

LBCA Advocate Chat Series 2021

Advocacy and Social Media



lobularbreastcancer.org

Welcome and Today's Session

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:
 - Write your questions in the chat throughout the presentation
 - During the Q & A portion, questions from the chat will be read. The moderator may call on people as well 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



Advocacy and Social Media

A Conversation with Diane Mapes and Colleen Fitzwater

*Diane Mapes
(@double_whammied)*

*LBCA Founding Advocate and
Writer, Fred Hutch News Service*



Colleen Fitzwater (@cfitzwater)

LBCA Communications Director



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Learning Objectives

- ✓ LBCA's online presence
- ✓ Audiences for social media platforms
- ✓ Why use social media to advocate?
- ✓ Getting started
 - ✓ LBCA social media resources
- ✓ Twitter
 - ✓ Who to follow/influencers



LBCA Online Presence

- **Lobularbreastcancer.org (Relaunched March 25)**
 - Pages specific to Advocacy include Advocacy through Education and Research Advocacy Toolkit
- **Facebook:** facebook.com/lobularbreastcanceralliance (@lobularbreastcanceralliance)
 - Audience: majority is people affected by ILC
- **Twitter** (@LobularBCA)
 - Audience: people affected by ILC, clinicians, researchers, other organizations
- **LinkedIn** (Lobular Breast Cancer Alliance)
- **YouTube** (www.youtube.com/channel/UCewaLAMGP9Kgl8mSvO0kPlQ) Please subscribe!
 - Video content is invaluable/seeing a person and hearing their voice can help with telling stories
- **Instagram** – LBCA not using this platform yet!



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Why Use Social Media to Advocate?*

- Spread information and educate others about our cause
- Reinforce and grow relationships among supporters
- Promote dialogue
- Begin better collaboration
- Strengthening collective action through speed of collaborative communication

*Brunson & Valentine, 2010; Orbar, Zube, & Lampe, 2012

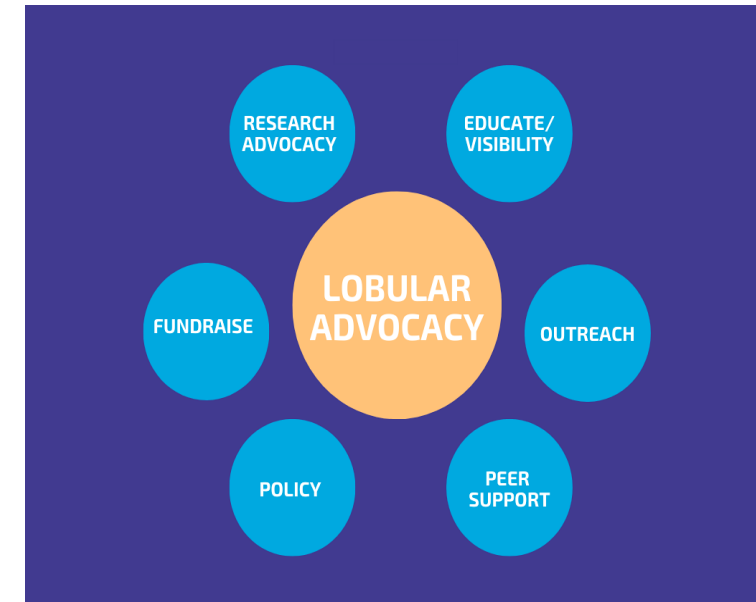


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Educate/Raise Visibility of ILC

- **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”

Path to Effective Advocacy



Getting Started

- How do you get started?
 - There is no right way
 - Use the social media channels you are comfortable using
 - Speak to what matters to you the most
- How can I help the most?
 - Share the new ILC information so it can excite others including scientists and researchers
 - Connect with others (patients, researchers, etc.) through public posting or direct messaging
 - Thank researchers for their work
 - Live tweet lobular breast cancer topics being discussed at conferences you are attending to increase awareness



Resources



Lobular Breast Cancer Alliance – Sample Social Media:
lobularbreastcancer.org/social-media/

Twitter

- Why Twitter?
- Guide to Twitter Lingo <https://help.twitter.com/en/twitter-guide>
 - Limit of 280 characters
- Hashtags
 - A keyword or phrase with the “#” symbol before it
 - Connect conversations/helps find content
 - They bring people together around a topic
 - Tap a hashtag to see other Tweets
 - Build a social media presence: #lobular #bcsm #LobularResearch #BreastCancer

Getting Started Guide

Welcome Twitter 101 Resources Help Center

Getting started with
Twitter



lobularbreastcancer.org

Twitter

- Username (ex. @LobularBCA)
 - Known as a handle, begins with an “@” symbol.
 - Use @ to call out usernames in Tweets (mentions), to send messages, or to link out to a profile
- Top influencers? Who should we follow for lobular breast cancer?
- Types of posts with the most engagement?
 - Ones that are “real”



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Thank you!



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Upcoming Advocate Chats

- May 14, 2021: Finding Local Research Advocacy Opportunities
- June 2021: Advocacy Through Supporting Others with ILC
- July 2021: Advocacy Through the Media





Questions & Answers