

2005 Current Fiscal Year Report: National Cancer Institute Director's Consumer Liaison Group

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1. Department or Agency

Department of Health and Human Services

2. Fiscal Year

2005

3. Committee or Subcommittee

National Cancer Institute Director's
Consumer Liaison Group

3b. GSA

Committee No.

5248

4. Is this New During 5. Current 6. Expected 7. Expected

Fiscal Year? Charter Renewal Date Term Date

No 08/17/2004 08/17/2006

8a. Was Terminated During 8b. Specific 8c. Actual
Fiscal Year? Termination Term Date
Authority

No

9. Agency 10a. Legislation 10b.
Recommendation for Next Req to Terminate? Legislation
Fiscal Year Pending?

Continue

11. Establishment Authority Authorized by Law

12. Specific 13. 14. 14c.
Establishment Effective Committee Presidential?
Authority Date Type

42 U.S.C. 285a-2(b)(7) 11/20/1985 Continuing No

15. Description of Committee Scientific Technical Program

Advisory Board

16a. Total Number of Reports 1

16b. Report Date Report Title

09/30/2005 Annual Report to the Secretary

Number of Committee Reports Listed: 1

17a. 6 17b. Closed 0 17c. Partially Closed 0 Other Activities 0 17d. Total 6
Open

Meetings and Dates

| Purpose | Start | End |
|-----------------------|------------|--------------|
| NIH Committee Meeting | 11/04/2004 | - 11/04/2004 |
| NIH Committee Meeting | 12/14/2004 | - 12/14/2004 |
| NIH Committee Meeting | 01/18/2005 | - 01/18/2005 |

| | | |
|-----------------------|------------|--------------|
| NIH Committee Meeting | 02/28/2005 | - 03/01/2005 |
| NIH Committee Meeting | 05/26/2005 | - 05/26/2005 |
| NIH Committee Meeting | 09/14/2005 | - 09/15/2005 |

Number of Committee Meetings Listed: 6

| | Current FY | Next FY |
|--|-------------------|----------------|
| 18a(1). Personnel Pmts to Non-Federal Members | \$44,200.00 | \$44,200.00 |
| 18a(2). Personnel Pmts to Federal Members | \$0.00 | \$0.00 |
| 18a(3). Personnel Pmts to Federal Staff | \$214,454.00 | \$209,060.00 |
| 18a(4). Personnel Pmts to Non-Member Consultants | \$600.00 | \$600.00 |
| 18b(1). Travel and Per Diem to Non-Federal Members | \$19,813.00 | \$20,070.00 |
| 18b(2). Travel and Per Diem to Federal Members | \$0.00 | \$0.00 |
| 18b(3). Travel and Per Diem to Federal Staff | \$0.00 | \$0.00 |
| 18b(4). Travel and Per Diem to Non-member Consultants | \$0.00 | \$0.00 |
| 18c. Administrative Costs (FRNs, contractor support, In-person/hybrid/virtual meetings) | \$0.00 | \$0.00 |
| 18d. Other (all other funds not captured by any other cost category) | \$49,968.00 | \$50,967.00 |
| 18e. Total Costs | \$329,035.00 | \$324,897.00 |
| 19. Federal Staff Support Years (FTE) | 2.30 | 2.30 |

20a. How does the Committee accomplish its purpose?

The committee is composed of consumer advocates who are involved in cancer advocacy and the cancer experience, and work with a constituency with which they communicate on a regular basis. The committee provides advice and recommendations on developing and establishing processes and criteria for identifying appropriate consumer advocates to serve on a variety of NCI program and policy advisory committees; serves as a primary forum to discuss issues and concerns and exchange viewpoints that are important to the broad development of NCI program and research priorities and establishes and maintains collaborations between the NCI and the cancer advocacy community to reach common goals. The major activity for the NCI Director's Consumer Liaison Group (DCLG) in fiscal year 2005 was the launch and development, in cooperation with NCI staff, of NCI Listens and Learns. NCI Listens and Learns is a Web site designed to improve communication between the Institute, the cancer advocacy community and the public. NCI Listens and Learns allows advocates and interested members of the public to participate in an open dialogue with NCI on a range of cancer research topics. By accessing the Web site and posting comments in response to topics posted by various offices throughout NCI, participants can help to shape the direction of future NCI activities. The DCLG has played a role in the monitoring the comments posted to the site. Additionally, the DCLG has been involved in the continued promotion of the site and has advised NCI on the policies and procedures for operating the site. Additionally, the DCLG began planning for a 2006 Summit titled "Listening and Learning Together: Building a Bridge of Trust." The Summit

will assemble representatives from all segments of the cancer community, with special attention to including the medically underserved, to (1) demystify NCI and facilitate its navigation, (2) provide a forum for first-hand cancer community input and interaction, and (3) foster two-way communication between NCI and the cancer community and collaboration. The preliminary goals/objectives of the Summit include the development of mechanisms for post-Summit two-way communication and collaboration and the formation of alliances between groups and individuals and NCI. DCLG members also participated in other activities including: Consumer Advocates in Research and Related Activities (CARRA) Program: Provided feedback to the Office of Liaison Activities (OLA) in evaluating the program, and revision of the training program for CARRA members involved in peer review. President's Cancer Panel: Participated in the 2004-2005 President's Cancer Panel series of meetings. Survivorship: Served on the planning committee on the NCI/ACS Cancer Survivorship Conference.

20b. How does the Committee balance its membership?

The Committee consists of 15 members, including the Chair, appointed by the Director, NCI. The members are consumer advocates who are involved in cancer advocacy and the cancer experience, and represent a constituency with which they communicate on a regular basis.

20c. How frequent and relevant are the Committee Meetings?

The Committee met six times during this reporting period to advise and make recommendations to the Director, NCI, from the perspective and

viewpoint of cancer consumer advocates on a wide variety of issues, programs and research priorities. All meetings were relevant to the purpose of the DCLG and its current priorities. The full DCLG had two face-to-face meetings – February 28 – March 1, 2005, September 14-15, 2005; three conference call meetings – December 14, 2004, January 18, 2005, May 26, 2005; and twenty one working group meetings. The DCLG Operations Working Group met on October 5, 2004, October 21, 2004, December 14, 2004, and May 10, 2005. The Summit Working Group met on October 5, 2004, October 19, 2004, November 3, 2004, December 1, 2004, February 17, 2005, April 6, 2005, May 11, 2005, June 1, 2005, July 13, 2005, and August 17, 2005. The Promotions Working Group met on October 7, 2004 and April 26, 2005. The Evaluations Working Group met on October 13, 2004, October 25, 2004, December 9, 2004 and June 27, 2005. The Program Working Group met on July 28, 2005 and August 31, 2005.

20d. Why can't the advice or information this committee provides be obtained elsewhere?

The Committee is composed of consumer advocates who are involved in cancer advocacy and the cancer experience, and shall represent a constituency with which they communicate on a regular basis. The advice is not available from NCI staff or existing committees.

20e. Why is it necessary to close and/or partially closed committee meetings?

N/A

21. Remarks

Designated Federal Officer

BROOKE HAMILTON EXECUTIVE SECRETARY

| Committee Members | Start | End | Occupation | Member Designation |
|-------------------------------|------------|------------|---|--------------------|
| ANTHONY, MARGARET | 08/27/2004 | 06/30/2006 | REGISTERED NURSE/NURSE MANAGER | Special |
| | | | | Government |
| | | | | Employee |
| | | | | (SGE) |
| BRANCH, VERNAL | 07/27/2004 | 06/30/2007 | HEALTH EDUCATOR CONSULTANT | Member |
| | | | | Special |
| | | | | Government |
| | | | | Employee |
| BRO, WILLIAM | 12/23/2004 | 06/30/2008 | PRESIDENT/CHIEF EXECUTIVE OFFICER | (SGE) |
| | | | | Member |
| | | | | Special |
| | | | | Government |
| CAMPOS, LOURIE | 09/13/2004 | 06/30/2008 | ASSISTANT DIRECTOR OF POLICY | Employee |
| | | | | (SGE) |
| | | | | Member |
| | | | | Special |
| DAVENPORT-ENNIS, NANCY | 09/16/2004 | 06/30/2008 | CHIEF EXECUTIVE OFFICER & PRESIDENT | Government |
| | | | | Employee |
| | | | | (SGE) |
| | | | | Member |
| DE CORDOVA-HANKS, BOBBI | 08/27/2004 | 06/30/2006 | COMMUNITY HEALTH EDUCATOR/DIRECTOR | Special |
| | | | | Government |
| | | | | Employee |
| | | | | (SGE) |
| LAIRD, BEVERLY | 08/27/2004 | 06/30/2007 | MEMBER/OWNER | Member |
| | | | | Special |
| | | | | Government |
| | | | | Employee |
| RAMOS, SYLVIA | 09/13/2004 | 06/30/2006 | CLINICAL PROFESSOR OF SURGERY | (SGE) |
| | | | | Member |
| | | | | Special |
| | | | | Government |
| ROSENTHAL, ERIC | 08/27/2004 | 06/30/2006 | MEDICAL JOURNALIST | Employee |
| | | | | (SGE) |
| | | | | Member |
| | | | | Special |
| SCROGGINS, MARY | 09/13/2004 | 06/30/2007 | FREELANCE WRITER/EDITOR | Government |
| | | | | Employee |
| | | | | (SGE) |
| | | | | Member |

| | | | | |
|-----------------------|------------|------------|--------------------------------------|--|
| SUMPTER, SUE | 09/13/2004 | 06/30/2007 | PATIENT SERVICES MANAGER | Special Government Employee (SGE) Member |
| ULMAN, DOUGLAS | 07/27/2004 | 06/30/2008 | DIRECTOR OF SURVIVORSHIP | Special Government Employee (SGE) Member |
| WEISS, MARISA | 07/27/2004 | 06/30/2007 | DIRECTOR, BREAST CANCER RADIOLOGY | Special Government Employee (SGE) Member |
| WHITEWOLF, CELESTE | 08/27/2004 | 06/30/2006 | VOLUNTEER DIRECTOR | Special Government Employee (SGE) Member |
| WILLIAMS, JAMES | 08/27/2004 | 06/30/2008 | COLONEL(RET) | Special Government Employee (SGE) Member |

Number of Committee Members Listed: 15

Narrative Description

The goal of NIH research is to acquire new knowledge to help prevent, detect, diagnose, and treat disease and disability, from the rarest genetic disorder to the common cold. The NIH mission is to uncover new knowledge that will lead to better health for everyone. NIH works toward that mission by utilizing the Director's Consumer Liaison Group (DCLG) of the National Cancer Institute (NCI). The committee was established to: assist in developing and establishing processes and criteria for identifying appropriate consumer advocates to serve on a variety of NCI program and policy advisory committees; serve as a primary forum to discuss issues and concerns and exchange viewpoints that are important to the broad development of NCI program and research priorities; establish and maintain collaborations between the NCI and the cancer advocacy community to reach common goals.

What are the most significant program outcomes associated with this committee?

Checked if
Applies

- | | |
|---|-------------------------------------|
| Improvements to health or safety | <input type="checkbox"/> |
| Trust in government | <input checked="" type="checkbox"/> |
| Major policy changes | <input type="checkbox"/> |
| Advance in scientific research | <input type="checkbox"/> |
| Effective grant making | <input type="checkbox"/> |
| Improved service delivery | <input type="checkbox"/> |
| Increased customer satisfaction | <input checked="" type="checkbox"/> |
| Implementation of laws or regulatory requirements | <input type="checkbox"/> |
| Other | <input type="checkbox"/> |

Outcome Comments

NA

What are the cost savings associated with this committee?

Checked if Applies

- | | |
|----------------------------|-------------------------------------|
| None | <input type="checkbox"/> |
| Unable to Determine | <input checked="" type="checkbox"/> |
| Under \$100,000 | <input type="checkbox"/> |
| \$100,000 - \$500,000 | <input type="checkbox"/> |
| \$500,001 - \$1,000,000 | <input type="checkbox"/> |
| \$1,000,001 - \$5,000,000 | <input type="checkbox"/> |
| \$5,000,001 - \$10,000,000 | <input type="checkbox"/> |
| Over \$10,000,000 | <input type="checkbox"/> |
| Cost Savings Other | <input type="checkbox"/> |

Cost Savings Comments

NA

What is the approximate Number of recommendations produced by this committee for the life of the committee?

5

Number of Recommendations Comments

The DCLG approved multiple recommendations related to the operational procedures and promotion of NCI Listens and Learns.

What is the approximate Percentage of these recommendations that have been or will be Fully implemented by the agency?

0%

% of Recommendations Fully Implemented Comments

Section 9(b) of the Federal Advisory Committee Act states that unless otherwise specifically provided by statute or Presidential directive, advisory committees shall be utilized solely for advisory functions. Determinations of action to be taken and policy to be expressed with respect to matters upon which an advisory committee reports or makes recommendations shall be made solely by the President or an officer of the Federal Government.

What is the approximate Percentage of these recommendations that have been or will be Partially implemented by the agency?

0%

% of Recommendations Partially Implemented Comments

Section 9(b) of the Federal Advisory Committee Act states that unless otherwise specifically provided by statute or Presidential directive, advisory committees shall be utilized solely for advisory functions. Determinations of action to be taken and policy to be expressed with respect to matters upon which an advisory committee reports or makes recommendations shall be made solely by the President or an officer of the Federal Government.

Does the agency provide the committee with feedback regarding actions taken to implement recommendations or advice offered?

Yes No Not Applicable

Agency Feedback Comments

The Director of NCI gave feedback directly to the DCLG through meetings with the full advisory group and through senior NCI staff.

What other actions has the agency taken as a result of the committee's advice or recommendation?

Checked if Applies

- Reorganized Priorities
- Reallocated resources
- Issued new regulation

- Proposed legislation
- Approved grants or other payments
- Other

Action Comments

NA

Is the Committee engaged in the review of applications for grants?

No

Grant Review Comments

NA

How is access provided to the information for the Committee's documentation?

Checked if Applies

- Contact DFO
- Online Agency Web Site
- Online Committee Web Site
- Online GSA FACA Web Site
- Publications
- Other

Access Comments

NCI Division of Extramural Activities website: Advisory Boards and Groups
<http://deainfo.nci.nih.gov/advisory/boards.htm> - Each NCI committee's information is listed here such as the committee charter, minutes, agenda and future meeting dates. Weekly e-mails are sent to Board Members via a list serv on the NCI 2015 Goal and on various NCI Initiatives and activities. -This provides the NCI Director with a forum to keep the members abreast of current activities and ongoing scientific information related to cancer research, grant activity and the goals of the NCI.