

**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  
January 30, 2008  
3:00 P.M., EST**

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

**January 30, 2008  
3:00 P.M., Eastern Standard Time  
TELECONFERENCE**

**Minutes**

**NCI 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**

Dr. Richard Gorlick

**NCI Clinical Trials Cooperative Groups**

Ms. Nancy Roach

**Members at Large**

Ms. Vernal Branch

**NCI-Designated Cancer Centers**

Ms. Francine Huckaby  
Mr. Gerald (Buddy) Leo  
Dr. H. Kim Lyerly, Duke University Cancer Center  
Dr. Kirby Bland, University of Alabama at Birmingham Medical School

**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  
Dr. Kirby Bland, University of Alabama, Birmingham

**NCI Program Staff**

Dr. Shamala Srinivas  
Dr. Jaye Viner

**NCI Office of Advocacy Relations**

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

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## **Welcome**

Ms. Kelly Cotter thanked members of the Working Group on Involving Advocates in National Cancer Institute (NCI) Programs for participating in this teleconference.

## **Review and Approval of Teleconference Summary, January 9, 2008**

The working group unanimously approved the January 9, 2008, teleconference minutes.

## **Advocacy Involvement Tool Intake**

### Summaries of Responses

Mr. Ben Carollo thanked the working group members for responding to the questions in the advocacy involvement tool and distributing it to their networks.

The Office of Advocacy Relations (OAR) received 82 responses to the tool, including 25 from investigators and 57 from advocates. The investigators represented several different NCI programs (including Cooperative Groups, Specialized Programs of Research Excellence [SPOREs], and cancer centers), Department of Defense programs, and community public health programs. The advocates were affiliated with the Consumer Advocates in Research and Related Activities (CARRA) program, cancer centers, Cooperative Groups, SPOREs, Department of Defense programs, and nonprofit organizations (including the Lance Armstrong Foundation and Susan G. Komen for the Cure).

Mr. Carollo plans to create a summary of each response. He will provide each subgroup with the summaries of the responses that are most relevant to that subgroup. He will also provide all subgroups with an overview of all of the responses.

Ms. Nancy Roach requested the summaries for all of the responses. Mr. Carollo will provide them. Other working group members who would like all 82 summaries should contact Mr. Carollo.

Mr. Buddy Leo asked how Mr. Carollo will determine which responses are most relevant to a given subgroup. Mr. Carollo explained that many of the responses are clearly relevant to only one subgroup, and responses that are relevant to more than one subgroup will be given to all relevant subgroups.

### Level of Detail in Subgroup Recommendations

Mr. Carollo provided examples of issues raised in responses to the advocacy involvement tool that the subgroups might consider addressing in their recommendations. These examples were also designed to demonstrate the level of detail for the subgroup recommendations:

- Ways to tap into advocates' networks.
- Whether successful advocacy involvement depends on the advocate's physical proximity to the advocacy opportunity.

- Training needed (e.g., in science, clinical trials, or other issues) for advocate participation in peer-review activities.
- Types of skills and experience (such as editing, nursing, or law) that are beneficial for advocacy and types of advocacy activities for which these skills are useful.

### **Review of Articles on Research Advocacy Involvement**

Michelle Hathaway reported that all working group members have received literature on advocacy involvement in cancer research. She summarized four recurring themes in this research:

- Advocate roles in cancer research—By sitting on advisory boards and steering committees, advocates can expedite the bench-to-bedside process. They also assist with clinical trial accrual and eligibility criteria.
- Advocacy benefits and outcomes—Advocates link researchers from different fields, and this can enhance interactions between, for example, basic and applied researchers. One article noted that by requesting explanations for scientific terms, advocates can help scientists understand the languages of different scientific fields. Advocates also create a sense of urgency in the research community and help ensure that research is grounded in patient needs.
- Challenges—Communications between researchers and advocates must be clear and consistent, but this is time-consuming. Researchers need to be open to working with advocates, and advocates need to overcome the sometimes negative perceptions that investigators have of advocates. The cancer research enterprise does not have an effective infrastructure for advocacy involvement.
- Training, tools, and models for advocacy involvement—The best training is hands-on, and advocates must be involved in activities from the beginning.

Michelle Hathaway will distribute a copy of her literature synthesis to the working group.

### **Guidelines for Subgroup Discussions**

Peter Garrett explained that each subgroup will have two teleconferences. The subgroups will begin their first call by reviewing the data collected from the advocacy involvement tool. Subgroup members will then provide their expert perspectives on the topics assigned to their group. The next step is to prioritize observations and develop recommendations. The working group will review the subgroup recommendations at its February 20 meeting.

OAR staff will develop a draft working group report incorporating the recommendations from the subgroups by March 5. The draft report will be distributed for public comment with a teleconference for public input scheduled for March 11. The working group will review the feedback received and prepare the next version of its draft report by March 19. The DCLG will review the report at its March 27-28 meeting and submit the report to the NCI Director.

Ms. Shannon Bell added that once the NCI Director approves the working group's recommendations, OAR will oversee the implementation phase. Ms. Bell urged the subgroups to develop recommendations that are both feasible and ambitious.

Ms. Bell noted that because of the aggressive time frame, subgroups might not have sufficient data to make recommendations on certain topics. In these cases, the subgroup recommendations can call for more information on a given issue.

Peter Garrett suggested that during the first call, subgroups agree on the parameters for their discussions and review the feedback from the advocacy involvement tool and literature synthesis. In the second call, the subgroups should identify and agree on recommendations.

Mr. James Hadley, Ms. Bell, and possibly one other OAR staff member will listen to all of the calls. After each call, OAR staff will compare notes to ensure that the subgroup discussions do not overlap.

Ms. Bell encouraged the subgroups to develop recommendations that relate to OAR and/or NCI and how the Institute interacts with external organizations. Collaboration is likely to play a major role in maximizing advocate involvement.

OAR suggested that the subgroups address the following topics, which are relevant to all subgroups:

- Activities
- Core responsibilities
- Experience
- Skill sets and qualifications
- Selection
- Training
- Information resources
- Engagement processes
- Compensation

Ms. Roach asked whether the advocate's constituency should be a separate category. The working group agreed that constituency fits under qualifications. But if a subgroup creates a recommendation specifying advocate qualifications for an activity, the group should define the advocate constituency required for that activity.

Ms. Deborah Collyar suggested adding communications, including communications between NCI or investigators and advocates and between advocates, to the list. The group discussed whether communications falls under engagement, which refers to the process NCI uses to communicate with advocates and ensure that they are appropriately involved in relevant activities. The group agreed that communications and engagement address different issues.

Ms. Bell commented that this discussion shows that OAR needs to provide very clear definitions of all of the topics. However, subgroups may determine that some definitions need to be changed. She also noted that after each subgroup meets, OAR staff will immediately share the results of these discussions with all of the other groups.

## **Closing**

The next meeting of the Working Group on Involving Advocates in NCI Programs will take place on Wednesday, February 20, at 3:00 p.m. EST.

**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. Mr. Carollo will provide each subgroup with the summaries of the responses to the advocacy involvement tool that are most relevant to that subgroup. He will also provide all subgroups with an overview of all of the responses.
2. All working group members who would like summaries of all 82 responses to the advocacy involvement tool should contact Mr. Carollo.
3. Michelle Hathaway will distribute a copy of her literature synthesis to the working group.
4. OAR will provide definitions of the recommended discussion topics to the subgroups prior to their first teleconferences.