



## RESOURCE ADVOCACY RESOURCE LIST & Questions and Answers

(Learn more about Research Advocacy at <https://lobularbreastcancer.org/>)

Research advocacy focuses on involving advocates in cancer research. Research advocates make an impact by presenting a patient perspective to the science behind cancer and its treatment. Advocates can undergo patient-oriented training in scientific methodology, research design, basic statistics, epidemiology, and other areas so they can make knowledgeable contributions to research and ensure clinical trials and studies are patient focused with an eye on outcomes.

Please review and pursue any and all of the research advocacy opportunities listed that are of interest. We encourage Invasive Lobular Cancer (ILC) advocates to participate. Following the list of resources are some frequently asked questions and answers and tips about getting involved in research advocacy.

### Research Advocacy Training Opportunities

**National Breast Cancer Coalition (NBCC) Project LEAD:** <https://www.stopbreastcancer.org/what-we-do/education/project-lead/> - Project LEAD is a competitive and intense week-long breast cancer science training program for advocates held each summer. Scholarships are available. LBCA will consider recommendations for qualified candidates.

**American Society of Clinical Oncology:** <https://www.asco.org/> - Resources for advocates with an emphasis on policy training. Covers all cancers, so some of the information is related to cancer advocacy in general.

**Komen Advocates in Science (Komen AIS):** <https://www.komen.org/how-to-help/advocacy/komen-advocates-in-science/become-an-advocate-in-science/> - Susan G. Komen Foundation provides training opportunities to advocates and connects advocates with researchers seeking Komen grants. Application required for membership.

**Alamo Breast Cancer Foundation:** <https://www.alamobreastcancer.org/> - The Alamo Breast Cancer Foundation is a Texas based group with global reach. They coordinate and host the intensive advocate programs at the San Antonio Breast Cancer Symposium (SABCS) every year. They offer training and competitive scholarships to advocates to support attendance at SABCS.

**Young Survival Coalition:** <https://www.youngsurvival.org/> - The Young Survival Coalition was formed to aid breast cancer patients under the age of 40. Their website offers advocacy advice in both research and policy areas and a funded program called RISE to train advocates.

**Research Advocacy Network:** <https://researchadvocacy.org/> - The Research Advocacy Network website contains extensive educational information including tutorials, webinars, and fact sheets. They host a scholarship program for training advocates at the annual ASCO meeting as well as other selected meetings.

**American Association of Cancer Research (AACR):** <https://www.aacr.org/> - AACR offers a variety of training and education programs for advocates including a competitive training/mentorship program for advocates for all types of cancer called the Scientist Survivor Program.

**Guiding Researchers and Advocates to Scientific Partnerships (GRASP):** <https://graspcancer.org/> - GRASP connects patients, caregivers, and advocates with researchers and clinicians who study all types of cancer. The organization leads advocate/research poster walk-throughs at conferences and other educational programs.

### **Grant Review Opportunities for ILC Research Advocates**

**Komen Advocates in Science:** <https://www.komen.org/how-to-help/advocacy/komen-advocates-in-science/become-an-advocate-in-science/> - Matches trained advocates with Komen research grants. Advocates can help write proposals, review grants, and be involved from start to finish.

**Department of Defense (DOD) Congressionally Directed Medical Research Programs (CDMRP) Breast Cancer Research Program:** <https://cdmrp.army.mil/> - Every year the DOD recruits research advocates to participate in the review of innovative, high-risk high reward breast cancer research proposal grant peer review. They prefer some type of science training such as Project LEAD.

**Patient-Centered Outcomes Research Institute (PCORI):** <https://www.pcori.org/> - Formed in 2010 as part of the Affordable Care Act, PCORI's goal is to make health care more effective. Research advocates can sign up to help PCORI guide studies and give input on patient centered questions. PCORI offers a free comprehensive training titled "Research Fundamentals: Preparing You to Successfully Contribute to Research" and can be found here: <https://www.pcori.org/engagement/research-fundamentals>

**Cochrane:** <https://www.cochrane.org/> - Cochrane is a worldwide organization that summarizes research to help health care professionals and patients make informed health decisions. Research advocates can contribute to the review process. The website has information on many ways to obtain training and make a contribution.

**Institutional Review Boards (IRB):** IRBs are required for all research that involves human subjects. Many cancer research institutions have IRBs. The IRB reviews the methods proposed for research to ensure they are ethical. Committees make up the boards and comprise a range of experience including patient advocates. Search your local institutions for IRBs.

## National, Local, and Regional Advocate Opportunities

**National Cancer Institute (NCI) Office of Advocacy Relations (OAR):** <https://www.cancer.gov/about-nci/organization/oar> – This office engages the cancer advocacy community with the NCI funded research programs.

**Federal Drug Administration (FDA):** <https://www.fda.gov/> – The FDA engages the patient advocacy community in regulatory work protecting the public health by ensuring the safety and efficacy of drugs, biological products, and medical devices.

Some **state governments** have their own breast cancer research programs. For example, in California there is the **California Breast Cancer Research Program:** <https://cbcrp.org/> – where California advocates are invited to sit on review panels for research proposals they are funding. Search for similar programs near you.

**Local Cancer Research Centers and Institutions** may seek Patient Volunteers to partner with researchers or participate in committees at their institutions. Contact your local cancer research institution to inquire about their patient advocate opportunities.

**Academic Institutions** may also seek volunteer advocates to partner with scientists.

### Questions and Answers Regarding How to Find and Get Involved in Research Advocacy

*Question:* I have had a little training on breast cancer research advocacy and I want to get involved locally in reviewing grant proposals and having the chance to advocate for ILC research and patient/ research advocacy generally. How do I make a connection with the breast cancer researchers in the medical center near me?

*Answer:* LBCA is developing a list of key contacts at medical centers and breast cancer support and advocacy organizations around the country. Contact the LBCA research committee to inquire about key contacts near you. If LBCA does not have a name or contact for you in your area, the following are some steps you can take to identify someone who can potentially help you get connected.

1. Meet other breast cancer advocates in your local community by signing up for events, institutional and organizational functions, volunteering and letting other advocates, staff and researchers you meet know you want to get more involved with research advocacy.
2. You may be more successful if you start out searching broadly for the BC researchers and oncologists in your area before focusing only on ILC.
3. If you already know of an ILC researcher in your area or there is a particular researcher whose research interests you, but do not know them personally, contact them to inquire about the area BC labs where they conduct their research, visiting their lab and hearing more about their research. They are often very willing and happy to welcome interested patient advocates into their lab and to explain their research.
4. Ask your oncologist whether they know of the BC researchers in your area and how they suggest you can connect with them. Sometimes it is easier to reach out to and get through

- to the junior researchers and post-doctoral students in a lab.
5. Depending on your comfort level and experience with speaking to groups of clinicians, you can seek out your local teaching hospital breast cancer team and offer to provide a “grand rounds” presentation on their ILC story and the importance of more ILC research
  6. Contact the National Breast Cancer Coalition, Breast Cancer Research Foundation, or local breast cancer organization representative in your area – they may know of the BC experts and possibly the ILC experts in your area and good people to whom you can outreach. They may also know of whether a patient/research advocacy committee exists in your area and can help connect you.
  7. Ask around – your clinicians and other breast cancer organizations may know about whether there is a particular breast cancer or lobular breast cancer researcher or clinician who believes in patient advocacy who you might cultivate to become a champion and help you build support for ILC patient advocacy in your area.
  8. Look at the Department of Defense Breast Cancer Program list and the KOMEN Advocates in Science (AIS) list of recently awarded grantees in your state. You can then write to those grantee researchers whose research interests you to inquire more about their research letting them know that you are a research advocate and very interested in being more involved as a research advocate.

*Question:* I have had some patient advocacy training and want to find other patient advocates in my geographic area with whom to connect. How might I find them?

*Answer:* LBCA has begun to compile a list of patient advocates and their contact information including location and can share that with you. In addition, you might try to reach out to:

- The National Breast Cancer Coalition to see if they would share with you the contact information for Project LEAD graduates in your geographic area.
- The Metastatic BC Alliance, KOMEN AIS and FORCE: Facing Our Risk of Cancer Empowered for the same sort of information/contact lists.
- Your local breast cancer organization, which may have patient advocate groups that you can join. For example, there may be local Komen Affiliates, or YSC affiliates in your area. Attending local breast cancer related events is also another good way to make connections with other advocates and other clinicians and researchers.
- Last, it is always helpful to attend the larger breast cancer conferences, particularly those that are very inclusive of patient advocates, such as the International Lobular Breast Cancer Symposium, the annual San Antonio Breast Cancer Symposium, the annual Metastatic Breast Cancer Symposium, the American Association for Cancer Research, and the annual ASCO – American Society of Clinical Oncology conference. You may find it helpful to seek out any local patient advocacy organizations that might be supporting advocates in attendance (such as the Alamo Breast Cancer Foundation in San Antonio) while you are at the conference or following. They may be able to help connect you to patient advocate attendees from your geographic area during or following the conference.

To keep in touch with others advocating for ILC research and/or education please visit our website volunteer page.