

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE
47th MEETING OF THE
DIRECTOR'S CONSUMER LIAISON GROUP**

**Summary of Teleconference
January 24, 2008
1:00 p.m. EST**

DIRECTOR'S CONSUMER LIAISON GROUP

January 24, 2008

1:00 p.m. EST

TELECONFERENCE

Minutes

Members Present

Mr. Doug Ulman, Chair

Dr. Beverly Laird, Vice Chair

Ms. Peggy L. Anthony

Mr. Bill Bro

Dr. Grace Butler

Ms. Lourie Campos

Dr. Yvette Colón

Ms. Kelly Cotter

Ms. Nancy Davenport-Ennis

Mr. Everett Dodson

Ms. Joyce Wilcox Graff

COL (Ret.) James E. Williams, Jr., USA

NCI Office of Advocacy Relations Staff

Ms. Shannon Bell, Director, OAR, NCI

Ms. Barbara Guest, DCLG Executive Secretary

Mr. James Hadley, Advocacy Program Manager, OAR, NCI

Ms. Linda Ticker, Program Assistant

Liaison Representatives to the DCLG

Dr. Shobha Srinivasan, Division of Cancer Control and Population Sciences, OD, NCI

Welcome and Opening Remarks 1

Director's Update..... 1

Office of Advocacy Relations Update 2

DCLG Working Group Reports..... 3

DCLG Member Activities Reports 3

DCLG Recommendations Regarding the Director's Priorities 4

Public Comment..... 6

Closing 6

Certification 7

Director's Consumer Liaison Group Action Items 8

Welcome and Opening Remarks

Mr. Doug Ulman welcomed participants to this meeting of the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG). He reviewed the rules governing confidentiality and conflict of interest, and Ms. Barbara Guest determined that a quorum was present.

The DCLG unanimously approved a motion to approve the minutes from the DCLG's October 24-25, 2007, meeting.

Mr. Ulman was delighted to announce that all four new DCLG members have been confirmed.

Director's Update

Dr. John Niederhuber, Director of NCI, announced that Congress finalized the National Institutes of Health (NIH) budget appropriation at the end of December 2007. NCI had hoped for an increase, but its budget remained essentially the same as it has been for the past few years. NCI's original fiscal year (FY) 2008 budget plan was based on a 2 percent increase, so the Institute must make more cuts than it had anticipated. NCI has been trying to find other sources of support, such as the NIH Foundation and private sector companies, to maintain NCI's critical programs.

The President will announce his FY 2009 budget in early February 2008. NCI will soon visit members of the House Appropriations Committee. In addition, Dr. Niederhuber will appear with Dr. Elias Zerhouni, Director of NIH, before the House and Senate appropriations committees for their annual hearing.

NCI is continuing to implement the recommendations of the Clinical Trials Working Group and the Translational Research Working Group (TRWG). Dr. Lynn Matrisian, who co-chaired the TRWG, will split her time between Vanderbilt University and NCI to oversee the TRWG implementation.

Discussion

Mr. Ulman asked Dr. Niederhuber to identify some of the most exciting developments at NCI. Dr. Niederhuber replied that whole genome scans are beginning to show genetic information on the genome that can be used to predict a person's risk of developing cancer during his or her lifetime. This work, which has focused initially on breast and prostate cancer, will significantly inform NCI's prevention program. A second story is being built on this first layer of information—the whole genome sequencing of three tumors (glioma, lung cancer, and ovarian cancer) to identify the genetic changes that occur as these cancers develop. All of these developments will provide an increasing wealth of potential intervention targets.

Dr. Niederhuber is also excited about the research on imaging in subcellular spaces. Scientists are trying to isolate individual cancer cells circulating in a patient's body, because these cells might be early markers of disease.

Ms. Nancy Davenport-Ennis asked Dr. Niederhuber to identify areas that DCLG members, as patient advocates, should target in their efforts to assist NCI in finding additional resources.

Dr. Niederhuber explained that more than 80 percent of the Institute's funding is used to support extramural research. In the past, NCI cut the size of its awards while continuing to support the same number of investigators. However, NCI cannot decrease these awards any further, because they are becoming too small for investigators to complete their studies.

In addition, NCI will reduce the number of trials it supports or delay the start of some of its trials. Its prioritization process for trials will become more rigorous, and trials will accrue fewer participants. Dr. Niederhuber hopes that other funders from the private or nonprofit sector might support some of the clinical research activity that NCI can no longer fund.

Finally, the Specialized Programs of Research Excellence (SPORes) and cancer centers are trying to maintain their programs with the same amount of funding. These programs will have less purchasing power over time as the cost of salaries and resources increases.

Office of Advocacy Relations Update

Ms. Shannon Bell reported that the Office of Advocacy Relations (OAR) is providing support to the DCLG's Involving Advocates in NCI Programs Working Group. The outcomes from this process will have significant implications for OAR's work and how the office engages advocates on behalf of NCI. OAR will continue to interact with advocacy groups and professional societies as it seeks to identify opportunities to collaborate, fill gaps, and create new opportunities.

Ms. Bell recently met with a professional society that has private funding to help four South American countries establish clinical trials in their communities. OAR is facilitating a collaboration between NCI and the organization so that NCI will provide scientific oversight for this project.

OAR will continue to seek additional opportunities to maximize its recent elevation at NCI and plans to become an even more valuable resource to NCI's intramural and extramural communities.

Discussion

Mr. Ulman asked about the changes that OAR has experienced since its elevation. Ms. Bell explained that Dr. Niederhuber and the Executive Committee had previously demonstrated a strong commitment to engaging the advocate perspective at NCI, but OAR's elevation has made it possible to maximize this commitment. OAR staff are invited to all relevant meetings and are asked to facilitate the appropriate types of opportunities. Furthermore, OAR has begun to interact with some principal investigators who had not worked with OAR in the past.

Dr. Grace Butler asked whether the office has any new expectations. Ms. Bell explained that Dr. Niederhuber does not have a list of expectations for OAR; however, he is providing the office with the opportunity to establish its vision and strategies and move forward on them.

DCLG Working Group Reports

Agenda Working Group

Ms. Guest reported that the DCLG Agenda Working Group had a successful meeting in January, when it discussed the agenda for the DCLG's meeting on March 29-30, 2008. Each working group member is assigned to one or two speakers to help them develop a presentation that addresses the DCLG's priorities. Working group members will also ask all presenters to send their PowerPoint slides to OAR for distribution to the DCLG in advance of the meeting.

DCLG Working Group on Involving Advocates in NCI Programs

Ms. Kelly Cotter reported that the DCLG Involving Advocates in NCI Programs Working Group plans to develop a report with detailed, data-driven recommendations on how to maximize advocate contributions across the entire NCI research portfolio. The report will also describe a comprehensive process for mapping advocate involvement and skills to programmatic needs. The working group has developed a timeline listing all of the tasks required to achieve its goals and when it will complete each step.

Mr. James Hadley explained that the working group is collecting information from advocates and investigators on the impact of advocacy involvement on NCI processes and outcomes. To date, NCI has received responses from a broad range of investigators and advocates. OAR staff members are analyzing this feedback, and the working group will use the results to develop evidence-based recommendations. Mr. Hadley thanked all of the OAR staff members for their hard work in supporting the working group.

Mr. Hadley asked DCLG members to respond to the working group's questions on advocacy involvement, if they had not already done so, by February 1.

Ms. Cotter explained that based on the feedback that the working group has received to date, it has formed four subgroups to develop recommendations on specific areas of advocacy activity. The working group will review and refine the recommendations of the subgroups and develop a report incorporating these recommendations. Prior to finalizing the document, the group will invite the advocacy community to discuss the report in a community teleconference, and this feedback will be incorporated into the report. The working group will submit the report to the DCLG for its consideration at its March meeting. Once the document is finalized, the DCLG will submit it to Dr. Niederhuber.

More information on the working group's activities is available at the following Web site: <http://dclg.cancer.gov/working-groups/involving-advocates>. Ms. Bell welcomed feedback from the DCLG and the public on the working group's activities.

DCLG Member Activities Reports

NCCCP Program Advisory Committee

Dr. Beverly Laird is a member of the NCI Community Cancer Centers Program (NCCCP) Program Advisory Committee (NPAC), which meets monthly. Most of the pilot sites indicated are not familiar with all of the resources provided by advocacy and other organizations in their communities and would like some information on these resources. The NPAC will soon ask each DCLG member to provide information on his or her organization for the NCCCP pilot sites. This will allow the DCLG to provide important assistance to the NCCCP in the form of no-cost resources that can help the sites provide quality care in their communities.

Mr. Bill Bro is conducting informal site visits with patient contacts who request a meeting. He will report on his findings at the DCLG's March meeting.

Clinical Trials Advisory Committee

COL (Ret.) James E. Williams, Jr., USA, is a member of the Clinical Trials Advisory Committee (CTAC) patient advocate steering committee that brings together advocates from the CTAC's disease-oriented steering committees. In the coming months, COL Williams hopes to identify the needs (e.g., for training) of all of the advocates on the CTAC and discuss ways to meet these needs with the DCLG.

Report on the American Association for Cancer Research Conference, "The Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved"

Mr. Everett Dodson attended the American Association for Cancer Research (AACR) conference on cancer health disparities among racial/ethnic minorities and the medically underserved on November 27-30, 2007. He summarized several of the presentations he attended and encouraged DCLG members to listen to the presentations, which are available on the AACR Web site (<http://www.aacr.org/home/scientists/meetings--workshops/cancer-health-disparities/webcast-sessions.aspx>).

NCI Intramural Scientific Retreat

Ms. Joyce Graff was impressed by the amount of talent assembled at the NCI Intramural Scientific Retreat. Dr. Niederhuber welcomed the participants, shared the news about the Institute's flat budget, and discussed plans to increase salaries and expand the number of investigators. Ms. Graff provided a brief summary of the three keynote presentations and described some of the posters that she visited.

DCLG Recommendations Regarding the Director's Priorities

Mr. Ulman asked the DCLG to discuss whether it will be ready to present recommendations to the NCI Director on the group's three priority areas at its March meeting. Dr. Beverly Laird emphasized that these recommendations must be realistic and actionable by NCI. The three priority areas will always be priorities for the DCLG, and the group might not need to create separate recommendations for each area.

COL Williams commented that NCI does not have sufficient resources to implement many of the DCLG's potential recommendations. Ms. Davenport-Ennis therefore suggested that the DCLG identify resources that the nonprofit organizations they represent could provide to help NCI move forward in the three priority areas. For example, the DCLG could compile a list of organizations with effective programs in minority recruitment and patient outreach for clinical trials to share with NCI. Dr. Laird supported this idea, commenting that it is similar to what advocates are doing for the NCCCP pilot projects. Ms. Davenport-Ennis also suggested engaging media leaders who are sensitive to cancer issues and could serve as advocates for NCI. Perhaps, for example, each of the top print and electronic media could provide NCI with one free public service announcement per year to promote the enrollment of underserved populations in clinical trials.

Dr. Laird pointed out that the outcomes from the Involving Advocates Working Group will provide an important infrastructure for leveraging external resources on behalf of NCI. This will require input from advocates beyond the DCLG.

Mr. Ulman suggested including more information at the next DCLG meeting that will assist the DCLG in making its recommendations to Dr. Niederhuber. Ms. Davenport-Ennis suggested that given Department of Health and Human Services (DHHS) Secretary Michael Leavitt's emphasis on cross-agency collaboration, the DCLG might invite a representative from the Centers for Medicare and Medicaid Services or other DHHS agency to discuss cancer care delivery. Dr. Laird suggested that the next DCLG meeting include a presentation on the logistics of contributing to NCI through the NIH Foundation. Ms. Guest will identify a speaker on this issue.

Ms. Guest commented that the DCLG might consider recommending that it work with other advocacy organizations to leverage resources for NCI around the group's three priorities. Another potential recommendation is for NCI to continue to involve advocates in its activities, and perhaps expand this involvement once the Involving Advocates Working Group develops its recommendations.

Ms. Davenport-Ennis suggested that the DCLG consult with Drs. Mark Clanton and Armin Weinberg and other individuals with expertise in the DCLG's priority areas. These experts could provide advice to the DCLG as it develops its recommendations. In addition, DCLG members should identify the names of individuals and organizations that could be approached about assisting NCI.

The DCLG decided to form a working group to develop recommendations based on this discussion. The following DCLG members volunteered to serve on this committee: Ms. Davenport-Ennis, Mr. Dodson, Dr. Butler, and Ms. Lourie Campos. Mr. Ulman asked DCLG members who would like to serve on or chair this group to contact Ms. Guest.

Dr. Butler noted that DCLG members could invite Dr. Niederhuber or another NCI leader to participate in discussions at community events about the DCLG's three priority issues. The sponsoring organizations could underwrite the travel costs. Ms. Bell replied that NCI would be delighted to reach out to the community and communicate its priorities and needs. Dr. Niederhuber can sometimes take advantage of these opportunities; in other cases, NCI is

committed to finding an NCI leader who is an expert in the topic to speak in his stead. Inquiries about participation in community events should be directed to OAR.

Mr. Hadley pointed out that the Understanding NCI teleconference series also provides an opportunity for members of the public, regardless of their locations, to listen to NCI staff discuss their programs. Dr. Sanya Springfield, director of the Center to Reduce Cancer Health Disparities, will lead an upcoming Understanding NCI teleconference on cancer health disparities. Mr. Hadley also reminded the DCLG that they may copy any of the information in the *Nealon Digest* into their newsletters and distribute this information to their constituencies to educate them about NCI.

Public Comment

No public comment was offered.

Closing

Dr. Shobha Srinivasan invited the DCLG to the one-day symposium of the Centers for Population Health and Health Disparities. This event will take place on February 28 from 9:00 a.m. to 6:00 p.m. at the Natcher Center on the NIH campus. The DCLG heard a report on this program at an earlier meeting, and this symposium will provide an opportunity to learn about more recent accomplishments. Ms. Guest will forward information to members of the DCLG on the symposium and how to register. Admission to the meeting is free.

Mr. Ulman thanked the DCLG members for all of their hard work and said that he looks forward to seeing them in person at the end of March.

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

DIRECTOR'S CONSUMER LIAISON GROUP

ACTION ITEMS

1. DCLG members will respond to the Involving Advocates in NCI Programs Working Group's questions on advocacy involvement, if they have not already done so, by February 1.
2. The DCLG will form a working group to develop draft recommendations for the NCI Director. The following DCLG members volunteered to serve on this committee: Ms. Davenport-Ennis, Mr. Dodson, Dr. Butler, and Ms. Campos. Other DCLG members who would like to chair or join the working group should contact Ms. Guest.
3. Ms. Guest will invite a speaker from the NIH Foundation to present at the DCLG March meeting.
4. Ms. Guest will distribute information to members of the DCLG on the February 28 symposium of the Centers for Population Health and Health Disparities.