

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

**March 6, 2001
12:30 - 2:30 p.m. EST
Minutes**

The NCI Director-s Consumer Liaison Group (DCLG) convened a teleconference Tuesday March 6, 2001. The teleconference, which began at 12:30 p.m. and was open to the public. Mr. Michael Katz presided as Chair.

DCLG Members

Mr. Michael Katz, Chair
Ms. Susan Lowell Butler
Ms. Kerry Dewey
Dr. Felicia Schanche Hodge
Ms. Barbara K. LeStage
Ms. Ruth Lin
Ms. Gena Love
Dr. Pamela McAllister

Mr. Daniel Moore
Mr. Henry Porterfield
Ms. Nyrvah Richard
Ms. Lillouise Rogers
Ms. Paula Kim (Simper)
Ms. Susan Stewart
Dr. Brad Zebrack

NCI Liaison Activities Staff

Ms. Elaine Lee, Executive Secretary, DCLG
Dr. Yvonne Andejski
Ms. Tracy Clagett
Ms. Keisha Martin
Ms. M.. Kathleen Joyce (Consultant)

CALL TO ORDER AND OPENING REMARKS

Mr. Michael Katz called the meeting to order and determined that a quorum was present. He reviewed the rules governing confidentiality and conflict of interest.

DCLG Members Participation

Ms. Elaine Lee thanked the DCLG members for their timely responses and hard work over the last few weeks.

Mr. Michael Katz asked for opinions on whether the new chair should have a term of one or two years. Dr. Klausner has indicated that he is willing to change the DCLG charter as needed to accommodate the committee-s decision. Members noted that a one-year term would allow more members to serve in leadership positions, while a two-year term would allow the chair to gain additional experience and

become a more visible presence at NCI. Katz agreed that there is a considerable learning curve, but that experience could also be gained by electing both a chairman (with one year to serve), backed up by a vice chairman (with two years to serve). When the matter came to a vote, the committee divided evenly, and the chair tabled the issue until the April meeting.

MS. Gena Love reported that DCLG members will have a role in NCI's Quality of Cancer Care activities. A DCLG member will attend the next meeting of the Special Populations Working Group on April 22, 2001. Mr. Katz will select someone from those who volunteer. Ms. Lee noted that DCLG representatives are also needed for the Bypass Budget and Extraordinary Opportunities Working Groups.

April DCLG Meeting

Ms. Lee reviewed the agenda for the April meeting. She asked members to inform her of topics that they would like Dr. Klausner to cover in his remarks, or that they would like to address during the open session on Wednesday. Members asked that time be added for follow-up questions and discussion. They also suggested that at least part of the CARRA discussion might be moved to Monday morning. All presenters for the advocacy session will remain for discussion and have been invited to dinner on Monday night. LA has been promoting the meeting within NCI, including all of the CARRA participating offices.

Ms. Kathy Joyce reported that, in response to feedback from members, the morning of day 2 has been set aside for discussion of DCLG's vision and agenda, a sort of baseline planning process, with the afternoon reserved for operational issues. In response to questions, she added that there are no predetermined limits on DCLG's role, and that members are urged to bring questions and issues from their constituencies. NCI wants DCLG to become a voice for the cancer community, and, while Dr. Klausner has a list of five or six areas where he wants input from that community, he is open to other issues as they arise. Ms. Love indicated that DCLG expects to have a role in identifying issues of concern. Ms. Kim suggested that the question of how DCLG communicates with its constituencies would also be a good topic for discussion on the second day..

CARRA Program

Dr. Yvonne Andejaski reported that the CARRA program is accepting nominations. LA is making presentations to numerous groups both inside and outside NCI, plus media appearances and PSAs. In addition, NCI has produced pieces for distribution through the NIH radio service, which serves smaller markets. DCLG members also described the actions they've taken to promote CARRA to their organizations, including leadership meetings, websites, listserves, and newsletter. Other members who want promotional materials can download them from the CARRA website, liaison.cancer.gov/CARRA. LA recently sent each member CARRA brochures to most members and will provide additional copies on request. Mr. Porterfield, Ms. Butler and Ms. Lin indicated that they needed 50 more brochures apiece.

Scoring of CARRA applications will be done by two NCI representatives and one DCLG member. Dr. Andejaski said several hours of the April meeting will be set aside to get the DCLG members views. Dr. Zebrack thought it was particularly important to discuss mechanisms for evaluation and accountability, and to build these mechanisms in now rather than trying to add them later. Candidates who meet the minimum requirements have been identified the network will be balanced for cancer site, ethnicity etc.

Current DCLG members who want to be CARRA members can be grandfathered in or can apply. If they wish to be grandfathered, they will need a recommendation from someone at NCI who is not LA staff. Incoming members of DCLG, however, will not be allowed to serve on CARRA during their three-year terms. NCI needs the DCLG members to be addressing the priorities set forth by Dr. Klausner. The network is expected to provide opportunities for advocate involvement and training for future DCLG members. Dan Moore asked if CARRA members will be permitted to apply for membership in DCLG.

Working Group Updates

1. **Survivorship. C** Ms. Kim reported that the working group held discussions with Dr. Rowland and has reviewed the Liaison Activities Database. They suggested several fields that should be added, and advocacy groups that should be added to the distribution. Dr. Rowland's goal is to gather input from the advocacy community about research issues important to cancer survivors.
2. **Clinical Trials. C** Ms. Butler reported that the working group reviewed the clinical trials training manual for advocates and made several suggestions to reduce redundancy. They want another look at it and a chance to discuss it at the April meeting. Their goal is to make the manual useful to local groups and it should be compact and user-friendly. DCLG and CARRA members can help by presenting the manual to grass-roots groups.
3. **Health Disparities. C** Activities are on hold pending review and guidance from Dr. Freeman.
4. **NCI Branding C** The working group wants a presentation from Nelvis Castro, possibly at the April meeting.

Adjournment

The teleconference was adjourned at 2:30 p.m. EST.

Date

Chair,
Director's Consumer Liaison Group

Date

Executive Secretary,
Director's Consumer Liaison Group

ACTION ITEMS

March 6, 2001

- \$ Mr. Michael Katz and LA staff will prepare papers describing various options, for discussion and a vote during the April meeting.
- \$ The DCLG will take nominations for chairman and vice chairman during the April meeting, with election by email thereafter.
- \$ Ms. Tracy Clagett will provide members with the URL of the Special Populations Network.
- \$ LA staff will revise the matrix of all opportunities for DCLG members to serve on NCI committees and working groups, with information on the mandate and term of the activity, how often the group meets, the term of the DCLG rep, the expertise or qualifications sought.
- \$ DCLG members provide Ms. Elaine Lee with job descriptions for the groups on which they have served, along with other ideas and suggestions.
- \$ The DCLG will discuss other opportunities and develop a process for selecting DCLG representatives who will participate in NCI activities at the April 2001 meeting.
- \$ DCLG members will email Ms. Lee with topics for discussion by Dr. Klausner and during the open session.
- \$ LA will revise the April meeting agenda to add time for questions and discussion.
- \$ LA will revise the April meeting agenda to move the CARRA discussion from day 3 to day 1 and/or 2, and move the working group sessions from day 2 to day 3.
- \$ LA will compile a list of DCLG working groups, current memberships, and past reports.
- \$ DCLG members will consult their constituencies on questions and issues that should be raised with NCI leadership and pass them along to LA, which will build them into the agenda for day 2 of the April meeting.
- \$ LA will set aside time on day 2 to discuss DCLG communication with their constituencies.
- \$ DCLG members will contact Ms. Clagett for addition copies of CARRA brochures and promotional materials.
- \$ Dr. Yvonne Andejaski will conduct a teleconference with the Advocacy Involvement working group, prior to the April meeting.
- \$ Dr. Andejaski will distribute the draft orientation packages (for CARRA members and NCI contacts) to DCLG members at least one week before the April meeting.
- \$ LA will identify areas of the CARRA discussion that will be addressed on day 1 and which ones can be held for day three.
- \$ LA will provide members with instructions for nomination and application to CARRA, as well as draft rules for CARRA and DCLG membership in the future, for discussion at the April meeting.
- \$ LA will ask Ms. Mango Micaela, the editor of the clinical trials training manual, to join the discussion at the April meeting.
- \$ LA will solicit advice from the working group on distribution of this manual.

