

**NATIONAL CANCER INSTITUTE
DIRECTOR'S CONSUMER LIAISON GROUP
Teleconference**

**Summary of Meeting
March 11, 2002**

The teleconference of the NCI Director's Consumer Liaison Group (DCLG) was convened on Monday, March 11, 2002. 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. Paula K. Kim
Ms. Ruth Lin, absent
Ms. Gena Love
Mr. Christopher Pablo
Ms. Karen G. Packer
Mr. Henry A. Porterfield
Ms. Nyrvah Richard
Mr. Doug E. Ulman
Dr. Marisa Weiss
Dr. Bradley J. Zebrack

NCI Liaison Activities Staff –

Ms. Elaine Lee, Executive Secretary
Ms. Tracy Clagett
Ms. Nina Ghanem
Ms. Brooke Hamilton
Ms. Elizabeth Handley
Ms. Rosalyn Lemak

NCI Office of Education and Special Initiatives Staff

Dr. Charmaine Cummings
Ms. Margo Michaels

CALL TO ORDER AND OPENING REMARKS

Ms. Barbara LeStage called the meeting to order and noted that several members of the public were listening in on the teleconference. Members of the public may not contribute to the discussion, but they are welcome to submit any questions or comments on the teleconferences in writing to Liaison Activities (LA) within 10 days of the meeting. Ms. LeStage reminded DCLG

members that they must identify any potential conflicts of interest that arise during the discussion.

DCLG members have now received copies of the minutes of the October meeting and the January and November conference calls. They must review these minutes and submit their comments to Ms. Elaine Lee, even if they do not suggest any changes. Unless Ms. Lee receives the approval of a majority of DCLG members, the minutes cannot become official.

APRIL MEETING AGENDA

The DCLG will meet on April 22 and 23. On Wednesday, April 24, some members of the Patient Advisory Board (PAB) and four members of the DCLG clinical trials working group (Ms. LeStage, Mr. Michael Katz, Ms. Kathy Giusti, and Ms. Vernal Branch) will meet to discuss the NCI clinical trials cooperative group system. All other DCLG members should plan to depart on Tuesday evening, if possible.

Dr. Andrew von Eschenbach, the new NCI director, will attend the meeting on the morning of April 22. DCLG members with questions or topics for Dr. von Eschenbach to address should submit those questions to Ms. LeStage before March 18, when she will meet with him to discuss his vision for the DCLG.

The DCLG, working groups, should plan conference calls before the April meeting to discuss what they will do in the coming year and how the DCLG will make a difference. Working groups that would like certain NCI staff members to participate in their meetings should determine their availability as soon as possible and let Ms. LeStage and LA staff know so that they can schedule the working group sessions accordingly.

Ms. Karen Packer and Ms. Nina Ghanem will present a draft of the agenda for the orientation for incoming DCLG members at the meeting. DCLG members should e-mail suggestions for the orientation to Ms. Packer. Ms. Elaine Lee will provide Ms. Packer with the evaluations of the last orientation.

Mr. Katz requested that the April meeting include a 30-minute, overview of the cooperative group clinical trials system to prepare DCLG members for the upcoming conference call.

REPORTS ON WORKING GROUP ACTIVITIES

Survivorship. Mr. Doug Ulman and Ms. LeStage will represent the DCLG at the Resilience Across the Lifespan Survivorship Meeting. Dr. Marisa Weiss will also attend the meeting, although not as an official DCLG representative. She will coordinate her attendance with Mr. Ulman and Ms. LeStage.

NCI will hold a state-of-the-science meeting on Symptom Management in Cancer: Pain, Depression and Fatigue on July 15–17. Dr. Zebrack will attend this meeting and report on it to the DCLG.

The DCLG will send a letter to Dr. von Eschenbach about the extraordinary opportunity it submitted, which should emphasize the importance of this initiative and invite Dr. von Eschenbach to discuss this issue. Ms. Paula Kim will schedule a conference call to draft the letter before the April meeting.

NCI has assembled an internal working group on palliative and supportive care issues that is considering whether to create a new coordinator position. Mr. Doug Ulman is to be the DCLG's representative on patient education, which is one of the issues being considered by this broader working group. Mr. Ulman will work with Ms. Lee to ensure that the DCLG is represented in the NCI working group's deliberations.

Clinical Trials. Mr. Katz reported that some progress has been made in the joint effort by the DCLG and PAB to collect grassroots input into NCI's cooperative groups process. The partnership has completed 25 interviews to date and will synthesize and summarize the results of the interviews once all 40 have been completed. Some cooperative groups have provided data, and NCI's Protocol Information Office has agreed to offer additional information.

Advocacy Involvement and CARRA Update. Ms. Tracy Clagett informed the DCLG that LA has received more than 30 requests since September for CARRA members to participate in NCI activities. An ethics module and a module for NCI staff on how the CARRA program works have been added to the Web site. DCLG members should review these new modules and send Ms. Clagett their comments.

NCI staff have now received the first wave of the attitude survey to assess current NCI staff members' perceptions of consumer involvement in NCI activities. The questionnaire will be distributed again in 2 or 3 years to see how these perceptions have changed. LA is working with an evaluation expert on post-activity questionnaires for CARRA members and NCI staff to complete following activities involving CARRA members. LA is also soliciting proposals for a contractor to fully evaluate CARRA.

Ms. Giusti reported that the working group's recent conference call focused on building awareness of CARRA within NCI.

The list of CARRA members who agreed to publish their names will soon be available, and will include the organizations with which they are primarily affiliated. The selection committee for CARRA members did not know their names or organizational affiliations, so it did not select members based on these characteristics.

Mr. Henry Porterfield has written an article for the *Nealon Report* on the relationship between the DCLG and CARRA. He will also write a monthly Web column on the use of CARRA members by NCI staff.

DCLG members may request input from CARRA members for their working group issues through the CARRA program director, Ms. Clagett.

Health Disparities. Ms. Branch, Ms. Nyrvah Richard, and Ms. Gena Love plan to discuss how to divide responsibilities now that the former health disparities and quality of care working group has been split into two different working groups. Ms. Ghanem will coordinate the teleconference.

A conference call will be scheduled for all members of the former Health Disparities and Quality of Care Working Group to discuss the composition of the new working groups. Ms. LeStage will ask all DCLG members at the April meeting whether they want to change their working group assignments.

Quality of Care. Dr. Marisa Weiss reported on the Quality of Care Committee meeting (QC3) she attended in December, which is attempting to establish standards of cancer care and develop a system to enforce those standards. Ms. Branch will be the DCLG's representative to this group at future meetings. LA staff will make sure that Ms. Branch is informed of future QC3 meetings.

DISSEMINATION OF NEW CLINICAL TRIALS SERIES

Dr. Charmaine Cummings reported that the first phase of the dissemination process involves notifying all NCI-sponsored groups of the clinical trials educational program. The Office of Education and Special Initiatives (OESI) has published approximately 5,000 copies of the four main books and several hundred thousand patient brochures. This phase focuses on "possible partner groups" who might use and disseminate the product. The Oncology Nursing Society, for example, is creating an online continuing education program for its members using the program. NCI is also working on similar efforts with other professional societies.

Ms. Margo Michaels added that OESI has asked several organizations to review and evaluate the materials. She will e-mail a note to DCLG members, asking if they would like to disseminate and promote the product and provide feedback on how it is used and might be improved. The feedback should focus on the use of the product, not the content.

Ms. Giusti told the DCLG that the Multiple Myeloma Research Foundation is offering some of the information on its Web site, along with a link to the NCI site for more information. The organization's newsletter also published a description of the program, along with the number to call for more information. Ms. LeStage asked all DCLG members to consider whether their organizations might do something similar. The advocacy and clinical trials working groups should work together to encourage the advocacy groups in the database to include this information in their newsletters and Web sites.

When future copies of the booklet are printed, the resource section should list the organizations that helped evaluate and build awareness of the program.

DCLG MEMBER REPORTS

All DCLG members should review the activities grid, including all meetings they attended on behalf of the DCLG, to ensure that the information is correct and complete. Members must submit reports on the meetings they attend. The grid covers the year between October 1, 2001, and September 30, 2002, and serves as the resource for the DCLG's annual report.

Ms. LeStage reported briefly on the Communications Opportunities Leadership Training (COLT) meeting she attended and promised to write a report on the National Cancer Advisory Board (NCAB) meeting. Mr. Ulman attended a meeting on physical activity and cancer survivorship and learned that little is known about this area. Many physicians tell their cancer patients to rest, but cancer patients subsequently suffer from the consequences of this inactivity.

NEW BUSINESS

DCLG members agreed that the recent issue of the *Nealon Report* was excellent. Ms. Packer will serve on the report's editorial board and welcomes ideas on future articles from her DCLG colleagues.

DCLG members should provide comments on the 2001 NCI Cancer Progress Report to Ms. LeStage. The report is available on the Internet.

This week, Ms. Lee will distribute potential dates for future meetings through 2003. DCLG members are to indicate any potential conflicts with major meetings or personal obligations.

ADJOURNMENT

The meeting adjourned at 3:56 p.m.

_____	_____
Date	Chair, Director's Consumer Liaison Group
_____	_____
Date	Executive Secretary Director's Consumer Liaison Group

ACTION ITEMS

- DCLG members should review the minutes of recent meetings and submit their comments to Ms. Elaine Lee as soon as possible.
- DCLG members should submit possible topics for Dr. Andrew von Eschenbach to address at the April meeting to Ms. Barbara LeStage before Monday, March 18.
- Working groups that would like NCI staff members to attend their discussions at the April meeting should ascertain the availability of those staff members and communicate this information to Ms. LeStage and LA staff.
- DCLG members should e-mail suggestions for the new members orientation to Ms. Karen Packer. Ms. Elaine Lee will provide Ms. Packer with the evaluations of the previous new DCLG member orientation.
- Ms. LeStage will add a 30-minute session to the April meeting agenda to provide an overview of NCI's cooperative group clinical trials system.
- Dr. Marisa Weiss will coordinate her attendance at the June survivorship meeting with Ms. LeStage and Mr. Doug Ulman.
- Dr. Brad Zebrack will report on the state-of-the-science meeting on symptom management that he will attend in July.
- Ms. Paula Kim will schedule a conference call of the survivorship working group to draft a letter to Dr. van Eschenbach about the group's extraordinary opportunity submission.
- Mr. Doug Ulman and Ms. Lee will ensure that the DCLG is represented on NCI's new internal working group on palliative and supportive care issues.
- Ms. Margo Michaels will e-mail all DCLG members to ask if they want to use and assess the use of the new clinical trials program.
- The advocacy and clinical trials working groups will discuss ways to encourage advocacy groups to publicize the clinical trials program in their newsletters and Web sites.
- DCLG members should review the new modules on the CARRA Web site and submit comments to Ms. Tracy Clagett.
- Ms. Vernal Branch, Ms. Gina Love, and Ms. Nyrvah Richard will hold a teleconference before the April meeting, to be coordinated by Ms. Nina Ghanem, to discuss the allocation of responsibilities between the two new working groups.
- Members of the combined working group will participate in a teleconference to discuss whether they plan to join one or both of the new working groups.
- At the April meeting, Ms. LeStage will ask all DCLG members whether they want to change their working group assignments.
- LA staff will ensure that Ms. Branch is informed of future QC3 meetings.
- DCLG members should review the activities grid to make sure that its information is correct and complete.
- Ms. LeStage will write a report on the NCAB meeting she attended.
- DCLG members should e-mail Ms. Packer with suggestions for *Nealon Report* articles.
- DCLG members should submit comments to Ms. Lee on the cancer progress report.
- Ms. Lee will distribute potential dates for future meetings and teleconferences. DCLG members should inform her of potential conflicts.
- Dr. Weiss will work with Ms. LeStage to coordinate discussions between working groups and NCI Office of Communications staff on communication priorities.