



# Educating Patient Advocates to be Involved in Research

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## Why Involve Advocates?

- **No agenda save improving outcomes of cancer patients**
- **Advocates' Role**
  - Challenge: ask the hard questions
  - Question: everything
  - Collaborate: on meaningful issues
  - Explain: advocate perspective
  - Report: to their constituencies
  - Oversight: call it "like it is"

## Educated Advocate

- Responsible and accountable to a patient constituency (e.g., via a patient organization)
- Has been personally affected by the specific disease or condition; (BUT not about your disease; represent a constituency)
- Knowledgeable, trained, and confident in her/his ability to participate in the research.

## Why is Advocate Education Needed?

- NBCC's Advocacy Activities → Ensure that Advocates are at all tables where breast cancer decisions are made (research, policy, public health)
  - Advocate influence and involvement
- NBCC's Education and Training Activities → Ensure that advocates are sufficiently grounded in science and public health concepts to serve in these roles
  - Advocate empowerment

## Project LEAD<sup>®</sup> Institute: Advocate Led

- Project LEAD Workshops
- Clinical Trials Project LEAD
- Quality Care Project LEAD
- Continuing education for LEAD graduates
- Annual Advocate Leadership Summit
- Advanced Project LEAD
- Team Leader Training
- Public Policy Project LEAD

## Project LEAD Core Curriculum

- Basic Science  
(cell/molecular biology, genetics, genomics)
- Immunology
- Epidemiology
  - Biostatistics, study design, clinical trials, critical appraisal of scientific literature
- Evidence-based healthcare perspective
- Advocacy Development



# 2019 Project LEAD Class



## Development of Project LEAD

- Initial meeting of scientists to develop the initial curriculum
  - Key competencies
- Faculty and instructional designer drafted and revise course materials; annual updates to all core courses done by faculty, annually
- Adult learning principles built into the program
  - One-hour lectures are the primary means of presenting new material
  - Lectures interspersed with multiple small group discussions of content facilitated by mentors (prior LEAD graduates) and faculty or postdocs
  - Case study analyses
  - Group projects
  - Pre-work completed asynchronously in the month prior to the Institute

## What do LEAD Grads Do?

- >2500 LEADgrads from all states, 35 countries
- Resource to local communities
- Interpret information
- Scientific peer review
- **Clinical trials:** design, monitor, implement
- Nat'l policy committees
- Members of Artemis research teams

## They have helped

- Shape research agenda
- Strengthen evidence based medical policies
- Change breast cancer conversation and focus
- Create a model for:
  - Other advocacy groups
  - ACA/PCORI advocacy
  - DOD, NCI, AHRQ, FDA, etc.
  - International advocate efforts



## Some Examples of How Advocates Are Involved

### DOD BCRP

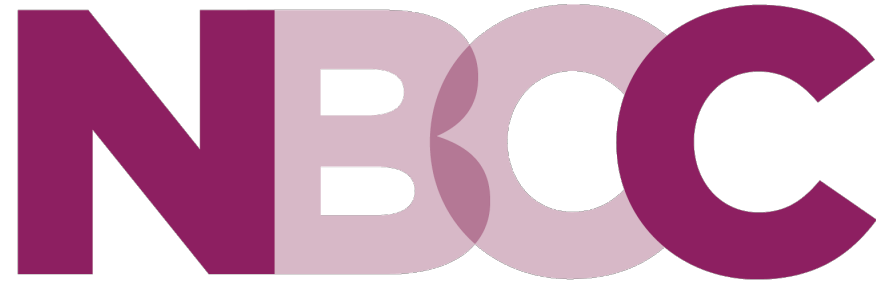
- Scientific community decides on questions
- Program role is to determine what mechanisms and criteria questions should respond to, in order to achieve mission
- BCRP does not direct the science
- Sets context
- ***Advocates involved at every level***
- ***Program input focused on relevance of research***
- ***But also participate as partners in projects***

### ARTEMIS

- Innovative, mission-driven approach of strategic summits, catalytic workshops; focused on two areas
  1. **Primary Prevention** →  
Prevention vaccine going into Phase 1 trial
  2. **Prevention of Metastasis:** →  
Focused research on disseminated dormant tumor cells (characteristics, role of immune system, ways to target)
- ***Advocate-led***

## Challenges in Maintaining Project LEAD

- Costs of the program (initial development; staff, scholarships, faculty, lodging, etc.)
- Keeping the program current
- Recruitment – identifying advocates committed to continue advocacy
- Advocate opportunities



NATIONAL BREAST CANCER COALITION

# Questions and Discussion

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