

LBCA Advocate Chat Series 2021



lobularbreastcancer.org

Welcome and Outline for Today's Session

- LBCA Update: organizational growth and funding research
- Information about today's session:
 - Presentation portion will be recorded and all participants will be muted
 - Question and Answer period, which will not be recorded, will follow:
 - Please feel free to write your questions in the chat throughout the presentation
 - During the Q & A portion, the presenter will address questions from the chat and the moderator will call on people who indicate in the chat that they would like to ask a question
 - NOTE: Please avoid any questions about personal issues or specific medical questions as they can not be addressed during this event



Leigh Pate
LBCA Founder
@LPSeattle

Introduction to Lobular Breast Cancer Advocacy



lobularbreastcancer.org

Learning Objectives

- ✓ What is breast cancer advocacy
- ✓ Who can be a lobular breast cancer advocate?
- ✓ Approaches to becoming an advocate
- ✓ Getting Started with lobular advocacy
- ✓ Resources to learn more

What is an Advocate?

“A person who supports or promotes a particular cause”
(Webster’s Dictionary)

“A breast cancer survivor, patient or individual affected by breast cancer who *provides a unique and valuable perspective about the breast cancer experience* with the intent of informing or influencing.”
(National Cancer Institute)

ADVOCATE

[ad-vuh-kit]

a patient or former patient, caregiver, family member or interested volunteer who wants to learn more about lobular breast cancer and use that knowledge to advance research, educate or help others impacted by lobular breast disease



lobularbreastcancer.org

Attributes of Great Advocates



Desire to make things better and represent **ALL** patients, not just yourself



Curiosity and drive for acquiring knowledge



Clear idea of the message you want to convey



Good communication skills



Ability to work collaboratively



A sense of humor!



Science or Healthcare Expert



Rush into advocacy



No Fear!



Goals of Lobular Advocacy

Advance Research

- 1) Better understand invasive lobular carcinoma (ILC)*
- 2) Refine current therapies*
- 3) Identify and advance targeted therapies*

How do we get there?

- Educate/Raise Awareness*
- Fundraise to support research and advocacy directly*
- Integrate ILC into existing breast cancer resources*
- Research Advocacy*

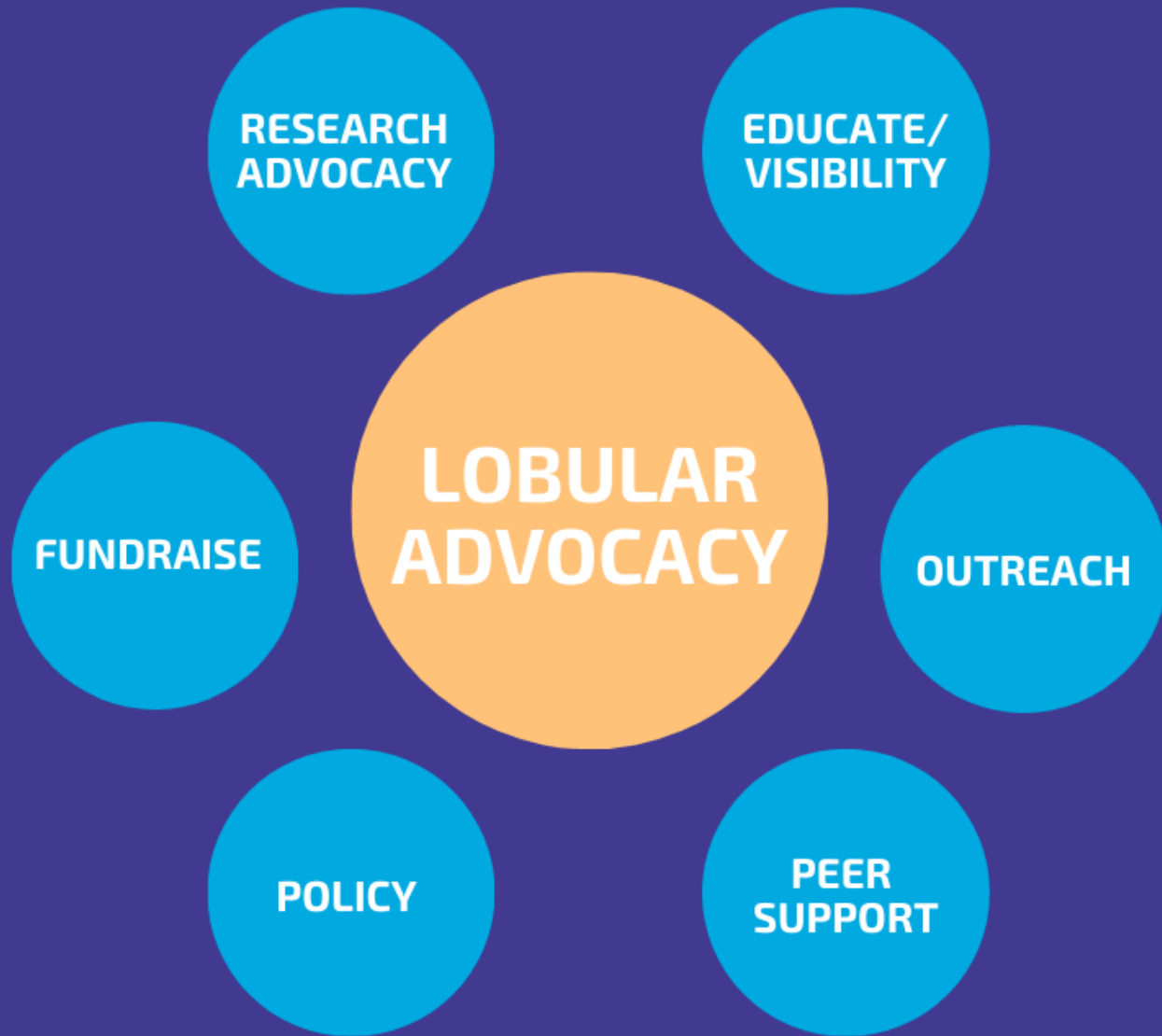
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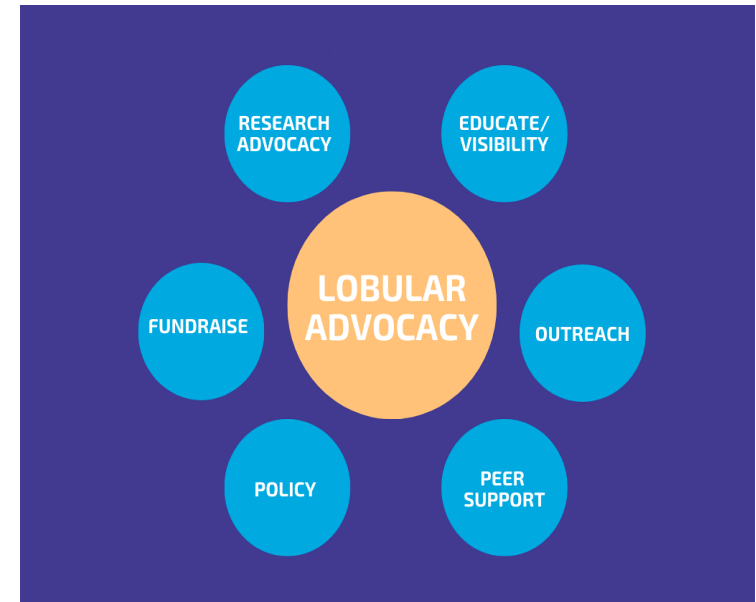


Paths to Effective Advocacy

Lobular Advocacy

Educate/Raise Visibility of ILC

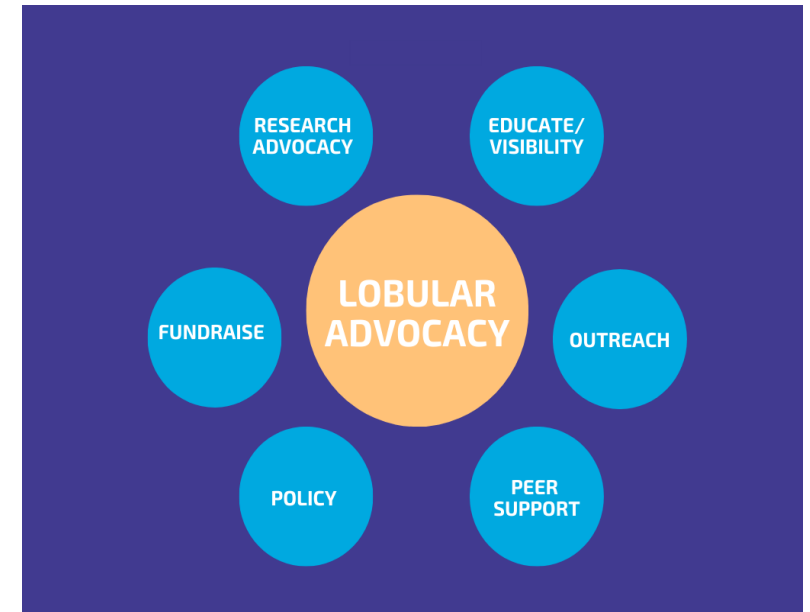
- **Message: Not all Breast Cancer is the Same**
- **Goal 1:** Articulate and amplify *patient needs* for research to refine therapies and better understand ILC.
- **Goal 2:** Educate - What is ILC and how it is different
- **Audience:** Researchers, Clinicians, Organizations, Advocates, Patients, Public
- **Where?** Social media. Attend conferences, meetings, events. Media opportunities. One-on-one
- **How?** Tell your story. Share lobular breast cancer information. Ask questions. Start conversations: “I have Lobular Breast Cancer”



Lobular Advocacy

Outreach and Inclusion

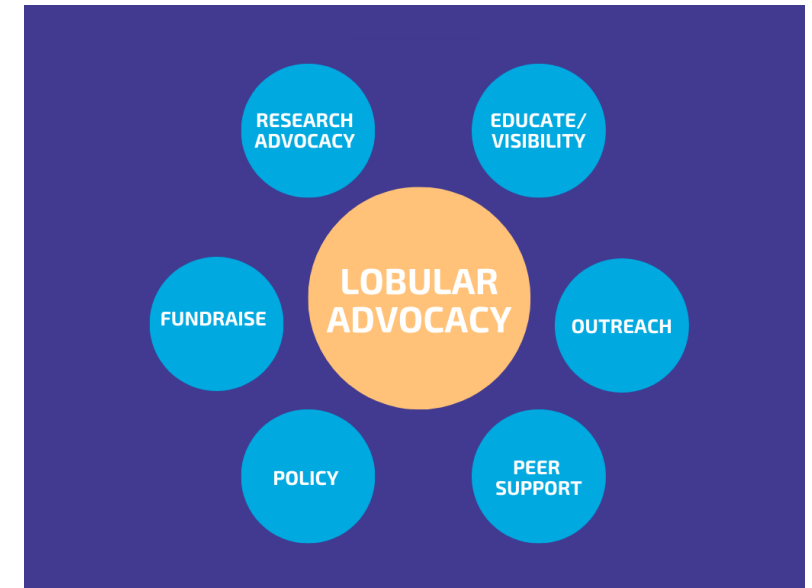
- **What:** Integrate ILC into existing breast cancer organization and cancer research institution activities and resources
- **How?**
 - Network locally: cancer institutions, breast cancer organizations, patient advocacy groups
 - Build relationships
 - Volunteer
 - Organize a lobular program as part of a larger event
 - Lobular represented in programs, committees, funding, educational resources



Lobular Advocacy

Research Advocacy

- **What:** Link patients and scientific researchers so patient perspectives are integrated into scientific decisions
- **Goal:** Include lobular in appropriate studies. Support new ILC research. Represent lobular patient needs with research institutions, researchers, organizations.
- **Examples:** grant applications, grant peer review, institutional based advocacy (Institutional Review Board (IRB) and patient advocate groups), professional conferences and events, conduct and present research
- **How:**
 - Get involved locally to meet advocates and researchers
 - Contact researchers directly
 - Sign up/apply for research advocacy programs
 - Advocacy Training
 - LBCA's Research Advocacy Toolkit <https://lobularbreastcancer.org>



Lobular Advocacy

- **Fundraising**

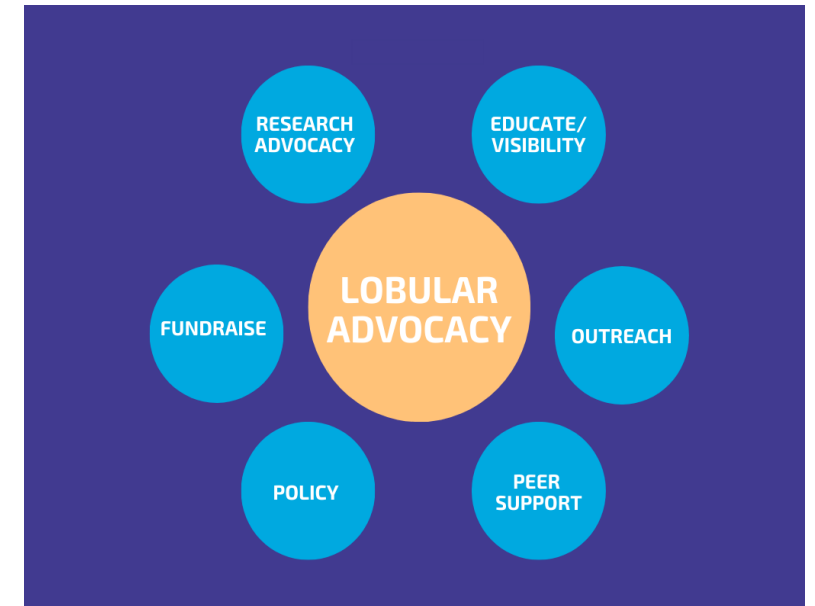
- **What:** Raise funds to support lobular breast cancer advocacy, communications and research
- **How:** Support LBCA to promote advocacy and fund ILC research. Institution-based lobular research funds. Advocate organizational focused lobular research grants and grant review.

- **Peer Support**

- **What:** Volunteer with organizations that train peer mentors and support for patients with ILC
- **How:** SHARE Cancer Support. After Breast Cancer Diagnosis. Local Support Programs. Online patient groups.

- **Policy Advocacy**

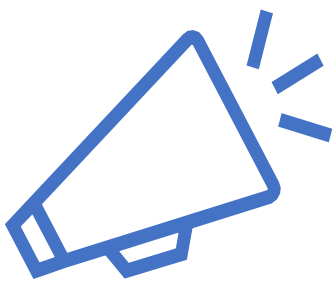
- **What:** Change policy to benefit cancer patients. Secure funding for cancer research. Lobby for policies that expand insurance coverage requirements. Federal, state, local
- **How:** National Breast Cancer Coalition. Komen Policy Advocacy. American Cancer Society Cancer Action Network (ACS CAN). Metavivor. Breast Density. State coalitions.



Getting Started

- **Dig in:** LBCA's online Research Advocacy Toolkit and Resource List
- **Plug in:** Explore local advocacy resources and opportunities
 - Ask your care team/ Patient services
 - Meet other advocates
 - Local breast cancer organization
 - Institutional Patient Advisory Committee, conferences, events
- **Network:** Sign up and Show up
- **Take the Initiative:** Make your own seat at the table
- **Learn:** Explore research advocacy training opportunities and advocates' networks
- **Volunteer:** locally, with LBCA, integrate ILC in other organizations
- **Speak out:** Build a social media presence
 - #lobular @LobularBCA #bcsm tweetchats





Advocacy Resources



Lobular Breast Cancer Alliance - Research Advocacy Toolkit:

lobularbreastcancer.org

Research Advocacy Training and Policy Advocacy:

National Breast Cancer Coalition/Project Lead StopBreastCancer.org

Komen Advocates in Science Komen.org

Lobular Peer Support Volunteer Opportunities:

SHARE Cancer Support sharecancersupport.org

After Breast Cancer Diagnosis abcdbreastcancersupport.org



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Thank you for joining today!

Question & Answers



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