



The role of the patient advocate as an active member of the research team

Daniel Garcia, Ph.D., Breast Cancer Research Advocacy Network (bcRAN)
UPMC/Hillman Cancer Center

Building advocate-researcher relationships to strengthen research
(Contents for this presentation were taken from Susan G. Komen's [Advocate-Researcher Working Together Toolkit](#), July 2017)

A Rationale for Advocate-Researcher Relationships

Why is it important that advocates actively participate in the grant application process?

- To ensure patients' perspectives are integrated into the research decision-making process;
- To energize science to find cures;
- To facilitate advocates becoming well-versed in the science of breast cancer, other cancers, and the complexities of research;
- To empower advocates to be more effective community ambassadors for research, and contributors to the research enterprise;

A Rationale for Advocate-Researcher Relationships

Why is it important that advocates actively participate in the grant application process?

- Advocates are a critical part of the research/mentor team;
- Advocates should be involved in every step of the research project, including the planning, implementation and public dissemination of the research; and
- An advocate's experience better informs the research decision-making process by providing the unique and valuable perspectives on what it's like in "real life" to be a cancer survivor or co-survivor.

Who can serve as a research advocate?

- Advocates who have been diagnosed with breast cancer or any other cancer; have a known genetic mutation; or have a strong personal connection or experience with breast cancer or any other cancer (i.e., family, friend, caregiver).
- Advocates do not advocate for “oneself”; they instead must represent a collective breast cancer, or any other cancer patient/survivor perspective (i.e., insights & experiences of other breast cancer/other cancer survivors).
- Advocates should be actively involved in the broader breast cancer, or other cancer research advocacy community.
- Advocates should have a basic understanding of the science of breast cancer, other cancers, & the peer review cancer research process.

How research advocates can be effectively involved in research

- Research advocates should be involved early (and often) in developing a research project;
- Researchers and advocates should develop a mutually beneficial relationships. (e.g., researchers educate advocates about their project; advocates educate researchers about patients' concerns & experiences.);
- Advocates can review early drafts of applications to identify possible patient concerns;
- Advocates can provide regular input about the project; and as they learn more about the project, they may be able to identify additional ways to assist;

How research advocates can be effectively involved in research

- Advocates collective perspective on cancer can help focus the research on what matters to patients;
- Researchers and advocates should communicate regularly to stay informed about the projects progress via: e-mail, phone calls, or team meetings;
- Advocates work closely with researchers to ensure terminology used is clear for all audiences;
- Tax dollars, donors, and investors fund research;
- Effectively sharing results with the general public benefits the breast cancer, or other cancer research field, and Advocates play a crucial role as community ambassadors for disseminating and sharing research results;

How research advocates can be effectively involved in research

- Patients and funders want to know how your research may ultimately improve patients' care and survival, and Advocates play an important role in sharing your research goals with patients and funding organizations;
- Advocates and researchers should work together to determine the advocate's role and responsibilities;
- Researchers should seek out Advocates for their respective research projects, and they too, need to nourish their interaction with patient/advocates as well;
- Researchers should consider including Advocates as a line item in their grant budgets; and
- The Researcher-Advocate Relationship is strengthened through mutual respect and understanding of the important roles each play in cancer research.

The Breast Cancer Research Advocacy Network (bcRAN) Its Mission & Commitment

Mission

Building a partnership between breast cancer survivors, covivors, previvors and scientists to accelerate the progress of cancer research

The Breast Cancer Research Advocacy Network (bcRAN) Its Mission & Commitment

bcRAN is committed to:

- Influence research questions so that they are more meaningful to patients with breast cancer, survivors, covivors and previvors
- Connecting scientists with research advocates who speak for the concerns of the breast cancer population so that research goals keep the patient at the forefront
- Educating and increasing awareness about participation in research among patients (wrcanswers.com)
- Providing community outreach

Identifying a research advocate

- For Komen grants, the Advocates in Science (AIS) program has advocate members across the US & in other countries. Researchers may contact program staff at advocatesinscience@komen.org.
- Advocates with the **Breast Cancer Research Advocacy Network (bcRAN)** at UPMC/Hillman Cancer Center have received training on Komen's grant review process. Thus, bcRAN can serve a resource for other cancer centers wishing to establish or strengthen its cancer research advocacy efforts.
- Researchers may contact bcRAN: Carola Neumann, MD, Breast Cancer Researcher, Co-Director; Karen M. DiVito, BS, Breast Cancer Survivor, Co-Director; or Pricilla McAuliffe, MD, PhD, Breast Cancer Surgeon & Researcher, bcRAN Physician Advisor at UPC|bcran@upmc.edu.