

September 15, 2000  
DRAFT

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

**Time: 2:30 - 3:30 p.m.  
Summary of Teleconference  
July 21, 2000**

The 6<sup>th</sup> meeting of the NCI Director-s Consumer Liaison Group (DCLG) was convened at 2:30 p.m. on Wednesday July 21, 2000. Thursday June 1, 2000 as a teleconference. The teleconference was open to the public. Mr. Michael Katz presided as Chair.

**DCLG Members**

Mr. Michael Katz, *Chairperson*  
Ms. Susan Lowell Butler  
Ms. Kerry Dewey  
Dr. Felicia Schanche Hodge  
Ms. Ruth Lin  
Ms. Gena Love  
Mr. Daniel Moore  
Ms. Lillouise Rogers (Absent)  
Ms. Susan Stewart (Absent)  
Dr. Brad Zebrack

**NCI Office of Liaison Activities Staff**

Ms. Elaine Lee (Executive Secretary, DCLG)  
Dr. Yvonne Andejaski  
Ms. Tracy Clagett  
Ms. Sabrina Ferguson  
Ms. Sabrina Reed  
Ms. Julie Townshend

**Other NCI Staff:**

Ms. Jane Reese-Coulborne  
Dr. Maureen Wilson

**CALL TO ORDER AND OPENING REMARKS**

The meeting was called to order by the chair, Mr. Michael Katz. The purpose of the teleconference is to bring the DCLG members up-to-date on the activities of each working groups.

## REPORTS OF THE DCLG WORKING GROUPS

**DCLG Operations.** Ms. Ruth Lin reported that she had review the proposed orientation sent by Ms. Lee. She also addressed the issue of who would be responsible for writing the DCLG Annual Report. The DCLG members agreed that Ms. Lee will provide an outline and after it is approved, a science writer will prepare the report. She noted, DCLG orientation package is under revision. Ms. Ruth Lin will review the package and report back to Ms. Lee by Monday, July 24. Ms. Lee announced that new DCLG members have been selected but have not been announced.

**NCI Website.** Mr. Michael Katz reported no new developments with the NCI Web site.

**Advocacy Involvement.** Dr. Brad Zebrack, Ms. Kristie Dionne and Dr. Yvonne Andejaski outlined the activities to date. The NCI staff interviews are almost complete. Initially the Advocacy Involvement Working Group was planning to interview advocates who have participated in NCI activities. Since this is a very time consuming project, the DCLG members agreed to OLA's assistance. OLA will arrange the calls. OLA staff, (along with DCLG members who would like to participate) will conduct the interviews. Dr. Andejaski requested that the DCLG provide OLA with the names of advocates (with prior NCI experience) who they would like us to interview. As these interviews are scheduled, OLA will alert the DCLG members and provide instructions on how they may participate. Once established, the questionnaire will be placed on the advocate listserv. Advocates would receive an invitation letter informing them about the listserv and/or alternative ways to communicate.

Dr. Zebrack then turned his attention to the listserv. The proposed listserv for cancer advocates would:

- \$ Be set up on the Association of Cancer Online Resource (ACOR) site, a non profit organization for free cancer communication., or hosted by NCI.
- \$ Be monitored by a group of DCLG members working as private citizens. Monitoring would consist of review of daily messages, setting up archives, and searchers for keywords.
- \$ Have listserv owners who would establish policies and procedures for participation on the listserv.

**Discussion and Questions.** In response to Dr. Zebrack's suggestions, there were concerns about using the listserv as the mechanism for advocate interviews because of the time required (see above). Dr. Zebrack will complete a draft invitation letter within two weeks for distribution and comment by the DCLG. OLA will provide a list of advocates who have been involved in NCI activities and who will receive the invitation letter.

After a discussion regarding the concerns if hosted by NCI, the DCLG's initial decision was to use the ACOR site.

**September 2000 Meeting.** Dr. Yvonne Andejaski proposed a workshop for September 21-22, 2000. The purpose of the meeting is to share information about involving advocated with organizations such as the Komen Foundation, Food and Drug Administration, Department of Defense, American Cancer Society, NCI programs and Cancer Cooperative Groups. These groups include consumer advocates in their scientific decision making processes.

Discussion and Questions. Members of the DCLG requested more information about the September meeting, including goals and outcomes. Dr. Andejaski said she will provide more details in a letter next week. Dr. Zebrack also shared his vision of a future meeting with advocates from around the country and NCI to discuss and respond to the needs of the community.

**Quality Cancer Care and Health Disparities.** Dr. Felicia Hodge and Ms. Gena Love commented on the Cancer Control Academy held July 17-18 in Bethesda, MD. The Academy addressed several important issues about special populations and the underserved. Dr. Hodge strongly believes that the goal of research and its application to special population communities has not been reached. Dr. Maureen Wilson requested the help of DCLG members as the Presidents Cancer Panel continues its series of meetings on health disparities. The PCP is holding town hall meetings around the U.S. to get the input of people who are not usually heard. DCLG members were invited to contribute questions, identify local advocates who would make presentations to the PCP, and observe as ad hoc members of the panel at these meeting.

**NCI Brand.** The brand campaign is proceeding. A contractor is conducting interviews on how the NCI is perceived in the community.

**Communications Extraordinary Opportunity.** Mr. Michael Katz reported that there was no new information since the last DCLG meeting.

**Clinical Trials Promotion.** Ms. Susan Butler announced that she will meet with the Cancer Leadership Council to get their viewpoint about clinical trials promotion.

Ms. Jane Reese-Coulbourne said that she will report on the finding of the pilot project at the next DCLG meeting. The clinical trials pilot project is nearing completion. A self-study module is being developed. The materials developed for the program will serve as a basic clinical trial education for the patient community. The book should be ready in October. The DCLG will be helping with promotion of the program .The DCLG can then proceed with a plan and develop appropriate messages.

**Discussion and Next Steps.** The next DCLG teleconference meeting will be held in early September.

The meeting was adjourned at 3:30 p.m.

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Date

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Michael Katz

Chair  
NCI Director's Consumer Liaison Group

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Date

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Elaine Lee  
Executive Secretary  
NCI Director's Consumer Liaison Group

## ACTION ITEMS FROM JULY 21, 2000 DCLG TELECONFERENCE

### DCLG Operations

- C Annual Report - using the outline developed by the Operations Working Group (outline); the report will be drafted by a technical writer. The DCLG will review and approve the report.
- C Orientation package - Ms. Lee sent a revised plan to Ms. Lin who approved the changes.

### Clinical Trials

- C Ms. Lee will arrange for media training to occur.
- C Ms. Coulbourne will be asking for DCLG review and comments on the book developed as part of the clinical trials pilot and suggestions for dissemination.

### Advocacy Involvement

- C Dr. Andejaski will develop a proposal and timeline for developing a formal process to involve advocates in NCI programs and activities.
- \$ OLA with the team members will continue to work on establishing a listserv for advocates who have participated in NCI activities including the following
  - S Identify Advocates who served in various NCI activities.
  - S Dr. Zebrack will prepare a letter to go to the advocate community about the listserv.
  - S The questionnaire developed by Dr. Andejaski will be posted on the listserv.
  - S The AIWG will develop policies and procedures on how to monitor listserv.
  - S A teleconference to discuss listserv will be scheduled.

### Quality of Care/Health Disparities

- C The DCLG members suggested that the DCLG act as advocacy advisors as NCI's new initiatives are developed and implemented.
- C Dr. Maureen Wilson requested the help of DCLG members as the President's Cancer Panel continues its series of meetings on health disparities. The PCP is holding town hall meetings around the U.S. to get the input of people who are not usually heard. The DCLG members are invited to attend the meetings, suggest speakers, and local advocates who will participate in the town meetings.

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