

Research Advocacy at NCI

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Overview

Susan

An Advocate Perspective

- Journey from patient to advocate
- Types of advocacy
- Research advocacy at NIH and the Clinical Center
- Keys to Success

Shannon

An NCI Perspective

- Research advocacy at NCI
 - What is a research advocate
 - How NCI engages advocates
- How advocates contribute

My Journey as an Advocate

- Breast and ovarian cancer survivor
- Co-founder, Ovarian Cancer National Alliance
- NCI Peer Review
- Federal Advisory Boards
- Author
- Executive Director, DC Cancer Consortium
- Keynote Speaker



Advocacy Continuum

Personal Advocacy to Community Advocacy to National Advocacy



National Advocacy

- Lobby Congress
- Provide testimony
- NCI or DOD Peer Review



Community Advocacy

- Support groups
- Speaking at the local level
- Community-based fundraising



Personal Advocacy

- Finding information
- Getting a second opinion
- Knowing what questions to ask
- Working for rights around insurance, employment, privacy, etc.

The Advocacy Continuum from the National Coalition for Cancer Survivorship (NCCS)

Types of Advocacy*



Fundraising



Outreach & Education



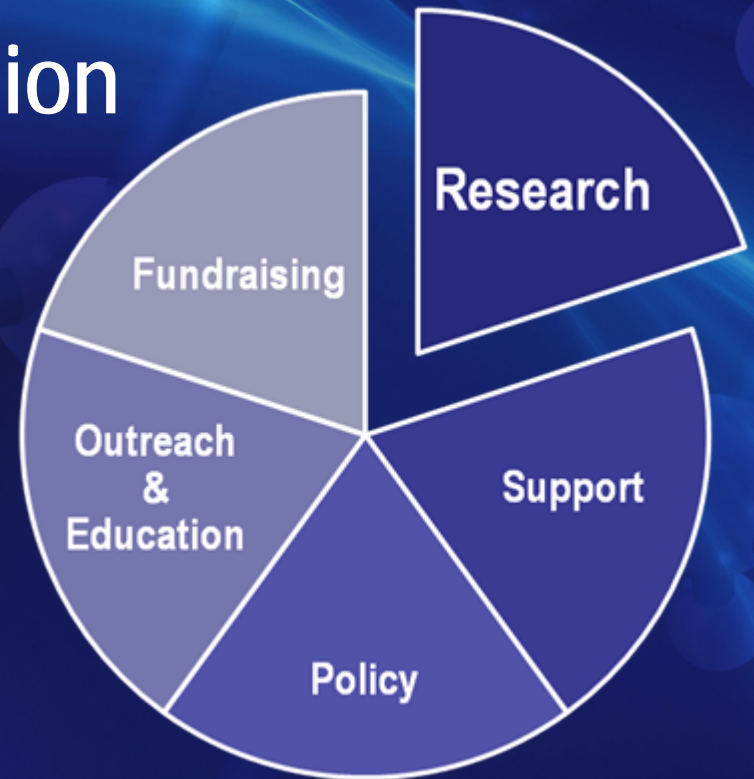
Policy



Support



Research



NCI Office of Advocacy Relations (OAR)

The NCI's Office of Advocacy Relations engages the advocacy and NCI communities in dialogue about cancer research opportunities and priorities in order to advance progress and improve outcomes.

OAR:

- Serves as the Institute's expert and central resource for advocacy matters.
- Facilitates dynamic relationships and collaborations to promote mutual goals.
- Disseminates information and fosters understanding of key cancer issues and priorities.

What Makes a Research Advocate?

- A research advocate brings a non-scientific viewpoint to the research process and communicates a collective patient perspective.

Note:

- A patient perspective is created when a person goes through personal or professional experience with the disease.
- A collective patient perspective is created when the person has knowledge of others' disease experiences and conveys this collective patient perspective rather than their singular experience.

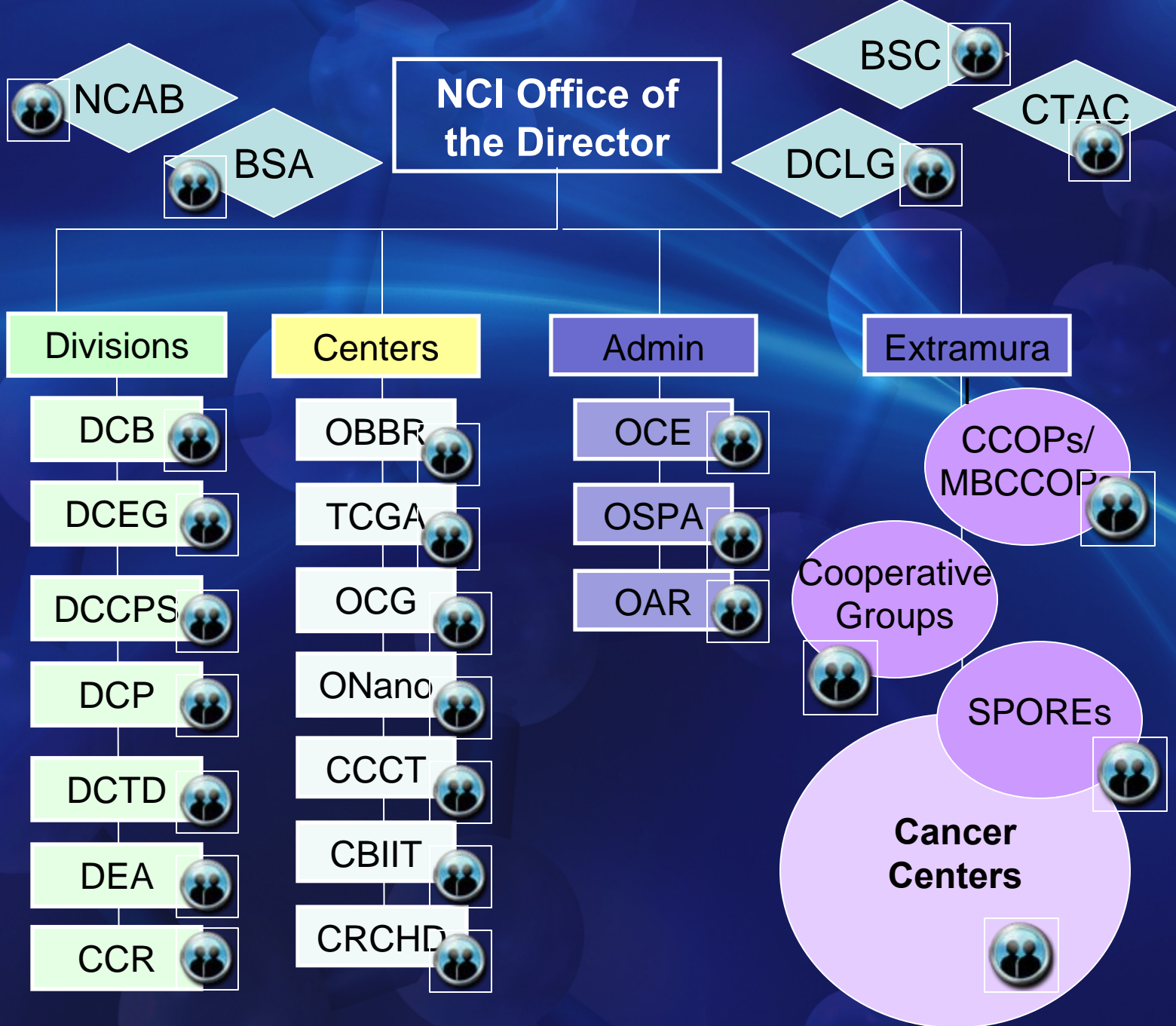
Who Isn't A Research Advocate?

A Patient \neq An Advocate \neq A Research Advocate



Photo Credit: Rhoda Baer





Research Advocate Roles at NCI

Advise - provide recommendations or advice that focuses on strategic directions or broad policy issues.

- formal advisory body
- speaking to a group
- participating on a panel discussion

~~**Review** - evaluate and analyze research proposals and ongoing research activities~~

- peer review
- concept review

Design - participate in developing new programs or enhancing existing ones.

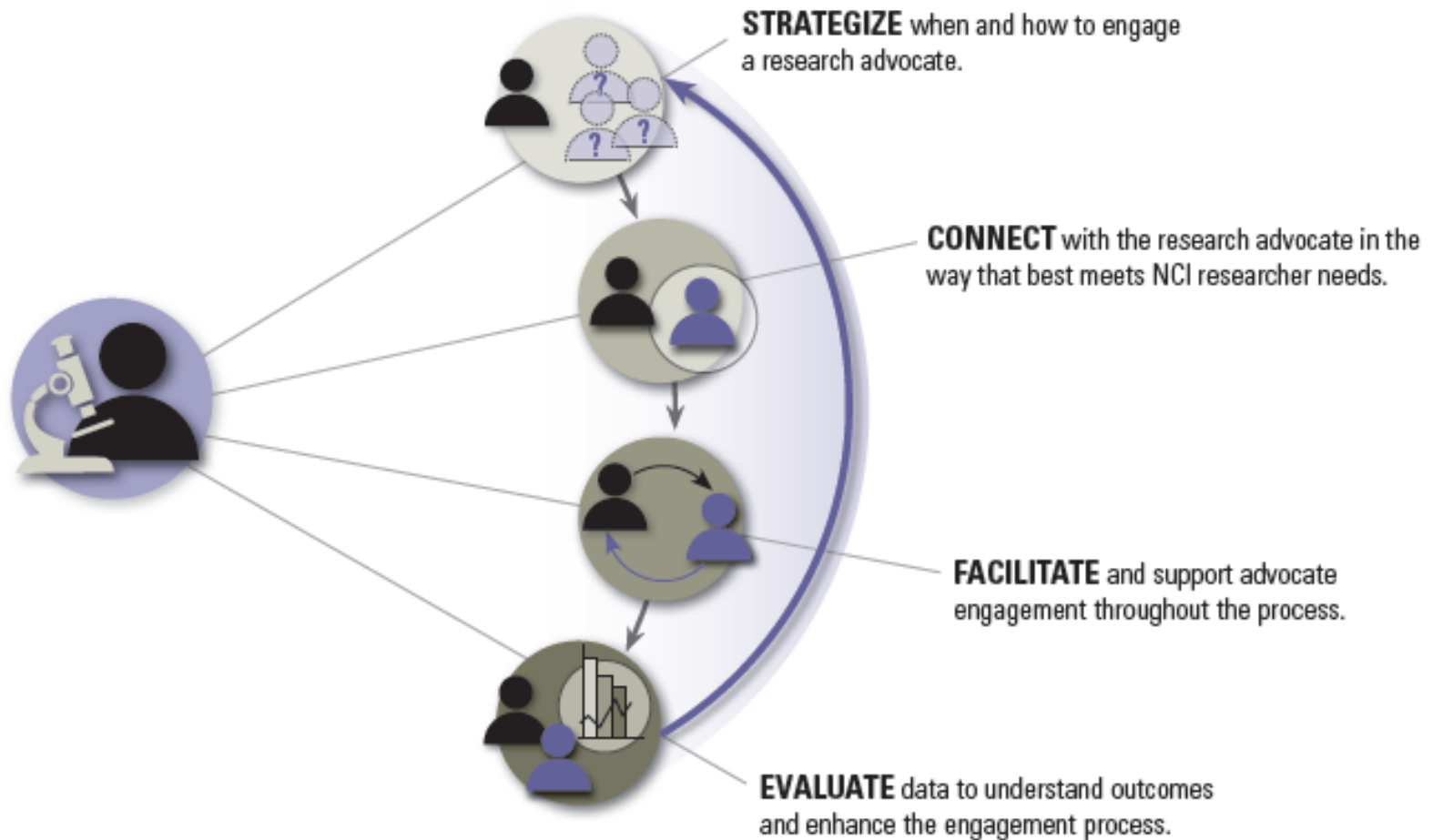
- developing new grant programs (i.e. NIH Partners in Research program)
- advancing existing programs

Disseminate - translate and communicate information into the community.

- editing materials
- distributing cancer related information

How NCI Engages Advocates

An enhanced model of partnership



How Advocates Contribute

- Enhance your research
 - Contribute lived experience, i.e. experiential knowledge
 - Improves research feasibility and probability
 - Naïve or simple question can lead to:
 - Innovative research questions
 - Diverse perspectives
 - Introduction of issues with colleagues
 - Serve as a reminder of what and who we are working for

How Advocates Contribute

- Increase public understanding & support of research
 - Increase public trust; enhanced transparency & accountability
 - Help break down barriers between the public and researchers
 - Establish a conduit for regular communication
 - Give researchers practice discussing their work in clear and understandable ways
 - Enable advocates to better understand and justify the need for science

Case Study of Advocate Engagement at NIH

Bringing the Voice of the Patient to NIH

May 19, 1997	Ovarian Cancer Quilt	Dissemination
1997 – 2004	NCI Director's Consumer Liaison Group Member	Advise
1998 - present	NCI Peer Review Panels	Review
1998 - present	Patient Advisory Group	Advise
Oct and Nov, 2002	CRC & Safra Lodge Groundbreaking	Dissemination
October 12, 2004	CRC Dedication	Dissemination
January 2006 & November 2007	Understanding NCI Featured Speaker (patient education teleconference)	Dissemination
2007 – 2008	NCI Coordinating Center for Clinical Trials, Ovarian Cancer Task Force (clinical trial concept review)	Review
2008 - present	NIH Clinical Center Board of Scientific Advisers - Liaison	Advise



Keys to Success

- Early involvement
- Ongoing communication
- Flexibility
- Willingness to consult with non-scientists

Contact OAR: Support in engaging an advocate

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