

**DEPARTMENT OF HEALTH AND HUMAN SERVICE
NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE
DIRECTOR'S CONSUMER LIAISON GROUP**

Teleconference

July 29, 2002

2:00 – 4:00 p.m. EDT

The 19th meeting of the NCI Director' Consumer Liaison Group (DCLG) was convened on Monday, July 29, 2002. The meeting was opened to the public from 2:00 p.m. - 3:25 p.m. EDT. Ms. Barbara LeStage presided as Chair.

DCLG Members Present

Ms. Barbara LeStage, Chair
Ms. Vernal H. Branch
Ms. Susan L. Butler
Ms. Kathy Giusti
Mr. Michael Katz
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

DCLG Members Absent

Ms. Paula Kim

NCI Liaison Activities Staff

Ms. Heather Burns
Ms. Tracy Clagett
Ms. Elisabeth Handley
Ms. Elaine Lee

I. CALL TO ORDER AND OPENING REMARKS

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

II. UPDATE FROM THE FUTURE OF THE DCLG WORKING GROUP

As a result of DCLG's discussion with Dr. Andrew von Eschenbach at the April meeting, a working group is discussing the future of the DCLG. The group includes Ms. LeStage, Ms. Paula Kim, Mr. Michael Katz, and Dr. Bradley Zebrack and is chaired by Ms. Kathy Giusti.

The working group had a conference call with Ms. Ellen Stovall to develop a framework for its activities. After developing an interview guide, working group members interviewed 15 leaders of advocacy organizations and eight NCI managers to assess their awareness of the DCLG perceived strengths and weaknesses, and what the DCLG should do in the future. The NCI managers were more familiar with the DCLG than the advocacy organization leaders, and wanted the DCLG to help move NCI's priorities forward although they did not want to have to train DCLG members. They regarded the DCLG as representative of all advocacy organizations. The advocacy organization leaders' perspective on what they would like the DCLG to do varied depending on their organizations' priorities.

The working group met with Dr. von Eschenbach who stated that the DCLG should communicate NCI's priorities to the advocacy community, serve as an advisory board to the director, and develop and implement working groups as needed. At Dr. von Eschenbach's request, the working group will hold a conference call with Dr. Julia Rowland on August 7. Based on the recommendations of Dr. von Eschenbach and the DCLG, the working group will develop and present another framework to Dr. von Eschenbach on September 12.

The DCLG will need to determine its role before deciding what kind of working groups to form. Although the existing groups should not be disbanded, they should not hold meetings or teleconferences at present, until the questions about the DCLG's future are resolved.

Although Dr. von Eschenbach would like the DCLG to serve as a conduit to the advocacy community, the advocacy community wants the DCLG to communicate its priorities to the NCI.

Dr. von Eschenbach is very interested in measuring performance and holding the staff more accountable for what they do. To measure whether the DCLG is effective in communicating NCI's activities to the advocacy community, the DCLG needs to identify endpoints that can be measured, for example, the number of items the DCLG communicates, how many people it reaches, and the feedback it receives.

DCLG members should e-mail any suggestions they have for the Future of the DCLG Working Group to Ms. Giusti, Ms. LeStage, Ms. Handley, or Ms. Lee.

In response to a question related to how a different member selection process would be implemented, Ms. Lee noted that the current recruitment process for new DCLG members requires about 6 months. The primary reason is to allow enough time for call for nominations to reach the grass roots advocates.

DCLG Charter. The DCLG's charter expires on August 17, 2002 and the new charter was submitted to the NIH on July 17, 2002. Ms. Lee and Ms. Handley will check to determine whether the new charter has been approved. The new charter changes the term length of DCLG members from 3 to 4 years, and other changes relate to including of a vice-chair, selecting the chair, obtaining input from advocates, and communicating priorities to the NCI Director. However, the charter does not increase the number of DCLG members to 20, as was suggested at the April meeting although this can still be considered at a later time. Since the charter says that the DCLG needs to meet face to face at least twice a year, this language did not need to be changed to allow the DCLG to meet in person more frequently.

III. CLINICAL TRIALS

The discussion of the DCLG's activities on clinical trials was postponed. Mr. Katz will distribute the working group's document by e-mail.

IV. UPDATE ON CARRA

Mr. Henry Porterfield stated that communications from the DCLG to Consumer Advocates in Research and Related Activities (CARRA) members need to be improved, and many CARRA members are still concerned about the fact that they have not been called on to participate in NCI activities.

Ms. Tracy Clagett reported that NCI staff has submitted approximately 75 requests for CARRA members since the program's inception last September. Most requests are for science activities, often by the Division of Extramural Activities and usually involve peer review. The DCLG listserv will soon start receiving monthly reports about the CARRA program. DCLG members who want to be added to the CARRA listserv should contact Ms. Clagett.

A small planning group that includes Ms. Giusti representing the DCLG, as well as two CARRA members and two NCI staff members, is serving as a sounding board for evaluation for the CARRA program. The DCLG's input on the evaluation approach is being sought.

Both NCI staff and CARRA members have requested that CARRA members receive more training, mostly for science-related activities. Ms. Nina Ghanem taking the lead in planning a pilot training program that will be held in the spring or summer of 2003. The DCLG will be involved with this.

Ms. Heather Burns, who has joined Liaison Activities (LA) as a presidential management intern, will help with internal promotion of CARRA to NCI staff. Ms. Burns will be with LA until October.

Ms. Vernal Branch recently made a presentation to California CARRA members, in conjunction with the Northern California Cancer Center, which would like to use CARRA members in its work. Ms. Branch discussed the cancer center, NCI Cancer Information Service programs and how to bring information to CARRA members' own organizations. This meeting was brought about by an NCI staff member in the Cancer Information Service who works with the Northern California Cancer Center. Liaison Activities contacted CARRA members in the area to invite them to participate. Other DCLG members might be able to participate in similar meetings in their own regions.

V. REPORTS ON DCLG ACTIVITIES

Survivorship Town Hall. Mr. Doug Ulman and Ms. Vernal Branch participated in the Survivorship Town Hall, where they related their own cancer stories and talked with other survivors. The content of the conference was very good, and the speakers were excellent. Several CARRA members attended the event, which will be repeated every 2 years. A summary should be ready by the end of the summer. Ms. LeStage will pass on the comments of Mr. Ulman and Ms. Branch.

Bypass Budget. Ms. Kim has distributed the draft 2004 NCI bypass budget to DCLG members, who should submit their comments to her by August 7. She will collate and submit the comments from the DCLG as a whole.

Survivorship. NCI has accepted survivorship as an investment opportunity for the Bypass Budget. As Ms. LeStage learns more about this, she will inform the DCLG members. Ms. Margo Michaels has requested the assistance of DCLG members and their organizations in evaluating NCI's new book on life after cancer treatment, which is part of the Facing Forward series for survivors and family members. Anyone whose organization would like to help with this should contact Ms. LeStage, who will forward their names to Ms. Margo Michaels.

Health-Related Quality of Life (HRQoL) Committee. Ms. Nyrvah Richard has forwarded the agenda and minutes from the HRQoL Committee's last meeting, which was part of the American Society of Clinical Oncology (ASCO) meeting. The meeting focused on different ways to integrate HRQoL research, and committee members would like to hold an educational series on HRQoL in clinical trials at the next ASCO meeting. Several papers have been proposed, including one focused on issues for teenagers, whose needs have not been satisfactorily addressed. Ms. Richard will continue to forward relevant e-mails on HRQoL activity to DCLG members.

When Ms. Richard attends the clinical trials training in September, she and Ms. LeStage would like to meet with Dr. Harold Freeman, who heads the NCI Center to Reduce Cancer Health Disparities, to discuss how the DCLG might work with the new Center. Ms. LeStage will contact Ms. Richard next week to discuss this.

Quality of Care Committee. Ms. Branch attended the May meeting of the Quality of Care Committee and distributed a brief report on this meeting. The committee is working with several organizations that are developing quality of care measures for cancer, including the American Cancer Society, Centers for Medicare and Medicaid Services, Foundation for Accountability, National Comprehensive Cancer Network, and National Committee on Quality Assurance. As soon as Ms. Branch obtains information from Dr. Robert Hyatt about the last meeting of the committee, she will distribute it to the DCLG.

Advisory Committee to the Director. Ms. LeStage participated in a meeting of the Advisory Committee to the Director, which approves Progress Review Group (PRG) reports. The committee received the report of the Kidney and Bladder Cancers PRG, which noted the lack of advocacy group for bladder cancer survivors. One of the PRG co-chairs is trying to start such a group, as this would be helpful to research progress. DCLG members who know of bladder cancer survivors or family members who might be interested in helping form an advocacy group, should

pass their names onto Ms. LeStage. Ms. Clagett offered to forward the names of some survivors she knows about to Ms. LeStage.

VI. FUTURE MEETINGS

The DCLG's next conference call will be held on Thursday, September 5, 2002, from 2:00 to 4:00 p.m. east coast time.

The next meeting is scheduled for Tuesday, October 22, 2002. Much of what happens at this meeting will be determined by what occurs in the September discussion with Dr. von Eschenbach. Although the meeting is unlikely to be canceled, it might be shortened. But as the October meeting is on Dr. von Eschenbach's calendar, it will provide a good opportunity for the Director to meet with the entire DCLG to discuss the group's future.

VII. ADJOURNMENT

The meeting adjourned at 3:25 p.m. on July 29, 2002.

Certification

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

10/30/02

/s/

Date

Chair, Director's Consumer Liaison Group

11/01/02

/s/

Date

Executive Secretary

Director's Consumer Liaison Group

Attachments:
Roster
Action Items

ACTION ITEMS

July 29, 2002 Teleconference

DCLG members should e-mail any suggestions for the Future of the DCLG Working Group to Ms. Kathy Giusti, Ms. Barbara LeStage, Ms. Elizabeth Handley, or Ms. Elaine Lee.

Ms. Lee will distribute a summary of the current process for recruiting DCLG members, and DCLG members should provide input on this process.

Ms. Lee and Ms. Handley will check to determine whether the new charter has been approved.

Mr. Michael Katz will distribute the Clinical Trials Working Group's document by e-mail.

DCLG members who want to be added to the CARRA listserv should contact Ms. Tracy Clagett.

Ms. LeStage will pass on the comments of Mr. Doug Ulman and Ms. Vernal Branch about the Survivorship Town Hall.

DCLG members should submit their comments on the 2004 bypass budget by August 7, 2002 to Ms. Paula Kim.

As Ms. LeStage hears more about the DCLG's extraordinary opportunity on survivorship, she will inform the DCLG members.

Any DCLG member whose organization would like to help evaluate NCI's new book on life after cancer treatment should contact Ms. LeStage, who will forward their names to Ms. Margo Michaels.

Ms. Branch will keep DCLG members informed about quality of life activities.

Ms. LeStage will contact Ms. Richard next week to discuss the possibility of setting up a meeting with Dr. Harold Freeman to discuss the link between his office and the DCLG, the NCI Center to Reduce Cancer Health Disparities.

Ms. Branch will distribute information on the Quality of Care Committee's last meeting to the DCLG.

DCLG members who know of bladder cancer survivors or family members who might be interested in helping form an advocacy group, should pass their names on to Ms. Branch

Ms. Clagett will forward the names of some survivors she has.

L:\OLA\DCLG\MEETINGS\Conference Calls\July 2002\Minutes 7-29-02.doc