The NCI Director’s Consumer Liaison Group (DCLG)

Presentation to the National Cancer Advisory Board

Doug Ulman, DCLG Chair

Wednesday, June 14, 2006
What is the DCLG?

- Established in 1997 as the first all-consumer advisory committee at the NIH
- 15 consumers selected through a national nomination and review process; appointed by the NCI Director.
- Makes recommendations to the Director of NCI from the consumer advocate perspective on a wide variety of issues, programs, and research priorities.
- Provide an important link between NCI and the advocate community
- FACA committee similar to the NCAB, BSA, BSC, & PCP
Who are the members of the DCLG?

- Consumer Advocates were broadly defined as: Survivors of cancer or anyone who has been affected by the suffering and consequences or risk of cancer.
- Our members are cancer survivors, family members, caregivers, health care professionals, and consumer advocates.
- Our membership reflects the breadth and diversity of the cancer consumer advocacy community in expertise, regional distribution and cultural, ethnic and sexual orientation.
The DCLG Charter

The DCLG 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; provides recommendations to the Director, NCI, in response to specific advice and requests from the Director, NCI, and to the needs of the cancer advocacy community; and establishes and maintains strong collaborations between NCI and the advocacy community to reach common goals.
DCLG Members Involved at NCI

- DCLG Chair attends NCI Budget Planning Retreat
- caBIG™ - Liaison with CARRA Members
- Representative to the Clinical Trials Advisory Committee (in formation)
- The Cancer Genome Atlas (TCGA) Project
  - External Scientific Committee Representative
  - Data Release Workshop
- Office of Liaison Activities/Office of Cancer Survivorship
  - Survivor/Research Mentoring Program
Current Activities of the DCLG

- **NCI Listens & Learns website**


- Town Hall Meeting hosted by the DCLG

- Five new DCLG members will be appointed in July to replace members with expired terms
Upcoming DCLG Meetings

• The DCLG has two in-person meetings per year, and holds at least two meetings by teleconference.

• Fiscal Year 2007 October 25–26, 2006
  March 29–30, 2007

• Fiscal Year 2008 October 24–25, 2007
  March 27–28, 2008

• Fiscal Year 2009 October 28–29, 2008
DCLG Working Groups

- Agenda Working Group
- Summit Planning Working Group
- NCI Listens and Learns Working Group
NCI Listens and Learns

• The DCLG created the NCI Listens and Learns website and the Summit as a result of the responses to a 2003 NCI/DCLG survey of cancer advocacy groups.

• A Pilot on-line dialogue between the NCI, the cancer-related advocacy community and the general public:

http://www.ncilistens.cancer.gov

• NCI Programs posts topics for discussion and feedback for a two month period.

• NCI then responds describing how the feedback was used.

• The website is currently being evaluated.
Next Steps for the DCLG

• Considering new collaborations between NCI and the cancer-advocacy/survivorship community

• Call to Action – the DCLG is a part of NCI, and is eager to help.

• The DCLG will update the NCAB annually.

• We are open to questions and discussion.
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About the Director’s Consumer Liaison Group

- About DCLG
- DCLG Charter Summary
- Reports and Surveys
- DCLG Membership
- Member Activities
- History of the DCLG
- NCI Listens and Learns
- 2006 Summit

About DCLG

[Image of the Director's Consumer Liaison Group]