

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE
21ST MEETING
DIRECTOR'S CONSUMER LIAISON GROUP
TELECONFERENCE
November 19, 2002
Summary of Meeting**

The 21st meeting of the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG) was convened on Tuesday, November 19, 2002. Ms. Barbara LeStage presided as Chair.

DCLG Members

Ms. Barbara LeStage, Chair
Ms. Vernal H. Branch
Ms. Susan L. Butler
Ms. Kathy Giusti, absent
Mr. Michael Katz
Ms. Ruth Lin
Ms. Gena Love
Mr. Christopher Pablo, absent
Ms. Karen G. Packer
Mr. Henry A. (Hank) Porterfield
Ms. Nyrvah Richard
Mr. Doug E. Ulman
Dr. Marisa Weiss, absent

NCI Liaison Activities Staff

Ms. Elaine Lee [Executive Secretary]
Ms. Claire Benfer
Ms. Nina Ghanem
Ms. Brooke Hamilton
Ms. Elisabeth (Lis) Handley
Ms. Keisha Martin

Notetaker

Ms. Mary Cerny

I. WELCOME

Ms. Barbara LeStage called the meeting to order. She reminded DCLG members that they must identify any potential conflicts of interest that arise during the discussion. Ms. Elaine Lee determined that a quorum was present.

II. FUTURE OF THE DCLG WORKING GROUP REPORT

Mr. Michael Katz reported on the marketing survey and on recent meetings between the working group and NCI management team leaders. The working group continues to have an active dialogue with NCI Director, Dr. Andrew von Eschenbach, and with NCI management. They all strongly endorse the DCLG as the liaison between NCI and the advocacy community. Dr. von Eschenbach also expressed support for the DCLG as a more active participant in the Institute's strategic planning, and NCI senior staff are receptive to including members of the DCLG to serve in that role. However, the strategic planning process is diffuse and not consistently well defined across topics. Identifying the best or most appropriate role for the DCLG is still not clear and will require further discussions.

An outline for the marketing research survey has been developed. The survey will ask advocates a range of questions, including their perception of the DCLG; the survey will also ask advocacy groups to characterize their activities, constituent groups, and priorities. A new component to the survey design involves collecting information on the advocacy community's opinions about specific NCI programs, such as communications initiatives and research priorities; Dr. von Eschenbach has approved the inclusion of this component to the survey. Mr. Hank Porterfield suggested that the survey include a question about the role of advocates in the NCI strategic planning process; callers did not have a chance to discuss this issue further, however.

Ms. Nina Ghanem is the contact person in the Office of Liaison Activities (OLA) for the marketing survey project. Bids from contractors interested in assisting with the survey design and implementation are due to OLA by December 2. Depending on the number of bids submitted, OLA anticipates about a 2-week period to review applications and to make a final decision. At this point, the survey is expected to begin in March or April of next year, and the results should be available by summer. The first draft of the survey probably will not be available for review at the January meeting, but the process by which the survey will be rolled out will be discussed at that time. Ms. Ghanem will forward the draft survey to the full group as soon as it is available. Suggested advocacy groups to be added to the survey list should be submitted to Ms. Ghanem by March 1.

Ms. LeStage noted that it would be preferable to have the survey results to best address the advocacy community's priorities and concerns; thus, the nomination process for new DCLG members most likely would not occur until later summer or early fall. The working group will meet with Dr. von Eschenbach after the survey is completed to match NCI priorities with the advocates' priorities; the full DCLG may wish to discuss this process with him at the January 2003 meeting. Because of the likely delay in the nomination process, current members expecting to rotate out of the DCLG in summer 2003 may be asked to remain in the group until new members have been identified. One suggestion for recruitment of national-level advocates was to contact the advocates directly about serving on the DCLG. Ms. Lee noted that any changes in the recruitment of new DCLG members will be reviewed with the DCLG and Dr. von Eschenbach. The group will continue to discuss recruitment strategies to identify potential members.

III. JANUARY MEETING AGENDA

Ms. LeStage, Ms. Lee, and Ms. Elisabeth Handley have been working on the agenda for the January 2003 in-person DCLG meeting. Ms. LeStage explained that the first day of the meeting, Monday, January 6, is especially full because of limited availability of several invitees to attend the meeting on January 7. The agenda for Tuesday, January 7, includes 1 hour for discussion of advocacy input into the NCI strategic planning process. Ms. Vernal Branch requested that the agenda be revised to allow 45 minutes for discussion of issues relating to the Quality of Cancer Care Committee. She will contact Dr. Robert Hiatt to determine his availability to attend the DCLG meeting on Tuesday morning.

Another agenda item involves a meeting with members of the NIH Director's Council of Public Representatives (COPR), which serves a similar function as the DCLG. The COPR includes health professionals, advocates, patients, and others, and covers a wide spectrum of diseases. The Council is a forum for discussing issues affecting the broad development of NIH policy, programs, and research goals, and advises the NIH Director on these matters. The Council also advises and assists the NIH in enhancing participation by the public in NIH activities, increasing public understanding of the NIH, and bringing important matters of public interest forward for discussion in public settings. Ms. LeStage noted that the DCLG could benefit from understanding how the COPR functions and from obtaining feedback and solutions on problems the Council has faced. She stated that the COPR recently held a 2-day workshop to discuss strategic planning issues. Information about the Council can be found at <http://copr.nih.gov>.

Ms. LeStage also mentioned that Dr. Anna (Ann) Barker has been recruited by Dr. von Eschenbach to serve as the Deputy Director, Strategic Scientific Initiatives. The DCLG Working Group interviewed Dr. Barker, who will focus on public-private partnerships, among other issues. Part of her role at the NCI will be to bring together diverse groups to identify gaps in cancer research and diagnosis. Dr. Barker has expressed an interest in bringing the DCLG into this process and possibly other activities. She may also oversee several demonstration projects focused on tissue access, surrogate endpoints, and drug development. Ms. Vernal Branch noted that Dr. Barker has a strong interest in advocate perspectives and will add to the development of NCI initiatives.

IV. UPDATE ON CARRA

Ms. Brooke Hamilton reported that NCI staff have submitted a total of 106 requests for CARRA members since the program's inception in September 2001. Most requests are for science activities, often by the Office of Extramural Activities and usually involving peer review. Additional information may be found at the CARRA web page <http://liaison.cancer.gov/CARRA/>.

CARRA Evaluation Planning Group. This group met November 14 and will meet again in December. Ms. Giusti is the DCLG representative on the evaluation group, which also includes NCI staff and CARRA members; Ms. Hamilton is the contact person for the group. The general evaluation plan for CARRA is being developed by a contractor, which is expected to complete its formal, written evaluation plan within 3 months. Once implementation of the plan begins, feedback on various activities will be obtained from CARRA and NCI on an ongoing basis.

CARRA Training Group. Ms. Ghanem reported that the training group has met twice and is working on developing its mission and identifying its goals. The group includes CARRA members, NCI staff, OLA staff, and one DCLG representative, Ms. Karen Packer. Ms. Ghanem noted that the group is conducting a brief training-needs assessment among CARRA members. Additional information about the training group should be available in time for the January DCLG meeting.

V. INTEGRATING THE ADVOCACY PERSPECTIVE INTO NCI'S BYPASS BUDGET

Ms. LeStage briefly summarized NCI's strategic planning process, which kicks off in January and is followed in February and March with Director and "Champion" meetings. A draft plan is usually available in April or May, internal reviews and revisions are made in June, and external reviews and final revisions are made in July and August. DCLG and other external groups currently provide feedback during the final revision phase. Ms. Cherie Nichols and Ms. Kathie Reed are seeking to modify the process to engage advocates and other outside groups earlier in the planning process.

VI. CTEP RESPONSE TO DCLG/PAB REPORT

Ms. LeStage and Mr. Katz provided updates on the CTEP response to the DCLG/PAB (Patient Advisory Board) report. Ms. LeStage noted that the response was positive. The Clinical Trials Working Group and representatives from the PAB will be meeting with Dr. Rick Kaplan, Dr. Jeff Abrams, and Dr. Bob Comis on January 7 to discuss ways that the DCLG and PAB can work together to further the goals for NCI's clinical trials programs.

Mr. Katz reported that CTEP has recommended that the Concept Evaluation Panels (CEPs) be discontinued because they have not substantially improved the trials concept approvals process. (The CEP was designed to provide a mechanism for quick feedback on new ideas and to select the best trials, regardless of the source.) The NCI's Board of Scientific Advisors (BSA), which provides oversight to the NCI Cooperative Groups, has accepted the recommendation, but it is not clear whether the CEPs will be terminated. Mr. Katz noted that the entire CTEP program has been facing increased financial pressures.

The DCLG/PAB report has been sent to the CLC, patient advocacy groups, Cooperative Group chairs, the Cancer Leadership Council, and a few others. Ms. LeStage stated that DCLG members who would like to share the report informally may do so.

VII. REPORTS FROM DCLG MEMBERS

Cancer Survivorship Knowledge Exchange Team. Mr. Doug Ulman reported that the Knowledge Exchange Team has begun to develop its strategic plan for identifying ways to partner with cancer groups to disseminate results from the NCI's Office of Cancer Survivorship (OCS). The next meeting has not been scheduled yet. Ms. LeStage noted that the Knowledge Exchange Team is another example of DCLG input into NCI strategic planning. She reported

that two DCLG members (Mr. Pablo and Dr. Marisa Weiss) will be contributing to the team that is revising the clinical trials section of the cancer.gov web site; Ms. Susan Butler offered to assist with this project if Dr. Weiss cannot.

Quality of Cancer Care Committee. Ms. Branch reported that the next conference call of the Cancer Care Committee will be held in December and that the group will meet in person in January. There were no updates since the October DCLG conference call.

Clinical Research Roundtable. Ms. Butler attended a recent clinical research roundtable sponsored by the National Academy of Sciences (NAS) Institute of Medicine (IOM). One of the many issues raised during the meeting was the growing interest in increasing awareness of clinical research among the public. Ms. Butler will prepare a summary of the meeting and forward it to Ms. Handley for additional comment. Ms. Handley, in turn, will distribute the final summary report to DCLG members.

VIII. COMMENTS FROM THE PUBLIC

There were no comments from the public.

IX. ADJOURNMENT

The meeting was adjourned at 3:10 p.m.

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

ACTION ITEMS

- ◆ Ms. Vernal Branch will contact Dr. Robert Hiatt to determine his availability to attend the DCLG meeting on Tuesday morning, January 7, 2003.
- ◆ Ms. Elisabeth Handley (OLA) will revise the draft agenda of the January DCLG meeting to allow 45 minutes for discussion of issues relating to the Quality of Cancer Care Committee.
- ◆ Ms. Nina Ghanem will forward a copy of the first draft of the marketing survey to all DCLG members for review once the draft is available.
- ◆ Ms. Susan Butler will prepare a summary of the National Academy of Science Institute of Medicine roundtable meeting on clinical research. She will forward her draft to Ms. Handley for additional comment. Ms. Handley, in turn, will distribute the final summary report to DCLG members.