

**116TH MEETING OF THE NATIONAL CANCER ADVISORY BOARD (NCAB)
MEETING OF THE SUBCOMMITTEE ON PLANNING AND BUDGET**

**December 4, 2000
7:00 p.m. - 8:30 p.m.**

Ms. Ellen Stovall chaired the meeting of the Subcommittee on Planning and Budget with Ms. Cherie Nichols, Director, Office of Science Planning and Assessment, serving as Executive Secretary. Ms. Stovall asked those in attendance to introduce themselves. Following the introductions, she explained that most of the meeting would focus on the feedback from professional societies regarding NCI's planning and priority setting document, *The Nation's Investment in Cancer Research* (NCI's Bypass Budget). The agenda included a review of the process, an update on NCI actions relevant to the comments from the American Society of Clinical Oncologists (ASCO) and the American Association for Cancer Research (AACR), and a discussion of how the NCAB wants to proceed.

For the benefit of those who were not present at the last Subcommittee meeting, Ms. Stovall indicated that the Subcommittee on Planning and Budget helps orient the NCAB to the budget and planning process. One of the Subcommittee's roles is to advise the NCI Director about the process of obtaining input from outside the Institute on the planning and budget document. She noted that Dr. Klausner is very open to advice from his staff, the Board, and the public, and actively solicits such advice. Since she was appointed to the NCAB in 1996, Ms. Stovall has witnessed the transformation of the Bypass Budget from a long, detailed document to the concise format used today. This current format reflects the dynamic nature of planning and provides a clear justification for the budget. Ms. Stovall mentioned that John Hartinger has prepared an Annual Report, which was reviewed at the last meeting. She indicated that this report is now in final form and noted that this report will be a good tool for use by Dr. Klausner and others.

Review of the Process for Feedback

Ms. Stovall described the process for obtaining feedback from the extramural community on the Bypass Budget. She noted that the National Cancer Act included a requirement for public input into the budget, and indicated that the process has evolved through different stages over the years. She explained that the NCI sent out letters to about 200 organizations requesting input on the Bypass Budget. Of the 200 organizations that received the letter, approximately 30 responded, and the most substantive comments were submitted by ASCO and AACR. Ms. Stovall noted that many of these comments have been or are being addressed by the NCI. She stated her intention to meet with Dr. Phillip Sharp, Chair of the NCAB, and Dr. Klausner to discuss the best use of the Subcommittee's time and its future focus.

Ms. Nichols distributed copies of the minutes from the last Subcommittee meeting and the handout describing NCI actions with regard to ASCO and AACR comments to the Bypass Budget.

Update on NCI Actions Relevant to ASCO and AACR Comments

Ms. Nichols commented that both ASCO and AACR indicated, as they have in prior years, that they need more time to review the document and prepare their comments. They were given 4 weeks to review the 2002 Bypass Budget, which is more time than was provided in previous years. Ms. Nichols noted that the timeline for finalizing the document is tight if the NCI is to submit it to the President by late September/early October.

Ms. Nichols indicated that the NCI plans to begin the planning cycle for the new Extraordinary Opportunities earlier than in the past. The NCI will solicit input from a wide group of people and organizations beginning in early spring. She noted that the Bypass Budget Planning Committee will review the current opportunities to determine which should be continued, which should be retired, and which new opportunities should be included in the next cycle. The NCI will begin soliciting ideas for new extraordinary opportunities in the spring to allow organizations adequate time to consult their boards and provide input. Ms. Nichols stressed the importance of this process for obtaining input from outside the Institute.

In response to Dr. Koh's question regarding Extraordinary Opportunities, Ms. Nichols explained that Extraordinary Opportunities is one of the three arms in the Institute's planning process, the other two being capacity building and infrastructure (Challenges), and disease-specific research. She indicated that there are six Extraordinary Opportunity areas identified in the 2002 Bypass Budget.

In response to AACR's suggestion that the magnitude of the current and potential future cancer epidemic be reflected in the Bypass Budget, Ms. Nichols pointed out that a short description of its magnitude and the social and economic ramifications has been added to the "Highlights of Progress" section of the 2002 Bypass Budget.

The AACR suggested that the Institute use the "NCI Challenge" to address major questions of incidence, mortality, and disparities. Ms. Nichols indicated that, in the 2002 document, the NCI Challenge section on "Study Emerging Trends" has been expanded and two new Challenge areas that focus on the "Quality of Cancer Care" and "Reducing Cancer-Related Health Disparities" have been added.

In response to AACR's suggestion that, in the Progress Section, progress should be tied to prior investments, Ms. Nichols stated that the NCI has attempted to tie proposed investments in the 2002 document to progress reporting and to future potential in two ways. First, a new section has been added at the end of the document entitled "How It All Comes Together." Second, statements have been added to most of the descriptions in "Highlights of Progress" to indicate how proposed continued investments in Extraordinary Opportunity and NCI Challenge areas will build upon the progress described. Ms. Nichols added that the NCI will examine other ways to present progress descriptions in the future to more clearly show these relationships.

The AACR recommended that the plan be shortened to make it more concise and clear. Ms. Nichols explained that to make the plans in the 2002 document more concise, clear, and informative, a single goal statement for each Extraordinary Opportunity and NCI Challenge area was added; this statement articulated the objectives and milestones in more specific, measurable terms. She noted that the presentation format for the objectives and milestones was changed to make the plan easier to follow, and milestone level funding amounts were added.

The AACR suggested that the vision contained in the document be more aggressive and reflective of both the lay and scientific communities' sense of urgency to increase progress against cancer. Ms. Nichols commented that, following the stakeholder reviews of the 2002 document, a strong overall goal statement was added to the beginning of the document. Also in response to stakeholder input, a thorough edit of the document was conducted to ensure that it did not overstate what has been done to date or overpromise what might result from it. She indicated that these changes have brought a better balance to the document. She added that the NCI may want to look at other things that we can do in the future to address this concern.

The AACR suggested that the NCI develop an Annual Report. Ms. Nichols commented that the NCI is working with the NCAB Planning and Budget Subcommittee to develop an Annual Report to provide information on how funding is distributed by mechanisms, cancer site, etc. She added that a draft of the report was distributed and discussed at the last meeting (in closed session), and it has been revised based on those comments.

The AACR recommended that the NCI provide more explicit information on the role of the extramural program and emphasize the diversity of both locations and programs supported by the NCI. Ms. Nichols indicated that the NCI is examining ways to better provide this type of information using the NCI Plans and Priorities Web Site. She mentioned that maps showing locations of the cancer centers, Community Clinical Oncology Program centers (CCOPs), and research institutions could be helpful.

The AACR suggested that the document include more information on collaborative interactions with other funding and regulatory agencies (e.g., DOD, NIH, CDC, FDA). Ms. Nichols agreed that this is a good idea and it will be considered for the 2003 document.

Dr. Ralph Freedman commented that the document is very good and easy to read; and the message is presented well. He asked about the responses to the ASCO comments, and Ms. Nichols replied that these actions addressed the comments from both AACR and ASCO. Dr. Freedman asked if other organizations provided input. Ms. Nichols responded that input is solicited from a large number of organizations, including numerous public health organizations that were added to the list this year. She noted that they receive quite a few comments, but they tend to be very short.

Dr. Freedman supported the suggestion for posting more graphical information on the Web site, and he proposed adding such information to the document. Ms. Nichols replied that there are space constraints that will limit what can be added to the document. She commented that the Web offers a venue for distributing information that cannot be included in the document. Ms. Nichols mentioned that they are doing information mapping of the document for the Web to make the dense text of the document easier to read, use, and understand. Dr. Freedman asked if users can search this Web site to retrieve all of the information on a particular cancer. Dr. Kalt replied that they are working to achieve this. They are building a search engine designed to answer such queries. Ms. Nichols noted that the document could indicate how to access the Progress Review Group (PRG) reports. She added that the cancer research portfolio will soon be available to the public on a new Web site and it can be searched by cancer site and scientific topics. This site will include both intramural and extramural efforts, but it will not contain any funding data. Ms. Nichols pointed out that there is some trend information in the Annual Report.

How the NCAB Wants to Proceed

Ms. Stovall expressed concern about the uncertainty of funding. She noted that all of these initiatives come with large price tags and any “blips” in funding can be quite disruptive; in addition, the uncertainty creates poor morale among the researchers. Ms. Stovall mentioned that there will be numerous changes with the new administration and she believes that the members of this Subcommittee can play a role in supporting the need for consistent funding. She stressed that it is not just an issue of getting the research to the people—that is a health care delivery issue and not within NCI’s mission. Ms. Stovall indicated that the NCAB members have opportunities to support increased funding for the NCI and she asked them to become more involved in this issue. She added that the Bypass Budget is an excellent tool for promoting the uniqueness and importance of NCI’s programs.

Dr. Freedman asked if patient advocacy groups are becoming involved in the budget and funding issues, and Ms. Stovall replied that they are paying a lot more of attention to these issues than they have in the

past. She indicated that few advocacy groups comment on the Bypass Budget and she asked how the Subcommittee could encourage more input from these organizations. She believes that the Web is an excellent tool for reaching these groups. Dr. Freedman commented that it would be helpful to obtain more input from advocacy groups; it would be useful in deflecting criticism about limiting coverage of certain areas. Dr. Kalt pointed out that there is a difference between the requested budget and the actual budget; as the gap between the two increases, the Bypass Budget document becomes less meaningful.

Ms. Stovall indicated that the more the public understands and invests in the Bypass Budget document, the more it will become the people's cancer budget. She supports the PRGs and pointed out that they can become much more if there is adequate funding and staff available. Dr. Freedman noted that it will be important to review what the PRGs have accomplished in 3 years—something important will need to come out of each one. Ms. Stovall commented that combining leukemia, lymphoma, and myeloma has already led to collaborative efforts and sharing of information across research disciplines and areas. In addition, advocacy groups are becoming more involved in promoting the cancer agenda to other agencies that can help fund the research. She agreed that the PRGs may be a good mechanism to get community advocates involved. Dr. Freedman commented that the Bypass Budget document should start to reflect the accomplishments of the PRGs. Dr. Kalt replied that the NCI hopes it will be able to cite major advances resulting from the PRGs in prevention, early detection, and treatment in future Bypass Budget documents. Dr. Freedman noted that this is the paradigm for the future.

Ms. Stovall indicated that the Subcommittee members need to be supportive of the NCI and its path forward. She stressed the importance of advocating support of the NCI whenever opportunities arise. She believes that more can be done by the Subcommittee, but she would like to meet with Dr. Klausner and Dr. Sharp before developing long-range plans. Ms. Stovall indicated that the response to the ASCO and AACR suggestions is a good start on which to build.

Ms. Nichols mentioned that the NCI is working on the Extraordinary Opportunities cycle for 2004 and beginning to prepare the 2003 Bypass Budget. She hopes to get a draft of the 2003 document out earlier than in the past to allow more time for comments. Dr. Freedman suggested that the NCI send out copies of the 2002 document with a letter explaining that the Institute is preparing the 2003 document and will be soliciting comments on that document in the future. He pointed out that this could pave the way for soliciting the comments and may improve the response rate. Ms. Nichols asked if organizations other than ASCO and AACR should be invited to provide testimony, and Dr. Freedman replied that others should be invited, particularly organizations that are broadly focused such as biological and biochemical societies. He suggested that immunologists also may provide interesting ideas.

One Subcommittee member asked if the 200 organizations from which comments are solicited had ever been invited to a meeting to discuss the document. Ms. Nichols replied that the NCI has never conducted such a meeting, but she noted that this could be accomplished through videoconferencing or teleconferencing. She agreed to give some thought to how this could be implemented.

Ms. Stovall noted that there are numerous efforts within the private sector to increase collaboration, but pointed out that the NCI is reticent to lead such efforts for fear of excluding organizations. She commented that most of the Subcommittee members spend very little time focusing on these issues

except during the Board meetings four times each year. Ms. Nichols suggested that some of the members may be willing to work with the NCI staff to explore some of the suggestions that were raised at this meeting. Ms. Stovall noted that Ms. Nichols has already started this effort with the document she prepared for the Cancer Leadership Council.

Ms. Stovall thanked the members for their participation and adjourned the meeting at 8:25 p.m.

Participants

The following NCAB members were present: Amelie Ramirez, Ralph Freedman, Howard Koh, Ellen Stovall, and Samir Abu-Ghazaleh. NCI staff and public representatives also were present.

Cherie Nichols 12/6/00

Ms. Cherie Nichols Date
Executive Secretary

Ellen Stovall 12/5/00

Ms. Ellen Stovall Date
Chair