

**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
December 12, 2007
3:00 P.M. EST**

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

**December 12, 2007
3:00 P.M. Eastern Standard Time
TELECONFERENCE**

Minutes

NCI's Director's Consumer Liaison Group

Ms. Kelly Cotter, Chair

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

Ms. Deborah Collyar

Ms. Cindy Geoghegan

Ms. Lori Monroe

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

NCI Program Staff

Dr. Shamala Srinivas

NCI Office of Advocacy Relations

Mr. Ben Carollo

Ms. Shannon Bell

Ms. Barbara Guest

Mr. James Hadley

I. Welcome 1

II. Review and Approval of Teleconference Summary, November 11, 2007 1

III. Review of Strategic Process Outline..... 1

IV. Review of Advocacy Involvement Tool 1

V. Next Steps 3

Certification 4

DCLG Working Group on Involving Advocates in NCI Programs Action Items..... 5

I. Welcome

Ms. Kelly Cotter thanked members of the Working Group on Involving Advocates in National Cancer Institute (NCI) Programs for participating in this teleconference and for providing feedback on the documents they had received from the Office of Advocacy Relations (OAR).

II. Review and Approval of Teleconference Summary, November 11, 2007

Working group members reviewed the minutes of the teleconference on November 11, 2007. Mr. James Hadley asked that the minutes reflect his invitation to working group members who miss a teleconference to contribute to the discussions by communicating with OAR via e-mail or telephone. The working group approved of the minutes with Mr. Hadley's addendum.

III. Review of Strategic Process Outline

Mr. Hadley reviewed the proposed strategic process outline for the working group. Ms. Shannon Bell explained that OAR plans to collect data from the working group, members of the Director's Consumer Liaison Group (DCLG) and Consumer Advocates and Research and Related Activities (CARRA), and NCI staff who have worked with advocates.

Ms. Cindy Geoghegan suggested that OAR set up a Web page to collect and analyze the data. Ms. Bell explained that the Federal Government must obtain clearance from the Office of Management and Budget and approval from an institutional review board to conduct a survey; these are both very time-consuming processes. OAR can provide working group members with the tool, but the office may not approach others without undergoing the time-consuming approval process.

Ms. Peggy Devine commented that the Coalition of Cancer Cooperative Groups is using similar questions to survey its advocate members about their involvement in cooperative groups. She offered to share the responses from these questions with OAR. Ms. Deborah Collyar also offered to share the data from a recent survey of Specialized Program of Research Excellence (SPORE) patient advocates with OAR.

IV. Review of Advocacy Involvement Research Tools

Mr. Hadley explained that working group members have provided several suggestions for changing the wording of the questions in the advocacy involvement research tools. OAR will incorporate these changes into the document.

Ms. Kim stated that potential respondents will ask whether their participation in this process will make a difference. Ms. Vernal Branch added that they would want to know what action would result from the collection of their feedback.

Dr. Richard Gorlick commented that retrospective data, or information on what people remember, are not as accurate as prospective data but retrospective data cover a larger period of time. It is important to determine the purpose of the data collection to define the most

appropriate methodology. Ms. Cotter explained that the working group will use the data to develop recommendations on advocacy at NCI. The working group will give these recommendations to the DCLG, which will consider them and pass them onto the NCI director. The goal of the data collection activity is to learn what has happened in the past and what has worked well and not so well. Dr. Gorlick commented that the accuracy of the data is more critical than its completeness.

Ms. Geoghegan was concerned that people who feel disenfranchised because previous efforts have had no results will not respond. Ms. Cotter said that if working group members know people who feel this way, they should invite them to respond to the questions.

Ms. Geoghegan suggested that calling what is collected “data” is misleading, because the tool will be used to collect anecdotes, opinions, and feelings. Ms. Kim suggested calling the process an “information-gathering” activity. Others supported this suggestion.

Ms. Collyar emphasized the importance of collecting data on the advocacy activities at cancer centers, Community Clinical Oncology Programs (CCOPs), and other programs with community activities. Ms. Kim suggested that OAR provide working group members with a list of NCI programs that have community activities, such as those listed by Ms. Collyar and the NCI National Community Cancer Centers Program. Working group members can send the questions to representatives of these groups.

Ms. Devine emphasized the importance of collecting information in a structured format; otherwise, analyzing the information will be very difficult. The advocacy involvement research tool should categorize the responses and include check boxes rather than open-ended questions.

Working group members suggested that the tool collect responses on the following issues:

- Advocate qualifications and training.
- Reasons why advocates have not been used.
- How long they have been involved in advocacy.
- Advocacy skills.

Ms. Bell suggested that the tool collect information from NCI staff on:

- Whether they have worked with advocates.
- Whether advocates have had a positive impact.
- Whether any outcomes changed as a result of advocacy involvement.

Ms. Kim suggested that OAR ask advocates to provide their resumes. This information need not be analyzed, but it could be useful in the future. Others noted, however, that if advocates are asked for too much information, they might not be willing to be candid.

A working group member suggested that the tool be prefaced with a statement about NCI's commitment to taking action based on the information gathered. Ms. Bell explained that the request for this information comes from Dr. John Niederhuber, director of NCI, and his asking for the information speaks volumes about NCI's commitment. Ms. Bell also provided her personal commitment as director of OAR that the results of this activity will not end up in a

“report on the shelf.” This process is only the first step and will not end in March. Once NCI collects that data and the working group creates recommendations, OAR and the working group will create implementation plans for the recommendations and collect prospective data on the impact of these implementation strategies. This process will become part of OAR's workload.

Ms. Francine Huckaby asked whether the tool should specify the time period for the advocacy activities of respondents. Some participants suggested limiting the time period to the last few years, but others pointed out that advocates sometimes take time off for treatment and might have very little to report from the last 2 or 3 years. Ms. Bell suggested that the tool ask respondents to identify the dates of their activities.

V. Next Steps

Ms. Bell said that OAR will integrate the comments from this teleconference into the advocacy involvement research tool and will distribute the tool to the working group within 1 week. OAR staff will be available throughout the process to assist working group members in any way possible.

Ms. Bell explained that although responses to the questions in the tool are not due until January 9, 2008, it would be helpful if working group members could provide their responses earlier. This will give OAR more time to analyze the results prior to the January 9 teleconference. OAR will not require earlier responses, but it will send out periodic reminders to encourage rapid responses.

Ms. Cotter thanked the working group members for taking the time to provide input into the information-gathering process. This activity will provide an important starting point to develop some concrete recommendations for developing a strong advocacy program at NCI.

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. Ms. Peggy Devine will share the results of a survey of patient advocates conducted by the Coalition of Cancer Cooperative Groups with the Office of Advocacy Relations (OAR). Ms. Deborah Collyar will share the data from a recent survey of Specialized Program of Research Excellence (SPORE) patient advocates with OAR.
2. OAR will provide working group members with a list of National Cancer Institute programs that have community activities.
3. OAR will distribute a revised advocacy involvement research tool to the working group within 1 week.