

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE
DIRECTOR'S CONSUMER LIAISON GROUP**

**Summary of Teleconference
June 13, 2007
1:00 P.M. EDT**

DIRECTOR'S CONSUMER LIAISON GROUP

**June 13, 2007
1:00 P.M. Eastern Time
TELECONFERENCE**

Minutes

Members Present

Ms. Peggy Anthony
Ms. Vernal Branch
Mr. Bill Bro
Dr. Grace Butler
Ms. Lourie Campos
Ms. Yvette Colón
Ms. Kelly Cotter

Mr. Alan Kaye
Dr. Beverly Laird, *Vice Chair*
Ms. Mary Jackson Scroggins
Ms. Sue Sumpter
Ms. Cece Whitewolf
COL (Ret.) Jim Williams

NCI Office of Liaison Activities Staff

Ms. Barbara Guest, DCLG Executive Secretary
Ms. Brooke Hamilton, Program Analyst

Other NCI Staff

Ms. Joy M. Beveridge, Cancer Therapy Evaluation Program (CTEP) Manager
Ms. Maureen Johnson, Special Assistant to the Director
Ms. Anne Lubenow, Special Assistant to the Director
Ms. Carmina Valle, Program Analyst, Office of Cancer Survivorship

Others

Dr. Debby Berlyne, Writer, Palladian Partners, Inc.
Ms. Shannon Davis, Project Manager, Palladian Partners, Inc.

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I. Welcome and Opening Remarks

Dr. Beverly Laird welcomed participants to this teleconference of the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG). She noted that Mr. Doug Ulman, Chair of the DCLG, was unable to join the meeting because he was participating in the signing of two bills in Texas that would provide \$3 billion in funding for cancer research.

Conflicts of Interest

Dr. Laird reviewed the rules governing confidentiality and conflict of interest, and Ms. Barbara Guest determined that a quorum was present.

Approval of Minutes

A motion to approve the minutes of the March 29–30, 2006, DCLG face-to-face meeting was carried unanimously.

II. Message from the Director

Ms. Anne Lubenow explained that NCI Director Dr. John Niederhuber was unable to participate in the teleconference because of a last-minute change in schedule. He had asked Ms. Lubenow to represent him on the call and report to him any issues that emerged.

Dr. Niederhuber will provide an update on NCI activities to the National Cancer Advisory Board (NCAB), which is meeting later this week. Ms. Lubenow will send this update to Ms. Guest for distribution to the DCLG.

Dr. Niederhuber has offered to participate in an additional teleconference with the DCLG later in June to discuss any concerns or issues that arise during this teleconference.

III. DCLG Member Activities Reports

American Society of Clinical Oncologists (ASCO)

Mr. Bill Bro attended the ASCO meeting in Chicago earlier in June. During the meeting, Mr. Bro gave a presentation about the DCLG to a group of voluntary health organization representatives from the United Kingdom. The U.K. representatives were particularly interested in the role of voluntary health organizations in the United States because this concept is mostly unknown in the United Kingdom. A major issue in that country is the lack of easy access to cutting-edge cancer therapies. Although Britain has universal health coverage, this is not the same as high-quality care for all.

The U.K. representatives are eager to learn from the experiences of similar organizations in the United States. Mr. Bro encouraged DCLG members who are interested in working with their British counterparts to contact him so that he can help make appropriate connections.

National Institutes of Health (NIH) Advisory Committee to the Director

Ms. Kelly Cotter attended the June meeting of the NIH Advisory Committee to the Director. She will develop a detailed summary of the meeting for distribution to the DCLG.

During the meeting, Dr. Niederhuber expressed his pleasure with the unexpected increase in the NIH budget; the NIH Reform Act calls for \$30.3 billion in 2007 and \$30.8 billion in 2008. The Act also establishes funding for the NIH Common Fund, which supports innovative and cross-cutting initiatives. With funding provided directly to the Common Fund, the Institutes and Centers will no longer be required to contribute money for this purpose.

The committee also discussed the NIH Working Group on Women in Biomedical Careers, whose goal is to address barriers to hiring and promoting women in the biomedical research field. The committee has learned that the number of grants per principal investigator (PI) is higher for males than for females, and the average funding request per project is lower for females than for males. The committee plans to develop mentoring programs and identify best practices.

Mr. Alan Kaye asked about the percentage increase in the NIH budget provided by the NIH Reform Act. Ms. Guest will find this information and add it to Ms. Cotter's report.

IV. DCLG Working Group Reports

NCI Listens and Learns

COL (Ret.) Jim Williams reported that at the DCLG's March meeting, Dr. Michael Burke presented the results of his evaluation of the *NCI Listens and Learns* Web site. Based on this evaluation, the DCLG voted to recommend to the NCI Director that NCI continue the site with some modifications. Mr. Ulman and Dr. Laird have sent a letter to Dr. Niederhuber with this recommendation and some suggested modifications to the site. The *NCI Listens and Learns* working group has now completed its work.

Dr. Laird thanked the *NCI Listens and Learns* working group for all of its hard work.

Agenda Working Group

Dr. Laird reported that the DCLG's next face-to-face meeting will take place October 24–25, 2007. New members will participate in an orientation program on October 23. Dr. Niederhuber will attend for about 1.5 hours on the first day and 2 hours on the second day.

The primary focus of the meeting will be on cancer health disparities. Dr. Julia Rowland will give a presentation on survivorship activities and the meeting will also cover the issues that the DCLG has identified as essential for all its face-to-face meetings, including updates on NCI's budget and legislative activities.

The working group plans to ask the NCI speakers to send information on their presentations to the DCLG prior to the meeting. These presentations will be brief to allow more time for questions, answers, and discussions.

One of these presentations will be on electronic medical records. Ms. Guest explained that Dr. Alaina Fournier had distributed a request for DCLG perceptions of electronic medical records and privacy issues. Ms. Guest asked DCLG members who have not yet responded to do so before the next Agenda Working Group meeting on June 27. To facilitate their responses, Dr. Fournier will distribute the request a second time. Dr. Laird also asked DCLG members to let her know if the proposed agenda is missing any critical elements.

V. NCI Community Cancer Centers Program (NCCCP)

Ms. Maureen Johnson reported on progress made by the NCCCP since the DCLG's March meeting. Working groups in the four key areas have now developed work plans for the NCCCP sites. At the beginning of the 3-year pilot program, each site will produce a baseline assessment that will be used to identify intermediate milestones, with a final assessment at the end of the 3 years.

The NCCCP Evaluation Oversight Committee members have expertise in community-based cancer programs, models of cancer care, health care outcomes research, cost analysis, survey methodology, and health behaviors. They have recommended that the program's evaluation start as soon as it is launched. The NCCCP program evaluation will focus on the entire process of care and outcomes, and must consider the fact that quality of care is affected by many factors, including support from the hospital's executives and physicians, community resources, and state and national support.

An independent evaluation contractor will be involved in the program from the start. Quantitative and qualitative metrics will be used to evaluate the program. The evaluation will measure the ability of sites to implement the tasks outlined by NCI, as well as their operations and performance. The process evaluation component will assess best practices, relationships with community and state programs, model replicability, and financial soundness. The impact assessment component will focus on whether the program enhances delivery of evidence-based screening and therapy, improves physician participation in clinical trial accrual, and other such questions.

NCI has chosen 10 sites instead of the 6 originally anticipated. These were to be announced the following day at the NCAB meeting. They represent a broad spectrum of rural and urban populations, regions of the country, and ethnic groups. The sites will meet with the NCCCP advisory committees on June 25–26, when NCI will launch the program.

Ms. Johnson will have the press release about the sites sent to Ms. Guest for distribution to the DCLG.

Ms. Joy Beveridge explained that the 10 sites include 8 standing cancer centers and 2 health systems. They have different capabilities in each of the program's focus areas (disparities,

clinical trials, biospecimens, and information technology). Some see up to 5,000 cancer patients a year whereas others only meet the program's minimum requirement of 1,000 cancer patients each year.

Dr. Laird is the DCLG representative on the NCCCP advisory committee. She will attend the June kickoff meeting and invited other DCLG members to join her. Dr. Laird will make a presentation to the site representatives on the DCLG and Consumers Advocates in Research and Related Activities (CARRA) program. The DCLG and CARRA will also be discussed during breakout sessions. The goal is to make the pilot sites aware of resources available in their communities at no cost.

Dr. Laird invited DCLG members to share their organizations' materials and Web sites with the NCCCP sites. She specified that if they want to distribute materials to all participants in the meeting, they should provide 120 copies. If they simply want to provide a copy to each site, 11 or 12 copies will be sufficient. They can send these materials to Ms. Guest, who will send them on to Ms. Beveridge. Ms. Beveridge asked the DCLG members to provide this material by June 18, if possible.

Discussion

Ms. Cece Whitewolf asked about NCCCP sites that serve Native Americans. Dr. Laird explained that this information would not be released until the following day. Ms. Whitewolf expressed concern that the DCLG could not have access to this information before the general public. Ms. Johnson explained that these awards are being issued as research subcontracts through SAIC-Frederick, Inc., so they are not NCI grants. The guidelines for this type of grant stipulate that the recipients cannot be announced until the subcontracts are ready to be awarded.

Ms. Whitewolf was also concerned about the requirement that NCCCP sites see at least 1,000 cancer patients a year, because this might exclude sites that work with Native American patients. Ms. Johnson explained that this number of patients is required to make it possible to assess all aspects of the pilot study. A site with fewer patients will not have the volume required to truly test the model. Ms. Johnson hopes that once the pilot phase ends, the program can be implemented nationally without requiring a minimum number of patients. Ms. Beveridge added that some of the selected sites serve large numbers of Native Americans.

Dr. Grace Butler also expressed concern about the 1,000-patient minimum because it might exclude some sites that treat large numbers of African American patients. She asked whether the program's technical support will be available to sites that are not participating in the program.

Ms. Johnson explained that the program has a public Web page (<http://ncccp.cancer.gov>) that will include the minutes of all the NCCCP committee discussions. NCI wants to share what it learns with all community cancer centers as quickly as possible, regardless of whether they participate in the pilot program or not.

Ms. Beveridge explained that she and the NCI Program Advisory Committee will organize monthly conference calls on the pilot project's four focus areas to provide technical support.

They will also respond to questions by telephone. The minutes of the monthly calls will be posted on the Web site, as will the sites' best practices documents. However, institutions not participating in the pilot will not have access to hands-on technical support.

Dr. Laird stated that the program is offering DCLG members a role as advisors to the pilot sites. DCLG members might also participate in some of the monthly teleconferences. Dr. Butler supported having DCLG members serve as advisors to the NCCCP sites. Dr. Laird suggested that DCLG members decide whether to give permission for their contact information to be shared with the sites.

Ms. Beveridge explained that each participant in the kickoff meeting will receive a binder with a list of relevant NCI and related resources. Dr. Butler asked whether the DCLG members could receive a copy of this binder. Ms. Johnson replied that Dr. Laird will receive a copy of the binder, which is designed for the kickoff meeting and will include the agenda and other meeting materials, as well as a list of resources. The main room will also have a table with larger packets of information for each site.

Dr. Laird suggested that once the sites are identified, it would be valuable to assemble a community resource profile with local information for each site.

VI. The Cancer Genome Atlas (TCGA)

Ms. Cotter stated that at the DCLG's March meeting, several members had questions about the TCGA presentation. Ms. Cotter developed a draft set of questions about the presentation and these questions were sent to Dr. Anna Barker. Ms. Guest added that Dr. Barker's office plans to respond to each question.

VII. Public Comment

No public comments were offered.

VIII. Closing

Dr. Laird thanked the four members of the DCLG who were retiring this month: Dr. Marisa Weiss, Ms. Sue Sumpter, Ms. Mary Jackson Scroggins, and Ms. Vernal Branch. Each will receive a certificate and photo of themselves and Dr. Niederhuber. Ms. Guest also thanked the retiring members for all of their contributions to the DCLG.

Ms. Brooke Hamilton announced the sad news that former DCLG member Ms. Karen Packer had recently died of stomach cancer. A card will be sent to her family.

Dr. Laird thanked the participants for their contributions to this meeting. She reminded the DCLG members to expect e-mails on the NCCCP launch in the coming weeks, and to look out for messages with the program's name in the subject line.

Certification

I hereby certify that the foregoing minutes are accurate and complete.

Date

Chair
Director's Consumer Liaison Group

Date

Executive Secretary
Director's Consumer Liaison Group

DCLG ACTION ITEMS

- Ms. Anne Lubenow will send Dr. Niederhuber's update on NCI activities to Ms. Guest for distribution to the DCLG.
- DCLG members interested in working with British voluntary health organizations should contact Mr. Bill Bro.
- Ms. Kelly Cotter will send a detailed summary of the June meeting of the NIH Advisory Committee to the Director to Ms. Guest for distribution to the DCLG. Ms. Guest will add information to the summary on the percent increase in the NIH budget provided by the NIH Reform Act.
- DCLG members who have not already done so will send their responses to Dr. Alaina Fournier's request for comments on electronic medical records to Dr. Fournier before June 27.
- DCLG members will submit suggestions for items for the DCLG's face-to-face meeting in October to Dr. Laird.
- Ms. Maureen Johnson will have the press release about the NCCCP sites sent to Ms. Guest for distribution to the DCLG.
- DCLG members should send materials and websites for their organizations to Ms. Guest for distribution to the NCCCP site representatives. Ms. Guest will forward these materials to Ms. Joy Beveridge.