

**NATIONAL CANCER INSTITUTE
DIRECTOR'S CONSUMER LIAISON GROUP
Teleconference
June 1, 2000
12 Noon - 1:00 p.m.**

The 5th meeting of the NCI Director's Consumer Liaison Group (DCLG) was convened at 12 noon on Thursday June 1, 2000 as a teleconference. The teleconference was open to the public. Mr. Michael Katz presided as Chair.

DCLG Members

Mr. Mike Katz, *Chairperson*
Ms. Paula Bowen (absent)
Ms. Susan Butler
Dr. Manuel Castillo
Ms. Kerry Dewey
Ms. Venus Ginés
Dr. Felicia Hodge (absent)
Ms. Susan Leigh
Ms. Ruth Lin
Ms Gena Love (absent)
Mr. Dan Moore
Ms. Lillouise Rogers
Ms. Susan Stewart
Dr. Brad Zebrack

NCI Speakers

Dr. Jed Rifkind
Ms. Nelvis Castro
Ms. Jane Reese-Coulbourne
Dr. Joseph Lipscomb
Dr. Jon Kerner

Office of Liaison Activities Staff

Ms. Elaine Lee, Executive Secretary, DCLG
Dr. Yvonne Andejas
Ms. Tracy Clagett
Ms. Amanda Cook
Ms. Kristie Dionne
Ms. Sabrina Ferguson

CALL TO ORDER AND OPENING REMARKS

The meeting was called to order by Ms. Elaine Lee in the absence of the Chair who joined the call later. Ms. Lee outlined the objective of the meeting for the DCLG to hear the reports of each

of the working group established at the April 2000 DCLG meeting. These working groups prepared background materials and will present their topics for discussion to aid the DCLG as it develop a plan for future activities for the group, as well as determine the extent of advocacy involvement at NCI.

REPORTS OF THE DCLG WORKING GROUPS

Dr. Brad Zebrack presented the report of the **Advocacy Involvement Working Group (AIWG)** (Appendix A). The DCLG has a role in the development of a community of advocates within NCI. The DCLG believes it is in a unique position to convene advocates involved in NCI programs. Objectives for organizing this community include:

- Exchanging information about NCI committees and working groups
- Providing a forum for sharing information and providing support to help advocates be more effective in their involvement
- Providing feedback to NCI regarding those experiences.

One mechanism to accomplish this would be the establishment of a Internet listserv . Advocates without Internet access could be informed via a newsletter. Eventually the DCLG could develop workshops, a buddy system and written materials to assist advocates who are invited to participate in NCI activities. The DCLG members agreed that the listserv was a good idea and asked OLA to explore the ramifications of NCI sponsorship of the listserv.

The AIWG emphasized that another goal of the DCLG is to enhance involvement of advocates in NCI activities. Dr. Yvonne Andejaski (OLA) described a plan to evaluate how advocates are currently participating at NCI. The evaluation will include interviews with Senior NCI staff and advocates with experience with the NCI. OLA will shortly begin interviewing NCI staff while DCLG Members will interview the advocates. The information obtained during the interviews will be used to develop a more formal process for consumer advocate inclusion at the institute

Ms. Susan Butler presented the report of the **Clinical Trials Working Group** (Appendix B). This group suggested that the DCLG develop an action plan for working with key NCI players, obtain some guidance in speaking with the media, and develop ways to provide assistance with grassroots groups in the pilot projects in Baltimore and North Carolina being conducted by Jane Reese-Coulbourne. Ms. Coulbourne noted, the pilot project is currently based on those two communities but that when the pilot is expanded there will be a chance for DCLG involvement. Ms. Butler emphasized that there is some urgency in promoting clinical trials. Ms Leigh suggested that the DCLG work with the Cancer Leadership Council (CLC) on this issue, working with them to gather information from patient advocacy organizations. The DCLG agreed that the working group should draft an action plan and present it to the group. In addition, Ms Coulbourne and Ms. Butler will approach the CLC to get their input.

The report of the **Extraordinary Opportunities Working Group** was presented by Mr. Michael Katz (Appendix C) . He reported that the NCI Communications Opportunities Leadership Team (COLT), has been formed to develop baseline information about the state of cancer communications – the populations reached, types of messages prepared, challenges for the future; the research currently funded or proposed and pilot projects. The kickoff for

presenting the plan is scheduled for December 2000.

Dr. Hodge presented the report of the **Health Disparities and Quality of Care Working Group** (Appendix D). Dr. Jon Kerner provided a brief description of NCI's concerns and goals. He said that NCI has prepared a Strategic Plan to Reduce Health Disparities NCI's overall goal is to understand the causes of health disparities in cancer and to develop effective interventions to address these disparities. New initiatives will be planned and implemented with other federal agencies, local governments and private entities.

NCI has also announced a **Quality of Cancer Care Initiative (correct title?)** that will define, evaluate, and seek to improve the quality of care in cancer prevention, diagnosis, therapy and palliation. Dr. Joe Lipscomb is heading this effort.

Dr. Hodge noted that Drs. Lipscomb and Kerner would let the DCLG know when there was a role for them. They have been invited to participate in an interactive session with the DCLG at their October 2000 meeting.

Ms. Kerry Dewey presented the report for the **NCI Brand Working Group** (Appendix E) . NCI is working to establish a brand/identity to build public recognition and support. NCI's Office of Communications under the leadership of Dr. Susan Sieber is leading this effort. The first phase in development has been completed. From interviews with NCI staff, the concept of "Connections" has been proposed. During the next phase development, the public, including advocates, will be consulted. Suggested actions for the DCLG members include:

- Identify DCLG members to interview
- Identify key stakeholders to interview
- Identify materials to include in the inventory of current NCI publications
- Provide feedback on the brand statement and communication tools

The ultimate goal will be for the DCLG to promote NCI's identity in all communications and actions.

Ms. Ruth Lin described the activities of the **DCLG Operations Working Group** (Appendix F). This group is working with OLA staff to prepare the DCLG Annual Report for the NCI. It is also responsible for developing an orientation for new DCLG members by October. Mr. Katz volunteered to write the report. The group provided suggestions for changes to the draft orientation provided by Ms. Elaine Lee. Ms. Lee will prepare a revised draft for review and comment by this working group.

Mr. Katz led the discussion related to the final topic for the teleconference, the report of the **Website Working Group** (Appendix G). The DCLG members expressed their concerns that few, if any changes have occurred as a result of recommendations the DCLG made in its review of selected communication programs to in June 1999. They recognize that the reorganization of the Office of Communications, and the transition to a new Webmaster has contributed to this delay. They strongly encouraged Dr. Jed Rifkind, the current Webmaster, to communicate their concerns to appropriate NCI staff.

The call was adjourned at 1:00 p.m.

Date

Michael Katz
Chair
NCI Director's Consumer Liaison Group

Date

Elaine Lee
Executive Secretary
NCI Director's Consumer Liaison Group

ACTION ITEMS FROM JUNE 1, 2000 DCLG TELECONFERENCE:

General Action Items:

- Identify policies and procedures relevant to subcommittees (OLA).
- Develop October 2000 agenda; two topics should be Quality Cancer Care and Health Disparities

Advocate Involvement

- The DCLG will set up a separate listserv for advocates to exchange ideas and experiences related to participation on NCI committees and groups.
- Ms. Lee will determine the requirements for an NCI owned listserv
- Dr. Zebrack will begin a discussion of listserv operations including responses to inquiries with DCLG members; this will be an agenda item for July 2000 teleconference (DCLG).
 - The working group will develop policies and procedures for the listserv. (DCLG)
 - The working group and OLA will develop an interview plan for advocates.
 - Dr. Andejaski will proceed with NCI staff interviews.
 - The Advocacy Involvement Working Group will have another teleconference within 2 weeks to further discuss these issues.

Clinical Trials Promotion

- The working group suggests that there be a subcommittee on Clinical Trials Promotion. Subcommittee members would be Kerry Dewey, Susan Butler, and Dan Moore.
- The working group will develop proposed action plan for advocate participation in NCI's Clinical Trial Promotion with Jane Reese-Coulbourne and other key NCI/OLA staff. This plan should include the DCLG assistance in the Baltimore/NC pilot project. Ms. Butler and Ms. Coulbourne volunteered to approach the Cancer Leadership Council (CLC) to learn more about thoughts of major advocacy organizations related to Clinical Trials Promotion.
- OLA will arrange for media training; staff will work with the DCLG and OC staff to determine how to do this and who will participate.

Extraordinary Opportunity in Communications

The DCLG currently has a member on the Communications Opportunity Leadership Team (COLT) and he will continue to be involved in the development of communications initiatives.

NCI Website:

The website is under continual development. Recruitment of a new webmaster will begin soon. It will be his/her responsibility to ensure overall integration of NCI's sites.

NCI Branding:

The time line for completion of the branding activity is December 2000 when the Extraordinary Opportunity in Communication Meeting will be held. Action items requiring follow-up include;

- NCI will provide the DCLG with language describing NCI's mandate. Note: NCI is evaluating its mandate as a government research institute and wants to be true to that mandate in the proposed brand.
- The working group will identify ways that the DCLG can be involved in the NCI Brand campaign, particularly in the planning process and interviews. The DCLG will identify members to work with the NCI Brand campaign. The DCLG working group leader will contact Ms. Castro (Health Promotions Branch) to discuss these actions.
- The working group will ask the DCLG to suggest ways to bridge the potential gap between the public and scientists with one brand (i.e. logo and one tagline).

Quality Cancer Care/Health Disparities

- The working group chair or designee will contact Drs. Lipscomb and Kerner to arrange their sessions for the October 2000 meeting
- (Drs. Lipscomb & Kerner) and the DCLG working group members agreed that Dr. Lipscomb, Dr. Kerner and possibly Dr. Julia Rowland (Office of Cancer Survivorship) will present their initiatives at the October 2000 DCLG meeting. These sessions should allow the DCLG members to talk with the presenters about how advocates can participate in these initiatives
- Ms. Claggett will brief Dr. Hodge and Ms. Love (who were absent) and begin to formulate plans via e-mail.
- Dr. Lipscomb and Dr. Kerner stated that they both want DCLG and other consumer advocate input on these initiatives. For Health Disparities, Dr. Kerner is looking to the public to determine what their concerns are.
- The working group will develop a mechanism for continuing communication with Drs. Lipscomb and Kerner.

DCLG Operations/Orientation

- Mr. Katz will prepare the annual report for the DCLG due to OLA in September.
- Ms. Lin, Ms. Leigh and Ms. Love will work on the orientation package, along with OLA staff.
 - Essential orientation elements will be identified by early July
 - Speakers will be identified by mid July; – both the DCLG presenters and the NCI staff

Advocacy Involvement in NCI Programs and Activities Working Group

Prepared by Dr. Brad Zebrack, Chairperson

May 2000

Definition and Scope:

When Eleanor Nealon initially developed the concept of the DCLG she envisioned a “community of advocates within the NCI who could help the institute advance its mission to address the burdens of cancer.”

The DCLG currently see its natural role and obligation as being that of developing a community of advocates within NCI. The DCLG is in the unique position to convene advocates serving the NCI. Objectives for organizing this community of advocates include (1) exchanging information about advocates’ experiences in NCI activities such as scientific peer review and serving on advisory committees and working groups, (2) providing a forum for sharing information and support to be more effective in their roles, and (3) providing feedback to NCI regarding those experiences. Advocates could be contacted and invited to join a listserv that would enable them to talk with one another, share experiences, and offer concrete suggestions and support for effective participation in NCI activities. Advocates without Internet access could be “kept in the loop” via a newsletter. Eventually, this network of advocates could develop workshops, a buddy system and written materials to assist advocates who are invited to participate in NCI forums.

History: Advocates and public representatives have been involved in various NCI Advisory Groups/Planning and Oversight Groups. Currently, consistent and systematic procedures for involving advocates in these NCI activities are not in place. Advocates’ involvement and invitation to participate varies depending upon the federal status and/or policies specific to those bodies.

Key Players:

Advocates who have been involved in NCI committees, advisory boards, etc., Dr. Klausner, and whoever else would be involved in setting up a listserv and newsletter and securing NCI approval to contact these folks. Probably some OLA staff.

Status/ongoing Activities:

OLA staff have charted a 6-month plan to evaluate how advocates are currently being used by various departments of NCI, and how NCI staff as well as advocates view the value of advocate participation on NCI committees and boards. Involvement of advocates in peer review continues, and NCI staffers/administrators monitor the recruitment and evaluation of these efforts. The current status of these efforts are not known to the DCLG.

Important Issues:

At present, and before developing and implementing these and other strategies for enhancing advocates’ involvement in NCI activities, the DCLG needs to know if the NCI will commit resources (i.e. staff support, funding) to support the DCLG in these efforts.

DCLG members should remain focused on the goal of addressing its mission and stated goals, including the enhancement of advocate's involvement in NCI activities. In the meantime, NCI staff can proceed with data collection to assess advocates' and NCI staffers' attitudes and experiences around involvement of advocates.

Time line:

Through this committee, NCI/OLA staff will distribute a draft of an NCI and advocates needs assessment to DCLG for feedback prior to the June 1 DCLG conference call.

Appendix B

Clinical Trials Promotion Working Group

Prepared by Ms. Susan Butler, Chairperson

May 2000

Definition and Scope: The DCLG shares with NCI a growing concern regarding the implications of the fact that only about five percent of cancer patients currently participate in clinical trials. The figure remains low despite evidence that clinical trials represent the single most direct hope for scientific advancement in cancer, and despite the growing interest of the cancer community as a whole to generate greater degrees of trial participation. While NCI's Office of Clinical Trials Promotion works in a variety of media to promote trial participation (print, new website, etc.), including the present Clinical Trials Awareness Campaign being developed, there remains widespread public lack of knowledge about trials and, in some instances, significant misunderstanding about trials. Further, physicians, managed care organizations and others capable of making potential participants aware of trial opportunities often do not do so, for a variety of reasons. The media inclines toward sensationalistic stories or silence, rarely using the capacity to inform for the public good on this topic. At present, no clear role has been developed in clinical trials promotion for the DCLG in particular, and the advocacy community in general.

History: It appears that only NCI, the Department of Defense, some pharmaceutical companies and their partners have made concerted efforts to promote clinical trials participation. While time has not permitted research on the topic, it does not appear that the cancer advocacy community (including very large players like the American Cancer Society) has made any systematic or organized effort to promote clinical trial participation to the public, survivors, or the health care community as a whole. Consumer involvement in the trials process (not to be confused with "promotion,") has grown to include representation on IRBs and NCI, DoD and some pharmaceutical company peer review panels.

The DCLG history with the issue came into focus at the October 1999 meeting in a discussion of media assaults on trials. A Talking Points paper on the topic was prepared by a DCLG member and introduced for discussion at the April 2000 meeting. Input was received and the DCLG renewed its commitment to pursue effective roles for advocates in the clinical trials promotion process.

Key Players: For the immediate task of designing a role for the DCLG and the advocacy community in clinical trials participation, key players would include NCI's Office of Clinical Trials Promotion, including the Clinical Trials Awareness Campaign, the Office of Liaison Activities, Office of Cancer Communications, and selected leaders of cancer advocacy organizations.

Status/Ongoing Activities: The Clinical Trials Awareness Campaign is designed to determine effective ways to get the attention of people not predisposed to learn about cancer and trials to absorb information about these topics, and to act on what they know. An array of materials and approaches is being piloted in two sites, Baltimore and North Carolina, with the Baltimore site for grassroots outreach. There is high interest from the field for training materials. Next steps in the pilot effort involve consideration of an array of issues, including assessment of what has been learned about delivering effective messages about trials to the public, and answers to questions such as: is the project essentially an R&D function, with partners needed to do the training? Who else will be involved? Can training materials be adapted to be used without training trainers for the purpose? What is the role of the advocacy community? For the larger NCI? The pilot, which will not be completed and analyzed for more than a year, should yield invaluable information on how to make the public aware of the availability and importance of clinical trials.

Important Issues: The DCLG needs to determine an appropriate role and direction for itself and for consumer advocate involvement in clinical trials promotion (a plan!), working in concert with the above-named Key Players. Once the role is defined and action steps determined, we need to move forward and execute the plan. Central to any further efforts is to secure the commitment of NCI that resources will be made available to facilitate this involvement.

Time line: Subcommittee further steps could emerge following the June 1 conference call, if the DCLG determines that continued involvement is warranted. Next steps and action recommendations reasonably could be developed within a few months, and an Action Plan determined from these recommendations.

Advocate Involvement: See above: "Important Issues." Clearly a role for the consumer advocacy community needs to be designed, involving many of the Key Players referenced above.

Potential Role of the DCLG: Again, see above: "Important Issues." Possible ideas for short-term involvement include preparing selected DCLG member volunteers to speak to the media when trials are under fire in the future (this includes refining the Talking Points paper into media messages); and providing assistance to the Awareness Campaign in identifying potential grassroots partners in the Baltimore area.

**Cancer Communications Extraordinary Opportunity Working Group
Communications Opportunity Leadership Team (COLT)**

Prepared by Mr. Mike Katz, Chairperson
May 2000

Definition and Scope: The Institute has a major initiative to fund research in Cancer Communications with the aim of advancing the state of the art and improving outcomes.

History: The Cancer Communications Extraordinary Opportunity included in the 2000 Bypass Budget was proposed by the DCLG and two other sources within the Institute. Communications Opportunity Leadership Team (COLT) was formed to help shape the implementation of this important initiative.

Key Players: Barbara Reimer chairs the COLT, which includes 30-40 members of the Institute and the advocacy community. Michael Katz represents the DCLG in this forum

Status/ongoing activities:

The COLT worked to finalize the original budget submission and is now working on implementation issues. A kickoff event has been planned to increase awareness of NCI's commitment to quality cancer communications, share information, and build partnerships wherever possible. The event is tentatively being scheduled for December 2000. COLT members have been working to flesh out the goals of the event and to identify the types of information and demonstration sessions we would offer to participants. All agreed that the Kickoff Event is a great way to bring researchers and practitioners together, to speed dissemination of ideas, and to help build skills for people in areas like creating tailored messages, and acquiring skills in usability testing for electronic and print publications.

Research to baseline the current state of cancer communications, both in terms of access and effectiveness of current vehicles is planned as part of this effort. Also included is research on communications techniques and tools.

Important Issues:

It will be important to keep the consumer perspective in this initiative to retain focus on outcomes and keep the research targeted at tangible benefits.

Time line:

The next COLT meeting is scheduled for September and the kickoff is to take place in December 2000.

Advocate Involvement:

The COLT has broad representation from the institute and the advocacy community.

Potential Role of the DCLG:

The DCLG can play a role via continued participation in the COLT as well as in identifying issues and communicating progress in this area to their constituencies.

Health Disparities and Quality Cancer Care Working Group

Prepared by Dr. Felicia Hodge, Chairperson

May 2000

The National Cancer Institute (NCI) has designed a national effort (Strategic Plan to Reduce Health Disparities) to identify and address the cancer-related health disparities facing large segments of our society. Because racial and ethnic communities carry an unequal burden of cancer-related disparities, the NCI is targeting these groups in areas of research, education and training. NCI's overall goal is to understand the causes of health disparities in cancer and to develop effective interventions to address these disparities. New initiatives will be planned and implemented with other federal agencies, local governments and private entities. Dr. Jon Kerner, who is co-leading this effort, requested an opportunity to appear before the DCLG to discuss the best ways in which advocates may be included in this process.

NCI has also announced a Quality of Cancer Care Initiative that will define, evaluate, and seek to improve the quality of care in all aspects of cancer prevention, diagnosis, therapy and palliation. Dr. Joe Lipscomb is heading the effort. By design, the initiative is institute-wide. There is an (internal) NCI Quality of Care Committee with representatives from each of the NCI Divisions. It is co-chaired by Dr. Robert Hiatt and Ms. Mary McCabe. There is also the Quality of Cancer Care Committee (QCCC), a trans-agency task force that will guide NCI's research efforts and help ensure that what NCI learns inform the decisions of its federal partners, including HCFA. Dr. Lipscomb is a member of this QCCC committee, which is chaired by Dr. Hiatt. In addition, Dr. Klausner has designated Quality of Care as a Challenge area for the 2002 Bypass Budget. Dr. Lipscomb and Dr. Martin Brown are co-leading this Challenge effort.

Dr. Lipscomb asked for our suggestions as to how to integrate advocates in this process. We suggested that Dr. Lipscomb utilize the DCLG for the purposes it was designed: as an advocacy resource/advisory body and as a liaison to the wider advocacy community.

The goal of the initiative is (1) to enhance the state of the science for defining, monitoring, and improving the quality of cancer care, and (2) to seek to ensure that federal-level decisions on cancer care delivery, reimbursement, and regulation are consistent with the best available scientific evidence on quality care. The five resource requirements identified for quality of cancer care are:

1. Develop core measures for evaluating cancer care.

These core measures include such endpoints as quality of life, satisfaction with care, economic burden, as well as traditional measures of survival, disease-free survival, and tumor response.

2. Strengthening the methodological and empirical foundations of quality assessment in cancer.

Support new community-based studies, and expand support for studies to improve methodological basis for quality of care assessment from observational data.

3. Enhancing quality-of care research within the restructured NCI clinical trials program.

Expand the use of patient-centered endpoints in trials and examines the rate of diffusion of findings into clinical practice, and investigate factors that either accelerate or impede the process.

4. Improve cancer care quality by strengthening the quality of communications.

Gather relevant data and identify and support research projects aimed at cancer care quality. Also to create new communication products and tools that would help individuals and providers in making informed decisions.

5. Ensure cancer care decision making needs of the Federal government are met by the research arm.

Create and enter into collaborative projects on outcome measures and quality-of-care assessment. DCLG members on the call voiced a concern that "science have bite," that the work proposed by these two committees results in social changes that improve people's lives. This involves a political process that exceeds the bounds of the NCI but can be carried out by advocates if they are involved in all stages of the process.

NCI Brand Campaign
Working Group Summary Findings
Prepared by Ms. Kerry Dewey, Chairperson
May 2000

1. **Definition and Scope**
A brand is a comprehensive strategy that communicates long-range goals and organizational thoughts. It is the organization's identity; it promotes a positive image and builds public recognition and support.
2. **History**
Very little has been previously done to create a comprehensive NCI identity. Many different logos are currently being used across NCI, including those developed for divisions and programs.
3. **Key Players**
NCI Office of Communications, headed by Sue Sieber, will take charge of this campaign. They will be supported by Prospect Associates, an independent contractor that specializes in health communication issues and marketing research.
4. **Status**
A first phase has been completed. That was to derive the perceived sense of identity from within NCI itself, gathering input from NCI senior staff. From this effort, a preliminary concept of Connections was drafted. Through Connections, NCI seeks to represent the best practices across the cancer continuum, so that the science community, health professionals and the public can each find the people and/or information desired.
5. **Important Issues**
 - To increase public awareness of NCI's role in cancer research and the distribution of accurate and credible cancer information
 - To increase understanding, appreciation and support of NCI
 - To increase the public's ability to positively distinguish NCI from other cancer-related organizations
6. **Time line**
This is intended to be a long-range effort, to be tackled in phases. The launch of the branding effort will be tied to the Extraordinary Opportunity in Communications kick-off being coordinated by Dr. Barbara Rimer, currently scheduled for December 2000.
7. **Advocate Involvement**
Next phases are set to involve external constituents, including advocates, to determine how external people see NCI.
8. **Potential Roles for DCLG**
There are currently five primary ways envisioned in which DCLG can participate in this effort:
 - Help identify DCLG members to be interviewed
 - Help identify key stakeholders to be interviewed
 - Help identify materials to be included in the communication inventory
 - Provide feedback on the brand statement and communication tools

· Promote NCI's identity in all communications and actions

DCLG Operations Working Group
Prepared by Ms. Ruth Lin, Chairperson
May 2000

Definition and Scope: The mission of DCLG is to expand communication with the cancer advocacy community and help NCI develop programs and set research priorities, as well as find new ways to increase consumer representation at the NCI and provide a forum for exchanging views between the cancer advocacy and scientific communities.

History: In late 1996, the Director of the NCI, Richard Klausner, M.D., decided to establish a Director's Consumer Liaison Group. The NCI's Office of Liaison Activities began the process of planning for the establishment of the DCLG. A planning group comprised of consumer advocates and NCI staff was formed and began developing a blueprint by which the DCLG would be created. The first 15 members of the DCLG were selected in November 1997 and first met in December 1997. DCLG became a chartered advisory board in 1999.

Key Players: Dr. Klausner; OLA; DCLG; NCI

Status/Ongoing Activities: Members of the DCLG are participating in numerous initiatives, providing input and helping to drive change inside and outside of NCI, e.g.,

- Driving the creation of the Genetics Primer
- Proposing the Cancer Communications Extraordinary Opportunity
- Providing input and support for new informed consent template
 - Input to design
 - Field work on the rollout
- Reviewed draft position paper on confidentiality issues
- Provided input on consumer involvement in peer review
- Participated in numerous NCI forums
 - National Cancer Advisory Board Liaison
 - Testimony at President's Cancer Panel
 - Special Populations Working Group Liaison
 - Applied Sociocultural Research Working Group
 - Bypass Budget Planning Committee
 - NCI meeting with Oncology Nursing Society
 - 5-A-Day Review Group
 - Communications Extraordinary Opportunity Working Group
 - Peer Review (including site visits and SPORE Review Panel)
 - Clinical Trials Implementation Group
 - Confidentiality Best Practices Conference
 - NCI Advisory Committee to the Director
- Helping in overall NCI effort to improve its communications initiatives
 - Gathered consumer feedback on NCI communications initiatives
 - Reviewed potential remedial actions with the staff
 - Provided input to the NCI's special study of its communications programs
 - Participated as subjects and evaluators of PDQ Redesign usability testing
 - Synthesized requirements for NCI's consumer web presence

Important Issues:

- Informed consent template
- Confidentiality issues
- Genetics Primer
- Criteria for consumers to participate in peer review
- Cancer Communications Extraordinary Opportunity
- Quality of Cancer Care

Time line:

DCLG Orientation—Fall 2000; DCLG Annual Report—September 2000

NCI Web Presence Working Group
Prepared by Mr. Michael Katz, Chairperson
May 2000

Definition and Scope: The NCI's web presence is in a state of flux. The question here is how the DCLG can act as a catalyst to ensure that the investments in web redesign that will be made of the next few years yield the desired result.

History: The DCLG NCI Communications Review completed more than a year ago. The review confirmed what many within the NCI had known, that the NCI's web presence was content-rich but poorly presented and under promoted, resulting in an underutilized resource that is not delivering on the promise of its rich reserves of content. Part of the issue is that the NCI web site structure embodies the fragmentation of the content development functions within the Institute. There are separate sites for CancerNet, Cancer Information Service, CancerTrials and others.

Key Players: Susan Sieber, Anne Thurn, Jed Rifkin, Chris Thomsen, Mary McCabe

Status/ongoing activities: Recent efforts to improve usability of CancerNet, deploy a more friendly entry portal and adopt the cancer.gov URL are steps in the right direction. Yet, there is much work that remains to be done and our perspective is that substantial consumer input is needed.

Important Issues: There is not yet consensus within the NCI about the ultimate web offering. Yet, to our knowledge, there is currently no process or timetable in place to address the NCI's web structure, content and promotional issues. Recommendations, which can be implemented in a straightforward fashion (e.g., disease-specific URLs), remain undressed over a year.

Time line: TBD

Advocate Involvement: Elements of the NCI web community have reached out individually (CancerNet, CancerTrials and the overall webmaster) to garner input and feedback. CancerNet had undergone usability testing for its new design, bringing a cross-section of consumers and advocates into the process and inviting advocates (including the DCLG) to observe/comment on the testing process. CancerTrials involved advocates from the DCLG and elsewhere on its editorial board.

Potential Role of the DCLG: The DCLG could contribute both directly via involvement in planning/steering committees/editorial boards as well as in recruiting representative consumers to provide an appropriately diverse review group.

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