

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

**January 29, 2001
12:30 - 2:30 p.m. EST
Minutes of Teleconference**

The NCI Director-s Consumer Liaison Group (DCLG) convened for a teleconference January 29, 2001. Mr. Michael Katz presided as Chair.

DCLG MEMBERS

Mr. Michael Katz, Chairperson

Ms. Susan Lowell Butler

Ms. Kerry Dewey

Dr. Felicia Schanche Hodge (absent)

Ms. Barbara K. LeStage (absent)

Ms. Ruth Lin

Ms. Gena Love

Dr. Pamela McAllister

Mr. Daniel Moore

Mr. Henry Porterfield (absent)

Ms. Nyrvah Richard

Ms. Lillouise Rogers

Ms. Paula K. Simper

Ms. Susan Stewart

Dr. Brad Zebrack

LIAISON ACTIVITIES BRANCH STAFF

Ms. Elaine Lee, Executive Secretary

Dr. Yvonne Andejaski

Ms. Tracy Clagett

Ms. Nina Ghanem

Ms. Keisha Martin

Ms. Kathy 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.

ADVOCACY FORUM

Dr. Brad Zebrack announced plans for the session on advocacy as part of developing ways for the DCLG to work with NCI on health disparities at the next meeting of DCLG scheduled for

April 16-18, 2001. Dr. Harold Freeman, newly appointed Director of the NCI Center for Reducing Cancer Health Disparities, will make a brief presentation. This will be followed

- \$ session will include a description of the advocacy movement by Ms. Ellen Stovall
- \$ presentations on different models of cancer advocacy, including the national perspective from Mr. Hank Porterfield of US TOO Inc; local or grass roots (speakers to be determined),
- \$ description of concerns of minority and underserved communities by Ms. Karen Jackson, Sisters Network in Texas
- \$ presentation related to minority research organization by Dr. Grace Ma of Temple University. This will be followed by a discussion of next steps.

Under consideration is whether DCLG's role should be the narrow one of helping the Center find partners on the single issue of health disparities, or the broader one of facilitating partnerships between NCI and a wide range of advocacy groups on a continuing basis.

CONSUMER ADVOCATES IN RESEARCH AND

RELATED ACTIVITIES (CARRA) PROGRAM

Dr. Yvonne Andejski presented the CARRA program at the January 2001 meeting of the Cancer Leadership Council (CLC), a coalition of 28 membership organizations. She also said that CARRA was discussed by the NCI Executive Committee in December. The CLC expressed concern about whether there were enough qualified advocates for the 150 places in the program. The DCLG members did not believe it would be a problem. However, DCLG members share CLC's concern that the program would not be mandatory throughout the Institute but would apply only to patient-orientated and clinical research. As currently planned, CARRA membership will be required for all NCI programs in epidemiology, population studies and clinical medicine; only basic science would be excluded. Individuals who are already involved in these programs might be grandfathered in, but they must be recommended by an NCI staff member who should send Ms. Clagett an email or letter. Ms. Clagett will provide an application to the designated advocates. DCLG members, and advocates in the various Cancer Cooperative Groups, are not automatically included in CARRA; they must apply for membership. DCLG members expressed concern that, as members of a very senior advisory group, they would not be allowed to participate in other NCI activities (e.g., peer review). Their recommendation is that NCI should not exclude DCLG members from the CARRA pool, or dictate their roles, or restrict their additional activities.

DCLG Recruitment For CARRA

Promotional materials for CARRA recruitment include a flyer, an application instruction booklet and a press release. Distribution will encompass LA's advocacy organizational mailing list, the NCI Public Affairs Networks, Cancer Centers, Special Populations Networks, Cancer Patient Education Network, CIS partners, etc. DCLG members recommended that distribution also include the Association of Cancer Online Resources (ACOR) list of owners, which could disseminate the announcements to a wide range of organizations.

CARRA Website

The website is on track for its February 1 launch date. The prototype is already online. DCLG members indicated that advocacy organizations will promote the CARRA website once they know about it. They suggested that the URL should be linked to the Cancer Trials web site.

DCLG MEMBERS PARTICIPATION

Feedback/Communication With Liaison Activities

Dr. Andejaski reported that LA has been sending a lot of materials to DCLG members but has gotten little feedback. A recent example is the second draft CARRA announcement and application instructions. Another example is the minutes of DCLG meetings and teleconference. DCLG members said that they didn't know a response was required, but that they would be glad to provide one in future. They asked LA staff to provide up-to-date calendars and rosters.

Process for Selecting Next DCLG Chair

Mr. Katz reported that the DCLG charter does not specify a process for selecting a chair, merely stating that DCLG members will serve for three years and there shall be a chair. Mr. Katz was designated by Dr. Klausner, rather than elected, but he believes that the group should choose its own chair and establish an orderly process for the future. One possibility would be to choose a member entering his or her third year to be chairman, and another entering his or her second year to be vice-chair or chair-elect. The April meeting would be a good time to finalize the process for selection, since it would put the selection in the hands of experienced members and allow a two-meeting overlap between old and new chairs.

Orientation Programs

Dr. Andejaski asked DCLG members to provide LA with guidance on what materials should be included in the orientation package for CARRA program members and for the NCI scientists. Members suggested that LA staff review the materials that are included in orientation packages for other organizations, such as Eastern Cooperative Oncology Group (ECOG) and the National Coalition of Cancer Cooperative Groups.

Agenda for April Meeting

Mr. Katz reported that the April meeting will be extended to two and one-half days, with the extra time devoted to DCLG process and priorities. This will also allow time for the various working groups to meet face-to-face. The meeting will begin in the morning of Monday April 16th, there will be a dinner to honor outgoing members on Monday night.

WORKING GROUP UPDATES

Cancer Survivorship

Ms. Kim reported that this working group held a teleconference with Dr. Julia Rowland of the NCI Office of Cancer Survivorship, who wants to establish a master list of all cancer advocacy groups, preferably in database format. The current Liaison Activities list contains 150-200 organizations, mostly national. Dr. Rowland wants to expand this list to include regional and local groups, with consistent information on their membership and activities. It might be possible, within a year, to provide online registration for new groups. Dr. Rowland also asked if advocacy groups would be willing to help NCI conduct unofficial outcome surveys and studies, for example; What information and services most survivors need? DCLG members indicated that most groups would be willing to help, as long as they had input into the list and the questions. They pointed out that NCI has excluded local groups in the past and should reverse this policy since national groups do not pass along pertinent information. Members asked whether NCI would be willing to reimburse advocacy groups for the costs of distributing survey materials, and hire someone to collect and analyze the responses. The sharing of mailing lists might raise privacy issues. Members indicated that the best results came from community meetings and the physical distribution and collection of survey materials. This might be possible if NCI could provide the materials and reply envelopes, along with sufficient lead time (several months) to set up local meetings.

Clinical Trials

Ms. Susan Butler reported that the revised Clinical Trials Handbook has been distributed to the working group for review and comment. They will also advise NCI on how to use the document, and then decide on future activities. The deadline for comments is February 16, 2001.

Health Disparities

Ms. Love reported that the working group's activities have focused on organizing the AAAdvocacy@forum at the April meeting. Other activities are on hold as NCI makes decisions about policies and programs. The DCLG should develop a process for selecting people to serve as the need arises.

Quality of Cancer Care

Ms. Love noted that the DCLG should determine how members should be chosen for new NCI opportunities. Dr. Zebrack will represent the DCLG to the NCI Cancer Outcomes Measurement Working Group beginning with the February 10-11 meeting. A second advocacy

member was selected by LA. In the future, the second member will come from the CARRA program. In the future there will be a number of smaller, disease-specific focus group meetings. The working group will have a better focus on this issue after the April meeting. The DCLG will establish a process for selecting DCLG representatives at the April 2001 meeting.

NCI Branding

Ms. Kerry Dewey reported that the Identity Action Plan, approved by the NCI Executive Committee, is designed to articulate who NCI is, what it does, and to develop a single logo phasing out others. The draft logo is under development and should be approved by the end of February. Ms. Dewey has seen the draft plan, which she considers pretty general, but not the draft logo. She distributed the draft plan to the other members of the working group but received no feedback.

NCI Website

Mr. Katz reported that several DCLG members participated in the usability testing of the new CancerNet website but that there has been no final decision or announcement on the launch. The DCLG has yet to find a vehicle for participating in this activity. He will speak with Dr. Klausner and Ms. Lee before taking the next step.

Extraordinary Opportunity In Cancer Communications

Mr. Katz reported that activities continue with development of an RFA on CANCORS. It will be possible for the DCLG to suggest new opportunities when the next round of the National Investment in Cancer Research planning begins in March.

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

Date

Michael Katz
Chair, DCLG

Date

Elaine Lee
Executive Secretary, DCLG

ACTION ITEMS
JANUARY 29, 2001 TELECONFERENCE

- \$ Ms. Elaine Lee will distribute prepared materials on the topic of health disparities and on the efforts of NCI, NIH and HHS to address this topic, including the Center, NCI.
- \$ The Advocacy Forum Working Group will reconvene to choose a presenter on local partnerships.
- \$ Ms. Tracy Claggett will clarify the NCI's objectives for the Advocacy Forum session with Dr. Kerner.
- \$ Dr. Andejaski will clarify the participation of DCLG members in the CARRA network.
- \$ Ms. Claggett will check with the NCI Press Office to ensure that the CARRA announcement is sent to ACOR and other electronic press release services.
- \$ Ms. Lee will post the URL for the CARRA website prototype to the DCLG listserv, and members will forward their comments to her.
- \$ Future communications from LA to DCLG will indicate whether a response is desired, and members will give a reply such as A received and approved or No comment.
- \$ Ms. Martin will provide members with a calendar of meetings and teleconference, as well as current roster of DCLG members.
- \$ Mr. Katz will compile a list of his tasks and time commitment as chair, for the information of potential candidates. He will distribute this, with suggestions for the process of selecting a chair, for discussion by DCLG members over the next month.
- \$ The DCLG will submit nominations for chair at the April meeting.
- \$ At the next teleconference, the DCLG will begin discussions of how to select members to represent DCLG on various NCI committees.
- \$ The DCLG members will send suggestions to Ms. Martin, who will ensure that they are included as orientation materials for the new DCLG members are developed.
- \$ Ms. Kim will consult with Dr. Andejaski about compiling a master list of advocacy organizations, and with Dr. Rowland on the content of an outcomes survey.
- \$ The Clinical Trials Working Group will hold a teleconference to collect comments and suggestions on the draft revised Clinical Trials Handbook.
- \$ Dr. Brad Zebrack will report to the DCLG on the COMWG meeting and get information on the schedule of disease specific group meetings to which DCLG may send representatives.
- \$ Ms. Kerry Dewey will redistribute the draft Identity Action Plan to the entire DCLG, along with the logo when available, for review and comment.
- \$ Ms. Lee will invite Ms. Ann Lubenow or Ms. Nelvis Castro to give an update on the Identity Action Plan at the April meeting.
- \$ Ms. Lee will include an agenda item for the April meeting to have the DCLG discuss what they want to submit as an extraordinary opportunity for the 2004 Bypass Budget.

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