

# 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 dialogue and decisions impacting Komen's 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 AIS Steering Committee, takes a multi-pronged approach to research 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 serve on Komen advisory boards, providing strategic guidance and input on the research grant focus, and many others participate as advocate reviewers of our research grants.

**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 toward advocates and others targeted toward researchers – to facilitate effective advocate engagement in 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:** The AIS Update keeps advocates up-to-date 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.

Engaging patient advocates is increasingly being recognized as a fundamental factor in developing, implementing, and overseeing research that more effectively meets patients' needs. With its rich and growing experience in research advocacy, Komen is one of the pioneers of "patient-centric" research programs. Through the AIS Program, Komen continues to build a cadre of knowledgeable and experienced research advocates who bring the patient voice to Komen's – and other organizations'—research programs, in all areas of breast cancer research from the bench to the bedside to the curbside and back. AIS members are also active in their communities and serve as bridges between advocates, scientists and Komen Affiliates to enhance understanding and excitement about research; foster greater support for research and its funding; build stronger researcher->community connections; and energize hope for finding cures.

## Advocates in Science Governance

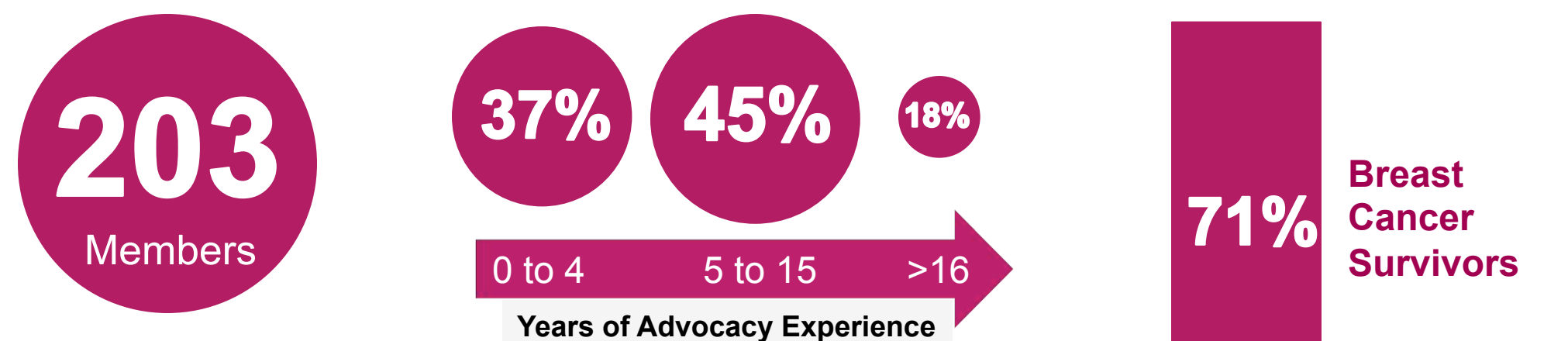
### AIS Steering Committee

The Advocates in Science Steering Committee (AIS-SC) provides guidance and recommendations for Komen's AIS Program and works with Komen staff to develop and implement AIS' activities and initiatives.

### AIS-SC Members

Karen Durham, Sandy Finestone (Vice Chair), Cheryl Jernigan, Judy Johnson, Peggy Johnson, Patty Spears and Kim Wright (Chair)

## Advocates in Science Members



### 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 research advocates (i.e., Advocates In Science) are men and women, laypersons and healthcare professionals, Komen Affiliate members, and individuals involved in advocacy with other breast cancer organizations.

### AIS Steering Committee A<sup>2</sup>SPIRE Grants

*Advocates, Affiliates & Scientists: Partners in Research Excellence*

A<sup>2</sup>SPIRE grants were awarded jointly to Affiliates and AIS-SC members to provide opportunities for Advocates, Affiliates & Scientists to partner in the community. In 2015-16 A<sup>2</sup>SPIRE grants supported:

- The A<sup>2</sup>SPIRE Young Researchers Roundtable Breakfast in **North Carolina** that brought together survivors/advocates, young researchers and Komen Scholars.
- A Breast Cancer Conference to educate the community and surrounding area including a Komen Scholar and Komen research staff in rural **Texas**.
- The Komen's 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 Forum in rural **Kansas** including survivors, young researchers and Komen Scholars.
- An intimate Breakfast where Komen Scholars presented research to Komen **Maryland** stakeholders.
- A Research Symposium in **California** with a discussion between a leading researcher and Komen Scholar, including presenting Komen lab coats to young researchers.



## Involvement in Research Grant Review (FY16)

### Resources

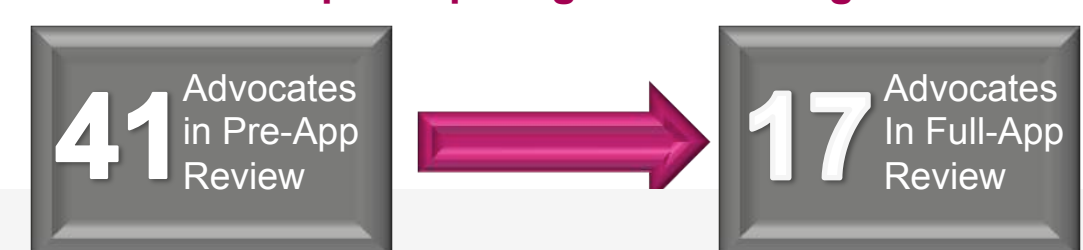
#### Webinar

How to Be an Outstanding Reviewer – Explains the review process and the role of advocates in research grant review.

#### Advocate Liaisons

Experienced advocates who mentor and guide advocates who are new to Komen in the grant review process.

# of advocates participating in research grant review



## Involvement in Research

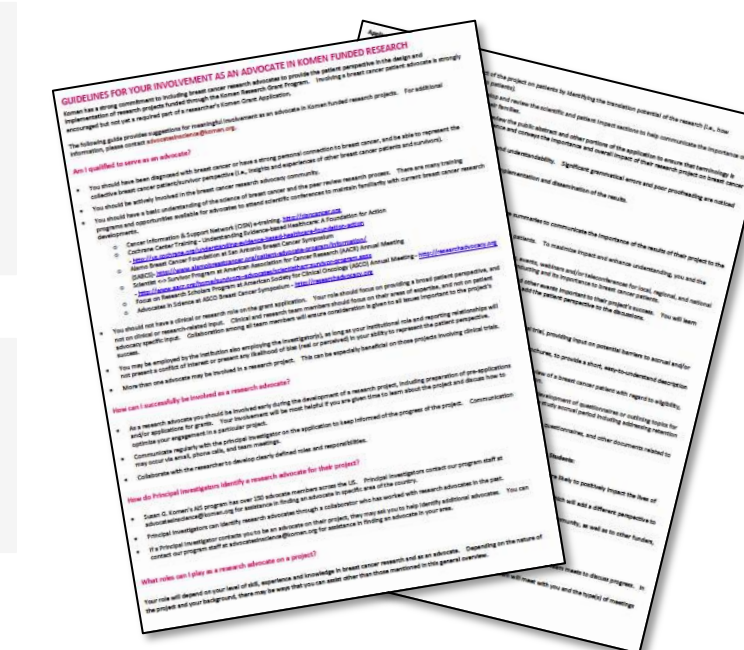
### Research Advocate Regional Roster

A list of AIS members interested in working with Komen researchers and grant applicants. Helpful to match researchers with advocates in their area.

Interested in working with researchers **100**

### Webinar

Working Together – Explains how advocates can work with researchers through the continuum of research from basic to clinical research.



### Guidance

Guidelines and tools for advocate Involvement in Komen funded research.

## ARMs

ADVOCATES, RESEARCHERS, MENTORS

- Komen requires the inclusion of advocates in all grants including early 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

## Resources

### Webinar

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 Faculty



Cheryl Jernigan, CPA, FACHE  
Komen Scientific Advisory Board  
Advocate In Science



Danny Welch, Ph.D.  
Komen Scholar



Zach Hartman, Ph.D.  
Komen CCR Grantee



Geoff Wahl, Ph.D.  
Komen Scholar

### Guidance Document

Building advocate ↔ researcher relationships to strengthen research.

### Testimonials

Several written testimonials and a video have been created highlighting different research advocate relationships in basic research, translational/clinical research and public/community health.

## Education and Training

## Meetings



**AAADV Fundamentals, in collaboration with Susan G. Komen**

This collaboration introduces patient advocates to the U.S. Food and Drug Administration's drug development and approval process. This custom course held in advance of the annual AAADV Workshop focuses on how advocates can work more effectively with all stakeholders in the research process – industry, academia, government and technology – to ensure the patient voice is incorporated across all conversations and decision making.



**Breast Cancer Symposium 2015**

### Komen AIS Class at the ASCO Breast Cancer Symposium

The purpose of Advocates in Science at the ASCO Breast Cancer Symposium 2015 was to prepare AIS members to better understand research findings and to disseminate those findings to their local Affiliate of Susan G. Komen and breast cancer community.

## Webinars 2013-2016



### Webinar Topics (selected)

- Young Women and Breast Cancer
- Toxicities of Breast Cancer Treatments
- Genetic Testing for Breast Cancer Susceptibility: What is it, Who Needs it and Why?
- Breast Cancer Care in Older women: Opportunities and Challenges
- Patient-Reported Outcomes (PROs)
- Collaborative Efforts to Develop New Biomarkers for the Treatment of Triple Negative Breast Cancer: a TBCRC Initiative
- Ductal Carcinoma in SITU
- Disparities in Breast Cancer

## Communication

### AIS Update

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

AIS receiving Update **197**

Opened **48%**

Clicked Thru **13%**