

Guidelines for Advocate Involvement in Komen Funded Research

Komen is strongly committed to including breast cancer research advocates in the design and implementation of Komen-funded research projects. Advocates provide essential patient perspectives and are real life experts on living with breast cancer 24/7.

This guide, developed by Susan G. Komen® Advocates in Science (AIS), suggests ways to effectively involve advocates in Komen-funded research. For more assistance in identifying trained advocates or questions about involving advocates in a research project, please contact advocatesinscience@komen.org.

Who can serve as a research advocate?

- Advocates who have been diagnosed with breast cancer; have a known genetic mutation; or have a strong personal connection or experience with breast cancer (i.e., family, friend, caregiver).
- Advocates must represent a collective breast cancer patient/survivor perspective (i.e., insights and experiences of other breast cancer survivors).
- Advocates should be actively involved in the broader breast cancer research advocacy community.
- Advocates should have a basic understanding of the science of breast cancer and the peer review research process.
- Advocates are not required to be an AIS member. Information about AIS and joining AIS is at <http://sgk.mn/2lBg8vC>

Identifying a research advocate

- The AIS program has advocate members across the US and in other countries. For help in finding an advocate, contact our program staff at advocatesinscience@komen.org.
- Ask for recommendations from collaborators, who have worked with research advocates.

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 relationship. For example: researchers educate advocates about their project; advocates educate researchers about patients' concerns and experiences. For a copy of the "Building advocate↔researcher relationships to strengthen research" toolkit, contact advocatesinscience@komen.org.
- Advocates can review early drafts of applications to identify possible patient concerns. Do not wait until the last minute to work with an advocate. Be respectful of her/his time, commitment and expertise.
- Advocates can provide regular input about the project. As advocates learn more about a research project, they may identify additional ways to assist. Their collective patient perspectives help focus the research on what matters to patients.
- Researchers and advocates should communicate regularly to keep informed about the project's progress. Use email, phone calls, and team meetings – whatever works best for the researcher and the advocate.
- Advocates work closely with researchers to ensure terminology used is clear for all audiences. For a copy of "Writing a Lay Abstract," contact advocatesinscience@komen.org.
- Tax dollars, donors and investors fund research. Effectively sharing results with the general public benefits the breast cancer research field. Patients and funders want to know how your research may ultimately improve patients' care and survival.
- Advocates and researchers should work together to determine the advocate's role and responsibilities.
- For testimonials from Komen Scholars about how they have involved advocates, contact advocatesinscience@komen.org.

What roles can a research advocate fill on a research project?

Advocates have a wide range of skills, experience and knowledge to enhance a research team's work. Advocates may have specific suggestions on how they can contribute to a project. Some possibilities are described below. For a copy of the "Patient Advocate Involvement Plan – Suggestions for Researchers," contact advocatesinscience@komen.org.

Possible Advocate Roles in the Application's Development

- Provide feedback on a project's impact on patients by identifying the research's translation potential (i.e., how meaningful or important the outcome(s) could be to patients).
- Work with researchers to develop and review the application's Innovation and Significance section. Advocates can help assure this section highlights the project's importance to breast cancer patients and their families.
- Work with the research team to develop and review the lay abstract and other portions of the application to assure terminology is understandable to a general, non-scientific audience; and conveys the project's potential overall impact on breast cancer research and patient care.
- Help define their role during the project's implementation, annual reporting, and articulating the impact of the research findings.

Possible Roles of Advocates in Research Project Implementation

- Work with researchers to develop plain language summaries highlighting the project's potential impact on patients.
- Be a community ambassador speaking about the research and its potential significance to patients. Public speaking engagements are an excellent opportunity for advocates and researchers to co-present. Refer to Komen Scholar Testimonials for further guidance. Contact advocatesinscience@komen.org for these testimonials.
- Assist researchers in connecting with their local Komen Affiliate and the broader breast cancer community.
- Work with researchers to create educational materials, events, webinars and teleconferences for local, regional, and national groups and organizations to inform them about the research and its importance to breast cancer patients.
- Participate in research project team's update/planning meetings, seminars and other events essential to the project's success.

Possible Roles of Advocates in a Clinical Project (involving clinical trials)

- Work with the project team to design and develop the clinical trial to identify potential barriers to accrual and/or retention.
- Help develop patient-focused education materials. For instance: co-author study brochures to give a short, easy-to-understand description of the clinical trial.
- Review the clinical trial's proposed design. Provide a breast cancer patient point-of-view regarding eligibility criteria, frequency of invasive testing, costs, logistical requirements, and patient feelings when deciding whether to participate.
- Help define how the patient experience will be monitored. For example, developing patient reported outcomes (PROs) or questionnaires; or identifying topics for personal interviews. As appropriate, provide assistance and support throughout the study accrual period, including ways to address recruitment or retention issues.
- Help develop and review the language used in Informed Consent forms, questionnaires, and other documents for patients. Advocates help maximize readability and sensitivity to patient concerns and needs.
- Review the Informed Consent process to assure patients have ample opportunities to discuss and truly understand the nature of the research, what they are expected to do, the risks/benefits, their costs, and what information they will receive on the clinical trial's progress, completion, and results.

Possible Roles of Advocates in a Training Project for Junior Faculty, Postdoctoral Researchers, and Graduate Students

- Advocates can help make a research project more patient-focused and likely to positively impact the lives of breast cancer patients. Researchers can learn more about what is critical to patients.
- Provide a patient point-of-view in mentoring committees and project presentations. Advocates add a different, more poignant perspective to your project and its relevance to patients.
- Review publications and communications. Advocates help clarify why the research is critical and relevant to patients and the community.

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

- Frequency of meetings should be driven by the project plan and the schedules of the people involved.
- The application should include mutually agreed upon details on how often the research team will meet with the advocate(s) and the type(s) of meetings that will occur.

Should research advocates be compensated?

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

- Reasonable compensation is allowed when advocates perform services that would otherwise be a contracted expense. Compensation may be a salary, per-hour compensation, or honoraria.
- Offer to cover out-of-pocket expenses incurred to attend meetings and conferences identified in the project application (e.g., travel expenses, conference fees, mileage, parking, etc.). All meetings and conferences must be directly related to the proposed training or research plan.
- Researchers and advocates should agree on compensation and expenses to be reimbursed. These should be identified and supported in the budget justification section of the application, especially project and/or consulting fees.

Advocates must provide a Letter of Support and Biosketch

- A biosketch (no more than 5 pages in an NIH or other acceptable format) should be submitted for advocates listed as key members of the research team. Examples are provided on the Komen website at <http://sgk.mn/2lBg8vC>.
- All advocates, listed on your project, must submit a Letter of Support. Their letter should identify their level of commitment to and role(s) in the project. An example is provided on the Komen website at <http://sgk.mn/2lBg8vC>.