

**DRAFT**

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

**Time: 11:00 a.m. - 1:00 p.m.**

**Summary of Teleconference**

**September 11, 2000**

The NCI Director's Consumer Liaison Group (DCLG) convened for its September 2000 teleconference meeting at 11:00 a.m.(Eastern Standard Time). 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. Barbara LeStage

Ms. Ruth Lin

Ms. Gena Love

Mr. Daniel Moore

Dr. Pamela McAllister (Absent)

Mr. Henry Porterfield

Ms. Nyrvah Richard

Ms. Lillouise Rogers

Ms. Paula Simper

Ms. Susan Stewart

Dr. Brad Zebrack

**NCI LIAISON ACTIVITIES STAFF**

Ms. Elaine Lee (Executive Secretary, DCLG)

Dr. Yvonne Andejaski

Ms. Tracy Clagett

Ms. Sabrina Reed

Ms. Keisha Martin

Other NCI Staff:                      Ms. Nelvis Castro

**CALL TO ORDER AND OPENING REMARKS**

The meeting was called to order by the chair, Mr. Katz. The purpose of the teleconference was to update DCLG members about the activities of the working groups, and to discuss the proposed topics for the Consumer Advocate Research (CAR) Workshop in September and the October 2000 DCLG meeting. Members of the DCLG who can not attend the CAR Workshop will receive a summary of the meeting.

## **AGENDA FOR OCTOBER DCLG MEETING**

**Report from Dr. Klausner.** Mr. Katz led the DCLG members in a discussion to define the agenda for the October Meeting. The DCLG requested that Dr. Klausner identify specific areas where NCI would like advocates to make a contribution within the Institute.

**Quality of Care/Health Disparities.** Ms. Gena Love suggested that the NCI brief the DCLG on the Quality of Care/Health Disparities. Included in this report should be Dr. Joseph Lipscomb's plans for advocate participation. The DCLG requested that Dr. Lipscomb develop a list of questions for them to consider. Mr. Katz recommended that the DCLG meeting focus on issues and not process discussions.

The DCLG members agreed that it would be beneficial for them to receive this list from NCI and focus the DCLG meeting on interactive issues. Dr. Yvonne Andejaski proposed that the DCLG formulate several questions they would like NCI to address. In response, Mr. Katz again stated that the DCLG preferred the NCI to develop a list of structured questions. Dr. Andejaski will coordinate this effort and report back to the DCLG.

Dr. Jon Kerner will address the Quality of Care and provide an overview at the DCLG meeting.

**Quality of Life/Survivorship.** The DCLG members asked that Dr. Julia Rowland, Director of the Office of Cancer Survivorship, be invited to make a presentation about her offices and suggested a similar format.

**Status of Communications Reorganization.** The DCLG requested information on the status of the Office of Communications Reorganization. The DCLG would like to know the key players, and NCI's status within its reorganization process. Additionally, the DCLG requested that Dr. Susan Sieber provide input on where she sees the DCLG making a contribution within the Institute.

Dr. Andejaski and Ms. Nelvis Castro briefed the DCLG on the Office of Communications reorganization plan.

**Communications Review Progress Report.** The DCLG also requested additional information on the status of the Communication Review Report..

**Advocate Involvement (CAR).** Mr. Katz inquired about the agenda for the Consumer Advocates in Research Workshop. Dr. Andejaski explained that representatives from other groups (DOD, ACS, etc.) will describe their process for identifying appropriate advocates. She will present the results of the interviews with the NCI staff and advocates and participants will develop guiding principles and best practices for the process.

## **REPORTS OF THE DCLG WORKING GROUPS**

**Clinical Trials Promotion.** Ms. Susan Butler announced that she is trying to get on the Cancer Leadership Council=s agenda. She is developing an action plan to engage a the of advocacy community in increasing awareness about clinical trials. The Clinical Trials Summit will be held on October 4-6, 2000. Ms. Barbara LeStage volunteered to serve on the clinical trial working group. She suggested educating individual clinicians about clinical trials so that they will increase their patient referrals. Ms. LeStage believes that the low number of patients participating in clinical trials are due to a lack of communication efforts between clinicians and patients.

Ms. Butler and Mr. Hank Porterfield inquired about the status of media training. They highly recommend media training because it would give DCLG members confidence. Currently a contractor is working on the media training and Liaison Activities will report back.

**Advocacy Involvement.** Dr. Andejaski is leading efforts to collect information on how advocates have been used at the NCI. Mr. Katz reported that he would announce the new listserv at the October meeting. Liaison Activities will assist the DCLG by distributing a press release through their advocacy channels. The purpose of this listserv is to bring NCI advocate communities together and collect information on how advocates have been involved at NCI. Additionally, share information about NCI activities and possibly develop a newsletter to broaden a community of advocates on regional, local and national levels.

**Discussion and Questions.** Mr. Dan Moore raised concerns about how NCI would ensure that organizations participating in the Car Workshop meeting are going to share their best practices. Dr. Andejaski believes those participating organizations are interested in establishing best practices as well. The resulting documents will be distributed widely.

**Health Care Disparities.** Dr. Hodge and Ms. Gena Love requested at least two hours to discuss the Quality Cancer Care and Health Disparities at the October Meeting. The DCLG requested information on these initiatives and how they fit into the NCI=s agenda prior to the DCLG meeting. Dr. Hodge and Ms. Love suggested both the Quality of Health Care and Health Disparities sessions be devoted to discussing why, how, and where advocates should be involved in at the NCI. The President=s Cancer Panel continues its series of meetings on health disparities. The PCP is holding its next town hall meeting in Montana on October 12-13, 2000. The purpose of the PCP meetings is to evaluate efforts against cancer, treatment, ethical issues, and disparities across America. The PCP meeting will present real life testimonials and provide time for questions and answers. The DCLG members are invited to attend the meetings, suggest speakers, and local advocates who will participate in the town meetings. Ms. Lee will forward the town hall meeting dates and the names of the PCP members.

**NCI Brand.** Ms. Kerry Dewey reported that NCI has completed the internal and external interviews regarding the awareness and perception of NCI. NCI has begun to synthesize these interviews for a summary report. The report will be presented to Dr. Klausner in October. Ms. Nelvis Castro announced that the December kick-off has been postponed until further notice. Ms. Castro will provide the DCLG with a campaign update so they can provide feedback.

**Communications Extraordinary Opportunity.** The Communications Extraordinary Opportunity working group will meet on September 21, 2000 to discuss how to improve cancer communications to the public, patients and medical communities. NCI Staff, Health and Human Services, Center of Disease Control, private firms, and other organizations will attend the meeting. Mr. Katz requested the list of attendees prior to the DCLG meeting. He will report back to the DCLG.

**DCLG Operations.** Ms. Ruth Lin will work with Ms. Lee to send the annual report to a professional writer by September 31, 2000. Ms. Lin will review the final report prior to the DCLG meeting.

**NCI Website.** The NCI website continues its reconstruction. NCI is trying to pull together a common interface for the institute. Mr. Katz offered his assistance and he is awaiting a response from NCI. Mr. Katz would like to address the DCLG website at the October meeting as well, he requested information prior to this meeting particularly if NCI needs some local participants.

The meeting adjourned at 1:00 p.m.( Eastern Standard Time)

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Date

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Mike Katz  
Chair, DCLG

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Date

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Elaine Lee  
Executive Secretary  
DCLG