

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

**Summary of Teleconference
January 25, 2007
1:00 P.M. EDT**

DIRECTOR'S CONSUMER LIAISON GROUP

January 25, 2007
1:00 P.M. Eastern Standard Time
TELECONFERENCE

Minutes

Members Present

Ms. Peggy Anthony	Dr. Beverly Laird
Ms. Vernal Branch	Ms. Mary Jackson Scroggins
Mr. Bill Bro	Ms. Sue Sumpter
Dr. Grace Butler	Mr. Doug Ulman, <i>Chair</i>
Ms. Lourie Campos	Ms. Cece Whitewolf
Ms. Kelly Cotter	Col. (Ret.) Jim Williams
Ms. Nancy Davenport-Ennis	
Mr. Alan Kaye	

Speakers

Dr. John Niederhuber, Director
Dr. Shobha Srinivasan, Health Disparities Research Coordinator

NCI Office of Liaison Activities and other NCI Staff

Ms. Jennifer Fritz, *NCI Listens and Learns* Coordinator
Ms. Barbara Guest, DCLG Executive Secretary
Mr. James Hadley, Advocacy Program Manager
Ms. Brooke Hamilton, Program Analyst
Ms. Lenora Johnson, Acting Director
Ms. Linda Ticker, Program Assistant
Ms. Anne Lubenow, Special Assistant to the Director
Mr. Richard Folkers, Director of the Office of Media Relations
Ms. Andrea Collins, Committee Management Office

Others

Dr. Debby Berlyne, Writer, Palladian Partners, Inc.
Ms. Valerie Franzen, Project Manager, Palladian Partners, Inc.

I. Welcome and Opening Remarks 1

II. Message from the Director..... 1

III. Introduction of New Office of Advocacy Relations 3

IV. Report on the Initial Meeting of the National Cancer Institute Community Cancer
Center Program (NCCCP) Advisory Committee..... 4

V. Introduction of the NIH Centers for Population Health and Health Disparities
(CPHHD) 4

VI. DCLG Member Activities Reports 5

VII. Public Comment..... 6

VIII. Action Steps 6

Certification 7

DCLG Action Items 8

I. Welcome and Opening Remarks

Mr. Doug Ulman welcomed participants to this teleconference of the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG). He thanked all of the DCLG members, especially Vice Chair Dr. Beverly Laird, for their hard work in recent weeks.

Conflicts of Interest

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

Approval of Minutes

Ms. Mary Jackson Scroggins noted that in the minutes of the DCLG's September 28 teleconference, the first sentence in the second paragraph under "Two Summit Reports" should end after "summit participants."

A motion to approve the minutes of the September 28, 2006 DCLG teleconference, with the above change, and the October 25, 2006 face-to-face meeting was carried unanimously.

II. Message from the Director

NCI Update

Dr. Niederhuber reported on the recent visit by President George W. Bush to the National Institutes of Health (NIH) campus. The President focused much of his attention during the visit on cancer. Dr. Niederhuber thanked Ms. Anne Lubenow for working with the White House staff to organize the event and Dr. Grace Butler for her participation.

NCI's current budget is not clear because the Institute is operating under a continuing resolution. NCI has been working with the Department of Health and Human Services through NIH to develop the President's budget proposal for 2008 and will soon begin planning for the 2009 budget.

Reorganization of the Director's Office

Dr. Niederhuber and the NCI staff have been examining the structure and functions of the NCI Director's office to identify ways of making the office's activities more efficient and effective. As a result of this review, a reorganization plan has been developed that has been well received by NCI staff.

As part of the reorganization, Dr. Niederhuber has reviewed the DCLG's role in the Institute. In the new organizational chart, the DCLG is now on the same level as the National Cancer Advisory Board and Board of Scientific Advisors. In the future, the DCLG will have a direct line to the Director and Ms. Lubenow will help maintain this connectivity. The DCLG will focus less

on specific projects and more on serving in an advisory role and helping enhance communications between NCI and the public.

Dr. Niederhuber highlighted three NCI priorities on which he would like the DCLG to focus:

- **Minority recruitment and patient outreach**—translating this issue to the cancer advocacy community and bringing the community's perspective to NCI. For example, the DCLG provides a representative, Col. Jim Williams, to the newly created Clinical Trials Advisory Committee (CTAC).
- **Cancer care delivery**—providing ongoing feedback to the Director about community experiences with this pilot program and providing a representative (Dr. Beverly Laird) to the National Community Cancer Centers Program (NCCCCP) advisory committee that will advise and direct the program.
- **Eliminating cancer health disparities**—communicating the consumer advocate perspective on this important topic to NCI.

Discussion

Mr. Bill Bro and Ms. Vernal Branch thanked Dr. Niederhuber for developing this exciting new charge for the DCLG. Dr. Butler added that as a new DCLG member, she finds it very gratifying to see such a high level of attention given to issues, such as minority recruitment and patient access to clinical trials and high-quality care that are important to her constituency.

Ms. Scroggins noted that a relatively small proportion of NCI's budget is devoted to health disparities. She wondered how NCI's goals in this area could be achieved with this limited budget. Dr. Niederhuber agreed that many important activities cannot be accomplished without adequate funding. The first step is to determine NCI's actual investment in health disparities research. This information can then be used to explain why funding for health disparities research is so important.

Dr. Niederhuber added that until recently, much of the focus in health disparities was on behavior and education only. However, with the scientific tools that have recently become available, a new cadre of biologic scientists is being attracted to the field. These scientists are examining some of the biological differences in various populations that could account for some of the discrepancies in cancer survival rates. . This will significantly increase awareness of this issue and help answer some important questions.

Col. Williams suggested that the biology of cancer health disparities would be an appropriate discussion topic for the next DCLG face-to-face meeting. Ms. Guest reported that Dr. Sanya Springfield, Director of NCI's Center to Reduce Cancer Health Disparities, will discuss NCI's activities in cancer health disparities at the DCLG's next meeting.

Dr. Butler noted that during his visit to NIH, the President stated that cancer research funding has increased significantly during his time in office. However, NCI still needs more funding. Ms.

Branch noted that in the President, in his State of the Union address, expressed a strong commitment to healthcare initiatives. She hoped that this would lead to increased funding for NCI.

Ms. Lourie Campos shared her experience in Santa Clara County CA, where her group was able to raise \$500,000 through education and advocacy to purchase a new mobile mammography unit. Even though no money was originally available, this did not stop the advocates. Similarly, even though NCI does not have enough funding to accomplish all of its priorities, community members are not discouraged. Through their passion and their work, they can help make progress toward eliminating health disparities.

Dr. Niederhuber expects that the priorities for the DCLG could change in the future. The issues identified in the charge are only guidelines and the process needs to be dynamic.

III. Introduction of New Office of Advocacy Relations

Ms. Lenora Johnson said that NCI staff and DCLG members are excited about the DCLG's new charge, which provides clear guidance about Institute priorities that the DCLG should address. The DCLG, with the support of staff from the new Office of Advocacy Relations (currently the Office of Liaison Activities [OLA]), will need to determine how the group can best work to present the NCI Director with clear recommendations and advice on the three priority areas.

Every NCI office, unit, and staff member is assessing their work and how to move their responsibilities to the next level. OLA needs to determine how to maximize the Institute's access to consumer perspectives related to cancer care in general and the three priority areas in particular. The office is preparing to implement systems that can support the DCLG's work and broaden the Institute's understanding of consumer needs. OLA will work with the DCLG to obtain the support and resources that the group needs to make clear recommendations to Dr. Niederhuber.

Discussion

Col. Williams stressed the importance of appointing a permanent director of the Office of Advocacy Relations. Ms. Johnson said that efforts have begun to identify a permanent director. A position description needs to be developed and approved, and this process will take time.

Ms. Lubenow reported that Dr. Niederhuber has emphasized the need for the Office of the Director and OLA to continue to support the DCLG's work. Dr. Niederhuber is committed to the success of the DCLG's and OLA's efforts.

Ms. Davenport-Ennis requested an announcement of the DCLG's new charge for distribution to DCLG members' constituencies. The announcement should clearly explain the role of the CTAC and NCCCP in addressing the three priority areas. OLA staff agreed to develop an announcement that can be distributed to the public. This announcement could also be included in some of the publications developed in preparation for the major cancer meetings that will take

place in the spring and summer. Publicity for the DCLG's new charge will bring NCI a broader base of support for its priority issues.

IV. Report on the Initial Meeting of the National Cancer Institute Community Cancer Center Program (NCCCP) Advisory Committee

Dr. Laird serves on the new NCCCP advisory committee, which was very pleased to learn that 45 proposals from 22 states were received from institutions interested in serving as one of the six pilot sites for this new program. This initiative will address prevention, screening, and treatment with a constant focus on reducing cancer health disparities. The pilot program will be overseen by a contractor and the pilot sites will be selected in the next few months. The American Cancer Society and other organizations are considering the possibility of joining this program as partners.

The committee meets monthly and Dr. Laird will distribute updates on its activities to the DCLG. She predicted that other DCLG members are likely to become involved in the committee's work in the future.

V. NIH Centers for Population Health and Health Disparities (CPHHD)

Dr. Shobha Srinivasan, NCI Division of Cancer Control and Population Sciences (DCCPS) is NCI's Program Director for the CPHHD, which is cosponsored by the National Institute on Aging, National Institute of Environmental Health Sciences, and Office of Behavioral and Social Science Research. The program was established in September 2003 to study the relationships among the social and physical environment, behavioral factors, and biology to help understand and reduce health disparities. This 5-year initiative funds eight centers in Chicago, Boston, Santa Monica, Galveston, Detroit, Columbus, Ann Arbor and Philadelphia. When these projects end, the Board of Scientific Advisors will develop recommendations regarding the program's future.

All of the centers must conduct a community-based project and community groups inform the science of all of the centers at every level. The community's perspective and the results of the centers' research are already having an impact on the practices of clinicians in these centers.

Discussion

Ms. Sumpter expressed surprise that only one of the centers is based on the West Coast. In addition, she asked whether the centers are studying issues related to cancer in children, adolescents, and young adults because these groups experience health disparities. Dr. Srinivasan explained that when the program was established, a decision was made to allow the applicants to identify the issues that need to be studied because they know their communities best. But perhaps this could be changed in the future. Ms. Sumpter explained that the cultures of the East and West Coast are very different.

Ms. Whitewolf suggested that the centers include Native American and gay and lesbian populations in their research. Other populations to include are people who are homeless and those with disabilities. It is also important to remember that people in rural areas have very

different issues than people in cities. Finally, Ms. Whitewolf suggested that the centers involve the advocacy community in hypothesis development and identify community-based organizations to participate in center research. Dr. Srinivasan clarified that the centers do not focus only on racial disparities; for example, some are studying disparities related to geographic location.

Dr. Butler asked if the centers address the disparities experienced by older adults. Dr. Srinivasan said that several of the centers are studying older populations.

Dr. Srinivasan asked the DCLG to forward additional comments on the program to Ms. Guest, who will pass them on to Dr. Srinivasan.

VI. DCLG Member Activities Reports

Joint Board Retreat

Dr. Laird attended the joint board retreat on January 8. During the meeting, participants discussed the decrease in federal funding for cancer research and Dr. Niederhuber reported on the NIH reauthorization. The discussion also focused on the difference between NCI and the other NIH institutes and centers and the fact that NIH directives that work well for other NIH components might not work well for NCI.

President's Cancer Panel

Ms. Sumpter attended the President's Cancer Panel meeting in Portland on December 5. The meeting focused on promoting healthy lifestyles to reduce the risk of cancer. The panel members presented very compelling scientific evidence on obesity's role in causing certain kinds of cancer. Obesity is also associated with poorer survival and increased risk of recurrence. One presentation focused on the need to prevent childhood obesity, which is a critical public health threat. This meeting led Ms. Sumpter to wonder about the potential role of the DCLG in promoting healthy lifestyles and reducing obesity.

Ms. Davenport-Ennis noted that C-Change has developed guidelines for employers on ways to encourage employees to lose weight and increase their physical activity. Perhaps the DCLG could communicate this information to NCI. Ms. Sumpter relayed a suggestion she heard that daily physical activity and healthy school cafeteria food be mandated in public schools as part of the No Child Left Behind legislation.

Mr. Ulman noted that the President's Cancer Panel's mandate is to oversee the nation's cancer program and report directly to the President. Although the panel is administered by NCI, its mandate is broader than NCI's.

Ms. Whitewolf wondered whether progress has been made on the panel's recommendations for Native Americans. Mr. Ulman suggested asking panel staff for a summary of progress on the panel's recommendations regarding cancer in Native Americans that Ms. Whitewolf could share with her constituents.

Clinical Trials Advisory Committee (CTAC)

Col. Williams attended the CTAC's first meeting on January 10, which served as an orientation session for the 25 committee members. Dr. Niederhuber chairs the committee, demonstrating his commitment to this process. The committee's charge is to oversee all of NCI's clinical trials and assess the return on investment. The CTAC is the first new advisory committee at NCI in 15 years.

White House Roundtable

Dr. Butler described her participation in the White House roundtable at NCI on January 17, 2007 as a "wonderful opportunity." Other roundtable participants included Secretary of Health and Human Services Michael Leavitt, NIH Director Dr. Elias Zerhouni, Dr. Niederhuber, National Human Genome Research Institute Director Dr. Francis Collins, and Becky Fisher` Breast cancer survivor. The President showed a high level of interest and expressed strong support for the participating Institutes.

Dr. Butler noted that although the President said that cancer research funding has increased in recent years, it is clear that much more funding is needed and it is important to disseminate this message. Ms. Branch suggested that DCLG members discuss this issue with their constituencies.

VI. Public Comment

No public comment was provided.

VII. Action Steps

The DCLG's Agenda Working Group will have a teleconference within the next 2 weeks to discuss the agenda for the March 29-30 DCLG meeting. Ms. Cotter suggested that during the March meeting, the DCLG discuss how it will operate in the future, given its new charge, and what steps it will take to address its three new priorities.

Dr. Laird suggested that because the approval process for the DCLG minutes is time consuming, Ms. Guest should distribute action items from the group's meetings as soon as possible, in advance of the minutes.

Certification

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

Date

Chair, Agenda Working Group

Date

Executive Secretary
Director's Consumer Liaison Group

DCLG ACTION ITEMS

1. OLA staff will develop an announcement of the DCLG's new charge for distribution to DCLG members' constituencies.
2. DCLG members should forward comments on the NIH Centers for Population Health and Health Disparities to Ms. Guest so that they can be sent to Dr. Srinivasan.
3. The DCLG's Agenda Working Group will hold a teleconference within the next 2 weeks to discuss the agenda for the March 29-30 DCLG meeting.
4. Ms. Guest will distribute action items from the DCLG's meetings as soon as possible, in advance of the minutes.