

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

**Summary of meeting  
November 8, 2001**

The teleconference of the NCI Directors Consumer Liaison Group (DCLG) was convened on Thursday, November 8, 2001. Ms. Barbara LeStage presided as Chair.

**DCLG Members –**

Ms. Barbara LeStage, Chair  
Ms. Vernal H. Branch  
Ms. Susan Butler  
Ms. Kathy Guisti, Absent  
Mr. Michael Katz  
Ms. Paula K. Kim  
Ms. Ruth Lin  
Ms. Gena Love  
Mr. Christopher Pablo  
Ms. Karen Packer  
Mr. Henry Porterfield  
Ms. Nyrvah Richard  
Mr. Doug Ulman, Absent  
Dr. Bradley J. Zebrack

**NCI Liaison Activities Staff –**

Ms. Elaine Lee, Executive Secretary  
Ms. Tracy Clagett  
Ms. Elisabeth Handley  
Ms. Brooke Hamilton  
Ms. Keisha Martin  
Ms. Julie Tu

**WELCOME**

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. Ms. LeStage, began the teleconference on a sad note, recognizing the death of Dr. Yvonne Andejaski. Dr. Andejaski loved the DCLG and contributed greatly to it. Ms. Elisabeth Handley will serve as Acting Program Director until Dr. Andejaski's replacement is selected. The DCLG observed a moment of silence in honor of Dr. Andejaski's memory.

**DCLG Business Items.** All DCLG members must sign and return the minutes from the last two teleconferences to Ms. Elaine Lee, Executive Secretary. A majority is needed before the minutes can become part of the official record of the Committee. Members can simply note that the

minutes are fine before signing and faxing them to Ms. Lee. Ms. Lee will e-mail additional copies of the minutes to committee members who need them.

New DCLG members must complete their orientation evaluation forms and return them to Ms. LeStage.

Ms. LeStage requested that when DCLG members represent the DCLG at a meeting, they provide a written and oral report to the DCLG.

### **FOLLOW UP ON SURVIVORSHIP FORUM**

**Extraordinary Opportunity Submission.** The DCLG submitted its proposal for the extraordinary opportunity, which is currently under review by the executive committee. The Executive Committee's decision should be made by Friday, November 9. Ms. Lee will inform the DCLG of the committee's decision as soon as it is available.

**Bypass budget.** Ms. Paula Kim will determine how the DCLG can be involved in the next year's budget process on an earlier and more ongoing basis than for the FY2003 budget discussions.

**Public outreach.** Ms. Kim will schedule a meeting with Ms. Margo Michaels to improve lines of communication between the DCLG and the Office of Education and Special Initiatives. The DCLG needs to be involved in planning public outreach activities from the beginning instead of being asked to review plans once they have been completed. Ms. Michaels had asked that all DCLG members provide feedback on the "*Giving Back*" and "*Facing Forward*" publications.

### **REPORTS ON WORKING GROUP ACTIVITIES**

**Clinical Trials Working Group.** Mr. Michael Katz has prepared a proposal on DCLG's role in NCI's Clinical Trials Cooperative Group Program. This program supports 1,500 institutions that enroll approximately 20,000 patients in 370 large-scale clinical trials. Unfortunately, this system's protocol approval process can take more than a year, which presents a significant barrier to expediting the trials, especially those that are high priority.

Mr. Katz proposes a joint undertaking of the DCLG and the Patient Advisory Board (PAB) of the Coalition of National Cancer Cooperative Groups, Inc. The PAB is comprised of the chairs of the patient representation committees of each of the nine cooperative groups that make up the coalition. The goal of this joint undertaking is to conduct an objective assessment of the strengths and weaknesses of both the current clinical trials system and the improvement activities being pilot tested. The DCLG and the PAB would focus on the interface between the NCI, the groups, and the related processes and infrastructures. Ms. Deborah Collyar, Chair of the PAB, is enthusiastic about working with the DCLG on this effort.

Ms. Barbara LeStage met with Dr. Jeff Abrams at the NCI who is responsible for the clinical trials process. Dr. Abrams believes that many groups are addressing the issues of concern to the DCLG and the NCI is well aware of the barriers. He has asked that the DCLG and the PAB focus on education about clinical trials from the consumer viewpoints.

Ms. Butler will schedule a teleconference within the next week to discuss Mr. Katz's proposal.

**Advocacy Involvement Working Group.** Dr. Bradley Zebrack has distributed a new draft of the letter from the DCLG to the advocacy organizations on NCI's mailing list. The letter still needs to tell the readers what they should do next. Some possible next steps to suggest include:

- Attending a DCLG meeting or public forum that addresses an issue of relevance to the advocacy community
- Submitting nominations for the next DCLG
- Submitting nominations for CARRA
- Identifying high-priority issues
- Requesting a telephone call from Ms. LeStage

DCLG members agreed that the letter is too long. Some suggested that the letter be shortened and followed by a more detailed letter at a later date. Others supported the development of a brochure outlining the DCLG and its accomplishments, and will be accompanied by a letter focusing on actions for the advocacy organizations to consider. Dr. Zebrack will schedule a teleconference of the working group to discuss how to use the letter and what to do after it is sent.

If DCLG members are planning to attend a conference, they should offer to give a presentation at that conference on the DCLG and the nomination process. Ms. Lee noted that LA is developing a slide presentation in PowerPoint that DCLG members can use for this purpose. The DCLG budget for travel is limited.

**Health Disparities/Quality of Care Working Group.** At the October meeting, members of this working group decided to contact the principal investigators (PIs) of the Special Population Networks to obtain the names of the community organizations with which they are working. The DCLG will contact these organizations and encourage them to nominate candidates for the DCLG. The goal is to increase awareness about NCI and the DCLG among community survivors particularly those from minority and underserved populations.

Ms. Ruth Lin made initial telephone calls to 17 of the 18 PIs, and 5 have tried to call her back. Some of the projects involve prevention, so their PIs do not work with groups of cancer survivors. Ms. Lin will continue to try to reach the five PIs who have tried to return her call. On Monday, November 12, she will share the remaining names with the DCLG and ask for volunteers to contact these individuals, possibly by e-mail. DCLG members will share the names of any survivor groups identified through this process with Ms. Tracy Clagett or Ms. Brooke Hamilton. Talking points for these contacts are available from Ms. Hamilton. Once the survivor groups are identified, Ms. Love will ask for volunteers to follow up with the groups.

Dr. Edward (Ted) Trimble of the NCI has requested assistance from the DCLG, or possibly CARRA, with a newly formed group. Ms. Nyrvah Richard will request clarification from Dr. Trimble.

Ms. Gena Love will distribute a list of assignments for members of the working group.

## CARRA

**CARRA activities at the NCI.** Mr. Henry Porterfield and Ms. LeStage attended two teleconferences with CARRA members, who are eager to participate in NCI activities. The response from NCI staff to involve CARRA members has been favorable, and Ms. Clagett has begun assigning CARRA members to projects, primarily peer review, and assigning mentors to those who request one.

**CARRA evaluation.** Although LA has planned a thorough evaluation of the entire program, this plan is on hold due to budget issues. In the meantime, Ms. Hamilton will assist with the evaluation and work with a consultant to obtain feedback from NCI staff and CARRA members on particular activities. This should start by the beginning of January 2002.

NCI staff who work with CARRA members, as well as CARRA members themselves, are encouraged to provide feedback by e-mail or telephone to LA. Any DCLG members involved in CARRA activities should also provide feedback.

## NEW BUSINESS

**Applying to the DCLG.** The easiest way to learn how to apply to the DCLG is by visiting the <http://cancer.gov> Web site. Visitors should click on “partnerships” and then click on “request a nomination package.”

**Next teleconference.** The next teleconference is scheduled for January 22 from 2:00 to 4:00 p.m. EST.

## ADJOURNMENT

The meeting adjourned at 3:55 p.m.

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Date

\_\_\_\_\_  
Chair, Director’s Consumer Liaison Group

\_\_\_\_\_  
Date

\_\_\_\_\_  
Executive Secretary  
Director’s Consumer Liaison Group

**ACTION ITEMS**  
**November 8, 2001**

- Ms. Lee will e-mail copies of the last teleconference minutes to DCLG members who did not receive them. All DCLG members should review, sign, and submit these minutes to Ms. LeStage.
- New DCLG members must complete their orientation evaluation forms and return them to Ms. Lee.
- When DCLG members represent the DCLG at a meeting, they must provide written and oral reports to the DCLG.
- Ms. Lee will inform the DCLG of the executive committee's decision concerning the extraordinary opportunity submission as soon as it is available.
- Ms. Kim will schedule a meeting with Ms. Michaels to improve lines of communication between the DCLG and the Office of Education and Special Initiatives.
- All DCLG members should provide feedback on the Giving Back and Facing Forward conferences.
- Ms. Butler will schedule a teleconference of the Clinical Trials Working Group before Thanksgiving to discuss the proposal for a joint DCLG-PAB effort to assess the Clinical Trials Cooperative Group Program.
- Dr. Zebrack will schedule a teleconference of the Advocacy Involvement Working Group to discuss how to use the letter to the advocacy organizations and what to do after the letter is sent.
- When DCLG members attend a relevant conference, they should offer to give a presentation on the DCLG and its nomination process.
- Ms. Lin will continue to try to reach the five PIs who have tried to return her call. On Monday, November 12, she will share the remaining names with the DCLG and ask for volunteers to contact these individuals. DCLG members will provide the names of any survivor groups identified with Ms. Hamilton or Ms. Clagett. Once the groups are identified, Ms. Love will ask for volunteers to follow up with the groups.
- Ms. Richard will request clarification from Dr. Trimble on the project for which he has requested assistance from the DCLG.
- Ms. Love will distribute a list of assignments for members of the Health Disparities/Quality of Care Working Group.
- Any DCLG members involved in CARRA activities should provide feedback on those activities to the CARRA office.