

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE
38th NCI DIRECTOR'S CONSUMER LIAISON GROUP**

**Summary of Teleconference
December 1, 2005
2:00 P.M.–3:30 P.M. Eastern Standard Time**

**NATIONAL CANCER INSTITUTE
DIRECTOR'S CONSUMER LIAISON GROUP**

**DECEMBER 1, 2005
2:00 P.M.–3:30 P.M. Eastern Time
TELECONFERENCE
SUMMARY**

Members Present

Mr. Doug Ulman, Chair
Ms. Peggy L. Anthony
Ms. Vernal H. Branch
Mr. William P. Bro
Ms. Lourie Campos
Ms. Bobbi de Córdoba-Hanks
Ms. Nancy Davenport-Ennis
Dr. Beverly Laird
Dr. Sylvia M. Ramos
Mr. Eric Rosenthal
Ms. Mary Jackson Scroggins
Ms. Sue Sumpter
Ms. Cece Whitewolf
Col. (Ret.) James E. Williams, Jr., USA

NCI Staff

Dr. John Niederhuber, Deputy Director, NCI
Ms. Brooke Hamilton, Acting Director, Office of Liaison Activities (OLA)
Ms. Jane Jacobs, CARRA Program Manager, OLA
Ms. Devon McGoldrick, *NCI Listens and Learns* Coordinator, OLA
Ms. Linda Ticker, Program Assistant, OLA
Ms. Anne Willis, Health Communications Intern, OLA
Ms. Bethany Piernikowski, Cancer Research Training Fellow, OLA
Ms. Lynn Swanson, Technical Assistant to the Speech Writer, Public Affairs Branch, NCI
Ms. Carmina Valle, Program Analyst, Office of Cancer Survivorship
Ms. Elaine Lee, Former DCLG Executive Secretary

TABLE OF CONTENTS

I. Opening Remarks..... 1

II. Approval of Minutes September 14–15, 2005 DCLG Meeting..... 1

III. NCI Leadership Update 1

IV. Working Group Structure Update..... 3

V. Update on DCLG Nominations Process 4

VI. Update on *NCI Listens and Learns*..... 4

VII. Update on Listening and Learning Together: Building a Bridge of Trust..... 5

VIII. Update on Executive Secretary Search Process..... 6

IX. Public Comment..... 6

X. Next Steps 6

Certification 7

DCLG Action Items..... 8

I. Opening Remarks

Mr. Doug Ulman convened the meeting at 2:00 p.m. EST and reviewed the rules governing confidentiality and conflicts of interest. Ms. Brooke Hamilton determined that a quorum was present.

II. Approval of Minutes September 14–15, 2005 DCLG Meeting

It was moved and seconded that the minutes of the DCLG meeting of September 14 and 15 be approved with the following correction: Typographical error p. 7, last paragraph, change “principle” to “principal.” The motion carried. Ms. Nancy Davenport-Ennis expressed appreciation for the very comprehensive nature of the minutes.

III. NCI Leadership Update

Dr. Niederhuber thanked the DCLG members for the opportunity to address them, and expressed appreciation on behalf of everyone at NCI and NIH for their dedication and service. Noting that he is a cancer surgeon and former researcher, Dr. Niederhuber gave a brief summary of positions he held prior to coming to NCI this past summer. They included administrative experience as a Dean at the University of Michigan, Department Chair at Stanford University, and Center Director at the University of Wisconsin. He served as chair of the National Cancer Advisory Board for the past three years, and worked closely with Dr. von Eschenbach in that capacity. Now, with Dr. von Eschenbach busy with his new duties at the FDA, Dr. Niederhuber looks forward to working with the outstanding NCI staff and the other Deputy Directors to continue Dr. von Eschenbach's vision and plans for NCI.

Dr. Niederhuber discussed three areas:

1. Key Personnel Changes

Recent appointments include:

- Dr. Sanya Springfield, Acting Director of the NCI Center to Reduce Cancer Health Disparities. Dr. Springfield is a highly respected researcher, minority scientist and administrator.
- Dr. Jerry Collins, Associate Director, Division of Cancer Treatment and Diagnosis, and will assume leadership of the division's Developmental Therapeutics Program. Dr. Collins is a nationally and internationally recognized pharmacologist.
- Dr. Carolyn Compton, Director of Biorepositories and Biospecimen Research in the Office of the Director. Dr. Compton holds an M.D., Ph.D. from Harvard University and is a board-certified anatomic pathologist.
- Dr. Ken Buetow, Associate Director for Bioinformatics and Information Technology. In this position Dr. Buetow now also serves on the NCI Executive Committee

Recent recruitment efforts include:

- Head of Pathology at the Clinical Center—this position serves not only the cancer program, but also supports all clinical programs. This has traditionally been an appointment from within NCI, and that will continue.

- Radiation Oncology in the Clinical Center—a nationally known candidate has been interviewed and the position is close to being filled.
- Head of Medical Oncology—40–50 viable applications have been received by the search committee, headed by Dr. Steve Rosenberg.
- Genetics Program—this position has been filled and will be announced in January.

2. *Changes in NCI Publications*

Previously the Bypass Budget document also contained progress reports on NCI projects and the NCI strategic vision. Rather than continue to have these all in the same document, three separate documents have been created this year, making it easier to present NCI accomplishments and its vision for the future, and providing a better opportunity to discuss ways to accomplish that vision through discovery and the delivery of discoveries to the bedside. The three publications are:

- Budget Proposal for Fiscal Year 2007—The Bypass Budget is presented as a business plan designed to sustain current services. Five areas of new investment are listed: 1) Fostering more integration within and among NCI-designated Cancer Centers, 2) Reengineering the clinical trials system, 3) Building better linkages between cancer science and emerging technologies, 4) Advancing medical informatics, and 5) More integrative approaches to understanding cancer. The document identifies how additional resources can better integrate interdisciplinary efforts in cancer research.
- NCI Strategic Plan—This document will be released later this month. It elucidates the collective thinking of NCI about what must be done to reach the NCI vision of a “nation free from the suffering and death due to cancer by 2015 with dramatic reductions in the incidence of cancer.” The plan lists eight strategic priorities, and DCLG members will find this document useful in their work with their own organizations.
- Annual Progress Report—This document will communicate to the public and to Congress recent intra- and extramural scientific advances. This will also be a useful tool for DCLG members.

3. *Budget*

At this time the NIH budget is on the second Continuing Resolution (at 2005 funding levels), which will expire around December 15. It is unclear at this point what will happen with the budget, and staff members are doing their best to inform the public and Congress how a flat or deficit budget will affect the goals of the NIH. Currently, during this uncertain period, payments to grants are not being made in full, and directors are planning budgets for about a 2% decrease, which translates to about \$200 million below the 2005 budget.

Despite the budget concerns, the NIH remains as committed as ever to maintaining momentum and addressing its important strategic priorities. The challenge is to adapt to survival in lean times, just as in the evolutionary process, smart organisms that have adapted best to the stresses of the environment have the best survival rates.

The voices of the public and of the organizations represented by DCLG members can affect the congressional decision-making process, particularly by being able to translate the issues into patient needs, as opposed to research needs. This is an exciting time in research with unbelievable opportunities ahead, and these public voices make a great difference.

Dr. Niederhuber noted that this past week, clinical and laboratory scientists gathered to celebrate the 50th anniversary of the Cancer Discovery and Development Therapeutics Program at NCI. This program has generated more than 38 cancer-fighting drugs, the majority of which are still in use today. This output of nearly a drug a year reminds us that the future of NCI is bright and exciting.

Dr. Niederhuber expressed his enthusiasm for the Summit conference next June, and observed that the participants will get a great sense of pride from their visit to the NIH campus and the opportunity to see the extraordinary work that is done there. He noted that his own antidote to discouraging times is simply to walk through the Clinical Center. Seeing so many children in the throes of difficult cancer treatments inspires a great sense of pride in what NCI has accomplished, and a sense of purpose for what can be done.

Dr. Niederhuber thanked all the DCLG members once again, noting that they are the NCI's ambassadors and that NCI is extremely indebted to them for their efforts. He opened the floor to questions or comments.

Ms. Vernal Branch thanked Dr. Niederhuber for his remarks and stated that all the members realize the important role they must play in ensuring that funding for the NIH and NCI continues at high levels.

Ms. Davenport-Ennis noted that the National Patient Advocate Foundation has been encouraged to make their voices heard on these budget issues, and thanked Dr. Niederhuber for his comments and efforts.

Mr. Ulman thanked Dr. Niederhuber for joining the meeting and addressing the DCLG.

IV. Working Group Structure Update

Mr. Ulman explained that the proposed changes to the number and membership of the Working Groups were designed to streamline the committees and ease the workload. Ms. Hamilton asked for comments.

Ms. Branch said that she liked the two-group split, which allows for more people to work on the projects.

Dr. Ramos asked whether the CARRA liaison was a Working Group or consisted of only one person. Ms. Hamilton replied that while initially we thought it would be a Working Group, the CARRA members participating in caBIG asked for one person to serve as a liaison. It was decided that Ms. Anthony would fill this role.

Ms. Scroggins said that she liked the reconfiguration and asked how promotion or evaluation questions would be handled now that those groups were disbanded. Ms. Hamilton explained that people in each of the two groups who had experience in those matters from their prior work on the committees would help handle them. Ms. Hamilton also clarified that the *NCI Listen and*

Learns Working Group would focus on all aspects of the Web site and hopefully eliminate an overlap or work between the groups.

It was moved and seconded that the proposed Working Group reconfiguration be approved. The motion carried unanimously.

V. Update on DCLG Nominations Process

Ms. Hamilton reported that the application material for new members is now undergoing clearance and should be released next week. Five current members will rotate off the DCLG at the end of June 2006, and the term of the new members will begin on July 1, 2006. All current members will receive applications. Their help in identifying nominees for the five new vacancies is appreciated. Ms. Hamilton noted that DCLG members who are rotating off can apply for a new appointment, and that all applications must be postmarked by March 31. She added that a selection process is in place that includes evaluation of the applications by an outside contractor with OLA guidance, phone interviews for top candidates, a second application evaluation for finalists, with final selection being done by the NCI director.

VI. Update on *NCI Listens and Learns* Website

Ms. Devon McGoldrick reported that:

- 19 new groups were invited to join in October and one did, thanks to the efforts of Col. Williams.
- Letters to the 37 groups who have not yet identified a spokesperson have been sent. To date, none has appointed a spokesperson.
- A new topic about NCI's Cancer Information Service was posted on the Web site today. The question asked what NCI could do to encourage people with cancer needs to contact the free Cancer Information Service, either by telephone or online. Ms. McGoldrick thanked those who helped develop the question.
- A help page has been added to the site to assist with user registration and site navigation.
- The *NCI Listens and Learns* e-mail address has been added at various locations on the site allowing users to send a request to be reminded of their username and/or password, or for other technical assistance.
- The logic model is in the final stages of refinement. The completed logic model will be useful in the development of the evaluation tool.
- A copy of the latest topic will be sent to all DCLG members. Prior to being posted on the site, the topic was sent only to Operations Work Group members.

In answer to questions from members, Ms. McGoldrick stated:

- Under the new reconfiguration, the *NCI Listens and Learns* Working Group will handle all questions relating to new topics.
- More than 120 cancer advocacy groups are registered and all but 37 have named spokespersons.

- The number of responses varies by topic. The biorepository question generated approximately 50 comments; other topics have generated around 10–12 comments. Leaving the question up longer (2 months) might increase the number of comments.
- Reminders that the new topic is posted are sent at the beginning and at the midway point, and all are told that they have 2 months to respond.
- There have been about 2,000 hits per month—spiders and robots are not included in this figure.

Ms. Sumpter stated that the “post a comment” button should be more accessible, rather than having to scroll to the bottom of the page to find that one can respond. She suggested that one solution would be to add a tag line at the end of the question, such as “Scroll down to post a comment.” Ms. McGoldrick said that she would add this tag line.

Col. Williams suggested that the hit data from the Web site be reviewed to find ways to further enhance the operation. Ms. Whitewolf asked how the number of hits compares to other sites. Ms. McGoldrick replied that review of this type of data would be done as part of the evaluation.

Ms. Davenport-Ennis offered the help of the DCLG in getting organizations to name spokespersons.

Dr. Ramos asked about the availability of post cards publicizing the *NCI Listens and Learns* Web site. The OLA staff offered to send these cards to any member who wishes to distribute them.

VII. Update on Listening and Learning Together: Building a Bridge of Trust

Ms. Mary Jackson-Scroggins reported on the progress of the Summit as follows:

- Mr. James Hadley, Ms. Anne Willis, OLA staff, and Palladian Partners have given great support to the Summit.
- The scholarship application process is being developed.
- The Summit Web site should be up and running by late January or early February 2006.
- The working group is considering how to get information to people without access to computers.
- The Summit agenda meets the evaluation/logic model criteria and a logic model specific to the Summit will be forthcoming.
- Participants in the Summit will be asked to fill out evaluation forms and their participation certificate may be withheld until the form is turned in.
- The Summit will not have to pay for rooms in the Natcher Center under a new NIH policy. This will save thousands of dollars.
- Ms. Scroggins will present information about the Summit to the Cancer Leadership Council on January 10. This is an informational presentation—no input from that group on the agenda will be sought.
- Tour packages for the Summit meeting are being finalized.
- Dr. von Eschenbach has expressed his intent to address the Summit.
- Save-the-date cards will soon be available.

- A Webcast is planned, but will not be advertised.
- A marketing plan has been drafted and is being reviewed and revised.
- DCLG members are asked to continue to recommend groups that should be contacted about attending the Summit, especially hard-to-reach groups.

Dr. Ramos asked how to obtain save-the-date cards. Ms. Hamilton replied that anyone who wants cards should e-mail her and cards will be supplied.

Dr. Ramos inquired about the criteria for scholarship eligibility. Ms. Scroggins explained that all participants must represent an organization, as verified by a letter from the leadership of the organization, so that participants can take information back and disseminate it as widely as possible through their organizations. The application, which will be approximately three pages in length, is straightforward and includes three essay questions covering the applicant's role in their organization, why he or she wants to attend the conference, and how information will be shared.

Ms. Hamilton noted that the scholarship application was going through the clearance process and should be available in late January or early February 2006.

Dr. Ramos asked how scholarship applications would be made available. Ms. Scroggins suggested that the best approach would be for applicants to contact the NCI directly for an application. Dr. Ramos and Ms. Whitewolf noted that this process might intimidate smaller organizations. Ms. Scroggins agreed that in those cases applications should be made available by whatever is the most convenient means because these are among the very organizations that the Summit wants to reach.

VIII. Update on Executive Secretary Search Process

Ms. Hamilton reported that the Department of Health and Human Services had added the restriction that the DCLG Executive Secretary position must be filled by someone who already works for the Department or within the NIH. The search process is continuing with this restriction in mind.

IX. Public Comment

There were no public comments.

X. Next Steps

Ms. Hamilton stated that DCLG members would receive an e-mail outlining meeting dates for the next 3 years. She asked members to inform her about their availability of these dates.

Mr. Ulman thanked all the participants.

The meeting was adjourned at 3:25 P.M.

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

Attachments:
Roster

A complete set of handouts is available from the executive secretary.

DCLG ACTION ITEMS

1. DCLG members will recommend to Ms. Scroggins or to OLA staff groups that should be contacted about attending the Summit, especially hard-to-reach groups.
2. DCLG members will help identify candidates to fill the upcoming five vacant slots on the DCLG.
3. Ms. McGoldrick will add a tag line to the question on the Listens and Learns Web site to "scroll down to make a comment."
4. Members will inform Ms. Hamilton about their availability for meeting dates for the next 3 years.