

**DEPARTMENT OF HEALTH AND HUMAN SERVICES  
NATIONAL INSTITUTES OF HEALTH  
NATIONAL CANCER INSTITUTE  
40th NCI DIRECTOR'S CONSUMER LIAISON GROUP**

**Summary of Teleconference  
June 8, 2006  
1:30 P.M.–3:00 P.M. Eastern Standard Time**

**DIRECTOR'S CONSUMER LIAISON GROUP  
NATIONAL CANCER INSTITUTE**

**June 8, 2006  
1:30 P.M.–3:00 P.M. Eastern Time  
TELECONFERENCE**

**Summary of Meeting**

**Members Present**

Mr. Doug Ulman, Chair  
Ms. Vernal H. Branch  
Mr. William P. Bro  
Ms. Lourie Campos  
Ms. Bobbi de Córdova-Hanks  
Ms. Nancy Davenport-Ennis  
Dr. Beverly Laird  
Dr. Sylvia M. Ramos  
Ms. Mary Jackson Scroggins  
Ms. Sue Sumpter  
Dr. Marisa Weiss  
Ms. Cece Whitewolf  
Col. (Ret.) James E. Williams, Jr., USA

**Member Absent**

Ms. Margaret L. Anthony

**NCI Staff**

Ms. Barbara Guest, DCLG Executive Secretary  
Ms. Brooke Hamilton, Acting Director, Office of Liaison Activities (OLA)  
Mr. James Hadley, Advocacy Program Manager, OLA  
Ms. Jane Jacobs, CARRA Program Development Manager, OLA  
Ms. Linda Ticker, Program Assistant, OLA  
Ms. Devon McGoldrick, Coordinator, *NCI Listens and Learns*  
Ms. Anne Willis, Advocacy Program Fellow  
Ms. Jennifer Fritz, Health Communications Intern  
Ms. Bethany Piernikowski, Cancer Research Training Fellow

Ms. Pat Kaufman, Palladian Partners

Ms. Terry LaMotte, Palladian Partners

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## **I. Opening Remarks**

Mr. Doug Ulman convened the meeting at 1:30 p.m. EST and reviewed the rules governing confidentiality and conflicts of interest. Ms. Barbara Guest determined that a quorum was present.

## **II. Approval of Minutes**

### **a. Planning Working Group Minutes**

It was moved and seconded to accept the Planning Working Group minutes of March 30, 2006. The motion carried unanimously.

### **b. DCLG Minutes of March 29–30, 2006**

It was moved and seconded to accept the minutes of the March 29–30 DCLG meeting. The motion carried unanimously.

## **III. Summit Working Group Update**

Mr. James Hadley reported that 65 scholarships had been awarded to advocates.

Ms. Terry LaMotte from Palladian Partners reported that 310 completed registrations had been received; the total number of participants, including speakers, presenters, and DCLG members will be approximately 350. Ms LaMotte added that there are 85 poster presenters and 10 exhibitors. Dr. Ramos asked about geographic distribution of participants. Ms. LaMotte stated that the breakdown is 146 national and 41 local advocacy groups.

Mr. Hadley updated the DCLG members on the Summit agenda as follows:

- Ms. Pattie Labelle will not perform at the conference due to insufficient funding from the Foundation for the National Institutes of Health. Palladian staff is looking into other options.
- Each DCLG member has a role at the conference as a moderator, performing introductions, and/or facilitator. DCLG members are urged to network with participants as much as possible. However, DCLG members who are making introductions should sit up front for easy access to the stage at the appropriate time.
- At 1:00 p.m. on Monday, June 19, when the conference begins, all DCLG members will be seated on the stage. Ms. Hamilton noted that this would give the DCLG visibility as the hosts of the conference. After the plenary session, DCLG members will take seats in the audience.

Ms. Sue Sumpter joined the call.

- Dr. Elias Zerhouni will welcome the guests by a video presentation. Dr. Zerhouni is not able to attend in person because of a prior commitment.

- Dr. John Niederhuber will present his scientific talk on Monday, make closing remarks and give a charge to the advocates on Tuesday. Dr. Niederhuber will also present certificates to the DCLG members whose terms are ending.
- Both a pediatric and an adult speaker will give their perspectives about being treated at the NCI.
- The program booklet will contain full biographical data about the speakers and those introducing them. DCLG members who are introducing speakers will receive thumbnail biographical sketches by e-mail of the person(s) they are introducing, and these thumbnail bios will also be available on-site. The introductions are short because the agenda is very full. Ms. Bobbi de Córdova-Hanks asked for a clarification about the roles of panel moderators and facilitators. Mr. Hadley stated that the moderator presides over the panel's discussion, and the facilitator is there to help the moderator. He added that Ms. de Córdova-Hanks' role was being switched to moderator.
- The Summit will be webcast.
- On Monday evening at the Town Hall meeting at the Hyatt Hotel, all DCLG members will be sitting up front. Mr. Ulman will introduce the DCLG members, speak about the DCLG mission, and take questions. Although it will not be possible to answer questions at that time, the questions will serve as a basis for thought in the coming months. Questions and comments can be written on cards or asked through an open microphone.
- Writers will be on-site to capture all the sessions, including the question and answer period at the Town Hall meeting.

Ms. Mary Jackson Scroggins asked if participants would receive certificates of attendance at the Summit. Mr. Hadley replied that participants will receive certificates when they hand in their evaluation forms.

Mr. Hadley thanked members of the Summit Working Group for their comments about the evaluation forms. He explained that there will be two separate forms—one for the break-out sessions and one for the conference—because it was felt that trying to combine all this information into one format made the evaluation too long and complicated.

Ms. Sumpter asked about name badges. Mr. Hadley stated that all DCLG members would wear name badges with ribbons that identified them as members of the DCLG. Ms. Scroggins asked whether former DCLG members had been invited. Mr. Hadley said they had, and former members would be recognized by Mr. Ulman in his introductory remarks, but they would not wear special name tags.

DCLG members expressed their appreciation for Dr. Niederhuber's level of engagement with the Summit. Ms. CeCeWhitewolf asked that Palladian Partners be recognized for their excellent work, especially with the scholarships. Mr. Ulman commended all the DCLG members for their efforts in bringing this significant undertaking to fruition. Ms. Scroggins thanked the members of the Summit Working Group for their dedication, and acknowledged the invaluable help of the OLA staff.

#### IV. DCLG Member Activities Updates

*a. Report on the communication with Dr. Niederhuber regarding the SPORE Program.*

Mr. Ulman asked for comments from DCLG members on Dr. Niederhuber's response.

Ms. Nancy Davenport-Ennis expressed her appreciation for receiving the response prior to the Summit, and noted Dr. Niederhuber's comment that congressional appropriations drive the level of research. She wondered if some recommendations from his office might be forthcoming about how the DCLG could help in this process.

Ms. Hamilton reminded the group that government employees are prohibited from lobbying Congress. She explained that DCLG members, in their official capacity, also may not lobby for increased funding.

Ms. Scroggins said that she was pleased that the DCLG had taken its responsibilities a step further with this communication. Ms. Sumpter agreed that it is important for the DCLG to be proactive.

Mr. Ulman asked if the DCLG communication to Dr. Niederhuber and his response were public documents. Ms. Hamilton replied that they could be.

Mr. Ulman suggested that the documents be posted on the Web site as an indication of the level of activity and interaction between the DCLG and the Acting Director. Other members agreed that posting these documents on the Web site might serve as a rallying point for advocacy groups and be another way to engage the public.

COL James Williams urged caution in publicizing the DCLG communications with the Director's office, and suggested that the DCLG members take time to consider the best ways to communicate with the Director and the public. Ms. Whitewolf asked that this topic be made an agenda item at a DCLG retreat.

Dr. Beverly Laird agreed with Ms. Whitewolf, noting that Dr. Niederhuber's response read as if he expected that it might be made public. She suggested that it was important for the DCLG to have an opportunity for closed discussions and private consultation with the NCI leadership to obviate concerns about publicity and encourage frank discussion.

Mr. Ulman recounted that Dr. Niederhuber had specifically sought him out at a meeting to apologize for not meeting the DCLG deadline for his response. Mr. Ulman called this a step in the right direction as the DCLG worked to keep a high level of visibility with the Director.

Ms. Scroggins suggested that perhaps the process started with these communications was more significant than the response itself.

DCLG members agreed that a good dialogue had been begun. Ms. Davenport-Ennis suggested that advocacy groups might be able to build on what the DCLG has started here.

Ms. Hamilton mentioned that Dr. Niederhuber had been the biggest advocate in securing funding for the Summit.

*b. caBIG™ Understanding NCI Teleconference.*

Ms. Jane Jacobs reported on the May 18, 2006, teleconference in which Dr. Kenneth Buetow gave an overview of the caBIG™ program and Mr. Gregory Bielawski explained the goals and purpose of the program, including a discussion of the poster depicting the journey from diagnosis to treatment. Ms. Jacobs reported that the number of participants on the live call was small, although more people called in later.

Ms. Jacobs referred the DCLG members to the caBIG™ Web site. She noted that a link to the caBIG™ Web site will be added to the DCLG Web site, and asked for input on how technological topics could be made more accessible to the general public.

Ms. Sumpter suggested that, where appropriate, the *NCI Listens and Learns* question could allude to the fact that there would be a caBIG™ teleconference on the topic. She felt that this might be very useful for complicated topics like nanotechnology.

Ms. Vernal Branch suggested that perhaps the teleconference was scheduled too early in the day, and wondered if more explanation about what caBIG™ is would be helpful. Ms. Jacobs noted the difficulty in scheduling nationwide teleconferences due to time differences.

Ms. Davenport-Ennis observed that it takes time for the public to recognize and engage with new groups. She stated that her organization has had success holding national teleconferences on Saturdays or after 7:00 p.m.

Ms. Whitewolf encouraged caBIG™ to consider alternate forms of communication, such as videos, to reach people who do not have computers or telephones.

Ms. Branch signed off the call.

*c. Report of The Cancer Genome Atlas (TCGA) Data Release Workshop.*

Col. Williams related the follow-up of Dr. Barker's offer to develop a consumer-friendly PowerPoint version of the TCGA, which she presented at the March meeting. Her presentation was very important and it was felt to be too technical for the advocacy constituency. He stated that Mr. Bro and Dr. Laird's review and input into the revision of this presentation had helped make the most recent version of The Cancer Genome Atlas (TCGA) presentation more accessible to people who wanted to understand what TCGA means and how to become involved with it. He stressed the importance of the DCLG taking a proactive role in supporting and helping with the dissemination of new developments from the NCI

Dr. Ramos asked whether this presentation was ready for public consumption. Col. Williams stated that the PowerPoint version is not quite ready and he would like it reviewed by the DCLG.

Ms. Davenport-Ennis mentioned that Dr. Barker had given a very compelling and interesting presentation about TCGA at a meeting that she had attended recently, and wondered if this presentation was the newest version. Col Williams referred Ms. Davenport-Ennis to Ms. Amy Bulman in the Office of Communications to check on this. Mr. Ulman recalled a conversation he had with a scientist who believed that TCGA had the potential to be one of the most important programs at the NCI.

d. *NCI Listens and Learns Working Group Web Site Update.*

Col. Williams reported that the question on Nanotechnology appeared on the Web site beginning June 1. He noted that by the time the question is presented for review and comment, very little turnaround time is available. Ms. Sumpter agreed that it would be beneficial if there could be more time to coordinate the question with the *NCI Listens and Learns Working Group* Conference call.

Col. Williams suggested that in the future it would be good if the *NCI Listens and Learns Working Group* could initiate some questions for the Web site. He added that the other challenge is getting the public to respond the questions. So far, the response has not been large, and this is a concern that will be considered at the one-year evaluation in 2007.

Ms. Sumpter signed off the call.

Ms. Hamilton informed the DCLG members of some personnel changes. Ms. Devon McGoldrick is leaving the NCI to join the Lance Armstrong Foundation. Ms. Jennifer Fritz, currently the OLA Health Communications Intern, will fill her position as the *NCI Listens and Learns* Coordinator. Ms. Jane Jacobs will also be leaving the OLA to join the NCI Office of Science and Planning Assessment.

**V. DCLG In-Person Meeting of October 25–26, 2006**

Ms. Guest encouraged DCLG members to volunteer as members of the Agenda Working Group to help plan the next in-person meeting, and expressed the hope that this Group could begin work shortly after the Summit conference.

Ms. Guest suggested that the DCLG consider the Council of Public Representatives (COPR) model for meetings, in which one day is set aside for working groups and the next day of meetings open to the public.

Ms. Davenport-Ennis stressed the importance of the DCLG constructing time to meet outside of the public eye. Ms. Whitewolf agreed that the DCLG should have a “retreat” day, and Ms. Scroggins agreed that a day of working group meetings would be beneficial.

Ms. Davenport-Ennis signed off the call.

Ms. Hamilton noted that Ms. Linda Ticker was on the call and thanked her for her work in making travel arrangements for the Summit.



**VI. Public Comment**

There were no public comments.

**VII. Next Steps**

See action items below.

Mr. Ulman thanked all the participants and adjourned the meeting at 2:50 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. Mr. Hadley will e-mail thumbnail biographical sketches of the speakers to all DCLG members who are introducers, and will also have these sketches available on-site at the conference.
2. OLA staff will add a discussion about the best ways for the DCLG to communicate with the NCI Director and the public as an agenda item for the next DCLG meeting. This will include consideration of opportunities for private communication between DCLG members and the NCI Director.
3. Ms. Guest will send an e-mail with suggested dates for the meeting of the Agenda Working Group.