

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

MINUTES of the DIRECTOR'S CONSUMER LIAISON GROUP

November 4, 2004

The 28th meeting of the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG) was convened as a teleconference at 3:00 p.m., November 4, 2004. Mr. Doug Ulman presided as Chair.

Members Present

Mr. Doug Ulman, Chair
Ms. Margaret L. Anthony
Mr. William P. Bro
Ms. Lourie Campos
Ms. Bobbi de Córdova-Hanks
Dr. Beverly Laird

Dr. Sylvia M. Ramos
Mr. Eric Rosenthal
Ms. Mary Jackson Scroggins
Ms. Sue Sumpter
Dr. Marisa Weiss

NCI Office of Liaison Activities Staff

Ms. Nancy Caliman, Executive Secretary, DCLG
Mr. James Hadley, Advocacy Program Manager
Ms. Brooke Hamilton, Professional Societies Liaison and CARRA Program Analyst
Ms. Elisabeth Handley, Acting Director
Ms. Jane Jacobs, CARRA Program Manager
Ms. Devon McGoldrick, Communications Intern

NCI Center for Strategic Dissemination Staff

Ms. Nina Goodman
Dr. Holly Massett

NCI Office of Communications Staff

Ms. LaTonya Kittles

Palladian Partners

Ms. Adonia Calhoun-Coates
Ms. Debby Berlyne, Writer

Members of the Public

Mr. Greg Bielawski, Consumer Advocates in Research and Related Activities (CARRA)
Mr. Tony Caputi, American Foundation for Urologic Disease
Mr. Jay Bitkower, Action to Cure Kidney Cancer
Mr. Fred Atkin, Action to Cure Kidney Cancer

I. OPENING REMARKS

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

II. REPORT FROM *NCI LISTENS AND LEARNS* OPERATIONS WORKING GROUP/DISCUSSION

Recommendations. Ms. Sue Sumpter presented the recommendations of the Operations Working Group:

1. Criteria for qualification as an advocacy organization:

- 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 that is unrelated to cancer, but have an active interest in cancer. These groups might 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.

2. Where a national organization exists with affiliates, *NCI Listens and Learns* will seek a single opinion from the organization that reflects the full flavor of its constituent chapters. *NCI Listens and Learns* will encourage national organizations to poll their members.

Coalitions would be treated differently. Each constituent of a coalition each would be asked to submit responses.

- ### 3. The site should be launched by close of business on January 14, 2005.
- ### 4. The Operations Working Group should perform the reviews of the summaries of responses for the initial months following the Web site launch with the knowledge that this process will be modified in time.

Upon motion properly made and seconded, the recommendations of the Operations Working Group were approved.

Criteria for Advocacy Organizations. In response to a question from Ms. Mary Jackson Scroggins, Ms. Sumpter explained that the Working Group recommended that national groups have a single voice on the *Listens and Learns* Web site, but they should seek opinions from their subgroups and summarize those in their responses to questions posed on the site. Ms. Scroggins pointed out that some groups are only loosely affiliated with one another.

Ms. Scroggins wondered whether groups like the National Council of Negro Women, which do not focus on health but has a medical division, would qualify to join the site. Ms. Sumpter replied that groups whose primary focus is not on health may join, as long as they have an interest in cancer. Ms. Lis Handley added that the Office of Liaison Activities (OLA) would be happy to include such groups in its list of advocacy organizations if DCLG members provide the contact information to Ms. Devon McGoldrick.

The group discussed whether professional societies, such as the National Hispanic Medical Association or the American Society for Clinical Oncology, would qualify to join. Ms. Handley explained that the pilot program was developed specifically for advocacy organizations and the members of professional societies are primarily scientists, not advocates. These scientists could join the site as individuals.

Some DCLG members pointed out that many professional societies do advocacy. Moreover, physicians often advocate for their patients.

Ms. Brooke Hamilton explained that she serves as the professional societies liaison for NCI, and Dr. Andrew von Eschenbach meets regularly with professional societies. As a result, professional societies already have a mechanism for input and feedback to NCI.

Ms. Scroggins suggested that if professional societies will not qualify to join the site as advocacy organizations, the site should make this very clear. DCLG members agreed that the site would specify that only “consumer advocacy organizations” would qualify to join the site as organizations. Using the word “consumer” is consistent with the focus of the Consumer Advocates in Research and Related Activities (CARRA), as well as the DCLG itself.

Monitoring the Site. Dr. Sylvia Ramos requested clarification on the DCLG’s monitoring role. Ms. Sumpter replied that, at least at first, members of the Operations Working Group would rotate responsibility for reviewing the advocacy group comments and the summary of comments that will be prepared by a contractor. Dr. Marisa Weiss emphasized that this will be a flexible process that may change as the DCLG observes the dynamics and actions of the community.

III. REPORT FROM *NCI LISTENS AND LEARNS* PROMOTIONS WORKING GROUP/DISCUSSION

Recommendations. Mr. Bill Bro stressed that due to budgetary constraints, promotion of *NCI Listens and Learns* will be a grassroots efforts. The Promotions Working Group made the following recommendations:

1. NCI should launch the *NCI Listens and Learns* Web site on January 14.
2. The DCLG should submit ideas for promoting the site to him by e-mail.
3. DCLG members should encourage advocacy organizations with which they have relationships to participate in the site when it is launched.
4. DCLG members should arrange for their own groups to submit comments in response to the first question posed on the site. These comments should be prepared in advance so that they are ready when the site is launched.

Upon motion properly made and seconded, the recommendations of the Promotions Working Group were approved.

Site Launch. Mr. Bro explained that the plan is to circulate the first question to DCLG members' organizations prior to the site's launch date. In this way, responses from those organizations can be posted on the site and the site will show activity as soon as it is launched. OLA will distribute the initial question and collect and post the responses. Dr. Weiss added that in this way, people can join in an ongoing conversation when they visit the site on its first day.

Ms. Hamilton explained that OLA will also invite the approximately 120 organizations on its list to register and appoint a spokesperson before January 14. The site will provide sample archived questions for them to look at. Once organizations are registered, OLA can send them an e-mail thanking them for registering, and then another e-mail with the first question and an invitation to respond. On the launch date, the first question will be posted and, hopefully, responses from DCLG members' organizations will also be posted.

The online registration process will highlight the need for organizations to speak for all their constituents, which will require gathering information from those constituents. Prior to the site's launch, registration will be open only to those invited by NCI. But once the site is launched, registration will be open to all organizations that meet the criteria.

Several DCLG members emphasized the importance of explaining that the site is open only to invited organizations prior to January 14, but that it will be open to all once the site is launched. This explanation should be worded very carefully.

Publicizing the Site. Mr. Ulman pointed out that DCLG members will need to encourage the groups they work with to sign up for the site. Ms. Hamilton asked DCLG members to make personal follow-up phone calls to organizations that do not respond to the initial e-mail invitation. OLA will distribute the phone numbers to DCLG members, who will then split up the list and make the calls.

Mr. Eric Rosenthal will help publicize the site through an article in *Oncology Times* to be published in the January 10 issue, which will coincide with the site's launch. This is a way to reach out to the professional oncology community, and members of this community can send the information on to other groups.

Ms. de Córdova-Hanks suggested contacting health or science writers from DCLG members' local newspapers to spread the word. Ms. LaTonya Kittles volunteered to work with NCI's press office to develop a press release with blanks that can be filled in by advocacy organizations.

Ms. Hamilton noted that the site will also be publicized through buttons or links on NCI's cancer.gov Web site.

IV. Report from *NCI Listens and Learns* Summit Working Group/Discussion

Working Group Progress. The Summit Working Group has met three times since September. Ms. Scroggins offered to forward a copy of the group's report to Ms. Caliman for distribution to all DCLG members. She asked for comments on the report.

Some of the issues addressed by the group are:

- The summit's focus could be closely linked to one of the topics discussed on the *Listens and Learns* Web site. The Working Group needs to identify the summit's purpose very soon because many other aspects of the planning process will depend on this purpose.
- The summit should be a face-to-face meeting, with the possibility of videotaping the proceedings.
- The Working Group will obtain a list of cancer conferences in 2006 and will tie the summit to one of those meetings. DCLG members suggested that the meeting be held in conjunction with the 2006 Intercultural Cancer Council meeting or the survivorship conference. But before deciding whether to join forces with another meeting, it will be necessary to address how this linkage fits the DCLG mission of increasing communication between NCI and the cancer community.
- The 2006 meeting will serve as a pilot, with the possibility of more meetings to follow.
- Target audiences could include the general cancer community or just the advocacy community. Both groups might not be well served by the same meeting.
- Working group members who attend conferences and meetings will report back on their experiences, and the group may invite some organizations to share the details involved in planning their meetings.
- NCI has not set aside funding for the summit, so once the DCLG decides what type of summit it wants to hold, it should write a proposal with a budget. The group can also seek partners to share the costs.
- The summit might include different tracks for participants with different interests and backgrounds. This might be an opportunity to extend communications with grassroots organizations and the people they serve.

Director's Council of Public Representatives (COPR) Workshop. Ms. Scroggins attended the COPR Workshop, *Inviting Public Participation in Clinical Research: Building Trust through Partnerships*. The goal was to explore ways to engender trust in medical research.

The first day of the conference included a panel discussion, three breakout sessions, and a closing session. During each breakout session, seven different breakout groups considered the same questions, such as what patients and other study participants want from scientists. Each breakout group had a facilitator and note taker, and the composition of the groups changed with each session. COPR members circulated among groups observing and taking notes. The day ended with an interactive, facilitated closing session. The DCLG should not duplicate what COPR did but it can learn from the experience.

Ms. Handley added that on the second day of the workshop, COPR members summarized the results of the previous day and developed recommendations, which they presented at the end of

the day to Dr. Elias Zerhouni, NIH Director, and several NIH Institute directors. Ms. Handley will distribute these recommendations to DCLG Members.

Reflective Practices. Ms. de Córdova-Hanks discussed reflective practices as a potential activity at the summit. Facilitators meet with those involved in a program to lead discussions about whom the group is serving and why, what the group has accomplished, whether the group is making headway, and whether the group is providing the services it intended to provide. As a result of these discussions, groups often change their approaches.

Next Steps. The Working Group will write a brief proposal to present to the DCLG for its review and approval.

By November 17, all Working Group members will receive a series of questions and their responses will be the focus of the group's December 1 teleconference. A tentative schedule for planning the summit will also be ready by December 1. By December 15, the group will select a purpose for the summit to present to the full DCLG. The Working Group welcomes suggestions from other DCLG members.

V. Report from NCI Listens and Learns Evaluation Working Group/Discussion

Draft Logic Model and Logic Model Evaluation Overlay. Dr. Beverly Laird reviewed the draft logic model and evaluation overlay for the *NCI Listens and Learns* Web site. The logic model lists resources, activities, and outputs, as well as the short- and long-term outcomes of the activities and their impacts. The evaluation overlay provides questions that must be answered to assess the items in the logic model.

The Working Group is looking into some content analysis software that can be used by the contractor to summarize input to the Web site from the general public. The public comments will not be analyzed to the same degree as the advocacy organization comments, but this type of software can give a sense of themes expressed by the public.

Several of the columns in this document need additional input from the other working groups. As DCLG members plan activities related to *NCI Listens and Learns*, they should consider what questions will need to be asked to determine the impact of these activities. Also, DCLG members should keep the items in the fourth and fifth columns of the evaluation overlay in mind as they plan activities, to ensure that the activities and outputs are moving in the right direction.

The Working Group welcomes questions and suggestions on the document from DCLG members. Ms. Caliman suggested that the other Working Groups discuss the Evaluation Working Group's document during their next meetings.

Customer Satisfaction Survey. Dr. Laird explained that NCI has a contract with an organization that manages the American Customer Service Index survey, a customer satisfaction survey, for the agency. The survey uses popup screens on NCI's Web site, cancer.gov, to collect customer satisfaction data. The Office of Liaison Activities was offered the opportunity to use the same survey to evaluate certain aspects of the *Listens and Learns* Web site. Most of the

questions are standard but the DCLG can include some of its own questions in this survey, such as demographic information, for the *Listens and Learns* Web site. However, the contractor will only analyze the findings from the survey after at least 300-350 individuals respond.

Ms. Caliman will distribute a list of the required questions in the survey, and DCLG members should submit additional questions that should be asked about the *Listens and Learns* site. Ms. Hamilton noted that the survey should not include more than four additional questions because of the possibility of user fatigue. Only about five percent of users complete the surveys. Dr. Laird suggested encouraging advocacy group members to respond to the survey.

Next Steps

Mr. Ulman asked whether any of the members of the public wanted to address the DCLG members. None of the members of the public responded with a question or comment.

Mr. Ulman expressed his appreciation to all DCLG members for their Working Group participation. He noted that Ms. Caliman has distributed potential dates for the DCLG's next teleconferences (December 14, 2004, and January 18, 2005) and face-to-face meeting (February 28-March 2, 2005), and asked all DCLG members who have not already done so to respond to Ms. Caliman's request for their availability.

Ms. Caliman informed DCLG members that they will soon receive letters from her confirming their participation in the Working Groups. This is a procedure required by NCI.

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

November 4, 2004

- If DCLG members would like to invite advocacy organizations not on NCI's list to register for the new *NCI Listens and Learns* Web site, they should forward the names and contact information to Ms. Devon McGoldrick (mcgoldrd@mail.nih.gov) of the Office of Liaison Activities (OLA).
- DCLG members should contribute their ideas for promoting the *Listens and Learns* Web site by e-mail to Mr. Bill Bro, with a copy to Ms. Nancy Caliman.
- DCLG members will make personal phone calls to encourage advocacy organizations to register for the *Listens and Learns* site. OLA staff will work with DCLG members to ensure that they contact the organizations with which they have relationships and to ensure that no one DCLG member is burdened with too many calls.
- DCLG members will encourage their organizations to prepare a response to the initial question for the *Listens and Learns* Web site so that the site has activity as soon as it is launched. OLA will inform the DCLG members of the initial question in advance.
- Ms. Brooke Hamilton will send a copy of the advocacy organizations list to Ms. Bobbi de Córdova-Hanks.
- Mr. Eric Rosenthal will write a column on the *Listens and Learns* Web site for *Oncology Times*, to be published close to the time of the site's launch date.
- Ms. Caliman will distribute the required user satisfaction survey questions to DCLG members, who should respond with suggested optional questions to add to the survey.
- The Promotions, Operations, and Summit DCLG working groups should discuss the Evaluation Working Group's logic model during their next meetings and provide their feedback to Dr. Beverly Laird, and Ms. Caliman.
- DCLG members should respond promptly to Ms. Caliman's request concerning their availability for the proposed DCLG teleconference dates (December 14 and January 18) and face-to-face meeting dates (February 28 to March 2).
- Ms. Handley will send the draft recommendations from the COPR workshop on *Inviting Public Participation in Clinical Research: Building Trust through Partnerships*. The final recommendations will be presented at the Advisory Committee to the Director of NIH on December 2 and 3rd and Ms. Handley will share the final recommendations and report following that meeting.