

CARRA ORIENTATION

CARRA Orientation
Conference Call
September 29, 2004
2:00-3:00 p.m.



CARRA Consumer Advocates
in Research and Related Activities

Presentation Outline

- ❑ Overview of the National Cancer Institute (NCI)
- ❑ Overview of the Office of Liaison Activities (OLA)
- ❑ Overview of the CARRA Program
- ❑ Roles and Responsibilities of CARRA Members

Overview of the National Cancer Institute



CARRA Consumer Advocates
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NCI Milestones

- ❑ NCI was established in 1937.
- ❑ NCI became a part of the NIH in 1944 through the PHS act.
- ❑ In 1971 NCI gained special status through the National Cancer Act:
 - NCI Director appointed by the U.S. President
 - NCI Budget Request to President (“Bypass”).



NCI Mission

- ❑ NCI is the Federal Government's principal agency for cancer research and training.
- ❑ The NCI's primary mission is to **conduct** and **fund** cancer-related research.

Where is NCI?

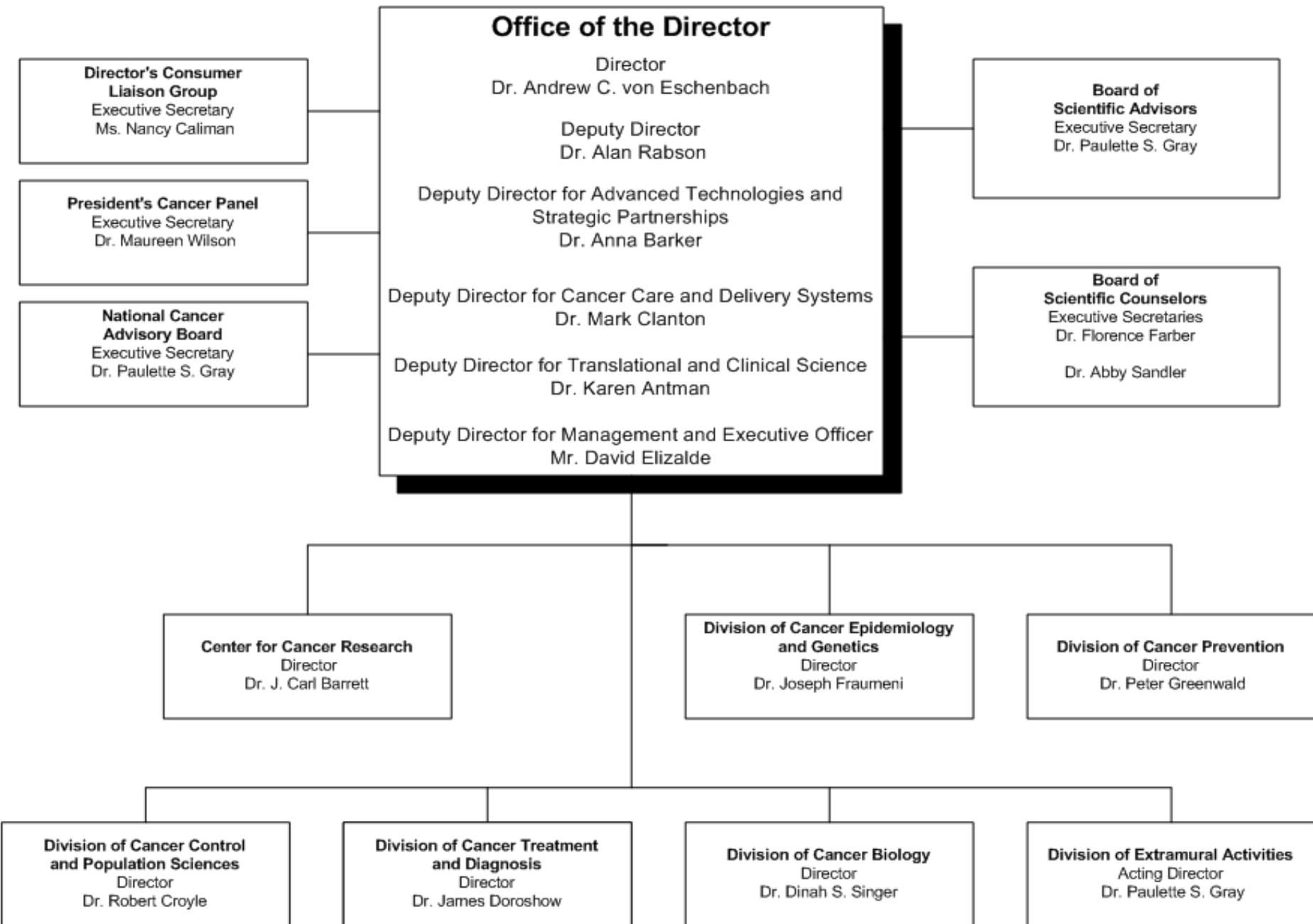
- ❑ U.S. Constitution → Federal Government
 - ❑ Executive Branch
 - ❑ Department of Health and Human Services (DHHS)
 - ❑ National Institutes of Health (NIH)
 - ❑ National Cancer Institute (NCI)



NIH/NCI

- ❑ The National Institutes of Health (NIH) is made up of 27 Institutes and Centers (ICs).
- ❑ NCI is one of the 27 ICs that makes up the NIH.
- ❑ The NCI and NIH Directors are appointed by the U.S. President.

National Cancer Institute



NCI Organizational Structure

- ❑ Extramural Divisions
 - ❑ Work with NCI-funded researchers around U.S.
(≈ 80% of NCI budget)
- ❑ Intramural Divisions
 - ❑ Conduct research at NCI (≈ 15% of NCI budget)
- ❑ Office of the Director
 - ❑ Offices and Centers that help administer research
(≈ 5% of NCI budget)

NCI Extramural Divisions

1. Division of Extramural Activities (DEA)
2. Division of Cancer Prevention (DCP)
3. Division of Cancer Biology (DCB)
4. Division of Cancer Treatment and Diagnosis (DCTD)
5. Division of Cancer Control and Populations Sciences (DCCPS)

NCI Intramural Divisions

1. Center for Cancer Research (CCR)
2. Division of Cancer Epidemiology and Genetics (DCEG)

NCI Office of the Director (OD)

- Provides direction & support for research infrastructure and areas of emphasis including clinical research and over 60 cancer centers.
 - Cancer Centers Program
 - Center for Bioinformatics (caBIG)
 - Office of Education and Special Initiatives
 - Center to Reduce Cancer Health Disparities

NCI Challenge Goal:

Eliminate the suffering and death
due to cancer by 2015



Overview of the Office of Liaison Activities



CARRA Consumer Advocates
in Research and Related Activities

Where is the Office of Liaison Activities?

- Department of Health and Human Services (DHHS)
 - National Institutes of Health (NIH)
 - National Cancer Institute (NCI)
 - Office of the NCI Director (OD)

- Report to Deputy Director Dr. Alan Rabson; and work closely with other senior leadership

Office of Liaison Activities Staff

- Lis Handley, Acting Director
- Jane Jacobs, CARRA Program Development Manager
- Elizabeth Neilson, CARRA Program Coordinator
- Brooke Hamilton, CARRA Program Analyst, Professional Societies Liaison
- Linda Ticker, Program Assistant
- James Hadley, Advocacy Program Manager
- Nancy Caliman, Executive Secretary of the DCLG
- Devon McGoldrick, NCI Health Communications Intern



Office of Liaison Activities

- Support NCI's research and related programs by fostering communications and relationships with
 - Consumer Advocates
 - Advocacy Groups
 - Professional and Scientific Societies
 - Federal Agencies



Advocacy Groups and Consumer Advocates

- Portal and “One-stop-shopping” for advocacy needs at NCI through:
 - Consumer Advocates in Research and Related Activities (CARRA) program
 - NCI Director’s Consumer Liaison Group (DCLG)
 - Outreach to cancer advocacy community
 - Biweekly e-news
 - Meetings on an ad hoc basis
 - Nealon Report
 - Email alerts on as needed basis

“Consumer advocates are playing such an important role with their support of cancer research. They are providing critical analyses and insights that help ensure that research advances are more quickly and carefully translated to the patient and public health settings.”

-Christopher L. Hatch, Ph.D.
Health Scientist Administrator



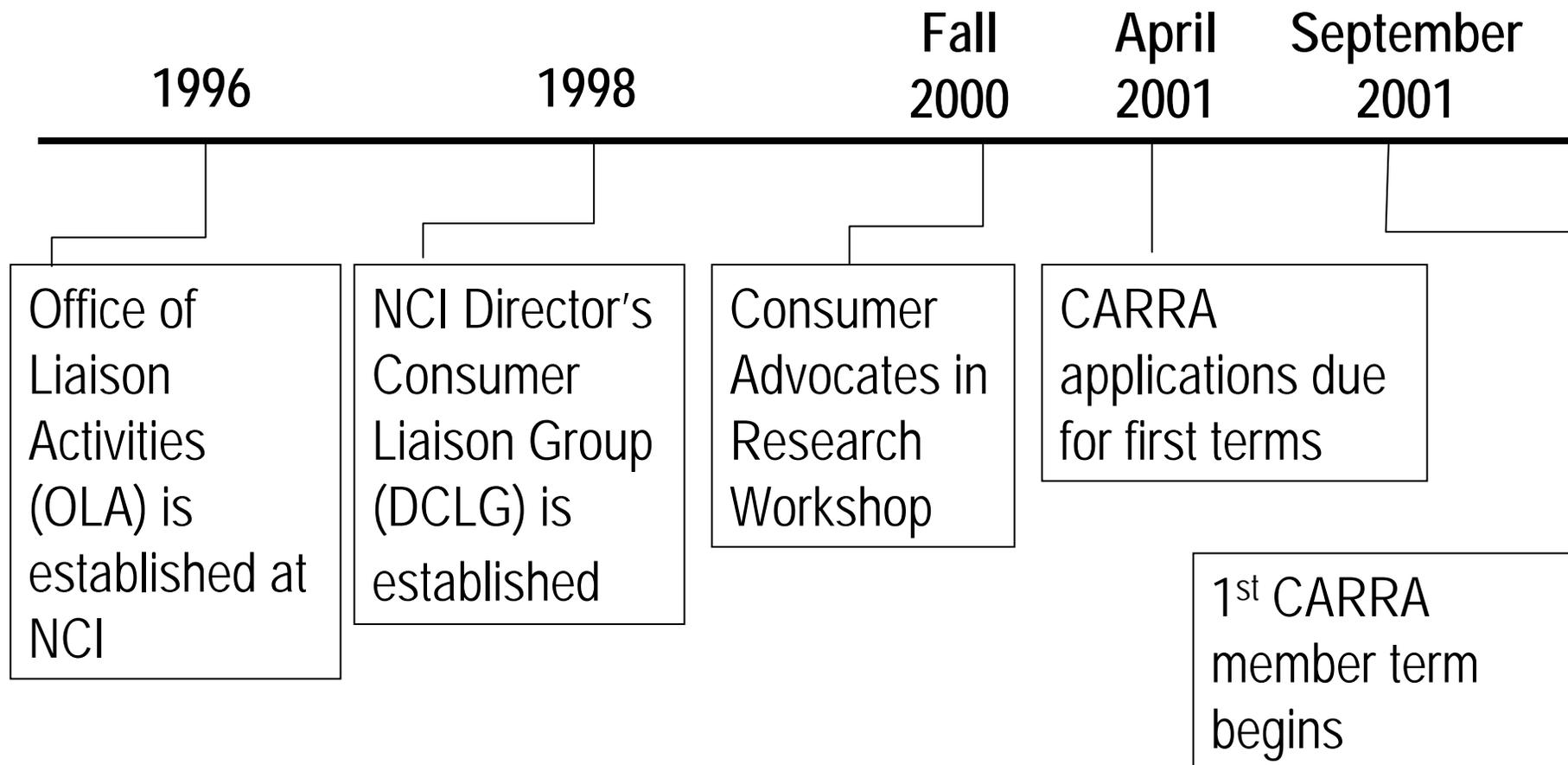
Overview of the Consumer Advocates in Research Related Activities (CARRA)



CARRA Program Goals

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

CARRA Program Timeline



CARRA Program Timeline

September 2002 June 2003 January 2004 May 2004 June 2004 October 2004

101 requests received in the first year of the CARRA program

CARRA program evaluation plan finalized

Pilot CARRA peer review training held

CARRA applications due for new members

Application period open for new members

2nd CARRA term begins – 255 requests (as of 9/30/04)

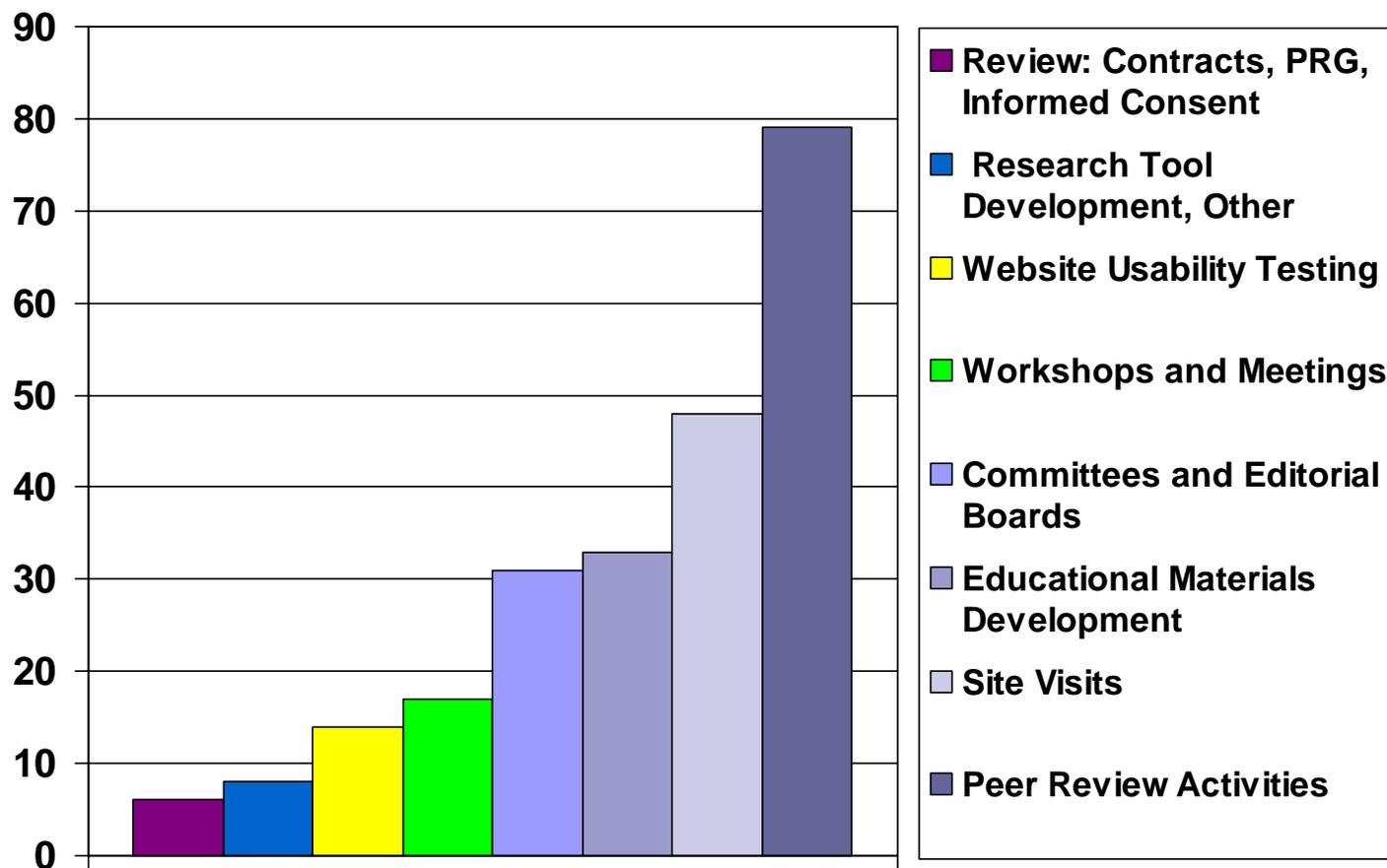
How Does CARRA Work?

- NCI staff member makes a 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.

CARRA Requests

- Year 1 = 101 requests
 - September 2001 through September 2002
- Year 2 = 70 requests
 - October 2002 through September 2003
- Year 3 = 84 requests
 - October 2003 through September 2004

CARRA Request Categories



CARRA Members' Roles, Responsibilities, & Contributions

- Participate in NCI activities as an individual representing the collective viewpoint of your cancer community.
- Communicate with your cancer community and CARRA staff.
- Educate yourself and your cancer community.



CARRA Members' Roles, Responsibilities, & Contributions

- Strengthen and increase the value of advocate involvement in NCI's research and related activities.
- Understand how the CARRA request process works.
- Contribute to cancer research *progress* and the role of advocates in the *process*.

Sample NCI-CARRA Activities

- Participate in NCI's peer review groups to help evaluate requests for research funding.
- Travel to research facilities to help NCI assess first hand the quality and suitability of institutions requesting funding
- Review information for patients and the public as part of NCI's educational materials development process.
- Serve on NCI planning groups for workshops and conferences.

CARRA Accomplishments

- Bring in new and diverse voices. In September, 2001 NCI accepted 220 consumer advocates into the program; 150 had no previous experience working with the NCI.
- Help NCI scientists and other staff see different perspectives on a broad range of activities including: peer review, publications review, conference planning, and others.



CARRA Accomplishments

- Increase the reach of NCI cancer information, by sharing it with CARRA members who disseminate it to their cancer communities.
- Involve consumer advocates in new cancer research initiatives, such as the caBIG (cancer Biomedical Informatics Grid) project.



Tips for CARRA Members

- Accept to participate in activities only if you are certain you can attend.
- Notify NCI staff immediately if you can not fulfill an obligation.
- Act collaboratively with others whenever possible.

Tips for CARRA Members

- Try not to refer to your personal experience with cancer, but represent the collective viewpoint of your cancer-related constituency.
- Listening does not necessarily imply acceptance or action.
- Be Passionate, But Positive!

Upcoming Events

- CARRA Update Calls: October 14, 2:00-3:00 p.m. & October 19, 10:00-11:00 a.m.
- CARRA Peer Review Training: November, 15th-17th