



Educational and Support Resource List

One of the most important ways a patient can advocate for their own care is to learn about their disease. There are many organizations and websites available to help patients learn more about breast cancer. A sampling of breast cancer educational and support resources is below.

*Information about lobular and lobular metastasis is often limited, even at top breast cancer educational sources. ILC advocates can help change that by requesting that educational materials include information on lobular and that lobular be included at organizational conferences and meetings as well as on relevant websites. See LBCA's *Tips for ILC Advocacy: Education and Elevate* to learn more (lobularbreastcancer.org/advocacyeducate)*

LobularBreastCancer.org - Archive of lobular specific webinars and papers. Information about research and studies focused on ILC. Newsletter sign-up.

BreastCancer.org - Educational links as well as patient-to-patient support via organized chat boards. Includes lobular specific educational information and patient message boards.

Breast Cancer Research Foundation bcrf.org - Advances research with grants to top researchers and institutions around the world. BCRF funded the First International Lobular Breast Cancer Symposium in Pittsburgh in 2016. Webinars and newsletter sign up.

ShareCancerSupport.org - For breast and ovarian cancers. Includes a section on Tools and Resources such as webinars, videos, and blogs. Offers support services via help lines and groups. Newsletter sign-up. View a webinar on outcomes from the First ILC symposium hosted by SHARE at Lobularbreastcancer.org/webinar-invasive-lobular-carcinoma.

Metastatic Breast Cancer Network: mbcn.org - Their mission is to educate, advocate and empower those with metastatic breast cancer. They provide materials for both education and support. MBCNetwork is funding research to better understand lobular metastasis. Newsletter sign-up.

Susan B Komen Foundation: ww5.komen.org - Offers educational links, hosts conferences and funds breast cancer research grants. They host a patient research advocate program - Advocates In Science. *Komen Puget Sound features lobular breast cancer in their annual Northwest Metastatic Breast Cancer Conference.* Learn more komenpugetsound.org

MBCproject.org – The Metastatic Breast Cancer Project is new approach to cancer research where patients share samples and clinical information with researchers. This project is prioritizing lobular tumor samples for researchers. LBCA is a partner of the MBCProject. *If you are a patient with metastatic ILC learn how to sign up and identify yourself as lobular at Lobularbreastcancer.org/metastatic-breast-cancer-project*

After Breast Cancer Diagnosis: abcdbreastcancersupport.org - Produces a monthly webinar with guest speakers from various breast cancer fields. Provides one-on-one or phone support for patients and caregivers. ILC Advocates are invited to go through ABCD's the online training to become a mentor for one-on-one peer support.

BreastCancerTrials.org: Searchable breast cancer clinical trials database and information

Cancer.gov – Site of the National Cancer Institute, part of the National Institutes of Health. Government funded organization with educational materials and guidelines for all cancers.

Cancer.org – Site of the American Cancer Society, focuses on all cancers including breast cancer. Sponsors support programs for breast cancer patients throughout the country.

NationalBreastCancer.org - Educational tools and support services.

Living Beyond Breast Cancer: lbbc.org - Various learning as well as support services for all breast cancers. Newsletter sign-up.

MBCalliance.org – The Metastatic Breast Cancer Alliance is a coalition of breast cancer groups with timely information and resources on metastatic breast cancer.

Metavivor.org – Metavivor has educational materials on research and awareness and peer-to-peer support for metastatic breast cancer patients. Newsletter sign-up.

FORCE (Facing Our Risk Empowered) FacingOurRisk.org - Focus on Education and Advocacy around Hereditary Breast, Ovarian and related cancers, with information about genetic mutations linked to breast cancer, including the rare CDH1 mutation (Hereditary Diffuse Gastric Cancer Syndrome) which increases the risk of ILC and stomach cancer.

HereditaryDiffuseGastricCancer.org shares in-depth information specifically about the rare CDH1 inherited genetic mutation and the link to ILC and stomach cancer.

Social Media for ILC

Facebook: Lobular Breast Cancer Alliance LBCA - a Project of SEE

Twitter: Hosts a number of researchers to follow who focus on lobular breast cancer. Follow #lobular #LBCA.

ILC Patient Support Groups on Social Media

Facebook group: Lobular Breast Cancer (ILC) Invasive Lobular Carcinoma

Facebook group: Support for People with Metastatic Lobular Breast Cancer

Breastcancer.org hosts a lobular specific discussion board
Community.breastcancer.org/forum/71

Inspire.com hosts a Metastatic ILC in the GI Tract and Abdomen patient discussion group
Inspire.com