

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE
23rd DIRECTOR'S CONSUMER LIAISON GROUP
MEETING
March 13, 2003**

SUMMARY

The 23rd meeting of the NCI Director's Consumer Liaison Group (DCLG) was convened on Thursday, March 13, 2003, as a teleconference. Ms. Barbara LeStage presided as Chair.

DCLG Members:

Ms. Barbara K. LeStage, Chair
Ms. Vernal Branch
Ms. Susan Lowell Butler
Ms. Kathy Giusti
Ms. Ruth Lin
Ms. Gena Love

Mr. Christopher Pablo
Ms. Karen Packer
Mr. Henry Porterfield
Ms. Nyrvah Richard
Dr. Marisa Weiss

Members Absent:

Mr. Michael Katz
Mr. Doug Ulman

ORC Macro Staff:

Ms. Carol Freeman
Mr. Larry Luskin
Mr. Matt Suljak

NCI Liaison Activities Staff:

Ms. Jamelle Banks	Ms. Elisabeth Handley
Ms. Nancy Caliman, Executive Secretary, DCLG	Ms. Keisha Martin
Ms. Sarah Dash	Ms. Heather Williams
Ms. Nina Ghanem	

Other NCI Staff:

Ms. Claire Benfer, Committee Management Officer
Division of Extramural Activities

I. WELCOME AND APPROVAL OF MINUTES OF JANUARY 6-7, 2003 MEETING

Ms. Barbara LeStage called the meeting to order and reminded DCLG members to identify any potential conflicts of interest that arise during the group's discussions. Ms. Nancy Caliman determined that a quorum was present.

Motion: The DCLG approves the minutes of the January 6-7, 2003, meeting. The motion was made by Mr. Chris Pablo, seconded by Ms. Karen Packer, and approved unanimously.

II. UPDATE ON DCLG ADVOCACY SURVEY and

III. REPORT FROM THE FUTURE OF THE DCLG WORKING GROUP

Ms. LeStage introduced representatives of ORC Macro, a market research and management consulting firm that has contracted with NCI to support the design, development, and analysis of the DCLG/NCI survey of cancer advocacy organizations. Ms. Carol Freeman of ORC Macro will ensure that the survey is designed to meet its objectives and will analyze the survey results. Mr. Larry Luskin will assist in the survey design and analysis. Mr. Matt Suljak is responsible for writing meeting minutes, conducting interviews, administering the survey, and writing the report.

The survey is being developed in collaboration with NCI's Office of Liaison Activities (OLA) staff, as well as members of the Future of the DCLG Working Group. Survey results will be useful to the DCLG and NCI.

Ms. Freeman described the survey in detail. The first page informs respondents about the purpose of the survey and the confidentiality of results. The survey will be administered on the Internet and will include quantitative and qualitative questions in four major sections. The first section is not confidential, as the information gathered with these questions will be used to develop a contact database for NCI and the DCLG. The remaining three sections are confidential and address the perspectives of advocacy organizations on NCI, the DCLG, and future activities of the DCLG. ORC Macro will summarize responses to these three sections in aggregate form so that individual responses remain confidential.

Section I: About Your Organization. The items in this section will provide useful information for the database, such as organization type, organization finances and staffing, and organization contact preferences.

Ms. Susan Butler suggested that Question 12, which addresses how the advocacy organizations raise funds, might be intrusive. Ms. Kathy Giusti explained that the question's purpose is to determine how reliant the organizations are on government grants and other sources of income. The database will be used for quick and efficient external outreach to certain members of the advocacy community. Ms. Freeman added that many questions in the survey will make it possible to segment the data in ways that will prove useful for internal strategic and external communications efforts. Several DCLG members suggested that Question 12 be optional, but Mr. Luskin said that including optional questions might lead respondents to answer fewer questions. Most advocacy organizations that will complete the survey are nonprofits whose financing is public information. Moreover, the pretest will show how organizations react to this and other potentially sensitive questions.

Ms. Giusti suggested asking respondents to prioritize the areas in which they are currently working or interested (Question 6). Respondents could also be asked to rank their top five areas of interest.

At Ms. Giusti's suggestion, Mr. Luskin will add an option of between 10,000 and 100,000 to the question about the organizations' number of constituents (Question 10) and an option of between \$1 and \$4.9 million to the question about the organizations' annual operating budget (Question 11).

Section II: NCI. Questions in this section will obtain the advocacy community's perspective on NCI, so that this information can be tracked over time.

At Ms. Giusti's suggestion, Mr. Luskin will delete the question on the importance of the cancer.gov site to the organization but will retain the question on the Web site's importance to the organization's constituents. He will also change the wording from "important" to "useful resource."

Section III: DCLG. Questions in this section will be used to track the perspectives of advocacy organizations on the DCLG over time. The questions ask respondents to rate how well the DCLG is fulfilling its core functions as described in the DCLG charter.

Section IV: Future Focus of DCLG. The purpose of the fourth survey section is to obtain information the DCLG can use to determine future focus areas. The questions ask respondents to rate the importance of DCLG involvement in:

1. Research
2. Clinical trials
3. Survivorship
4. Health disparities

The Working Group identified these four as offering the most potential benefit for advocacy involvement, but these may not be issues that advocacy organizations want the DCLG to address. Perhaps the questions should solicit reactions to the DCLG's role in identifying areas of fit between the NCI director's agenda and that of the advocacy community.

Ms. Butler expressed concern about asking respondents to rate the DCLG's performance in areas that the DCLG has tried to address with limited success due to external forces. Ms. Freeman explained that these questions focus on the DCLG's future, not its past. Ms. LeStage added that survey results can be used to show Dr. von Eschenbach that the DCLG's role needs to be changed or the group disbanded. Ms. Gena Love pointed out that, although the DCLG has not been as effective as it might have been with a different structure, it has many accomplishments.

Participants agreed that Question 1 in Section IV should be reworded to allow respondents to add other areas for DCLG attention. Ms. LeStage suggested adding "providing consumer advocates to a large variety of NCI committees" as an option to this question. Ms. Freeman will redraft this question and distribute it for comments.

Ms. Karen Packer pointed out that an important DCLG role is to clarify the function of NCI. Ms. Freeman added that internal and external interviews indicate that NCI is not well understood. Another important area to address in Section IV is the DCLG's role in making

recommendations to the NCI director based on information from the advocacy community. This might be added to Question 3.

Respondents may not be familiar with NCI's center and office structure, as well as other issues raised in the survey. The survey should allow respondents to click on unfamiliar terms for definitions.

Selection of Survey Respondents. ORC Macro plans to invite the advocacy organizations on NCI's current list to participate in the survey. For large organizations with many offices, only the national office will be asked to participate. Ms. Nancy Caliman explained that OLA staff and working group members have reviewed the list to ensure that it is representative. Organizations not on the list will not be able to participate in the survey because the contract with ORC Macro is limited to a certain number of respondents.

Invitations to Survey Respondents. ORC Macro will send an e-mail that invites advocacy organizations to complete the survey. The e-mail will mention NCI sponsorship and provide instructions for accessing the survey on the Internet. This e-mail will be signed by Ms. Freeman as ORC Macro's project director.

Dr. Marisa Weiss suggested offering an incentive to respondents, such as access to the advocacy organization database that will be produced as a result of the survey. However, Ms. Freeman pointed out that ORC Macro promises not to release this information beyond NCI and the DCLG. Instead, participating organizations could receive a report summarizing findings from Sections II-IV. This should be mentioned in the e-mail from ORC Macro to advocacy organizations.

The Future of the DCLG Working Group will draft a pre notification letter to be sent before the ORC Macro e-mail to alert advocacy organizations of the upcoming survey, and ORC Macro will provide comments on the letter. Ideally, the letter will be signed by Dr. von Eschenbach.

Pilot Phase. Members of the Future of the DCLG Working Group will be asked to provide names of organizations that might be willing to participate in the survey pretest. ORC Macro will pretest the survey with approximately five to eight organizations and, if no problems are identified, administer the actual survey.

Timeline. The anticipated timeline is as follows:

- March 17: Finalize the survey instrument.
- March 31: Complete the pilot survey.
- April-June: Administer the survey and compile results.
- June 9-10: Present results to the Future of the DCLG Working Group.
- June 30: Present results to the full DCLG.
- July 9: Present results to Dr. von Eschenbach.

Ms. LeStage thanked the Working Group and ORC Macro for their work on the survey.

Motion: The DCLG approves the draft survey of cancer advocacy organizations, with the stipulation that there may be changes based on the DCLG conference call and internal review of the survey. The motion was made by Dr. Weiss, seconded by Mr. Chris Pablo, and passed unanimously.

IV. UPDATE ON CONSUMER ADVOCATES IN RESEARCH AND RELATED ACTIVITIES (CARRA)

Ms. Elisabeth Handley thanked the Future of the DCLG Working Group and the entire DCLG for their strategic assistance with the Consumer Advocates in Research and Related Activities (CARRA) program at the January meeting. The DCLG's efforts have encouraged Dr. von Eschenbach to express the intent that NCI staff will use CARRA members when they need cancer advocates' involvement unless they are granted an exemption.

OLA has developed an implementation plan for Dr. von Eschenbach's directive and is currently meeting with NCI divisions and offices to discuss the directive and explain how to obtain a CARRA member for an activity. Ms. Handley hopes usage statistics will improve as a result of these meetings, which begins in April.

The contractor who will conduct the CARRA program evaluation has submitted an evaluation plan. OLA is reviewing this plan and will share it soon with the CARRA evaluation planning group, of which Ms. Giusti is a member.

Ms. Nina Ghanem reported that the CARRA training planning group has met once since the DCLG's January meeting. This group has reviewed the results of a survey of CARRA members on training and examined other training programs, and is now addressing curriculum development. Ms. Ghanem is moving to the Office of Communications, so Ms. Brooke Hamilton will take over the planning group, with the assistance of Ms. Heather Williams and Ms. Sarah Dash.

V. TISSUE BANKING PROJECT

Ms. LeStage reminded DCLG members that Dr. Anna Barker (NCI Deputy Director for Strategic Scientific Initiatives) suggested at the January meeting that the DCLG address tissue banking. Dr. Barker informed Ms. LeStage that a National Dialogue on Cancer working group is examining tissue banking and plans to issue a report that will identify several areas in which the advocacy community could and should be involved. Dr. Barker suggested that the DCLG review these recommendations and identify one or two areas to address.

The National Dialogue has identified three priority areas: tissue banking, surrogate endpoints, and public-private partnerships. Ms. LeStage will obtain a copy of the National Dialogue's most recent report for the DCLG. Ms. Giusti noted that former DCLG member Paula Kim chairs the National Dialogue's tissue banking committee, which plans to issue a report this summer.

Dr. Barker had suggested that the DCLG produce educational materials on tissue banking for advocacy groups. However, Ms. LeStage noted that the Patient Advocacy Board (PAB) of the

Coalition of Cancer Cooperative Groups has developed educational materials) on tissue resources, and the DCLG might consider working with the PAB to help distribute these materials.

VI. DCLG ACTIVITIES REPORT AND IMPLICATIONS

Ms. LeStage noted that when NCI pays for DCLG members to attend various meetings, members are responsible for providing a report on their activities. These reports help justify the money spent and are helpful in producing the DCLG annual report. If official minutes of these meetings exist, these are sufficient for the members' report. DCLG members should also identify the impact of their participation or of potential DCLG recommendations as a result of this participation.

VII. UPDATE ON THE DCLG-PATIENT ADVISORY BOARD (PAB) CLINICAL TRIALS PROJECT

Mr. Pablo reported that he, Mr. Mike Katz, and Ms. LeStage met with representatives of the PAB and NCI's Cancer Therapy Evaluation Program (CTEP) on January 7 to discuss progress and areas for improvement concerning the Clinical Trials Transition Project. Discussion addressed the Central Institutional Review Board, the Clinical Trials Support Unit, and the Concept Evaluation Panel. At this meeting, participants identified several follow-up items but no action has yet been taken.

Mr. Pablo, Mr. Katz, Ms. Handley, and Ms. LeStage will set up a meeting with the PAB to decide how to proceed on the follow-up steps and whether a conference call is needed with representatives of CTEP and the PAB.

Mr. Pablo will distribute Mr. Katz's notes from the January 7 meeting to all DCLG members.

VIII. DCLG MEMBERS REPORTS

Annual Report. Ms. Gena Love reported that the version of the DCLG's annual report distributed on March 13 was similar to the version distributed in January. Ms. Caliman has incorporated changes provided by DCLG members and edited the resulting report. Ms. Love noted that the passage on page 6, "Members serve on many NCI standing committees..." has been changed to, "Members provide their unique perspective to many NCI committees..." because their status does not allow DCLG members to serve on these committees.

Motion: The DCLG approves the final version of the 2002 annual report. This motion was made by Ms. Butler, seconded by Ms. Vernal Branch, and passed unanimously.

Ms. LeStage thanked Ms. Love for her "super job" on this report and Ms. Caliman for her advice and editing.

The DCLG will send the report to Dr. von Eschenbach and request his response, which it hopes will arrive in time to distribute at the American Association for Cancer Research (AACR)

meeting in April. Ms. LeStage will attend this meeting and hopes to share copies of the report with other advocates. DCLG members should inform Ms. Caliman of the number of copies they need to distribute to their own organization constituents, as well as at meetings they plan to attend.

Ms. Handley announced that Ms. Jamelle Banks, a new Fellow in the OLA, has produced a poster describing the DCLG that Ms. LeStage will display at the AACR meeting. This promotional tool will be available to DCLG members for future meetings.

PDQ Clinical Trials Patient Abstract Project. Mr. Pablo reported that he and Dr. Weiss have reviewed a survey that NCI plans to send to advocacy groups to solicit opinions about the clinical trials abstracts. Mr. Pablo and Dr. Weiss have recommended several revisions to make the survey more understandable to laypersons.

American Association for the Advancement of Science Meeting. Ms. Packer reported that, although this group typically addresses research developments and scientific reports, it focused more on issues at its last meeting. Several DCLG members expressed appreciation for Ms. Packer's excellent written report on this meeting. Ms. Packer will e-mail suggestions from the relevance statement of her report that address the impact of her attendance at this meeting.

Quality of Cancer Care Committee. Ms. Branch asked DCLG members to recommend projects for the Quality of Cancer Care Committee, which has identified seven focus areas. The Health Resources and Services Administration (HRSA) has asked Ms. Branch for input on the experience of DCLG members who have worked with patient navigators. Ms. Branch will distribute an e-mail requesting feedback on this issue by Monday, March 17.

The committee is considering forming a technical working group that may have a place for an advocate, possibly a CARRA member with expertise in this area. Ms. Branch will e-mail information about the needed expertise to Ms. Handley.

Health-Related Quality of Life Intergroup Working Group. Ms. Nyrvah Richard represents the DCLG on this group but has not been able to attend any meetings because travel money has not been provided by the group's sponsor. Ms. Caliman suggested that the DCLG inform OLA when advocates have difficulty participating in regular committee meetings. Ms. LeStage noted that NCI Centers and Offices should provide travel funds if they want advocate participation.

Central Institutional Review Board. This is a pilot project under the auspices of CTEP. The board meets monthly for an initial review of all phase III clinical trials by Cooperative Groups and for annual reviews. The minutes are confidential so Ms. LeStage cannot share them. Ms. LeStage believes that more could be done to promote an understanding of this pilot project. DCLG members should inform Ms. LeStage of any upcoming meetings with groups that might like to learn more about the Central Institutional Review Board so Ms. LeStage can identify an appropriate speaker.

Early Reproductive Events and Breast Cancer Conference. Ms. LeStage attended this conference at Dr. von Eschenbach's request and has distributed the meeting report. She believes

that this is the first time Dr. von Eschenbach has requested DCLG representation at a meeting of this sort.

National Cancer Advisory Board (NCAB). Ms. LeStage and Ms. Handley attended the NCAB meeting in December. During the meeting, Dr. Niederhuber, the NCAB Chair, announced that the NCAB would form an ad hoc subcommittee on bioinformatics vocabulary and reactivate the ad hoc subcommittee on confidentiality of patient data. In response to a request from Ms. LeStage, Dr. von Eschenbach asked Dr. Niederhuber to appoint two DCLG members as special consultants to these subcommittees. Dr. Niederhuber agreed to do so.

Cancer Health Disparities Progress Review Group (PRG). Ms. Handley reported that health disparities has been identified as a priority area throughout the Department of Health and Human Services (DHHS), and Dr. von Eschenbach is leading a trans-HHS group that is addressing this issue. The group is planning a process similar to that used in PRGs, in which a group of experts identify gaps and develop recommendations. Dr. von Eschenbach requested that the DCLG recommend members for participation on the PRG.

NCI Center to Reduce Cancer Health Disparities. Ms. Richard is attempting to set up a meeting in New York in April with Dr. Harold Freeman of NCI's Center to Reduce Cancer Health Disparities. Ms. Richard will inform the DCLG of the outcome of this meeting.

Certification

I hereby certify that the foregoing minutes are accurate and complete.

Date

Chair, Director's Consumer Liaison Group

Date

Executive Secretary
Director's Consumer Liaison Group

Attachments:

Roster

Reports Cited:

NCI/DCLG Survey of Cancer Advocacy Organizations

DCLG 2002 Annual Report

A complete set of handouts is available from the Executive Secretary.

DCLG ACTION ITEMS

March 13, 2003

- Ms. Freeman will distribute a rewritten Question 1 of Section IV of the cancer advocacy organization survey for comments.
- When the survey is launched, ORC Macro will send an e-mail that invites advocacy organizations to complete the survey.
- The Future of the DCLG Working Group will draft a pre notification letter to alert advocacy organizations of the upcoming survey.
- ORC Macro will provide comments on the pre notification letter.
- Ms. Caliman will send an e-mail to DCLG members asking if they are available for a June 30, 2003, teleconference to discuss the results of the advocacy organization survey.
- DCLG members should inform Ms. Caliman of the number of copies they need of the DCLG's 2002 annual report.
- Ms. LeStage will obtain a copy of the most recent report of the National Dialog on Cancer.
- The DCLG will consider working with the Patient Advisory Board to help distribute educational materials for advocacy organizations on tissue banking.
- DCLG members should inform OLA when they have difficulty participating in regular committee meetings to which they have been assigned, due to lack of funds for travel.
- Mr. Pablo, Mr. Katz, Ms. Handley, and Ms. LeStage will set up a meeting to decide on next steps with respect to the clinical trials project.
- Mr. Pablo will distribute Mr. Katz's notes from the January 7 meeting with CTEP and the PAB to all DCLG members.
- Ms. Packer will address the impact of her attendance at the American Association for the Advancement of Science meeting through an e-mail to the DCLG.
- Ms. Branch will distribute an e-mail requesting feedback by Monday, March 17, from DCLG members who have worked with patient navigators.
- Ms. Branch will e-mail information about expertise needed for the Quality of Cancer Care Committee's technical working group to Ms. Handley, so Ms. Handley can identify a suitable CARRA member to serve on this working group.
- DCLG members should inform Ms. LeStage about any upcoming meetings with groups that might like to learn more about the Central Institutional Review Board so she can identify an appropriate speaker.
- Ms. Richard will inform the DCLG of the outcome of her meeting with Dr. Harold Freeman of the Center to Reduce Cancer Health Disparities, which is expected to take place in April.