

**U.S. Department of Health and Human Services  
National Institutes of Health  
National Cancer Institute**

**41st Meeting  
Director's Consumer Liaison Group (DCLG)**

**Teleconference  
September 28, 2006**

**DCLG Participants**

Mr. Doug Ulman, Chair  
Ms. Peggy L. Anthony  
Ms. Vernal H. Branch  
Mr. William P. Bro  
Dr. Grace L. Butler  
Ms. Lourie A. Campos  
Ms. Yvette Colón  
Ms. Kelly L. Cotter  
Ms. Nancy Davenport-Ennis  
Dr. Beverly Laird  
Ms. Mary Jackson Scroggins  
Ms. Sue Sumpter  
Ms. Celeste Whitewolf

**NCI Participants**

Ms. Jennifer Fritz  
Ms. Barbara Guest  
Mr. James Hadley  
Ms. Lenora Johnson  
Ms. Elizabeth Nielson  
Ms. Linda Ticker

**Welcome and Opening Remarks**

Mr. Doug Ulman welcomed the DCLG members and other participants, noting that this meeting would be instrumental in preparing them for the face-to-face DCLG meeting on October 25–26, 2006. He read the Conflict-of-Interest statement, which requires government employees to report any financial conflicts that they might have. Ms. Barbara Guest affirmed that a quorum for the meeting was present. The DCLG members approved the minutes of the 40<sup>th</sup> meeting of the DCLG by teleconference on June 8, 2006.

Mr. Ulman welcomed new DCLG members—Dr. Grace Butler, Ms. Yvette Colón, Ms. Kelly Cotter, and Mr. Alan Kaye (who was not present). Dr. Butler expressed her delight at being selected to join the DCLG, stating that she looked forward to learning the many facets of the work of the NCI. Ms. Colón stated that she is an oncology social worker, now working at the American Pain Foundation in Baltimore. Ms. Peggy Anthony and Ms. Celeste Whitewolf, who were recently reappointed to the DCLG, also took part in the conference call.

Mr. Ulman announced that Dr. Beverly Laird was chosen by the Director as Vice Chair of the DCLG. And her term was extended by one year to 2008.

### **Report from the DCLG Summit Working Group**

#### *Two Summit Reports*

Ms. Mary Jackson Scroggins thanked the Summit Working Group members, who worked for about 18 months to develop the Summit. Two reports have been produced as a result of the Summit: A Summary of the Summit including the Town Hall Meeting which is 39 pages; and a shorter Evaluation Report of participant's opinion of the Summit.

Mary Jackson Scroggins asked how each of the documents should be disseminated to the Summit participants. Both the Summary and the Evaluation report will be posted to the NCI Summit Website for general access and announced as posted in the online Nealon Digest. The Summit Web site also includes PowerPoint presentations from the Summit and the Webcast. Ms. Jackson Scroggins asked the DCLG members to consider additional uses for the document. Ms. Nancy Davenport-Ennis suggested that independent groups be allowed to post it on their Web sites or at least post a link to the document on the NCI site.

Mr. Ulman proposed that the DCLG distribute the 39-page report to all Summit speakers. Dr. Butler suggested indicating where the results in the 39-page report link to the NCI's Strategic Plan. Ms. Lourie Campos proposed sending e-mail messages or postcards to Summit attendees, informing them that the reports are available. Ms. Davenport-Ennis suggested distributing the reports to groups that have not joined the NCI Listens and Learns program, to promote the program's potential. Ms. Vernal Branch suggested placing the reports on a CD-ROM.

The group members wondered about a possible benefit in reducing the size of the 39-page document. Mr. James Hadley noted that the shorter executive summary and evaluation would serve that purpose. He expressed the hope that persons who participated in the Summit would help to disseminate the reports in their communities. His office will forward hard copies to anyone who requests them. Ms. Lenora Johnson suggested that the text of the larger summary be reduced. Ms. Davenport-Ennis stated that her organization would be pleased to distribute hard copies. Perhaps the NCI should distribute the documents to other government agencies (that is, to their advocacy offices).

Ms. Jackson Scroggins pointed out that the two documents (long and short reports) contain different information and are useful in different ways. She and Mr. Hadley will ensure that the reports or links to the reports are disseminated to all Summit participants.

#### *Town Hall Meeting*

The Summit report contains the proceedings of the Town Hall Meeting held during the Summit. The intent of the Town Hall meeting was to hear participant's questions and respond after the meeting. Ms. Jackson Scroggins asked how the DCLG should respond to the questions raised in the Town Hall meeting. Discussion centered on the level of response, and how to categorize the questions to make the most appropriate responses to the attendees. Advocates also asked questions on the NCI Listens and Learns website which will have to be answered. It was decided to continue the Summit Working Group to work through the questions and come up with responses. It was also suggested that this be done on a tight timetable since the Summit occurred 4 months ago. Perhaps a new subcommittee could review the Town Hall issues. Mr. Hadley noted that he distributed a list of questions and statements lifted from the report of the Town Hall Meeting to the DCLG members.

Ms. Branch proposed creating a subcommittee to discuss the questions raised during the town hall session and report back to the larger group. Mr. Ulman stated that the Summit Working Group with changed membership, could work on coming up with answers to the questions raised by Summit Participants. Mr. Ulman agreed that the Summit Working Group should continue to complete the Summit report and respond to the Town Hall meeting questions. Ms. Vernal Branch Ms. Cece Whitewolf and Dr. Beverly Laird agreed to join the Summit Working Group II. Ms. Mary Jackson Scroggins will continue as chair of the Working Group. The DCLG members accepted the report of the Summit Working Group on the results of the Summit and the evaluation report of the Summit.

### **Working Group Updates**

#### *NCI Listens and Learns Web Site*

In the absence of Col Jim Williams, Ms. Sue Sumpter updated the members on the NCI the Listens and Learns Web site. Currently, 607 members of the public and 137 cancer advocacy groups are registered to use the site. The current posted topic concern Complementary and Alternative Medicine. The next topic for the website will be a questions posted by, the Office of Policy Analysis and Response on the State Cancer Legislative Database. At the same time, the DCLG will post a question for advocates' response about potential topics and issues for future DCLG meetings.

An evaluation of the NCI Listens and Learns Web site is being conducted by Dr. Michael Burke of RTI International. He currently is conducting interview with key stakeholders, which include groups that chose not to register with the NCI Listens and Learns site. Dr. Burke will provide a more complete update on the evaluation at the October DCLG meeting. Ms. Sumpter thanked Ms. Jennifer Fritz for her help with the Listens and Learns Web site.

#### *Cancer Survivorship Research Conference*

Ms. Lourie Campos is the DCLG representative to the OCS conference on *Cancer Survivorship: Embracing the Future* which takes place October 4-6, 2006. The first day of the meeting will feature an orientation for 20 mentees (joined by their mentors), during which they will learn about integrating and applying research to their advocacy work.

Ms. Campos will facilitate a panel discussion on support groups. The conference is collaboration between the American Cancer Society, the NCI, and the Lance Armstrong Foundation. The meeting registration is full. Ms. Campos will report on the conference at a future DCLG meeting.

*October in-person DCLG Meetings*

Dr. Beverly Laird, chair of the Agenda Working Group described the agenda for the DCLG in-person meeting on October 25–26. NCI Director John Niederhuber will attend on both days. The public meeting on the first day will include the following topics:

- An update by Dr. Niederhuber
- The President's Cancer Panel
- The NCI budget and legislative activities
- A report from the Office of Cancer Survivorship
- A report on the status of the Translational Research Working Group
- An update on The Coordinating Center for Clinical Trials
- A report on the tobacco lawsuit
- DCLG working groups
- Health Disparities Integration and Implementation Team
- The CARRA program
- Public comments.

The second day will be a Working Group day and will feature discussions and presentations on Knowledge Management, the SPORE advocacy program, and advocate involvement in the cancer genome atlas (TCGA).

Ms. Guest noted that a dinner to welcome the new DCLG members is being organized for Tuesday evening, October 23<sup>rd</sup>, and is an optional event for DCLG members. The DCLG members will have a group photograph with Dr. Niederhuber on the October 26<sup>th</sup>, the second day of the meeting.

Mr. Ulman asked for a motion to approve the creation of a Program Working Group to consider the issues that will be presented at the DCLG Working Group Day on October 26<sup>th</sup>. The motion to create the working group was passed by the DCLG members.

**Public Comment:** There was no public comment.

Mr. Ulman adjourned the meeting at 3:11 pm.

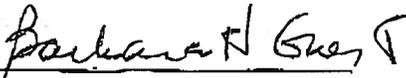
**Action Steps:**

1. Re-form the Summit Working Group to answer the questions raised by the Summit participants at the Town Hall Meeting.
2. The Summit Summary and the Summit Evaluation will be posted on the Summit Website and announced to participants.
3. Methods suggested by DCLG members will be used to disseminate the results of the Summit to the wider advocate community.

1/30/07  
Date

  
Doug Ulman, Chair  
Director's Consumer Liaison Group

1/25/2007  
Date

  
Executive Secretary  
Director's Consumer Liaison Group