



Komen Advocates in Science ARMs: Advocates, Researchers, Mentors

March 31, 2020

Driven by the Best and Brightest

Scientific Advisory Board

Provide overall
strategic direction for
the scientific focus of
the organization

Komen Scholars

Committee chairs and
reviewers in Komen's
scientific peer review
process

Advocates in Science

Ensure that unique and
valuable perspectives of
breast cancer patients
are integrated into the
scientific dialogue



Komen is Uniquely Positioned in the World of Breast Cancer: **Fighting Breast Cancer on All Fronts**



What is Research Advocacy?

- **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.**



Komen Advocates in Science

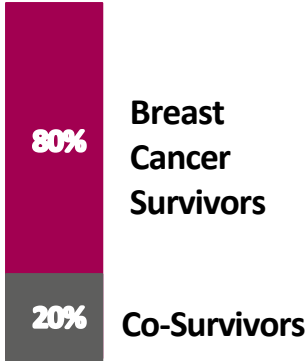
Bringing the Patient Voice to Research

200+
Members

Bring the patient perspective to research discussions and decision-making

Drive change through scientific ↔ community connections

Tell their stories to emphasize urgency & impact



8 Steering Committee Members = Komen Scholars

- Involvement in Komen's research grant strategy
- Engagement of advocates in Komen-funded research projects
- Participation in research grant peer review
- Active in communities - Education and training - Communication





ARMs: Advocates, Researchers, Mentors

ARM Initiative

- **Purpose:**
 - Build & cultivate productive & lasting Advocate ↔ Researcher relationships
 - Assess what worked well & what could be improved to achieve effective, mutually rewarding ***long-term*** relationships



What is the role of an Advocate Mentor?



- Survivors/Co-Survivors
- Independent from the researcher, AND
- Tied to the broader community of breast cancer survivors/co-survivors...able to present a more **collective** patient experience/perspective

To ensure these unique real life experiences/perspectives are integrated into the scientific discussions, issues and decisions impacting those with breast cancer...throughout the research decision-making process.

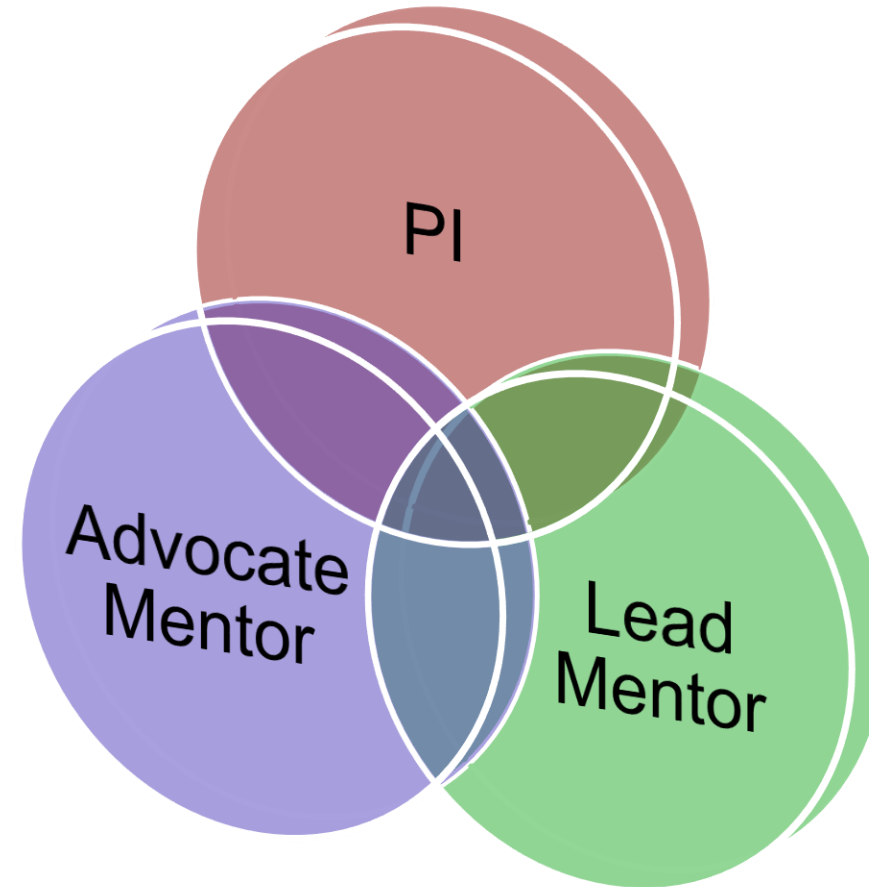


Advocate ↔ Researcher Relationships: Key Players

Principal Investigator
(grantee/trainee)

Advocate Mentor

Lead Mentor



Common Goals

PI / Advocate Mentor / Lead Mentor

- **Advancing research**
 - ...achieving meaningful progress for patients
- **Creating/Participating in a top-notch training PI experience**
- **Building rewarding, lasting advocate↔researcher relationship**



Advocate and Scientists Working Together

Advocate Activities

Less Active

Advocate
Involvement

More Active



- Informing – Reviewing Lay Abstract/Summary for Clarity; Attend lab meetings
- Consulting – Educational Brochure; Disseminate information; test approach for feasibility
- Joint Decision Making – Input on Patient Recruitment Practices, Study Design to improve Patient Accrual
- Independent Activities – Presenting work; speaking to the community



Resources/Tools: Building Advocate↔Researcher Relationships

- Building Advocate↔Researcher Relationships to Strengthen Research
- Testimonials/Stories demonstrating successful Advocate↔Researcher Relationships
- Guidelines for Advocate Involvement
- Suggestions for Patient Advocate/Advocate Mentor Plan
- Webinar: Advocates & Researchers Working Together



By Working Together, Advocates and Researchers Can Achieve More!



THANK YOU!

