

**NATIONAL CANCER INSTITUTE
DIRECTOR'S CONSUMER LIAISON GROUP
Teleconference
Summary of Meeting
January 22, 2002**

The teleconference of the NCI Director's Consumer Liaison Group (DCLG) was convened on Tuesday, January 22, 2002. Ms. Barbara LeStage presided as Chair.

DCLG Members

Ms. Barbara LeStage, Chair
Ms. Vernal H. Branch
Ms. Susan L. Butler
Ms. Kathy Giusti
Mr. Michael Katz
Ms. Paula K. Kim
Ms. Ruth Lin
Ms. Gena Love

Mr. Christopher Pablo
Ms. Karen G. Packer
Mr. Henry A. Porterfield
Ms. Nyrvah Richard
Mr. Doug E. Ulman
Dr. Marisa Weiss
Dr. Bradley J. Zebrack

NCI Liaison Activities Staff

Ms. Elaine Lee, Executive Secretary
Ms. Tracy Clagett
Ms. Nina Ghanem
Ms. Brooke Hamilton
Ms. Elizabeth Handley
Ms. Keisha Martin
Ms. Rosalyn Lemak

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. She wished DCLG members and Liaison Activities (LA) staff a happy new year.

ANNUAL REPORT 2001

Prior to the teleconference, Ms. LeStage distributed a draft of the DCLG's fiscal year 2001 annual report, which covers activities between October 1, 2000, and September 30, 2001. She asked DCLG members to review the list of activities and note any changes or additions. Because the DCLG's charter is up for renewal this year, it is particularly important to document all of the group's accomplishments during the last fiscal year.

Mr. Doug Ulman suggested rewording a passage of the report, and Ms. LeStage asked Mr. Ulman to rewrite that section, and e-mail the changes to her. Ms. LeStage will add a conclusion to the report.

APRIL 2002 MEETING AGENDA

Ms. LeStage led the discussion to determine the agenda for the April 2002 meeting. All DCLG members will attend the meeting on April 22 and 23. Some members of the Clinical Trials Working Group will meet the morning of the 24th to discuss plans to look at NCI's clinical trials cooperative group process. To accommodate travelers from the west coast, the meetings will be held from 9:00 a.m. to 5:00 p.m., not 8:00 a.m. to 4:00 p.m.

If working groups want specific NCI staff to attend their sessions at the meeting, they should determine when those staff members are available, so that a schedule of the working groups can be developed that will accommodate staff availability. Some groups will meet on the afternoon of the first day and the others will meet on the morning of the second day.

REPORTS ON WORKING GROUP ACTIVITIES

Advocacy Involvement. The Advocacy Involvement Working Group's letter has been sent to several advocacy organizations. Ms. LeStage has already spoken to, or has scheduled conversations with, several of these groups. Responses have been enthusiastic. One group that did not receive the letter is conducting a training session on clinical trials on April 12 and 13 and asked the DCLG to present at the meeting. Since DCLG members Mr. Henry Porterfield, Ms. Paula Kim, and Mr. Michael Katz will probably attend this meeting, Mr. Porterfield will try to arrange a presentation. The Working Group will now send letters to the remaining organizations on the list, and will assign follow-up calls to Working Group members.

Ms. Kathy Giusti will take over as chair of the Advocacy Involvement Working Group beginning with the April 2002 DCLG meeting.

Health Disparities/Quality of Care Working Group. The DCLG is working closely with the CRCHD to broaden its outreach to minority and underserved populations. Ms. Ruth Lin contacted the principal investigators of the special population networks for lists of the community organizations that they were working with. However, the process turned out to be time consuming and has not resulted in much information to date. Ms. Nyrvah Richard, who will become chair of the new Health Disparities Working Group in the spring, will determine how to pursue this activity.

This working group will be split into two groups with Ms. Vernal Branch serving as chair of the Quality of Care Working Group in the spring.

Ms. LeStage will clarify with Dr. Robert Hiatt whether the DCLG has a voting member, or merely an observer, on the Quality Cancer Care Committee (QC3).

Clinical Trials Working Group. The Patient Advisory Board (PAB) of the Coalition of National Cancer Cooperative Groups has concerns about the way clinical trials are accruing patients in the nine cooperative groups funded by NCI's Cancer Therapy Evaluation Program (CTEP). The PAB and DCLG Clinical Trials Working Group will discuss how wish to proceed at the working group meeting on April 24th.

Mr. Christopher Pablo will become chair of the Clinical Trials Working Group in the spring.

Survivorship Working Group. For “The Nations Investment in Cancer Research. A Plan and Budget Proposal for Fiscal Year 2004”, the DCLG submitted a proposal for an extraordinary opportunity in survivorship. The Survivorship Working Group has not received a formal reply to this submission. Apparently, the submission does not fit the requirements of the extraordinary opportunities program. But because the level of enthusiasm for the concept is high, the reviewers are seeking other opportunities to support the research.

Ms. Paula Kim agreed to continue as chair of the Survivorship Working Group.

Ms. Handley suggested that the DCLG determine its long-term plans for all of its working groups, perhaps at the April meeting. She noted that the new NCI Director will be very interested in what the group is doing. Ms. LeStage asked each working group to update its white paper before the April meeting.

Travel Budget. Because the DCLG’s travel budget is limited, when DCLG members are invited to present at meetings, they should ask the meeting sponsors to pay for their travel. If this is not possible, DCLG members should consider teleconferencing. Preference for travel budget funds will be given to meetings in which DCLG members have a voting role.

CARRA UPDATE

Ms. Tracy Clagett provided information about the NCI’s Consumer Advocates in Research and Related Activities (CARRA) program.

Web Site. She noted that a number of orientation/training modules are already available for CARRA members. Several new modules have recently been added. Ms. Clagett asked DCLG members to review the new peer review, research review, and funding modules on the LA Web site, at <http://la.cancer.gov/carra>.

Evaluation. LA has distributed to NCI staff a survey on attitudes and behaviors toward consumer involvement and has received 150 completed surveys from over 400 sent. LA is developing two other questionnaires for NCI staff and CARRA members to complete following CARRA member participation in NCI activities.

CARRA participation in NCI activities. LA has received approximately 30 requests from NCI programs since October for CARRA involvement. Many CARRA members are concerned about their lack of activity. Mr. Porterfield is writing a letter to reassure CARRA members that they will eventually receive assignments. LA will promote CARRA internally at NCI to increase the number of requests.

FAQs. CARRA members are asking LA many questions. LA will develop a list of frequently asked questions (FAQs) to distribute biweekly, possibly by e-mail or fax.

List of CARRA Members. Many CARRA members and advocacy organizations are interested in who the CARRA members are. NCI's ethics office advised LA that CARRA members may give their permission in writing for release of their names and affiliations. They will be asked to sign a permission form providing this information. Mr. Porterfield suggested that Ms. Clagett notify CARRA members of this plan on the Web site. Ms. Clagett will discuss plans with Mr. Porterfield.

Confidentiality. Ms. Clagett reminded the DCLG members were reminded to keep certain information, such as details about CARRA members and the scoring process confidential.

DCLG MEMBER REPORTS

Dr. Marisa Weiss reported on a very successful meeting on the doctor/patient relationship. The committee had no other consumer advocate. DCLG members considered inviting Dr. Gary Kreps, Chief of NCI's Health Communication and Informatics Research Branch, to speak to the DCLG at the April meeting, but decided to postpone the invitation until a later meeting.

Ms. LeStage asked DCLG members to carefully review the grid of DCLG activities and send her any corrections or additions, with copies to Ms. Elizabeth Handley and Ms. Elaine Lee.

Ms. LeStage reminded DCLG members who attend meetings that they should prepare a brief report on the meetings, including future opportunities for DCLG members to participate and the role of the DCLG member's participation.

Ms. Branch and Ms. Richard will discuss the possibility of DCLG representation on the Effects of Racism on Cancer Care Committee.

NEW BUSINESS

Meeting Schedules. Mr. Pablo may be unable to attend the April DCLG meeting and asked if future meetings could be scheduled in May. However, many conventions are held in May. LA will distribute a calendar on which DCLG members should indicate future conflicts before finalizing the dates for DCLG meetings.

Consumer Involvement in Presidential Committees. Dr. Zebrack wondered how to ensure that the President's new bioethics committee includes advocates. The Council of Public Representatives (COPR) may be addressing this issue at the NIH level. Dr. Zebrack and Ms. Giusti will look into developing a relationship with COPR.

Prevention. Mr. Porterfield expressed his interest in a DCLG focus on prevention of cancer. Ms. LeStage will put prevention on the agenda for the March conference call.

The next conference call will be held on Monday, March 11, 2002 from 2:00 to 4:00 p.m.

ADJOURNMENT

The meeting adjourned at 4:05 p.m.

Date

Chair,
Director's Consumer Liaison Group

Date

Executive Secretary,
Director's Consumer Liaison Group

ACTION ITEMS
January 22, 2002

- Working group members should review the list of activities for the DCLG annual report and submit any changes or additions to Ms. Barbara LeStage.
 - Mr. Doug Ulman will rewrite a section of the annual report.
 - Ms. Barbara LeStage will add a conclusion to the annual report.
- If working groups want specific NCI staff to participate in their discussions at the next DCLG meeting, they should determine when those staff members are available.
- Mr. Henry Porterfield will try to arrange a presentation with the meeting representative and the other two DCLG members for the April 12–13 clinical trials training.
- The Advocacy Involvement Working Group will send letters to the remaining advocacy organizations on the list, and will assign follow-up calls to Working Group members.
- Working groups should update their white papers before the April meeting.
- Ms. Nyrvah Richard will assess the possibility of continuing to contact the principal investigators of the special populations networks for lists of community organizations.
- Ms. LeStage will clarify with Dr. Robert Hiatt whether the DCLG has a voting member, or merely an observer, on the Quality Cancer Care Committee (QC3).
- DCLG members should review the peer review, research review, and funding modules on the LA Web site, at <http://la.cancer.gov/carra>.
- Ms. Tracy Clagett will discuss with Mr. Porterfield plans for listing CARRA member names.
- DCLG members who attend meetings should prepare a brief report.
- Ms. Vernal Branch and Ms. Richard will discuss the possibility of DCLG representation on the Effects of Racism on Cancer Care Committee.
- LA will distribute a calendar for DCLG members to use to indicate future conflicts.
- DCLG members should carefully review the grid of DCLG activities and send Ms. LeStage any corrections or additions, with copies to Ms. Handley and Ms. Lee.
- Dr. Brad Zebrack and Ms. Kathy Giusti will look into developing a relationship with the NIH Council Of Public Representatives (COPR).
- Ms. LeStage will put prevention on the agenda for the March conference call.