

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE
20th DIRECTOR'S CONSUMER LIAISON GROUP
MEETING
October 22, 2002**

SUMMARY

The 20th meeting of the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG) was convened on Tuesday, October 22, 2002 as a teleconference. Ms. Barbara LeStage presided as Chair.

DCLG Members

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

NCI Liaison Activities Staff

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

Notetaker

Ms. Mary Cerny

I. CALL TO ORDER AND OPENING REMARKS

Ms. Barbara LeStage called the meeting to order. Ms. Elaine Lee determined that a quorum was present and noted that all portions of the meeting were open. She reminded DCLG members that they must identify any potential conflicts of interest that arise during the discussion. Ms. Lee also introduced Ms. Claire Benfer, the Office of Liaison Activities' (OLA) Committee Management Officer. Ms. LeStage offered congratulations from the group to Ms. Brooke Hamilton, who recently joined OLA staff.

II. UPDATE FROM THE FUTURE OF THE DCLG WORKING GROUP

As a result of DCLG's discussion with NCI Director Dr. Andrew von Eschenbach at the April meeting, a working group is discussing the future of the DCLG. Ms. Kathy Giusti serves as chair of the group.

On June 7, the working group met with Dr. von Eschenbach to discuss the results of the group's interviews with 15 leaders of advocacy organizations and 8 NCI managers to assess their awareness of the DCLG, perceived strengths and weaknesses, and what the DCLG should do in the future. The working group presented Dr. von Eschenbach with a report of the findings of the interviews, which indicated that awareness of the DCLG is somewhat low and that both groups interviewed were not always able to pinpoint DCLG's successes. However, Ms. Giusti noted, the interviewees offered support for the DCLG. Key discussion points during the June 7 meeting were to identify ways to balance the priorities of the NCI with the priorities of the advocacy organizations, to communicate more effectively with advocacy groups, and to increase the involvement of DCLG members in NCI's strategic planning. Dr. von Eschenbach was receptive to these ideas, and the group has done considerable follow-up in the last few months.

In July and August, the working group examined the role of advocates within the NCI. The group found advocates participating in many activities. The working group interviewed NCI management staff from various areas of the Institute to identify ways to integrate DCLG members into the strategic planning process. Among those interviewed were Dr. Julia Rowland (Office of Cancer Survivorship), Ms. Cherie Nichols (Office of Science Planning and Assessment), and Dr. Michaele Christian (Cancer Therapy Evaluation Program, Division of Cancer Treatment). They suggested the following would need to happen for the DCLG to be integrated into the planning process:

- ◆ The NCI would need a more formal process with specific dates and locations identified in advance so that DCLG member(s) would be able to participate fully.
- ◆ The DCLG should include members who have a clear and solid understanding of science and research as well as advocacy issues. Ms. Giusti noted that this is a key point for the NCI.
- ◆ DCLG members need to be proactive to remain involved in the entire planning process, even though they may not physically attend all meetings.
- ◆ DCLG members need to take NCI's successes back to the advocacy community. The NCI seeks assurance that the DCLG has the vehicles in place to maintain strong outreach throughout the advocacy field.

Based on the deliberations of the working groups and the approval of the entire DCLG, the working group then developed and presented another framework to Dr. von Eschenbach on September 12, with the following recommendations:

- ◆ Develop a comprehensive advocacy database that would allow tailored communication to the advocacy community.
- ◆ Develop a quantitative survey of a wide range of advocacy organizations to obtain information including:
 - Key contacts at each organization, including outreach staff, and update names and other contact information on a routine basis.
 - Priorities and focus of each group constituency.
- ◆ Bring the priorities of the advocacy organizations to Dr. von Eschenbach once the results of the survey. Dr. von Eschenbach in collaboration with the DCLG would then determine the priorities for the group.
- ◆ Bring common priorities back to the DCLG and advocacy groups to identify and recruit advocacy representatives to participate in the DCLG. The format and structure for recruitment has not been determined.

Immediate next steps in this process include continuing to discuss DCLG's role in the strategic planning process, including contacting Dr. Anna Barker (public-private partnerships at the NCI), Dr. Leslie Ford (Division of Cancer Prevention), and Dr. Marvin Kalt (Division of Extramural Activities); working with Ms. Nina Ghanem on development of the survey in conjunction with a contractor, working with the OLA on a comprehensive advocacy list. Mr. Henry (Hank) Porterfield suggested that the survey also collect information about trends in growth of the organizations. Ms. Giusti noted that the working group has already sent out a letter that outlines the group's progress to the advocates and NCI staff interviewed thus far. The DCLG also may work with the NCI on Web site development in support of advocacy issues and activities. Ms. Ghanem provided the following steps and time frame for developing, implementing, and compiling the results of the survey:

- ◆ Define the scope of the questionnaire, complete NCI paperwork, secure a contractor, develop a draft survey, have the full DCLG review the draft, and finalize and distribute the DCLG-approved survey. The first draft survey currently is scheduled to be ready for review on January 20, 2003, approximately two weeks after DCLG meeting.
- ◆ Implement survey in March 2003, with a 3-week turnaround for replies plus additional time for follow-up to obtain missing information and contact those who did not respond.
- ◆ Enter survey results into a database and begin to analyze findings, with a target date of mid-April for results.

The DCLG will participate in all phases of development and review all key materials generated. Ms. Elisabeth Handley noted that the timeline could shift depending on the response from contractors bidding on the project. The estimated budget for the survey development and implementation is approximately \$100,000, which is based on recent similar projects with *quick turnaround* times that have been done within the NCI. The survey will be developed by a firm with the specific expertise outlined in the solicitation; the goal is to have a product that is qualitatively sound and can be built upon for future survey activities. The estimated cost of

creating and implementing the database, which can be used for future projects, is \$175,000. Callers pointed out that these estimates are about two to three times higher than similar projects done within the private market. Given the limited time frame for this task, the NCI expects to accept bids only from vendors on a preapproved list. Ms. Lee added that opening the bidding process would require the NCI to follow different procedures and could add six months to the entire process. Ms. Lee will confirm time frames for soliciting, responding to, and awarding open bids in contrast with the current award mechanism that is open to a pool of already qualified contractors.

The DCLG will work with OLA staff in constructing the list of advocacy organizations to survey. Ms. Hamilton will facilitate this process by distributing NCI's current database list of advocacy groups to DCLG members. Discussion of issues related to the survey will be included on the agenda for the January 2003 meeting. Once the advocacy groups' priorities are identified the DCLG will work with NCI to determine next steps for the group.

III. CLINICAL TRIALS WORKING GROUP UPDATE

Mr. Christopher Pablo reported on his visit to the NCI on September 16 and 17 and on the joint report by the DCLG and the Patient Advisory Board (PAB) of the Coalition of National Cancer Cooperative Groups on NCI's Cooperative Group Clinical Trial System.

The NCI visit focused on generating ideas for projects for the working group and identifying potential partners for DCLG's activities. Mr. Pablo noted that the DCLG is in the process of defining its role under Dr. von Eschenbach's leadership and that as the group moves forward, some of its plans may shift. The key areas of focus in the discussions with NCI staff during the visit were prevention trials, communications, and clinical trials for the elderly. Regarding communications, for example, the DCLG may have a role in disseminating public education materials about clinical trials. Mr. Pablo anticipates that the role for the DCLG in these areas will solidify as the group defines its mission more clearly. Mr. Pablo also noted that in his meeting with Dr. von Eschenbach on September 16, the NCI Director recognized the efforts of the DCLG working group and Ms. Giusti.

Mr. Pablo then reported that NCI's Dr. Michael Christian has responded to the DCLG/PAB report, for which Mr. Michael Katz had the lead. The report and Dr. Christian's response have been sent to Dr. von Eschenbach's office. Upon further discussion, it appeared that at least some of the DCLG members had not received the comments from Dr. Christian; Ms. Handley will e-mail the NCI response to the DCLG for discussion during the DCLG's next conference call. Ms. LeStage noted that Ms. Mary Lou Smith, Ms. Deborah Collyar, and Mr. Katz have indicated that the response concentrates more on deficiencies in the DCLG/PAB information instead of concerns about the system. Plans for a conference call (date TBA) between members of the DCLG and the PAB are underway; the meeting will focus on how to proceed.

IV. UPDATE ON CARRA

Ms. Hamilton is serving as the lead contact for CARRA activities while Ms. Tracy Claggett is on maternity leave. Upon Ms. Claggett's return, Ms. Hamilton will continue as the CARRA Program

Coordinator, handling the day-to-day activities of the program and serve as liaison with professional societies.

CARRA Planning Group. Ms. Hamilton reported that the first conference call of the CARRA Planning Group was held on October 17; among the attendees were DCLG members Ms. Giusti and Ms. Karen Packer. The purpose of the CARRA Planning Group is to convene stakeholders in the CARRA program who can assist and guide OLA with the program. The Planning Group includes several subgroups, which will address specific issues as they arise. One subgroup, the Evaluation Planning Group, provides input to the evaluation of the CARRA program. Ms. Giusti is the DCLG representative on the evaluation subgroup, which also includes NCI staff and CARRA members; Ms. Hamilton is the contact person. The contractor is developing a general evaluation plan for CARRA. The next meeting of the full Evaluation Planning Group is scheduled for November 14, 2002. Another subgroup, the Training Group, will provide input to the pilot training for CARRA members; this subgroup includes CARRA members, DCLG representatives, NCI staff, and contractors. Ms. Ghanem is the contact person for the Training Group.

In response to a question about the timeline for the evaluation, Ms. Hamilton noted that the NCI has a two-year contract with the contractor. The contractor will prepare and present a formal, written evaluation plan within three months following the next Evaluation Planning Group meeting. Once the plan is in place, it will be implemented, and feedback on various activities will be obtained from CARRA participants, and the NCI staff on an ongoing basis.

Ms. Handley noted that the Training Group has not yet met and that an early goal in establishing this group is identify advocates and staff to serve on the group before bringing in a contractor. The first training is planned for late spring or early summer of 2003, with a goal of training approximately 25 people from the CARRA pool over a two-day period. The training will focus on research and scientific issues and will likely include activities such as a mock peer review session.

Other CARRA Activities. Ms. Hamilton reported that NCI staff have submitted more than 100 requests for CARRA participation since the program's inception last September; 10 requests were made in September 2002. Most requests are for science activities, often by the Division of Extramural Activities and usually involving peer review. All requests have been filled. Additional information about CARRA activities may be found on the CARRA Web page (<http://liaison.cancer.gov/CARRA>).

Ms. LeStage noted that in the working group's last meeting with Dr. von Eschenbach, he had requested more information about the CARRA and suggested that a white paper on the program be prepared. The Office of Liaison Activities sent a memo to Dr. von Eschenbach outlining the history of the CARRA as well as key aspects and functions of the program. Ms. Handley noted that he has not yet responded to the memo; however, NCI Deputy Director Dr. Alan Rabson has expressed his support of the program. OLA staff will e-mail DCLG members the memo responding to Dr. von Eschenbach's questions about CARRA. The group will consider including a discussion with Dr. von Eschenbach on CARRA.

Ms. Hamilton also reported that the CARRA annual report should be available by the end of the month and that the biweekly e-mails with NCI updates to CARRA members have been well received. Many CARRA members disseminate the information in the e-mails to other advocates and advocacy organizations.

V. INPUT FOR NCI's BYPASS BUDGET

One area in which the DCLG may be able to contribute more substantively to NCI's strategic planning is by providing input early in the Institute's Bypass Budget process. The budget development process 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. The DCLG and other external groups currently provide feedback during the final revision phase. Modifications to this schedule may seek outside input prior to the development of the draft budget, that is, as an adjunct to the Champion meetings, which highlight extra opportunities and Director's challenges. Revisions approved in the upcoming calendar year would take effect for the fiscal year 2005 budget, for which planning will begin in January 2004.

Ms. Cherie Nichols will be developing a revised budget development process that will be submitted to Dr. von Eschenbach for approval. Ms. Kathie Reed, Chief, Science Planning Branch, NCI Office of Scientific Planning and Assessment (OSPA), leads the bypass budget development process. She also is spearheading the effort to submit ideas to NCI upper management on how to modify the process so that comments from advocates and others may be received and considered through a manageable process before the draft budget is prepared. Ms. Reed, who expects to begin forwarding these ideas to NCI management in mid-November, is open to suggestions from the DCLG. Mr. Porterfield will take the lead for the group and prepare an outline of a process by which the DCLG and other external organizations may contribute to the NCI Bypass Budget early in the process. His summary will identify forms and mechanisms by which advocates and other groups outside the NCI may achieve this goal. Two possible mechanisms suggested by Ms. Reed are an online chat room and NCI "listening sessions" at professional meetings. DCLG members should forward additional ideas to the group prior to the next conference call for review. Ms. LeStage noted that a specific amount of funding will not be available at this point in the budget process. The group will discuss their ideas during the November conference call.

VI. REPORTS FROM DCLG MEMBERS

Quality of Cancer Care Committee. Ms. Vernal Branch reported on the Quality Care Forum, held on September 4-5, which she was not able to attend. The forum attendees drafted a statement of the purpose of the quality of care measures. The group also established criteria for selecting focus areas for analysis, including national goals, impacts on outcome, survival, quality of life, prevalence, and cost, patient-centered care experiences, and disparities. The priority areas chosen for qualitative measures included symptom management, end-of-life care, and survivorship, breast cancer diagnosis and treatment, communications and coordination of care, colorectal cancer diagnosis and treatment, cultural competency, prostate cancer diagnosis and treatment, and screening and prevention. Three projects are underway at the Veteran Administration, Health Research Services Administration, and Centers for Medicare and Medicaid Services. The forum is working on how to disseminate information and findings

generated from these projects. Ms. Branch noted that Dr. Robert Hyatt, who chairs the committee, is leaving the NCI in February; to date, no one has been appointed to become chair, but Dr. Hyatt has recommended Dr. Joseph Lipscomb, who is a member of the committee. The forum will hold its next meeting in December, which Ms. Branch will attend via conference call.

Ms. Branch attended the Quality of Cancer Care Committee meeting on October 7; she will prepare a short summary of the meeting and distribute the report to DCLG members.

Ms. Branch explained that the purpose of the committee is to identify measurements, particularly for patients in the VA or Medicare systems, by collecting information from patients, doctors, and other health care providers. The ultimate goal of the committee is to disseminate these quality cancer care measures.

Clinical Trials Transition Committee. Mr. Pablo reported that the committee met via conference call on October 21. The meeting focused on Central Institutional Review Board (CIRB) issues and pilot projects. Mr. Pablo noted that the NCI is recruiting IRBs across the country to increase the number of institutions involved in the CIRB effort. Mr. Katz added that the committee also discussed the evaluation of the CIRB program and how to engage a larger number of institutions in the process. Regarding the Clinical Trials Support Unit (CTSU), the group discussed enrollment issues, including reporting of enrollment trends, historical enrollment statistics, cumulative enrollment, and enrollment by various groups and other factors (e.g., Hispanic enrollment and recruitment). Another issue raised was evaluating how shifts in registration have affected recruitment and enrollment of specific groups. Mr. Katz also reported that since the American Society of Clinical Oncology (ASCO) announced plans to expand enrollment to outside groups, the Cancer Therapy Evaluation Program (CTEP) has reviewed 20 applications. Thus, in the future, the CTSU will be focused more on persons currently in the group rather than in outside groups. Mr. Katz continued by stating that the components of the pilot projects that relate to the deployment of infrastructure (e.g., the registration system) will cut down on paperwork redundancy. However, it is too early to determine the impact on recruitment or enrollment.

Cancer Survivorship Knowledge Exchange Team. Ms. LeStage reported that the first meeting of this internal NCI group was held last week. Ms. Hamilton, Ms. Giusti, and Ms. LeStage were among those in attendance, and DCLG will have permanent representation in this group. The purpose of this group is to identify ways to disseminate results of survivorship research as they become available. Ms. Handley added that there are numerous grants and products and a wide range of knowledge in this field that may not be reaching the appropriate audiences, including patients, advocates, and health care providers. She noted that this general concept holds for other areas of cancer research, not just for survivorship, and for other diseases and conditions. The ultimate goal is to diffuse and disseminate information so that it has a real impact on cancer care and the delivery of care.

FUTURE MEETINGS

The DCLG's next conference call will be held on Tuesday, November 19, 2002, from 2:00 p.m. to 4:00 p.m. Eastern standard time.

The meeting in Bethesda is scheduled for January 6–8, 2003.

ADJOURNMENT

The meeting adjourned at 3:35 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

- ◆ The OLA will:
 - Distribute the draft agenda for the January 2003 DCLG meeting to DCLG members within the next week. (Ms. Elaine Lee and Ms. Barbara LeStage)
 - Confirm with the Procurement Office time frames for soliciting, responding to, and awarding *open* bids, in comparison with time frame for the current award mechanism of a pool of already qualified contractors, to secure a contractor to assist with the surveying of advocacy organizations. (Ms. Lee)
 - Produce and distribute to DCLG members the current database list of advocacy groups. (Ms. Brooke Hamilton)
 - E-mail to DCLG members Dr. Michael Christian's response to the DCLG/PAB Report on Clinical Trials. (Ms. Elisabeth Handley)
 - E-mail to DCLG members the OLA memo responding to Dr. Andrew von Eschenbach's questions about the CARRA.
 - Include the following on the agenda for the November 19 conference call:
 1. Response to DCLG/PAB Clinical Trials report.
 2. Integrating the DCLG and advocacy groups into the early steps in the NCI bypass budget development process. (Ms. Lee and Ms. LeStage)
 - Provide draft of the one page document to the Future of the DCLG Working Group regarding whether to gather advocates perceptions of the NCI. This document will be submitted to Dr. von Eschenbach for his approval. (Ms. Nina Ghanem)
- ◆ DCLG members should:
 - Submit to the OLA comments and feedback on the draft agenda (when available) for the January 2003 meeting.
 - Provide the OLA with feedback on NCI's list of advocacy organizations for the proposed survey. Suggest organizations to add to the list, and include as much information about these organizations as possible (e.g., full name of organization, key contact persons, contact information, address, phone number, e-mail address). (Ms. Hamilton)
 - Ms. Branch will prepare a summary of the October 7 Quality of Cancer Care Committee meeting and distribute the report to DCLG members.
 - Mr. Porterfield will prepare an outline of a process by which the DCLG and other external organizations may contribute to the NCI bypass budget early in the budget development process. The summary will identify forms and mechanisms by which advocates and other groups outside the NCI may achieve this goal. Mr. Porterfield will distribute the outline to DCLG members and OLA staff prior to the November 19 conference call.