

GUIDELINES FOR ADVOCATE INVOLVEMENT 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. Breast cancer patient advocate involvement is strongly encouraged but not yet a required part of your Komen Grant Application.

The following guide, presented by Susan G. Komen® Advocates in Science (AIS), provides suggestions for meaningful involvement of advocates and how to effectively choose advocates for your research project. For additional assistance in identifying trained advocates or for questions about how to include advocates in your proposed research program, please contact advocatesinscience@komen.org.

Who can serve as an advocate?

- Advocates should be individuals who have been diagnosed with breast cancer or have a strong personal connection to breast cancer, and who are able to represent the collective breast cancer patient/survivor perspective (i.e., insights and experiences of other breast cancer survivors).
- Advocates should be actively involved in the breast cancer research advocacy community.
- Advocates should have a basic understanding of the science of breast cancer and the peer review research process. There are many training programs and opportunities to attend scientific conferences to help advocates maintain familiarity with current breast cancer research developments.
- Advocates should not have a clinical or research role on your grant application. The advocate 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.
- Advocates may be employed by your institution, as long as their role will not present a conflict of interest or present any likelihood of bias in their ability to represent the patient perspective.
- More than one advocate may be involved in your project. This can be especially beneficial on those projects involving clinical trials.

How can I successfully involve research advocates in my project?

- Involve research advocates early during the development of your research project. Advocate involvement will be most helpful if they are given time to learn about the project and discuss how to optimize their engagement in your particular project.
- Communicate regularly with advocates on your application to keep them informed of project progress. Communication may occur via email, phone calls, and team meetings.
- Have clearly defined roles and responsibilities for the advocates on your project.
- Seek input from advocates on your project. Let them know you want and value their input and insight they bring to the project.

How can I identify a research advocate for my project?

- Susan G. Komen's AIS program has over 150 advocate members across the US. Feel free to contact our program staff at advocatesinscience@komen.org for assistance in finding an advocate in your area.
- If you have a collaborator who has worked with research advocates in the past, ask for their recommendations.
- When you identify a primary research advocate, ask for their assistance to recruit additional advocates for your project.

What roles can research advocates play in my project?

Advocates vary in the variety of skills, experience and knowledge they bring to the team. Depending on the nature of your project and the background of the advocate(s), there may be other ways that they can assist other than those mentioned in this general overview.

Application Submission:

- Provide input and feedback on the impact of your project on patients by identifying the translation potential of your research (i.e., how meaningful or important is the outcome to patients).
- Work with you to develop and review the scientific and patient impact sections to help communicate the importance of your project to breast cancer patients and their families.
- Work with your research team to develop and review the public abstract and other portions of the application to ensure terminology is understandable to a general, non-scientific audience and to convey the importance and overall impact of your research project on breast

cancer research and patient care.

- Collaborate in defining their role during the project's implementation and dissemination of the results.

Research Project:

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

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

Working with research advocates early in your career will help make your project more patient-focused and more likely to positively impact the lives of breast cancer patients. Advocates 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 your project.
- Review publications and communications to help better explain the importance of your project to the community, as well as to other funders, in ways that are meaningful to them.

How often should the research team meet with the research advocate(s) listed on the application?

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

How should research advocates be compensated?

Compensation will vary depending on the extent of the advocate's involvement.

- At a minimum, advocates 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 advocate team members 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 the advocate submit a statement of commitment and/or biosketch?

- A biosketch (no more than 4 pages and in NIH or another format) should be submitted for advocates listed as key members of the research team.
- All advocates listed on your project should submit a statement of commitment, which should identify their level of commitment and role in the project.