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

MINUTES of the DIRECTOR'S CONSUMER LIAISON GROUP MEETING

October 24–25, 2007

Members Present

Mr. Doug Ulman, Chair
Dr. Beverly Laird, Vice Chair
Ms. Peggy L. Anthony*
Mr. Bill Bro
Dr. Grace Butler
Ms. Lourie Campos
Dr. Yvette Colón**
Ms. Kelly Cotter
Ms. Marie Dahlstrom
Ms. Nancy Davenport-Ennis†
Mr. Everett Dodson
Ms. Joyce Wilcox Graff
Mr. Alan Kaye
Ms. Arlene Wahwasuck
Ms. Cece Whitewolf
COL (Ret.) James E. Williams, Jr., USA

*Participated by telephone.
**Present on October 24.
† Present on October 25.

Speakers

Dr. Karen Albritton, Director, Adolescent and Young Adult Oncology, Dana-Farber Cancer Institute
Ms. Shannon K. Bell, Director, Office of Advocacy Relations (OAR), NCI
Dr. Kenneth C. Chu, Chief, Disparities Research Branch, Center to Reduce Cancer Health Disparities (CRCHD), NCI
Ms. Susan Erickson, Director, Office of Government and Congressional Relations, NCI
Dr. Roland Garcia, Program Director, Patient Navigation Research Program, CRCHD, NCI
Mr. James Hadley, Advocacy Program Manager, OAR, NCI
Dr. Ernest Hawk, Director, Office of Centers, Training, and Resources, NCI
Dr. Maureen R. Johnson, Project Officer, NCI Community Cancer Centers Program, and Special Assistant to the Director, NCI
Dr. LaSalle D. Leffall, Chair, President's Cancer Panel
Ms. Charlene Liggins, Public Health Advisor, Office of Science Planning and Assessment, NCI
Ms. Anne Lubenow, Special Assistant to the Director, NCI
Ms. Tarsha McCrae, Public Health Analyst, Community Networks Program, CRCHD, NCI
Ms. Devon McGoldrick, Young Adult Alliance Program Specialist, Lance Armstrong Foundation
Ms. Elizabeth Neilson, Consumer Advocates in Research and Related Activities (CARRA) Program Coordinator, OAR, NCI
Dr. John Niederhuber, Director, NCI
Dr. Peter Ogunbiyi, Program Director, Minority Institution/Cancer Center Partnership Program, CRCHD, NCI
Dr. Sheila Prindiville, Director, Coordinating Center for Clinical Trials, NCI
Dr. Julia Rowland, Director, Office of Cancer Survivorship, NCI

Office of Advocacy Relations Staff

Ms. Barbara Guest, DCLG Executive Secretary
Ms. Brooke Leggin, Program Analyst
Ms. Jessica Pyjas, Advocacy Program Fellow
Ms. Linda Ticker, Program Assistant
Mr. Ben Carollo, Presidential Management Fellow

Liaison Representatives to the DCLG
Dr. Shobha Srinivasan, Division of Cancer Control

and Population Sciences, OD, NCI
Dr. Keith Bellizzi, Division of Cancer Control and Population Sciences, Office of Cancer Survivorship, NCI
Ms. Patricia C. Delaney, Food and Drug Administration (FDA)
Ms. Joann M. Minor, FDA
Mr. Craig Beam, Director's Council of Public Representatives, NIH

EXECUTIVE SUMMARY

At the Director's Consumer Liaison Group in-person meeting on October 24-25, 2007, the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG) received updates from the NCI Director on the latest scientific advances, the status of NCI grant making during the last fiscal year, as well as the budget and administrative aspects of the NCI programs. The Director described the reorganization of the Office of Advocacy Relations (formerly Office of Liaison Activities) and introduced the new Director, Ms. Shannon K. Bell. The NCI's Office of Advocacy Relations (OAR), provides staff support for the DCLG. Ms. Bell will supervise the office's day-to-day activities, while Ms. Anne Lubenow as Special Assistant to the Director, will provide a pipeline between OAR and the NCI Director. Ms. Susan Erickson of the renamed Office of Government and Congressional Relations reported on the recent legislation proposed and enacted that affects NCI.

Dr. LeSalle D. Leffall gave an update on the work of the President's Cancer Panel for 2006-2007, where the topics were obesity, nutrition and physical activity as well as tobacco and environmental tobacco smoke. The report of these meetings has just been published. Dr. Leffall also described the 2007-2008 meetings, focused on the topic of Strategies for Maximizing the Nation's Investment in Cancer and described the work of the Panel to date.

There were five major presentations over the two days. The members heard updates on emerging scientific committees involving advocates developed by the Clinical Trials Working Group and the Translational Research Working Group. Dr. Maureen Johnson and the DCLG members updated the group on the development of the NCI Community Cancer Centers Pilot Program (NCCCP), its Program Advisory Committee and the subcommittees. Dr. Ken Chu and the staff of the Center to Reduce Cancer Health Disparities described its programs of Health Disparities Research, and Dr. Julia Rowland the Director of the Office of Cancer Survivorship described initiatives in cancer survivorship care including integrating concepts of survivorship in the NCCCP.

A staff member of the Lance Armstrong Foundation, a PI from the Dana Farber Cancer Center, and NCI staff of the Office of Science Planning and Assessment presented the findings of the Adolescent and Young Adult Oncology (AYAO) Progress Review Group (PRG) and the activities that are resulting from this initiative.

The members heard a report from the Chair of the new DCLG Working Group, *The Working Group on Involving Advocates in NCI Programs.* DCLG member Ms. Kelly Cotter is chair and James Hadley is providing staff guidance to the Working Group, with OAR support. The Working Group mission is to develop and provide recommendations to the DCLG on how NCI can more consistently integrate the involvement of advocates across the Institute's programs to ensure appropriate representation of the patient advocate perspective. The membership includes current and former DCLG members as well as other advocates, NCI staff members, and extramural researchers.

NCI Director, Dr. John Niederhuber - in a discussion session with the DCLG members, described the challenges of managing expectations in the current climate of flat or declining

Institute budgets and in communicating NCI's mission and accomplishments. DCLG members expressed an interest in helping to communicate their own stories and that of NCI to the general public. The members were concerned about the level of NCI funding for cancer health disparities research. DCLG members developed several recommendations and action steps for NCI and the DCLG that are attached to this meeting summary.

I. Welcome and Announcements

Mr. Doug Ulman welcomed participants to this 46th meeting of the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG). He reviewed the rules governing confidentiality and conflict of interest, and Ms. Barbara Guest determined that a quorum was present. Mr. Ulman announced that the DCLG's meeting would be broadcast over the Internet.

The DCLG unanimously approved a motion to approve the minutes from the DCLG's June 13, 2007, teleconference.

Mr. Ulman announced that the DCLG's next in-person meetings would take place on the following dates:

- Thursday and Friday, March 27–28, 2008
- Tuesday and Wednesday, October 28–29, 2008
- Thursday and Friday, March 26–27, 2009
- Wednesday and Thursday, October 21–22, 2009
- Thursday and Friday, March 25–26, 2010
- Wednesday and Thursday, October 20–21, 2010

II. Update on the Office of Advocacy Relations

Ms. Anne Lubenow characterized the cancer research enterprise as a web involving industry, biotechnology, pharmaceutical companies, universities, NCI-designated cancer centers, NCI Community Clinical Oncology Programs (CCOPs), and NCI community cancer centers. NCI brings these different players together through many programs, including the Advanced Technology Partnership Initiative, the NCI Community Cancer Centers Program (NCCCP), the National Institutes of Health (NIH) Clinical Research Center, and NCI's drug discovery and development resource.

Ms. Shannon Bell, the incoming Director of NCI's new Office of Advocacy Relations (OAR), explained that she hopes to broaden the scope of NCI's links with traditional patient advocacy organizations, professional societies, foundations, and think tanks.

As Director of OAR, Ms. Bell provides day-to-day supervision of the office's activities. Ms. Lubenow provides a pipeline between OAR and the NCI Director. The office's name change from the Office of Liaison Activities (OLA) to the Office of Advocacy Relations reflects a shift in philosophy. For example, OLA was responsive to NCI requests, but OAR will provide proactive advice. OAR also plans to identify the needs of both the advocacy community as a whole and of individual organizations. It will then identify opportunities for partnership and create powerful relationships that develop programs. Finally, the office plans to create a historical perspective so that new interactions build on previous ones.

OAR will continue to involve advocates in its activities, including peer review and NCI advisory boards and committees. OAR will evaluate these efforts and identify ways to meet its goals more

effectively and efficiently. OAR will seek new ways in which advocates can contribute to NCI's work and will create best practices for advocacy contributions.

Discussion

Ms. Marie Dahlstrom noted that many advocacy organizations that represent underserved populations do not regard themselves as traditional cancer advocacy organizations. She therefore supports OAR's plans to reach out beyond such traditional organizations.

Ms. Cece Whitewolf asked for clarification on lines of communication for DCLG members. Ms. Guest replied that DCLG members should communicate with her about issues related to the DCLG. Ms. Bell added that although Ms. Guest is the primary point of contact for DCLG members, they are welcome to contact other OAR staff members as needed.

Mr. Ulman suggested that NCI add advocates to the list of stakeholders in the cancer research web. Ms. Lubenow will make this change to the slide showing the web. Ms. Joyce Wilcox Graff pointed out that the cancer research web and other star networks can create bottlenecks; NCI should try to serve as an efficient hub and not a bottleneck. Ms. Lubenow agreed, noting that NCI Director Dr. John Niederhuber is reorganizing NCI to make it more of a facilitator or enabler than a bureaucratic research organization. Given NCI's large size and complexity, however, this might take time. OAR and the DCLG can help by pushing NCI to improve.

Ms. Bell added that NCI would sometimes serve as an intermediary between two or more organizations; at other times, it will simply connect organizations and then step back.

Dr. Grace Butler asked for a description of OAR's new reality. Ms. Bell replied that OLA has provided outstanding customer service, but the office needs to shift its focus from customer service to an internally and externally proactive approach. OAR needs to understand the advocacy community as a whole and each individual organization. The office plans to find new ways to connect organizations.

Mr. Alan Kaye noted that when NCI reaches out to professional societies and other organizations, it would require them to set aside their vested interests and avoid conflicts of interest; DCLG members must also meet this requirement. Ms. Lubenow agreed. Dr. Niederhuber is encouraging everyone in the cancer research enterprise to look beyond his or her vested interests and focus on NCI's broader mission of making a difference in the lives of everyone affected by cancer.

COL Jim Williams noted that NCI's main focus is on research, and the results of this research need to be delivered to patients. NCI needs to make its mission clear to the advocates with whom it works to avoid establishing expectations it cannot meet. Ms. Bell agreed, noting that NCI can participate in only those activities that are related to its mission. Perhaps NCI needs to make its mission clearer to the advocacy community.

III. NCI Legislative Affairs Update

Ms. Susan Erickson, Director of the Office of Government and Congressional Relations (OGCE) reported that the President's fiscal year (FY) 2008 budget, announced on February 5, 2007, included $4.78 billion for NCI. Congress passed a continuing resolution allowing NCI and other federal agencies to continue operating at the previous year's funding level, but the resolution expires on November 16, 2007. The full House passed its version of the appropriations bill, which included $4.87 billion for NCI, on June 19, 2007. The Senate passed its version of the appropriations bill, with $4.91 billion for NCI, on October 23, 2007.

The conference committee needs to resolve differences between the different appropriations bills, after which the House and then the Senate must pass the final appropriations bill. If this happens before November 16, 2007, the bill will be delivered to the President for his signature. If not, Congress will need to pass another continuing resolution. Once Congress passes the bill, the President can sign it into law or veto it. If the President vetoes the bill, the process will begin again.

Ms. Erickson described several recent bills of potential interest to DCLG members:

- Access to Cancer Clinical Trials Act (HR 2676)—Representative Deborah Pryce (R-OH) introduced this bill in June to protect people who participate in clinical trials from denial of insurance coverage for routine costs. No further action has been taken on this bill.

- Cancer Screening, Treatment, and Survivorship Act (HR 2353, S 1415)—Representative Jan Schakowsky (D-IL) introduced this bill in the House on May 15, and Senator Tom Harkin (D-IA) introduced it in the Senate on May 16. The goals of the legislation are to detect cancer earlier, reduce cancer mortality rates, improve quality of life for cancer survivors, and save health care dollars. Neither bill has seen further action.

- Cancer Screening Coverage Act (HR 3425)—Representative Carolyn Maloney (D-NY) introduced this bill on August 3 requiring health plans to cover cancer screening in some circumstances. No further action has been taken on this bill.

- Genomics and Personalized Medicine Act (S 1976)—Senator Barack Obama (D-IL) introduced this bill on March 23. According to Senator Obama, the bill will expand/accelerate genomics research, create a capable genomics workforce, and provide incentives for developing genetic tests. No further action has been taken on this bill.

- Small Business Act Amendment (S 1932)—Senator Evan Bayh (D-IN) introduced this bill on August 1 to increase funds set aside by NCI and other NIH Institutes for Small Business Innovation Research and Small Business Technology Transfer programs. The Senate Small Business/Entrepreneurship Committee conducted a "roundtable" on this issue on August 1, and the House Science & Technology Committee held a related hearing on June 26. However, no votes have been taken on the bill.

Ms. Erickson invited DCLG members to visit the new Office of Government and Congressional Relations Web site at http://legislative.cancer.gov.

Discussion

Ms. Lourie Campos noted that a key provision of the Cancer Screening, Treatment, and Survivorship Act is Medicaid coverage for patients referred for treatment as a result of Centers for Disease Control and Prevention (CDC) screening. She wondered whether any CDC programs do not provide treatment. Mr. Ulman noted that unlike California, some states do not provide treatment for people with positive screening test results.

Ms. Whitewolf asked whether the Federal Government would provide funding for patient navigation. Ms. Erickson explained that the Health Resources and Services Administration will implement the patient navigator program, but no funding has been established to support this activity.

Mr. Ulman encouraged all DCLG members to stay current on all of the pieces of legislation discussed by Ms. Erickson.

IV. President's Cancer Panel Update

Dr. LaSalle D. Leffall provided an update on the activities of the President's Cancer Panel. In 2006–2007, the Panel held two meetings on obesity, nutrition, and physical activity and two meetings on tobacco and environmental tobacco smoke. The panel recently issued its 2006–2007 Annual Report, *Promoting Healthy Lifestyles: Policy, Program, and Personal Recommendations for Reducing Cancer Risk*. Dr. Leffall reviewed the major recommendations and research needs included in the report.

In 2007–2008, the President's Cancer Panel will focus on Strategies for Maximizing the Nation's Investment in Cancer. At the first two meetings in this series, participants stated that regulatory restrictions (including those in the Health Insurance Portability and Accountability Act [HIPAA]) make it difficult to share important information. Other concerns were raised about intellectual property, the number of adults who participate in clinical trials, and access to care. Dr. Leffall argued that if we simply applied what we already know about cancer screening, we could decrease morbidity and mortality significantly.

Discussion

Ms. Whitewolf asked whether the Panel received any testimony last year on the use of tobacco as a sacred medicine among Native Americans. Dr. Leffall replied that the report does not address this issue. He asked Ms. Whitewolf to provide this information to the Panel.

Ms. Whitewolf then asked about the status of efforts to address the recommendations in the Panel's 2002 report, *Facing Cancer in Indian Country: the Yakama Nation and Pacific Northwest Tribes*. She also invited a representative from the Panel to participate in a 2008 conference for Native American cancer survivors in Salt Lake City.

Dr. Butler asked whether the President is responsible for implementing the Panel's recommendations. Ms. Karen Parker, Special Assistant to the President's Cancer Panel, explained that the Panel is an advisory body that does not have the authority to implement its recommendations or provide any funding. The reports tend to address issues that are related to the work of many agencies, organizations, and Congress. Advocates from the DCLG and other organizations can use the reports to initiate discussions with members of Congress or NIH leaders.

Dr. Butler suggested establishing a liaison between the President's Cancer Panel and the DCLG to provide the DCLG with updates on the Panel's reports and the implementation of the Panel's recommendations. Ms. Lubenow attends Panel meetings and offered to serve as a liaison between the Panel and the DCLG. She also urged the Panel to elevate the amount of attention, awareness, and resources committed to cancer prevention. Dr. Leffall noted that the top priorities of C-Change—a collaboration of nonprofit, for-profit, and government organizations to address cancer—are cancer prevention and access to care.

Dr. Yvette Colón encouraged the Panel to address the outcomes of its previous recommendations in each report, which would help the group track any changes that result from its work. COL Williams asked about feedback to the Panel on its reports. Dr. Leffall responded that the feedback has been positive. Many groups have said that the reports have helped them initiate certain activities.

V. NCI Director's Report

Dr. Niederhuber welcomed the four new DCLG members: Ms. Marie Dahlstrom, Mr. Everett Dodson, Ms. Joyce Wilcox Graff, and Ms. Arlene Wahwasuck.

Restructuring the Office of the Director

Dr. Niederhuber reported that NCI has finished restructuring the Office of the Director. This effort included appointing Ms. Bell as Director of OAR and elevating the activities of the DCLG. Ms. Lubenow will oversee the OAR's activities, providing a direct link between the DCLG and Dr. Niederhuber. NCI also combined the Office of Communications and the Office of Education and Special Initiatives into the new Office of Communications and Education led by Ms. Lenora Johnson. Finally, NCI appointed Lawrence J. Ray as the new Deputy Director for Management and Executive Officer.

NCI Budget

NCI restructured its activities, moved resources around, and made other changes to increase the percentage of successful funding applications. The funding pay line for research project grants increased from the 11th to the 15th percentile for the fiscal year. Exceptions were funded up to the 20th percentile, and Star RO1 funding for new investigators rose to the 21st percentile for the fiscal year. Although NCI met its funding targets, it did so by reducing the size of its grants. As a

result, laboratory investigators had to reduce their staffs and the specific aims in their applications.

NCI funded new cancer centers at Baylor College of Medicine (Texas) and Stanford University (California). Dr. Niederhuber hopes that with support from advocates, NCI will obtain the resources needed to continue to add one or two centers each year for the next few years.

NCI's congressional appropriations grew substantially between 1998 and 2003, but budgets have remained flat since then. The President's 2008 budget would reduce NCI's 2007 budget by $9 million, but the House would increase the Institute's appropriation by 1.5% and the Senate would increase it by 2.3%.

NCI is assuming in its planning that its budget will decrease by approximately 3%, which means that the divisions, centers, and Office of the Director must reallocate about 3% of their budgets to make up the shortfall and create a fund of $60–$70 million to restore, increase, or start programs.

Genome-Wide Association Studies

Cancer comprises many diseases, and numerous variants can begin in the same site; each variant has a genetically different program. Scientists are developing treatment solutions that attack both the tumor and the surrounding tissue (microenvironment); this tissue is needed to prevent the spread, or metastasis, of a tumor.

NCI is focusing not only on the genes with which people were born but also on changes to those genes as a result of exposure to environmental factors. NCI is collaborating with the National Human Genome Research Institute to sequence tumor samples in large numbers of people. In its pilot phase, this project, The Cancer Genome Atlas, is focusing on brain, lung, and ovarian cancers.

The technology for this type of research is advancing rapidly and making it possible to learn so much more about cancer. NCI researchers are helping to identify more and more genetic contributors to different cancers. This progress shows the size of the opportunity and why NCI needs more resources. NCI is currently conducting many genome-wide association studies.

Drug Discovery

In the United States, it takes 10–12 years and $1 billion to develop a new cancer drug. Dr. Niederhuber believes that NCI has a responsibility to work with the private sector and academic communities to reduce the drug development time to 3–6 years.

Subcellular Imaging

As researchers develop new molecules and agents, mechanisms need to be developed for following those agents in patients. Researchers need to determine in real time whether the drug reached its target, saturated the target, and changed the target's function. Imaging is becoming an increasingly important component of NCI's research.

NCI as a Convener

Dr. Niederhuber emphasized NCI's role as a convener and honest broker. One major effort in this area is the new NCCCP, which was designed to "enable the provision of state-of-the-art multispecialty care and early-phase clinical trials in community-based locations." Ten organizations have been selected for this program, including six community hospitals, two rural hospitals, and two national health systems.

Winning the war on cancer will require:

- Increasing the resources to invest in science and speed the process up.
- Recruiting and retaining the next generation of researchers.
- Reducing the time and expense required for translating research results to humans.
- Replacing the old clinical trials system and regulatory process.
- Ensuring access for all patients.

Dr. Niederhuber thanked the DCLG members for sharing their time, vision, and experience to help NCI do a better job with patients and families.

Discussion

Mr. Ulman asked who sets NCI's funding targets and whether these targets reflect the most effective way to spend NCI's money. Dr. Niederhuber replied that the congressional appropriations committee establishes NCI's targets with respect to numbers of investigators and new investigators funded. Mr. Ulman suggested that the DCLG consider this issue. Although setting a target number of investigators might be useful for building infrastructure, it might not be the best way to spend NCI's money.

Ms. Whitewolf asked for clarification on the involvement of advocates in the NCCCP. Dr. Niederhuber explained that advocates have been involved in the program from the beginning.

Mr. Kaye asked whether products developed by NCI in partnership with biotechnology companies could be generic from the beginning. Dr. Niederhuber said that this would not be possible, because NCI works with companies that are accountable to their stockholders.

Ms. Graff expressed concern about access to care. If the cost of bringing a drug to market is reduced, she hoped that the cost of the product for the consumer would also drop. Dr. Niederhuber explained that this is a complex policy issue that goes far beyond the purview of NCI. NCI's role is to create knowledge upon which policy makers can draw.

Ms. Campos asked about ways to encourage young people to become scientists. Dr. Niederhuber replied that young people must understand that a science career is a viable option and that scientists can make a difference. Young people also need to know that if they contribute a reasonable amount of effort, they can expect a reasonable income. When they talk to older scientists, however, they often quickly sense the stress due to non-funded grants and labs that must close. Consequently, Dr. Niederhuber never turns down an invitation to visit a high school,

and whenever he visits an academic institution, he spends time with graduate students and postdoctoral fellows. By sharing his experiences with these young people, he gives them confidence that science is a good career. Scientists need to work with high school students to encourage their interest in science.

Ms. Dahlstrom asked whether funding is still available for minority supplements, which have helped pair undergraduate and graduate students with seasoned researchers. Dr. Niederhuber responded that NCI has several programs that encourage young people from minority groups to work in the sciences, especially in cancer. NCI's cancer centers also help the Institute recruit and mentor minorities. However, these programs would benefit from additional resources.

VI. Closing the Gap: Adolescent and Young Adult Oncology Progress Review Group and Implementation

Dr. Karen Albritton defined the scope of the adolescent and young adult oncology (AYAO) issue by noting that approximately 68,000 people aged 15–39 years (6% of new cancer diagnoses) were diagnosed with cancer in 2002. Although pediatric cancers represent only 1% of new cancer diagnoses, they receive proportionately much more attention in the form of research programs, clinical trials, and dedicated funding.

Furthermore, AYAO has no "home," because it does not belong in either pediatric or adult medical oncology departments. This lack of focus has led to fewer improvements in cancer in this age group. Between 1975 and 1997, 5-year relative survival improved far more among children and adults aged 40 and older than among adolescents and young adults (AYAs). In addition, during 1975, 5-year survival was much higher among AYAs than among older adults; however, between 1975 and 1998, survival rates improved among adults aged 35 and older but did not change among AYAs. Detailed graphs and information on different types of cancers and cancer rates for AYAs of different ethnic groups are available in *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Year of Age, Including SEER Incidence and Survival: 1975–2000* (http://seer.cancer.gov/publications/aya/).

The Lance Armstrong Foundation worked with NCI to create an AYAO Progress Review Group (PRG), which brought together an array of stakeholders at a roundtable meeting in April 2006. The roundtable included 11 breakout sessions focused on different aspects of AYAO. Each breakout group developed recommendations, and the group as a whole developed five priority recommendations. These recommendations are described in the PRG's first report, *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer* (available at http://planning.cancer.gov/disease/AYAO_PRG_Report_2006_FINAL.pdf).

Ms. Devon McGoldrick explained that the Live**STRONG™** Young Adult Alliance is a coalition of more than 75 public and community organizations whose goal is to improve the survival rates and quality of life for AYAs with cancer. The alliance has task forces that focus on science, standards, and awareness.

In November 2006, the Lance Armstrong Foundation, the Young Adult Alliance, and NCI organized a second roundtable meeting to develop implementation strategies for each of the five

PRG recommendations. Ms. McGoldrick listed the implementation strategies developed at the meeting, which are described in detail in the meeting report, *Closing the Gap: a Strategic Plan* (available at http://www.livestrong.org/atf/cf/%7BD0794917-422C-499C-9C48-9ED3DDC42947%7D/LAF%20YAA%20Report.pdf).

The Young Adult Alliance is making progress in acting on the implementation strategies in the report. Specifically:

- A request for proposals (RFP) has been created for a review of existing tissue specimens from AYAs with cancer that can be used for research on the unique cancer burden among AYAs.
- Experts in AYA programs have prepared a position statement on the professional development of AYA cancer providers.
- The Lance Armstrong Foundation has launched a survey to identify existing standard-of-care guidelines for AYAO programs and patients.
- The Lance Armstrong Foundation is issuing an RFP to evaluate and catalog existing peer-to-peer support programs and patient navigator programs that serve the AYA community.

Ms. Charlene Liggins reported that NCI formed an AYAO implementation group in May 2007 to identify current NCI projects that could be expanded to reach the AYA population and explore new programs. NCI's implementation activities in Year 1 are:

- Explore the use of a request for applications (RFA) to assess the biological distinctiveness of AYAs with cancer.
- Assess the quantity and quality of tissue banks of AYA biospecimens through a query of NCI-supported tissue banks.
- Analyze the Department of Defense (DOD)/Walter Reed Hospital's cancer registry data for AYA patients as a possible baseline for studies, such as the Patterns of Care study.
- Fund the AYA-focused Patterns of Care study to survey patients and survivors about their quality of life, treatment received, insurance status and access, and ability to participate in clinical trials.
- Develop an NCI Web portal for AYA patients to provide information on clinical trials, cancer literature, fact sheets, and other resources.
- Collaborate with the Lance Armstrong Foundation to explore ways to expand the reach of the patient navigation program to target AYAs.
- Include an AYAO chapter in the April 2008 issue of *Cancer Statistics Review*.
- Develop an AYA disease snapshot to provide the community with an update on cancer-related trends and research advances.

Discussion

Ms. Graff asked whether teens tend to experience delays in receiving a cancer diagnosis because young people lack credibility in the health care system. Dr. Albritton replied that this is a research topic for the PRG to address. AYAs do not have experience advocating for themselves, and if a doctor tells them not to worry, they typically do not seek additional advice.

Ms. Graff asked whether the PRG addressed the role of hormones in cancers that affect AYAs. Dr. Albritton explained that the biology breakout group discussed the role of hormones in AYAO during the initial PRG roundtable. Ms. Graff pointed out that any hormonal shift, including those that occur during adolescence or when a woman begins or stops taking the contraceptive pill is a hotspot for tumor activity in von Hippel-Lindau syndrome and probably in many cancers.

COL Williams wondered why different disciplines have not come together to address AYAO as they have for pediatric oncology. Dr. Albritton stated that pediatric oncologists can study the entire field because the disease is sufficiently rare and many cases can be grouped together. This situation is not possible in adult oncology, and oncologists who focus on adults tend to specialize in a specific cancer site. A researcher can become a pediatric oncologist or a prostate cancer oncologist, for example, but very few departments encourage their members to become AYA researchers. Part of the PRG's job is to create a sense that AYAO is an acceptable career track.

Mr. Kaye asked which field is responsible for the human papillomavirus (HPV) vaccine. Dr. Albritton explained that primary care pediatricians take responsibility for ensuring that their patients are vaccinated; however, the cancer community as a whole is not disseminating the message that because of this vaccine, cervical cancer can be prevented. The Children's Oncology Group has expressed some discomfort about focusing on HPV vaccines because the cancers that these vaccines prevent do not occur during childhood, and pediatricians are rarely involved in treating HPV-related cancers.

Ms. Graff noted that if a person gets cancer at age 15, some genetic factor is probably involved, a point that could be used to encourage many disease groups to rally around this cause.

Ms. Kelly Cotter asked whether the PRG's recommendations address the issues of AYAs who developed cancer as children. Dr. Albritton replied that the PRG decided to focus on patients diagnosed with cancer while they were in the AYA age group because resources for childhood cancer survivors are robust and growing. However, the survivorship issues faced by AYAs with cancer overlap with those of children.

Ms. Cotter asked about the percentage of AYAs treated in adult centers versus pediatric centers. Dr. Albritton responded that through age 10, 95% of cancers are treated in pediatric centers. Between ages 15 and 19, 35% of patients are treated in pediatric centers, even though most clinicians consider patients younger than age 18 and living at home to be children. Almost no patients older than age 20 are treated in pediatric centers. Patients with diseases that are more common among children, such as acute lymphoblastic leukemia and sarcomas, are more likely to be treated at a pediatric center, whereas patients with diseases that are more common among adults, such as testicular cancer, are more likely to be treated at an adult center.

Ms. Whitewolf asked which cancers are most common among AYAs. Dr. Albritton replied that the most common cancers among AYAs are leukemia, lymphoma, sarcoma, testicular cancer, melanoma, breast cancer, colorectal cancer, and brain tumors.

VII. Plans for the Implementation of the Clinical Trials Working Group and the Translational Research Working Group Recommendations

Dr. Ernest Hawk provided an update on the implementation of the Translational Research Working Group (TRWG) recommendations. The TRWG focuses on taking discoveries from the bench and transforming them into tools that affect people living with or at risk of cancer. The TRWG includes more than 60 leaders in translational science. The budget for the TRWG's first-year activities is $1,550,000.

The TRWG developed 15 recommendations that were transformed into 6 activities:

1. Integrate NCI management—The TRWG proposes adding six staff members to the Coordinating Center for Clinical Trials (CCCT), which is implementing the recommendations of the Clinical Trials Working Group (CTWG). The group will be overseen by an internal oversight body, the Translational Research Oversight Committee (TROC), and an external advisory group, the Clinical Trials Advisory Committee (CTAC).
2. Establish a refined translational research coding system—The TRWG requested a staff member to develop a new coding strategy for identifying translational science.
3. Implement Special Translational Research Acceleration Project (STRAP) awards—A CTAC working group will prioritize applications for these awards.
4. Modify/coordinate translational research awards—The TRWG proposed modifying guidelines for multi-project collaborative translational research awards. By mid-2008, NCI could analyze its core services to improve their efficiency and standardization. The TRWG also plans to integrate the projects that fund the early stages of translational research with preclinical resources and improve the approach to translational research training.
5. Establish a project management system—The TRWG called for training staff in project management and funding project managers to work on certain projects in cancer centers.
6. Coordinate activities with external constituents (foundations, advocates)—A DCLG working group has been created to address issues such as those identified by the TRWG and establish more solid and consistent advocacy participation in the TRWG's programs.

Dr. Sheila Prindiville provided an update on the activities of the CCCT, which oversees implementation of the CTWG activities. The CCCT will begin supporting the implementation of TRWG activities in FY 2008.

NCI has organized several disease-specific steering committees. The first committees will focus on gastrointestinal cancer, gynecologic cancer, head and neck cancer, and symptom management and health-related quality of life. These committees have reviewed several phase III concepts; developed task forces focused on specific organ sites, and organized state-of-the-science meetings. The committees have broad memberships representing the full spectrum of stakeholders in the clinical trials process. NCI will add lung and mesothelioma steering committees in 2008 and the remaining committees in FYs 2009 and 2010.

A patient advocate steering committee is planned in collaboration with OAR. NCI has also established an investigational drug scientific steering committee to provide strategic input into the NCI Cancer Therapy Evaluation Program's drug development planning process.

The CTWG report called for a new funding model for cooperative group or large phase III trials. In the current system, the actual costs of including a patient on a trial are much higher than the amount that NCI reimburses. NCI therefore completed a financial analysis of the costs of clinical trials to identify areas of inadequate funding and overlap, duplication, or redundancy that could be addressed to save money. NCI plans to use the results of this analysis to work collaboratively with the cooperative groups in developing a new funding model that will match reimbursement rates to the complexity of the trial; provide incentives for and reward high-accruing, cost-efficient sites; reduce duplication of administrative functions; and establish minimum accrual standards.

About $5 million will be used to support correlative studies that are integral to or required for trials. CCCT is also collaborating with the Life Science Consortium of the CEO Roundtable to develop a plan for standardized clinical trials agreements based on existing clinical trials agreements from industry, academic institutions, and cooperative groups. The standardized agreements will reduce the time required to negotiate contracts.

COL Williams reported that advocates play an important role in the CCCT process. For example, COL Williams represents the DCLG on the CTAC, and many of the disease-specific steering committees have patient advocates. The patient advocate steering committee, chaired by COL Williams and Susan Leigh, brings together the advocates assigned to the disease-specific steering committees. The committee will enable advocates to share best practices, discuss ways to participate successfully in the steering committees, and communicate training needs to OAR.

Discussion

Ms. Campos asked whether clinical trial sites are ever closed because of low accrual. Dr. Prindiville explained that NCI does not currently plan to close any sites, but it might ask sites to stop accruing more patients if their patient numbers are low. It can be very costly to enroll patients and establish the infrastructure needed for a trial, and the CCCT's cost analysis will determine whether NCI should stop enrolling patients at low-volume sites. Once a patient has enrolled in a trial, the site is committed to providing care to that patient. In addition, trials must provide access to any patient who wants to enroll.

Ms. Graff pointed out that the "disease-specific" steering committees are really organ specific. Dr. Prindiville agreed that the term "organ specific" is more accurate, but the CTWG report calls them "disease specific." These scientific steering committees review clinical trial concepts from cooperative group and CCOP networks.

Ms. Graff asked whether any of the committees would address neuroendocrine tumors. Dr. Prindiville replied that the gastrointestinal cancer steering committee has a neuroendocrine task force, because carcinoid tumors often develop in the gastrointestinal tract. Ms. Graff pointed out that these tumors have the same genetic causes and symptoms, and they are monitored in the

same way regardless of where they occur. Dr. Prindiville explained that the gastrointestinal steering committee will bring in experts from outside the gastrointestinal field to provide input into the design of neuroendocrine tumor trials. She invited Ms. Graff to share any concerns with the advocates on the gastrointestinal steering committee.

Ms. Dahlstrom asked about activities to reduce barriers to participation in clinical trials. Dr. Prindiville replied that the CCCT is focusing on barriers to completing trials rather than barriers to access, although the CCCT does have some initiatives to increase the accrual of minority and underserved populations to clinical trials. In FY 2007**,** additional funds will be provided to the minority-based CCOPS (MB-CCOPs) to enhance their accrual.

Dr. Butler pointed out that many centers find it challenging to accrue minorities. NCI should consider offering incentives to recognize successful minority accrual efforts to inspire others. Dr. Prindiville explained that this is why the CTWG decided to provide supplements to those MB-CCOPs that are successful in accruing patients. Ms. Johnson added that NCI has several initiatives focused on recruiting, accruing, and retaining minorities in clinical trials. In particular, the Institute's Cancer Health Disparities Integration and Implementation (I^2) Team is addressing this issue.

Ms. Whitewolf asked about the process for recruiting advocates to the steering committees. COL Williams replied that the advocates are recruited from OAR's Consumer Advocates in Research and Related Activities (CARRA) program.

Mr. Dodson wondered whether clinical trials could be designed with fewer exclusion criteria. Dr. Prindiville explained that the reasons why patients are excluded from a trial relate to safety and scientific issues. It might not be safe for some populations to participate in a trial, for example.

Mr. Kaye noted that even though he represents the National Cervical Cancer Coalition, he had not been aware of the state-of-the-science meeting on cervical cancer organized by the gynecologic cancer steering committee on September 27–28. Dr. Prindiville offered to work with the DCLG to improve the CCCT's communications efforts.

Mr. Kaye asked whether unsuccessful STRAPs could be stopped. Dr. Hawk said that these projects would be evaluated by the broad community to determine whether they are successful.

Ms. Graff asked about plans to integrate the Institute's intramural and extramural translational efforts. Dr. Hawk explained that NCI's intramural and extramural programs have been kept separate for several years, but the shortcomings of this strategy have become progressively more evident. The TRWG plans to bring these groups together by having representatives from both programs on its oversight and management committees. Dr. Prindiville added that each scientific steering committee has an intramural investigator.

VIII. DCLG Working Group on Involving Advocates in NCI Programs

Ms. Cotter, Chair of the DCLG Working Group on Involving Advocates in NCI Programs, stated that this working group was formed in response to Dr. Niederhuber's call for advocate

involvement in NCI through the CARRA and Specialized Program of Research Excellence (SPORE) programs and to respond to the formation of advocate groups articulated in the TRWG report. The group's mission is to develop and provide recommendations to the DCLG on how NCI can more consistently integrate the involvement of advocates across the Institute's programs to ensure that the patient advocates' perspectives are appropriately represented.

Mr. James Hadley explained that patient advocates are involved at NCI from the development of concepts to their implementation. OAR wants to know which programs are using advocates and what these advocates are doing. Some NCI staff identify advocates through the CARRA program, but once they find advocates they like, they do not let OAR know that they are continuing to call on these advocates. The working group will also determine what the advocates at NCI need to learn, such as communication and negotiation skills or the services offered by the DCLG and OAR.

The working group has two DCLG members, two former DCLG members, eight advocates, several NCI staff, two SPORE directors, and two center directors. The purpose is not to change the way advocates work with NCI but to ensure that all advocates at NCI are under the same umbrella and to address their training needs.

Ms. Cotter will chair the committee, and Mr. Hadley will serve as the OAR liaison. The group will present its recommendations to the DCLG at the March 2008 meeting. Once the DCLG approves the group's recommendations, it will deliver them to Dr. Niederhuber for his consideration.

Mr. Hadley expressed the hope that the synergy from this new group will benefit not only advocates but also NCI as it brings the patient perspective into everything it does in a systematic way.

Discussion

Mr. Bill Bro said that this activity could be one of the DCLG's most significant contributions. He encouraged the newest DCLG members to offer the working group their full and enthusiastic support.

Ms. Whitewolf asked how advocates were selected for the working group. Mr. Hadley explained that the working group members were appointed by Dr. Niederhuber or selected from CARRA.

Ms. Graff wondered whether the working group's activities might overlap with the activities of the SPORE advocates. Mr. Hadley replied that the SPORE advocates and those from NCI's biorepository and biospecimen research program and cancer centers would be included in the working group's activities. Ms. Lubenow added that Dr. Niederhuber requested this working group in response to the discussions at the recent SPORE advocates meeting. The goal is to integrate the expertise of the SPORE advocates more effectively into NCI. A wealth of opportunities for the involvement of advocates exists at NCI, and OAR wants to bring these activities together to manage them more effectively and increase their impact.

IX. Current Issues in Cancer Survivorship

Dr. Julia Rowland stated that the ultimate goal of NCI's Office of Cancer Survivorship (OCS) is to enhance the length and quality of survival of all cancer survivors. According to NCI's Surveillance, Epidemiology, and End Results (SEER) program, an estimated 10.8 million cancer survivors were living in the United States in 2004. The vast majority of these survivors will live for a long time after diagnosis; about 66% of newly diagnosed people will survive for at least 5 years, and 14% of current survivors were diagnosed 20 years ago or more.

Every winter, OCS reviews all grants related to survivorship (defined as those addressing the health and life of a person with a history of cancer beyond the acute diagnosis and treatment phase encompassing both "prevention" and "control" aspects of chronic disease epidemiology) that were active at NIH during the preceding fiscal year. Although most are funded by NCI, several other NIH Institutes support research on cancer survivorship. About one-third of the 2006 grants involved intervention studies, which are important because we need new interventions to prevent or ameliorate the difficulties faced by cancer survivors.

Dr. Rowland described several initiatives related to cancer survivors' care:

- Follow-up Care Use among Survivors (FOCUS)—This study uses two California-based SEER registries to assess the frequency, content, and setting of follow-up care received by long-term survivors. Data from this study are currently being prepared for analysis.
- Survey of Physician Attitudes Regarding the Care of Cancer Survivors (SPARCCS)—This study currently under development will collect information on providers' (both primary care and cancer specialists) knowledge, attitudes, and practices pertaining to survivors' post-treatment care. Results will be available in 2009.
- Cancer Care Outcomes Research and Surveillance Consortium (CanCORS)—CanCORS has collected comprehensive data on the care delivered to and early patient-reported outcomes of lung and colorectal cancer patients. A supplemental study also collected information on the impact on caregivers of providing support to participants in the larger CanCORS project.
- NCCCP—This program will evaluate ways to bring state-of-the-art care and early-phase clinical research to the community. NCCCP addresses several issues related to survivorship, including comprehensive psychosocial care, coordination of care, development and delivery of survivorship care plans, education about psychosocial care and palliative care issues, and the patient/survivor/caregiver experience.
- *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*—This Institute of Medicine (IOM) report was just released electronically. It describes recommendations, guidance, and tools to ensure that people diagnosed with cancer receive the psychosocial services optimal to helping them live as long and as well as possible.

Dr. Rowland announced that the fourth biennial cancer survivorship research conference would take place on June 18–20, 2008, in Atlanta, Georgia, and is being sponsored by the National Cancer Institute, the American Cancer Society, and the Lance Armstrong Foundation.

<u>Discussion</u>

Ms. Whitewolf noted that SEER data do not capture the Native American community and asked whether OCS will consult statistical sources other than SEER. Dr. Rowland explained that SEER has tried to collect data on Native Americans, but the community holds these data very closely. OCS will soon publish shorter-term data for a more diverse population on its Web site (http://dccps.nci.nih.gov/ocs/).

Ms. Whitewolf noted that research on sexual function in survivors is important. Dr. Rowland explained that the OCS Web site provides information on the office's active research portfolio. If DCLG members want more information on the research funded by OCS, they should contact the OCS staff. The staff member responsible for research on sexual function is Dr. Diana Jeffery.

Ms. Graff wondered whether AYAs are warned that cancer treatment might lead to infertility and whether they are told what they might do to have children in the future. She also wondered whether OCS is sponsoring research on cancer as a chronic illness. Many questionnaires used in studies do not apply to people with hereditary cancer syndromes, for whom cancer is a chronic illness. Dr. Rowland noted that Dr. Keith Bellizzi would try to include relevant questions in the questionnaire being developed for use in the planned SEER-based sample of AYA cancer survivors. She added that "cancer as a chronic illness" is a very controversial area, because many survivors want to think of their cancer as "gone" once they complete treatment. However, SEER data suggest that 16% of new cancer cases are second, third, or even fourth malignancies. Very little research has been done on the psychosocial impact of recurrences or second malignancies.

Ms. Graff wondered how many people with multiple cancers have been screened for a genetic condition. Because many are not screened, their diagnoses are often delayed.

Ms. Campos commented that members of medically underserved minority communities are often more comfortable seeing a primary care physician for all of their care. But if a patient with coverage from California's Medicaid program sees a primary care provider for depression, that provider cannot be reimbursed for this diagnosis. In addition, federally qualified health centers that treat patients who are depressed as a result of cancer cannot bill for two visits in one day. These issues put stress on primary care physicians, and Ms. Campos wondered about research on support and reimbursement for these providers. Dr. Rowland replied that the new IOM report and the Institute's earlier report on mental health should inform policy makers and advocates about ways to remedy these situations.

Mr. Hadley noted that Dr. Rowland would be leading the Understanding NCI toll-free teleconference on December 11 from 1:00 p.m. to 2:00 p.m. EST. He urged DCLG members to inform their communities of this event.

Mr. Ulman asked about OCS's role in evaluating the impact of the President's Cancer Panel report on survivorship. Dr. Rowland said that all too often, no action is taken to implement the recommendations in reports like this one. It was therefore important for the panel to revisit its recommendations on survivorship and translational science. She reflected on the vital leadership role that the advocacy community could play in making sure that action is taken to implement the Cancer Panel's recommendations.

X. Public Comment

Ms. Barbara Holtz, a member of the Adult Patient and Family Advisory Council for Nursing and Patient Care Services at the Dana-Farber Cancer Institute, provides peer counseling to newly diagnosed breast cancer patients. She is always astounded by how surprised patients are when they become depressed, and this surprise increases their suffering. Ms. Holtz wondered whether patient education could diminish the impact of depression associated with a cancer diagnosis.

Dr. Rowland noted that the new IOM report recommends that patients' psychosocial needs be evaluated and that clinicians should not ignore depression. Ms. Graff added that too many doctors respond to reports of depression by giving patients a prescription without addressing the cause. Depression is not part of the normal grieving process in cancer patients, who need counseling during this difficult period. Dr. Rowland observed that data suggest that most cancer patients do not become depressed. However, a number of risk factors for poor outcomes have been identified and include certain medical, personal, and social characteristics Many treatment centers are beginning to test screen for distress. If a patient reports depression, that patient's clinician needs to follow the outcomes of the patient's treatment and critically make changes when needed.

XI. NCI Community Cancer Centers Program Pilot Update

Dr. Maureen Johnson provided an update on the NCCCP pilot. The program's goal is to identify the best methods for enabling the provision of state-of-the-art, multispecialty care and early-phase clinical trials in community-based locations. NCI selected 10 pilot sites with 27,000 new cancer cases in the previous year. These sites have invested $47 million in the project. They represent a broad range of program maturity, size, geographic and community setting, program model, and strengths and areas for improvement. Seven of the sites are linked to NCI's CCOPs.

RTI International, the evaluation contractor, will conduct annual site visits to assess patient and caregiver satisfaction. A cost study will measure start-up costs and ongoing annual program costs and feasibility. A patient survey will be used to assess how well patient health care and information needs are met.

Progress made by each subcommittee includes:

- The **Disparities Subcommittee** has surveyed breast and colorectal cancer screening activities to establish baseline metrics for outreach and patient navigation activities. The survey showed that one-third of the sites had no colorectal cancer screening program.
- The **Clinical Trials Subcommittee** has surveyed clinical trial activity at each site. The co-chairs have used the survey results to identify phase III clinical trials that need to increase their accrual. The subcommittee is also surveying patient navigator activities and has created a minority recruitment working group in collaboration with the Disparities Subcommittee.
- The **Information Technology Subcommittee** will assess existing health information technology systems, infrastructures, and interfaces at baseline. The group will also help expand existing implementation of electronic health records.

- The **Biospecimen Subcommittee** has standardized how pilot sites process some biospecimens and is exploring the collection of biospecimens at pilot NCCCP sites for The Cancer Genome Atlas.
- The **Quality of Care Subcommittee** has completed an informal survey of multidisciplinary care program activities and created a working group to identify site barriers and facilitators of multidisciplinary program planning. The subcommittee asked the Commission on Cancer to establish procedures for sharing patient quality-of-care data within and across pilot sites.
- The **Communications Subcommittee** helps sites build local and regional support and assists with programmatic activities. The NCCCP's Web site (http://ncccp.cancer.gov) provides details on all of the pilot sites.

Dr. Beverly Laird pointed out that the NCCCP's goal is to conduct research on health care delivery, not to deliver care, and that NCI does not tell the sites what services to provide. DCLG members are very involved in NCCCP. For example, Dr. Laird is the DCLG's representative on NCI Program Advisory Committee (NPAC), and DCLG members serve on several subcommittees. In addition, the sites have been given the names of CARRA members in their local areas, and some sites have already contacted and used CARRA members in their activities.

Dr. Laird reported that the project just started, and many sites have already launched initiatives. For example, one site held a community-wide launch for its disparities and survivorship activities; almost 40 community representatives attended the event and learned what the site offers. Sites are also learning about existing clinical trials, opening new trials, and sharing information about electronic health records. Two sites have initiated the American Cancer Society "I Can Cope" education program for people living with cancer.

The evaluation committee is preparing to conduct its baseline survey. The questionnaire was developed with input from the DCLG on advocacy participation and use of no-cost resources. Mr. Bro has volunteered to conduct site visits and meet with the advocacy representative at each site. He will report his findings to the DCLG.

Ms. Cotter is a member of the Survivorship Subcommittee, which has identified four critical areas: medical treatment summaries, long-term survivorship programs, end-of-life care, and palliative care. The entire group will address each issue sequentially; the first focus will be on medical treatment summaries and care plans. The subcommittee is examining different models of existing plans and identifying best practices. The group plans to evaluate the American Society for Clinical Oncology guidelines and decide whether to adopt or amend them.

Ms. Peggy Anthony is the DCLG's representative to the Clinical Trials Subcommittee, which is very energetic and enthusiastic. One of the group's teleconferences focused on patient navigation and the development and dissemination of job descriptions for patient navigators. Minority accrual is the subcommittee's top priority. Ms. Anthony co-chairs the advocacy and policy task force for the South Carolina Cancer Alliance, which plans to invite the two sites in its region to give a presentation on their activities at a quarterly meeting. This is one way to build partnerships.

Discussion

Ms. Whitewolf asked how to find the names of the contact people for each site. She is eager to contact representatives of the Native American sites and find ways for the DCLG to become involved with them. Dr. Johnson replied that this information is available on the NCCCP Web site.

Dr. Butler represents an organization that provides information and education about colorectal cancer screening. She wondered whether the pilot sites would have an opportunity to collaborate with organizations like hers. Dr. Kenneth C. Chu replied that sites would be encouraged to use community organizations as resources.

Ms. Dahlstrom noted that sites might find it difficult to develop relationships with community-based organizations and advocacy groups that are not traditional cancer organizations. She recommended that NCCCP broaden its circle of advocates to include those who are not often represented. She also suggested that NCCCP find ways to partner with advocacy organizations without making community organizations shoulder all of the responsibility for overcoming barriers to collaboration.

Mr. Kaye asked about the proportion of cost shifting versus new funding. Dr. Johnson explained that NCI funds were designated primarily for personnel funding, but sites have the discretion to determine whether to hire new staff or use existing staff. Each site receives approximately $500,000 a year and must provide some matching funds. Mr. Kaye asked about the cost per patient. Dr. Johnson explained that NCI is not supporting sites for their accrual to clinical trials through NCCCP. The sites receive funding for trials through cooperative groups; CCOPs; or other mechanisms, such as industry-sponsored trials. Ms. Wahwasuck wondered whether members of her Kansas community could be screened at the Sioux Falls site, because the Indian Health Service (IHS) does not cover the cost of colonoscopies. Drs. Johnson and Chu explained that NCI is still collecting data on the services provided by each site. The DCLG will be informed of the results of the NCCCP surveys. Ms. Wahwasuck noted that the Native American sites are not IHS sites or tribally owned clinics, although they serve Native Americans. Ms. Whitewolf asked how these sites were selected and whether tribal governments were involved in the discussions. Dr. Johnson explained that the 10 sites were selected based on their written proposals and whether they met all of the eligibility criteria (such as having at least 1,000 cancer cases a year). NCI did not obtain input from the IHS or the tribes in selecting the sites.

Ms. Whitewolf expressed concern about how well the sites will work with the tribal governments in their catchment areas. Dr. Johnson replied that the baseline assessment will provide information on the sites' current outreach, and one goal of the sites is to increase their outreach. Dr. Johnson encouraged Ms. Whitewolf to communicate with the Native American sites about how the community can help the sites achieve their goals. She also invited Ms. Whitewolf to participate in a teleconference of the Disparities Subcommittee to share information with the sites.

Ms. Nancy Davenport-Ennis suggested that the NCCCP hospitals establish relationships with nearby National Comprehensive Cancer Network sites. She added that the Patient Advocate

Foundation has already communicated with 12 NCCCP hospitals about resources that the foundation can share. Because the program was established only recently, groups that want to help should perhaps wait until the sites have established their programs before offering to share resources.

Dr. Chu explained that sites are required to identify community groups serving populations that could benefit from cancer screening and with which the NCCCP sites will interact. The sites are also establishing community regional advisory groups. Because 6 of the 15 participating hospitals do not have patient navigation activities, NCI is helping them establish such programs.

Ms. Dahlstrom asked how the sites spend their health disparities funds; Dr. Chu replied that the baseline questionnaire is collecting this information.

Dr. Johnson emphasized that the NCCCP is an experiment designed to define indicators of quality care in the community. NCI selected a broad range of sites so that it could determine what works in different environments. She welcomed the DCLG's input.

XII Consumer Advocates in Research and Related Activities Program Update

Ms. Elizabeth Neilson discussed the results of the CARRA program evaluation. The evaluation had several components:

- Post-activity surveys with CARRA members—90% reported that the CARRA activities in which they participated met their expectations, and 98% would be willing to participate again. Most members said 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.

- Post-activity surveys with NCI staff—80% are satisfied with the process to select advocates, 99% plan to request a consumer advocate again, 100% would recommend CARRA to a colleague, and most found CARRA members to be professional and meet their needs for consumer involvement.

- NCI staff attitudes and behaviors survey—Most staff value the involvement of CARRA members in NCI activities. Those who work with CARRA members are much more enthusiastic about involving advocates than staff who do not work with CARRA members. Staff value CARRA member involvement most highly in developing and disseminating information and improving the public perception of NCI.

- CARRA member attitudes and behavior survey—The main motivation of most CARRA members is to convey the consumer perspective and inform NCI about the views and concerns of their constituencies. Most reported that NCI activities matched their interests. They believe that the program has 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. The program's primary challenge is under use of members.

This past summer, the CARRA program interviewed several CARRA and NCI staff members. The interviews showed that CARRA members are enthusiastic and expect to participate in two to four activities per year. Although they are dissatisfied with their low level of involvement, they do not resent the program for this, and they support more selective recruiting to maintain the program's reputation for having high-quality advocates. NCI staff said that CARRA members add value to the research process. However, they are concerned that advocates might have their own agendas or be disruptive rather than productive. Both CARRA members and NCI staff identified training that would be useful for CARRA members.

Discussion

Ms. Whitewolf asked about the diversity of the CARRA membership. Ms. Neilson will send these data to Ms. Guest for distribution to the DCLG. New CARRA members were last recruited 3 years ago, and the program wanted input from the DCLG before beginning a new recruitment cycle.

XIII Determinants of Cancer Health Disparities and the Programs of the Center to Reduce Cancer Health Disparities

Dr. Chu discussed the programs of NCI's Center to Reduce Cancer Health Disparities (CRCHD). Health disparities occur when beneficial medical interventions are not shared by all people. The causes of these disparities include culture (beliefs, attitudes, and language), social injustice, and socioeconomic status. Poverty and culture magnify the impact of risk-promoting behaviors, inadequate information and knowledge, inadequate physical and social environments, and diminished access to care. The result is poor survival.

Dr. Chu views the DCLG's role as providing a "reality check" for NCI. NCI's programs need to have an impact that the DCLG can perceive.

Ms. Tarsha McCrae discussed CRCHD's Community Networks Program (CNP). The program offers community-based participatory education, research, and training to racial and ethnic minorities and underserved populations. This 5-year, $100 million program is funding 6 national, 8 multi-state or statewide, and 11 local networks. NCI has hired a contractor to evaluate the program.

The networks have formed relationships with approximately170 clinical and 640 nonclinical partners. In addition, they have developed educational brochures, posters, DVDs, and other materials in many different languages. They promote clinical prevention services and have developed innovative strategies to reach disparities populations. For example, one site has implemented a healthy-eating program in African American churches, while another organized an art and essay contest on the dangers of secondhand smoke for youth. All community networks conduct research projects with their communities, and many administer community grants ranging from $500 to $10,000.

The program supports pilot studies to train junior investigators in community-based participatory research. In 2007, 53 pilot applications (1 year, direct costs up to $50,000) were submitted and 20 were recommended for funding.

To sustain the program, grantees have requested support for research, education, and trainees from non-CRCHD funders including foundations and other NIH Institutes. They have also leveraged support from their institutions for salaries, space, information technology, and supplies.

All grantees must attend the annual CRCHD summit. The report of the 2006 summit is now available online (http://www.cancermeetings.org/CHDSummit06/). More information on the CNP is available on the CRCHD Web site (http://crchd.cancer.gov/).

Dr. Roland Garcia described the Patient Navigation Research Program (PNRP), which supports nine sites across the country. NCI funds eight of the sites, and the American Cancer Society funds the ninth. With support from the American Cancer Society and NCI, the program has sponsored several national training workshops and "webinar" training sessions for more than 200 navigators. The projects developed more than 600 metrics for four cancers for which patients can be screened.

Dr. Peter Ogunbiyi discussed the Comprehensive Minority Institution/Cancer Center Partnership (MI/CCP) program. Although most large cancer centers are located in inner cities, they treat very few patients from these communities. The partnership program targets research, education, and training and outreach activities in the communities they serve. The program was established in 2001. Ten partnerships were funded between 2001 and 2003. After the program's evaluation in 2004, progress was found to be satisfactory and it now supports 27 partnerships. Most minority-serving institutions (MSIs) offer training and education, while cancer centers conduct state-of-the-art research. It has taken most partnerships about 2 years to resolve differences, establish communications, and become significantly productive. But by the third year, the number of publications by junior faculty from the MSI and senior faculty from the cancer center typically increases, and more undergraduate and graduate students become involved. Cancer health disparity research and outreach efforts of the cancer center also increase significantly.

As a result of the partnerships, MSIs have recruited faculty involved in cancer research, and cancer centers have recruited more minority faculty. The partnerships have also produced a broad range of outreach materials targeted to underserved and minority populations in the cancer center catchment areas.

Discussion

Mr. Kaye asked whether the CNP addresses cancers associated with HPV, which can be prevented with vaccines. Because people might be reluctant to have the vaccine, they need to be educated to overcome fear, stigma, and other barriers. Ms. McCrae said that the networks are working with their communities to develop educational interventions regarding HPV transmission and prevention.

Ms. Campos asked whether the PNRP includes community health centers that are not federally qualified health centers and whether the services are available to undocumented immigrants. Dr. Garcia explained that most of the 66 sites involved are community health centers; some are federally qualified and others are not, although they share many characteristics with federally qualified centers. Ms. Campos noted that if someone is undocumented and receives a positive screening result, that person cannot receive treatment under Medicaid. Dr. Garcia explained that the program tries to find other funding sources to cover treatment for those who are uninsured.

Ms. Campos asked about support for doctoral training. Dr. Ogunbiyi explained that the Comprehensive Minority Biomedical Branch offers several training programs for graduate students. For example, NCI's Continuing Umbrella of Research Experiences (CURE) program offers training support from high school through the first academic appointment.

Ms. Dahlstrom noted that communities want to participate in research by designing studies and becoming researchers. In addition to partnerships with MSIs, communities need equitable partnerships in which research institutions and communities educate one another. Dr. Ogunbiyi said that the MI/CCP program recognizes this and provides funding to enable investigators to work with communities and communities to offer feedback to investigators. Dr. Chu pointed out that three community-based organizations have obtained grants through the CNP, and one grantee is an intertribal council, not a university. Dr. Chu asked the DCLG to consider whether the program should be open for applications more frequently than every 5 years so that more communities can conduct their own research.

Ms. Dahlstrom emphasized the need for more M.D. or Ph.D. researchers from underserved populations. It is also important to honor the expertise and skills of community leaders and build equitable partnerships that ensure two-way learning. It is difficult to eliminate cancer health disparities without community partnerships.

Dr. Butler was encouraged and inspired by NCI's level of involvement in eliminating cancer health disparities, but she is concerned about the many basic barriers that still exist. She asked whether progress in combating these barriers could be measured. Dr. Garcia explained that the greatest barriers, such as transportation, lie outside the control of the health care system. NCI's PNRP is not geared to address all barriers; instead, the navigators help patients navigate the health care system and overcome their individual barriers.

Dr. Butler asked what the new reality would be if CRCHD succeeds. Dr. Chu explained that CRCHD is trying to develop the science of reducing cancer health disparities. The first step is building community partners, followed by working with the community to develop interventions for that community. The next step is to conduct controlled trials to test those interventions against a control group and then disseminate the results. Everyone knows the barriers, which are not the problem—the problem is finding solutions. Patient navigation is one way to address several barriers simultaneously. Dr. Ogunbiyi emphasized that some barriers can only be affected by policy changes.

Dr. Shobha Srinivasan commented that the NIH Partners in Research program supports equal partnerships between universities and communities. These grants have two coinvestigators: a

community member and a university member. The applications are reviewed by a group of community members and a group of faculty members. The NIH Community Participation in Research program supports joint research by communities and researchers on health promotion, disease prevention, and health disparities. Dr. Srinivasan will forward information on these programs to the DCLG.

Ms. Whitewolf requested reports on the progress of the CNP. She also noted that participants in the patient navigator training provided by the American Cancer Society have commented that the training needs to do more to address cultural diversity.

Ms. Graff suggested that NCI sponsor a general public relations campaign to eliminate the misconceptions in some groups about cancer.

XIV Discussion with the NCI Director

Health Disparities

COL Williams asked about NCI's partnerships with other federal agencies to eliminate cancer health disparities. Dr. Niederhuber explained that NCI regularly works with other federal agencies. However, this is difficult when neither NCI nor its potential partner has sufficient funding for a joint initiative. Combating cancer health disparities would be an appropriate focus for joint programs with other federal agencies, such as the CDC.

COL Williams noted that according to a report presented to the DCLG in 2006, only about 5% of NCI funding is used for initiatives in cancer health disparities. Dr. Niederhuber agreed that this area is under funded.

Budget Issues

Mr. Kaye noted that DOD receives approximately $16 million for ovarian cancer research. Dr. Niederhuber added that DOD also sponsors research on breast and other cancer sites. NCI supports this research program because it is peer reviewed and can benefit patients. The difficulty for the Institute is the groups that demand more money for a specific cancer site without understanding that the NCI chooses recipients for its funding based on whether applicants propose projects that involve good science. In addition, research on one cancer can benefit patients with other types of cancer. It is difficult to help people understand that the focus should be on the broader investment in science.

Another challenge is managing expectations. Every time a group of experts comes together to discuss cancer research, there is the expectation that NCI will implement the group's recommendations. A 2% increase in NCI's budget will make it difficult to keep the same amount of money in many current programs, such as the SPOREs and cancer centers. More than 80% of NCI's budget is already committed, and NCI has very little flexibility to establish new programs.

NCI is taking steps to support more new programs by leveraging its resources. For example, NCI brought teams of scientists together to study nanobiology and was able to leverage these investments at least 10 times over.

Mr. Ulman noted that the DCLG must make some tough decisions about its recommendations. If it recommends, for example, that NCI expand the funding for NCCCP, the group must recognize that NCI will need to cut another program. The DCLG must keep in mind what is most important for patients. Although NCI needs more money, this is not the only answer.

Communications

Mr. Bro asked whether the most recent breakthroughs in cancer have resulted from translational research. Dr. Niederhuber explained that translation is visible—survival is increasing and the press is covering this news. But other breakthroughs beneath the surface are equally important.

One of the Director's most challenging jobs is communicating NCI's mission and accomplishments. Members of the public are not familiar with NCI, and they need to understand the work supported by their tax dollars. The Institute is using some of the latest technologies to communicate its message without using too many resources.

Ms. Whitewolf has recommended that NCI or NIH create an Indian desk. Other federal agencies use these offices to advise them on the complexities of working with tribal governments. She also noted that tribal governments were not involved in selecting the NCCCP sites that are working with Native Americans. . She recommended that NCI form a team to communicate with Native American communities about NCI's mission, ways for communities to work with NCI, the status of the President's Cancer Panel recommendations on Native Americans, and plans to work with tribal governments.

Dr. Butler wondered about the impact of President Bush's visit to NCI and noted that several congressional representatives are sympathetic to the cancer cause, as demonstrated by the many bills introduced in Congress that would benefit cancer patients. The DCLG should harness some of the commitment that has already been established to gain greater support for NCI's work.

Dr. Niederhuber replied that if any group can have an impact on the President and the leaders of the House and Senate, it is the DCLG and its contacts. All DCLG members should leverage their relationships with equally influential people. They should also tell their own stories and encourage others to tell stories of their experiences with cancer. Dr. Niederhuber's role is not to tell stories about cancer but to educate the DCLG and others about what NCI does so that they can carry this message forward. Dr. Niederhuber also noted that many other issues, such as education, are of passionate interest to him, the DCLG, and many others and that these issues compete for the same limited portion of the budget as NCI.

Mr. Kaye commented that the recent news about declining cancer incidence rates in the United States is exciting and is probably the result of previous funding. Perhaps the American Association of Cancer Research could help disseminate this message. Mr. Kaye reported that the National Cervical Cancer Coalition brought 100 cervical cancer survivors to the Hill. Dr.

Niederhuber said that this is important. He noted that the HPV vaccine is the result of two NCI researchers who devoted their entire careers to creating an effective vaccine. These scientists earned much less than they would have from other employers, but their contribution will have a huge impact on the world. This work happened at NCI with a relatively small investment of money. The public needs to understand that NCI's dedicated researchers work long hours and do not make high salaries. Many of the people trained by NCI have made major contributions to laboratories outside NCI.

Other NCI Activities

Incentives are needed to encourage researchers from other fields, who have different types of training and think about problems in a different way, to work on cancer. Theoretical physicists, for example, have valuable experience working with vast amounts of data and addressing problems in very theoretical ways. This experience could be useful for research on genetics, which generates huge amounts of data. NCI plans to bring a small group together to discuss this idea and perhaps form a few centers to bring different experts together around biology problems.

Mr. Kaye asked about NCI research on HPV with respect to other cancer sites. Dr. Niederhuber replied that NCI's intramural and extramural research programs are addressing several HPV-related cancers.

XV Recommendations and Action Items

Mr. Ulman asked DCLG members to list recommendations for Dr. Niederhuber.

Recommendations for NCI

Ms. Dahlstrom strongly encouraged NCI to consult underserved communities, which have historically not been at advocacy tables. Extra funding on its own will not reduce cancer health disparities; we need to do business differently and reallocate resources to ensure equity. Community-based participatory research and community partners need more opportunities to work in an equitable partnership in research.

Ms. Graff proposed that NCI launch a public relations campaign to break through basic barriers that affect all populations, but especially the medically underserved. The campaign should emphasize the need to consult a doctor about certain symptoms and encourage people to have DNA testing. The campaign should be run by communities and states, which know how to reach their populations.

Ms. Davenport-Ennis plans to help the NCCCP sites in their efforts to accrue enough patients to their trials, which will require mobilizing disparate populations. NCI should inform the DCLG about NCI's plans to disseminate information in these markets so that the DCLG can determine whether members' organizations can support these activities.

Ms. Wahwasuck recommended that the Director report to the DCLG on how the Native American NCCCP sites communicate with the Native American communities they are serving.

Ms. Whitewolf agreed, explaining that the Native American community has its own governments and does not need to follow all federal and state laws. She recommended that NCI establish a government-to-government relationship with tribal governments for all NCI programs.

Dr. Butler suggested bringing the organizations working on cancer health disparities together with NCI to strengthen NCI's efforts. Ms. Campos agreed, noting that community clinics have experience bringing community members to their sites, and NCI could learn from them how to eliminate disparities in cancer health. However, she is concerned about putting too much pressure on primary care providers, especially those in undeserved communities. They rarely say no to accepting more patients, but many are already overburdened. Perhaps NCI could form a partnership with the primary care associations in the states.

COL Williams noted that most NCI initiatives require that research include minorities, women, and children if appropriate, but these requirements are not enforced. Dr. Laird commented that the advocates on peer review panels focus on the inclusion of minorities, women, and children in research applications. Some projects are not funded if the advocates point out that their investigators have not addressed these issues. However, Dr. Butler has sat on peer review panels in which centers did not achieve their accrual goals, and these centers were simply asked to submit an acceptable 5-year plan. Stricter enforcement measures are needed.

COL Williams also noted that comprehensive cancer centers compete with one another to the detriment of patients in their catchment areas. Dr. Laird commented that the comprehensive cancer centers were initially reluctant to support the NCCCP concept, but now that it has been implemented, they are eager to work with the newly funded centers. Cancer centers need incentives to collaborate with other centers and with one another. Mr. Ulman commented that the President's Cancer Panel learned that cancer centers accept funding from tobacco companies. NCI should require its award recipients to refuse funds from tobacco companies.

Ms. Davenport-Ennis recommended that each DCLG meeting include a comprehensive report to the DCLG on the performance of each NCCCP site and the original proposals from the sites. This process would allow the DCLG to determine whether each site is meeting its objectives and to identify areas where the group can provide support. Dr. Laird noted that the NCCCP has a strong evaluation program that will address these issues. She is more concerned about accrual in comprehensive cancer centers.

Ms. Whitewolf pointed out that people with disabilities and the gay, bisexual, lesbian, transgender (GBLT) population also experience disparities, but they do not seem to be represented in the discussions of cancer health disparities or in CARRA and the DCLG. Ms. Guest explained that NCI chooses DCLG and CARRA members who represent a broad range of geographic areas, ages, cancer types, and racial/ethnic backgrounds. Although these groups do not include representatives of every community, they are tasked with representing the larger community. Even if members do not have disabilities, for example, they can address disabilities-related issues. Ms. Bell asked DCLG members to collect perspectives from other communities and bring them to the table.

Ms. Davenport-Ennis recommended that NCI increase funding for the PNRP so that it can fulfill its 5-year commitment.

Ms. Davenport-Ennis also recommended that NCI initiate clinical trials within the NCCCP that track the enrollment of people with comorbidities in clinical trials to determine whether they have more adverse events than those without comorbidities. Mr. Dodson supported this recommendation, noting that many patients are lost to clinical trials because of comorbidities.

Recommendations for the DCLG

Ms. Dahlstrom recommended that every presentation to the DCLG include an explanation of the relationship between the presentation and the three DCLG priorities articulated by Dr. Niederhuber. She also recommended that presenters highlight not only their successes but also their challenges. The DCLG could then use its expertise to help solve these problems. Mr. Ulman said that presenters at the next DCLG meeting would be asked to do as Ms. Dahlstrom recommended.

COL Williams wondered how to ensure that the DCLG members speak with one voice when they represent NCI to ensure that the DCLG has an impact on decision makers. He suggested that the DCLG consider developing a white paper or other document (Ms. Whitewolf suggested an annual report) summarizing the information collected by the group. Group members could take this with them when they meet with decision makers. Mr. Ulman agreed that if the DCLG is to serve as the honest broker that NCI needs, it must be more aggressive in promoting the activities of NCI and the DCLG.

Ms. Guest noted that the letters from the DCLG to NCI scientists and Dr. Niederhuber summarizing the results of the DCLG meetings are posted on the Web. Perhaps these documents could be made more user friendly.

Ms. Davenport-Ennis recommended that all DCLG members ask themselves the following questions after each meeting:

- When we go back from this meeting and begin receiving materials from NCI, what will we do with those materials within our own organization?
- What will we do to distribute these materials to our constituencies?
- What will we do with our media?

DCLG members should ensure that when their organizations are featured in the media, they include a statement recognizing NCI's work in bringing care into the community through such programs as NCCCP and PNRP. The DCLG should create a tip sheet of actions to take whenever members receive materials from NCI.

Ms. Davenport-Ennis commented that DCLG members want to help the NCI staff complete their work and wondered how to increase the dialogue needed to create the necessary partnerships.

Ms. Whitewolf volunteered to provide a half-day training session for the DCLG prior to its next meeting to teach the group about tribal government relations, the IHS, and how this complex system interacts with clinical trials.

Recommendations for the Advocacy Community

Mr. Kaye proposed establishing an ambassador program for advocates. These advocates could be given PowerPoint slides and a short video to use in presentations in their communities on the difference made by NCI programs in their communities.

Mr. Kaye noted that about 10 years ago, the Coalition for Cancer Survivorship organized a march of 350,000 people on Capitol Hill to support an increase in the cervical cancer budget, and this budget increased significantly as a result. Perhaps the coalition and other partners, such as the Lance Armstrong Foundation, could organize another march.

Other Issues

Ms. Whitewolf asked for an update on the status of the NCI Listens and Learns Web site. Ms. Brooke Hamilton explained that the site is currently down because NCI staff are fixing a security flaw. OAR plans to put the site back up with the discussions made to date. Without a permanent director, it has been difficult to decide what the future of the site should be. Now that Ms. Bell has become the Director of OAR, it should be easier to move the process along.

Ms. Graff emphasized the importance of early diagnosis. Patients need to be empowered to report their symptoms, and physicians need to be educated about diagnosing cancer. She wondered how to transmit the results of research to primary care physicians.

Mr. Dodson commented that most community members do not understand clinical trials. Doctors could explain that clinical trials usually mean receiving a new intervention, a new combination of existing interventions, or standard care. However, doctors do not always think about clinical trials when they see patients. Once people understand what clinical trials involve, their attitudes change and they become more likely to participate.

Next Steps

Mr. Ulman explained that Ms. Guest and the OAR staff would assemble a list of the recommendations made by the DCLG members. Ms. Guest will circulate the letter to the Director with the recommendations to the DCLG members for their approval. Mr. Ulman invited DCLG members to send additional recommendations for NCI to Ms. Guest.

Public Comments

Ms. Holtz noted that clinical trials exclude people with comorbidities to protect patients and eliminate bias. However, she supports a recommendation to explore options other than excluding patients. Ms. Holtz also reported that the annual conference of the Center for Information & Study on Clinical Research Participation (http://www.ciscrp.org) brings together people who

have participated in clinical trials to share their experiences. This event is helpful for informing patients about what clinical trials involve.

Ms. Holtz suggested that the DCLG consider establishing a speaker's bureau. The group could distribute information on each member's biography and areas of expertise and other groups could call on them to make presentations.

Closing Comments

Mr. Ulman asked DCLG members to forward comments on the meeting agenda or the meeting itself to him, Dr. Laird, or Ms. Guest. He also explained that Ms. Guest would ask each DCLG member to prepare a thank-you note for one or two speakers at this meeting.

Mr. Ulman closed the meeting by distinguishing between a crowd and a community. In a crowd, people push and shove to get ahead. In a community, everyone realizes that no one makes progress unless everyone makes progress. He stated that it is truly a pleasure to work with the DCLG community. By continuing to talk and make recommendations to the Director, the DCLG will help everyone advance.

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

DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE
DIRECTOR'S CONSUMER LIAISON GROUP
October 24–25, 2007

Action Items

- DCLG members will inform their communities that Dr. Julia Rowland will lead NCI's Understanding NCI toll-free teleconference on December 11 from 1:00 p.m. to 2:00 p.m. EST. *
- Ms. Elizabeth Neilson will send information on the diversity of the CARRA membership to Ms. Guest for distribution to the DCLG. *
- Dr. Shobha Srinivasan will forward information on the NIH Partners in Research program and the NIH Community Participation in Research program to the DCLG. *
- Ms. Lubenow will modify her presentation to explicitly include advocates in the slide showing the cancer research web.
- Anne Lubenow will serve as liaison between the President's Cancer Panel and the DCLG and provide updates on the Panel's reports as well as implementations of the Panel's recommendations.
- Ms. Guest will ask each DCLG member to prepare a thank-you note for one or two speakers at this meeting.*
- DCLG members will forward any comments on the meeting agenda or the meeting itself to Mr. Ulman, Dr. Laird, or Ms. Guest.*
- DCLG members will send additional recommendations to Ms. Guest.*
- Ms. Guest and the OAR staff will assemble a list of the recommendations made by the DCLG members. They will then circulate the letter to the director with the recommendations to the DCLG members for their approval.
- DCLG presentations include an explanation of how they relate to one of the three DCLG priorities.*
- Presentations to the DCLG should not only highlight successes, but also challenges, so that the DCLG has the opportunity to use its expertise to help solve these problems.*

NOTE: Action Items with an * have been completed.

Recommendations

Recommendations for NCI

- Find ways to include non-traditional cancer organizations in a way that does not put the responsibility for overcoming barriers to collaboration wholly on the shoulders of the community organization.
- The Cancer Centers are now willing to support the NCCCP pilot concept, and may need incentives to promote collaboration with NCCCP and with each other.

- Request award recipients refuse funding from tobacco companies.

Health Disparities

- Consult underserved communities. Create and strengthen partnerships with organizations working on cancer health disparities, such as community clinics, state level primary care associations, and community-based participatory research.
- DCLG would like reports on the progress of the Community Networks Program.
- The DLCG would recommend increasing funding for the Patient Navigator Program so it can fulfill its 5 year commitment.
- Review patient navigator training that is provided by the American Cancer Society. Does this program appropriately address issues of cultural diversity?

Clinical Trials

- Enhance enforcement of existing requirements regarding inclusion of minorities, women and children in research and clinical trials as appropriate.
- Encourage incentives for minority recruitment to clinical trials.
- Encourage enrollment of people with co-morbidities in clinical trials associated with the NCCCP. Study the population of people placed in these studies to see if they have more adverse events than people without co-morbidities.
- Work with the Dr. Prindiville to improve the communication efforts of the CCCT, specifically ensuring that the right folks in the advocacy community are informed of upcoming state of the science meetings.

Communication

- Sponsor a general public relations campaign to break through barriers and eliminate misconceptions that affect all populations, especially the medically underserved.
- Develop an advocate ambassador program, so advocates can use PowerPoint slides and a short video to conduct presentations in their community regarding the difference NCI programs make in the community.
- Identify tools (white paper, annual report, user-friendly meeting notes, etc) and use them to speak with one voice when representing NCI to ensure maximum possible impact on decision makers.

NCI Community Cancer Clinics Program

- NCCCP broaden its circle of advocates to include non-traditional cancer organizations.
- Keep the DCLG informed of the results of the NCCCP evaluation surveys.
- Keep the DCLG informed of how the Native American NCCCP sites are communicating with the Native American communities they are serving.
- Inform the DCLG of NCI plans to disseminate information regarding NCCCP sites to disparate populations so that the DCLG can learn if and how community organizations can support these activities.
- DCLG should receive reports regarding the NCCCP site and the DCLG can determine how it can be supportive of the pilot.
- Communicate with the advocacy community about the NCCCP and encourage advocacy organizations to support and collaborate with the NCCCP sites

- Dr. Maureen Johnson recommended that Ms. Cece Whitewolf support the NCCCP by communicating with the Native American sites about how the community can help them achieve their goals.
- Dr. Maureen Johnson recommended that Ms. Cece Whitewolf participate in a teleconference of the Disparities Subcommittee to share information with the NCCCP sites.
- Dr. Ken Chu recommended that Dr. Grace Butler describe her programs at a monthly meeting of the NCCCP Disparities Subcommittee in order to introduce the possibility of collaborating.

American Indian Affairs

Ms. Cece Whitewolf asked Dr. Leffall if the PCP studied the issue of the ceremonial use of tobacco among Native Americans, Dr. Lefall asked that Ms. Whitewolf provide him with this information:

- Ms. Cece Whitewolf offered to conduct a training session for DCLG members regarding tribal government relations, Indian Health Services, and how this complex system interacts with clinical trials, prior to the next DCLG meeting.
- Modify how NCI works with tribal governments in the following ways; create an Indian desk and form a team to communicate with Native communities about NCI's mission and opportunities for collaboration.

Recommendations for the DCLG

- The DCLG should carefully consider its recommendations for NCI. If it recommends expanded funding for NCCCP, the group must recognize that NCI will need to cut another program. The DCLG must keep in mind what is most important for patients.
- The DCLG should become familiar with the way funding targets are established – Congressionally setting a target number of investigators might be useful for building infrastructure, but might not be the best way to spend the NCI's money.
- The DCLG members should stay current on legislation presented by Ms. Erickson. This is done by her presentation at each meeting
- The DCLG members should collect perspectives from the broad patient/advocate community and bring them to the DCLG.
- Recruit representatives from populations with disabilities and gay/lesbian/transgender (GLBT) communities to CARRA and the DCLG.
- Assist NCI with patient accrual, particularly under-served populations, at their NCCCP sites by communicating with advocates in their communities and asking other organizations to do likewise.
- DCLG members should, after each DCLG meeting ask themselves the following:
  - What will I do within my own organization with the DCLG meeting materials I receive?
  - What will I do to distribute DCLG meeting materials to constituencies?
  - What will I do with my organizations media?
- Be more aggressive in promoting the activities of NCI and the DCLG.
- When members' organizations are featured in the media, include a statement recognizing NCI's work in bringing care into the community through programs such as NCCCP and the Patient Navigator Research Program. (e.g. highlight NCI successes)

- Within members' organizations create a tip sheet of actions to take whenever a member receives materials from NCI. OSPA tried to do this with the at-a-glance of the bypass and now they are creating an at-a-glance of the strategic plan.
- Establish a speaker's bureau for use by the public.

Recommendations for the President's Cancer Panel

- Address the outcomes of previous PCP report recommendations in order to track changes relating to their work.
- Elevate the amount of attention, awareness, and resources committed to cancer prevention.
- Ask that action be taken to implement the recommendations of the PCP reports.

Resource List

- NCI Government and Congressional Affairs – http://legislative.cancer.gov
- PCP Report: *Promoting Healthy Lifestyles: Policy, Program, and Personal Recommendations for reducing Cancer Risk*
- *Facing Cancer in Indian Country: The Yakama Nation and Pacific Northwest Tribes*
- *Cancer Epidemiology in Older Adolescents and Young adults 15 to 29 Year of Age, Including SEER Incidence and Survival: 1975-2000* - http://seer.cancer.gov/publicaitons/aya
- *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer* - http://planning.cancer.gov/disease/AYAO_PRG_Report_2006_FINAL.pdf
- *Closing the Gap: A Strategic Plan - 1*http://www.livestrong.org/atf/cf/%7BD0794917-422C-499C-9C48-9ED3DDC42947%7D/LAF%20YAA%20Report.pdf
- *Cancer Care for the hole Patient* – Institute of Medicine report
- Office of Cancer Survivorship data on diverse populations – http://dccps.nci.nih.gov/ocs/
- PCP Report: on survivorship
- NCI Community Cancer Centers Program (NCCCP) Pilot - http://ncccp.cancer.gov
- *2006 CRCHD Summit Report* – http://ww.cancermeetings.org/CHDSummit06/
- Community Networks Program – http://crchd.cancer.gov/
- Center for Information and Study on Clinical Research Participation – http://www.ciscrp.org