114th MEETING OF THE NATIONAL CANCER ADVISORY BOARD

AD HOC SUBCOMMITTEE ON COMMUNICATIONS

National Institutes of Health, Building 31C
Bethesda, Maryland
June 13, 2000

Discussion Summary

Dr. Susan Love, Adjunct Professor, Department of Surgery, University of California School of Medicine, chaired the meeting of the Ad Hoc Subcommittee on Communications with Dr. Susan Sieber, Director of the National Cancer Institute's (NCI's) Office of Communications serving as Executive Secretary. The meeting focused on two presentations covering the mission, goals, capabilities, and future directions of the NCI's Office of Communications, which officially became part of the NCI approximately 1 month ago.

NCI Office of Communications—Dr. Susan Sieber

Dr. Sieber provided an overview of the NCI's Office of Communications and its activities. Dr. Sieber explained that the Office was established in response to:

- Increased NCI budget allocations from Congress makes it essential to communicate with NCI constituencies about cancer research activities and achievements.
- Emerging and rapidly evolving technologies that are constantly changing the way the NCI must communicate with its constituencies.
- Identification of cancer communication as an Extraordinary Opportunity in the NCI ByPass Budget.

The goals of the Office are to:

- Enhance and broaden the NCI's ability to respond to issues.
- Incorporate new communication technologies.
- Increase the NCI's ability to interact with its constituencies.
- Maximize the cancer communication resources of NCI staff.
- Consolidate similar functions within the NCI to reduce the duplication of communication efforts.

The operating principles of the Office are to:

- Integrate the NCI's communication activities for consistency.
- Ensure that messages are presented in a scientifically valid, understandable, and culturally appropriate manner.
- Establish a framework to proactively deal with cancer communication issues.

- Provide infrastructure for NCI-wide communication activities.
- Ensure and promote the NCI's developing identity.
- Establish and maintain partnerships with other government entities, professional organizations, and patient/consultant groups.
- Improve internal communications.
- Integrate new technologies.
- Ensure that NCI communication efforts are planned, developed, implemented, and evaluated in a scientific manner.

The Director of the Office works with Strategy and Operations Teams and is responsible for conducting strategic communications planning, creating an NCI identity, and improving internal communications. The Strategy Team meets quarterly to discuss long-range planning and "big ticket" items. The Operations Team meets weekly to plan immediate and medium-range communication efforts. NCI Branch Chiefs and Acting Associate Directors are included in these meetings. The Operations Team also oversees the five programs of the Office. The five Programs in the Office of Communications are the:

- Technologies and Services Group, which is responsible for:
    - Graphics and publications design and audiovisual support.
    - Web design services and usability testing. The Group is working on creating a consistent format and standards for the NCI Web Site.
    - Canvassing and researching new technologies that may be adopted/adapted by the NCI.
    - Training and professional development in the area of new technology. Office of Communications staff will sponsor monthly seminars conducted by communicators from outside agencies and organizations.

- Media and Public Communications Program, which is responsible for:
    - The NCI Press Office.
    - The Cancer Information Service (CIS).

- Outreach and Partnerships Program, which is responsible for:
    - Health promotion, including the development and implementation of national cancer communication campaigns.
    - Market research and evaluation of communication materials and activities.
    - Liaison with advocacy groups, professional organizations, and other government agencies.

- Communications Coordination, which is responsible for:
    - Liaison with all NCI Divisions (the Office will have a representative in each Division).
    - Issues management. Groups focusing on prevention/intervention, breast cancer and the environment, childhood cancer, diet/nutrition/physical activity, and other issues will work together to quickly develop and execute communication plans.

- Cancer Information Products and Systems, which is responsible for:
  - The International Cancer Research Database (Protocol Data Query, CancerNet).
  - The Computer Communications Branch.
  - The Scientific Publications Branch (Journal of the National Cancer Institute).

Dr. Sieber concluded her presentation with an overview of some Office of Communications activities. These include:

- National awareness campaigns, including campaigns focusing on clinical trials in collaboration with NCI's OCRP and, I-131 exposure and DES (in collaboration with the Centers for Disease Control and Prevention).
- Support of NCI priority programs, such as the Special Populations Network.
- The Eleanor Nealon Lecture Series, which commences with a series of "Extraordinary Communicator" lectures on June 16th.
- Planning of the Conference on Cancer Communications as an Extraordinary Opportunity (title of conference not confirmed). This conference will be held at the Grand Hyatt Hotel in Washington, DC, on December 18–19, 2000. About 400 health communicators, advocates, research scientists, and health care providers are expected to attend this conference designed to strengthen the NCI's position as a leader in the field of cancer communications. The conference will focus on new communication directions and technologies, as well as strategies for overcoming the digital divide. The conference will include a technology expo, a second Eleanor Nealon Lecture, a reception, workshops, and plenary sessions.

The Future of Cancer Communication: Divining and Designing—Bernard Glassman

Mr. Glassman gave a presentation focused on future directions in the field of cancer communication. Mr. Glassman is a Special Expert in Informatics at the NCI and has over 30 years of experience in the fields of market research and technology communication.

Mr. Glassman began by emphasizing the importance of "branding" (giving authority) to NCI content. He noted that the purpose of biomedical research is to produce information; that information needs to be reliable, accessible, and usable. Anything that blocks the transfer of accurate information adds cost without value. The failure of the medical community to meet the health information needs of the public is revealed in the increased reliance on the Internet for health information. Mr. Glassman cited the success of the Association of Cancer Online Resources (ACOR) Web Site, a cancer information Web Site developed by Gilles Frydman. He also noted that one-third of patients logging onto the Melanoma Patients Information Page bought a computer because of a cancer diagnosis. He added that cancer is the number one health information topic on the Internet.

According to Mr. Glassman, the NCI needs to begin asking basic questions about how and why it communicates as it does. The NCI also needs to examine what can be done with information

technologies and ask why it is not doing everything it can to improve the dissemination of cancer information. Mr. Glassman suggested that the NCI:

- Influence the content of dedicated Internet applications.
- Systematically send information to dot.coms and dot.orgs (in PDF format, to keep the NCI logo).
- Investigate of the use of technologies such as bar code scanners and e-books to deliver detailed cancer information.
- Create a testing laboratory for new devices and formats.
- Create news releases in WordPerfect format, then convert them to HTML format.
- Have a registered RSS file for all content.
- Exploit high-speed digital printing.

Mr. Glassman emphasized the need to conduct online surveys to evaluate Web sites with large numbers of users. He asked whether any meeting participant was aware of a way to do this without obtaining Office of Management and Budget (OMB) clearance. Dr. Love indicated that she knew how to do this.

Joining Organizations with Leading Technologies (J-O-L-T)

Mr. Glassman offered a brief overview of NCI's J-O-L-T program. This program organizes 6 to 10 meetings annually to promote a two-way discourse between the NIH and outside communicators to discover and discuss new and emerging technologies.

As part of the J-O-L-T program, Mr. Glassman recently organized a meeting with the NIH and the World Wide Web Consortium on Cancer (W3Ca), a group of cancer Webmasters and listserv operators in the United States. This meeting produced three objectives for the NCI: (1) creating a "Web-in-a-Box" (a template for a cancer Web site into which content can be placed), (2) creating a cancer Web site development and testing environment, and (3) creating a cancer Web site hosting environment. If these objectives are met, an online environment will be created that allows individuals with no Web site development knowledge to build a cancer information Web site.

Participant Discussion

Participants indicated that the NCI should:

- Develop a single Web site on all cancers. Such Web sites (i.e., CancerLink and Open Directory) are available outside of the NCI, so the NCI need not duplicate these efforts. The NCI Web Site also has links to these sites.
- Send e-mails to other cancer Web sites regarding NCI link updates. Mr. Glassman tries to identify sites with outdated links and sends e-mails to these sites.
- Make all NCI content available to the public (with the NCI logo retained).

- Link to academic health centers to inform students about NCI training/education programs.
- Create a Web site of cancer information for children.

Subcommittee members asked what they could do to contribute to the NCI's cancer communication efforts. Dr. Love suggested that participants e-mail ideas and suggestions to her for further consideration.

6/14/00
Date

Dr. Susan Love, Chairperson

6/14/00
Date

Dr. Susan Sieber, Executive Secretary