GUIDELINES FOR YOUR INVOLVEMENT AS AN ADVOCATE IN KOMEN FUNDED RESEARCH

Komen has a strong commitment to including breast cancer research advocates to provide the patient perspective in the design and implementation of research projects funded through the Komen Research Grant Program. Involving a breast cancer patient advocate is strongly encouraged but not yet a required part of a researcher's Komen Grant Application.

The following guide provides suggestions for meaningful involvement as an advocate in Komen funded research projects. For additional information, please contact advocatesinscience@komen.org.

Am I qualified to serve as an advocate?

- You should have been diagnosed with breast cancer or have a strong personal connection to breast cancer, and be able to represent the collective breast cancer patient/survivor perspective (i.e., insights and experiences of other breast cancer patients and survivors).
- You should be actively involved in the breast cancer research advocacy community.
- You should have a basic understanding of the science of breast cancer and the peer review research process. There are many training programs and opportunities available for advocates to attend scientific conferences to maintain familiarity with current breast cancer research developments.
    - Cancer Information & Support Network (CISN) e-training. http://cisncancer.org
    - Cochrane Center Training - Understanding Evidence-based Healthcare: A Foundation for Action - http://us.cochrane.org/understanding-evidence-based-healthcare-foundation-action
    - Alamo Breast Cancer Foundation at San Antonio Breast Cancer Symposium (SABCS)- http://www.alamobreastcancer.org/patient-advocate-program/information/
    - Scientist <-> Survivor Program at American Association for Cancer Research (AACR) Annual Meeting - http://www.aacr.org/home/survivors--advocates/scientistharr;survivor-program.aspx
    - Focus on Research Scholars Program at American Society for Clinical Oncology (ASCO) Annual Meeting - http://researchadvocacy.org
    - Advocates in Science at ASCO Breast Cancer Symposium - http://researchadvocacy.org
- You should not have a clinical or research role on the grant application. Your role should focus on providing a broad patient perspective, and not on clinical or research-related input. Clinical and research team members should focus on their areas of expertise, and not on patient advocacy specific input. Collaboration among all team members will ensure consideration is given to all issues important to the project's success.
- You may be employed by the institution also employing the investigator(s), as long as your institutional role and reporting relationships will not present a conflict of interest or present any likelihood of bias (real or perceived) in your ability to represent the patient perspective.
- More than one advocate may be involved in a research project. This can be especially beneficial on those projects involving clinical trials.

How can I successfully be involved as a research advocate?

- As a research advocate you should be involved early during the development of a research project, including preparation of pre-applications and/or applications for grants. Your involvement will be most helpful if you are given time to learn about the project and discuss how to optimize your engagement in a particular project.
- Communicate regularly with the principal investigator on the application to keep informed of the progress of the project. Communication may occur via email, phone calls, and team meetings.
- Collaborate with the researcher to develop clearly defined roles and responsibilities.

How do Principal Investigators identify a research advocate for their project?

- Susan G. Komen's AIS program has over 150 advocate members across the US. Principal Investigators contact our program staff at advocatesinscience@komen.org for assistance in finding an advocate in specific area of the country.
- Principal Investigators can identify research advocates through a collaborator who has worked with research advocates in the past.
- If a Principal Investigator contacts you to be an advocate on their project, they may ask you to help identify additional advocates. You can contact our program staff at advocatesinscience@komen.org for assistance in finding an advocate in your area.

What roles can I play as a research advocate on a project?

Your role will depend on your level of skill, experience and knowledge in breast cancer research and as an advocate. Depending on the nature of the project and your background, there may be ways that you can assist other than those mentioned in this general overview.

Application Submission:

- Provide input and feedback on the impact of the project on patients by identifying the translation potential of the research (i.e., how meaningful or important is the outcome to patients).
- Work with the Principal Investigator to develop and review the scientific and patient impact sections to help communicate the importance of their project to breast cancer patients and their families.
- Work with the research team to develop and review the public abstract and other portions of the application to ensure that terminology is understandable to a general, non-scientific audience and conveys the importance and overall impact of their research project on breast cancer research and patient care.
- Review the entire application for correct grammar and understandability. Significant grammatical errors and poor proofreading are noticed by reviewers, and reflect poorly upon the applicant.
- Collaborate in defining your role during the project's implementation and dissemination of the results.

Research Project:

- Work with the Principal Investigator to develop plain language summaries to communicate the importance of the results of their project to the general public.
- Speak in the community about the project and its importance to patients. To maximize impact and enhance understanding, you and the researcher can make the presentation as a team.
- Work with the Principal Investigator to create educational materials, events, webinars and/or teleconferences for local, regional, and national groups and organizations to inform them of the research they are conducting and its importance to breast cancer patients.
- Participate in the project team update/planning meetings, seminars and other events important to their project's success. You will learn more about the project and identify ways you can contribute. You will add the patient perspective to the discussions.

Clinical Project (involving clinical trials):

- Collaborate with the project team in the design and development of the clinical trial, providing input on potential barriers to accrual and/or retention.
- Participate in developing patient-focused education materials, including study brochures, to provide a short, easy-to-understand description of the clinical trial.
- Review the proposed design of a clinical trial to provide guidance from the point-of-view of a breast cancer patient with regard to eligibility, frequency of invasive testing, etc., and how patients may consider the trial as an option.
- Participate in developing how the patient experience will be monitored, such as in the development of questionnaires or outlining topics for personal interviews. Provide assistance and support where appropriate throughout the study accrual period including addressing retention issues.
- Participate in developing and reviewing the language contained in Informed Consent forms, questionnaires, and other documents related to patient involvement to maximize readability and sensitivity to patient needs.

Career Development or Training Project for Junior Faculty, Postdoctoral Researchers, and Graduate Students:

Working with researchers early in their career will help make their project more patient-focused and more likely to positively impact the lives of breast cancer patients. You should be invited to:

- Participate in mentoring committees and project presentations to provide the patient point of view, which will add a different perspective to their project.
- Review publications and communications to help better explain the importance of their project to the community, as well as to other funders, in ways that are meaningful to patients.

How often should I meet with the research team?

- Frequency of meetings with investigators should be driven by the research project plan and how often the team meets to discuss progress. In other words, you should be an active part of the team, not an infrequent or secondary participant.
- The researcher's application materials should include details on how often the research team will meet with you and the type(s) of meetings that will occur.

How should I be compensated?

Compensation will vary depending on the extent of your involvement.

- At a minimum, you should be compensated for out-of-pocket expenses incurred to attend meetings and conferences as defined in the project application (e.g., mileage, parking, etc.)
- Project honoraria or consulting fees for specific projects involving commitment of time and expertise that have a deliverable essential for the project are encouraged. Rates may be on an hourly basis or a fixed project fee as agreed upon by the project leader and advocate.
- Commitment to provide funding for you to attend one or more national breast cancer research meetings to learn, network and maintain knowledge of recent breast cancer research and clinical care developments (e.g. SABCS, ASCO, AACR) are encouraged.
- Compensation should be agreed upon during the submission of the application and justified in the budget justification section, including project and/or consulting fees, and attendance at national research update meeting(s).

Should I submit a Statement of Commitment and/or Biosketch?

- You should submit a Biosketch (no more than 4 pages and in NIH or another format) if you are listed as key members of the research team.
    - A blank NIH Biosketch form, directions and a sample are attached for your reference.
- You are strongly encouraged to submit a Statement of Commitment if you are listed as key members of the research team, which should identify your level of commitment and role in the project.
    - A sample Statement of Commitment is attached.