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

Global Programs

Community Programs

Research/Scientific Programs

Advocacy

Education
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

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

Members
- 200+
- 80% Breast Cancer Survivors
- 20% Co-Survivors

8 Steering Committee Members = Komen Scholars

Bring the patient perspective to research discussions and decision-making

Drive change through scientific ↔ community connections

Tell their stories to emphasize urgency & impact
ARMs: Advocates, Researchers, Mentors
ARM Initiative

• Purpose:
  o Build & cultivate productive & lasting Advocate↔Researcher relationships
  o 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

- **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!