

**DEPARTMENT OF HEALTH AND HUMAN SERVICES  
NATIONAL INSTITUTES OF HEALTH  
NATIONAL CANCER INSTITUTE**

**MINUTES of the DIRECTOR'S CONSUMER LIAISON GROUP**

**January 18, 2005**

The 30<sup>th</sup> meeting of the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG) was convened as a teleconference at 3:00 p.m., January 18, 2005. Mr. Doug Ulman presided as Chair.

**Members Present**

Mr. Doug Ulman, Chair

Ms. Peggy L. Anthony

Ms. Vernal Branch

Mr. William P. Bro

Ms. Lourie Campos

Ms. Bobbi de Córdova-Hanks

Ms. Nancy Davenport-Ennis

Dr. Beverly Laird

Dr. Sylvia M. Ramos

Mr. Eric Rosenthal

Ms. Mary Jackson Scroggins

Ms. Sue Sumpter

Dr. Marisa Weiss

Ms. Cece Whitewolf

Col. (Ret.) James E. Williams, Jr., USA

**NCI Office of Liaison Activities Staff**

Ms. Nancy Caliman, Executive Secretary, DCLG

Mr. James Hadley, Advocacy Program Manager

Ms. Brooke Hamilton, Professional Societies Liaison & CARRA Program Analyst

Ms. Elisabeth Handley, Acting Director

Ms. Jane Jacobs, CARRA Program Manager

Ms. Alissa Lewandowski, Health Communications Intern

**Other NCI Staff**

Ms. Kelly Blake, Division of Cancer Control and Population Sciences

Ms. Nina Goodman, Center for Strategic Dissemination

Ms. Heidi Harbach, Office of Communications

Dr. Holly Massett, Center for Strategic Dissemination

**Others**

Dr. Debby Berlyne, Writer, Palladian Partners, Inc.

Ms. Leris Bernard, Meeting Planner, Palladian Partners, Inc.

**I. OPENING REMARKS**

Mr. Doug Ulman called the meeting to order and reminded DCLG members to identify any potential conflicts of interest that might arise during the group's discussions. Ms. Nancy Caliman determined that a quorum was present.

Mr. Ulman announced that Ms. Elisabeth Handley would be leaving the Office of Liaison Activities (OLA), and said that the DCLG would miss her greatly. He thanked Ms. Handley for all she had done to make the DCLG successful, especially her efforts to develop the *NCI Listens and Learns* Web site. Ms. Handley thanked Mr. Ulman and said that she would miss working with the DCLG. Mr. Ulman then welcomed Ms. Alissa Lewandowski, a new health communications intern to the Office of Liaison Activities (OLA).

## **II. APPROVAL OF THE MINUTES**

Ms. Mary Jackson Scroggins requested the following changes to the minutes of the DCLG’s December 14, 2004, meeting:

On page 3, first paragraph under item III:

Change “each member of the Summit Working Group...proposed 12 possible themes for the Summit.”

To “The Working Group submitted a total of 12 proposed themes for the Summit.”

On page 4, first full paragraph:

Change “Ms. Scroggins replied that the Working Group plans to talk to advocacy groups to find out what issues they would like discussed at the summit before finalizing the summit purpose.”

To “Ms. Scroggins replied that the Working Group believes that these themes will emerge during the session on demystifying NCI, and the Working Group plans to talk to advocacy groups to find out what issues they would like discussed at the summit before finalizing the summit purpose.”

A motion to approve the minutes, with the above amendments, of the DCLG’s December 14, 2004, meeting was approved.

## **III. UPDATE ON *NCI LISTENS AND LEARNS* OPERATIONS**

**Launch Update.** Ms. Handley announced that OLA will launch the *NCI Listens and Learns* Web site on Wednesday, January 26, 2005. More than 60 organizations have registered for the site.

Ms. Handley said that she would distribute the final version of the initial question to be posted on the site to DCLG members on January 19. Ms. Brooke Hamilton asked DCLG members to work with the organizations they represent to prepare a response to the initial question that could be posted on the site when it is launched. In this way, those who visit the site on launch day will see an active discussion underway and be more likely to participate.

Col. James Williams asked whether the question pertains only to breast cancer, or is broader. Ms. Handley explained that breast cancer is the first site for this pilot, but the overarching question pertains to all cancer sites.

Ms. Cece Whitewolf asked whether the original wording of the first question for *NCI Listens and Learns* had been rewritten so that the question could be answered both by individuals and by groups. Ms. Caliman replied that the question has been rewritten to apply to both.

Mr. Ulman asked whether other questions had been submitted for posting in the future. Ms. Handley has three additional questions and OLA will talk to those who submitted these questions to determine their time frames.

**Other Operational Updates.** Col. Williams reported that the Operations Working Group plans to monitor the site and review the responses. The group is developing standards for what to seek in the responses, such as the language used, timelines, and whether the responses are relevant to the questions posed. Col. Williams asked DCLG members to submit additional suggestions of things the Working Group should look for when it reviews the responses, so that it can provide useful updates to the full DCLG.

#### **IV. UPDATE ON *NCI LISTENS AND LEARNS* SUMMIT**

Ms. Scroggins reported that the Summit Working Group has not met since the last DCLG teleconference. The primary concern during that meeting was whether all five proposed themes would be covered during the Summit. The Working Group believes that these themes will emerge during discussions in the “NCI 101” session. The group plans to work with the Evaluation Working Group to develop a logic model for the Summit. The Summit Working Group will probably begin meeting again on a monthly basis in February.

#### **V. UPDATE ON *NCI LISTENS AND LEARNS* PROMOTION**

Mr. William Bro reported that each DCLG member now has a list of approximately six organizations to contact regarding registration for the *NCI Listens and Learns* Web site, and the Promotions Working Group will follow up with other DCLG members shortly to discuss any problems in completing the calls.

Mr. Bro asked whether the launch of *Listens and Learns* would be covered in the *NCI Cancer Bulletin*. Ms. Hamilton replied that this publication, which has more than 17,000 subscribers, would include an article about the site in its January 25 issue. OLA is also working with NCI’s press office to distribute a press release on January 26 when the site launches.

Ms. Hamilton also noted that the appointments of the new DCLG members to the group would be reported in this week’s *NCI Cancer Bulletin*.

**Promotional Materials.** Mr. Bro asked about the status of the printed promotional materials that DCLG members will use to publicize the Web site. Ms. Hamilton asked that those DCLG members who have not ordered any materials let her know soon what they will need. The office

can provide the materials either in print or as PDF files on CD, so DCLG members should let her know which version they need.

Several DCLG members stated that they would be participating in various upcoming conferences, and Ms. Hamilton told them that the promotional materials would be available for distribution at these meetings. Ms. Vernal Branch noted that several major meetings are coming up in the spring. Ms. Hamilton will attend the American Association of Cancer Research (AACR) meeting, among others, and will use these opportunities to promote the Web site.

**Contacting Advocacy Organizations.** Dr. Beverly Laird expressed concern that other DCLG members might have already contacted the organizations she has been asked to contact. Mr. Eric Rosenthal reported that some of the phone numbers he has been given are fax numbers. Ms. Hamilton asked DCLG members to report such concerns to her and Ms. Lewandowski, who will address them.

Ms. Caliman asked DCLG members to review the entire list of organizations to be contacted, to see if they have established contact already with any organization that has been assigned to someone else.

**Diversity of Advocacy Organizations.** Ms. Sue Sumpter noted that very few of the 60 organizations that have registered for the *NCI Listens and Learns* Web site to date represent childhood cancers or blood cancer. Some disease sites, such as breast cancer, are likely to have more representation on the Web site than others, and Ms. Sumpter wondered how to address this possibility.

Ms. Hamilton said that the DCLG would have the opportunity to review summaries of the comments made on the site to ensure that these summaries accurately represented what was said. OLA would be pleased to add additional organizations to the site, if DCLG members had any more names to suggest.

Mr. Ulman thanked the Promotions Working Group for its efforts and encouraged the DCLG members to make their calls to advocacy organizations promptly.

## **VI. UPDATE ON *NCI LISTENS AND LEARNS* EVALUATION**

Dr. Laird reported that she, as chair of the Evaluation Working Group, met recently with the chairs of the other working groups. The chairs agreed to talk to their working group members about providing feedback on the logic model. Prior to the DCLG's face-to-face meeting in February and March, the Evaluation Working Group will finalize its logic model and develop a draft evaluation plan. The Working Group is working to identify software that can be used to analyze comments from the public.

The Evaluation Working Group would like time at the face-to-face meeting to begin working on the logic model for the Summit with the Summit Working Group.

Ms. Hamilton reported that the pop-up survey based on the American Customer Satisfaction Index (ACSI) would not be available until a week after the *Listens and Learns* site is launched.

## **VII. PREPARATION FOR FACE-TO-FACE DCLG MEETING (FEBRUARY 28-MARCH 1, 2005)**

Mr. Ulman reported that a draft agenda for the DCLG's upcoming face-to-face meeting had been distributed to all DCLG members, and asked for questions or comments.

Ms. Branch asked for clarification on the working lunch with the NCI Director on Day 2. Ms. Handley explained that all DCLG members were to participate in the lunch, at which the Working Group chairs would report to Dr. von Eschenbach prior to his report to the group. The Working Group chairs' reports should be high level and brief.

**Working Group Sessions.** Ms. Lourie Campos asked what DCLG members who are on more than one working group should do when the working groups meet separately on Day 2. Mr. Ulman suggested that the Evaluation and Summit Working Groups meet together, and the Operations and Promotion Working Groups meet together because they are addressing some related issues.

Dr. Laird pointed out that many of the Evaluation Working Group's issues could be covered during the two-hour session on the logical model on Day 1, a session to be attended by all DCLG members. The Summit logic model could also be discussed during this session. Members of the Evaluation Working Group who belong to a second working group could then attend the other group's session on Day 2.

Mr. Ulman suggested that if the Summit logic model discussion was not completed during the Day 1 session, the Evaluation and Summit Working Groups could finish the discussion on Day 2. The chairs of the Operations and Promotion Working Groups could decide whether they wanted to meet separately or together on Day 2.

**Reports from NCI.** Ms. Handley stated that the Office of Science Planning and Assessment (OSPA) had submitted a question for the *Listens and Learns* site, and she had met with the Center to Reduce Cancer Health Disparities and the Office of Cancer Survivorship. Their questions are not yet ready.

Ms. Kelly Blake offered to follow up with Dr. Julia Rowland of the Office of Cancer Survivorship. Ms. Handley explained that Dr. Rowland was currently sorting through recommendations from several major reports. Perhaps Dr. Rowland would like input from advocates concerning which two of the top five recommendations were most important to them. The DCLG is particularly interested in soliciting questions from the Center to Reduce Cancer Health Disparities and the Office of Cancer Survivorship because Dr. von Eschenbach has asked the DCLG to focus its efforts on survivorship and health disparities, as well as on building the *NCI Listens and Learns* Web site.

Ms. Scroggins asked that when the Center to Reduce Cancer Health Disparities addresses the DCLG at its next meeting, that it provide more specifics on the Center's initiatives, rather than general information. She would like to hear more about the Center's efforts to reduce health disparities and the advocacy role within the Center's initiatives.

Dr. Sylvia Ramos requested that speakers be asked to distribute their slides prior to the meeting, so that DCLG members could follow the handouts while listening to the presentations. Ms. Caliman stated that she would continue to work with NCI staff to obtain their slides prior to the meeting but it is not always possible to do so.

**Logistics.** In reply to a question from Ms. de Córdova-Hanks, Mr. Ulman said that most DCLG members would arrive on the Sunday before the meeting starts. Travel information was to be provided the following week.

Ms. Caliman announced that the DCLG would gather for an informal dinner, probably on Monday evening.

#### **VIII. PUBLIC COMMENT**

No public comments were offered.

#### **XI. NCI ADVISORY BOARD RETREAT**

Mr. Ulman reported that he had recently attended a retreat with members of NCI's Board of Scientific Advisors (BSA), Board of Scientific Counselors (BSC), and National Cancer Advisory Board (NCAB), as well as the chair of the President's Cancer Panel. Participants spent a full day discussing the state of NCI and where the Institute is headed. An underlying theme of the meeting was that the Institute received large budget increases for several years, but such increases are much more limited now. As a result, the Institute must make difficult choices. During discussions of priorities regarding NCI and its funding, participants repeatedly commented that the advocacy community would take care of these issues. Mr. Ulman tried to emphasize the importance of partnerships between the scientific and advocacy communities. Mr. Ulman believes that the *Listens and Learns* Web site will be a good way for the advocacy community to show the Institute and the scientific community that the advocacy community has a major role to play, but true partnerships are also needed on many levels.

**X. NEXT STEPS**

Mr. Ulman encouraged DCLG members to call the advocacy organizations this week. He looked forward to the face-to-face meeting and asked DCLG members to send him any questions or suggestions concerning the agenda for that meeting.

Certification

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

\_\_\_\_\_  
Date

\_\_\_\_\_  
Chair, Director's Consumer Liaison Group

\_\_\_\_\_  
Date

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

Attachments:  
Roster

A complete set of handouts is available from the Executive Secretary.

## DCLG ACTION ITEMS

January 18, 2005

- DCLG members should work with the organizations they represent to develop a response to the initial question that will be posted on the *NCI Listens and Learns* Web site. Members should then forward these responses to Ms. Brooke Hamilton by January 24. Ms. Hamilton will have the responses posted to the site when it launches on January 26.
- DCLG members should submit to Col. Williams their suggestions for standards the Operations Working Group should use in reviewing the initial responses to the questions posed on the *NCI Listens and Learns* Web site.
- Each DCLG member is to contact the organizations assigned to him or her and encourage these groups to register for the *NCI Listens and Learns* Web site.
- DCLG members who have not ordered any promotional materials for *NCI Listens and Learns* should let Ms. Hamilton know soon what quantity and version (CD or print) they will need.
- DCLG members should report by e-mail to Ms. Hamilton and Ms. Lewandowski any incorrect contact information for the organizations they have been assigned to call.
- DCLG members should review the entire list of organizations to be contacted, to see if they have already established contact with any that has been assigned to another member.
- DCLG members are to submit comments on the *Listens and Learns* logic model to Dr. Laird.
- Ms. Caliman will continue to work with speakers at the DCLG's face-to-face meetings to obtain their slides in advance of the meeting.
- DCLG members should send Mr. Doug Ulman any questions or suggestions concerning the agenda for the DCLG's face-to-face meeting.