Advocate Engagement and Clinical Trials

October 12th, 2017

NATIONAL CANCER INSTITUTE
Office of Advocacy Relations
NCI’s Office of Advocacy Relations

- NCI's Office of Advocacy Relations (OAR) engages cancer research advocates and **serves as a link for advocate stakeholders to collaborate with NCI**. OAR works with individual research advocates, local and national advocacy groups, and professional societies to ensure the collective patient perspective is included in NCI efforts to advance cancer research and improve patient outcomes.
Advocates and Clinical Trials

- NCI’s Council of Research Advocates (NCRA) – Federal Advisory Committee comprised solely of cancer research advocates

- National Clinical Trials Network (NCTN) – externally funded network responsible for clinical trials, including precision medicine portfolio

- Scientific Steering Committees and Task Forces – guide for NCI’s clinical trial enterprise

- Division of Extramural Activities (DEA) – Division responsible for extramurally funded research

- Clinical Trials and Translational Research Advisory Committee (CTAC) – external oversight committee that advises NCI on it’s clinical and translational portfolios.
National Clinical Trials Network

NCI National Clinical Trials Network Structure

LEGEND
- Centralized Functions:
  - Centralized Institutional Review Board
  - Cancer Trials Support Unit
  - Imaging and Radiation Oncology Core (IROC) Group
  - Common Data Management System Central Hosting
- 30 Lead Academic Participating Sites (LAPS)
- Operations
- Statistics & Data Management
- Tissue Banks
- Member Sites

- SWOG
- Alliance
- Canadian Network Group
- COG (Pediatric)
- NRG Oncology
- ECOG-ACRIN
- NCORP Site Participation
Common Areas for Advocate Input within our Clinical Trials Network

- Portfolio analysis
- Informed consent
- Eligibility criteria
- Study design
- Patient-facing materials
- Recruitment strategies
- Outcome data
- Data Safety and Monitoring Boards
- Dissemination
Role of Advocates in Prioritizing Clinical Trials

- The Scientific Steering Committees (SSCs) were created to guide NCI’s Clinical Trials Enterprise

- SSCs are composed of leading cancer experts, advocates from outside the Institute as well as NCI senior investigators who meet regularly to:
  - Evaluate clinical trial concepts and set disease specific strategic priorities
  - Increase community involvement in clinical trial design and prioritization
  - Evaluate & provide input into design and implementation of clinical trial concepts
  - Patient advocates are voting members
The NCRA focuses on matters that facilitate research and often identifies and responds to challenges facing the Institute at the request of NCI leadership.

The NCRA focuses on enhancing community input, optimizing community outreach, and promoting strong collaborations to improve research outcomes.
Thank you!

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