

**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

March 5, 2008

3:00 P.M. EST

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

March 5, 2008

3:00 P.M., Eastern Standard Time

TELECONFERENCE

Summary

NCI's Director's Consumer Liaison Group

Ms. Kelly Cotter, Chair

Col. Jim Williams (Ret)

Biorepository and Biospecimen Research Program

Ms. Paula Kim

Consumer Advocates in Research and Related Activities

Ms. Peggy Devine

NCI Clinical Trials Cooperative Groups

Ms. Nancy Roach

Member at Large Ms. Vernal Branch

NCI-Designated Cancer Centers

Ms. Francine Huckaby

Mr. Gerald (Buddy) Leo

Specialized Programs of Research Excellence Program

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

Ms. Lori Monroe

NCI Program Staff

Dr. Shamala Srinivas

Dr. Jaye Viner

NCI Office of Advocacy Relations

Ms. Shannon Bell

Mr. Ben Carollo

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, February 20, 2008

The working group unanimously approved the February 20, 2008, teleconference minutes.

Report on the Working Group Process

Ms. Shannon Bell noted that the Office of Advocacy Relations (OAR) has begun sharing some of the working group's findings with NCI colleagues, who are very enthusiastic about the group's work. Ms. Bell thanked the working group members for their time, energy, expertise, and enthusiasm.

Based on feedback from working group members and a great deal of consideration, OAR has determined that the working group and OAR need more time to complete the process. By taking the time to produce a report with a concrete, actionable implementation plan, the working group can ensure that its plan will truly guide NCI in the future.

OAR examined several other successful working group models, especially that of NCI's Translational Research Working Group (TRWG). The office concluded that the reason why the TRWG and other working groups have made a difference is that they have produced reports that went beyond merely listing recommendations. These groups developed a concrete implementation plan showing exactly what NCI should do to address the issue at hand. Following the example of the TRWG could make all the difference in ensuring that the working group's recommendations have a substantial impact on NCI.

Ms. Bell summarized the working group's activities to date, which include gathering and analyzing background information and developing subgroup recommendations. OAR proposes the following next steps:

1. Report to the Director's Consumer Liaison Group (DCLG) at its March 27-28, 2008, meeting on the working group's activities to date.
2. Assess advocate involvement at NCI.
3. Identify challenges, barriers, and missed opportunities.
4. Develop initiatives for increasing advocacy involvement.
5. Create an implementation plan.
6. Submit a report to the DCLG at its October 2008 meeting.
7. Incorporate feedback from the DCLG and submit the final report to the NCI Director.

OAR hopes that the current working group members will continue to participate in this effort, because they have the knowledge, background, and expertise to move the process forward in a meaningful way. Working group members should expect an invitation shortly to continue their participation. In the future, participation will probably be less labor-intensive than in the past. OAR plans to hold approximately eight to ten 90-minute teleconferences in the next 6-8 months.

Discussion

Ms. Paula Kim suggested that the working group continue to hold some discussions in smaller groups and leave some decisions to the entire group. This process has been effective, and both formats are valuable.

Ms. Bell reported that OAR plans to establish a wiki site shortly that will allow OAR and working group members to post and edit shared documents. Ms. Kim suggested that OAR compare wiki software on www.wikimatrix.org.

Several working group members expressed support for the idea of taking the time to complete all of the steps needed to produce a meaningful and actionable report.

Col. Williams emphasized the need to involve NCI staff, in addition to OAR staff, in the process because they are the “target audience” for the working group’s recommendations.

Col. Williams asked if the group’s goal is to develop proposals for revitalizing the Consumer Advocates in Research and Related Activities (CARRA) program. Ms. Bell explained that the CARRA program is very effective, and one recommendation might be to expand this program. However, the working group’s recommendations are likely to extend beyond CARRA to the creation of additional programs.

Dr. John Minna suggested that the working group identify activities that could benefit from the involvement of advocates and prioritize these activities. The group should also identify different measures of success for each of these activities. For example, NCI might use advocates to recruit participants to some of its clinical trials. If the clinical trials with advocates recruited more participants than trials without advocates, this would clearly show the need to involve advocates in all clinical trials.

Ms. Bell asked working group members to share additional comments on the process with her and Mr. James Hadley. She also asked working group members to suggest NCI staff members who should contribute to the process.

Working Group Recommendations

OAR has organized all of the recommendations and comments from the subgroups by theme. However, OAR found it difficult to combine recommendations from all four subgroups because recommendations from different subgroups are often similar but not identical, and some recommendations came from two but not all four subgroups. It would be more appropriate for the subgroups to determine which recommendations pertain to all four groups. Perhaps this could be accomplished through the new wiki site.

The next step is for the working group to identify challenges, barriers, and missed opportunities for involving advocates. Several working group members said that they would prefer to identify

challenges, barriers, and missed opportunities by working with the document online. The group will subsequently identify which recommendations can be combined.

NCI's Advocate Committees

Ms. Nancy Roach asked Ms. Bell to explain the difference between the Working Group on Involving Advocates in NCI Programs and the Patient Advocate Steering Committee.

Ms. Bell explained that the Patient Advocate Steering Committee is part of NCI's Clinical Trials Working Group (CTWG). The CTWG's Clinical Trials Advisory Committee (CTAC) created several disease-specific steering committees to prioritize clinical trials. Each of these committees includes advocates, and the Patient Advocate Steering Committee brings together all of these advocates.

Col. Williams, who serves on the Patient Advocate Steering Committee, added that the committee discusses policies and procedures that advocates can use in their disease-specific steering committees. The committee also provides an opportunity for these advocates to learn from one another. However, the Patient Advocate Steering Committee focuses only on clinical trials, in contrast to the Working Group on Involving Advocates in NCI Programs, which addresses the involvement of advocates throughout the Institute.

Ms. Bell offered to distribute a diagram showing the relationships among the CTWG steering committees.

Relationship Between Advocates and NCI

Ms. Lori Monroe asked how advocates can communicate with NCI about the Institute's programs. For example, many advocates would like to talk to NCI about the importance of preserving the Specialized Programs of Research Excellence (SPOREs).

Ms. Bell explained that OAR is the access point to NCI for the advocacy community. OAR listens to advocates, helps them understand how NCI sets its priorities, and connects advocates to NCI staff who make decisions. Col. Williams added that advocates are welcome to communicate their messages to the DCLG, which is responsible for directing their concerns to OAR and the NCI Director.

Next Steps

Mr. Hadley announced that an upcoming Understanding NCI teleconference will feature Col. Williams and the CTAC.

The March 11 community teleconference to discuss the working group's report has been canceled. OAR will reschedule the teleconference after the working group develops a draft implementation plan.

OAR will develop the working group's wiki site as soon as possible.

The next working group call will take place on Wednesday, March 19, at 3:00 p.m., DST. During the call, the working group will review and provide feedback on the presentation for 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. Working group members will be invited to continue their participation for an additional 6-8 months.
2. OAR will compare wiki software on www.wikimatrix.org to select the most appropriate package for the working group's needs.
3. Working group members should share additional comments on the proposed working group process with Ms. Bell and Mr. Hadley.
4. Working group members should suggest additional NCI staff members who should be invited to contribute to the process.
5. Ms. Bell will distribute a diagram showing the relationship among the CTWG steering committees.
6. OAR will create a grid of advocates who serve on different NCI committees and the names of the committees on which they serve, as well as a primer describing these committees.
7. Ms. Kim will send Ms. Bell some materials she has written on NCI committees that involve advocates.
8. The next working group call will take place on Wednesday, March 19, at 3:00 p.m. DST.