

**NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE
DIRECTOR'S CONSUMER LIAISON GROUP**

**December 4, 2000
12:30 p.m. - 2:30 p.m. EST
TELECONFERENCE
Minutes**

The teleconference of the NCI Director's Consumer Liaison Group was convened at 12:30 p.m. on Monday, December 4, 2000. The teleconference was open to the public. Mr. Michael Katz presided as chair.

DCLG members:

Mr. Michael Katz, *Chairperson*
Ms. Susan Butler (absent)
Ms. Kerry Dewey (absent)
Dr. Felicia Schanche Hodge
Ms. Barbara LeStage
Ms. Ruth Lin
Ms. Gena Love
Mr. Daniel Moore

Dr. Pamela McAllister
Mr. Hank Porterfield
Ms. Nyrvah Richard (absent)
Ms. Lillouise Rogers
Ms. Paula Simper
Ms. Susan Stewart
Dr. Brad Zebrack

NCI Liaison Activities staff participating in teleconference:

Ms. Elaine Lee, *Executive Secretary*
Dr. Yvonne Andejaski
Ms. Tracy Clagett
Ms. Elisabeth Handley
Ms. Laurie Rosenberg
Ms. Keisha Martin
Ms. Sabrina Reed

Consultant:

Ms. Kathy Joyce

CALL TO ORDER AND OPENING REMARKS

Mr. Katz called the meeting to order and determined that a quorum was present. He reviewed the rules governing confidentiality and conflict of interest. Dr. Yvonne Andejaski introduced Ms. Elizabeth Handley, the new Associate Director for Outreach and Partnership in the NCI Office of Communications.

**Follow up: Priorities Set by Dr. Klausner
(UPDATE ON DCLG WORKING GROUP ACTIVITIES)**

Advocacy Involvement Working Group

Health Advocates Listserv.

Dr. Brad Zebrack reported that the health advocates listserv is now operational. About 45 people have signed up so far. Part of the intent of this listserv is to broaden the cancer advocacy community; for this reason, participation in this listserv is open to those interested in becoming advocates as well as to those with experience in cancer advocacy.

Clinical Trials Working Group.

Jane Reese-Coulbourne, an advocate and consultant to NCI, has developed a self-study clinical trials education program for the general public, which includes a "train-the-trainers" component. The goal of the program, which is being piloted in North Carolina and Baltimore, is to change public perceptions of clinical trials.

Mr. Katz reported that the chairs of the NCI Clinical Cooperative Groups have agreed to provide their registration files to the Clinical Trials Support Unit. This should help to increase accrual to clinical trials nationally.

Quality of Cancer Care Working Group.

Ms. Gena Love reported on a conference call with Dr. Lipscomb, the NCI staff person leading the Quality of Cancer Care Challenge. Together they have identified two specific areas for immediate advocate involvement:

- The Cancer Outcomes Measurement Working Group, which is currently being constituted, will consist of about 15 to 20 members, including two consumer representatives, one of whom will be a DCLG member. This group will be evaluating outcome measurement instruments to assess quality of care. Participants will be expected to attend about three meetings, take part in several teleconferences and write a report within the next year.
- A Quality of Care Working Group will be convened within the next year and will include two or three consumer representatives. This group will review and evaluate existing recommendations on quality of care across the spectrum of cancer care.

Dr. Andejaski said that both of these working groups offer the opportunity for DCLG members to be involved in influencing the type of research that NCI supports to improve quality of care. Ms. Love noted that because quality of cancer care was designated as an NCI challenge in the National Cancer Institute's *Investment in Cancer Research. A Budget Proposal for Fiscal Year 2002.* There are likely to be many opportunities for advocate participation. The DCLG Working Group on Quality of Care is asking that more DCLG members volunteer to serve on the QOC group to enable it to meet this work demand (Current members of this working group are: Ms. Felicia Hodge, Ms. Ruth Lin, Ms. Love (chair), Ms. Lillouise Rogers, and Dr. Zebrack.). Ms. Clagett said there are likely to be a total of eight or ten opportunities for advocate involvement all relating to quality of cancer care. Volunteers can e-mail Ms. Clagett.

Health Disparities Working Group.

Ms. Love reported on a conference call with Dr. Jon Kerner, who is acting director of the new NIH Center for Reducing Health Disparities until a permanent director is appointed. Dr. Kerner identified several potential opportunities for advocate involvement, which are likely to evolve within the next year:

- There will be Health Disparities Working Groups with members from the Division of Cancer Control and Population Sciences staff, and a Health Disparities Coordinating Council in which there will be an Office of Cancer Survivorship (OCS) participant. The DCLG/advocate perspectives may be represented through OCS.
- It is anticipated that the Special Populations Working Group will evolve into an advisory committee for the Center. The DCLG currently has representatives on the SPWG and it is anticipated that this representation will extend to the Center's Advisory Committee.

Cancer Survivorship Working Group.

DCLG members who indicated interest in serving on this working group are: Ms. Susan Butler, Ms. Kerry Dewey, Mr. Katz, Dr. Pamela McAllister, Dr. Zebrack, and Ms. Paula Simper. The initial objective of this working group is to determine how the DCLG and its constituencies wish to interact with OCS. A teleconference will be scheduled with Dr. Julia Rowland, Director of the NCI Office of Cancer Survivorship, before the end of December.

UPDATE ON CONSUMER ADVOCATES IN RESEARCH AND RELATED ACTIVITIES PROGRAM

Dr. Andejaski said that senior NCI staff have made very positive comments about the Consumer Advocates in Research and Related Activities (CARRA) draft program overview and its supporting documents. The size of the CARRA pool of advocates is initially being limited to 150 people because this seems to be an adequate number to fill all requests from NCI programs and provide an opportunity for everyone to serve.

The DCLG discussed the feasibility of requiring all advocates who participate in NCI activities to be selected from the CARRA network. Dr. Andejaski said the Liaison Activities Branch does not currently have a mechanism for tracking all advocate involvement in NCI activities. The approach the Branch is taking is to communicate to NCI staff that they are encouraged to (a) involve advocates in all Institute activities; (b) use the CARRA program to simplify the process of finding suitable advocates; and (c) if they use advocates identified from outside the CARRA pool to register those individuals with the program and provide them with access to CARRA orientation and training opportunities.

The members also discussed mechanisms for broadly publicizing the existence of the program, recruiting applicants, and notifying individuals who have served in advocacy capacities in the past about the creation of the pool and encouraging them to apply. Dr. Andejaski said Liaison Activities staff are working with the NCI Health Promotion Branch on a recruitment strategy for the call for applicants and will be aiming for the widest possible dissemination. A briefing of the Cancer Leadership Council will take place at its meeting on January 9, 2001.

The following issues relating to CARRA were also discussed:

- C There was a consensus that members of the advocates' program should not be limited to serving three 3-year terms if they wish to continue beyond that time. Individuals should be notified that they need to reapply at the end of a 3-year term if they wish to continue to serve.
- C It was agreed that DCLG members whose terms will expire in 2001, should be encouraged to remain actively involved in NCI advocacy activities after their DCLG membership terminates and should apply for inclusion in the CARRA advocates' pool. DCLG members will not be allowed to be part of the program during their tenure on the DCLG.
- C The program overview will not be included in the package of materials that will be sent to potential CARRA applicants.
- C Applications for the CARRA pool will be accepted beginning in February 2001.
- C Applicants will be responsible for obtaining their own letters of recommendation.
- C Liaison Activities staff, in consultation with the DCLG, will make the final selection of individuals to be included in the CARRA pool.
- C DCLG members agreed that it would be helpful if the application could capture information about whether an applicant is a survivor of pediatric cancer or a parent of a child with pediatric cancer.

OTHER BUSINESS

The next conference call for the full DCLG will be held in mid-January 2001. Meetings and conference calls for DCLG working groups can be arranged by contacting Dr. Andejaski or Ms. Clagett.

DCLG members who expect to be traveling during the week before a scheduled conference call are asked to notify Ms. Martin in the Liaison Activities office to ensure that meeting papers are sent to them at their temporary address.

Date

Michael Katz
Chair, NCI Director's Consumer Liaison Group

Date

Elaine Lee
Executive Secretary
NCI Director's Consumer Liaison Group

ACTION ITEMS:

- Ms. Lee will ensure that copies of the clinical trials education program materials are sent to all DCLG members when they are available.
- Mr. Moore will follow up with Ms. Butler concerning the activities of the DCLG Clinical Trials Awareness Working Group.
- Those interested in serving on the Cancer Outcomes Measurement Working Group should indicate their interest by contacting Ms. Clagett by Friday, Dec. 8.
- Dr. Freeman will be invited to attend the next DCLG meeting as part of a one- to two-hour session on health disparities. The DCLG Working Group on Health Disparities, coordinated by Dr. Zebrack, will develop a draft agenda and consider who else should be invited to attend this session (To be discussed further at the next DCLG teleconference in January 2001.).
- DCLG members will confer via the listserv regarding who may wish to participate in the “Advocacy Forum” working group and who will chair it.
- Everyone with comments on the draft CARRA documents will submit them to Dr. Andejaski by fax or email by Tuesday, Dec. 12.
- DCLG members will provide information to Liaison Activities staff about individuals and organizations to whom the CARRA application package should be sent.
- DCLG members will notify advocacy listservs about the creation of the CARRA pool and encourage the submission of applications.
- Liaison Activities staff will investigate the feasibility of accepting requests for the CARRA application package via the Internet.
- Liaison Activities staff will send to DCLG members, by Jan. 1, 2001, a list of the materials that will be sent to potential CARRA applicants.

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