



RESEARCH ADVOCACY RESOURCE LIST

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. Learn more about Research Advocacy at lobularbreastcancer.org/researchadvocacy. See LBCA's Advocacy Toolkit at lobularbreastcancer.org/lbcaadvocacy.

Research Advocacy Training Opportunities

National Breast Cancer Coalition (NBCC): breastcancerdeadline2020.org - Project LEAD is a competitive and intense week-long breast cancer science training program for advocates held each summer. Scholarships are available. The LBCA will consider recommendations for qualified candidates.

American Society of Clinical Oncology: 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): ww5.Komen.org – Susan B. Komen Foundation provides training opportunities to advocates connects advocates with researchers seeking Komen grants. Application required for membership.

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 SABCS.

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.

ResearchAdvocacy.org - Website of the Research Advocacy Network with 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.

AACR Scientist Survivor Program aacr.org - Competitive training program for advocates for all types of cancer.

Grant Review Opportunities for ILC Research Advocates

Komen Advocates in Science www5.komen.org - Match trained advocates with Komen Grants. Advocates can help write proposals, review grants and be involved from start to finish.

Department of Defense (DOD) CDMRP Breast Cancer Research Program:

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 require some type of science training such as Project LEAD.

Patient-Centered Outcomes Research Institute: 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. Very informative website.

Cochrane.org - 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 - IRB's are required for all research that received support directly, or indirectly, from the United States federal government. The IRB reviews the methods proposed for research to insure they are ethical. Committee's make up the board from a range of experiences including patient advocates. Search your local institutions for IRB's.

Local and Regional Research Advocate Opportunities

Some **state governments** have their own breast cancer research programs. For example, in California there is the **California Breast Cancer Research Program** - cbcrcp.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. Contact your local institution's cell biology or cancer research departments.