

Consumer Advocates in Research and Related Activities

A Program of NCI's Office of Liaison Activities

FACT SHEET

CARRA Web Site http://carra.cancer.gov/

Office of Liaison Activities http://ola.cancer.gov/

National Cancer Institute www.cancer.gov/

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

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

NCI RESOURCES

NCI Cancer Bulletin

<u>cancer Biomedical Informatics</u> <u>Grid (caBIG)</u>

Cancer Information

Clinical Trials Information

Cancer Information Service

NCI News Center

Cancer Research Portfolio

Cancer Research Initiatives

NCI Bypass Budget

NCI Cancer Centers

Cancer Genetics Network

<u>Center to Reduce Cancer Health</u> <u>Disparities</u>

NCI DIVISIONS

Division of Cancer Biology

<u>Division of Cancer Control and</u> Population Sciences

Division of Cancer Prevention

<u>Division of Cancer Treatment</u> <u>and Diagnosis</u>

Division of Extramural Activities

Center for Cancer Research

<u>Division of Cancer</u> <u>Epidemiology and Genetics</u>

WHAT IS THE CARRA PROGRAM?

The National Cancer Institute (NCI) values the opinions of cancer survivors and others whose lives have been affected by cancer. The NCI Consumer Advocates in Research and Related Activities (CARRA) program was created to integrate the perspective of people affected by cancer into NCI's programs and activities.

The CARRA program is administered by the NCI Office of Liaison Activities (OLA). The program consists of approximately 200 consumer advocates from many different cancer types, age groups, and ethnic groups across the nation. CARRA members form a highly qualified, pre-screened group of people. As they participate in a wide range of NCI activities, they represent the collective viewpoint of their cancer community. CARRA members also play a critical role as two-way information links between their own cancerrelated networks and the NCI.

WHO CAN PARTICIPATE IN THE CARRA PROGRAM?

For each recruitment period, OLA accepts applications from individuals who are cancer survivors, family members or partners of cancer survivors, or those who have had more than 3 years of involvement in cancer-related activities. In addition, applicants must also:

- Communicate on a regular basis with a cancer constituency (an advocacy group, support group, or other similar organization)
- Demonstrate a willingness and ability to learn more about cancer and cancer issues
- Be fluent in English and have at least a high school diploma

The CARRA member selection process also strives to ensure diversity among members and balance across cancer types.

WHAT ARE THE GOALS OF THE CARRA PROGRAM?

There are two CARRA program goals, jointly established by consumers, researchers, and administrators:

- ► To increase opportunities for CARRA members to provide input on NCI's research activities involving scientific research and communication of scientific research.
- ► To help foster an organizational atmosphere that values the perspectives and contributions of consumer advocates, through the involvement of CARRA members in NCI activities.

HOW DOES THE CARRA PROGRAM WORK?

CARRA members participate in individual NCI activities on an as-needed basis. NCI staff across the span of the Institute's programs request the involvement of a consumer advocate. Then CARRA members are carefully matched to those NCI activities based on a combination of their skills, interests, experiences, and NCI program needs.

WHAT KINDS OF ACTIVITIES DO CARRA MEMBERS PARTICIPATE IN?

The primary mission of the NCI is to conduct and support cancer research. Accordingly, CARRA members participate in activities that focus on the scientific merit of proposed research and the communication of research results. CARRA members most frequently participate in the peer review process for evaluating research applications. They also help assess patient-oriented materials, such as Web sites, brochures, and videos, in their developmental stages. In addition, CARRA members are invited to participate in workshops or meetings to represent the consumer advocate viewpoint.

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WHY WAS THE CARRA PROGRAM STARTED?

The CARRA program was started as a way to systematically and effectively involve consumer advocates in NCI's daily work activities. Prior to CARRA, advocates had been involved with NCI for a number of years, participating in discrete activities. The CARRA program was created to provide an integrated, systematic mechanism for matching highly qualified advocates with research and research-related activities that span the Institute. The CARRA program also provides an infrastructure that promotes effective two-way communication between the NCI and members of cancer-related constituencies across the country.

HOW OFTEN IS THE CARRA PROGRAM UTILIZED AT NCI?

In the first 5 ½ years of the CARRA program (September 2001 to June 2007), NCI staff requested CARRA member participation in 577 activities. The actual number of opportunities for CARRA members to provide input to NCI's work is significantly higher, since one request can involve several CARRA members, for either a one-time or ongoing set of meetings or projects. Prior to the CARRA program, NCI staff contacted the Office of Liaison Activities (OLA) to request advocate participation about 25 times a year. The number and range of CARRA requests is updated monthly on the CARRA Web site at

http://carra.cancer.gov/about/whatiscarra/table-graph-and-charts.

DO CARRA MEMBERS RECEIVE ORIENTATION OR TRAINING?

OLA provides a general orientation about the NCI and the roles and responsibilities of CARRA members. Mentors (CARRA members with experience in participating in NCI activities) may also be provided on an individual basis. Peer review training workshops have also been conducted to assist consumer advocates in becoming more

effective participants in the scientific peer review process. In addition, NCI staff members provide orientation and guidance to CARRA members in individual activities.

ARE CARRA MEMBERS PAID TO PARTICIPATE IN ACTIVITIES?

Depending on the particular activity, CARRA members *may* or *may not* be paid an honorarium for their participation. CARRA members are compensated for approved travel expenses if travel is required for the NCI activity.

HOW CAN I GET MORE INFORMATION ABOUT THE CARRA PROGRAM?

- Visit the CARRA Web site at http://carra.cancer.gov/
- Email the CARRA program at ncicarra@mail.nih.gov
- Call the NCI Office of Liaison Activities at 301-594-3194

CONTACT US

The CARRA program is administered by the Office of Liaison Activities (OLA), which is the contact point for advocacy groups and professional societies at the NCI. To learn more about OLA, please visit our Web site at http://ola.cancer.gov/ or contact us at:

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