DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE

MINUTES of the DIRECTOR'S CONSUMER LIAISON GROUP MEETING

October 14–15, 2008

Members Present

Mr. Doug Ulman, Chair*	Ms. Kelly Cotter	Ms. Cheryl Jernigan
Dr. Beverly Laird, Vice Chair	Ms. Marie Dahlstrom	Mr. Alan Kaye
Mr. Bill Bro*	Ms. Gwen Darien	Ms. Phyllis Pettit Nassi
Dr. Grace Butler	Mr. Everett Dodson	Ms. Wendy Selig
Dr. Yvette Colón	Ms. Joyce Wilcox Graff	Ms. Arlene Wahwasuck

*Participated by telephone.

Speakers

Dr. Jeff Abrams, Acting Associate Director, Cancer Therapy Evaluation Program, Division of Cancer Treatment and Diagnosis, National Cancer Institute (NCI)
Ms. Shannon K. Bell, Director, Office of Advocacy Relations, NCI
Dr. Linda Burhansstipanov, Director, Native American Cancer Initiatives, Inc.
Ms. Stacy Collins, Project Coordinator, Education Network to Advance Cancer Clinical Trials (ENACCT)
Dr. Yvette Colón, Director's Consumer Liaison Group (DCLG)
Ms. Kelly Cotter, DCLG
Ms. Marie Dahlstrom, DCLG
Mr. Everett Dodson, DCLG
Ms. Susan Erickson, Director, Office of Government and Congressional Relations, NCI
Ms. Rebecca Fisher, Patient Advocate, Personalized Healthcare Workgroup, U.S. Department of Health and Human Services
Dr. Elise Kohn, Senior Investigator, Medical Oncology Branch and Affiliates, Center for Cancer Research, NCI
Ms. Lisa Krueger, Team Leader, Knowledge Management and Special Projects, Research Analysis and Evaluation Branch, Division of Extramural Activities, NCI
Dr. Beverly Laird, Vice Chair, DCLG
Ms. Margo Michaels, Executive Director, ENACCT
Dr. Kimberly Myers, Program Manager, Office of Biorepositories and Biospecimen Research, NCI
Dr. John Niederhuber, Director, NCI
Ms. Mary Lou Smith, Co-Chair, Patient Representative Committee, Eastern Cooperative Oncology Group (ECOG)
Dr. JoAnne Zujewski, Senior Investigator, Clinical Investigations Branch, Cancer Therapy Evaluation Program, Division of Cancer Treatment and Diagnosis, NCI

Office of Advocacy Relations Staff

Ms. Shannon Bell, Director
Mr. James Hadley, Advocacy Program Manager
Ms. Michelle Hathaway, Health Communications Intern
Ms. Brooke Hamilton Leggin, Program Analyst
Ms. Linda Ticker, Program Assistant
Ms. Amanda Woodfield, Presidential Management Fellow

Executive Summary

On October 14–15, 2008, the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG) received updates from the NCI Director, Dr. John Niederhuber, on NCI's budget and the need for a new translational research paradigm. Dr. Niederhuber and Ms. Lisa Krueger of NCI's Division of Extramural Activities reported on NCI's new Funded Research Portfolio and the National Institutes of Health Research, Condition, and Disease Categorization system for coding grants. Dr. Niederhuber also discussed plans to alter the Cancer Information System's Partnerships Program after the current contracts end in 2010.

Dr. Jeff Abrams of NCI's Cancer Therapy Evaluation Program (CTEP) and Ms. Mary Lou Smith of the Eastern Cooperative Oncology Group Patient Representative Committee discussed plans to modify NCI's Central Institutional Review Board (CIRB) process for CTEP clinical trials. Ms. Shannon Bell, Director of the Office of Advocacy Relations, reported on the office's activities to engage the advocacy and NCI communities in dialogue about cancer research opportunities and priorities.

Ms. Susan Erickson of NCI's Office of Government and Congressional Relations described several bills that Congress has recently signed into law, as well as other bills that Congress has considered. Dr. Linda Burhansstipanov of Native American Cancer Initiatives, Inc., described the challenges faced by Native Americans with cancer and suggested some strategies for addressing these challenges.

Dr. Beverly Laird of the DCLG led a discussion of strategies that the DCLG could use to develop recommendations for NCI in the future. Dr. Laird also described the progress made by the NCI Community Cancer Centers Program's pilot sites. The DCLG agreed that this program needs to be continued and should be expanded to more sites.

DCLG member Ms. Kelly Cotter reported that the DCLG's Advocates in Research Working Group is determining how and where advocates are involved at NCI and how they might be most effectively involved in the future. The group will develop initiatives and implementation recommendations for involving advocates across the spectrum of NCI activities. Dr. Yvette Colón, the new DCLG liaison to NCI's National Cancer Advisory Board, described the board's composition and responsibilities. Mr. Everett Dodson is the new DCLG representative to the Clinical and Translational Advisory Committee, which oversees the prioritization and review process for all NCI clinical trials.

Ms. Margo Michaels and Ms. Stacy Collins of the Education Network to Advance Cancer Clinical Trials described a new strategic plan for incorporating community-based participatory research principles and approaches into Phase III clinical trials.

Ms. Rebecca Fisher, a patient advocate with the Personalized Healthcare Workgroup, Dr. Elise Kohn of NCI's Center for Cancer Research, Dr. Kimberly Myers of NCI's Office of Biorepositories and Biospecimen Research, and Dr. JoAnne Zujewski of CTEP discussed the future of personalized medicine and the potential role of advocates in advancing this field.

Table of Contents

Welcome and Announcements

Dr. Beverly Laird welcomed participants to this meeting of the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG). She reviewed the rules governing confidentiality and conflict of interest, and Ms. Shannon Bell determined that a quorum was present.

The DCLG unanimously approved a motion to approve the minutes from the DCLG's June 30, 2008, teleconference.

Dr. Shobha Srinivasan, Health Disparities Research Coordinator, Division of Cancer Control and Population Sciences, reported that NCI's Board of Scientific Advisors approved the continuation of the National Institutes of Health (NIH) Centers for Population Health and Health Disparities. The new request for applications (RFA) is expected to be released in November.

Dr. Laird announced that DCLG members have been invited to join NCI's Consumer Advocates in Research and Related Activities (CARRA) program.

NCI Director's Report

Dr. John Niederhuber welcomed the new DCLG members. He reported that the FY 2009 President's budget calls for $4.8 billion for NCI, which is essentially the same as in FY 2008. NCI's appropriations have been level since 2004, resulting in a 19 percent decrease in purchasing power.

A big challenge for NCI is the need to create a new translational research paradigm, in which highly targeted agents will be matched to patients based on their individual genetic characteristics. To make this possible, NCI is working to make its clinical trials system more efficient.

DCLG members emphasized the need for multicenter trials that can accrue small numbers of patients with rare diseases who are scattered around the country. NCI is working to bring trials to patients' communities. The NCI Community Cancer Centers Program (NCCCP) will help make this possible.

Another DCLG concern is the need to develop more prevention interventions and programs. NCI has programs aimed at changing behaviors and teaching people about healthy lifestyles. The Institute's research on basic biological pathways is also designed to produce new prevention strategies.

Central Institutional Review Board (CIRB)

Dr. Jeff Abrams described the efforts of NCI's Cancer Therapy Evaluation Program (CTEP) to eliminate delays in its approval of clinical trials by modifying the CIRB review process. After CTEP reviews and approves clinical trial protocols, it will now send them to the CIRB and to local IRBs simultaneously. Sites that use the CIRB will be able to enroll patients in the trial after the CIRB approves the protocol. Sites that do not use the CIRB will be able to enroll patients after completing their local IRB review and will no longer be required to wait for the CIRB to complete its review. CTEP expects the entire CIRB review process to be completed within 30–35 days. The new parallel review process will be implemented by the end of the first quarter of 2009.

Ms. Mary Lou Smith reported that the Eastern Cooperative Oncology Group (ECOG) Patient Representative Committee supports CTEP's proposal to reduce the CIRB review turnaround time from 16 weeks to 4–5 weeks. However, the committee noted that key metrics (such as time from CTEP approval to first patient on study or percentage of overall accruals from sites using the CIRB) are not available to determine whether the program is meeting its original, patient-oriented objectives. The committee

believes that reports of the number of sites using the CIRB or data on facilitated reviews conducted by the CIRB do not provide needed information on the CIRB's impact on patient outcomes.

DCLG members asked about provisions to ensure inclusion of minority and underserved populations in clinical trials. In particular, the CIRB needs to consider the complexity of multicenter trials and protocols in Native American populations to prevent delays in protocol approval. Dr. Abrams explained that the CIRB reviews the science in the protocols, whereas the local IRBs are responsible for reviewing the science in the context of the local community. The CIRB takes into account the protocol's effects on the general U.S. population, but local IRBs must consider issues that are specific to their site.

The number of protocols opened by Cooperative Groups is not likely to be affected by the number of sites using the CIRB. Many factors beyond the CIRB's control, especially the amount of funding available, affect the number of patients accrued. However, the CIRB does save money by preventing the need for many IRBs to review the same protocol.

Ms. Smith wondered whether the CIRB has led to better care for patients. Dr. Abrams explained that the original goal of the CIRB was to reduce the number of redundant reviews and thus reduce the cost of opening new protocols in the United States for multicenter studies. Although funding per case has not increased since 2001, the number of protocols opened has not declined. Thus, the CIRB has achieved its original aim of allowing sites to open Cooperative Group protocols by removing an obstacle.

The parallel review process will show whether reviews by the CIRB or local IRBs result in more rapid openings of trials. However, many sites do not open trials immediately after approval because of the associated cost, preferring to wait until they identify eligible patients. Thus, the date on which a trial opens does not necessarily depend on when the IRB review is completed.

Patients can find information on major Phase III trials at http://www.cancer.gov. However, they might not be able to determine whether a trial has opened at a site near them if their local site is waiting for eligible patients before opening the trial. Moreover, investigators might not open the trial at their site unless a patient asks them to do so.

Because the childhood cancer CIRB has been so effective, the chair of the Children's Oncology Group (COG) does not believe that any changes need to be made to this CIRB. If the changes to the adult CIRB are effective, CTEP would be open to making similar changes to the children's CIRB if COG so desires.

CTEP plans to measure the length of time required for the CIRB to complete its reviews. Advocates might be able to address barriers, especially those pertaining to informed consent documents, that persistently hold up the process.

Dr. Abrams indicated that the CIRB is moving out of the pilot phase. The CIRB is the IRB of record for numerous protocols at hundreds of sites and it has been following these protocols for several years. About 40–50 percent of all sites that conduct Cooperative Group clinical trials are CIRB members. Many other sites do not join the CIRB because of concerns about risk among other reasons.

Cancer in the Native American Community

According to Dr. Linda Burhansstipanov, American Indian and Alaska Native (AIAN) people tend to be younger and have a lower median income, higher poverty rate, and lower rate of high school completion than the general U.S. population. Of those with cancer, 40 percent travel 100–300 miles each way to obtain cancer care. AIAN people tend to be diagnosed with cancer at younger ages and later stages than the general U.S. population, and only one-third have health insurance. Because of funding cuts to

Contract Health Services, the Indian Health Service (IHS) rarely provides timely referrals to high-quality care. As a result, people wait several months from the date of diagnosis or biopsy to initiation of cancer care.

Approximately half of all AIAN patients with cancer have diabetes, and substantial proportions have high blood pressure, habitual tobacco use, or other comorbidities. Many clinical trials exclude patients with these comorbidities. However, Dr. Burhansstipanov and her colleagues have persuaded individual investigators to grant waivers and accept individual patients on a case-by-case basis. Accomplishing this often requires well-trained patient navigators.

Most "evidence-based" interventions have rarely been tested in medically underserved communities. Although many AIAN programs are not supported by standard types of evidence, they are more effective and culturally appropriate than non-Native best practices.

Progress in enrolling AIAN people, as well as other medically underserved people, into clinical trials has been limited. Providers and researchers do not take the time to explain the trials in terminology that is appropriate for each community so that patients can make informed choices. In addition, providers do not always offer clinical trials to patients who might be eligible for them. Providing incentives to both providers and patients might increase accrual rates.

Update on the NCI Office of Advocacy Relations (OAR)

Ms. Bell discussed OAR's most recent project, the Science Serving People Web site (http://www.cancer.gov/aboutnci/servingpeople), which allows NCI to communicate directly with the community. The office is also coordinating advocate participation in the upcoming NCI Translates: NCI Translational Science Meeting.

OAR is working to institutionalize the role of advocates at NCI so that this role does not change with shifts in the Institute's leadership. Dr. Niederhuber has already moved OAR into the Director's office and hired Ms. Bell as the office's first permanent director in several years, so this will help maintain stability for NCI's advocacy programs.

DCLG suggestions were:

- NCI should include resources from advocacy organizations in its communications with the advocacy community to prevent duplication.
- The DCLG should identify issues that are important to the advocacy community for the next NCI Director in the event that the next President appoints a new Director.
- The DCLG should review its progress in meeting the three priorities established by Dr. Niederhuber for the group (minority recruitment and patient outreach, cancer care delivery, and eliminating cancer health disparities) and determine whether these priorities are still appropriate.

NCI Legislative Affairs Update

Ms. Susan Erickson explained that NIH received $150 million, including $25 million for NCI, through the 2008 supplemental spending bill. Congress did not pass a FY 2009 budget for the Department of Health and Human Services, which is now operating under a continuing resolution that expires on March 6, 2009. Between now and March, Congress might revisit its appropriations bills and bring them to the floor for a vote, write new bills, or pass another continuing resolution.

Ms. Erickson reported on the passage of the following bills:

- Genetic Information Nondiscrimination Act (HR493): Prohibits discrimination in health insurance and employment based on genetic information
- Conquer Childhood Cancer Act (HR1553): Expands and intensifies pediatric cancer research and establishes a national childhood cancer registry
- Breast Cancer and the Environment Research Act (HR1157): Expands and intensifies research on breast cancer and the environment

Others bills that NCI is watching would require insurance coverage of minimum hospital stays for breast cancer treatment, establish a national cancer fund in the U.S. Treasury, provide $5.2 billion in supplemental appropriations to NIH in FY 2008, reduce lung cancer mortality through an early disease research and management program, and advance pancreatic cancer research.

Ms. Erickson clarified that NCI can provide information when a member of Congress needs technical assistance for a bill. However, the Institute does not take a formal position on any bill and it cannot advocate for any piece of legislation.

The Web site of NCI's Office of Government and Congressional Relations (http://legislative.cancer.gov) provides more information on cancer-related congressional issues.

DCLG Recommendations Working Group

Dr. Laird asked the DCLG to discuss a process for developing recommendations and submitting them to the NCI Director in a timely way. In 2007, Dr. Niederhuber asked the DCLG to offer guidance on three issues: minority recruitment and patient outreach, cancer care delivery, and eliminating cancer health disparities. These issues continue to be major concerns and it would be helpful to obtain data on progress in addressing them.

Dr. Niederhuber identified the three priority areas because they were areas of immediate concern and had an obvious connection to the lay community. However, these areas were not intended to be the exclusive focus of the DCLG. NCI recognizes that the DCLG is in a unique position to identify opportunities for community involvement in NCI activities, such as personalized medicine or the next generation of clinical trials.

Ms. Anne Lubenow remarked that recommendations "come in all shapes and sizes." The DCLG need not offer only formal, written recommendations, and its recommendations need not be designed only for the NCI Director.

The DCLG suggested that in the future, the group:

- Establish a deadline and approach for developing recommendations as soon as it identifies an issue of interest or concern.
- Identify desired outcomes for the recommendations development process.
- Employ effective approaches used by DCLG members' organizations as a model for addressing priorities.
- Develop lessons learned from the less effective approaches used by the DCLG to develop recommendations.
- Leverage the expertise of DCLG members.
- Use a process similar to the effective approach developed for the DCLG's Advocates in Research Working Group (ARWG) to develop recommendations.

The DCLG also suggested that the group develop recommendations on the following issues:

- Breaking down barriers to participation in clinical trials for underserved communities by providing guidance, tools, and training that help researchers develop relationships with communities.
- Facilitating discussions with communities that are reluctant to share their genetic information with researchers.
- Ensuring the inclusion of representatives of medically underserved populations in all phases of clinical trials using the community-based participatory research (CBPR) approach.
- Developing prevention interventions, especially for people who experience health disparities.

Dr. Laird reported that the Recommendations Working Group needs a new chair because Ms. Nancy Davenport-Ennis, the previous chair, has rotated off the DCLG. She invited interested DCLG members to contact Ms. Bell.

Question and Answer Session with NCI Director

Dr. Niederhuber reported that Congress authorized and required NCI to code its research portfolio based on the cancer sites addressed by each project. Many NCI grants are very complex and address several cancer sites. However, the new NIH Research, Condition, and Disease Categorization (RCDC) system allows grants to be coded to one disease only. The Web site for the new NIH system will go live in February 2009.

NCI is concerned that its own system will be incompatible with the RCDC system and is attempting to find ways to reconcile the two approaches. Ms. Lisa Krueger provided an overview of NCI's newly integrated public reporting site, the NCI Funded Research Portfolio (NFRP, http://deais.nci.nih.gov/Query). This site provides scientific coding information on all NCI-funded research projects, including extramural projects, intramural projects, and contracts. The site also offers budget information, including overhead amounts. Ms. Krueger distributed a primer on the NFRP to the DCLG.

Dr. Niederhuber made the following announcements:

- Senator Ted Kennedy (D-MA) plans to introduce a bill in January 2009 that will reauthorize NCI. Dr. Niederhuber hopes that this bill will maintain the important authorities granted to the Institute in 1971.
- As of October 1, 2008, the NIH campus is tobacco-free.
- NCI has met the Gold Standard criteria established by the CEO Roundtable on Cancer for employee health benefits programs that maintain a culture of encouraging healthy lifestyles and providing support when a cancer diagnosis is made. NCI evaluation experts have volunteered to help the Roundtable evaluate the impact of the Gold Standard program.

Community members have expressed concern to several DCLG members because NCI does not plan to renew the Cancer Information Service (CIS) Partnership Program contracts. DCLG members expressed concern that CIS provides an important communications vehicle for underserved communities, and nonprofits do not have the funds to take over the services currently provided. Dr. Niederhuber explained that when NCI created the CIS Partnership Program in 1984, the program provided a critical service; however, many other organizations now provide similar services. NCI plans to end this program in 2010, when the current contracts end. However, the Institute will continue its toll-free cancer telephone service (1–800–4–CANCER). In addition, NCI will review the Partnership Program and identify other ways to meet the needs of communities that have difficulty obtaining health information. The DCLG asked to be kept informed on the CIS transition.

Update on the Advocates in Research Working Group (ARWG)

Ms. Cotter explained that in response to a request from Dr. Niederhuber, the DCLG created the ARWG. The working group has identified processes for enhancing advocate involvement and is completing its analysis of current advocate involvement at NCI. The next step will be to develop initiatives and implementation recommendations, which the group will document in its final report to be delivered to the DCLG.

DCLG Member Reports

Dr. Yvette Colón is the new DCLG liaison to the National Cancer Advisory Board (NCAB)

Mr. Everett Dodson is the DCLG's representative to the Clinical and Translational Advisory Committee (CTAC).

Update on Communities as Partners in Cancer Clinical Trials: Changing Research, Practice and Policy

Ms. Margo Michaels and Ms. Stacy Collins described a new strategic plan for incorporating community based participatory research (CBPR) principles and approaches into Phase III clinical trials. This report provides 58 recommendations in seven areas. Some of these recommendations overlap with the ARWG's aims. The program's sponsors plan to disseminate the report; present the recommendations at key stakeholder meetings; and issue small grants (approximately $8,000 for 12 months) to Cooperative Groups, advocacy organizations, and others interested in implementing some of the report's recommendations. The RFA for these grants will be issued when the report is published.

The definition of "community" in clinical trials is changing. Investigators are designing trials based on a tumor's molecular structure, so communities are no longer defined by location or type of cancer. Developing relationships with local oncologists can help investigators find patients with the required characteristics, and the report includes a definition of "community" that is not based on geography.

Investigators often find it difficult to identify potential community partners. The Intercultural Cancer Council has extensive networks of local groups that community partnerships project leaders plan to connect with researchers.

Ms. Michaels asked DCLG members to help review applications for the new RFA or to recommend others who might be qualified to serve as reviewers. The Education Network to Advance Cancer Clinical Trials (ENACCT) will send Ms. Bell a description of reviewer responsibilities, the final report, and the RFA.

Panel Discussion—Personalized Medicine: The Future for Patients

Ms. Rebecca Fisher listed four areas within personalized medicine that would benefit from advocacy:

- Guidance to help patients understand and conceptualize complex information
- Assistance for patients with complex concepts, such as clinical and analytical validity or sensitivity and specificity
- Tools to help patients and providers interact more effectively with one another

- Information for patients on the implications and consequences of donating tissue samples for research

Dr. Elise Kohn conducts laboratory studies that help identify new targets to identify patients and personalize their therapy. She conducts Phase I and II clinical trials to determine whether the drugs have the predicted effects.

Dr. JoAnne Zujewski listed four areas that need to be addressed in treating cancer:

- Tumor characteristics
- Host (or patient) characteristics (such as inherited genes)
- Individual risk-benefit profiles
- Patient preferences

Dr. Kimberly Myers explained that biospecimens are a driving force in personalized medicine because they provide critical data for identifying new markers of diseases and studying disease processes and mechanisms. Investigators also use biospecimens to make diagnoses, determine prognoses, and, increasingly, select treatments. NCI is developing standards for biospecimen practices to ensure the availability of high-quality biospecimens.

Discussion

The scientific community is currently collecting the critical mass of information needed and mining the data in different ways to develop diagnostic, prognostic, and predictive markers, as well as prevention and treatment targets. The products of this work are not yet available, and the implications of providing personalized medicine need to be considered. For example, it is not clear how to use genetic test results that indicate a patient's likelihood of developing a certain disease.

Although diagnostic tools have been developed, many if not all have very little validation. A logical, careful, and validated approach is needed to determine whether certain genetic factors that regulate the metabolism of certain drugs can be used to ensure that chemotherapy affects only cancer cells and not healthy cells. Without careful, prospective studies, these new technologies might not result in the best decisions for every patient.

Some trials have been conducted to identify single nucleotide polymorphisms (SNPs) that could predict which patients will have heart problems if they take Herceptin. However, the technology needed for this kind of research is not yet fully developed. Many hypotheses could be tested now, but these trials might not be valid and their implications might be difficult to interpret.

The rise in personalized medicine has paralleled the move to treat the whole person with cancer. A few years ago, physicians talked only about treating the cancer. Today, physicians learn about the importance of family history and treating the whole person. For example, they need to remember that depression is a normal reaction to a cancer diagnosis and can have an impact on quality of life.

One of the barriers to finding more cancer therapies is the shortage of tissue samples. NCI's Office of Biorepositories and Biospecimen Research coordinates a national effort to address this issue. Dr. Myers encouraged the DCLG and other advocates to offer input and visit the office's Web site (http://biospecimens.cancer.gov). The move toward personalized medicine requires different types of standards for specimen collection, and the office is working with groups to achieve these standards.

Biorepositories are increasingly interested in ensuring adequate representation of minority groups. One challenge is that certain minority groups do not participate in clinical trials because of distrust or other concerns. NCI's Cooperative Groups are required to include plans for minority accrual in their protocols. NCI has considered enriching certain trials with a minority arm to learn about the metabolism of chemotherapy in certain populations. However, it is not clear whether it is possible to recruit enough minority participants for this kind of study. Ms. Arlene Wahwasuck offered to connect Dr. Myers with a "Cancer 101" education program in Indian country that does not currently address biospecimen collection.

Many trials do not have the funding needed to pay for biopsies, specimen storage, or analyses. More funds are needed to mine the data collected and develop recommendations based on these analyses about the best treatments for different patients.

The medical and scientific communities need to work with advocates, academia, government agencies, and the private sector to move personalized medicine forward at a more rapid pace. Unless patients are encouraged to participate in trials and share their biospecimens, advances will not be possible; an extremely small percentage of patients with cancer participate in clinical trials, and an even smaller percentage from diverse backgrounds do so.

DCLG Member Report on the NCI Community Cancer Centers Program (NCCCP)

Dr. Laird explained that Dr. Niederhuber created the NCCCP to raise the level of cancer care in communities that lack access to high-quality cancer centers. There are eight free-standing hospitals and two hospital networks participating in the pilot. NCI provides each site with $500,000, which the site must use to address health care disparities, information technology, biospecimens, and clinical trials. To date, the sites have coinvested $47 million to support the program's goals. Top hospital management representatives at the sites have shown their commitment to the pilot and to sustaining the NCCCP activities.

DCLG members agreed that this program needs to continue and be expanded to more sites. However, the synergy and teamwork created by the original group should not be lost in the expansion. The leaders of the current pilot sites could be asked to help expand the program.

Public Comment

No public comment was offered.

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

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Action Items

- DCLG members interested in chairing or joining the Recommendations Working Group should communicate with Ms. Bell.
- NCI will keep the DCLG informed on the CIS transition.
- ENACCT will send the report *Communities as Partners in Cancer Clinical Trials: Changing Research, Practice and Policy*, the RFA for implementation projects, and a description of responsibilities for reviewing the community partnerships applications to Ms. Bell for distribution to the DCLG.
- DCLG members interested in reviewing applications for the community partnerships RFA will inform ENACCT.