



Advocates in Science



BRINGING THE PATIENT EXPERIENCE TO RESEARCH

Engaging patient advocates is increasingly being recognized as a fundamental factor in developing, implementing, and overseeing research that more effectively meets patients' needs. Research advocates provide a real-world understanding of what matters most to patients and a sense of urgency to find more-effective ways to prevent, diagnose, treat, and ultimately cure breast cancer. With the recent explosion of patient-centric programs led by nonprofit foundations, the government, regulatory agencies, and pharmaceutical companies, the demand for experienced, knowledgeable, and effective breast cancer research advocates, representative of the diverse breast cancer patient population is quickly outpacing the supply.

Most research advocates are volunteers who work to reduce the burden of breast cancer in their communities and drive progress toward ending breast cancer. They are driven by their passion to save lives and seek out opportunities to participate and learn more about breast cancer. They must engage in ongoing education and training activities to enhance their advocacy skills and expand their scientific knowledge. However, opportunities for research advocate training and education are quite limited, and as a result, not all research advocates are adequately prepared to participate to the fullest extent in the research process and scientific dialogue.

OUR APPROACH

Susan G. Komen established its Advocates in Science (AIS) Program to build a cadre of skilled, knowledgeable and broadly-networked breast cancer research advocates and actively engage them throughout the research process, where they bring the patient voice to Komen's – and other organizations'—research programs in all areas of breast cancer research. The AIS program, overseen by an AIS Steering Committee, takes a multi-pronged approach to advocacy that includes the following components:

Involvement in Komen's Research Grant Strategy and Peer Review

Through the AIS Program, Komen matches advocates to Komen activities that best fit their training, experience and preference. A few of our most experienced breast cancer advocates help shape Komen's research grant strategy by ensuring research priorities are in line with patients' greatest needs and concerns through their service on Komen's scientific advisory boards. Many other AIS members participate as advocate reviewers of Komen's research grants, ensuring that breast cancer research is focused on answering questions most important to those affected by breast cancer to maximize impact. Research advocates play a critical role in the review of Komen's research grant applications, providing input on such things as the projects' potential impact, approach and feasibility and patient advocate engagement plan.

Engagement of Advocates in Komen-funded Research Projects

Advocates are involved in all types of research projects, from basic research to translational research, to clinical trials. Advocate involvement is required in Komen-funded grants. Through the AIS Program, Komen has created a toolbox of resources – some aimed toward advocates and others targeted toward researchers – to facilitate effective advocate engagement in research projects. Komen Advocates in Science have raised the bar for how advocates and researchers work together to prioritize, develop and implement research projects.

Education & Training

Komen is committed to developing the next generation of breast cancer research advocates and strengthening the skills and knowledge of all AIS members. The AIS Program provides opportunities for advocates to learn more about breast cancer research and strengthen their research advocacy skills through a variety of educational sessions and rigorous training programs. These sessions/programs vary in format, from online tools, webinars, face-to-face meetings and peer-to-peer mentoring.

Communication

Research advocates are active in their communities, working as educators and advocates to inform and inspire others to act. They disseminate the results and impact of Komen-funded research, enhance community awareness and support of breast cancer research, participate in community outreach and influence legislative policy. They work to establish and strengthen connections and collaborations among different stakeholders to accelerate progress and drive change. To keep them informed, Komen provides AIS members with updates on recent scientific advances in breast cancer, Komen's research and its impact and upcoming educational and participation opportunities for advocates both within Komen and nationally.

Engagement of Advocates in Other Projects/Initiatives

Komen matches AIS members to other (non-research) Komen activities that best fit their training, experience and preference. For example, AIS members have participated in the review of community health program grants, participated in Komen's public policy activities and reviewed Komen educational materials. Komen is also sought out to provide the patient perspective in many national and international forums, and we often will ask AIS members to participate in such events on Komen's behalf to enrich these discussions and decision-making. Komen AIS members have provided testimony to the FDA on the patient experience, shared their experience with Vice President Biden's Office as part of the Moonshot Initiative and served on scientific conference program committees. In addition, we will work with other organizations or companies to identify advocates to participate in their focus groups, committees or other patient-centered programs.



"Being a volunteer for Komen at my local Affiliate and being an active Advocate in Science member, I have seen the difference Komen has made in the lives of those affected by breast cancer today and the progress in research that will help our children and grandchildren in the future."

Patty Spears, Advocate in Science

To learn more about Komen's Advocates in Science Program, please email advocatesinscience@komen.org.