

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE
24th DIRECTOR'S CONSUMER LIAISON GROUP
MEETING
July 29, 2003**

SUMMARY

The 24th meeting of the NCI Director's Consumer Liaison Group (DCLG) was convened on Tuesday, July 29, 2003, as a teleconference. Ms. Barbara LeStage presided as Chair.

DCLG Members:

Ms. Barbara K. LeStage, Chair
Ms. Vernal Branch
Ms. Susan Butler
Ms. Kathy Giusti
Mr. Michael Katz
Ms. Ruth Lin

Ms. Gena Love
Mr. Christopher Pablo
Ms. Karen Packer
Ms. Nyrvah Richard
Mr. Doug Ulman
Dr. Marisa Weiss

Members Absent:

Mr. Henry Porterfield

ORC Macro Staff:

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

NCI Office of Liaison Activities Staff:

Ms. Nancy Caliman, Executive Secretary, DCLG
Ms. Elisabeth Handley, Acting Director
Ms. Jamelle Banks
Ms. Sarah Dash
Ms. Brooke Hamilton
Ms. Jessica Horwath
Ms. Jane Jacobs
Ms. Keisha Martin

I. WELCOME AND APPROVAL OF MINUTES OF MARCH 13, 2003 MEETING

Ms. Barbara LeStage called the meeting to order and asked DCLG members to absent themselves from any discussion with which they have a potential conflict of interest. Ms. Nancy Caliman determined that a quorum was present.

Motion: The DCLG approved the minutes of the March 13, 2003 teleconference meeting. The motion was made by Ms. Vernal Branch and seconded by Ms. Karen Packer, and was approved unanimously.

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

Ms. Elisabeth Handley announced that the Office of Liaison Activities (OLA) had hired a new program manager for the Consumer Advocates in Research and Related Activities (CARRA) program, Ms. Jane Jacobs. Ms. LeStage welcomed Ms. Jacobs.

Evaluation. Ms. Handley thanked Ms. Kathy Giusti for her help on the CARRA Evaluation Planning Group. The Group has developed a logic model that outlines program goals, program activities, and anticipated short-term and long-term outcomes. The group has developed and is implementing an evaluation plan based on the logic model. One of the first evaluation products will be a post-activity questionnaire for CARRA members and NCI staff to complete each time a CARRA member participates in an NCI activity. In addition, a survey of NCI staff attitudes and beliefs about using consumer advocates will be available in the coming year. This survey will be similar to one that OLA administered in September 2001. Ms. LeStage asked Ms. Handley to share the logic model and evaluation plan with DCLG members.

Training. Ms. Handley thanked Ms. Karen Packer for her help in developing the CARRA pilot training program. Based on a survey of CARRA members and discussions with NCI staff, the initial training pilot will focus on peer review. The CARRA Training Group will meet in September to develop a curriculum and an evaluation plan for the pilot with the help of a contractor. Ms. Handley predicted that the pilot training program would be ready in early 2004.

Planning. Ms. Kathy Giusti and Ms. Packer are members of the CARRA Planning Group. The group recently discussed whether CARRA members, whose terms end in 2004, should be able to continue for a second term without reapplying. OLA has decided that it will extend current members for one more term. The planning group also discussed areas for which more CARRA members are needed, such as disease-specific representatives. A very limited application process will be implemented to identify potential CARRA members in those areas for terms beginning in September 2004, with a particular emphasis on recruiting minority group members.

Activity Level. The level of CARRA activity is lower than at this time last year, but this may change in the coming months as July through September are typically busy for CARRA. OLA will analyze the causes of any changes in activity level from past years. OLA has promoted CARRA to NCI staff through presentations to large and small groups.

III. PRESIDENT'S CANCER PANEL SURVIVORSHIP INITIATIVE

Mr. Doug Ulman reported that the President's Cancer Panel (PCP) will address cancer survivorship during 2003 and part of 2004. The PCP recently held a meeting in Lisbon, Portugal to address survivorship from a European perspective, and is planning meetings across the country on survivorship issues related to five populations:

- Children,
- Adolescents and young adults,
- Adults,
- Older adults, and
- Providers and the healthcare community.

The PCP plans to focus on survivorship and quality of life issues, as opposed to survivorship and quality of care issues. Mr. Ulman asked the DCLG members for suggestions for speakers for these five meetings, as well as feedback on the PCP's meeting concepts. All travel expenses of speakers will be covered.

Mr. Christopher Pablo was pleased that each meeting would address a different target group as this will make the issues easier to discuss. Ms. Vernal Branch suggested that the Wellness Community be asked to provide speakers. Mr. Ulman asked DCLG members to e-mail him the names of other potential speakers and he will pass the names on to the PCP. Ms. LeStage urged DCLG members to consider submitting their own names as potential speakers. She stated that some DCLG members are knowledgeable about certain underserved communities and may wish to speak on their behalf, as it may be difficult for the PCP to find members of those communities who are willing to address them.

The PCP selects speakers based on the results of interviews of potential speakers. Ms. Nancy Caliman will send DCLG members a copy of the questionnaire used to interview potential speakers.

Ms. Susan Butler stated that speakers at the PCP meetings should be aware that their written remarks will be made available to the public. In addition, formal presentations are often followed by discussions with members of the PCP and the audience.

The meetings will culminate in a report to the President and Congress. Mr. Ulman has urged the PCP to ensure that the report includes recommendations. Ms. LeStage asked Mr. Ulman to consider the potential role of the DCLG in responding to or helping disseminate the PCP's recommendations on survivorship.

IV. UPDATE ON COOPERATIVE GROUP CLINICAL TRIALS REDESIGN PROJECT

Mr. Michael Katz reported on the July 28 conference call on the NCI cooperative group clinical trials redesign project. The call was a continuation of dialogue between NCI's Cancer Therapy Evaluation Program, the Patient Advisory Board of the Coalition of National Cancer Cooperative Groups, and the DCLG.

- The Central Institutional Review Board (CIRB) will change the way it tracks protocol review time by starting the review period on the date on which protocols are submitted for review, as opposed to the date on which the protocols are first reviewed by the Board.
- Eight of the top 50 accruing Cooperative Groups are participating in the CIRB pilot project.

- New statistics will be shared about accrual rates to trials under the Clinical Trials Support Unit (CTSU), and rates will be compared to accruals under the old system.
- The Concept Evaluation Panels (CEP) have been disbanded but their functions are being integrated into the review process.
- NCI is implementing a quantitative scoring system to bring more rigor to the process. This will potentially allow NCI to reduce the number of clinical trials supported to those with the highest priority. The savings would be used to address issues such as increasing reimbursement per participants.
- Advocates will be asked to review proposed changes to the informed consent template.
- The group will meet in approximately six months when a survey of reactions to the CIRB pilot project is complete.

V. UPDATE ON NCI/DCLG ADVOCACY SURVEY

Ms. Kathy Giusti reported that due to the requirements of the Office of Management and Budget (OMB) for government surveys, the NCI/DCLG advocacy survey had to be revised and streamlined. The survey was pretested in late May with approximately five individuals from both large and small organizations to ensure that the questions were easy to understand and that respondents did not have difficulty completing the questionnaire. The survey has now been fielded, and complete surveys have been received from 80 of the approximately 145 organizations surveyed, which is an excellent response rate.

Mr. Matt Suljak of ORC Macro, the survey contractor, reported on some of the notable survey results:

- 58% of respondents were very aware of NCI activities.
- 43% disagreed that NCI's research funding is appropriately balanced across cancer types.
- 84% agreed that NCI is having an impact on making clinical trials available for cancer patients.
- Prior to receiving the survey, 86% of respondents were aware of the DCLG's existence and 67% were aware of both the DCLG's existence and some of its activities.
- 54% believed that the most valuable activity of the DCLG would be helping facilitate better collaboration between NCI and the cancer advocacy community.
- 49% believed that the least helpful activity of the DCLG would be to help the advocacy community better understand the work of the NCI.
- 69% thought that the DCLG activity that would most benefit their constituencies was participating with NCI in the development of NCI strategies and priorities.
- 56% thought that the DCLG activity that would least benefit their constituencies was monitoring the implementation of a specific set of NCI strategies.
- 75% would prefer receiving communications from the DCLG by e-mail.

Ms. LeStage noted a difference between what the advocacy community viewed as the least valuable activity of the DCLG and what many at NCI view as the most important task for the DCLG.

Ms. Giusti has received a letter from NCI Director Dr. Andrew von Eschenbach, who supports the project to enhance OLA's database of cancer advocacy organizations. This effort was

originally part of the advocacy survey but was separated from the survey because of OMB confidentiality requirements. In the letter, Dr. von Eschenbach requested a proposal for the project, including its cost and timing.

ORC Macro will submit a draft report on the survey by August 15 to members of the Future of the DCLG Working Group. Based on comments from working group members, ORC Macro will distribute a final report to DCLG members at the beginning of September. ORC Macro will facilitate the DCLG's face-to-face meeting on September 24, which will produce specific recommendations to present to Dr. von Eschenbach.

Ms. LeStage thanked the ORC Macro staff and the members of the Future of the DCLG Working Group for their efforts in making the survey happen. Ms. Handley and Ms. LeStage also thanked Ms. Caliman for her hard work.

VI. PREPARATION FOR THE SEPTEMBER 24, 2003 FACE-TO-FACE DCLG MEETING

Ms. LeStage announced that the entire face-to-face meeting on September 24 would be devoted to reviewing the results of the advocacy survey and developing recommendations on the future of the DCLG to present to Dr. von Eschenbach. Ms. Peg Anthony of ORC Macro will facilitate the meeting, as she is skilled in helping groups develop recommendations based on survey results. The Future of the DCLG Working Group will then meet with Dr. von Eschenbach on September 30 to discuss the DCLG's recommendations. Some of the issues that the group will discuss with Dr. von Eschenbach are whether the DCLG should continue to exist and, if so, what types of members it needs, what its focus areas should be, and what types of activities it should conduct. Therefore, the recommendations from the September 24 meeting will be very important.

The following NCI divisions have been invited to send a representative to the September 24 meeting:

- Center to Reduce Cancer Health Disparities,
- Cancer Therapy Evaluation Program,
- Office of Cancer Survivorship,
- Office of Communication,
- Office of Education and Special Initiatives,
- Office of Science Planning and Assessment.

There was some discussion of whether to invite other NCI staff members, especially those who are supportive of the DCLG. Ms. Handley pointed out that the list of invited staff was based on those whose programs were the subject of survey questions and would have the ability to act on the results. Ms. LeStage suggested that DCLG members send the names of additional individuals to Ms. Caliman, who will determine whether they should be invited. DCLG members can also invite additional participants themselves since the meeting is open to the public. However, those who have not been formally invited to the meeting may only speak during the public comment sessions. Ms. Freeman suggested that limiting the group's size might increase its productivity.

Ms. Caliman had prepared a draft agenda that she will share with the Future of the DCLG Working Group. The final agenda should be available shortly.

The meeting on September 24th will take place from approximately 8:00 a.m. to 5:00 p.m. If several DCLG members arrive early enough the night before, reservations can be made at a restaurant for a group dinner organized by the DCLG. Those who are unable to book flights after 5:00 p.m. on the 24th should let Palladian, the meeting contractor know that they will need to stay an additional night.

VII. PUBLIC COMMENT

There was no public comment.

VIII. ADJOURNMENT

The meeting adjourned at 1:30 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

Attachments:
Roster

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

DCLG ACTION ITEMS

July 29, 2003

- Ms. Elisabeth Handley will share the CARRA evaluation logic model and evaluation plan with DCLG members.
- DCLG members will e-mail the names of suggested speakers for the President's Cancer Panel meetings on survivorship to Mr. Doug Ulman.
- Ms. Nancy Caliman will e-mail DCLG members a copy of the questionnaire used by the President's Cancer Panel to select speakers.
- DCLG members should consider volunteering themselves as potential speakers for the President's Cancer Panel meetings on survivorship.
- Mr. Ulman will define the potential role of the DCLG in responding to or helping disseminate the President's Cancer Panel's recommendations on survivorship and share this with the DCLG and then the PCP.
- ORC Macro will submit a draft report on the results of the advocacy survey by August 15 to members of the Future of the DCLG Working Group. Based on comments from working group members, ORC Macro will distribute a final report to DCLG members at the end of August.
- DCLG members should submit the names of potential participants for the DCLG's September 24, 2003, meeting to Ms. Caliman.