

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE
NCI DIRECTOR'S CONSUMER LIAISON GROUP**

Summary of Public Meeting

March 29, 2007, 8:30 AM–5:30 PM Eastern Daylight Savings Time

March 30, 2007, 2:00 PM–3:30 PM Eastern Daylight Savings Time

**DIRECTOR'S CONSUMER LIAISON GROUP
NATIONAL CANCER INSTITUTE**

**March 29, 2007, 8:30 AM–5:30 PM Eastern Time
March 30, 2007, 2:00 PM–3:30 PM Eastern Time
Public Meeting**

Minutes

Members Present

Mr. Doug Ulman, Chair	Ms. Kelly Cotter
Dr. Beverly Laird, Vice Chair	Ms. Nancy Davenport-Ennis
Ms. Peggy L. Anthony	Ms. Mary Jackson Scroggins
Ms. Vernal H. Branch	Ms. Sue Sumpter
Mr. Bill Bro	Ms. Cece Whitewolf
Dr. Grace Butler	COL (Ret) James E. Williams, Jr., USA
Dr. Yvette Colón	

NCI Staff

Ms. Nelvis Castro, Deputy Director, Office of Communications and Education, NCI	Mr. James Hadley, Advocacy Program Manager, OLA
Ms. Jennifer Fritz, <i>NCI Listens and Learns</i> Coordinator, Office of Liaison Activities (OLA)	Ms. Jessica Pyjas, Advocacy Program Fellow, OLA
Dr. Alaina Fournier, Emerging Leader Intern	Ms. Elizabeth Neilson, Consumer Advocates in Research and Related Activities (CARRA) Program Coordinator, OLA
Ms. Barbara Guest, DCLG Executive Secretary	Ms. Linda Ticker, Program Assistant, OLA
Ms. Brooke Hamilton, Program Analyst, OLA	

Speakers

Ms. Peggy Anthony, Member, DCLG
Dr. Anna Barker, Deputy Director, NCI
Ms. Vernal Branch, Member, DCLG
Dr. Michael Burke, Research Scientist, RTI International
Dr. Carolyn Compton, Acting Director, Office of Technology and Industrial Relations; Director, Office of Biorepositories and Biospecimens Research, NCI
Ms. Susan Erickson, Director, Office of Policy Analysis and Response, NCI
Dr. Ernest Hawk, Director, Office of Centers, Training and Resources, NCI
Dr. Beverly Laird, Vice Chair, DCLG
Ms. Elizabeth Neilson, CARRA Program Coordinator
Dr. John E. Niederhuber, Director, NCI
Dr. Raymond A. Petryshyn, Program Director, Coordinating Center for Clinical Trials, NCI
Ms. Mary Jackson Scroggins, Member, DCLG
Dr. Lisa M. Stevens, Chief, Science Planning Branch, Office of Science Planning and Assessment, NCI
Mr. Doug Ulman, Chair, DCLG
COL (Ret) James E. Williams, Jr., Member, DCLG

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I. Welcome and Introductions

Mr. Doug Ulman welcomed participants to this meeting of the NCI Director's Consumer Liaison Group. He reviewed the rules governing confidentiality and conflict of interest, and Ms. Barbara Guest determined that a quorum was present.

Mr. Ulman announced that for the first time, the DCLG's public meeting would be broadcast over the Internet.

II. *NCI Listens and Learns* Evaluation Report

COL (Ret) James E. Williams, Jr., explained that NCI and the DCLG developed the *NCI Listens and Learns* Web site to enhance collaboration between NCI and advocates. To determine whether the site has achieved its purpose, RTI International and Westat recently completed an evaluation of the site.

Dr. Michael Burke explained that the evaluation was designed to assess the site's usefulness for cancer advocacy organizations (CAOs), the public, NCI topic hosts, and the DCLG. The evaluation also gathered suggestions for changes.

The evaluation found that the Web site is generally operating as planned. The comment posting period has changed from 1 month to 2 months and the number of comments posted has increased as a result. The dialogue is mostly transparent; all discussions are archived and readily available to the public. However, only the authors of posts can tell if their posts have been modified or deleted.

The *NCI Listens and Learns* Coordinator reaches the public through regular e-mails. Most survey respondents visit the Web site after receiving an e-mail announcing a new topic. DCLG members also promote the site, although they were more involved in promotional activities when the site was first launched. The CAOs also promote the site by distributing information on new topics through their newsletters and listservs.

On average, the site has 34 visitors a day, or 1,103 a month. Visitors spend an average of 5 minutes and 28 seconds viewing the site. Each topic receives an average of 24 comments—8 from CAOs and 16 from the public. The topic with the highest number of comments, 15 from CAOs and 39 from the public, was on biorepository networks. The topics on NCI's Guide to Finding Cancer Treatment Trials and the DCLG meeting both received 11 comments, the smallest number of all topics.

Since the site was launched in January 2005, 51 CAOs have commented on at least one topic, and the most active CAO has posted 19 comments. Reasons for not commenting cited by CAOs include lack of time, lack of interest in the topic, lack of expertise in the topic area, the belief that commenting will not make a difference, and the belief that they are not a CAO because they are a support organization.

Many people thought that the site was straightforward and easy to navigate. However, others found the site confusing. They said that the text was too dense, the site required too much scrolling, and they could not format their posts sufficiently. Most respondents liked the site even if they felt that it was not meeting their needs. They often mentioned the information provided by the site as a benefit. Ratings for satisfaction and trustworthiness were high, but ability to find information received a lower rating. Only a few people were satisfied with the official NCI responses; many thought that these responses were too vague, focused on the topic rather than the comments, and were not timely.

Topic hosts who asked simpler, more specific questions were more satisfied with the responses. They were generally pleased with the thoughtfulness of the comments and the opportunity to learn if the CAOs liked their approach. Topic hosts who asked more open-ended questions and sought a definitive answer, such as learning what percentage of the population has a specific viewpoint, identified fewer perceived benefits from the site.

Dr. Burke provided an example to illustrate the most effective kinds of topics for the site. If a topic host asked how NCI or CAOs could encourage providers to use evidence-based guidelines, this would probably generate very short responses with little depth. However, if the host asked whether CAOs would be willing to jointly certify with NCI that providers have read guidelines, then the answers are likely to be much more useful.

Some NCI topic hosts checked the comments daily, but others did not review responses until the topic's posting period ended. Many found writing the official response the most difficult part of the process. They had to be careful not to promise too much and to check with other offices before finalizing their responses. Most NCI respondents thought that the Web site and receiving input was a good idea.

Dr. Burke concluded that *NCI Listens and Learns* plays a valuable public relations and information dissemination role. Many visitors to the site believe that NCI values the input of advocates. The site is generally viewed favorably by all groups included in the evaluation. Participants offered a range of recommendations, including increasing promotion so that more people would be aware of the site, training users on how to navigate the site, reducing the text density and increasing font size, and reducing the amount of clicking and scrolling required.

The evaluation team provided the following recommendations based on their research:

- Simplify the Web site
- Simplify the process
 - Delete the "comments on summary"
 - Stop separating comments from CAOs and the public
- Expand text formatting options
- Automate some processes
- Consider ways to increase dialogue
 - Online discussions
 - More frequent, timely NCI responses
- Manage expectations of NCI staff and non-NCI users

Dr. Burke explained that the distinction between CAOs and the public was artificial because many members of the public who posted are affiliated with a CAO. Also, each CAO, even a large national organization like the American Cancer Society, is allowed only one spokesperson and one alternate. This rule was established because the site designers assumed that CAOs would poll their members before posting a response. However, most CAOs do not poll their members, so their comments may not reflect the opinion of the larger organization.

Discussion

Mr. Bill Bro recently tried to post a response to the current question and received an error message. Although he sent an e-mail to report the problem, he had not received a reply after several days. It would be helpful if responses were sent within 24 or at least 48 hours.

Mr. Bro also commented that the DCLG needed to know the cost of running the site to assess its value. Dr. Beverly Laird reported that it is not possible to conduct a cost-benefit analysis of the site, but OLA has provided an estimate of the amount of labor to maintain the site: approximately 125–150 hours per topic.

Dr. Yvette Colón has spoken to many people about the site, and almost all of them appreciate the opportunity to connect with NCI, although they find the process too formal. The site does not really permit dialogue with NCI, especially since it takes so long to receive the official NCI response. Also, some groups said that the topics posted have little relevance to their activities. They would like to know more about how NCI could help their members obtain access to treatment, NCI's activities in health disparities, and NCI's cancer pain research.

Dr. Grace Butler pointed out that the public has no input into the posted topics, and the public would benefit from face-to-face opportunities. Perhaps the Cancer Information Service could hold regional seminars or workshops introducing *NCI Listens and Learns* to the public. This might increase participation.

Ms. Vernal Branch has also found that advocates like the site, but they would also like online chats with NCI staff on a regular basis.

Ms. Sue Sumpter thought that *NCI Listens and Learns* is an invaluable tool for reaching out to minority and other underserved populations, which is one of the NCI Director's new charges to the DCLG. However, the questions need to be easier to understand. She also supported the recommendation to combine the comments from the public and the CAOs. Finally, Ms. Sumpter suggested that DCLG members become more active again in promoting the site.

Col. Williams commented that the site was not originally designed to allow the public to ask NCI questions. However, it has become clear that the public would like chat rooms and other ways to obtain more immediate responses from NCI. Col. Williams noted that NCI offices have to “jump through many hoops” to prepare a response to the comments. Perhaps NCI should not provide a response. He also suggested promoting the site by establishing relationships with online search engines. In addition, it would be helpful to identify the public that is the intended audience for *NCI Listens and Learns*.

Ms. Cece Whitewolf emphasized the importance of making sure that different groups can use *NCI Listens and Learns*. She supported the idea of face-to-face communications. The *NCI Listens and Learns* Working Group found that the scientists at NCI have difficulty writing questions and comments in lay terms. Finally, Ms. Whitewolf noted that electronic communications has changed a great deal in the two years since *NCI Listens and Learns* was launched, and new communications vehicles, such as online chats and blogs, should be considered.

Ms. Lourie Campos has found that CAOs are very interested in the site, although some find it difficult to post a comment. Ms. Campos was concerned that a majority of the CAO posts have come from just eight CAOs. If the site is to continue, promotional activities must be stepped up to ensure that more CAOs participate.

Ms. Mary Jackson Scroggins supported the idea of posting comments from a mix of sources, including the public. She also agreed that the language used is difficult for many people. If questions are posted in non-lay terms, those terms need to be defined in lay language. Some smaller organizations are reluctant to participate in the discussions because they do not have a communications representative who can put their ideas in writing. She also pointed out that it is not clear if past promotional efforts have been effective. For example, none of the cards that were distributed have been returned with requests for more information. If a method is not effective, it should be discontinued. In addition, more needs to be done to communicate with people who are often not reached.

Ms. Kelly Cotter suggested sending an automated response whenever someone posts a comment so that they know their comment has been received. An online discussion would also be valuable.

DCLG Recommendation to NCI

Dr. Laird asked the DCLG members to consider four potential recommendations regarding the *NCI Listens and Learns* Web site:

1. NCI consider **continuing** the *NCI Listens and Learns* Web site with no major changes
2. NCI consider **continuing** the *NCI Listens and Learns* Web site with modifications to the overall design, usability, and level of effort required to operate the Web site
3. NCI consider **alternate** Web-based options for communicating with advocates
4. NCI consider **discontinuing** the *NCI Listens and Learns* Web site entirely and devoting attention and resources to enhancing existing communication venues, considering alternate communications strategies, and exploring and gaining additional funding support for special outreach efforts

Dr. Butler requested clarification on the second and third recommendation options. Dr. Laird explained that the second option is to maintain the site but modify its format. The third option

would be to end the *Listens and Learns* site and replace it with a different form of electronic communication.

The DCLG Members voted on one of the 4 recommendations regarding the *NCI Listens and Learns* Web site. A majority of DCLG members voted for option 2: NCI consider **continuing** the *NCI Listens and Learns* Web site with modifications to the overall design, usability, and level of effort required to operate the Web site. A motion to accept the results of the DCLG's vote was carried unanimously.

Dr. Laird stated that after this meeting, the *NCI Listens and Learns* Working Group would officially disband. She also explained that the DCLG had been charged with providing a recommendation regarding the future of *NCI Listens and Learns* to NCI. NCI will make the final decision regarding the site's future. Dr. Laird suggested that the DCLG send its recommendation to continue *NCI Listens and Learns* with modifications in a two- or three-page letter with a list of proposed modifications. Ms. Whitewolf proposed that the DCLG members who have worked on *NCI Listens and Learns* prepare this letter. Ms. Guest explained that the letter needs to be completed within two weeks.

Ms. Sumpter asked who would be responsible for ensuring that the *NCI Listens and Learns* topics are easy for the public to understand because the DCLG will no longer have this responsibility. She also wondered whether the DCLG would have the opportunity to recommend specific modifications to the site.

Ms. Guest explained that the DCLG's recommendations would be delivered to OLA and NCI, which will decide the site's future based on these recommendations and other factors. If NCI decides to continue the site, it is likely to permit review of the topics by advocates in addition to DCLG members

Ms. Branch commented that Dr. Niederhuber wanted the DCLG to focus on providing advice rather than carrying out projects. Perhaps the DCLG could turn over its *NCI Listens and Learns* activities to the Consumer Advocates in Research and Related Activities (CARRA) Program.

Ms. Whitewolf suggested that the current *NCI Listens and Learns* Working Group continue to monitor the site until a final decision is made about the site's future. Ms. Fritz explained that the working group formally ended with this meeting.

Ms. Sumpter thanked Ms. Fritz on behalf of the DCLG for her tireless work on *NCI Listens and Learns*.

III. DCLG Working Groups and Member Reports

Agenda Working Group

Dr. Laird asked the DCLG members to send her suggestions for the agendas of future DCLG meetings.

caBIG™ Security Working Group

Ms. Peggy Anthony has been working with several CARRA members assigned to the cancer Biomedical Informatics Grid™ (caBIG™) pilot project, which is ending, and the CARRA advocates hope to continue their work on the *Enterprise Project*. A patient advocate will be chosen to become part of the caBIG Security Working Group. The CARRA advocates would like suggestions from the DCLG on ways for advocates to communicate with their constituencies about caBIG™.

Ms. Sumpter noted that the reluctance of patients to share their private medical information could become a major barrier for caBIG™, and the DCLG needs to address this issue. COL Williams agreed that patients are concerned about sharing their confidential information and tissue samples. Legislation and patient education could help address these concerns. Ms. Scroggins suggested explaining to researchers what patient concerns are and why patients have these concerns.

National Cancer Advisory Committee (NCAB) and President's Cancer Panel (PCP)

Ms. Branch attended the National Cancer Advisory Board (NCAB) meeting in February in Mr. Ulman's stead. This meeting included a report of the President's Cancer Panel; a legislative update from Ms. Susan Erickson; and a report from the American Association for Cancer Research (AACR), which is forming partnerships with NCI, the American Society for Clinical Oncology (ASCO), and industry to advance the cancer research agenda. A report on the breast cancer stamp initiative noted that NCI has received \$35.2 million from this initiative as of 2006. The NCAB also heard an update on tobacco control from Dr. Michele Bloch, who reported on efforts to increase excise taxes on cigarettes, implement smoke-free laws, and fund cessation and prevention programs in other countries.

Mr. Ulman noted that the President's Cancer Panel held a meeting in February that focused on tobacco. During this meeting, he learned that 145 countries have signed an international treaty on tobacco, but the United States is not one of these countries. In addition, the warning on cigarette packs has not changed in 15 years. Ms. Whitewolf noted that most Indian casinos allow smoking, and this needs to be addressed. Ms. Scroggins expressed concern about the number of passive smokers at risk. Ms. Sumpter reported that the President's Cancer Panel focused on physical activity and weight in its December meeting. The DCLG should take the results of the PCP meetings, and get the message out to advocacy groups. The PCP will publish a report of the 2006-2007 meetings in July 2007. Ms. Whitewolf noted that many of the recommendations in the panel's previous report on cancer in Indian country have not been yet implemented.

Summit Working Group II

Ms. Scroggins explained that the Summit Working Group II met on October 8, 2006, and discussed the need to respond to the questions raised during the town hall portion of the June 2006 Summit. With input from Working Group members, James Hadley, Advocacy Program Manager OLA, coordinated a comprehensive response to all of the town hall questions. These responses will be posted on the Summit Web site and will be sent to all Summit participants. Ms.

Scroggins also reported that a Summit summary and evaluation booklet is being printed for distribution to all participants and posting on the Web site. Several participants have requested another Summit. Ms. Scroggins asked the DCLG to consider recommending to the Director that NCI organize additional advocacy summits.

IV. Consumers Advocates in Research and Related Activities (CARRA) Program Update

Ms. Elizabeth Neilson reported the results of the CARRA program evaluation. CARRA includes approximately 185 people from across the country that has experienced cancer as patients, survivors, caregivers, and family members. CARRA members represent the collective viewpoint of people affected by cancer in a wide range of NCI activities.

The CARRA Evaluation Working Group was created in 2002. Surveys were developed and administered in 2003–2005, and the results were analyzed in 2006. The evaluation included a post-activity survey of all CARRA members who participated in an NCI activity and the NCI staff members who had requested a CARRA member. The attitudes and behaviors of NCI staff and CARRA members were also surveyed.

The survey found that 90% of CARRA members who participated in an NCI activity reported that the activity met their expectations, and 98% would be willing to participate again. Most members thought that their contributions were valued by other participants, NCI staff helped prepare them to participate, the working environment was welcoming, and they had sufficient opportunities to express the consumer perspective. All NCI staff who involved a CARRA member in an activity would recommend the program to a colleague, 99% plan to request a consumer advocate again, and 80% are satisfied with the process for selecting advocates. Most staff reported that CARRA members were professional and met their needs for consumer involvement.

A survey of staff attitudes and behaviors found that most staff value the involvement of CARRA members in NCI activities. However, staff who work with CARRA members are much more enthusiastic about involving advocates than staff members who do not interact with CARRA members. Staff value CARRA member involvement in developing and disseminating information and improving the public perception of NCI. However, some staff are ambivalent about advocate participation in peer review and the planning process to set scientific priorities. Staff who work with CARRA members are more positive about including advocates in these activities. OLA plans to conduct focus groups and interviews with staff to identify the reasons for this ambivalence and ways to change this perspective.

The survey of CARRA member attitudes and behaviors found that NCI activities matched their interests to a moderate (24%) or great (65%) extent. Most believed that the program is having a positive impact on NCI's communication with the cancer community; NCI's grant review process, and NCI's accountability to those affected by cancer. However, the primary challenge for the program is underuse of CARRA members. Two-thirds reported that they had been used less than expected.

OLA has tried to increase opportunities for CARRA members and plans to interview them to find out the ideal number of members for the program and how to better manage expectations. In 2007, the number of requests for CARRA member participation increased significantly. Many of these requests were for committee representation, so these CARRA members will have ongoing involvement in NCI activities.

OLA plans to conduct focus groups and interviews with key stakeholders to determine how to better market the program to NCI staff, whether additional recruitment is needed, and how to improve program operations.

Discussion

Ms. Branch asked why some NCI staff members feel ambivalent about involving CARRA members in peer review. Ms. Neilson explained that the survey did not collect these reasons, but the planned interviews and focus groups should. She also asked if the number of CARRA members is balanced by cancer site. Ms. Neilson replied that some diseases have no CARRA representation, whereas many members have experience with breast or prostate cancer.

Ms. Sumpter asked if CARRA members represent childhood cancers. Ms. Neilson replied that 26% of CARRA members represent pediatric cancers. Ms. Sumpter also asked about future training plans. Ms. Neilson explained that OLA is not sure whether additional peer-review training is needed or if other training would be more beneficial.

Ms. Nancy Davenport-Ennis suggested encouraging NCI staff members who think that CARRA contributions are valuable to establish relationships with those who are ambivalent. Sometimes messages are most effectively communicated from one colleague to another. Ms. Davenport-Ennis also suggested that the program recruit more senior members to help recruit other seniors to clinical trials. Another suggestion is to publicize the biographies of CARRA members to help NCI staff understand the depth of their experience.

Ms. Scroggins asked if the underuse of CARRA members has an impact on retention. Ms. Neilson has not found retention to be a major concern.

Dr. Butler asked about communications with people who have left the CARRA program. Ms. Neilson explained that when a CARRA member resigns, he or she can ask to be placed on the mailing list for OLA correspondence, but this individual no longer receives CARRA correspondence. Dr. Butler also noted that some CARRA members are active with their local cancer centers, and this is an important contribution.

Ms. Whitewolf requested a report on the characteristics of the current CARRA members. Ms. Neilson will provide this information. **(A link to CARRA membership: <http://carra.cancer.gov/about/memberselection/about-members>)**

Ms. Branch reported on an advocate who wanted to work with a cancer center but was told that the cancer center can only work with CARRA members. Ms. Neilson was not sure why this happened because CARRA members are not assigned to cancer centers on an official basis.

V. The Cancer Genome Atlas (TCGA): Project Update and Advocacy Outreach

Dr. Anna Barker reported on a recent article that was critical of the TCGA in *Newsweek*. Unfortunately, this article is not based on fact. NCI informed *Newsweek* that the project's budget was \$50 million from NCI, but the article claims that the budget is \$1.5 billion. When NCI established TCGA, it ended its Cancer Genome Anatomy Project (CGAP) and used the money saved to establish TCGA.

Ms. Sumpter asked if NCI will publish a response to the *Newsweek* article. Dr. Barker replied that Dr. Niederhuber and Dr. Francis Collins, Director of the National Human Genome Research Institute (NHGRI), have written a letter that will be published in the next issue. Dr. Harold Varmus, former Director of NIH and a Nobel laureate, has also written a letter that will be published.

Other countries are very interested in TCGA. China is beginning a project similar to TCGA for liver cancer, and Singapore and India are planning studies on other cancers. Dr. Barker and Dr. Collins will be meeting with this international group.

Dr. Carolyn Compton explained that most patient management techniques are very broad based and do not suit most tumors very well. The primary therapy for colon cancer is surgery, for example. If surgery fails, only one major drug is available, and most tumors are resistant to this drug. Dr. Compton is looking forward to an era of personalized medicine when the pathologist will be able to identify the biology and molecular underpinnings of individual tumors. Therapies can then be developed that fit the specific biology of each tumor. TCGA could completely transform the field and give researchers a new vocabulary of underlying genetic changes with which to write the story of personalized medicine.

TCGA is a three-year pilot project of NCI and NHGRI to understand the genetic changes associated with cancer. If the project is successful, it will be expanded to more tumor types. The plan is to understand all of the genomic changes in three cancers and use this information to identify ways to create drugs that prevent their development or treat them successfully.

The project will initially focus on brain cancer (glioblastoma multiforme), lung cancer (squamous cell carcinoma), and ovarian cancer (serous carcinoma). These three cancers account for more than 210,000 cases in the United States every year. They all have a high mortality rate, and very few therapies are effective for them. These three tumors were chosen for several reasons, but one of the main reasons was that available biospecimen collections of these tumor types met TCGA's strict scientific, technical, and ethical requirements.

The first set of glioma samples will be shipped to all participating sites in early April. Investigators will analyze these samples in April and May and issue the initial data into public databases by June.

Patients have given permission for their specimens and data to be used in TCGA, and the genomic information generated by TCGA will be made widely available in public databases. Scientists will use this information to speed research advances. The results of this research will be translated into new products to help patients.

The informed consent form for TCGA was designed very carefully. The form requests permission to conduct detailed genomic research and use the resulting data broadly. It is not possible to guarantee that no patient will ever be identified from the information they provide. Patients are informed of this risk, as well as the fact that once their data are transferred into public databases, these data cannot be withdrawn. Most patients understand the project's power, and their only question is why the project did not begin sooner.

The project's Web site is <http://cancergenome.nih.gov>. Dr. Compton encouraged the DCLG to check this Web site frequently for updates.

Discussion

Ms. Amy Bulman from the Office of Communications and Education has worked with the DCLG to develop a set of PowerPoint slides that the DCLG can use to make presentations on TCGA to their constituencies. Ms. Bulman distributed an updated version of the slides and draft talking points. She also developed a brochure and fact sheet designed to explain the project to lay audiences. Ms. Bulman promised to send the materials electronically to the DCLG for additional feedback and discussion of how NCI can work with the DCLG to disseminate this information.

Ms. Whitewolf asked about the impact of this project on Native Americans. Dr. Compton explained that participation has been an issue for some Native Americans because they wanted to be able to retrieve their samples for burial, but the project could not guarantee that samples would be available after the research is completed. However, the transformative nature of this project will lead to advances that will benefit all people.

Ms. Anthony asked who explains the informed consent to the patient. Dr. Compton replied that informed consent is explained by treating physicians or highly trained nurses with experience in the clinical trials process.

Dr. Barker said that NCI is privileged to be able to do this project. NCI represents the first disease to benefit from NHGRI's experience in sequencing the human genome. She added that Congress is considering a genetic privacy bill that, if it passes, will resolve many concerns with TCGA. NCI is working with several congressional leaders to try to obtain reimbursement for those who collect biospecimens.

Ms. Davenport-Ennis asked about the role of the World Health Organization (WHO) in TCGA. Dr. Compton explained that NCI has not worked directly with WHO, but it has interacted with the International Agency for Research on Cancer, a subsidiary of WHO, to devise international standards for specimen collection.

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VI. DCLG Information Exchange

Ms. Cece Whitewolf asked each DCLG member to share information on advocacy activities within their organizations. (The members brought brochures, flyers and publications from their organizations for distribution).

COL (Ret). James E. Williams, Jr. is Chair Elect of the Intercultural Cancer Council, which helps minorities and the medically underserved who are diagnosed with cancer. The group's 11th biannual symposium will take place in April 2008 in Washington, DC. Col. Williams is also involved in the Alliance for Prostate Cancer Prevention, which educates men about the importance of annual prostate cancer screening.

Ms. Peggy Anthony is in charge of the Medical University of South Carolina hospital's new operating room. As a member of the hospital's policy and advocacy committee, she is trying to ensure that insurance companies cover certain types of care for patients in clinical trials. Ms. Anthony recently participated in peer review for Susan G. Komen for the Cure. She is also trying to increase the focus on patients with head and neck cancer. Ms. Anthony is a member of the patient advocacy committee for the American College of Radiology Imaging Network (ACRIN), which conducts patient education on imaging techniques.

Ms. Vernal Branch works with the Virginia Breast Cancer Foundation and is on the board of directors of the Silent Spring Institute. She is also a member of the board of the HER2 Support Group and the Breast Cancer Action Group, as well as a member of the integration panel for the U.S. Department of Defense Breast Cancer Research Program.

Ms. Whitewolf directs the Native People's Circle of Hope, which has grown from 4 chapters to 18. The group is providing training on how to start a cancer support group and is spreading the message that cancer is not a death sentence. One of its promotional activities is to encourage Native Americans to wear yellow in their traditional regalia. The group also donates items to people who are newly diagnosed with cancer, including hand-made medicine bags.

Mr. Bill Bro is President and CEO of the Kidney Cancer Association, which focuses on education, research, and advocacy. The association sponsors young investigator awards and represents patient interests in government and insurance issues.

Ms. Sue Sumpter works for the Leukemia and Lymphoma Society and is Vice President of the Oregon and Southwest Washington Chapter of Candlelighters for Children with Cancer. She also sits on the state's high-risk insurance board. Ms. Sumpter is concerned about the cognitive late effects of treatment, which schools do not always recognize. Neurocognitive evaluations are not covered by insurance.

Dr. Yvette Colón is an oncology social worker for the American Pain Foundation. She recently completed a five-year term on the American Cancer Society masters in social work peer-review

training grant committee and persuaded the society to include pain and palliative care in the curriculum for social workers.

Ms. Nancy Davenport-Ennis is the Founding Executive Director of the Patient Advocate Foundation, which serves 6.4 million Americans who need help removing obstacles to health care. The foundation recently developed an education series on health insurance products. Ms. Davenport-Ennis invited other DCLG members to attend the foundation's annual patient congress June 25–27, when the group will lobby for NCI.

Ms. Lourie Campos works for Community Health Partnership and is co-facilitator of Healthy Young Attitude, a support group for young adults with cancer. Her organization is developing a partnership to educate medical students on young adults with cancer and has launched a community mobile mammography access project for medically underserved women. Ms. Campos is also a member of the American Cancer Society board and participates in its Asian/Pacific Islander work group.

Dr. Grace Butler is founder and president of Hope Through Grace, which promotes education and colorectal cancer screening. The organization has a formal relationship with a local gastroenterologist who has agreed to perform colonoscopies at a reduced rate. Hope Through Grace has raised sufficient funds to pay for the colonoscopies of 6 people at high risk of colorectal cancer and without health insurance. The provider has also agreed to provide follow up treatment. An additional 17 people are scheduled for screening, and there is a waiting list of 10.

Dr. Beverly Laird works with Susan G. Komen for the Cure, which recently celebrated its 25th anniversary. The foundation is releasing a white paper on tissue access and ownership. The foundation is also meeting with 25 communities across the United States to recreate the sense of urgency around breast cancer. Komen has added four areas for focused research funding initiatives including DCIS, experimental model systems, biomarker identification and validation and environmental research methods.

Mr. Doug Ulman works with the Lance Armstrong Foundation and the Ulman Cancer Fund for Young Adults. The Lance Armstrong Foundation plans to make sure that for the first time in history, presidential campaigns will talk about cancer. The foundation's annual lobby day will take place on May 16 this year.

Ms. Kelly Cotter works with CureSearch, which supports the work of the Children's Oncology Group. The group's mission is to reach a day when every child with cancer is guaranteed a cure.

VII. NCI Director's Update

Dr. John Niederhuber reported on NCI's budget, which has risen less than the rate of inflation or several years. About a year ago, the Institute identified \$175 million that could be collected from reductions and phase-outs. The Institute's Executive Committee (EC) created a list of new initiatives and previously reduced projects to be considered from this pool of funding.

On February 14, the Senate passed the FY 2007 joint resolution. This bill provides \$28.9 billion for NIH (an increase of \$620 million from FY 2006). The bill also establishes the Common Fund (which includes the NIH Roadmap for Medical Research) in the NIH Director's Office at \$483 million, an increase of about \$150 million. The bill does not provide any specific increase to most NIH Institutes and Centers (ICs), but it does allow the ICs to retain the funds previously earmarked for the NIH Roadmap and the funds transferred to the Centers for Medicare and Medicaid Services (CMS) in FY 2006. NIH will also receive funds to pay for a portion of the 2007 cost-of-living increases in federal salaries.

The bill specifies that NIH should award about 500 more competing research project grants (RPGs) than in FY 2005, with an emphasis on new investigators. NIH agreed to an average cost of \$324,000 for these grants, the same as in FY 2006. The ICs will use half the funds saved from their previous Roadmap contributions to help support more research project grants. NIH will also reduce the number of noncompeting grants by 3%.

Congress instructed NIH to provide bridge funding to mid-career investigators whose grants are not renewed so that they can compete for new awards. These investigators play an important role in training new investigators.

The 2007 NCI budget is \$4,797,539,000, an increase of \$4,283,000, and represents no change in percent in the operating budget from 2006 to 2007. However, NCI must pay approximately \$100 million for certain NIH taps and assessments; increases in salaries, rents, leases, utilities, and research program grants; trans-NIH initiatives; and the NCI Director's reserve. NCI has identified \$265 million that could be recovered or redeployed through phase-outs and reductions to ongoing programs, reductions in noncompeting RPGs, and the NIH Roadmap. After NCI supports certain special initiatives, the cancer centers and Specialized Programs of Research Excellence (SPOREs), and clinical trials, it expects to have approximately \$67 million available for new initiatives/expansions.

NCI expects to award 5,192 competing RPGs this year, an increase of 20 projects from FY 2006. The payline will probably be at the 12th percentile, which means that most projects with scores in a higher percentile will not be funded. NCI would like to fund approximately one-third of the applications it receives.

The President's 2008 budget request calls for a 0.2% cut for NCI. It is not clear whether Congress will fund the NIH Roadmap through a separate line in the NIH budget.

Dr. Niederhuber made several announcements regarding recent activities at NCI:

- President Bush recently visited NIH and focused his attention on cancer. During his visit, the President announced the reduction in the number of cancer deaths between 2003 and 2004
- President Bush signed the NIH Reform Act of 2006 on January 15, 2007. NIH is assessing the impact of this bill on its operations
- NIH has organized several implementation groups to address the NIH Reform Act. Dr. Niederhuber is a member of the report group

- Dr. Alan Krensky will be the new NIH Deputy Director for the Office of Portfolio Analysis and Strategic Initiatives (OPASI). This designation becomes effective on July 8. Dr. Krensky and his wife are also joining NCI's intramural program
- The Clinical Trials Advisory Committee (CTAC) is the first new Federal Advisory Committee Act (FACA)-approved advisory committee to the NCI Director in the past decade
- The NCI Alliance for Nanotechnology funds eight Centers for Nanotechnology Excellence that are developing and applying nanotechnology and nanoscience solutions to the diagnosis and treatment of cancer
- The Clinical Proteomics Technologies Initiative for Cancer funded five centers to develop technologies, data, reagents and reference materials, analysis systems, and infrastructure to advance the understanding of protein biology in cancer
- The Integrative Cancer Biology Program brings clinical and basic cancer researchers together with researchers from mathematics, physics, information technology, imaging sciences, and computer science to work on key questions in cancer biology

Dr. Niederhuber extended his personal thanks to the retiring members of the DCLG: Ms. Vernal Branch, Ms. Sue Sumpter, Ms. Mary Jackson Scroggins, and Dr. Marisa Weiss.

Discussion

Mr. Ulman commented that it was unfortunate that the President spoke on national news about important advances in cancer at a time when NCI's budget is being cut. Ms. Branch agreed, adding that advocacy organizations need to do more to ensure that their constituents understand what is happening at NCI.

Dr. Niederhuber explained that every day, 1,500 people who have cancer do not make the front pages. Although cancer is in the news now, it will not be in a few days. Mr. Ulman commented that this shows why advocates need to do a better job of highlighting this issue.

Mr. Bro complimented Dr. Niederhuber and his staff for their exemplary work. NCI staff has provided much valuable assistance to his small charity over the years. Cancer advocates owe a large debt of gratitude to those who work in the trenches at NCI every day.

Ms. Davenport-Ennis said that DCLG members and advocates can all help educate members of Congress about NCI. CNN recently interviewed Senator John McCain, who said that he was not aware the Congress had reduced NCI's funding.

Dr. Butler participated in the discussion with President Bush, who discussed increases to the NIH and NCI budget. More research is needed on survivorship and quality of life. Dr. Butler also believes that more research is needed on colorectal cancer, which does not receive a great deal of public attention, even though it can be prevented.

Dr. Niederhuber explained that NCI does not deliver care but it is trying to affect delivery through its research programs. NCI does work to make the public aware of the importance of colonoscopy. The Institute is also conducting research on imaging that could provide a less

invasive way to provide the same results as colonoscopy. Dr. Niederhuber is also working with his colleagues in the U.S. Department of Health and Human Services to discuss tobacco legislation that the Senate is considering.

Ms. Campos heard Senator Tom Harkin mention proposed legislation to increase funding for NCI. She wondered if this proposed funding would be sufficient. Ms. Susan Erickson clarified that Senator Harkin and Senator Harlan Spector have proposed an amendment to the budget resolution that will increase the overall biomedical research budget. Dr. Niederhuber explained that if NIH receives the proposed increase, it is not clear what proportion NCI would receive.

Ms. Whitewolf pointed out that 67% of Native Americans live in urban areas, but the President plans to cut funding for urban Indian clinics. She hoped that this budget would be restored so that Native Americans can be cared for in their home communities. Dr. Niederhuber explained that NCI has several programs, including cancer centers, serving areas where Native Americans live.

Col. Williams asked about progress on the NCI Community Cancer Centers Program (NCCCP). Dr. Niederhuber reported that the program has received 45 applications from 22 states. These applications are being reviewed, and NCI plans to fund six pilot projects.

VIII. NCI Legislative Update

Ms. Erickson reported that the President's FY 2008 budget includes \$28.86 billion for NIH and \$4.78 billion for NCI. The Senate Appropriations Subcommittee on labor, HHS, and Education is now scheduling several hearings around certain themes, and NCI has been invited to the hearing on the preemptive/predictive theme, when Dr. Niederhuber and other IC Directors will have five minutes for their oral statements. It has been many years since IC Directors had the opportunity to provide individual oral statements, so NCI views this as a very positive sign of interest by the members of the Senate Appropriations Committee.

Senator Ted Kennedy visited NIH in December and expressed an interest in the research of several ICs, including NCI. Representative Mike Castle of Delaware met with NCI and two other ICs on January 22.

Ms. Erickson listed several pending pieces of legislation of potential interest to the DCLG:

- The Family Smoking Prevention and Tobacco Control Act (H.R. 1108, S. 625) would give the U.S. Food and Drug Administration (FDA) the authority to regulate tobacco. If this bill passes, the FDA could restrict ads for cigarettes, review industry claims about light products, and regulate cigarette ingredients. The Senate Health, Education, Labor and Pensions (HELP) Committee has held a hearing on this legislation, but the House version has not had any activity
- The Breast Cancer Stamp Reauthorization bill (H.R. 1064, S. 597) will extend the authority to issue breast cancer stamps through 2009
- The Stem Cell Research Enhancement Act (H.R. 3, S. 5) appears to be a priority for House and Senate leaders. However, the President has promised to veto this bill if it passes

- The House will soon vote on the Genetic Information Nondiscrimination bill (H.R. 493, S. 358)
- The Cancer Testing Education Screening and Treatment bill (H.R. 1030) would give grants to organizations to provide prevention information and education, screening, counseling, and treatment
- The Enhancing Drug Safety and Innovation Act (S. 484) would establish a central clearinghouse for information on clinical trials

Ms. Erickson also reported that the Centers for Disease Control and Prevention (CDC) National Breast and Cervical Cancer Early Detection bill had passed on March 29. On March 15, the House introduced a resolution honoring the contributions of patients in clinical trials.

Discussion

Ms. Sumpter asked who would coordinate the proposed clinical trials registry database. Ms. Erickson explained that NIH would coordinate this database, probably through the National Library of Medicine.

Ms. Branch recently met with members of the Senate and House who plan to pass the Breast Cancer and Environmental Research Act (H.R. 1746, S. 983) during the current session.

IX. A Year in the Life of Science Planning

Dr. Lisa Stevens described NCI's planning and budget lifecycle. She explained that every year in August, the Office of Management and Budget begins working on the President's budget for the fiscal year that begins 14 months later, on October 1. NCI's Office of Science Planning and Assessment (OSPA) tries to release the Bypass Budget at the beginning of October for the fiscal year that will start the following October. OSPA then develops the narrative part of the Congressional Justification explaining the Institute's budget choices for the previous year. All ICs participate in the Congressional Justification, which is released in late January. In late January or early February, the President's budget for the fiscal year that begins the following October is released. Appropriations hearings begin in late February and can continue throughout the spring. OSPA is now beginning to develop the Bypass Budget for the fiscal year that begins in October 2008 (FY 2009).

In 2006, NCI published a long-range strategic plan. The plan focused on eight strategic objectives based on more than 200 proposed initiatives. Four of these objectives focus on preemption and four on outcomes. The FY 2008 Bypass Budget was the first published since the strategic plan was released, and it is linked directly to the eight objectives. The FY 2009 Bypass Budget will also use the strategic plan as an organizing framework.

Dr. Stevens asked the DCLG to provide feedback on the FY 2008 Bypass Budget to help OSPA prepare its FY 2009 budget. OSPA would also welcome feedback on its other strategic planning products. Comments should be sent to nciplan@mail.nih.gov.

NCI is the only IC that prepares a Bypass Budget. This document allows the Institute to speak directly to members of Congress and the President. Dr. Stevens provided the DCLG with a letter that can be used to disseminate the Bypass Budget. OSPA has also developed a one-page "At a Glance" summary of the Bypass Budget in response to a request from the DCLG at its October 2006 meeting. PDF versions of the summary and the Bypass Budget document are available on the Web (plan.cancer.gov). Dr. Stevens asked for feedback on the summary.

DCLG members can use NCI's planning document in setting their own priorities. Dr. Stevens invited DCLG members to contact her if they would like to work with her and her office on strategic planning or implementation.

X. Restructuring the National Cancer Clinical Trials Enterprise

Dr. Raymond Petryshyn discussed the progress of the Clinical Trials Working Group (CTWG). As a result of a CTWG recommendation, NCI recently established the Clinical Trials Advisory Committee (CTAC) to advise the NCI Director on clinical trials. CTAC has 10 members from current NCI boards, including the DCLG, and 14 members from the extramural clinical trials community. CTAC plans to establish three subcommittees to address informatics, public/private partnerships, and coordination of NCI clinical trials programs.

The Clinical Trials Operations Committee (CTOC) is an internal NCI committee that provides strategic oversight for NCI clinical trials programs and infrastructure. CTOC has members from all NCI Divisions, Offices, and Centers involved in NCI-supported clinical trials. The Coordinating Center for Clinical Trials (CCCT) is a new office in the NCI Office of the Director that supports the implementation of the CTWG initiatives in conjunction with NCI's Divisions, Centers, and Offices.

The CTWG plan also called for the establishment of an Investigational Drug Steering Committee (IDSC) to prioritize early-phase trials. The IDSC has now been established and has five task forces. Disease-specific steering committees for gastrointestinal, gynecologic, and head and neck cancers as well as for symptom management and health-related quality of life have been established.

The CTWG plan also called for advocate and community oncologist steering committees and focus groups to solicit general input and promote efficient trial accrual. The focus groups will be conducted in collaboration with advocacy organizations and build on existing organizations.

The Cooperative Group review guidelines are being modified to encourage collaboration with SPOREs and NCI-designated cancer centers. The SPORE and cancer center review guidelines will be modified to encourage collaboration with Cooperative Groups. NCI is also evaluating the feasibility of accruing patients to SPORE and cancer center clinical trials through NCI's Cancer Trials Support Unit.

NCI plans to promote the establishment of a national clinical trial informatics infrastructure that is fully interoperable with caBIG™. The Institute will also develop a repository for investigator and site credentials that is recognized and accepted by NCI, industry sponsors, clinical

investigators, and clinical trial sites. In addition, the CTWG called for the establishment of commonly accepted clauses for clinical trial contracts.

To increase operational efficiency, NCI plans to restructure the funding model for phase III efficacy trials to provide incentives for more rapid patient accrual. The Institute is also identifying institutional barriers that prolong the time from concept approval to accrual of the first patient and developing solutions for overcoming these barriers. Other activities include promoting patient and public awareness and understanding of clinical trials, expanding current outreach programs to increase recruitment of minority populations, and enhancing adoption of the centralized Institutional Review Board (CIRB) process.

A study by D.M. Dilts identified more than 300 steps required to move from concept development to accrual of the first patient to a trial. NCI is analyzing this pipeline in additional cancer centers and cooperative groups for several cancers to identify areas in which the process can be accelerated to conduct trials more efficiently. A trans-NCI partnership has been formed to propose mechanisms and solicit concepts from minority outreach programs to enhance minority accrual. An analysis has begun of the barriers to the acceptance of the NCI CIRB.

Discussion

Ms. Branch serves on a local IRB that has too many protocols to review and plans to use the CIRB for its pediatric Cooperative Group trials.

Dr. Petryshyn stated that the CCCT would like to work more closely with the DCLG to understand the barriers to using the CIRB and establish general confidence and acceptance in using the CIRB where possible.

Ms. Sumpter noted that some patients live long distances from the centers conducting clinical trials, and this affects accrual. The best clinical trials system in the world will not work if patients are unable to get to the trial sites. Dr. Petryshyn agreed that practical issues like the one described need to be addressed.

Dr. Butler expressed concern about NCI's policy regarding centers that do not meet their minority recruitment goals. NCI requires these centers to submit a five-year plan to address the situation, and if they still do not meet the recruitment goals five years later, they are required to submit another plan. Dr. Petryshyn explained that the CTWG report recommended incentives for organizations that have been successful in accruing minorities and underserved populations.

Dr. Butler wondered whether researchers or institutions are responsible for adverse drug events that occur during clinical trials. Dr. Deborah Jaffe, Program Director, Coordinating Center for Clinical Trials (CCCT) explained that NCI-supported clinical trials and institutions conducting these trials must follow specific rules for reporting adverse events.

Dr. Butler asked about support for patients in trials, especially if their insurers do not cover clinical trials. Dr. Ernest Hawk explained that institutions are responsible for side effects that

occur as a result of clinical trials. Ms. Branch confirmed that the institution she works with takes care of adverse events, regardless of whether the patient is insured.

Ms. Davenport-Ennis encouraged NCI to include male head and neck cancer patients in its focus groups. The top killer of people with cancer is not the disease but the lack of access to high-quality care. As NCI reconfigures its clinical trials system, it should encourage institutions to develop on-site case managers who can ensure access for every patient. Even if hospitals take care of patients who have adverse events while on a clinical trial, they do not provide care for patients who have secondary events once they return to their communities.

Ms. Anthony stressed the need to involve patient advocates in reviewing protocols at the beginning as opposed to the end. They can help with such issues as accrual and transportation. Dr. Petryshyn said that advocates will participate in the process from the beginning.

XI. Translational Research: Harnessing Discovery for Patient and Public Benefit

Dr. Hawk reported that the Translational Research Working Group (TRWG) has evaluated the current status of NCI's investment in translational research and envisioned its future in an inclusive, representative, and transparent manner. The TRWG has more than 60 members, including 3 advocates.

The TRWG reviewed 11 foundational documents on translational research and analyzed the CTWG process for ideas, challenges, and lessons learned. The TRWG also developed a Web-based communications platform (www.cancer.gov/trwg). Input from the public, researchers, industry, foundations, and professional societies was gathered through several roundtable meetings and the Web site. In addition, the TRWG analyzed NCI's current investment in translational research and developed six developmental pathways listing decisions and key steps in moving credentialed scientific discoveries into early-phase clinical trials.

The TRWG defines translational research as "research that transforms scientific discoveries arising in the lab, clinic, or population into new clinical tools and applications that reduce cancer incidence, morbidity, and mortality." The TRWG focuses on early-phase (phase I and II) trials.

NCI's translational research projects have not been well coded. The portfolio analysis estimated that in FY 2004, \$1.3 billion of NCI's \$4.4 billion budget was spent on translational research. Of this amount, 56% was awarded to institutions with NCI-designated cancer centers.

The TRWG developed several sets of draft initiatives addressing coordinated management, tailored funding programs, and operational effectiveness.

The TRWG decided not to create a structure similar to but separate from the CTWG structure. Instead, the TRWG recommended that the new CTWG structure extend its mission to translational science. For example, the CTAC could oversee both translational science and clinical trials. A new Translational Research Prioritization Working Group (TRPWG) would be a subset of the CTAC to provide advice on new priorities. A new Translational Research

Operations Committee would issue requests for information and proposals for the TRPWG to address.

The TRWG also proposed the establishment of a funding program for early translational research that requires academic/industry collaboration involving resource sharing and/or co-funding. Perhaps two or three of these projects would be funded each year.

Implementing the TRWG's recommendations will require less than a 1% increase in NCI's budget. The TRWG plans to finalize its report and publish the six pathways to clinical goals. Other steps include implementing the recommended coding refinements, communicating the draft plans to the broader research community, and convening an internal working group to discuss implementation strategies.

Discussion

Ms. Branch asked if industry representatives helped develop the TRWG plan. Dr. Hawk replied that the TRWG has several industry representatives, and 45 people attended the TRWG's industry roundtable.

Ms. Davenport-Ennis commented that NCI's name should be included in every slide presentation so that the American public understands the Institute's role in these breakthroughs.

Ms. Sumpter asked if NCI shares in the profits from drugs that are developed based on the Institute's research. Dr. Hawk explained that Congress feels that the public is well served when NCI makes scientific discoveries and hands them off to industry. Developing a drug is so expensive that NCI cannot do it alone. In some cases, NCI can have a financial stake, but this depends on the circumstances and NCI's contributions relative to those of the company.

XII. Presentation of Program Working Group Deliberations and Discussions

In order that the DCLG consider advising the NCI Director on the three priorities: Eliminating Health Disparities; Minority outreach in Clinical Trials and Cancer Care Services through the NCCCP, Mr. Ulman suggested that the DCLG work on recommendations as a committee, rather than breaking into working groups or subcommittees.

Mr. Ulman noted that Dr. Tim Rebbeck had asked the DCLG to endorse the Center for Population Health and Health Disparities that he leads. Mr. Ulman proposed that the DCLG send a letter endorsing the project to Dr. Niederhuber, with copies to Dr. Rebbeck and the NCAB chair. Ms. Guest will write the first draft of the letter endorsing Dr. Rebbeck's project and will circulate the draft to the DCLG for comment.

The DCLG carried a motion to send letters to NCI for the following programs and initiatives:

- To recommend the continuation of *NCI Listens and Learns Program* with modifications
- To recommend that NCI produce a second cancer advocacy summit

- To endorse Dr. Rebbeck's project as part of the NIH Centers for Population Health and Health Disparities

Dr. Laird has received lists of good outcomes for NCCCP from the DCLG. Ms. Guest will distribute this list to the DCLG so that members can send additional suggestions.

Mr. Ulman noted that Dr. Niederhuber had requested information on which areas of NCI are not using CARRA members. The DCLG could ask OLA for this information and include it in a letter to Dr. Niederhuber. Ms. Nelvis Castro suggested that even if the DCLG cannot identify which segments of NCI are not using CARRA member, the DCLG could still request that all Offices, Divisions, and Centers use CARRA members for their projects.

Ms. Anthony noted that caBIG™ has used advocates in every workspace, and this involvement has been very successful. Mr. Ulman suggested that the DCLG highlight caBIG™ as an example of successful advocacy participation.

Ms. Cotter suggested that the DCLG indicate to Dr. Niederhuber how it intends to help promote the new Spanish version of the NCI Web site. Ms. Castro commented that the upcoming teleconference on the Web site would provide some ideas on ways that the DCLG could promote the site. Ms. Anthony asked about promotional materials for the Spanish-language Web site. Ms. Castro explained that NCI's promotional budget for this project is limited, so NCI is using electronic methods to promote the site. She asked the DCLG to send her comments on the site.

Mr. Ulman and Dr. Laird collected proposed recommendations for NCI from DCLG members. Based on these recommendations and the discussions during this meeting, Mr. Ulman and Dr. Laird will write a first draft of the DCLG's recommendation letter for Dr. Niederhuber.

Ms. Guest announced that the DCLG will have a teleconference meeting in June. The DCLG can ask NCI staff members to participate in the call to discuss areas of interest. DCLG members whose terms expire at the end of June 2007 may participate in this teleconference. Dr. Laird and the Agenda Working Group will develop the agenda and she asked. DCLG members to submit agenda items.

XIII. Public Comment

There was no public comment.

XIV. Adjourn

Mr. Ulman adjourned the meeting and thanked the DCLG members for their active participation.

Certification

I hereby certify that the foregoing minutes are accurate and complete.

Date

Chair
Director's Consumer Liaison Group

Date

Executive Secretary
Director's Consumer Liaison Group

March 29–30, 2007

DCLG ACTION ITEMS

- Ms. Elizabeth Neilson will report to the DCLG on the characteristics of current CARRA members.
- Ms. Amy Bowman will send electronic versions of TCGA PowerPoint slides and other dissemination materials to the DCLG. DCLG members will provide feedback on these materials and suggestions on ways to distribute them.
- The DCLG will provide NCI with feedback on the FY 2008 Bypass Budget and the “At a Glance” summary. Dr. Stevens invited DCLG members to contact her if they would like to work with her and her office on strategic planning or implementation.
- The DCLG will recommend that NCI continue *NCI Listens and Learns* with modifications in a two- or three-page letter and a list of proposed modifications. The DCLG members who have worked on *NCI Listens and Learns* will prepare this letter.
- The DCLG will recommend that NCI organize a second advocacy summit.
- The DCLG will recommend that the NCI Director encourage all Offices, Centers, and Divisions to use CARRA members when they need advocacy participation in their projects.
- The DCLG will inform Dr. Niederhuber of how it intends to help promote the new Spanish version of the NCI Web site.
- Mr. Ulman and Dr. Laird will draft a letter with the recommendations concerning the advocacy summit, CARRA, and the Spanish-language Web site, as well as others submitted by DCLG members during this meeting.
- The DCLG will send a letter to NCI endorsing Dr. Rebbeck's project. Ms. Guest will write the first draft of the letter and will circulate it to the DCLG for comment.
- Dr. Laird will distribute the preliminary list of good outcomes for NCCCCP submitted by DCLG members. The DCLG will provide additional suggestions for outcomes.
- DCLG members should submit suggestions for the June teleconference agenda to Dr. Laird.
- The DCLG will send comments on the new Spanish version of Cancer.gov to Ms. Nelvis Castro.