The Advocates in Science (AIS), a research advocacy program of Susan G. Komen®

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Abstract

Susan G. Komen® has a longstanding commitment to ensure that the unique and valuable perspectives of breast cancer patients, survivors, and co-survivors are integrated into the scientific discourse and decision-making processes impacting our progress toward ending breast cancer. Komen established the Advocates in Science (AIS) Program to build a cadre of skilled, knowledgeable, and broadly-networked breast cancer research advocates and engage patient advocates throughout the research process, where they 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.

The AIS Program, overseen by an Advisory Steering Committee, takes a multi-pronged approach to research advocacy that includes the following components:

1. Engagement of Advocates in Komen-funded Research Projects: Advocate involvement is required in most Komen-funded grants and strongly encouraged in all other Komen-funded research projects. Through the Program, Komen has created several tools – some aimed at bringing advocates and others targeted at researchers – to facilitate effective advocate engagement in research projects.

2. Education & Training: Komen is committed to developing the next generation of breast cancer research advocates and strengthening the skills and knowledge of all advocates. 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 interactive training programs with researchers and advocates in-person, online, and face-to-face meetings, and peer-to-peer mentoring.

3. Researcher Relationships: The AIS Update offers a unique opportunity for advocates to learn from scientific advances in breast cancer, Komen’s research and impact and upcoming educational and community engagement opportunities for advocates both within Komen and nationally.

Engaging patient advocates is increasingly being recognized as a fundamental factor in improving the quality of cancer research. Involving advocates in the research process leads to increased interest in scientific research, we welcome you to join us. Komen’s advocates bring unique perspectives: they live, learn, experience, and embrace the challenges and opportunities presented by breast cancer research.

The Advocates in Science (AIS) Program provides opportunities for advocates, Advocates & Scientists to partner in the community. In 2015-16, AIS-SPR grants supported:

- The Advocates in Science Young Researchers Breakthrough in North Carolina that brought together advocates and young researchers at Komen’s research and social event.
- A Breast Cancer Conference to educate the community surrounding area including a Komen Scholar and Komen research staff in Texas.
- The Komen Continuum of IMPACT featured a panel of Komen Scholars and staff to discuss key issues facing those who have been touched by breast cancer in the Greater Kansas City area.
- A Research Festival in Kansas City including survivors, young researchers and Komen Scholars.
- An intimate Breakfast where Komen Scholars presented to advocates in their area.
- A Research Symposium in California with a discussion between a leading researcher and Komen lab coat.

Involvement in Research

Research Advocate Regional Roster

A list of advocates interacting with Komen researchers and grant applicants. Helpful to match researchers with advocates in their area.

Webinar

Working Together – Explain how advocates can work with researchers to develop that continuum of research from basic to clinical research.

Guidance

Guidelines and tools for advocate involvement in Komen funded research.

AIS Steering Committee

Advocates in Science (AIS-SC) Members

Advocates in Science (AIS-SC) Members

The Advocates in Science Steering Committee (AIS-SC) provides guidance and recommendations to Komen’s research and education teams and works with Komen staff to develop and implement AIS activities and initiatives.

AIS-SC Members

- Karen Durham, Sandy Firestone (Vice Chair), Cheryl Jerminigan, Judy Johnson, Peggy Johnson, Patty Spears and Kim Wright (Chair)

Advocates in Science Governance

Advocates in Science Members

1. Become an AIS Member

If you are passionate about ending breast cancer and have an interest in scientific research, we welcome you to join us. Komen’s advocates bring unique perspectives: they live, learn, experience, and embrace the challenges and opportunities presented by breast cancer research.

2. AIS Steering Committee /AIS-SPR Grants

AIS-SPR grants were awarded jointly to Advocates and Advocates-SC members to provide opportunities for Advocates, Advocates & Scientists to partner in the community. In 2015-16, AIS-SPR grants supported:

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Resources

- A Call to ARMs – Explains the roles of advocates, researchers and mentors and how they work together throughout the grant and research project lifecycle.

ARMs

- Advocates, Researchers, Mentors

- Komen requires the inclusion of advocates in all grants including career awards (Postdoctoral Fellowship and Career Catalyst Awards).
- Advocates, Researchers and Mentors are expected to work together with the goal of building and cultivating productive & lasting Advocate–Researcher relationships.

Webinars

23 899 49

2013-2016

Webinar Topics (selected):

- Young Women and Breast Cancer
- Strides in Breast Cancer Treatments
- Integrating Social and Emotional Aspects of Care
- Social Determinants of Health
- What is it, Who Needs it, How to Do it: The Advocates in Science Symposium
- Breast Cancer Care in Older Women
- disparities in survival
- Collaborative Efforts to Develop New Approaches for Treating (and Preventing) Breast Cancer
- Disparities in Breast Cancer Treatment

AIS Update

An e-newsletter informing AIS members about Komen research news, education and research advocacy opportunities inside and outside of Komen.

Communication

AIS Update

197

48%

13%