

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

**Summary of Meeting
October 18-19, 1999**

The NCI Director=s Consumer Liaison Group (DCLG) convened for its 3rd regular meeting at 8:30 a.m., October 18, 1999 in Conference Room D, Natcher Conference Center, National Institutes of Health (NIH).

DCLG Members

Mr. Michael Katz, *Chairperson*
Ms. Paula Bowen (absent)
Ms. Susan Lowell Butler
Dr. Manuel Castillo
Ms. Kerry Dewey
Ms. Venus Ginés
Dr. Felicia Schanche Hodge
Ms. Susan Leigh
Ms. Ruth Lin
Ms. Gena Love
Mr. Daniel Moore
Ms. Lillouise Rogers
Ms. Susan Stewart (via telephone)
Dr. Brad Zebrack

NCI Speakers

Dr. Richard Klausner, Director, NCI
Dr. Jeff Abrams, Senior Investigator, Cancer Treatment Evaluation Program
Ms. Nelvis Castro, Chief, Health Promotions Branch
Ms. Mary Ann Guerra, Deputy Director for Management
Dr. Gary Kreps, Chief, Health Communication and Informatics Research Branch
Ms. Elaine Lee, Acting Director, Office of Liaison Activities
Mr. Nick Martin, Chief, Computer Communications Branch
Ms. Mary McCabe, Director, Office of Clinical Research Promotion
Dr. Jed Rifkin, Associate Director for Information Systems and Computer Services
Dr. Barbara Rimer, Director, Division of Cancer Control and Population Sciences
Dr. Ann Thurn, Acting Director, International Cancer Information Center
Mr. Paul Van Nevel, Associate Director for Cancer Communications

NCI OFFICE OF LIAISON ACTIVITIES STAFF

Elaine Lee (Acting Executive Secretary, DCLG)
Maria Stamos
Kristie Dionne

Sabrina Ferguson
Tracy Clagett

CALL TO ORDER AND OPENING REMARKS

Mr. Michael Katz called the meeting to order and asked for a moment of silence in honor of Eleanor Nealon, Director of the NCI Office of Liaison Activities, who has done so much to make the DCLG a success, and who is struggling with the effects of metastatic breast cancer.

REPORT OF THE DIRECTOR

Dr. Richard Klausner, Director, National Cancer Institute (NCI) echoed Mr. Katz=s remarks and announced that NCI would be creating an Aextraordinary communicators@ lecture series, named (during its inaugural year) in honor of Eleanor Nealon.

Health Communications. NCI=s communications initiatives continue to evolve in response to external advice, including the 75 issues and recommendations identified by the DCLG in its report to NCI. One example is the question of how NCI should be structured, internally, to deal with communications-related policy, priorities, reporting, and evaluation. NCI has established a Design Group to describe the functions, responsibilities and expertises that would be needed to effectively carry out communications and marketing activities for a complex research enterprise. Their report is expected in October 1999, and NCI will decide by Thanksgiving how to act on their recommendations. NCI will present its decision to the DCLG next April.

The Bypass Budget for 2001 contains an Aextraordinary opportunity@ in the area of health communications. NCI agrees with the DCLG that health communications should be a more central component of its mission, both part of and more closely integrated with its research activities.

Other activities that NCI will undertake in response to the DCLG=s recommendations in the area of health communications will include (1) broadening NCI=s marketing and public awareness campaign (e.g., CIS and CancerNet), (2) reviewing and applying the results of communications research, and (3) focusing on the communications needs of specific communities (e.g., the CancerVoice transcription technology). NCI has also built many of the DCLG recommendations into the design of PDQ and the NCI Website, including usability testing and keyword searches. NCI is also undertaking a Abranding@ campaign to increase its visibility.

NCI will continue to report to the DCLG on these and other activities in response to its 75 recommendations on health communications, and it will call on DCLG members for ad hoc advice on specific projects.

Quality of Cancer Care. In the Spring of 1999, the National Cancer Policy Board (a committee of the Institute of Medicine) issued a report entitled "Ensuring Quality Cancer Care." This report asserted that the federal government, and implicitly NCI, has a unique and central role in providing quality cancer care. The report presented ten recommendations, five in the area of research (e.g., measurement and definitions) and five in the area of delivery (e.g., standards and expectations). The National Cancer Advisory Board endorsed the report=s findings and recommendations, particularly with regard to definitions, measures, benchmarks, and standards.

NCI has identified six broad sets of issues on which it can act in response to this report:

1. There should be a generally accepted set of standards and measures for quality of care across the spectrum of cancer.
2. There should be a national system to measure and monitor quality of care.
3. Discoveries in the laboratory often should be not moved more quickly into clinical trials and to the aid of patients.
4. The communication of evidence-based information to populations and patients at risk should be a central component of quality cancer care.
5. More attention should be focused on identifying and reducing inequalities in the quality of care to vulnerable populations.
6. There should be better integration between research on quality of care and the actual delivery of care.

Dr. Klausner proposed the Department of Health and Human Services (HHS), to create the Quality Cancer Care Committee (QC3), a federal task force to develop an effective research program on the quality of cancer care. QC3 also would work with policymakers from HHS and other departments, such as the Departments of Defense and Veterans Affairs, to find out what information they need to facilitate the implementation of this research. A formal proposal will be made to the White House on December 14, 1999 and NCI will report to the DCLG at its next meeting on the progress of the proposal. Dr. Klausner suggested that Drs. Lipscomb and Hiatt from NCI=s Division of Cancer Control and Population Sciences present the proposal on quality of care.

Discussion and Questions. Ms. Butler asked about NCI=s response to a sensationalistic article on clinical trials that recently appeared in *U.S. News & World Report*. Dr. Klausner said that he wrote a letter to the editor, as have several advocacy groups, and he hopes that othersCincluding the DCLGCmight decide to do the same. He added that the response should be balanced and should show appropriate concern for the safety of individual patients, as well as the integrity of the clinical trial system. He believes that current discussions with policymakers, insurance companies, and patient groups are all making progress.

Other questions had to do with the appropriateness of NCI materials, the NCI Website, and the departure of Dr. Varmus, Director of the NIH. Dr. Klausner responded that NCI continues to struggle with the issue of appropriateness, particularly with regard to readability standards, and he asked the DCLG to identify other agencies that have successfully dealt with this issue. Regarding the Website, he cautioned that there were legal limits to what NCI could say and endorse, but that they could point users to other sources of information. He invited the DCLG to suggest possible links. Dr. Klausner does not believe that Dr. Varmus= departure at the end of the calendar year will have any effect on NCI=s ability to act.

Finally, Ms. Love asked about changes in the status of the Office of Research on Minority Health (ORMH). Dr. Klausner explained that there is a congressional request that ORMH become a separate Center, with its own grant-making authority, and that language to this effect might be included in the final appropriations bill. He is not convinced, however, that this change would improve the quality of minority-related research, and he shares Dr. Varmus= concern over the further balkanization of NIH. ORMH is already well situated to coordinate the efforts of other Institutes, such as NCI, that possess the personnel and expertise to pursue needed research.

DCLG CALL FOR NOMINATIONS UPDATE

Ms. Elaine Lee, Acting Director of the NCI Office of Liaison Activities, reported that the nomination process for five new members of the DCLG began in August. Nominations are due November 1, about 900 nomination packages have been requested. Interviews will be conducted by February 2000, and the new members will be announced in July 2000. They will attend the October 2000 meeting of the DCLG.

Ms. Lee explained that NCI is seeking diversity of all kinds and has announced the call for nominations to a wide variety of groups, mailing lists, and media. The 1997 nominees have also been contacted. Most of the requests for nomination packages have come from application forms on the NCI Website.

In response to questions, she added that the final selection will be made by Dr. Klausner. DCLG members are free to nominate or to submit letters of support. There has been no change in the constituency group requirement: it can be formal or informal.

CHANGES TO THE CLINICAL TRIALS SYSTEM

Ms. Stewart presented her report on changes to the clinical trials system by telephone. Dr. Jeff Abrams of NCI=s CTEP assisted her in the presentation. At present this system consists primarily of the twelve Cooperative Groups, which generate most of the ideas for trials and enroll about 20,000 patients each year. Despite its proven strengths, this system limits the input of ideas and patients from outside the Cooperative Groups. In addition, the system underemphasized innovative pilot trials, and there is much duplication of administrative functions among groups. In August 1997, NCI=s Cancer Clinical Trials Review Group made 48 recommendations to simplify and improve the system. These recommendations focused on six central goals:

1. Open up the process for generation of ideas
2. Increase enrollment in clinical trials
3. Continue ongoing efforts to make trials more patient-friendly
4. Reduce the administrative burden on Cooperative Groups and participating physicians
5. Increase emphasis on translation research and early clinical trials
6. Address funding and incentives to ensure the long-term viability of the system.

The planned changes will not happen immediately. Many of these changes must first be tested in pilot programs, and rapid accrual—the key to faster progress in the war against cancer—won=t happen without the cooperation of third-party payers and providers. Both of these steps may take years to come to fruition. As consumer representatives, the DCLG needs to be involved in the evolution of these programs in order to ensure that streamlining the system does not result in less vigilance in the areas of patient education and protection.

Discussion and Questions. Most questions focused on Aquality of life@ and minority recruitment. Dr. Hodge asked whether there would be targeted efforts to recruit minorities, particularly the American Indian patients and Indian Health Service physicians who are not currently encouraged to go into clinical trials. Dr. Abrams replied that these changes would open the system to *all* physicians and their patients, but that they do not currently include specific strategies to increase minority participation. Ms. Ginés asked if quality of life instruments have been tested for cultural appropriateness in different populations. Ms. Lin suggested that there should be an effort to recruit bilingual physicians, and to translate materials into more languages.

Dr. Castillo asked how these changes would address the economic barriers to participation. Dr. Abrams said that negotiations are underway with insurance companies, who at present may not cover the costs of medical care given in clinical trials. Other possibilities include reimbursing participating physicians for the cost of their research activities. Ms. Butler pointed out that, at present, there doesn=t seem to be a program of outreach to the general public. There was considerable debate about the best way to accomplish this, for example putting Dr. Klausner on the AOprah@ show, or putting on cancer patients. There was agreement that public information issues are important to the success of these changes, that they should address the barriers to participation by special populations, and that consumers should be involved at every level.

MEDIA SCRUTINY OF THE CLINICAL TRIALS SYSTEM

Mr. Katz suggested that the recent Aexpose@ in *U.S. News & World Report* could have an explosive impact on the credibility of the entire clinical trials system. He proposed that members of the DCLG, as consumers and advocates, prepare a white paper or a set of talking points on this topic, including the salient points that need to be made in response to the article. In addition, the DCLG should designate two or three spokespersons who could make themselves available to the media to comment on this issue, and should identify NCI resources who can help with media contacts.

From a personal perspective, Mr. Katz suggested that cancer treatment often involves horrendous choices and even guesswork for patients and doctors alike. Most cancers have no sure route to cure, health care professionals aren=t always current on the latest developments, and even patients receiving Astandard@ treatment can receive conflicting or bad advice. In addition, the financial pressures of today=s health care system are destroying the trust that is critical to the patient-physician relationship. As a result, it is virtually impossible to be sure that you=re getting the best care.

For these and other reasons, cancer patients will often jump at what seem like questionable options. Unproven therapies and off-label uses of drugs for cancer treatment are common. There are wide variations in quality among clinical trials, including isolated cases of professional negligence and misconduct. Yet the clinical trials system represents our best hope for discovering new therapies, and patients in clinical trials are better monitoredCand better protectedCthan patients receiving standard care. Mishaps involving the 3 percent of patients in clinical trials receive close official scrutiny and broad publicity, while mishaps involving the other 97 percent of patients, those getting standard care, go largely unnoticed.

It would be better to focus attention on the more serious threats to those battling cancer, including cost containment, the lack of a Astandard of care@ for many cancers, and the underfunding of promising research. In this environment, undue media attention on clinical trials can hurt accrual and slow the progress of cancer research.

Discussion and Questions. Ms. Butler suggested that the DCLG=s response should emphasize two points: (1) there can be no progress against cancer without clinical trials, and (2) NCI=s clinical trials involve the best possible controls and protections. She also suggested that several benchmark studies be used as examples and illustrations of these points. Ms. Rogers added another point, namely (3) no one goes untreated in clinical trialsCeven the control group gets the standard treatment. Both agreed that the DCLG should get this message to the broader public, not just cancer patients. Several studies are underway to determine how well the general public understands the clinical trial system.

Ms. Love suggested that the article achieved a strong impact because it played to people=s fears and prejudices, pointing to the need for broader education. Dr. Castillo said that the DCLG=s response should emphasize the point that clinical trials save lives. Ms. Leigh added that the public doesn=t understand what quality cancer care means, and for this reason it is vital to push the QC3 initiative, but the most effective testimony will come from participants and survivors, not from physicians. Ms. Stewart agreed: NCI should talk about the patients who survived cancer because they were in a clinical trial.

Ms. Butler suggested that the *U.S. News & World Report* article might lead to the detriment of clinical trials. Mr. Katz asked if another letter to the editor would be effective, or whether instead the DCLG should work with NCI to develop a Apitch@ on the importance of the clinical trial system, to be carried by the mass media. Dr. Zebrack suggested that advocacy groups should circulate the white paper among their constituencies, but several members agreed that the DCLG and the consumer community should cooperate with NCI=s media branch on a broader, proactive campaign.

INFORMED CONSENT PROGRESS REPORT

Ms. Mary McCabe reported that recommendations of the Informed Consent Working Group along with the sample template were mailed to the Cooperative Group cancer centers, NCI grantees, and local IRBs. The entire report has also been posted on the Web cancerTrials.nci.nih.gov, and presented to other NIH units and to overseas groups. Revisions are underway for pediatric patients, and future efforts will include translation to Spanish, studies of comprehension, and surveys of IRBs to determine their acceptance of the new document and understand any concerns they may have with this simplified approach. Experience to date indicates that investigator groups have been slow to change, especially if they think the change will delay the launch of a trial, and because they are concerned about the response of their IRBs.

Discussion and Questions. In response to questions, Ms. McCabe added that the feedback from IRBs about the new document has been positive thus far. IRBs are impressed that the forms are easy for people to use and do not contain legal jargon. Most investigators have been positive, as well, but many participating physicians don=t yet seem to be aware of the recommendations.

Dr. Castillo pointed out that there are many different dialects of Spanish, and that care should be taken that the form is translated to the appropriate dialect. Ms. Lin suggested that some investigators or institutions might feel that the streamlined form might not give them as much protection at the old form. Mr. Katz suggested that some users might need feedback on how well they're using the new template, and suggested that the next iteration include a list of dos and don'ts or best practices, based on initial experience with the revised form.

COMMUNICATIONS INITIATIVES

Mr. Katz reviewed the steps that have been taken since April in the DCLG's review of NCI communications initiatives. In general, he has found that the recommendations are based on moving targets, largely because NCI has already begun to respond to them. Many programs are already in place, but he emphasized the need for more effort to span initiatives and integrate activities, for example when a consumer requires information from several programs. In addition, he has found that NCI often takes a back seat to other groups in communicating with the public, and suggested that in at least some areas NCI should take more of a leadership role. Three top priorities emerged from the April meeting:

1. DCLG involvement in the extraordinary opportunity communications (this has already begun)
2. Appropriateness of communications materials
3. Accessibility of services

The DCLG has asked NCI components to report on their programs and resources in the areas of appropriateness and accessibility, and there followed presentations describing examples of some of these activities.

Appropriateness and Accessibility Programs. Ms. Mary Ann Bright and Ms. Lisa Rubenstein of the Cancer Information Service (CIS) described several culturally appropriate programs launched by the Partnership Program (previously called the Outreach Program). These included a number of Atrain-the-trainer@ and public information programs that have been developed in cooperation with African American, Arab American, American Indian, Native Hawaiian, and Latino groups. American Indian materials have been further adapted for use with different tribes. Culturally appropriate materials include speakers= kits, slides, local examples, and materials in a variety of written materials in numerous different languages.

NCI has also recompleted the contract for the CIS, reducing the number of regional centers from 19 to 14, of which three are Spanish-language centers -- one in Florida, one in Texas, and one in California. At present about two percent of calls to CIS are in Spanish, and NCI is taking a number of steps to identify regional differences in both terminology and cultural Atrigger points.@ NCI is partnering with a number of Latino organizations to increase the visibility and

use of these centers by underserved Spanish-language populations. Other programs are directed at underserved populations that don=t use the telephone.

NCI=s Patient Education Branch (PEB) maintains a number of educational resources for patients, families, and caregivers. Core resources include a number of booklets that are available in both English and Spanish; an inventory shows that about 50 cancer-related pamphlets, fact sheets, posters, videotapes are already available in Spanish. No other translations are currently available. However, Spanish has been the only language target thus far. The Cancer Patient Education Network has identified ten additional languages into which at least some of these materials could be translated, and NCI uses consumer groups to assist in translating, reviewing, and disseminating culturally appropriate versions of these materials. PEB is also adapting these materials for the Web.

NCI has also published Spanish translations of the online summaries in PDQ and the materials from its Office of Clinical Trials Promotion. The Health Promotion Branch has developed culturally appropriate materials on cancer screening and nutrition for older, Latino, African American, and American Indian women. Thus far, these materials have focused on breast cancer, but there are plans to include other cancers, and to translate into other languages, in the future. NCI is eager to get feedback and advice from the target audiences and will be grateful for input from the DCLG on which cancers and which languages should receive priority.

Discussion and Questions. Ms. Ginés pointed out that the needs and sensitivities of different Latino populations may be very different, and that CIS would do well to include cross-training at these three centers. She added that Mexican American women, in particular, are reluctant to ask for help because of a history of bad experiences.

Dr. Castillo suggested that a good goal, in terms of the percentage of CIS calls, would be the Latino percentage of the U.S. population. He added, however, that there are other groups that are even harder to reach and have other concerns. Examples include Vietnamese women (who have a very high rate of cervical cancer) and Chinese men (who have a relatively high rate of nasopharyngeal cancer). Consumer research on these and other Asian populations indicates that they are interested in receiving information from the federal government, which puts NCI in a good position to partner with community groups to improve outreach efforts.

Ms. Butler suggested that the reading level in NCI materials may be too high. Dr. Castillo estimated that they require a eighth or ninth grade reading level, and that a fourth grade reading level might be more appropriate, even in English. Technical terms in particular need to be better explained, and formats should include more pictures and graphics.

Mr. Katz suggested that DCLG members consult their constituencies and report back at the next meeting on how well different NCI messages and initiatives are reaching specific populations. He added, however, that the present list of NCI publications and materials are not synthesized.

That is, what are NCI=s outreach priorities in terms of specific programs, populations, and cancers? What components are in place, and which are missing? Mr. Katz suggested that a look at mammography campaigns and information might be a good place to start this kind of analysis.

Other suggestions included materials about liver cancer, which is common in Asian and Latino populations, and those targeted toward older patients.

Ms. Guerra pointed out that many of these outreach materials had been developed in isolation, as components of particular outreach initiatives, and not as part of an overall NCI strategy. With NCI program staff, she will assemble several samples of campaigns, including reasons for their development, the process or strategy that was followed, and evaluations of those efforts.

Mr. Katz suggested that she present this summary to a working session prior to the next meeting, so that the DCLG could if appropriate, seek input from constituencies to be presented at the meeting in April 2000.

UPDATE ON THE EXTRAORDINARY OPPORTUNITY

Dr. Rimer paraphrased the extraordinary opportunity as follows: To use decision aids and other tools of cancer communications to support research to reduce the risk of morbidity and mortality and to improve quality of life, especially for underserved populations, including the elderly and minorities. The plan currently contains four goals:

1. Accelerate the reduction in the overall burden of cancer
2. Integrate cancer communications into quality cancer care
3. Use communications to speed the dissemination of best practices
4. Develop the infrastructure for rapid advances in knowledge about cancer communications

NCI will pursue these goals through activities such as the following:

- X Developing a national data collection on cancer communications, including a triennial national survey
- X Promoting interdisciplinary research in cancer research, including the creation of Cancer Communications Centers of Excellence
- X Developing an integrated strategy for managing and disseminating knowledge about cancer communications

- X Developing practical tools for the dissemination of cancer communications
- X Enhancing partnerships with academia, industry, and other U.S. biomedical research organizations
- X Training the next generation of communications and decision scientists

Work has begun on an RFA in cancer communications and the AExtraordinary Communicators@ lecture series. The DCLG has a representative on the working group to refine, implement, and monitor these activities.

Dr. Gary Kreps outlined the topics that would be addressed by NCI=s new program of communications research, which includes the needs and preferences of different audiences. He asserted that information may be the single most important resource with regard to health care, and predicted that NCI=s communications research program would be the model for many others. One major initiative will be the Health Information National Triennial Survey (HINTS), which will provide baseline data on who has what information, from what sources, and how they decide which information is reliable. Repeated on a periodic basis, this survey will provide longitudinal data that will reveal trends and measure the impact of communications initiatives. The Communications Research and Informatics Branch (CRIB), will coordinate its activities with other NCI offices, NCI grantees, and NCI=s partners in outreach and education, to ensure the application of this new knowledge.

Mr. Katz said that he was pleased to hear the word Abaseline,@ since no such foundation currently exists. Mr. Moore suggested that the dissemination of this knowledge should take advantage of the facilities offered by public libraries across the nation.

CONSUMER REQUIREMENTS FOR THE NCI WEBSITE

Mr. Katz reported that NCI is working hard to upgrade its Web presence, including the redesign of the PDQ site and usability testing for other sites. ALook and feel,@ as well as search aids, are still under development. Based on his own exposure to a prototype Website, Mr. Katz suggested that these activities should be guided by a number of general principals:

- X Keep it simple, using what=s worked elsewhere on the Web (e.g., HHS Healthfinder site)
- X Make it easy to use, with simple search tools and a Abriefcase@ to collect documents as you browse
- X Integrate what CIS knows about consumer needs, including translations and a thesaurus
- X Include a link to a human, either by e-mail or phone (e.g., CIS)
- X Provide information at both simple and more complex levels, with an emphasis on the information that users need to deal with their physicians or families

- X Recognize that no single site can answer all possible questions and provide links to other sources of information (with disclaimers as necessary)
- X Provide a feedback mechanism to identify gaps in coverage or knowledge

The consumer portal to the NCI Website should focus on getting the users to the information they want as quickly and easily as possible. Given the wide variety of audiences involved, this will call for great flexibility and an array of Ahelp@ functions, such as AToo Complicated@ or AEspañol.@ Second-level pages will deal with disease-, age-, or community-specific questions, as well as more general issues such as treatments, quality of life, communicating with your doctor, and finding other sources of help and support. Consumer advocates, including the members of the DCLG, are particularly well situated to help NCI design audience-focused pages, and usability testing of the overall site.

Discussion and Questions. Ms. Dewey asked if the Website received hits from overseas and, if so, whether it could handle the language challenges. Ms. McCabe reported that most international hits came from Spanish-speaking countries, and that NCI tries to refer these users to CIS-like services in their home countries.

Mr. Moore suggested that, since some users would be dealing with end-of-life issues, there might be a link to information about wills and advance directives. He added that NCI should emulate useful features on the Websites of other institutes, such as the National Institute on Aging=s page on Atalking to your doctor.@ Ms. Leigh pointed out that consumer advocacy groups already have a lot of valuable information on their own sites; what=s needed is a mechanism to evaluate and link those sources to the NCI site. Ms. Guerra reminded the group of the need for NCI to place disclaimers on such links, and of the resources required for NCI to ensure that they (like the NCI site) are regularly maintained and updated. Ms. Butler agreed -- if this is to be the best cancer Website in the world, it can only have links to quality sites.

During a discussion of sample pages, DCLG members suggested that the coverage should be expanded to include more statistics, where they are available and reliable, and to address issues such as recurrence, sexuality, and referrals for problems other than cancer. Mr. Katz suggested that NCI recruit advocates to give advice on the content and links of specific pages. Ms. Leigh suggested that the DCLG help NCI to establish an oversight committee, with representatives from the various organizations to which the site might link to help NCI evaluate and maintain the outside consumer links on its Website.

It was agreed that Ms. Guerra and Dr. Rifkin would carry these comments and suggestions to Dr. Klausner and follow up with Mr. Katz, who would report back to the group.

DCLG STATUS REPORT

Mr. Katz reported on the evolution and accomplishments of the DCLG. It held its first meeting as a working group. In the first year as a working group its agenda was largely driven by NCI staff. It became a chartered group in August 1998. DCLG members participate in numerous

committees and activities involved in forming NCI programs and policies. During the first year, the DCLG identified issues that it would be interested in pursuing - to learn more about, or to provide input to NCI. For example, the DCLG members requested that NCI prepare a genetics primer to help them learn about genetic research and how it may impact individuals. This resulted in publication of AUnderstanding Genetic Research and Population-Based Studies.@ They also provided input on a simplified informed consent template project led by NCI and suggested ways for disseminating it.

During the past year, the DCLG began to gather, synthesize, and present consumer feedback about selected NCI communication initiatives. Specific accomplishments during its first two years include the following:

- X The DCLG initiated the creation of a genetics primer, AUnderstanding Genetic Research and Population-Based Studies@
- X It provided input on design and support for disseminating the new informed consent template
- X It reviewed the draft position paper on confidentiality issues
- X It provided input on consumer involvement in peer review and how to educate consumers in this role
- X The DCLG was one of several groups proposing the Extraordinary Opportunity in Cancer Communications for the 2001 Bypass Budget
- X Members participated in numerous NCI forums and served on review panels
- X It is helping NCI to improve its communications initiatives

Issues with which the group is still struggling include (1) the appropriate public profile of the DCLG and (2) the appropriate role of the DCLG within NCI. The first involves the DCLG=s interaction with the media, as well as their own advocacy community; the second involves the DCLG=s role in shaping and building support for NCI=s research and service agenda. In some areas NCI is leading NIH including consumers in Institute planning and programs. Nevertheless, there is a need for continued, explicit dialogue with NCI staff on these topics.

Mr. Moore will work with Mr. Katz and Ms. Lee to prepare a more detailed narrative version of this status report, which would be circulated to the other members for their review and input. The final report will be submitted to Dr. Klausner and posted to the NCI Website as an annual report.

NEW BUSINESS

Special Populations Working Group is a working group which reports to the Advisory Committee to the Director, NCI it serves as a link between NCI and special populations. Ms. Rogers reported on the first meeting of the ACD Special Populations Working Group (SPWG), which will help the ACD and NCI to identify and address the needs of minority and medically underserved populations. Dr. Klausner tasked the SPWG to review the IOM report on the AUnequal Burden of Cancer@ and offer the ACD feedback to it, as well as to NCI=s response to the report.

Ms. Ginés reported on the second meeting of SPWG, at which the group weighed the pros and cons of being an ad hoc group, rather than a chartered advisory board. The RFA on the special populations network (which had already been issued) and the number of applications received to date were discussed. NCI staff asked SPWG to provide input to the NCI=s Office of Special Populations Research develop a strategic plan for research on special populations. SPWG members suggested instead that NCI (1) establish a Program Review and Implementation Group to deal exclusively with IOM recommendations; and (2) develop a NCI-wide strategic plan for research on minority and medically underserved populations. A compromise was reached whereby sections related to minority and medically underserved or special populations research will be extrapolated from previous Program Review/Implementation Group reports and given to the SPWG to use as a starting point for the development of a NCI-wide Strategic Plan. SPWG members will be able to utilize additional ad hoc members, so that the final proposed strategic plan will be comprehensive and scientifically rigorous. The proposed strategic plan will be submitted to NCAB, the NCI Executive Committee, and other internal and external groups for review.

SPWG will meet again on December 8 and 9, 1999, and quarterly thereafter. Drs. Castillo and Hodge volunteered to attend the next SPWG meeting. Other members asked what definition of Aspecial populations@ was being used. For example, are the elderly included, or only if they are also underserved? Ms. Lee will get a clarification of this definition.

Applied Sociocultural Research Branch Working Group. Ms. Love reported on the meeting of the Applied Sociocultural Research Branch (ASRB) Working Group, which is designed to help that branch pursue its mission. The initial tasks were (1) to identify complementary groups, including advocacy groups, with which ASRB can partner; and (2) to assist in developing a strategic plan. The latter task involves identifying models of what works and then translating them for use by ASRB. This working group will meet annually, but no date has been set for its next meeting. Ms. Love will post her report to the Website as soon as she returns to her office.

April Meeting Planning. The group settled on April 17 and 18, 2000, for its next meeting, subject to confirmation. Agenda items will include the topics and assignments listed below. Mr. Katz suggested that the DCLG hold a ceremony dinner for outgoing members on April 17.

The following members volunteered to work with NCI staff on issues raised at this meeting, or to attend outside meetings, and to report in April 2000:

X *Extraordinary Opportunity* (date to be announced): Mr. Katz, Dr. Hodge, Dr. Zebrack.

- X *Accessibility and Appropriateness* (to interact with Ms. Guerra and report back to the DCLG at April meeting): No assignments at this time.

- X *Confidentiality* (meeting on December 1 and 2): Ms. Butler, Dr. Hodge, Ms. Leigh, Ms. Love).

- X *Clinical Trials*: Ms. Butler will prepare and circulate draft talking points. Ms. Butler, Ms. Dewey, Ms. Rogers, and Dr. Zebrack will be designated spokespersons. NCI will provide media contacts and media training.

- X *Status Report* (work with Mr. Katz and Ms. Lee to prepare narrative form by end December): Mr. Moore.

- X *Orientation of New DCLG Members*: Ms. Leigh will work with Ms. Lee to develop an information package for new members. Other members volunteered to participate in an orientation session prior to the October 2000 meeting: Ms. Dewey, Mr. Katz, Ms. Lin, Mr. Moore, Ms. Rogers, and Dr. Zebrack.

Future Meeting Dates. Ms. Lee suggested that future meetings of the DCLG be held on a Tuesday and Wednesday in October and on a Monday and Tuesday in April, in each year. This would allow for an orientation session for new members in October and an annual dinner in April. Exact dates for October 2000 and April 2001 will be announced after consultation with Dr. Klausner.

ACTION ITEMS

1. NCI will present the results of the communication review to the DCLG in April.
2. NCI will report to the DCLG annually on its continuing actions to implement the DCLG=s recommendations in the area of communications.
3. Drs. Lipscomb and Hiatt will be invited to present a status report on the QC3 initiative, including the broader topics of outcomes research and the linkage between research and delivery of cancer care.
4. DCLG members will provide NCI with examples of agencies and organizations that have dealt successfully with the issues of cultural appropriateness and readability standards.
5. DCLG members will suggest ways in which NCI can reach out to the general public in the proposed changes to the clinical trials system.
6. NCI will provide the DCLG with the results of ongoing research on public understanding of the clinical trial system.

7. Ms. Butler will prepare and circulate draft talking points on clinical trials. Ms. Butler, Ms. Dewey, Ms. Rogers, and Dr. Zebrack will serve as designated spokespersons. NCI staff will provide media contacts and media training as requested.
8. DCLG members will consult their organizations about how well CIS, PEB, and other NCI outreach and education efforts are serving their particular constituencies, and report back at the next meeting.
9. With NCI program staff, Ms. Guerra will assemble examples of outreach campaigns and evaluations of those efforts, and present a summary to a DCLG working group prior to April, for discussion at the next meeting.
10. Ms. Guerra and Dr. Rifkin will report to Dr. Klausner on the DCLG=s comments and suggestions about the NCI Website and follow up with Mr. Katz, who will report back to the group.
11. NCI will present a status report on consumer involvement in peer review at the April meeting.
12. Mr. Moore will work with Mr. Katz and Ms. Lee to prepare the narrative form of the DCLG status report, which he will circulate to other members.
13. Dr. Castillo or Dr. Hodge will attend the next SPWG meeting, December 8 and 9, and report to the DCLG at its next meeting.
14. OLA will provide the DCLG with the definition of Aspecial populations@ that is applicable to the work of the Special Populations Working Group.
15. Ms. Love will prepare a written report on the ASRB Working Group.
16. Ms. Leigh will work with Ms. Lee to develop an orientation package for new members, and Ms. Dewey, Mr. Katz, Ms. Lin, Mr. Moore, Ms. Rogers, and Dr. Zebrack will attend an orientation meeting for new members prior to the April meeting.
17. Ms. Butler, Dr. Hodge, Ms. Leigh, and Ms. Love will represent the DCLG at the NCI meeting on Patient Confidentiality, December 1 and 2.

The meeting was adjourned at 4:00 p.m. (E.D.T.)

Date

Michael Katz
Chair
NCI Director=s Consumer Liaison Group

Date

Elaine Lee
Acting Executive Secretary
NCI Director=s Consumer Liaison Group

L:\GROUP\OLA\DCLG\MEETINGS\Minutes\Minutes 10-99.doc