV clinical trials for novel breast cancer treatments worldwide.

It concludes that patients with ILC and particularly patients belonging to minority subgroups are neglected by clinical investigators and pharmaceutical industries, leading to significant unmet clinical need. Its findings highlight the importance of acknowledging that poor documentation and underrepresentation of ILC and minorities in clinical trials continues to impede personalized treatment of all those diagnosed with ILC.



LBCA Co-Authors Journal Article in Journal of Breast Imaging - Breast Radiologists' Perceptions on the Detection and Management of Invasive Lobular Carcinoma

LBCA Executive Director Laurie Hutcheson co-authored an article in a publication from the Journal of the Society of Breast Imagers (SBI) that presents the results of a survey developed and issued by LBCA jointly with members of the Society of Breast Imagers about radiologists' confidence in mammograms for detecting lobular breast cancer. LBCA reached out to SBI to conduct the survey in order to help raise awareness about the issues of lobular breast cancer and imaging. The findings do just that. LBCA also paid for open access so the full text can be downloaded and shared.

CREATED TRI-FOLD BROCHURE ON ILC AND LBCA

This brochure released in early 2024 contains an overview of ILC including information about key features and how it differs from other types of breast cancer, and current information on ILC imaging and treatment. It also describes the key resources that LBCA provides for anyone interested in understanding ILC and patient advocacy. The brochure is available in a digital version online and as a PDF to download. It can be viewed and/or be printed in 19 languages.



The brochure has been distributed on the LBCA website and via the newsletter and social media with over 1,450 views. Hundreds of copies have also been given out in person by LBCA SAB Members, LAT Ambassadors and staff at national and international events including SNMMI.

WHAT IS LOBULAR BREAST CANCER ?

Also known as invasive lobular carcinoma (ILC), it is the 2nd most common subtype of breast cancer after invasive ductal carcinoma (IDC).

About 15% of all breast cancers diagnosed in the U.S. each year are lobular.

- ILC is usually hormone receptor-positive (>90% of cases).
- Lobular tumors metastasize most commonly to the liver, lungs, and bones, but can also metastasize to uncommon sites such as the gastrointestinal tract, ovaries, or the lining of the brain (leptomeninges).
- Despite a generally good prognosis, some studies suggest an increased risk of late recurrence (after 5 years).
- More research is needed to understand relapse drivers and therapy resistance.

ILC DEMOGRAPHICS*

* Source: NCI SEER-22, 2016-2020.

Age/Gender: Most ILC diagnoses occur in women > age 60

Race/Ethnicity: 73% of ILC diagnoses are non-Hispanic White, 12% are Hispanic, 9% are non-Hispanic Black, 5% non-Hispanic Asian/Pacific Islanders

UNDER THE MICROSCOPE

ILC Tumor Cells	VS	IDC Tumor Cells
Cells grow in single file formation		Cells clump together in "lumps"

IMAGING AND TREATMENT

Imaging

Because it usually does not form lumps, invasive lobular carcinoma can be hard to feel and to see on imaging.

- ILC is often found larger when the tumor is already 2 cms, and involves the axillary lymph nodes (in the arm pit).
- There are not yet specific guidelines for best detecting initial, or screening for recurrent ILC tumors.

Treatment

Hormone therapy is recommended for both pre- and post menopausal patients with hormone receptor positive ILC.

- Aromatase inhibitors and tamoxifen are used most commonly.
- Chemotherapy may be beneficial for some patients with ILC, but there is ongoing research into when it is most effective for those with early stage hormone receptor positive disease.

Everyone is different. Discuss your imaging and treatment options with your care team.

WHAT IS THE LOBULAR BREAST CANCER ALLIANCE (LBCA)?

LBCA is a national nonprofit organization founded and guided by patients to address the lack of ILC information and research.

- LBCA is guided by an advisory board of international clinicians and researchers with ILC expertise.
- LBCA provides comprehensive information on ILC through documents and webinars.
- LBCA helps individuals and scientists work together on ILC advocacy and research.

LBCA RESOURCES

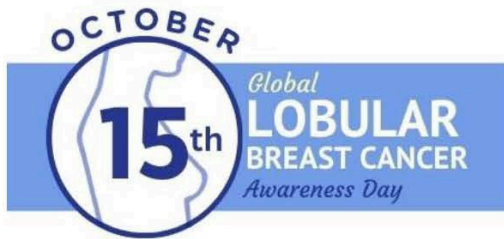
LBCA has resources to help you talk with your care team and more.

- Questions for My Doctor*
- ILC Fact Sheet*
- Frequently Asked Questions (FAQs)*
- Information on Metastatic ILC*
- ILC Stories
- Educational Videos
- Information on Open ILC Clinical Trials
- Breast Cancer Patient Support

*available in 15 languages

Scan here to visit the LBCA Resources Page lobularbreastcancer.org/resources

OCTOBER 15TH DECLARATION LETTER



LBCA led the drafting with 60+ scientists and patient advocates around the world

To Whom it May Concern,

We, the undersigned, declare October 15th as "Global Lobular Breast Cancer Awareness Day."

Invasive lobular carcinoma (ILC), also known as lobular breast cancer, comprises 15% of all breast cancer diagnoses¹. Despite this incidence, there has been a lack of attention paid to the disease and a lack of funding for scientific research. October is breast cancer awareness month worldwide; declaring October 15th **Global Lobular Breast Cancer Awareness Day** – will help raise worldwide awareness of this breast cancer type.

The hallmark of lobular breast cancer is the lack of the protein E-cadherin, which helps cancer cells adhere to each other. Because E-cadherin is lost in ILC, tumor cells often grow diffusely without forming distinct masses. This makes them extremely hard to detect on mammograms, especially in women with dense breast tissue, or elsewhere in the body if metastasized. Lobular breast cancer is often only diagnosed once tumors are larger than 2cm, and sometimes already metastatic. Sadly, because many clinical trials for treatments require that participants have measurable disease, lobular breast cancer patients are often not eligible for clinical trials. In addition, there have been very few clinical trials focused on metastatic lobular breast cancer.

Many scientific studies have confirmed that lobular breast cancer is a distinct breast cancer type and that it behaves differently from the more common non-lobular breast cancers. But, for decades, in part because of the smaller numbers of patients at any one site and the insufficient standardization of the diagnosis for pathologists and radiologists, there has been a paucity of research. Therefore, though quite different, lobular breast cancer is treated the same as other non-lobular tumors.

As scientists who study lobular breast cancer, patients who live with it and clinicians who treat them, we believe that more must be done. It is CRITICAL that we raise awareness of the need for more research, share what ILC research is underway and ensure that those diagnosed with lobular breast cancer are aware of the information that does exist about their breast cancer type and of the many supportive communities of patient advocates that are there for them around the world. *Everyone* must be made aware that lobular breast cancer needs more attention.

By declaring October 15th as Global Lobular Breast Cancer Awareness Day, we aim to make sure that women everywhere undergoing mammograms or other tests to screen for breast cancer learn that breast cancer has different sub-types and about lobular breast cancer specifically. We aim to make sure that all who are newly diagnosed with ILC are aware that there is information available online about ILC, including current research and clinical trials. We want to be sure that they know that there are nonprofit organizations and advocacy groups around the world that are dedicated to education about lobular breast cancer, such as the Lobular Breast Cancer Alliance, Lobular Breast Cancer UK, Lobular Ireland, the European Lobular Breast Cancer Advocates, Lobular Breast Cancer Canada Patient Action Group, and Lobular Breast Cancer Advocates in Australia, and to be aware of the supportive communities both online and off, including several private Facebook groups specifically for those with lobular breast cancer. We also want them to be aware of the fundamental, translational, and clinical ILC research that is being done around the world and that in Europe, such multidisciplinary efforts are currently streamlined within the European Lobular Breast Cancer Consortium. Please help us shine a spotlight on **October 15th as Global Lobular Breast Cancer Awareness Day**, raising awareness about the 15% of all breast cancers that lobular represents. Help us bring more attention -- and ultimately more research and improved treatments - to address the specific issues of this long-overlooked breast cancer type.

¹ There are approximately 45,000 lobular breast cancer diagnoses each year in the US. Invasive ductal carcinoma (IDC), the more common breast cancer type represents over 80% of the roughly 241,000 breast cancer diagnoses in the US each year.

OCTOBER 15TH CONTINUED

For more information about the events on October 15th, 2024, worldwide please reach out to the undersigned organizations that may represent your country.

Signatories and Affiliated Organizations

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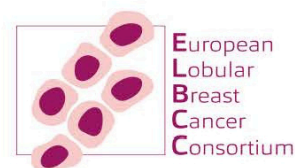
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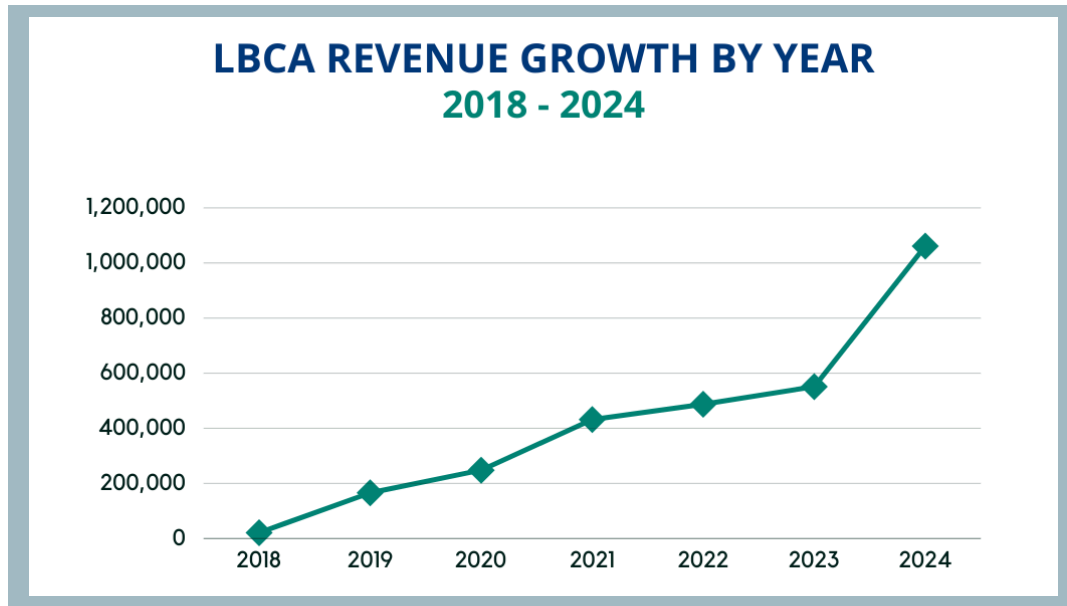
Mary Lloyd



FISCAL YEAR 2024 FINANCES

LBCA Revenue Continues to Grow Year Over Year!

LBCA saw new landmark accomplishments in its third year as an independent nonprofit organization. **Total contributions towards LBCA's mission and vision in Fiscal Year 2024 exceeded the \$1M mark at \$1,027,757.**



The generosity of donors has increased exponentially since 2018 and this past fiscal year hit an all time high. Gifts this past fiscal year once again supported key operations for our small but mighty organization and enabled LBCA to continue to expand its reach to broader audiences and prepare for getting the word out about October 15th events. Funds received also supported providing more educational materials for patients and making them more accessible. LBCA was able to increase translation of patient facing resources into multiple languages available for download, production of educational webinars and videos that are available for on demand viewing on our website support for patient advocate attendance at trainings and conferences. Donor generosity also enabled an increase in ILC focused research grantmaking.

LBCA will continue to build on these accomplishments over the coming fiscal year to reach new audiences and to change the way that ILC is understood and discussed in the world of breast cancer care and research and in wider public audiences.

LBCA engaged independent CPA firm Citrin Cooperman and Company, LLP to complete the required annual financial audit for FY24. The firm concluded that LBCA's financial statements were presented fairly and in accordance with accounting principles generally accepted in the United States of America.

FISCAL YEAR 2024 FINANCES

REVENUE	FISCAL YEAR 2024
Contributions	\$1,027,757
Sponsorships	-
In kind contributions	\$28,420
Interest Income	\$14,877
Total Revenue	\$1,071,961

EXPENSES	FISCAL YEAR 2024
Payroll & Related Expenses	\$284,352
ILC Research Grants Funded	\$262,500
Professional Fees	\$129,903
Office and Other	\$55,931
Scholarships and Sponsorships	\$21,441
Travel to Conferences	\$11,877
Insurance	\$3,008
Advertising	\$2,965
Total Expenses	\$771,977

Net Assets End of Year	2023	2024
	\$298,277	\$598,261

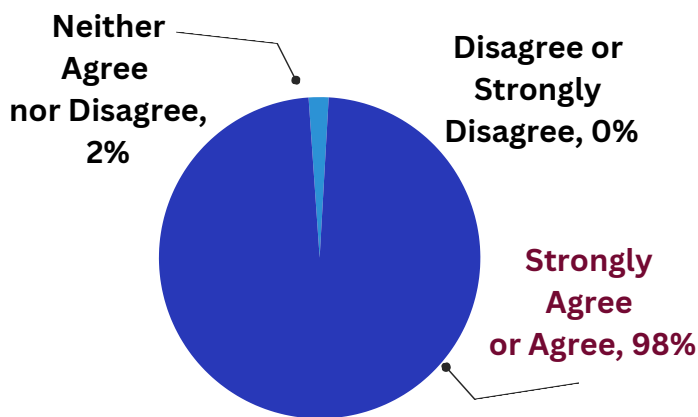
LBCA SURVEY RESULTS

In June 2024, LBCA asked its constituents (newsletter subscribers and social media followers) to participate in an electronic survey to help assess how LBCA is doing towards achieving our strategic plan goals. We very much appreciate the feedback that respondents have provided and use comments to continue to improve what LBCA provides. This year, 568 individuals shared their anonymous feedback in our survey. We asked about experience with the information and resources on the LBCA website and for input about what information respondents might wish to find on our website but currently do not. Highlights from this years survey are as follows:

- 97% of respondents agreed or strongly agreed that the information for patients on the website is useful
- 87% agreed or strongly agreed that LBCA is the “go to website” for information on ILC
- 87% agreed or strongly agreed that the LBCA website has the information they were seeking
- 53% or respondents have shared information from the LBCA website in conversations with their care team

“Your info and research has been a lifeline. Your information is my go to and who I trust. Thank you!”

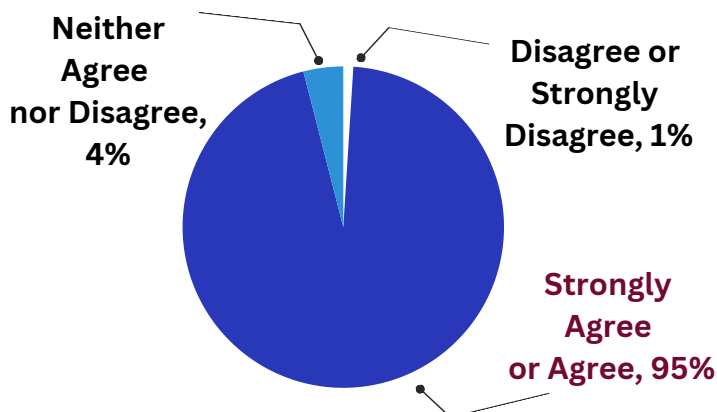
The information on the website helps explain ILC.



LBCA also received suggestions for content respondents would like to see which we will continue to develop and add new resources, in addition to improving how we present information on our website to ensure resources can be easily found. LBCA always aims to produce patient facing resources based on current ILC research and science and ensure that what we publicize is first vetted by members of our Scientific Advisory Board.

“The amount accomplished in a few short years is remarkable! Thank you”

The information on the website conveys the urgent need for more research.



“I hope LBCA continues to grow and expand, because the need is definitely there.”

LEGACY GIFT DONORS

We are grateful to our legacy donors whose great commitment to supporting LBCA led them to plan their gift as part of their estate plan and/or their family to set up a gift in their memory.

**Deb Mueller
Foundation Fund**

**Seattle
Foundation**

2024 CIRCLE OF COMPASSION DONORS

The Circle of Compassion is a treasured and growing group of dedicated donors who have committed to making a gift on a recurring basis.

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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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“I support LBCA’s Circle of Compassion given the incredibly important work LBCA conducts in providing needed resources about lobular breast cancer and promoting the critical expansion of research into diagnosis and treatment.”
Deborah Romer, LBCA Circle of Compassion Donor

While every effort has been made to ensure accuracy, we know mistakes may happen. We apologize for omissions.

LBCA TRAVEL GRANTS

Yvonne McLean Florence and Ciara Mohan Gustafson - two Recipients of LBCA Travel Grants to attend the 2023 ILC Symposium and the 2023 San Antonio Breast Cancer Symposium



"I left the ILC Symposium with a wealth of new and novel information to share with individuals in my community who are impacted by a diagnosis of invasive lobular breast cancer, as well as, the non-profit organizations and advocates who support them. From the bottom of my heart; thank you!"

Yvonne McLean Florence on attending the ILC Symposium in September 2023

"I cannot express enough how thankful I am for the LBCA and the scholarship program for us patient advocates. I personally feel by attending these conventions it offers me a level of control that I am getting out there and learning and asking questions about this disease, this is empowering to me and connects me with people who are going through very similar experiences and it helps to feel not so alone in this."

Ciara Mohan Gustafson on attending the San Antonio Breast Cancer Symposium 2023



THANKS TO YOU ...



"I'm really honored to be part of LBCA, an impressive example of what's achievable when patients, advocates, researchers, and medical professionals unite for a common goal: to transform lobular breast cancer research and care through collaborative efforts. It's truly inspiring to see the impact of our collective efforts, which further fuels my motivation for daily lobular research."
George Sflomos, PhD, Scientist, School of Life Sciences, EPFL Lausanne, Switzerland & LBCA SAB Member



My diagnostic journey was complicated and resources available through LBCA were invaluable and reinforced pursuing additional diagnostics which ultimately confirmed my lobular diagnosis. LBCA was there for me during this stressful time. I am also proud to support LBCA and all of the research it is promoting and sponsoring in consultation with leading scientists and physicians across the world to address the many unknowns about this significant disease. I am incredibly grateful and optimistic about these collaborations and the work underway to improve the detection and treatment of lobular breast cancer.
Deborah Romer, Loyal Supporter



"Losing my beloved brother to cancer at 58 added a personal purpose to the work I do at Daiichi Sankyo, which focuses on understanding and addressing the unique needs of those living with the disease. It has been a true honor supporting LBCA, which plays an indispensable role in highlighting the unique characteristics of invasive lobular breast cancer and the critical need for more research, ultimately striving for early detection, effective treatment and eradication of the disease."
Gissou DeCotiis, Global Head of Advocacy & Strategic Relations, Global Medical Affairs, Oncology, Daiichi Sankyo



"I donate my time and money to LBCA because my routine mammogram turned out to be not so routine. With no signs or symptoms, I was diagnosed with stage 3 lobular breast cancer. My hope is that our efforts to stimulate more lobular breast cancer research will lead to better, earlier detection and specifically targeted treatments for this poorly understood form of cancer. I am optimistic that LBCA is going to make this happen."
Barbara Neilsen, Patient Advocate, Ohio



"The LBCA has been an amazing group to which to refer my lobular patients who want information about lobular breast cancer and essential in getting recognition of and providing funding for lobular breast cancer research. LBCA's advocacy to get the ACS/SEER Cancer Stat Facts on Invasive Lobular Carcinoma published was a huge step forward aiding study of ways for improving outcomes for lobular patients."
Dr. Sasha Stanton, MD PHD, Earle A. Chiles Research Inst. Portland, OR

WE'RE MAKING A DIFFERENCE!

"Both volunteering and donating to LBCA allows me to be part of the solution to a problem where we have a disease that is not studied enough nor easy to detect. LBCA is shining a spotlight on these issues and I am proud to be a part of it."

Robert Oakes Jr., CPA, MBA, LBCA Treasurer and Board Member and Circle of Compassion Donor



"The Lobular Breast Cancer Alliance does tremendously important work on spreading knowledge and promoting new research on lobular breast cancer. Research on lobular is needed to better understand its peculiar characteristic so more personalized therapeutic approaches for patients with this disease can be developed. Thanks to LBCA, in 2024 I was awarded the AACR-Lobular Breast Cancer Alliance-Deborah Mueller Foundation Fund ILC Innovation and Discovery Grant, which will allow my team to conduct a new lobular breast cancer study to characterize lobular metastatic spread through liquid biopsy."

Dr. Carolina Reduzzi, Assist. Prof. Cancer Biology, Weill Cornell Medicine



"The LBCA is a lifeline. In the months after my stage IV diagnosis, I visited the website again and again, learning basics, watching videos, and eventually making use of the extensive publications library to navigate this terrible disease. LBCA has been my trusted anchor; those resources help me make decisions and be a better self-advocate. As I've turned to advocacy for others, the LBCA has buoyed me up again. LBCA has made this challenging diagnosis easier to face and I couldn't be more grateful."

Jade Moran, Research Advocate, Massachusetts



The educational resources LBCA provides on ILC was a game changer for me! Especially during the beginning of my journey when I frantically searched the internet to learn about this type of cancer and finally found the BEST source, LBCA. Knowing high standards and best practices are held at all levels of LBCA, a patient can feel equipped and ready to have discussions with their own medical team. It is an honor serving as a Patient Advocate, for LBCA.

Karan Garrison, Patient Advocate Advisory Board Member, Missouri



"I am very passionate about being involved with LBCA and donating my time as a lobular research advocate because they have given me so much, including unique resources that I could not get anywhere else. Until now, I had only met one other woman with metastatic breast cancer, and it was not lobular. So, I was absolutely delighted to hear of and join the new virtual metastatic lobular support group LBCA helped to launch! I am grateful to LBCA for helping to make this wonderful support group happen."

Beth Davis, LBCA Volunteer and Research Advocate, Massachusetts



**Developed Marketing Materials to
Declare October 15th
Lobular Breast Cancer Awareness Day**



Global
**LOBULAR
BREAST CANCER**
Awareness Day

**Help us continue our movement to raise awareness of
lobular breast cancer and promote more research.**



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



*Lobular Breast Cancer Alliance Inc. is a public
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