

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

MINUTES of the DIRECTOR'S CONSUMER LIAISON GROUP

December 14, 2004

The 29th meeting of the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG) was convened as a teleconference at 3:00 p.m., December 14, 2004. Col. James Williams presided as Acting Chair for the first half, and Mr. Doug Ulman presided as Chair for the remainder of the meeting.

Members Present

Mr. Doug Ulman, Chair
Ms. Peggy L. Anthony
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
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 & Consumer Advocates in Research and Related Activities (CARRA) Program Analyst
Ms. Elisabeth Handley, Acting Director
Ms. Jane Jacobs, CARRA Program Manager
Ms. Devon McGoldrick, Health Communications Intern
Ms. Elizabeth Neilson, CARRA Program Coordinator
Ms. Linda Ticker, Program Assistant

Others

Dr. Debbye Berlyne, Writer, Palladian Partners, Inc.
Ms. Molly Vaas, Reporter, Blue Sheets

I. OPENING REMARKS

Col. James Williams, who served as chair for the first half of the meeting, called the meeting to order and reminded DCLG members to identify any potential conflicts of interest that arose during the group's discussions. Ms. Nancy Caliman determined that a quorum was present.

A motion to approve the minutes of the DCLG's September 13-15, 2004 meeting was approved.

II. UPDATE ON *NCI LISTENS AND LEARNS* OPERATIONS

Criteria for Advocacy Organizations. Ms. Elisabeth Handley reminded DCLG members that at their last meeting, they had decided that advocacy organizations wishing to join the *NCI Listens and Learns* website should meet the following criteria:

- Have a national, regional, statewide or local focus; **or**
- Be representative of various diseases and sites; or
- Be representative of adult or childhood cancers; or
- Be a special interest organization representing a minority or medically underserved community. Such a group might have a primary focus unrelated to cancer, but have an active interest in cancer. These groups may represent American Indians or Alaska natives, Asians, blacks or African Americans, Native Hawaiians or other Pacific Islanders, whites, or Hispanics or Latinos; and
- Be not for profit.

Ms. Handley pointed out that these criteria, as they are currently written, would allow any national, regional, statewide, or local group to join the website, regardless of whether they have a focus on cancer.

A motion to change the first statement in the criteria as follows was approved:

- Have a national, regional, statewide or local focus; **and**

Site Launch. Ms. Handley reported that the Office of Liaison Activities (OLA) sent invitations to 137 advocacy organizations to register for participation in the *NCI Listens and Learns* Web site on December 10. To give organizations sufficient time to respond to these invitations and register for the site, Ms. Handley suggested that the site's launch be postponed from January 14 to January 28, 2005. All DCLG members agreed to this change.

Since receiving the invitations, 19 cancer advocacy organizations have registered for the site. Ms. Handley asked DCLG members to encourage their own organizations to register. She also asked DCLG members to continue to share the names of additional organizations that should be invited to register for *Listens and Learns*.

Col. Williams reported that a question regarding NCI's caMATCH project was ready to be posted when the site is launched. (caMATCH is a computerized system for matching breast cancer patients with clinical trials.) The question concerns the willingness of patients to submit personal information online in order to obtain access to a clinical trial. Ms. Handley will share the proposed wording with DCLG members for their feedback.

Monitoring the Site. The Operations Working Group suggested that instead of waiting to see the summaries of comments posted on the website, Working Group members should monitor the comments as they come in. Responsibility will be rotated among Working Group members, probably on a biweekly basis. This will allow the full DCLG to determine quickly what types of responses are coming in and make suggestions or recommendations based on regular reports from the Operations Working Group.

Ms. Bobbi de Córdova-Hanks supported this suggestion, but asked what would happen if the number of responses is overwhelming. Col. Williams clarified that Palladian Partners, Inc., the contractor, will be responsible for summarizing the comments. Instead of waiting for these summaries to be ready, the Operations Working Group will look at this material as it comes in. If the amount of work is too great, additional DCLG members will be asked to help out.

Ms. Mary Jackson Scroggins asked whether this monitoring would include participating in the dialogue. Col. Williams explained that Working Group members would observe the dialogue, but would not participate. Ms. Nancy Caliman clarified that DCLG members who are the designated spokespersons for their organizations would be able to participate in the dialogue.

Col. Williams explained that each question will be posted for approximately one month. After that, the contractor will review and summarize the input and submit its summary to the DCLG and OLA staff within 10 days. After the DCLG and OLA review the summary, it will be posted on the site.

Ms. Nancy Davenport-Ennis suggested that summaries include the number of responses received and the geographic distribution of those providing comments. Ms. Handley replied that the summaries would include the number of comments received. Since the advocacy organizations will register, it will be possible to determine their geographic locations. Ms. Handley will discuss with the summary writer the possibility of reporting the geographic locations of participants.

III. UPDATE ON *NCI LISTENS AND LEARNS* SUMMIT AND DISCUSSION

Ms. Scroggins reported that each member of the Summit Working Group completed a purpose-focused exercise to stimulate thinking. They then submitted a total of 12 possible themes for the Summit. Mr. James Hadley compiled these responses and Ms. Scroggins reviewed them for recurring themes and words. The Working Group then developed a statement of purpose based on these recurring themes.

The working title of the Summit is “Listening and Learning Together,” which ties into the Web site and emphasizes the two-way exchange between NCI and the cancer advocacy community (CAC). This working title will probably change and incorporate a more descriptive subtitle that addresses the purpose and participants. The Working Group also proposed three areas of emphasis:

- Demystifying NCI (“NCI 101”).
- A forum for cancer advocacy input and interaction with NCI.
- Two-way communication between NCI and the CAC, and among CAC members.

The Working Group’s proposed preliminary goals and objectives are to:

- Develop mechanisms for post-summit communication and collaboration.
- Form alliances between groups and individuals as well as between NCI and other participants.
- Identify and highlight replicable best practices.
- Develop recommendations for NCI on areas found to be critical by participants.

The Working Group also identified five overarching themes:

- NCI 101
- Clinical trials
- Underserved populations
- Survivorship
- Building trust.

The Working Group also proposed that the Summit provide a post-Summit document to participants and sponsors. A message board at the Summit could encourage participants to communicate with one another. The Summit might also include a reflective journaling session and provide certificates of completion for all participants.

Ms. Handley asked whether the Summit would cover all five overarching themes. 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. Ms. Handley said that OLA had some materials that could be used for the “NCI 101” portion of the Summit. She also pointed out that any one of the five overarching themes could serve as the focus of a two-day meeting.

Ms. Peggy Anthony suggested that the overall theme of the Summit be “Inside NCI,” and all of the other themes could be brought in as part of the discussion but would not necessarily be the focus. Mr. Eric Rosenthal suggested that participants in the Summit be asked to disseminate the lessons learned to the widest possible audience.

Ms. de Córdova-Hanks pointed out that many advocacy organizations are aware of what NCI does however smaller grassroots organizations and unaffiliated survivors need to be brought to the table because they are not familiar with NCI. Ms. Lourie Campos said that very few members of her community know much about NCI, and Ms. Sue Sumpter said that most people think that all NCI does is the 1-800-4-CANCER service. Dr. Sylvia Ramos pointed out that even physicians know little about NCI.

Ms. Scroggins said that education about NCI would shift the balance from “being at the mercy of people’s perceptions” to the power of action based on facts.

A motion to approve the *NCI Listens and Learns* Summit Working Group’s concept for further development was approved.

IV. UPDATE ON *NCI LISTENS AND LEARNS* PROMOTION EFFORTS

At this point, Mr. Doug Ulman took over as Chair.

Mr. Bill Bro said that his organization would be pleased to post a mini-survey on its Web site to collect responses about NCI. The pop-up box on the Kidney Cancer Association’s Web site generates 15–20 responses a day, and the group would be pleased to provide this tool for NCI.

Ms. Handley reported that OLA is pricing the items in the promotion plan approved by the Working Group. PDF versions of the promotional items will be available.

Mr. Bro reported that to help promote the site, those who register will be able to click on a button to send the URL to a friend. But until the site is about to be launched, there is little grassroots promotion that can be done.

Mr. Bro suggested that DCLG members make a concerted effort to add 50–70 organizations to OLA's list, so that instead of 137 organizations, 200 organizations could be invited to register. If the list could be expanded, the site would be more successful. DCLG members should send contact information for additional organizations to Ms. Caliman. Mr. Ulman pointed out that just a modest amount of effort on the part of DCLG members would pay huge dividends through increased participation from advocacy organizations.

Mr. Rosenthal reported that he had written an article on *NCI Listens and Learns for Oncology Times*. The article will be published in the January 10 issue. The article includes the photo of DCLG members with Ms. Handley and Ms. Caliman that was taken with NCI Director Dr. Andrew von Eschenbach in September. The article also provides a complete list of all DCLG members, including the one who was unable to attend the September meeting. Mr. Bro hoped the article would be posted on the *Oncology Times* website so that it could be forwarded to others by e-mail.

V. UPDATE ON *NCI LISTENS AND LEARNS* EVALUATION PLAN DISCUSSION

Dr. Beverly Laird reported that the Evaluation Working Group continues to develop its logic model. It has received good feedback from NCI but wants more in-depth feedback from the remaining DCLG members. Dr. Laird is scheduling phone meetings with the chairs of the other Working Groups, who can then solicit input from their members. Once the logic model is complete, the evaluation plan will come together rapidly.

As soon as the site is launched, a customer satisfaction survey will be in place. All visitors to the *Listens and Learns* website will be asked to participate in the pop-up survey, which will collect demographic information as well as data on how often participants visit the site, their primary roles, and ways to improve the site. However, data need to be collected from 300 respondents before the contractor can provide a data summary, which is one reason why the survey will be given to 100% of those visiting the site.

Ms. Brooke Hamilton pointed out that although the survey will pop up on the screens of all visitors to the site, they may use the site without completing the survey. The contractor has found that the typical response rate ranges from 3% to 5%.

Dr. Laird is working to identify software that can be used to analyze input from the general public. She also emphasized the importance of addressing the need to make *NCI Listens and Learns* accessible to all advocacy groups, not just those that have responded to the earlier survey or have easy Internet access.

Col. Williams noted that Dr. Laird had requested input from the Operations and Promotions Working Groups for the logic model evaluation overlay, and asked whether his earlier discussion on Web site monitoring was relevant. Dr. Laird replied that this activity does fit under the activities column of the logic model.

Dr. Laird pointed out that if NCI scientists did not support this effort, little would be accomplished. They are key stakeholders and need to buy into the *Listens and Learns* process. Col. Williams suggested that Mr. Bro and the Promotions Working Group help promote the site to NCI scientists. Mr. Bro agreed to take this on.

VI. PUBLIC COMMENT

There was no public comment.

VII. NEXT STEPS

Ms. Caliman reminded DCLG members of the upcoming call on January 18, 2005, from 3:00 to 5:00 p.m. Eastern Time. The next face-to-face meeting will take place February 28 and March 1, 2005. DCLG members will soon receive a draft agenda to review.

Ms. Campos asked if any data on the site would be available at the time of the face-to-face meeting. Ms. Hamilton replied that data would only be available if at least 300 individuals had completed the pop-up survey.

Ms. Handley noted that the Clinical Trials Working Group Web site has received a tremendous response from researchers and advocates, which leads her to predict that *NCI Listens and Learns* will also generate a great response.

Mr. Ulman concluded the meeting by wishing everyone a happy and safe holiday season. He predicted that the future of the DCLG would be bright in 2005. By working together, the group will accomplish a great deal.

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

December 14, 2004 DCLG Teleconference Meeting

Attachments:

Roster

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

DCLG ACTION ITEMS

December 14, 2004

- DCLG members will encourage the organizations they represent to register for the *Listens and Learns* website.
- Ms. Elisabeth Handley will share the proposed wording of the question concerning caMATCH to be posted on the *NCI Listens and Learns* website with DCLG members. DCLG members should submit any comments to Ms. Caliman.
- Ms. Handley will discuss with the *Listens and Learns* summary writer the possibility of reporting the geographic locations of participants in the discussions.
- DCLG members should send contact information for cancer advocacy organizations not already on OLA's list to Ms. Nancy Caliman.
- Dr. Beverly Laird will hold phone meetings with the chairs of the other DCLG Working Groups to discuss the proposed logic model and evaluation overlay. Working Group chairs will then solicit feedback from their members and provide this feedback to Dr. Laird.
- The Promotions Working Group will promote the *Listens and Learns* site to NCI scientists.
- Ms. Caliman will soon distribute a draft agenda for the DCLG's next face-to-face meeting (February 28 and March 1, 2005).