NCRA
Advocate Engagement Working Group Update

Nancy Roach

CTAC Meeting
July 8, 2015
Topics for Discussion

• NCI Research Advocates
• NCI Council of Research Advocates (NCRA)
• Advocate Engagement Working Group of the NCRA
What is a Research Advocate?

A research advocate brings a nonscientific viewpoint to the research process and communicates a collective patient perspective.

A collective patient perspective is created when a person has knowledge of multiple disease experiences and conveys this collective perspective rather than his or her own exclusive experience.
How Advocates Engage with Research at NCI

- **Advise**: help develop recommendations or advise on strategic directions or broad policy issues.
- **Design**: develop new or enhance existing programs or activities. Design activities include serving on a committee or panel involved in development of a new program or oversight of an existing program to provide the patient perspective or to identify patient barriers to implementation.
- **Review**: evaluate and analyze research proposals and ongoing research activities. Review activities include participating in peer or concept review panels.
- **Disseminate**: interpret and communicate scientific information for nonscientific audiences.
Outcomes

Enhancing research
- As part of a team, research advocates provide a different perspective that can improve accrual feasibility and patient acceptance of research projects.

Increasing public understanding and support of research
- Research advocates provide a bridge between the scientific community and the public.
Office of Advocacy Relations

WE MAINTAIN A POOL OF MORE THAN 200 QUALIFIED CANCER RESEARCH ADVOCATES READY TO PARTICIPATE IN NCI ACTIVITIES

ADVISORY BOARDS • MATERIALS REVIEW • PLANNING COMMITTEES
PEER REVIEW • STEERING COMMITTEES • USABILITY TESTING • AND MORE!

NIH National Cancer Institute

Office of Advocacy Relations
Learn more at advocacy.cancer.gov
Role:
- Identifies and responds to challenges facing the Institute at the request of NCI leadership
- Identifies new approaches, promoting innovation, recognizing unforeseen risks or barriers, and identifying unintended consequences that could result from NCI decisions
- Enhances community input, optimizes community outreach, and promotes strong collaborations to improve research outcomes.

Membership:
- Up to 16 advocate leaders who operate on a regional or national level
NCRA Advocate Engagement Working Group (AEWGG)
AEWG Mission and Activities

**Charge:** To explore best practices for engaging advocates to further the research goals of NCI; to identify opportunities to enhance and improve advocate engagement efforts (for both experienced and new advocates); and to identify processes and resources available to recruit and support the next generation of cancer research advocates.

**Mission:** To identify and explore feasible strategies for identifying, engaging and supporting research advocates in NCI activities
AEWG Members

Co-Chairs

- Joya Delgado Harris
  American Cancer Society
- Nancy Roach
  Fight Colorectal Cancer

- Carol Baas
  Physical Sciences-Oncology Centers Program, NCI
- Susie Brain
  University of California, San Francisco
- Liz Frank
  Dana Farber Cancer Institute, Harvard Cancer Center
- Barbara LeStage
  Dana Farber Cancer Institute, Harvard Cancer Center
- James Omel
  Central Nebraska Myeloma Support Group
- Senaida Poole
  California Breast Cancer Research Program
- Regina Vidaver
  University of Wisconsin School of Medicine and Public Health

NCI Consultants

- Deborah Jaffe
  CCCT
- Jennifer Kwok
  OAR
- Robin Rinker
  OAR
- Peter Wirth
  DEA
Mission: To identify and explore feasible strategies for identifying, engaging and supporting research advocates in NCI activities

1. Identify Advocates – identify advocates to participate in NCI opportunities
   • Broaden the pool of engaged research advocates known to NCI’s Office of Advocacy Relations

2. Engage Advocates – engage advocates in NCI activities
   • Identify opportunities to engage
   • Increase understanding of how to strengthen advocate engagement

3. Support Advocates – support advocates on effective ways to work with NCI
   • Identify training resources and gaps
   • Promote partnerships with groups that train advocates
Final Thoughts

• If you have know advocates who would be interested, please connect them to the NCI Office of Advocacy Relations
• Continually consider how advocates can be involved in your research activities
Questions?