

Consumer Advocates in Research and Related Activities Program (CARRA)

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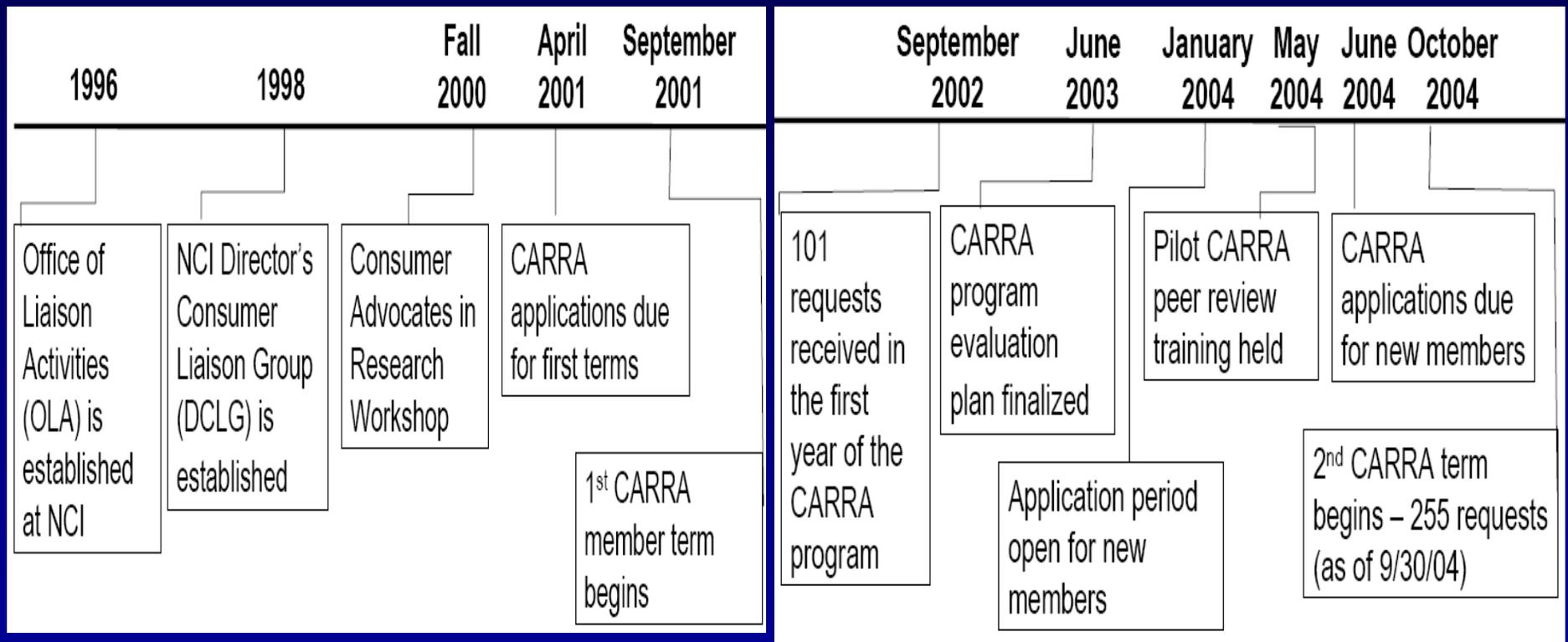
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What is the CARRA Program?

- The NCI CARRA program was created to integrate the perspective of people affected by cancer into the NCI's programs and activities.
- It is administered by the NCI Office of Liaison Activities.
- The program was created to provide an integrated systematic mechanism for matching qualified advocates with activities that span the institute.

CARRA Program Timeline



From CARRA Program Orientation

What are the goals of the program?

- To increase opportunities for CARRA members to provide input on NCI's research activities involving scientific research and its communication.
- To help foster an organizational atmosphere that values the perspectives of consumer advocates.
- Also play a critical role in two way information exchange between NCI and their own advocacy groups.

Who are the members?

- 200 advocates from many different cancer types, age groups and ethnic groups from across the nation.
- All members are cancer survivors, family members or partners of survivors or those who have had more than 3 years involvement in cancer related activities.
- Each term is for three years.
- A roster can be found at <http://carra.cancer.gov/about/whatiscarra/roster>

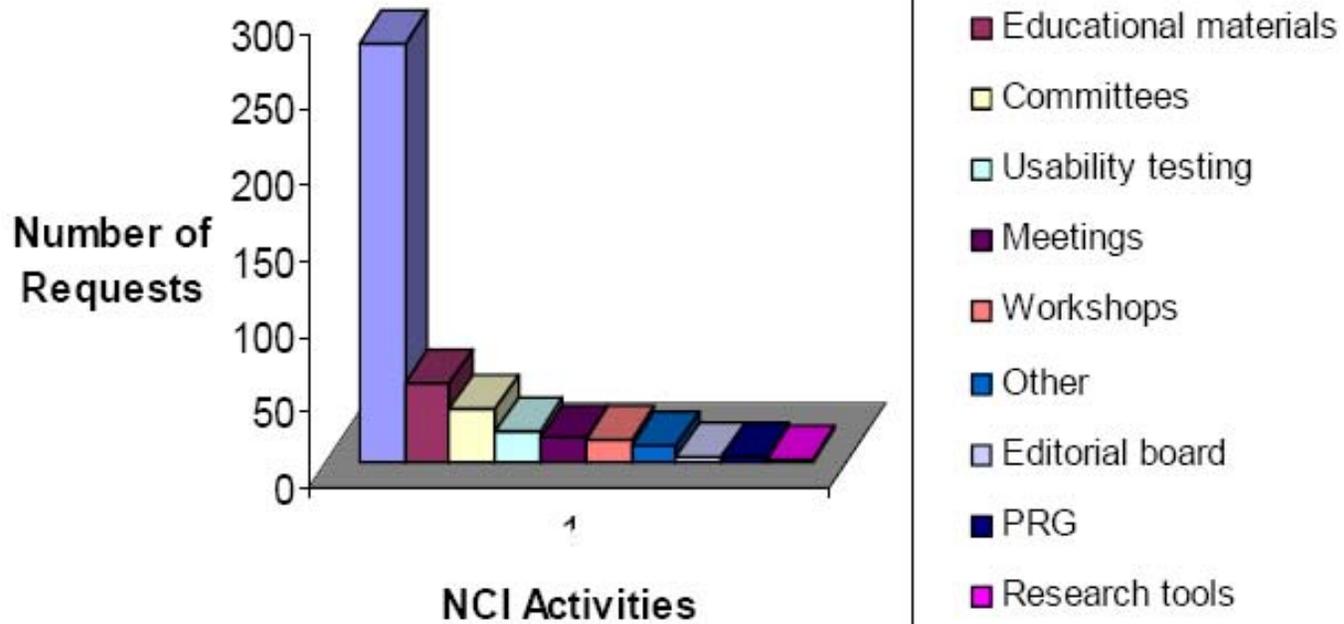
Current CARRA members associated with many groups that may be interested in rare cancers

- ThyCa: Thyroid Cancer Survivors' Association
- Spouses of Brain Tumor Patients online support group
- Von Hippel-Lindau Family Alliance
- International Myeloma Foundation
- Support for people with Oral and Head and Neck Cancer
- Bone Cancer International, Inc.
- Young Adults with Cancer
- Bladder Cancer Advocacy Network
- DES Cancer Network
- A.C.O.R.L-sarcoma Listserve
- Mycosis Fungoides Foundation
- Central Brain Tumor Registry of the United States
- The Brain Tumor Society
- Children's Brain Tumor Foundation
- Melanoma Research Foundation
- The Children's Brain Trust

How does it generally work?

- An NCI Staff member makes a request (online request form).
- The database of advocates is queried to determine who may be appropriate for a given request.
- CARRA program staff give them a customized short list of CARRA members with bios for that request.
- NCI staff member calls the CARRA member to invite participation.

What are the activities they participate in?



From CARRA Program Orientation

Examples of Advocacy Group Efforts

- Sarcoma Foundation of America
 - Advocacy – government support and access issues
 - Patient Education
 - Newsletters
 - Meet the Experts – online and conferences
 - Website
 - Research
 - Direct funding of small projects
 - Small awards - \$25,000 one year – 6 awarded in 2007 and 6 awarded in 2006
 - Registry – working on developing

Examples of Advocacy Group Efforts

- Children's Tumor Foundation – Ending Neurofibromatosis Through Research
 - Advocacy – Federal support of Research
 - NF Clinical Care Standards
 - Patient Education
 - Research
 - Funds drug discovery initiative, Young Investigator Award, others.
 - Funds and convenes scientific conferences
 - Tracks research resources – facilitates sharing of models, cell lines, etc...
 - Registry – working on developing

Examples of Advocacy Group Efforts

- Liddy Shriver Sarcoma Initiative
 - Patient Education
 - Electronic Sarcoma Update Newsletter
 - Website
 - Clinical Trials Listings
 - Bulletin Boards
 - Research Grants
 - Direct Funding of Small Awards

Conclusions

- CARRA Program
 - An integrated NCI program to match advocates to specific programmatic activities as well as facilitate two way communication between the NCI and the cancer advocacy community.
 - May be a means of identifying advocates with interests in specific rare diseases.
- Advocacy groups have varying interests but may have access to patient populations through educational interests, may provide specific research funding, advocate on behalf of a specific disease or help in other ways.

More Information?

- Visit the CARRA website at <http://carra.cancer.gov/>
- E-mail the CARRA program at ncicarra@mail.nih.gov
- Call the NCI Office of Liaison Activities at 301-594-3194