



Module 4:
How can advocates
improve and help
with research?

Technical Assistance
Materials for Investigators

California Breast Cancer Research
Program

What do Investigators Say?

"I cannot say enough good things about the support provided to our clinical trials research by the advocates involved with our research. Preparing to present our plans to these advocates and subsequently our findings helped us to focus on making our presentations logical, clear and understandable. They made critical suggestions relevant to how our presentation would be perceived by both scientists and lay people. Their input helped us to focus our research on the important issues and led to changes of a variety of things including the title of our trial to be more sensitive and considerate of the women in our trial. The advocates also made our involvement in breast cancer research more poignant and consequential adding some urgency to get things done."

—David Feldman, M.D., Stanford School of Medicine

"I have worked with advocates for several years and their patient perspective has helped shaped the goals of our breast research program. Our collaborations have enriched the lab and I look forward to continued interaction."

—Rob West, M.D., Stanford University Medical Center

"Working with advocates has brought a whole new dimension to our research. The advocates provide a unique perspective and critical feedback that helped strengthen our research proposals and projects. We are grateful for their involvement and participation as part of the research team"

—Sharon Pitteri, Ph.D., Stanford Cancer Institute

Roles Advocates Play in Your CBCRP Research Project

LOI & Application Preparation and Submission:

- Offer feedback on specific areas
 - Impact on patients
 - Critical path
 - Translational potential
- Develop and Review sections of proposal
 - Project Summary
 - Translational Goal
 - Impact on Breast Cancer
- Through these steps, help communicate the importance of project to BC patients and families
- Collaborate in defining their role during the project's implementation and dissemination of the results
- Work with your team to make public abstract accessible to non-scientific audience

Research Project:

- Participate in team meetings
- Help with crafting plain language summaries for talking with public about project and results
- Talk with community about projects, research, and importance
- Help with creating materials (educational and outreach)
- Impact translational potential of research

Roles Advocates Play in Research

Table 1. Examples of advocate involvement in cancer research

Strata/examples	Activities	Contributions
Allocating research funding <ul style="list-style-type: none"> • DOD CDMRP • NCI and NCI-funded programs; cooperative groups • Nonprofit organizations 	<ul style="list-style-type: none"> • Establishing research priorities • Writing research funding announcements • Peer review • Programmatic review 	<ul style="list-style-type: none"> • Ensure cancer relevance • Focus on impact rather than elegance • Increase attention to areas of importance to public (e.g., environmental causes of cancer, health disparities, palliative care) • Encourage collaboration across disciplines and among stakeholders
Participating in research teams <ul style="list-style-type: none"> • Funded research programs • University research groups • NCI-funded SPORE 	<ul style="list-style-type: none"> • Writing and providing feedback on grant applications • Participating in research group meetings • Bridging gaps among stakeholders 	<ul style="list-style-type: none"> • Maintain focus on helping patients • Stimulate discussion and collaboration • Bring outsider perspective to the research • Add a personal face and sense of urgency • Increase public understanding of science
Planning and implementing clinical trials <ul style="list-style-type: none"> • NCI and NCI-funded clinical research like cooperative groups • Academic cancer centers and consortia • Drug company trials 	<ul style="list-style-type: none"> • Designing trials • Reviewing informed consents • Developing patient support materials • Providing patient navigation and peer support • Focusing recruitment and retention plans • Membership on Protocol and Scientific Review Boards • Membership on Institutional Review Boards (IRB) • Membership on Data Safety Monitoring Boards (DSMB) • Writing patient-friendly research summaries 	<ul style="list-style-type: none"> • Sensitize researchers to issues that will have an impact on patient recruitment, retention, and satisfaction • Provide consumer perspective on ethical issues • Focus on toxicities as well as benefits • Encourage quality-of-life add-ons • Encourage collaboration across disciplines and among stakeholders • Add a personal face and sense of urgency • Increase public understanding of science
Translating and disseminating research <ul style="list-style-type: none"> • Professional societies, such as the American Association for Cancer Research (AACR) and the American Society of Clinical Oncology (ASCO) • Nonprofit organizations 	<ul style="list-style-type: none"> • Presentations at advocacy and scientific meetings • Planning and attendance at advocacy and scientific meetings and training • Publication in advocacy and scientific journals, websites, listservs, and blogs • Public outreach through national, regional and local organizations, and media 	<ul style="list-style-type: none"> • Develop future advocates • Sensitize researchers to issues that are important to public stakeholders • Help public understand the importance of cancer research • Increase awareness of cancer research progress
Research and public policy oversight <ul style="list-style-type: none"> • Government • Academia • Foundations 	<ul style="list-style-type: none"> • Clinical practice guideline committees • Working groups, study groups, and think tanks • Protocol and science review boards • IRBs and DSMBs 	<ul style="list-style-type: none"> • Increase transparency • Provide patient/consumer focus • Provide outsider perspective • Help disseminate results

Resource: Reading List on Advocacy Involvement

Samson et al. *EPJ Nonlinear Biomedical Physics* 2013, 1:1
<http://www.epjnonlinearbiomedphys.com/content/1/1/1>

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COMMENTARY

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Advocacy spurs innovation: promoting synergy between physical and biomedical sciences

Susan Samson^{1,2,3,9*}, Irene Acerbi^{1,4,5,10}, Carole Baas^{6,11}, Valerie Weaver^{1,4,5,7,12} and Hope Rugo^{3,8,13}

Perspective

Cancer
Research

Cancer Research Advocacy: Past, Present, and Future

Jane Perlmutter¹, Shannon K. Bell², and Gwen Darien³

Abstract

In this article, we present a brief history of cancer advocacy and discuss the variety of ways advocates have become involved in cancer research and subsequently present principles that establish a framework for successful research advocacy based on a review of many early initiatives coupled with our knowledge as long-time cancer advocates. Challenges to effective advocacy are described, and recommendations for increasing meaningful contributions by research advocates are proposed. The purpose of this article is to discuss the exciting field of research advocacy and to help shape a more productive future for advocates and their scientific collaborators.

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Reach out to CBCRP

- 1-888-313-2277
- Program Officers
 - Katie McKenzie, Ph.D. katherine.mckenzie@ucop.edu
 - Senaida Poole, Ph.D. senaida.poole@ucop.edu
 - Carmela Lomonaco, Ph.D. carmela.lomonaco@ucop.edu
 - General Email: getinfo@CABreastCancer.org