Communicating and Collaborating with Advocates

NCI's Office of Con Advocacy Relations

Science Serving People http://www.cancer.gov/ aboutnci/servingpeople

Office of Advocacy Relations http://advocacy.cancer.gov

National Cancer Institute http://www.cancer.gov

National Institutes of Health http://www.nih.gov

Department of Health and Human Services http://www.dhhs.gov

CONTACT INFORMATION

To learn more about the Office of Advocacy Relations visit our Web site at http://advocacy.cancer.gov

or contact us at:

Office of Advocacy Relations Building 31, Room 10A30 31 Center Drive, MSC 2580 Bethesda, MD 20892-2580

301.594.3194 301.480.7558 (FAX)

nciadvocacy@mail.nih.gov







WHAT IS THE OFFICE OF ADVOCACY RELATIONS (OAR)?

The National Cancer Institute's (NCI) Office of Advocacy Relations (OAR) engages the advocacy and NCI communities in dialogue about cancer research opportunities and priorities in order to advance progress and improve outcomes. OAR works to:

- 1) Serve as the Institute's expert and central resource for advocacy matters.
- 2) Facilitate dynamic relationships and collaborations to promote mutual goals.
- 3) Disseminate information and fosters understanding of key cancer issues and priorities.

WHAT DOES OAR DO?

OAR acts as a portal for cancer-related advocacy groups, helping to navigate the NCI and the National Institutes of Health (NIH) to gain information and achieve organizational goals. OAR identifies opportunities for organizational collaboration and advocate involvement. OAR also addresses advocate resource and training needs, in addition to building and maintaining relationships.

HOW DOES OAR KEEP THE ADVOCACY COMMUNITY INFORMED?

OAR has several avenues to keep the patient advocacy community informed about NCI.

- NCI Nealon Digest a biweekly electronic digest of Federal cancer news.
- *Understanding NCI* toll-free teleconferences featuring NCI researchers and patient advocates who discuss important NCI activities and programs with callers.
- OAR Listserv a way to be updated with periodic information about NCI and NIH events and hot topic news.
- Science Serving People a website that brings together information about NCI's budget, cancer-related legislation, and return on taxpayer investment in NCI.

WHAT DOES OAR DO TO INCLUDE CONSUMERS AT NCI?

OAR administers two formal programs to bring the voices of those affected by cancer into NCI activities and programs.

DCLG – Director's Consumer Liaison Group

The NCI Director's Consumer Liaison Group (DCLG) is a Federal Advisory Committee of 16 consumer advocates who advise the NCI Director from the viewpoint of the cancer patient. As a high-level advisory body, the DCLG works with the NCI to help the Institute increase its involvement with the cancer advocacy community.

ARWG – Advocates in Research Working Group

The ARWG is a working group that will provide recommendations to the NCI Director through the DCLG. The recommendations will focus on how NCI can more consistently integrate advocate involvement across the Institute in ways that will accelerate progress, benefit patients, and improve public health. The final report is due in the spring of 2009.

CARRA – Consumer Advocates in Research and Related Activities

CARRA members participate in the NCI peer review of all clinical and translational research applications. They also participate in bioinformatics initiatives, education projects, Web site development, and other NCI activities. These individuals are called upon by NCI staff to represent a broad consumer/patient perspective in a wide range of NCI programs. Through the CARRA program, OAR staff advise NCI leadership on when advocate involvement would be most beneficial and the most effective ways to involve advocates.