

**DEPARTMENT OF HEALTH AND HUMAN SERVICES  
NATIONAL INSTITUTES OF HEALTH  
NATIONAL CANCER INSTITUTE  
DIRECTOR'S CONSUMER LIAISON GROUP  
WORKING GROUP ON INVOLVING ADVOCATES IN NCI PROGRAMS**

**Summary of Teleconference  
November 11, 2007  
1:00 P.M. EST**

**DIRECTOR'S CONSUMER LIAISON GROUP  
WORKING GROUP ON INVOLVING ADVOCATES IN NCI PROGRAMS**

**November 11, 2007  
1:00 P.M. Eastern Standard Time  
TELECONFERENCE**

**Minutes**

**NCI's Director's Consumer Liaison Group**

Ms. Kelly Cotter, Chair  
Col. James Williams (Ret.)

**Biorepository and Biospecimen Research Program**

Ms. Paula Kim

**Consumer Advocates in Research and Related Activities**

Ms. Peggy Devine  
Dr. Richard Gorlick

**Member at Large**

Ms. Vernal Branch

**NCI-Designated Cancer Centers**

Ms. Francine Huckaby  
Mr. Gerald (Buddy) Leo  
Dr. Paul H. Bunn, Jr., University of Colorado at Denver Health Sciences Center  
Dr. H. Kim Lyerly, Duke University Cancer Center Specialized Programs of Research  
Excellence Program

**SPORE**

Ms. Lori Monroe  
Dr. John Minna, Chair, SPORE Executive Committee, University of Texas Southwestern  
Medical Center

**NCI Program Staff**

Dr. Shamala Srinivas  
Dr. Jaye Viner

**NCI Office of Advocacy Relations**

Mr. Ben Carollo  
Ms. Shannon Bell  
Ms. Barbara Guest  
Mr. James Hadley  
Ms. Elizabeth Neilson

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## **I. Welcome**

Ms. Kelly Cotter, Chair of the Director's Consumer Liaison Group (DCLG) Working Group on Involving Advocates in NCI Programs, thanked members of the working group for participating in this call, the first teleconference of the new working group.

All participants introduced themselves and described their roles as advocates or staff in National Cancer Institute (NCI) programs.

## **II. Teleconference Format**

Ms. Cotter explained that the working group teleconferences would provide an opportunity to discuss ways to maximize the impact of advocates across NCI. She asked participants to submit any potential discussion topics by e-mail in advance of the teleconferences. The working group will hold one teleconference in December and then hold teleconferences approximately every 3 weeks through March 2008.

## **III. Charge to the Working Group**

Mr. James Hadley explained that the working group is a Federal Advisory Committee Act (FACA) committee. All members of the working group will receive a summary of each teleconference.

Ms. Paula Kim suggested changing the last sentence of this mission statement to enhance the role of advocates at NCI beyond simply being represented. Ms. Shannon Bell agreed that the working group will not simply ensure that advocates are represented at NCI, as it will also identify ways for NCI and advocates to work together to create better research outcomes. The Office of Advocacy Relations will amend the mission statement to reflect this.

Ms. Cotter reported that the DCLG Working Group on Involving Advocates in NCI Programs is to develop and provide recommendations to the DCLG on how NCI can more consistently integrate the involvement of advocates across the programs of the institute to ensure that the patient-advocate perspective is appropriately represented.

The working group will submit its recommendations to the DCLG prior to the DCLG's meeting on March 27-28, 2008. After the DCLG discusses these recommendations, it will make recommendations on the involvement of advocates at NCI to the NCI Director.

## **IV. NCI's Office of Advocacy Relations (OAR)**

Mr. Hadley provided an overview of NCI's Office of Advocacy Relations (OAR). The office's new name reflects its focus on NCI's relationships with advocates to enhance the institute's effectiveness as the leader of the National Cancer Program. OAR uses a variety of communications vehicles to accomplish its goal, which include the following:

- *Nealon Digest*, a twice-monthly electronic newsletter
- A monthly teleconference series called "Understanding NCI"
- E-mail alerts on hot topics

- Teleconferences for advocates on advances in research
- A report on the NCI DCLG 2006 Patient Advocate Summit

The DCLG is made up of 16 advocates and survivors who make recommendations to NCI Director Dr. John Niederhuber from the perspectives of patient advocates and the public. As a FACA committee, the DCLG has the same status at NCI as the National Cancer Advisory Board (NCAB), the Board of Scientific Advisors (BSA), and the President's Cancer Panel.

OAR also coordinates the Consumer Advocates in Research and Related Activities (CARRA) program, which has 150 members. These cancer survivors and patients work with NCI scientists, program staff, and administrators on a range of NCI activities. Finally, OAR works with professional societies.

### **CARRA**

Ms. Elizabeth Neilson discussed the results of the evaluation of the CARRA program, an evaluation that had several components:

- Post-activity surveys with CARRA members—90% report that the CARRA activities in which they participated met their expectations, and 98% would be willing to participate again.
- Post-activity surveys with NCI staff—80% are satisfied with the process to select advocates, 99% plan to request a consumer advocate again, and 100% would recommend CARRA to a colleague.
- Survey of the attitudes and behaviors of NCI staff—Most staff value the involvement of CARRA members in NCI activities.
- Survey of the attitudes and behaviors of CARRA members —The main motivation of most CARRA members is to convey the consumer's perspective and inform NCI about the views and concerns of their constituencies.
- Interviews—CARRA members are dissatisfied with their low level of involvement. NCI staff are concerned that advocates might have their own agendas or be disruptive rather than productive.

Ms. Kim and Ms. Peggy Devine suggested that OAR collect testimonials about the contributions of CARRA members from NCI staff members who have worked with CARRA advocates. Ms. Neilson explained that OAR is collecting success stories that will be posted on OAR's website. Ms. Kim also suggested that the CARRA program offer training to NCI staff on how to engage advocates in their work.

Dr. John Minna asked what approaches OAR uses when difficulties arise with the participation of CARRA members. Ms. Neilson explained that all CARRA members who participate in peer review receive training on how to focus on broader issues rather than their personal agendas.

Ms. Bell added that OAR's role is to select the right people for CARRA, train them, and serve as a resource to NCI staff when difficulties arise.

## **V. Scope of Work**

Mr. Hadley explained that the working group needs to develop actionable recommendations on several issues regarding the role of advocates at NCI, such as:

- How to track the activities of all advocates at NCI, whether or not they are members of CARRA.
- How to help advocates contribute even more to NCI's work.
- Identification of the resources and training needed by advocates to enhance their contributions to NCI.

Ms. Bell asked members of the working group to identify the resources and information they require before the next teleconference to address these and other issues. The members requested the following:

- A spreadsheet listing the activities of advocates at NCI, including programs that use advocates, what the advocates did, and when these activities occurred.
- A list of NCI programs that do not use advocates.
- Information on whether advocates tend to participate in one program or many.
- A list of NCI programs where the participation of advocates could be valuable and a list of those programs that would not benefit from such participation.
- A list of NCI cancer centers that shows which use advocates and which do not.
- A survey of cancer centers and other centers, such as Community Clinical Oncology Programs (CCOPs), on their use of advocates.
- NCI policies and practices with respect to the use of advocates.
- A description of the OAR process for responding to requests for advocates.

## **VI. Next Steps**

Mr. Ben Carollo explained that OAR is establishing a central e-mail address for all correspondence of the working groups. Whenever an e-mail to this address comes in, OAR staff will decide whether it should be sent to the entire working group or only to certain individuals.

Mr. Hadley added that OAR is setting up a working group website that will offer meeting summaries, presentations from the teleconferences, and other materials.

Mr. Hadley stressed the importance of obtaining buy-in from the broader advocacy community on the working group's recommendations before the group sends its recommendations to the DCLG.

**Certification**

I hereby certify that the foregoing minutes are accurate and complete.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Chair  
Working Group on Involving Advocates in NCI Programs

\_\_\_\_\_  
Date

\_\_\_\_\_  
Executive Secretary  
Director's Consumer Liaison Group

**DCLG WORKING GROUP ON INVOLVING ADVOCATES IN NCI PROGRAMS:**

**ACTION ITEMS**

1. OAR staff will amend the working group's mission statement to explain that the working group's mission is to identify ways for NCI and advocates to work together to create better outcomes from research. Members of the working group should send suggestions to the OAR on wording for the mission statement.
2. OAR will distribute a spreadsheet with the activities of advocates at NCI to the working group.