

**NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE
DIRECTOR'S CONSUMER LIAISON GROUP**

**September 17, 2001
12:00 p.m. - 2:00 p.m. (EST)**

TELECONFERENCE

Minutes

The teleconference of the NCI Director's Consumer Liaison Group (DCLG) was convened at 12:00 p.m. on Tuesday, September 17, 2001. The teleconference was open to the public. Ms. Barbara LeStage presided as Chair.

DCLG Members

Ms. Barbara LeStage, Chair
Ms. Susan Lowell Butler, absent
Mr. Michael Katz, absent
Ms. Paula K. Kim
Ms. Ruth Lin
Ms. Gena Love
Mr. Henry Porterfield, absent
Ms. Nyrvah Richard
Dr. Bradley J. Zebrack

NCI Staff

Ms. Elisabeth Handley

NCI Liaison Activities Staff

Ms. Elaine Lee, *Executive Secretary*
Dr. Yvonne Andejaski
Ms. Tracy Clagett

CALL TO ORDER AND OPENING REMARKS

Ms. Barbara LeStage called the meeting to order and determined that a quorum was present. She reviewed the rules governing confidentiality and conflict of interest.

OCTOBER 2001 DCLG MEETING

October 15-17 meeting. Some minor changes have been made to the agenda for the October meeting:

- C The clinical trials and health disparities/quality of care working groups will meet on Monday afternoon.
- C The survivorship and advocacy working groups will meet on Tuesday morning.
- C According to the original agenda, the meeting will end at 12:30. However, the DCLG members agreed to extend the meeting until 1:00 to review the action items and evaluate the meeting.

The group dinner will be held on Monday evening. Anyone interested in getting together for an informal dinner on Sunday or Tuesday evening should inform Ms. LeStage, who plans to be available during those times.

Working Group Sessions

Quality of Care and Health Disparities Working Group. Ms. Gena Love listed the following agenda items for the Quality of Care and Health Disparities Working Group:

- C Review white paper as some changes have occurred following discussions with Ms. Tracy Claggett and NCI representatives and some new opportunities have arisen
- C Identify which working group members would like to represent the DCLG at appropriate opportunities. Some of these might be appropriate for members of the Consumer Advocates in Research and Related Activities (CARRA), others for DCLG members
- C Report on the outcome of the cervical cancer meeting which is looking at incidence and mortality in rural communities
- C Determine how to identify and collect survivor stories that can support NCI initiatives
- C Create a budget for the working group (this will require assistance)
- C Discuss how to make the transition from Ms. Love's chairmanship to that of her successor. Ms. Love plans to ensure that her successor is ready to lead the working group at the April meeting. A DCLG member who will be remaining on the committee needs to take over the leadership of this working group.

Ms. Love suggested splitting this working group into two different working groups. A single working group was originally chosen because the Center to Reduce Cancer Health Disparities was not operational, but this is no longer the case.

Reasons to support such a split:

- C There is no programmatic, governmental, or structural overlap between the two NCI centers.
- C This may be a good time to consider such a split.
- C The combined group has demanded a great deal of the chair.

Reasons to oppose such a split:

- C Dividing the working group would require two chairs.
- C The single working group has successfully completed all of its tasks to date.
- C It might be better to split the working group after the new center is fully operational.
- C There may not be sufficient DCLG members to staff and chair both working groups.

If anyone is interested in chairing either one of the two working groups, please let Ms. LeStage know.

Advocacy Working Group. Dr. Brad Zebrack reported that the Advocacy Working Group now has a list of all advocacy organizations in NCI's database. Dr. Zebrack has distributed a

working draft of a letter to be signed by DCLG members for distribution to advocacy organizations, which the working group can examine at the October meeting. This letter will introduce the DCLG to these advocacy groups and possibly obtain invitations for DCLG members to attend the groups' annual meetings.

All DCLG members should have received, or will receive shortly, a copy of this advocacy group database. Each member should review the database and add the names of any appropriate groups of which they are aware, including regional and local groups.

The Advocacy Working Group also needs to determine which organizational annual meetings might be most valuable for a DCLG member to attend or speak at. The number of groups that DCLG members attend will affect the working group's budget, which will be developed at the October meeting.

Dr. Zebrack will be leaving the DCLG in 2002 and would be happy to talk to anyone who might be interested in succeeding him as chair of the Advocacy Working Group.

Ms. Tracy Clagett announced the development of a CARRA Web site and welcomed suggestions from DCLG members about what this Web site should include, as well as the DCLG's role as an advisory body to CARRA. Ms. Clagett will prepare some information for the working group to review at the October meeting on these issues.

Survivorship Working Group. Ms. Paula Kim reported that the Survivorship Working Group plans to meet with Ms. Margo Michaels to discuss the entire department's objectives. The working group also needs to revisit its white paper and make a few changes. Although the working group has a basic budget, this needs to be finalized. At the October meeting, the working group will also develop a submission of an extraordinary opportunity.

Survivorship Forum

Ms. Paula Kim requested that all DCLG members respond to questions about their organization's survivorship programs, and literature. Responses are due to Ms. Kim on October 10 and will be used during the Survivorship Working Group session to identify existing resources and programs that can serve as models as well as areas of need. Every DCLG member needs to complete the survey, because each member organization represents a slightly different segment of the community. This survey will be used for fact-finding purposes only. Any questions should be directed to Ms. Kim.

In addition to responding to the questions, DCLG members should either bring to the October meeting or send 20 to 25 copies of their organizations' annual reports and survivor literature to Ms. Elaine Lee.

Ms. Kim discussed plans for the survivorship forum at the meeting. Dr. Julia Rowland will provide an overview of the goals, and research of the Office of Cancer Survivorship. Potential speakers for two of three topics have been identified.

C Ms. Susie Novis, President of the International Myeloma Foundation, will discuss

chronicity.

- C Dr. Brad Zebrack will discuss post treatment issues.
- C A speaker is still needed to discuss end of life.

Dr. Rowland will present at a session on adult survivorship at the National Cancer Policy Board meeting on October 11-12, and will inform this group of the DCLG's meeting and invite their participation. The DCLG would like to participate in or make a presentation at the policy board's meeting.

Ms. Kim hopes to submit a report to the Office of Cancer Survivorship representing the grassroots view on major issues of survivorship and in support of an extraordinary opportunity on survivorship which could be part of *The Nation's Investment in Cancer Research* (the Bypass Budget)

DCLG NOMINATIONS

Ms. Elaine Lee announced that the brochures and promotional materials for the next round of DCLG nominations are ready and that she will distribute copies of the materials to the DCLG members for their comments. The call for nominations will probably be issued as soon as the brochures are available, within the next week or two. The announcement will be posted on the listserv and the DCLG Web site and published in the *Federal Register*.

To increase the number of Native American nominees to the DCLG, Ms. Love will identify a representative in each of the Indian Health Service's 12 regions to add to the DCLG's organizational database.

UPDATES FROM DCLG MEMBERS

Cancer Control Academy. Ms. Nyrvah Richard reported that Ms. Gena Love and a representative of SHARE attended the Cancer Control Academy meeting in July. The SHARE representative wrote a summary and evaluation of this meeting, with suggestions for improvements, which will be distributed to all DCLG members. Although members of the DCLG did not help plan the academy, Ms. Tracy Clagett did communicate the DCLG's issues to the meeting planners, who were all NCI staff members.

Cancer Outcomes Measurement Working Group. Dr. Brad Zebrack explained that this group is part of the NCI initiative to study quality of cancer care and related issues. The group includes researchers from around the country who evaluate research on quality of life, outcomes adjustment, psychological adjustment, and well being in cancer patients. The group's papers are due in October. Dr. Zebrack will report again on this working group during the January conference call.

Bypass Budget Planning Group. The DCLG members received a draft of the Bypass Budget to review and provide comments. Ms. Kim sent a response to Ms. Kathie Reed and Ms. Cherie Nichols. Ms. Kim reminded DCLG members that it is important for DCLG members to respond to requests and make its views known when opportunities arise at NCI. One goal this

year is to identify an extraordinary opportunity for research to present to NCI for inclusion in the next Bypass Budget.

National Cancer Advisory Board (NCAB). Ms. LeStage reported that the NCAB advises the Secretary of Health and Human Services and the Director of NCI about the activities and policies of NCI as well as may recommend support for grants and cooperative agreements. She attended her first meeting on September 11. Unfortunately it was interrupted by the catastrophic events that occurred that morning in New York and Washington. At this meeting, Dr. Klausner announced that he would be leaving NCI at the end of September. Ms. LeStage will try to meet with him before he leaves. No interim director has been announced yet. Dr. Klausner had previously invited Ms. LeStage to attend an NCI executive committee meeting to discuss the DCLG and Ms. LeStage intends to do this.

When the interim director is appointed, the DCLG will write to the director to welcome him or her and introduce the DCLG. Ms. LeStage will prepare a letter at the appropriate time, in collaboration with Ms. Elaine Lee and Dr. Yvonne Andejaski, and will request comments from all DCLG members before sending the letter.

CARRA UPDATE

NCI has notified all candidates of their selection to CARRA. Those who were not selected were also notified and offered the opportunity to receive information about NCI from Liaison Activities. Ms. Clagett expects approximately 225 new CARRA members. After the new members are confirmed, they will receive a letter of welcome from Ms. LeStage on behalf of the DCLG. Ms. LeStage will join a teleconference with CARRA members. Ms. Clagett will e-mail the dates and times of the teleconference to Ms. LeStage.

Ms. Clagett is also developing the orientation modules for the new members, which are primarily Web based, as well as an evaluation component.

To ensure that the NCI staff really use CARRA members, Ms. Clagett plans to conduct several promotional activities, including sending e-mail to all NCI staff and talking to those who direct some of NCI's programs.

DCLG member Mr. Henry Porterfield has agreed to write a monthly column on DCLG activities for the CARRA listserv.

ADJOURNMENT

The meeting adjourned at 2:00 p.m.

Date

Chair, Director's Consumer Liaison Group

Date

Executive Secretary
Director-s Consumer Liaison Group

ACTION ITEMS
September 17, 2001

- C Any DCLG member interested in succeeding the retiring working group chairs (Ms. Susan Butler, Ms. Gena Love, Dr. Brad Zebrack) should contact Ms. Barbara LeStage.
- C All DCLG members should review the database of advocacy groups and add the names of any appropriate groups, including regional and local groups.
- C All DCLG members should visit the new CARRA Web site and share comments with Ms. Tracy Clagett as well as suggestions for ways for the DCLG to interact with CARRA.
- C All DCLG members should send their responses to the questions on their group=s survivorship activities to Ms. Paula Kim by October 10.
- C All DCLG members should bring 20-25 copies of their group=s annual report and literature on survivorship to the October meeting, or send them in advance to Ms. Elaine Lee.
- C Ms. Gena Love will identify a representative in each of the Indian Health Service=s 12 regions to add to the DCLG=s organizational database.
- C Ms. LeStage will attend an NCI executive committee meeting to discuss the DCLG.
- C When the interim director of NCI is appointed, Ms. LeStage will prepare a letter of welcome from the DCLG and will request comments from all DCLG members before sending the letter.
- C Ms. LeStage will join a teleconference with CARRA members. Ms. Clagett will e-mail the dates and times of the teleconference to Ms. LeStage.