

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE
26th Meeting
DIRECTOR'S CONSUMER LIAISON GROUP
September 13-15, 2004
HOLIDAY INN SELECT BETHESDA
8120 Wisconsin Avenue
Bethesda, Maryland 20814
DRAFT AGENDA**

Monday, September 13, 2004 -- OPEN

10:00 A.M. – 11:00 A.M.

I. WELCOME AND SELF INTRODUCTIONS Mr. Doug Ulman, Chair, DCLG
Purpose: This provides an opportunity for the new DCLG members to get to know each other and to make sure there are no conflicts of interest.

- a. OPENING REMARKS, OPENING EXERCISE
- b. CONFLICTS OF INTEREST

11:00 A.M. – 12:00 A.M.

II. REVIEW OF THE FUTURE OF THE DCLG WORKING GROUP PROCESS
Purpose: This provides context for the DCLG members about what has happened most recently in its history.

- a. REPORT Ms. Vernal Branch
- b. DISCUSSION

12:00 P.M. – 1:30 P.M.

III. LUNCH (ON YOUR OWN)

1:30 P.M. – 4:30 P.M. (with 15 minute break)

IV. ORIENTATION TO NCI
Purpose: To help new DCLG members understand what NCI's mission is (and isn't), where it is going in the future, how it gets funded, and how the money that it gets funds research.

- 1:30 a. HISTORY, MISSION, GOALS AND STRUCTURE OF NCI Ms. Lis Handley
- 2:00 b. STRATEGIC DIRECTIONS FOR NCI Ms. Cherie Nichols
- 2:45 c. BREAK
- 3:00 d. FUNDING MECHANISMS AND APPROVAL PROCESS Mr. Leo Buscher
- 3:45 e. BUILDING AN NCI BUDGET Mr. John Hartinger

4:30 P.M. – 5:00 P.M.

V. INPUT FROM THE PUBLIC

Purpose: To provide an opportunity for the public to comment on the proceedings.

TUESDAY, September 14, 2004 -- OPEN

8:30 A.M. – 10:00 A.M

VI. FACILITATING DIALOGUE – NCI LISTENS AND LEARNS WEB SITE

Purpose: This gives members a chance to learn more about the development of the site and to determine how they will work and what work they will do on the Web site when it is operational.

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| a. | REPORT FROM DCLG WORKING GROUP
TO FACILITATE DIALOGUE | Dr. Marisa Weiss |
| b. | DEMONSTRATION OF THE SITE | TBD |
| c. | DISCUSSION | DCLG Members |

10:00 A.M. – 10:15 A.M.

VII. BREAK

10:15 A.M. – 12:00 P.M.

VIII. FACILITATING DIALOGUE – NCI LISTENS AND
LEARNS WEB SITE - CONTINUED

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| a. | NEXT STEPS ON THE WEB SITE | Dr. Ed Maibach |
| b. | DISCUSSION | DCLG Members |

12:00 P.M. – 1:30 P.M.

IX. WORKING LUNCH

1:30 P.M.- 3:30 P.M.

X. FACILITATING DIALOGUE – SUMMIT WITH ADVOCACY COMMUNITY

Purpose: To build awareness and gain insights into creating the broadest, most responsive, and useful exchange between the NCI and the cancer advocacy community via the Summit the DLCCG has agreed to host next summer. The Summit will give the NCI/DCLG the opportunity to focus on key issues such as the Digital Divide and effective ways to extend the Dialogue to non-Internet individuals who would like to contribute their voice.

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| a. | POTENTIAL SUMMIT WITH ADVOCATES | Mr. Bill Bro |
| b. | DISCUSSION | DCLG Members |

3:30 P.M. – 3:45 P.M.

XI. BREAK

3:45 P.M. – 4:45 P.M.

XII. NIH COUNCIL OF PUBLIC REPRESENTATIVES (COPR)
PUBLIC TRUST INITIATIVE

Dr. Rafael Gonzalez-
Amezcu and
Mr. James Kearns,
COPR Members

Purpose: To learn from the consumer advisory board that advises the NIH Director about the work it is doing to enhance public trust in the National Institute of Health.

4:45 P.M. – 5:15 P.M.

XIII. INPUT FROM THE PUBLIC

Purpose: To provide an opportunity for the public to comment on the proceedings.

WEDNESDAY, September 15, 2004 -- OPEN

8:30 A.M. – 10:00 A.M.

XIV. ISSUES IN CANCER SURVIVORSHIP

Mr. Doug Ulman

Purpose: This session will provide a high level description of some of the issues that have been raised to date in survivorship by the President's Cancer Panel and by the Office of Cancer Survivorship. It will be a springboard for any future activity the DCLG may wish to undertake in this area.

- a. REPORT FROM THE OFFICE OF CANCER SURVIVORSHIP
- b. DISCUSSION

Dr. Julia Rowland

10:00 A.M. – 10:15 A.M.

XV. BREAK

10:15 A.M. – 11:45 A.M.

XVI. REDUCING CANCER HEALTH DISPARITIES

COL (Ret) James
Williams, Jr.

Purpose: DCLG Member Col. James Williams and Dr. Nada Vydelingum, the Deputy Director of the Center to Reduce Cancer Health Disparities, will provide background information on health disparities research at NCI and within HHS, including the Progress Review Group on Reducing Health Disparities on which Col. Williams participated. They will lead a discussion of areas in the health disparities arena that might be good for future DCLG action.

- a. TRANS-HHS CANCER HEALTH DISPARITIES
PROGRESS REVIEW GROUP REPORT
EXPERIENCE COL (Ret) James Williams, Jr.
- b. REVIEW OF NCI's WORK ON HEALTH DISPARITIES
AND PROGRESS TOWARDS 2015 GOAL Dr. Nada Vydelingum
- c. DISCUSSION DCLG Members

11:45 A.M. – 12:15 P.M.

XVII. INPUT FROM THE PUBLIC

Purpose: To provide an opportunity for the public to comment on the proceedings.

12:15 P.M. – 1:30 P.M.

XVIII. WORKING LUNCH - PLANNING FOR THE AFTERNOON/NEXT STEPS

Mr. Doug Ulman

Purpose: To prepare for the discussion with Dr. von Eschenbach and to summarize action steps developed during the meeting and confirm responsibilities.

1:30 P.M. – 1:45 P.M.

XIX. UPDATE FOR NCI DIRECTOR ON THE MEETING

Mr. Doug Ulman

1:45 P.M. – 2:45 P.M.

XX. DIRECTOR'S REMARKS AND DISCUSSION

Dr. Andrew von Eschenbach
Director, National Cancer
Institute

2:45 PM. – 3:00 PM.

XXI. RECOGNITION OF FORMER MEMBERS

Dr. Andrew von Eschenbach
Director, National Cancer
Institute

3:00 P.M.

XXII. ADJOURN