

**DEPARTMENT OF HEALTH AND HUMAN SERVICES  
NATIONAL INSTITUTES OF HEALTH  
NATIONAL CANCER INSTITUTE  
31st Meeting  
DIRECTOR'S CONSUMER LIAISON GROUP (DCLG)  
May 26, 2005, 3:00 P.M. – 5:00 P.M. Eastern Time  
TELECONFERENCE**

**SUMMARY MINUTES**

**Members Present**

Mr. Doug Ulman, Chair  
Ms. Peggy L. Anthony  
Ms. Vernal H. Branch  
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  
Ms. Cece Whitewolf  
Col. (Ret.) James E. Williams, Jr., USA

**NCI Staff**

Ms. Nancy Caliman, Executive Secretary, DCLG, Office of Liaison Activities (OLA)  
Ms. Laura D'Arcy, Intern, Cancer Care Delivery Systems  
Ms. Brooke Hamilton, Acting Director, OLA  
Ms. Jane Jacobs, CARRA Program Manager, OLA  
Ms. Alissa Lewandowski, Health Communications Intern, OLA  
Dr. Rochelle Rollins, Special Assistant to Dr. Mark Clanton, Deputy Director, Cancer Care Delivery Systems  
Ms. Linda Ticker, Program Assistant, OLA

**I. Opening Remarks**

Mr. Doug Ulman convened the meeting at 3:00 p.m. EST and reviewed the rules governing confidentiality and conflict of interest. Ms. Nancy Caliman determined that a quorum was present. Mr. Ulman noted with appreciation the *Director's Update* column (NCI Cancer Bulletin May 24, 2005) highlighting the work of advocates and OLA programs including the DCLG, CARRA (Consumer Advocates in Research and Related Activities), and advocacy teleconferences. He expressed the hope that the article would spur increased interest in the *NCI Listens and Learns* Web site.

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### II. Minutes

It was moved and seconded that the minutes of the February 28-March 1 DCLG meeting be approved with the following corrections:

1. Page 4 – Section entitled “Update from the Office of Science Planning and Assessment:” First paragraph, seventh line, delete “will be produced on colorectal and pancreatic cancer in 2005” and insert “may be produced for other sites.” Second paragraph, second line, insert the word “site” after the word “disease.”
2. Page 5, First paragraph, delete first sentence, “Ms. Nichols characterized the advocacy groups that participated in the PRG process as the workhorses of the PRG.”
3. Page 5, Second paragraph, change third sentence to read “Good animal models of prostate cancer were not available...”

The motion carried.

### III. Director’s Update

Mr. Ulman welcomed Dr. Rochelle Rollins, Special Assistant to Dr. Mark Clanton, NCI Deputy Director for Cancer Care Delivery. Dr. Rollins has been appointed as the Chair of the new Subcommittee on Cancer that was established by the Department of Health and Human Services (HHS) Health Disparities Council on March 28, 2005.

Dr. Rollins explained that the Subcommittee would focus on 6 of the 14 recommendations of the Trans-HHS Cancer Health Disparities Progress Review Group report *Making Cancer Health Disparities History*. She outlined the goals of the Subcommittee as facilitating a comprehensive analysis of the relevant HHS programs, establishing new approaches for data collection and sharing, and establishing partnerships and educational programs that are effective in addressing cancer health disparities. She reported that most agencies are currently in the process of identifying their representatives to the Subcommittee.

Dr. Rollins specified the need for a good information system across the entire department, containing fact sheets to keep agencies current on cancer developments. Quarterly reports will be given to the Assistant Secretary of HHS. Dr. Rollins noted the importance of this platform to facilitate working in a timely manner on cancer issues.

Dr. Sylvia Ramos inquired about diversity on the Health Disparities Council, and observed that people affected by disparities should be represented on the Subcommittee on Cancer. Dr. Rollins replied that the Health Disparities Council is a very diverse group. She added that not all the members of the Subcommittee on Cancer had been selected yet, but that ensuring diversity on the Subcommittee was a priority.

Ms. Vernal Branch inquired whether the Veterans Administration (VA) was represented on the Subcommittee. Dr. Rollins noted that the VA was not under the HHS umbrella, but felt that this should not be a barrier to participation. Dr. Rollins and Ms. Branch agreed to discuss ways to bring the VA onboard.

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Col. James Williams recalled that the Intercultural Cancer Council (ICC) would be holding an educational conference in September and a biannual conference in 2006, and suggested that the Cancer Disparities Subcommittee partner with the ICC.

Ms. Scroggins asked about the level of advocacy involvement. Dr. Rollins explained that although no advocates are on the Health Disparities Council, they could be represented on the Subcommittee. She asked DCLG members to spread the word about this.

Dr. Marisa Weiss offered help with survey studies of cancer populations through the [www.breastcancer.org](http://www.breastcancer.org) Web site, if those were needed.

In response to a question, Dr. Rollins described the database containing one-page summaries on each activity regarding cancer disparities across HHS. This database will be updated and will eventually allow for agencies to be linked. The database is online and Dr. Rollins offered to see if a password was needed for access.

Mr. Ulman thanked Dr. Rollins for her presentation.

### **IV. Update on *NCI Listens and Learns* Operations**

Col. Williams reported on the Operations Working Group as follows:

- The contractor that summarizes user comments is now summarizing public comments as well as the advocacy group comments.
- In February, the site recorded 2,184 visitors and 2,577 hits.
- Email reminders, for which OLA controls the timing, have been more effective than the automatic alert emails.
- The working group has revised its review procedure—it will now monitor the site without making formal reports. Recommendations will be made to the DCLG and OLA as needed.
- The working group agreed that the length of time a question could be posted can be extended beyond 30 days if the complexity of the question warrants. OLA staff will decide this matter on a case-by-case basis.
- The “Post comment” section will be positioned higher on the Web page.
- The American Customer Service Index survey will be offered to 100% of visitors, but only once every three months.
- Working group members will contact those groups that register but fail to name a spokesperson and encourage them to appoint one. OLA will let the DCLG know which groups they have contacted have appointed spokespersons.
- Organizations that have signed up but are not participating will be allowed to remain through the pilot period (one year) before any action is taken.

Col. Williams noted that it was possible to learn quickly about what works on the Web site, because of the immediate feedback from various tests. He thanked staff for their

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quick reactions and dedication to improving the site, and expressed his appreciation to NCI for advertising it.

Ms. Sue Sumpter voiced her concern that the questions were too broad and complex and not user friendly. Some members agreed that questions that seemed overwhelming could make groups feel that the answer must also be overwhelming, thus discouraging a reply. Other members noted that some groups might not be comfortable with technical terms, and that others, particularly small grassroots organizations, might find the complex questions intimidating.

Col. Williams noted that the Operations Working Group had also discussed whether it was appropriate for DCLG members to post responses on the *NCI Listens and Learns* Web site. After discussion, they recommend that it is appropriate for DCLG members to post responses representing their groups or themselves but not representing the DCLG.

The following actions were approved the by the full DCLG:

1. It was moved and seconded that the response period for questions posted on the *NCI Listens and Learns* Web site could be extended beyond the 30-day period, as determined on a case-by-case basis by staff. The motion carried.
2. It was moved and seconded that the Operations Working Group will contact groups that have registered, but which have not named a spokesperson, to encourage them to do so. The motion carried.
3. It was moved and seconded that all DCLG members would be allowed to post comments on the *NCI Listens and Learns* site, speaking on their own or their groups' behalf, but not as representatives of the DCLG. The motion carried.

### **V. Update on *NCI Listens and Learns* Summit**

Ms. Scroggins reported on the Summit Working Group as follows:

- The group has been meeting once a month to plan the Summit for 2006.
- The theme of the Summit is demystifying the NCI. The group intends to solicit input from the cancer advocacy community, but will make clear that this is a request for suggestions, not for micromanagement.
- DCLG members are asked to forward to Mr. Hadley names and contacts of medically underrepresented (also known as hard-to-reach) populations to be invited to the Summit. This will be an ongoing process.
- Ms. Lourie Campos, who is a member of both the Summit and Evaluation Working Groups, is the liaison to the Summit Working Group for the logic model. At this stage of the planning, no activity from the Promotions Work Group is needed.
- The Natcher Center on the NIH campus is the location for the Summit Conference, thus giving participants the opportunity to see the NCI firsthand.
- The proposed duration of the Summit is one and one-half days, to give participants time for networking and tours.

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- Three tentative dates have been proposed: June 15–16, June 19–20, and June 29–30. Holding the conference in June would mean that the five DCLG members whose terms end on June 30 would be able to attend.
- DCLG members are asked to notify Mr. Hadley of their date preference, and whether they are aware of any major conferences that conflict with these dates. The NCI Director's availability is a major factor in choosing the date.
- Registration will be a combination of open and invited registration to ensure inclusiveness.
- Funding through scholarships is being explored for members of underserved groups that lack the funds to attend. The number of scholarships that may be offered has not been decided. OLA is working on an appropriate scholarship application.
- DCLG members are asked to inform Mr. Hadley if they know of any organizations that would be willing to partner in providing scholarship funding.
- The number of participants, including committee members and staff, is estimated as between 250 and 300.
- The major emphasis of upcoming Summit Work Group meetings will be to outline the structure and format of the conference.

### VI. Update on *NCI Listens and Learns* Promotions

Mr. Bill Bro reported on the Promotions Work Group as follows:

- The working group recommends that DCLG members help staff NCI booths at various functions, keep a record of their ongoing promotional activities, mention the Web site in their organizations' publications, and provide links from their own Web sites to the *NCI Listens and Learns* site.
- There will be a monthly feature in the *NCI Cancer Bulletin* about the *NCI Listens and Learns* Web site.
- The working group is prepared to consider what needs to be done to promote the Summit.
- Mr. Rosenthal reported on the formulation of an announcement of the *NCI Listens and Learns* question to be aired weekly on *The Group Room* Radio Broadcast, which reaches one-half million people. This is directed at the public rather than organizations. It is done as a public service announcement with coverage all over North America.
- DCLG members were asked to keep a record of their efforts to promote the *NCI Listens and Learns* Web site. OLA will ask for these reports on a quarterly basis.

Ms. Bobbi de Córdova-Hanks suggested that promotional materials be provided for three upcoming survivorship conferences. She reported on two recent interviews she had done on mammography, in which a sidebar featured the *NCI Listens and Learns* Web site.

**VII. Update on *NCI Listens and Learns* Evaluations**

Dr. Beverly Laird reported on the Evaluations Working Group as follows:

- The working group has made the recommended changes to the logic model.
- The working group will email approximately eight evaluation questions to DCLG members and appreciates their attention to them.
- A review of the Web site comments indicates that some groups actually survey their members before answering, which provides very valuable information. It might be possible to find ways to help groups collect their data.
- Dr. Laird addressed the NIH Director's Council of Public Representatives (COPR) as a member of CARRA, and also spoke briefly about the DCLG. COPR is very interested in implementing an NIH-wide program similar to CARRA.

Mr. Ulman agreed that it was valuable to think about the work of the DCLG in the larger context of what the NIH is trying to accomplish. He suggested that the DCLG could be a model for other groups.

**VIII. Response to Questions on the Progress Review Group (PRG) Process**

Mr. Ulman thanked all those who had responded to the four questions posed by Ms. Cherie Nichols about the PRG process and directed the members' attention to the synthesis of those responses which had been distributed.

Mr. Ulman noted that the conceptual trend at NIH was to move away from specific diseases and into more crosscutting issues. He suggested that it would be important for the DCLG to play a role in the dissemination of this type of information.

Mr. Ulman directed the members' attention to the list (in the synthesis) of crosscutting topics in cancer research that would be of interest to the cancer advocacy community and asked the members to review them in light of key themes that could be recommended to Ms. Nichols.

Mr. Ulman stated that he would craft a response to Ms. Nichols and circulate a draft of the letter to OLA and to the members.

**IX. Public Comment**

There was no public comment.

**X. Other Business**

Dr. Weiss suggested putting a glossary onto the Web site of acronyms and terminology that might come up in *NCI Listens and Learns* questions and responses.

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Ms. Hamilton pointed out that unexplained acronyms were avoided, and that the cancer dictionary and search box are available to those using the Web site.

Members, citing the goal of simplification and ease of use of the Web site, made the following points:

- Dr. Weiss noted that some answers may contain unexplained acronyms, even if the questions do not.
- Mr. Rosenthal suggested that having a glossary available right on the site, without the need to use other search devices, would add to the site’s ease of use.
- While approximately 700 visitors per month look at the questions, about 30 respond.
- Analyzing how long visitors stay on the site might be a way of evaluating how inviting the site is.

Ms. Caliman agreed to continue working to try to simplify the questions, and to explore how to provide users with definitions for unexplained acronyms.

**XI. Next Steps**

The next DCLG conference call is scheduled for Wednesday, July 20, 2005, from 3:00 p.m. to 5:00 p.m. EST.

The next face-to-face meeting is scheduled for September 14–15, 2005.

Mr. Ulman thanked all the participants.

The meeting was adjourned at 4:45 p.m.

**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

### DCLG ACTION ITEMS

1. Dr. Rollins will explore the possibility of involving the Veterans Administration with the Subcommittee on Cancer of the Department of Health and Human Services (HHS) Health Disparities Council.
2. Dr. Rollins will check on the accessibility of the online HHS database on health disparities programs and determine if a password is needed.
3. OLA staff will provide DCLG members with an updated list of registered organizations who have assigned an *NCI Listens and Learns* spokesperson after being contacted, and of those organizations that still need to be contacted about assigning a spokesperson.
4. OLA staff will decide, on a case-by-case basis, which questions on the *NCI Listens and Learns* Web site require a response time frame that is extended beyond 30 days.
5. DCLG members will notify Mr. Hadley of the names of organizations and/or representatives of medically underrepresented populations that should be invited to the Summit.
6. DCLG members will notify Mr. Hadley of their preferences for the date of the Summit, and if they know of any major conference whose timing would conflict with any of the three tentative dates (June 15–16, 19–20, 29–30).
7. DCLG members will notify Mr. Hadley of any organizations that might be willing to partner with the DCLG to provide funding/scholarships for selected invitees to the Summit.
8. OLA staff will post a monthly announcement in the *NCI Cancer Bulletin* regarding the *NCI Listens and Learns* question beginning in July 2005.
9. Mr. Rosenthal will record a monthly announcement of the *NCI Listens and Learns* question for airing weekly on The Group Room Radio Broadcast. The Broadcast reaches one-half million people all over North America.
10. DCLG members are encouraged to mention *NCI Listens and Learns* in their organizations' publications and to provide a link on their Web sites to *NCI Listens and Learns*.
11. OLA staff will provide promotional materials to DCLG members who will be participating in the three upcoming survivorship conferences.
12. DCLG members will keep a record of their promotional activities and be prepared to report this to OLA on a quarterly basis.
13. The Evaluation Working Group will send DCLG members an evaluation questionnaire on the *NCI Listens and Learns* Web site.
14. DCLG members will review the list of PRG topics for key themes that could be recommended to Ms. Nichols.
15. Mr. Ulman will draft a letter based on responses from DCLG members to the four questions on the PRG posed by Ms. Nichols, and circulate the draft for comment to OLA and to the full DCLG.
16. OLA staff will continue efforts to simplify questions on the *NCI Listens and Learns* Web site, and will consider how to help users find the definitions of unexplained acronyms.