

NCRA Advocate Engagement Working Group Update

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**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!



Office of Advocacy Relations
Learn more at advocacy.cancer.gov



National Council of Research Advocates (NCRA)

- 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 (AEWG)



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

- **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

Fight Colorectal Cancer

- **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
- **Robin Rinker**
OAR
- **Jennifer Kwok**
OAR
- **Peter Wirth**
DEA



AEWG Priority Areas

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?