

**NATIONAL INSTITUTES OF HEALTH  
NATIONAL CANCER INSTITUTE  
DIRECTOR-S CONSUMER LIAISON GROUP  
August 13, 2001  
12:00 p.m. - 2:00 p.m (EST)  
TELECONFERENCE  
Minutes**

The teleconference of the NCI Director-s Consumer Liaison Group (DCLG) was convened at 12:00 p.m. on Monday, August 13, 2001. The teleconference was open to the public. Ms. Barbara LeStage presided as chair.

**DCLG Members**

Ms. Barbara LeStage, Chair  
Ms. Susan Butler  
Mr. Michael Katz  
Ms. Paula Kim  
Ms. Ruth Lin, absent  
Ms. Gena Love  
Mr. Henry (Hank) Porterfield  
Ms. Nyrvah Richard  
Dr. Brad Zebrack

**NCI Staff**

Ms. Elisabeth Handley

**NCI Liaison Activities Staff**

Ms. Elaine Lee, Executive Secretary  
Dr. Yvonne Andejaski  
Ms. Tracy Clagett  
Ms. Brooke Hamilton

**CALL TO ORDER AND OPENING REMARKS**

Ms. Barbara LeStage called the meeting to order and determined that a quorum was present. She reviewed the rules governing confidentiality and conflict of interest. Ms. LeStage deferred the discussion of the CARRA Program.

**Conference Call Schedule.** Ms. LeStage stated that the DCLG will be holding conference calls monthly between the regular scheduled April and October meetings. A tentative schedule of upcoming call dates and times has been set up, and Ms. Keisha Martin will forward a copy of the suggested schedule within a week.

**The Nations Investment in Cancer Research. (Bypass Budget).** DCLG members should have received NCI's draft Bypass Budget for fiscal year 2003. DCLG members should review the budget and forward comments to Ms. Paula Kim, who will consolidate and forward the Group's feedback to Ms. Kathie Reed and Ms. Cherie Nichols. Ms. Kim asked callers to pay special attention to issues in the budget that pertain to their areas of interest/Working Groups (e.g., Quality of Cancer Care, Health Disparities), extraordinary opportunities, and new initiatives. Ms. Kim noted that consolidating and submitting comments from the group as a whole is preferable to submitting individual comments. LA staff will resend copies of the Bypass Budget to those whose version was incomplete. In addition, Ms. Elaine Lee will contact Ms. Reed about extending the deadline for submission of comments on the Bypass Budget.

## OCTOBER 2001 DCLG MEETING

**Meeting Overview.** Dr. Yvonne Andejaski provided an overview of the meeting and agenda thus far. The next in-person meeting of the DCLG will be held October 15<sup>th</sup> through 17<sup>th</sup>. The first day of the meeting will begin at approximately 8:30 a.m. with a presentation by NCI Director Dr. Richard Klausner. This will be followed by a question and answer session. The meeting will include a short discussion and review of the ethics associated with being part of a chartered government committee; Ms. Lee explained that all staff, including special government employees, must be briefed annually on these ethical issues.

There was general agreement that a considerable amount of time during the meeting should be set aside so that each Working Group can meet. Dr. Andejaski noted that new members will receive materials about the working groups prior to the meeting.

Working Group leaders were asked to contact NCI staff with whom they are working and invite them to the DCLG meeting and they should notify Ms. Lee and Ms. LeStage of the availability of NCI staff. Dr. Brad Zebrack suggested that the DCLG spend some time identifying strategies to increase diversity and outreach with respect to CARRA and DCLG membership. Related issues include addressing how DCLG members are recruited and improving outreach to constituent groups. Nontraditional, innovative approaches are needed. DCLG members were asked to submit suggestions to Ms. LeStage, Ms. Lee, and Dr. Andejaski by the end of the week. Mr. Katz thought the group could also benefit from an

update on the status of the extraordinary opportunities in cancer communications; he will invite Dr. Barbara Rimer to the October meeting to address this topic.

Ms. LeStage, Ms. Lee and Dr. Andejaski will prepare a draft agenda based on these discussions. The agenda will be finalized at the September teleconference.

### **CARRA UPDATE**

**Consumer Advocates in Research and Related Activities (CARRA).** LA and NCI established CARRA as a way to facilitate consumer involvement in scientific (e.g., peer reviews, site visits) and communication (e.g., Web site development, publications development) activities. A call for nominations to CARRA was released in Spring 2001, and more than 500 applications were received. A total of 423 applicants met the initial eligibility criteria for scoring. Of these 423 applicants, 150 persons have been identified as potential new CARRA candidates. Final selections were made using a matrix of all variables of interest (e.g., cancer type, gender, age, ethnicity, and geographic location and distribution) to generate a balanced pool of members. Approximately 75 qualifying individuals will be grandfathered into CARRA, bringing the total pool to 225.

The next step involves contacting the candidates directly to ask them if they accept membership into the CARRA pool. A draft letter is being prepared and will be sent to DCLG members for comment. Candidates are expected to be contacted by Labor Day. Ms. Tracy Claggett will send group members a listing of the general demographics of CARRA candidates; a final list will go out only after candidates have agreed to join the CARRA pool.

CARRA orientation modules are expected to be placed on the Web site for testing around Labor Day.

### **WORKING GROUP UPDATES**

**Cancer Survivorship Working Group (SWG).** (Ms. Paula Kim, Chair; Dr. Brad Zebrack, Ms. Gena Love, Mr. Mike Katz, and Ms. Nyrvah Richard). Ms. Kim noted that the strong presentations relating to advocacy, moderated by Dr. Zebrack, that were made at the April DCLG meeting were very effective in generating productive discussions. The presentations provided background and history of cancer advocacy, key issues for cancer advocates, and constituent groups. The SWG suggests a similar forum for the October DCLG meeting that would include post-treatment issues and resources. SWG members will coordinate these efforts with Dr. Julia Rowland (NCI Office of Cancer Survivorship) and Ms. Margo Michaels (NCI Office of Education and Special Initiatives). Through this forum, the SWG hopes to assist Dr. Rowland's office in identifying research needs and gaps, untapped

areas, and develop a new extraordinary opportunity relevant to cancer survivorship. This is important because the number of cancer survivors continues to grow. The SWG will discuss and develop plans for this forum in future conference calls. Ms. Kim asked DCLG members to submit suggestions for the forum, including the names and contact information of individuals and organizations focused on survivor needs. Dr. Andejaski, Ms. Kim, Ms. LeStage, and Dr. Rowland will participate in the initial planning call on Friday, August 17<sup>th</sup>; a full SWG call will follow.

**Clinical Trials Working Group.** (Ms. Susan Butler, Chair; Mr. Hank Porterfield, Mr. Mike Katz, Ms. Gena Love) (Ms. Pam McAllister has resigned from DCLG). Ms. Butler has sent DCLG members Ms. Michaels= response regarding an update on the status of the workbook on clinical trials, which, she noted, has required an extensive period of time to finalize. It appears that the DCLG will not have another opportunity to review the workbook prior to its publication and release. However, it will be worthwhile for the DCLG to offer Ms. Michaels and her staff some concrete suggestions as to how to disseminate materials such as the workbook.

Another issue being discussed by the Working Group is whether the DCLG is interested in hosting a meeting on clinical trials and advocacy. Ms. Butler noted an upcoming Cancer Clinical Trials Summit Meeting (Summit) co-sponsored by the Cancer Research Foundation, ASCO, ONS, and others being held on October 3<sup>rd</sup> through 5<sup>th</sup> in Virginia. The purpose of this summit is to launch a public engagement effort in clinical trials. Mr. Porterfield noted that previous summits centered around increasing participation in clinical trials; however, little follow-up activity by the general public or advocates has been observed. He suggested attending the summit and then making an assessment regarding the extent of involvement of the DCLG.

Mr. Katz, who serves on the coalition sponsoring this Summit, suggested that DCLG and NCI seek official representation at the meeting. Mr. Katz, Dr. Andejaski, Ms. Butler and Mr. Porterfield are planning to attend the Summit. Mr. Katz suggested that NCI ask Ms. Mary McCabe, who heads NCI's clinical trials promotions efforts, to represent NCI.

It was noted that increasing clinical trials awareness is one of Dr. Klausner's priorities for the DCLG. Mr. Porterfield commented on the variable success and failure of different trials in recruiting and retaining study participants. He noted the highly effective advertising campaign associated with the upcoming SELECT trial, which will investigate the possible role of vitamin E and selenium in preventing prostate cancer. Others noted that certain activities and strategies, such as use of pamphlets, do not work and that the DCLG may be able to assist NCI in identifying more creative, effective recruitment approaches and tools. The SELECT program may serve as a solid starting point for further investigation. The Clinical Trials Working Group will take the lead on this issue.

**Health Disparities/Quality of Cancer Care Working Group.** (Ms. Gena Love, Chair; Ms. Ruth Lin, Dr. Brad Zebrack, Dr. Felicia Hodge, Mr. Mike Katz, Ms. Nyrvah Richard). Ms. Love addressed the *Health disparities* activities first. Ms. Love and Ms. Richard attended the July meeting of the Cancer Control Academy as representatives of the DCLG. A member of Ms. Richard's staff (the Director of the Latina Program at SHARE) also attended the meeting, and she and Ms. Richard will send Ms. Love notes and comments from the meeting. This was the second year in which DCLG was represented, and the meeting provides a good opportunity to network with the leaders in the field. Ms. Love suggested inviting some of these researchers and leaders to future DCLG meetings.

The Cancer Control Academy, held in July brought together the Principal Investigators of the Special Populations Networks (SPNs). The purpose of the Special Populations Network is to build relationships between large research institutions and community-based programs and to find ways of addressing important questions about the burden of cancer in minority communities.

A core group of NCI staff has met over the last year and recently established group and three subcommittees composed of SPN grantees and NCI staff. The focus areas of the subcommittees are research and development; training and evaluation; and communications. NCI is now considering expansion of the group to include grantees. CARRA members may be better suited to fill positions on the subcommittees. The DCLG will explore options for advocate involvement and how community partners are involved before making a recommendation.

Ms. Love met with Dr. Kerner the DCLG's contact to NCI Center for the Reduction of Cancer Health Disparities (CRCHD) directed by Dr. Harold Freeman to get an update on activities in health disparities. Dr. Kerner identified a set of initiatives in which DCLG members and/or advocates can participate. The first opportunity is a cervical cancer think tank of approximately 25 to 30 participants who will meet in September in Washington, DC. The focus of the meeting will be to sort out the challenges facing diagnosis and treatment of cervical cancer in women living in rural areas. Ms. Love will attend the think tank meeting in September. A follow-up meeting will be held in November 2001, and a final meeting is scheduled for Spring 2002.

The Special Populations Working Group which helped the office of Special Populations Research with a number of important issues may become an advisory committee to CRCHD. The DCLG which has a liaison to this group feels that this should continue if this group becomes an advisory committee.

A high priority for the Health Disparities Working Group is the collection and development of poignant survivor stories that highlight problems and successes with cancer diagnosis, care, and survivorship. Dr. Kerner supports the effort and feels these stories could be used to help NCI identify areas for research. Ms. LeStage suggested that the DCLG work with the American Cancer Society (ACS) to

take advantage of stories they already have. She will provide Ms. Love with contact information. The Zebrack National Coalition for Cancer Survivorship could be a source. Another strategy involves looking at stories gathered at the regional town hall meetings sponsored by the President's Cancer Panel. Ms. Tracy Clagett has follow up information on a report being prepared that summarizes the complement of town hall meetings; she noted that video tapes and transcripts are available for some of the meetings. The Working Group will take the lead on developing a process for evaluating the stories collected.

The issue of racialism and cancer care has been raised by Dr. Freeman as a new area of investigation under exploration. Ms. Clagett will follow up on the specifics of this issue and also suggested possible roles for DCLG or CARRA.

Ms. Love reported that the *quality of cancer care* activities are moving forward. She and Ms. Clagett met with Dr. Joe Lipscomb during the Cancer Control Academy meeting to discuss and review the WG's white paper, which has been revised and updated.

Dr. Brad Zebrack is a member of the Cancer Outcomes Measures Working Group (COMWG), which consists primarily of researchers studying the psychological, social, and quality of life outcomes of cancer patients and survivors. The group focuses on four cancers with the highest incidence and mortality in the United States (breast, lung, colorectal, prostate). The committee thus far has examined the available literature to identify the most reliable and valid approaches to measure quality of life, psychological, and social factors in cancer care. A draft of the committee's findings is anticipated for October, and a final report is expected to be published in late 2002. Once this phase of COMWG's investigations is over, the committee expects to link a set of measures and outcomes to assessment of quality of cancer care. Dr. Zebrack and Mr. Jim Williams of US-TOO, International are the two advocates on the committee. Dr. Zebrack offered to present highlights of COMWG's study at the April 2002 DCLG meeting, pending release of the findings.

Another activity involves the COMWG disease-specific focus groups that were held over the summer. Each group included seven to eight patients and survivors, some of whom are also advocates. All groups have been completed, and the results are being compiled and evaluated, Ms. Clagett will contact Dr. Lipscomb for an update on this project.

Ms. Love raised the issue of possibly splitting the current Health Disparities/Quality of Cancer Care Working Group into two smaller groups, one focused on health disparities and another on quality of cancer care. She encouraged callers and new members to consider joining the Working Group and contributing further to the efforts in either or both areas.

**Advocacy Involvement Working Group.** (Dr. Brad Zebrack, Chair; Mr. Mike Katz, Mr. Hank Porterfield, Ms. Barbara LeStage). This Working Group has been active in the CARRA recruitment and is also seeking to expand outreach to broaden advocate involvement. Dr. Zebrack drafted a sample letter to send to advocacy groups in an effort to more clearly engage the array of advocates within the community and to define DCLG strategies to target and engage advocates further. He asked DCLG members to review the letter within 1 to 2 weeks.

**NCI Branding Working Group.** Ms. Kerry Dewey, the chair of this working group ended her term as a DCLG member in June 2001. No replacement has been named. Ms. Clagett reported that the focus groups on the proposed NCI brand have been completed, and data from the focus groups are being collated. Ms. Clagett will follow up on the status of future DCLG involvement.

**Operations Working Group.** Originally this working group was formed to work on the 2000 DCLG Annual Report. That is complete and the group has not been active since that time. Ms. LeStage suggested on disband this Working Group.

## **ADJOURNMENT**

The meeting adjourned at 2:00 p.m.

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Director-s Consumer Liaison Group

**ACTION ITEMS**  
**August 13, 2001**

- \$ Ms. Keisha Martin will forward the proposed dates and times of future monthly calls for the group.
- \$ Ms. Martin and Ms. Lee will resend copies of the Bypass Budget to the group (every other page was missing in the previous copy).
- \$ DCLG members should forward their comments on the Bypass Budget to Ms. Paula Kin, who will consolidate the group's comments and forward them to Ms. Kathie Reed and Ms. Cherie Nichols.
- \$ Ms. Lee will e-mail the URL for the Bypass Budget and outline the new guidance on submitting comments on the budget.
- \$ Ms. Lee will contact Ms. Reed about extending the deadline for submitting comments on the Bypass Budget.
- \$ DCLG members should forward to Ms. Kim (by Friday, August 17<sup>th</sup>) the names and contact information of individuals and organizations that could provide input on cancer survivor needs and issues in support of the Cancer Survivorship Working Group's efforts to assist Dr. Rowland in developing innovative and comprehensive initiatives and identifying extraordinary opportunities in this area.
- \$ Working Group leaders should contact the appropriate NCI staff about availability to attend the October DCLG meeting (e.g., Ms. Susan Butler will contact Ms. Mary McCabe; Ms. Katz will contact Dr. Barbara Rimer). The Working Group leaders should then report back to Ms. Lee, Dr. Yvonne Andejas, Paula about the specific time(s) the NCI staff can attend the meeting. Ms. LeStage will work with LA to finalize the agenda.
- \$ DCLG members should forward to Ms. Lee and Dr. Yvonne (by Friday, August 17<sup>th</sup>) suggestions about improving outreach efforts to recruit new DCLG and CARRA members, with a focus on increasing the diversity of membership.
- \$ Ms. Tracey Clagett will distribute the general demographics of candidate CARRA members.
- \$ Ms. Love and members of the Quality of Care/Health Disparities Working Group will follow up on developing cancer patient and survivor success stories, many of which are available through the American Cancer Society. Ms. Clagett will follow up on locating and forwarding to Ms. Love a transcript of the President's Cancer Panel meeting and the names and contact information of those giving testimony at the meeting. The Working Group will begin to develop a process for gathering information for preparing and presenting these stories.
- \$ Ms. Love, Ms. Clagett, and Ms. Barbara LeStage will meet via conference call by the end of August discuss options for advocate involvement on the Special Populations Networks subcommittees and core group.
- \$ Ms. Clagett will update Dr. Lipscomb on the findings of the COMWG disease-specific focus



groups held over the summer.

- \$ Ms. Love will e-mail the revised copy of the Quality of Care white paper to Ms. LeStage.
- \$ DCLG members should respond within 1 to 2 weeks to Dr. Brad Zebrack's draft letter from the Advocacy WG seeking to improve and expand outreach to advocacy groups. Callers were asked to consider the types of questions and issues the letter should include, such as asking about the size and mission of an advocacy organization, identifying the most appropriate contact person, inquiring about involvement in or promotion of clinical trials, and others.
- \$ Ms. Clagett will distribute the draft of the letter inviting candidates to join CARRA. DCLG members should provide Ms. Clagett with feedback on the letter.
- \$ Ms. Lee will resend the NCI Liaison Activities Branch advocacy database list.
- \$ Ms. Clagett will follow up on the status of future involvement of the DCLG in NCI Abranding@ efforts.
- \$ Ms. Nyvah Richard will send Ms. Love notes and comments from the Cancer Control Academy meeting prepared by her colleague.
- \$ Ms. Clagett will send Ms. Love the names of two advocates who may be available to attend the November meeting on cervical cancer in women in rural communities.
- \$ Ms. Lee will forward a copy of the draft annual report of the Operations WG to DCLG members.