

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

MINUTES of the DIRECTOR'S CONSUMER LIAISON GROUP

April 22–23, 2002

The 18th meeting of the NCI Director's Consumer Liaison Group (DCLG) was convened at 9:00 a.m., April 22, 2002, at the Pooks Hill Marriott Hotel, Bethesda, Maryland. Ms. Barbara LeStage presided as Chair.

Members Present:

Ms. Barbara K. LeStage, Chair
Ms. Vernal Branch
Ms. Susan Butler
Ms. Kathy Giusti
Mr. Michael Katz
Ms. Paula Kim
Ms. Ruth Lin

Ms. Gena Love
Ms. Karen Packer
Mr. Henry Porterfield
Ms. Nyrvah Richard
Mr. Doug Ulman
Dr. Marisa Weiss
Dr. Brad Zebrack

Members Absent:

Mr. Chris Pablo

Speakers

Dr. Andrew von Eschenbach, Director, National Cancer Institute (NCI)
Ms. Jill Bartholomew, Deputy Director, Office of Communication (OC), NCI
Ms. Tracy Clagett, Advocacy Program Manager, Liaison Activities, OC, NCI
Dr. Charmaine Cummings, Acting Director, Office of Education and Special Initiatives, NCI
Ms. Nina Ghanem, Communications Coordinator, Liaison Activities, OC, NCI
Ms. Margo Michaels, Office of Education and Special Initiatives, NCI
Ms. Cherie Nichols, Director, Office of Science Planning and Assessment, NCI
Ms. Anne Tatem, Program Analyst, Office of Science Planning and Assessment, NCI

Other NCI Staff

Dr. Alan Rabson, Deputy Director, NCI
Dr. Jeff Abrams, Cancer Therapy Evaluation Program
Ms. Claire Benfer, Committee Management Officer, NCI

NCI Liaison Activities Staff

Ms. Elaine Lee, Executive Secretary, DCLG
Ms. Tracy Clagett
Ms. Nina Ghanem
Ms. Brooke Hamilton
Ms. Elisabeth Handley
Ms. Rosalyn Lemak
Ms. Keisha Martin

OPEN MEETING

I. Call to Order and Review of Confidentiality and Conflict of Interest Procedures

Ms. Barbara LeStage welcomed participants to the DCLG meeting. This meeting is historic because it is the last meeting for some of the original DCLG members. Ms. LeStage reviewed the rules governing confidentiality and conflict of interest, and Ms. Elaine Lee determined that a quorum was present.

II. Report from the Office Of Communications (OC)

Ms. Jill Bartholomew reported that NCI's Office of Communications (OC) is working with Dr. Andrew von Eschenbach, the new NCI Director, to establish a vision not only for the NCI but also for the OC. Ms. Bartholomew described some recent OC activities and upcoming events.

- Last fall, a *Lancet* review of evidence from mammography trials was reported on the front page of the *New York Times*, resulting in a flood of media interest. Reporters asked whether women should still obtain a mammogram, given the uncertain results of the trials. As of the end of February, the NCI had received more than 100 press calls on the topic, and more than 100 news stories had appeared in print and broadcast media (including *60 Minutes*). The press office also developed press releases, fact sheets, and information for NCI's Web site <http://cancer.gov>.
- This week an article will appear in *Journal of the American Medical Association (JAMA)* about a revised system for reporting Pap test results and will announce new guidelines for managing Pap test abnormalities from the American Society for Colposcopy and Cervical Pathology. The OC expects significant media coverage of this announcement.
- On May 5, the annual report on cancer incidence and mortality will appear in *Cancer*. This year's report focuses on aging and cancer and predicts that in 50 years, the number of cancer cases in the United States will double as the population ages. This is also the first annual report to use the year 2000 population standard (previous reports used the 1970 standard).
- The ENLIST screening trial, which compares randomized spiral CT scans for lung cancer to chest x-rays in current or former smokers will soon begin accruing patients. The OC has an opportunity to begin integrating its support capabilities on behalf of two key NCI divisions to prepare for and publicize this huge clinical trial. This trial will last approximately 8 years and will recruit 50,000 participants in 20 study sites throughout the United States.
- NCI's <http://cancer.gov> Web site was launched on January 22, 2002. Traffic has grown steadily since the site's launch, to approximately 50,000 "hits" each day. The Cancer Information Service has seen a doubling of instant messaging queries since the launch of <http://cancer.gov>.

Mr. Michael Katz expressed concern about the recent *Time* magazine cover story on clinical trials, entitled "Human Guinea Pigs." He said that he believes the Institute should play a more proactive role in ensuring that future articles are more positive. In addition, DCLG members could serve as spokespersons for such an effort. Ms. Bartholomew replied that the OC is drafting a response for the Director's review and approval.

Ms. Susan Butler pointed out that the most powerful advocates for clinical trials are the people whose lives have been saved by them. NCI's response should refer to the astonishing record of

survivorship in pediatric cancers, because most children with cancer participate in clinical trials. Most survivors who have done well on clinical trials are eager to tell their stories. Dr. Marisa Weiss suggested asking Consumer Advocates in Research and Related Activities (CARRA) members to list the topics on which they could speak and develop a press list of people who are available for interviews on those topics. CARRA members could be e-mailed to solicit quotes on clinical trials. Ms. LeStage added that almost everything that goes out from the NCI should include the consumer survivor perspective.

Ms. Bartholomew agreed that DCLG consider submitting its own response to the article, separate from NCI's response. Ms. Bartholomew also agreed that the NCI should develop collaborations to interest the media in the "good news." The NCI should encourage media coverage of "good news" and continue to provide facts about clinical trials online.

III. Report of the Director

Ms. LeStage welcomed Dr. Andrew von Eschenbach, the new Director of NCI and asked DCLG members and Liaison Activities (LA) staff members to introduce themselves to him. After introductions, Dr. von Eschenbach began by noting that it is important for him to relate to, and interact with the community of cancer survivors. He said that when he agreed to serve as Director of the NCI, he did so on the condition that he be able to continue to practice medicine because he wanted to continue to care for patients. He also feels that it is important to maintain a relationship with the DCLG, whose members are so keenly aware of the reality of cancer. In March, Ms. LeStage met with Dr. von Eschenbach to discuss the future of the DCLG, and he emphasized that although he is still thinking about his vision for the group, it will remain as one of his boards. Being the first director who is a cancer survivor adds an important dimension to Dr. von Eschenbach's new role as Director of NCI.

Dr. von Eschenbach came to NCI from The University of Texas M.D. Anderson Cancer Center in Houston. At M.D. Anderson, he was director of the Genitourinary Cancer Center, and of the Prostate Cancer Research Program. He has also served as Vice President for Academic Affairs at M.D. Anderson and as Executive Vice President and Chief Academic Officer, leading a faculty of almost 1,000 cancer researchers and clinicians. At Anderson, he found that multidisciplinary collaborations were the key to being able to deliver effective care to cancer patients. Furthermore, he emphasized that the solution to cancer requires that we understand that cancer is a societal problem, and its solution requires a comprehensive societal strategy. In addition to being a medical or scientific problem, cancer is an economic, cultural, political, and social problem. For NCI to provide leadership in achieving a comprehensive solution, each of these components be considered. Although he will pay attention to the Institute's medical and scientific agendas, it is important for the DCLG to provide their viewpoint and a sense of purpose for this shared endeavor.

One of the greatest challenges for NCI is not the lack of resources but under use of people. The DCLG needs to work with the Director to find meaningful ways for the group to bring its richness of insight, experience, knowledge, and, most importantly, passion to the table to help design and implement the most effective strategy possible for the NCI. He said he looks forward to the DCLG's continued service as an extremely important advisory group. He does not intend to impose an agenda on the group. Instead, he wants to create an agenda incorporating issues considered important by the DCLG.

In addition to driving the “incredible engine of discovery,” the NCI must provide leadership for translation of discovery into effective interventions for those in greatest need. The DCLG can bring the patients’ view to this process. Dr. von Eschenbach asked for the DCLG’s suggestions on how best to use the group’s talents to address some of these issues and promised that although he might not always do what the DCLG asks, he will always listen.

Survivorship is another area where Dr. von Eschenbach said that the DCLG could help him. A large portion of NCI’s supported research focuses on the cancer cell and how it works. Investigators have been “incredibly successful” in unlocking many of the secrets of the biology of cancer. But the behavior of cancer depends on the interaction between the cancer cell and its micro and macro environments, and NCI should explore this relationship. NCI needs to better understand, support, and nurture the person coping with cancer. He said that he needs the advice of the DCLG on how to accomplish this. Dr. von Eschenbach asked DCLG members to be patient with him as he takes on his new role and to not misinterpret his limited time at this meeting as a lack of interest or commitment.

Discussion. Ms. Paula Kim informed Dr. von Eschenbach that the DCLG’s Survivorship Working Group prepared a proposal for an extraordinary opportunity in survivorship that was submitted by the DCLG. To emphasize the importance of this proposal the working group asked for input from advocacy organizations and cancer survivors across the country on survivorship. Ms. Kim shared the approximately 100 responses the working group received with Dr. von Eschenbach.

Dr. von Eschenbach agreed that a much broader view of survivorship is needed. The cancer paradigm has changed fundamentally from “seek and destroy” to “target and control.” Cancer is becoming a chronic disease as more and more people live with cancer and die of something else. He would like to engage the DCLG in a larger, more visionary, and more proactive discussion of the implications of the biomedical revolution on the face of cancer and how to nurture and support those who survive as a result of this revolution.

Ms. Kim explained that the DCLG’s extraordinary opportunity encompassed the survivorship continuum. Cancer survivors are eager to address these needs, but many concerns are unique to particular communities. Mr. Doug Ulman added that although most DCLG members see themselves as cancer survivors from the day they are diagnosed, many others do not. Ms. Vernal Branch would like to see the survivorship discussion include health insurers, who need to understand that people survive with cancer. Mr. Henry Porterfield stated that when the DCLG receives information from the patient and advocate communities, NCI’s response must be communicated back out to the patient community. The DCLG and the CARRA program can help with this.

Ms. Giusti asked how collaborations between the academic community and industry in the development of new therapies could be improved. Dr. von Eschenbach replied that the NCI is attempting to facilitate public/private partnerships. He wants to ensure that this period of discovery continues, while the Institute builds on it to accelerate the development of interventions and to make sure that these interventions reach patients. Until someone’s life is actually saved or improved, the Institute has not done its job. NCI cannot accomplish this alone, but it can make sure it happens by contributing, collaborating, and cooperating.

Dr. Weiss expressed her excitement about the shift of cancer patients' roles from passive to active in their own care. The emerging field study related to host factors that make people more resistant or susceptible to cancer will require more patient empowerment to help promote the best environment in one's body. This requires a huge shift in translational medicine. Dr. Weiss noted that the activity level of patients often depends on their economic resources.

Mr. Katz noted the former Director, Dr. Richard Klausner, had helped the DCLG break through "brick walls" at the NCI to accomplish its goals and asked how he planned to continue this. Dr. von Eschenbach replied that he is developing a new model for the Office of the Director. In a large, complex organization, a single individual cannot have enough time or skills to effectively manage every aspect of the organization. He plans to assemble a group of individuals who will help him to lead the Institute. As a result, the DCLG may not always work with him personally, but it will have access to people in his office.

Dr. Brad Zebrack suggested that LA be moved back to the Office of the Director to increase the visibility of the office. Dr. Zebrack also asked Dr. von Eschenbach to consider including representatives of the DCLG in his "inner circle" to provide the survivorship perspective. Finally, Dr. Zebrack suggested changing the name of the DCLG to replace the term "consumer" with "advocate."

Ms. Butler predicted that people with cancer will need increasing resources for providing care and support. Planning is needed now, but the cancer community does not appear to recognize the implications of cancer as a chronic disease for health care providers. The DCLG should include people who can help it and the groups it represents address some of these concerns.

Ms. Nyrvah Richard asked for more details on Dr. von Eschenbach's view of the DCLG's place in the Institute. Dr. von Eschenbach replied that although his vision incorporates the DCLG, he has not yet organized his office or determined the DCLG's role.

Mr. Katz reported that the DCLG has been most successful when it has had a specific product to produce through grassroots collaboration. Other advocacy organizations do not want to use the DCLG as a communications channel to the NCI because they would rather deal with the Institute directly. Dr. von Eschenbach referred to two different models for the DCLG:

- Serves as a task force to work on projects assigned by the Director
- Is a conduit to and from the NCI for the advocacy community

Dr. von Eschenbach wants his boards and groups to have important objectives that truly assist the Institute. Ms. LeStage noted that CARRA members are eager to participate in NCI activities. She asked Dr. von Eschenbach to consider how best to use this very vital resource created for the NCI.

IV. Report on the Cancer Research Portfolio And Update On Progress Review Groups

Cancer Research Portfolio. Ms. LeStage introduced Ms. Cherie Nichols, Director of NCI's Office of Science Planning and Assessment (OSPA) who will provide some information about NCI's new tool for looking at its research portfolio and an update on the Progress Review Groups (PRGs). Ms. Nichols stated that DCLG members had received a copy of a new CD

ROM from the Office of Science Planning and Assessment that includes all of the reports and the 2003 bypass budget.

Ms. Nichols reported that the Common Scientific Outline (CSO) was developed to:

- Classify cancer research into categories
- Help coordinate research activities in and outside of the NCI
- Help shape cancer-related research planning and scientific resource decisions

The CSO, which resulted from recommendations by some of the PRGs, was developed with the U.S. Department of Defense (DOD) Congressionally Directed Medical Research Program and other partners who will use the CSO to categorize their own research portfolios. The NCI has invited eight other funding agencies to partner with NCI and the DOD by coding their own research portfolios using the CSO. This will enhance coordination among cancer research organizations and allow them to share information on funded projects and identify research gaps and opportunities.

The Cancer Research Portfolio (CRP) Web site (<http://researchportfolio.cancer.gov>) provides access to information on NCI-supported research. Users can view research projects by the CSO and other categories. The CRP database includes information on extramural and intramural research projects and is the first-ever complete collection of research supported by the Institute. The CRP database includes clinical trials, but the National Library of Medicine's <http://clinicaltrials.gov> site may have more complete information on clinical trials conducted by pharmaceutical companies.

The NCI uses the CSO to analyze its research portfolio for science planning, implementation, and assessment activities. For example, the PRGs used it extensively to identify gaps. NCI staff are mapping current NCI research projects to the PRG recommendations to produce a baseline so that, in a few years, they will be able to identify activities that resulted from the PRG recommendations.

Ms. Nichols informed DCLG members that they could help promote the CRP as a resource by, for example, linking to the CRP from their organizations' Web sites, including drop-in articles about the CRP in their newsletters, and distributing CRP rolodex cards at their meetings. Ms. Nichols also invited DCLG members to provide feedback on the design and usefulness of the CRP.

Ms. Anne Tatem from OSPA demonstrated the CRP Web site. Ms. Giusti asked if newly diagnosed patients could use the site to identify the best institutions to treat their type of cancer. Ms. Nichols replied that visitors to the site can sort projects on a particular cancer type by institution to identify how much work is being done at each institution. In response to a question from Ms. Kim, Ms. Nichols explained that organizations can easily set up a link between their Web sites and a given section of the CRP.

Ms. Nichols encouraged anyone seeking to join a clinical trial to use the PDQ, which is designed for that purpose. The CRP has a very different purpose. Ms. Nichols also announced that all of the partner agencies have committed to developing their own public Web site that will have the same look and feel as the CRP site. This will provide information on the research portfolios of many major funding organizations.

Progress Review Groups (PRGs). Ms. Nichols reported that the NCI will hold its 10th PRG roundtable in May on stomach and esophageal cancers, and a PRG on sarcoma will take place in 2003. However, the remaining PRGs on liver and bile duct cancers and skin cancers are on hold pending evaluation of the PRG process. The NCI is now developing an implementation strategy for the brain tumor, pancreatic cancer, and lymphoma PRG recommendations, and will present a strategy for all three to the NCI Executive Committee on June 10. Response meetings are planned for gynecologic cancers and lung cancer, and the kidney and bladder cancer report will be released after the Advisory Committee to the Director accepts it. The NCI is assessing the progress of implementation of prostate cancer and breast cancer recommendations and will soon address colorectal cancer. The NCI is considering the possibility of partnering with other organizations to implement some of the strategies recommended by the PRGs.

Dr. von Eschenbach is very committed to the PRG process, as a way for the Institute to receive advice on what science should be done in these areas. However, he realizes NCI cannot implement all of the PRG recommendations. Ms. Giusti suggested that some nonprofit organizations would probably be willing to partner with the NCI to accomplish these tasks. Perhaps a group could discuss these partnerships. Ms. Nichols asked if the DCLG might serve in this capacity. Ms. Giusti and Ms. Kim agreed that this is an appropriate task for the DCLG. Ms. Giusti proposed that the DCLG find out what has and has not worked well from the advocacy perspective on some of the PRGs. Ms. Branch sits on many review boards for organizations that want to help with filling the gaps not addressed by the NCI. Ms. Nichols reported that several partners are already using the CSO to do their own strategic planning based on the gaps identified.

Ms. Nichols's office has just submitted an outline for an evaluation of the PRG process to Dr. von Eschenbach, and it plans to solicit ideas on the improved PRG process from those who participated in them, especially the advocacy and consumer community. Ms. Nichols said she thinks that the Institute will always have some form of PRG, because this model has been very successful, but future PRGs might not be disease focused. For example, the NCI might develop a PRG that is tobacco oriented.

V. Consumer Advocates In Research Related Activities (CARRA) Update

NCI's CARRA program, which provides a mechanism for involving advocates with appropriate expertise in NCI activities, was launched in September 2001. Ms. Tracy Clagett reported the LA received 40 requests for advocates in the program's first 7 months. This compares to in the 14 months prior to the 37 requests for advocates.

The Institute supports the CARRA program by directing program staff to use advocates in the program when they need people to participate in patient-oriented research including clinical and population-based activities. Dr. von Eschenbach has not indicated any plans to change this directive.

Between September and March, LA received one to three requests per week for advocates from the CARRA program. Approximately two-thirds of the requests were for science-related activities, primarily involving scientific peer review or site visits. One-third were for communications activities such as publication review, usability testing, and a few asked for

people to serve on committees such as the Quality of Care disease-specific focus groups and the Cancer Genetics Working Group.

CARRA members are also responsible for proactively informing NCI about issues that are important in the patient community. LA has established an e-mail account that they can use for questions or communications to LA and the DCLG. LA also has a one-way e-mail distribution listserv for updates, announcements, and answers to the members' most frequently asked questions (FAQs).

When the DCLG asked CARRA members for feedback for the Survivorship Working Group, it received approximately 60 responses. Dr. Zebrack suggested reporting back to those who provided feedback to acknowledge their contributions. Ms. Kim has already done this. Ms. LeStage suggested that Mr. Porterfield provide some follow-up to CARRA members describing NCI's response.

Ms. Clagett announced that the CARRA Web site (<http://la.cancer.gov/carra>) now includes FAQs, announcements, and a directory of CARRA members who have agreed to list their names and the primary organizations they represent. The site also lists the activities of CARRA members at the NCI and will be updated monthly.

LA staff and Mr. Porterfield have described CARRA, and DCLG activities at several meetings at NCI and for other groups. LA prepared slides that can be used to explain the NCI, the DCLG, and the CARRA if members wish to make similar presentations.

As part of the CARRA program's evaluation, LA is obtaining feedback from CARRA members, NCI staff, DCLG members, and LA staff. A baseline attitude measure has been distributed to assess attitudes toward advocates at the NCI before the program was implemented. LA plans to distribute the survey again in a year or two. Several informal debriefing sessions have been held with NCI staff and CARRA members. LA has also issued a statement of work for a comprehensive evaluation program and plans to select a contractor within the next few weeks. The evaluation will be used to refine processes and policies. The DCLG suggested the potential need for additional science training for peer review, which LA plans to offer in collaboration with the DCLG. LA also plans to send post-activity questionnaires to NCI staff and CARRA members.

The DCLG's Advocacy Involvement Working Group is considering ways to increase the use of CARRA members, types of additional promotion, policy questions, and science training. Ms. Clagett encouraged DCLG members to continue to think of ways in which the DCLG can work with CARRA members. Mr. Porterfield serves as the DCLG's liaison to the CARRA. He is concerned that many advocacy organizations are not familiar with CARRA or the DCLG. LA and the DCLG want to build confidence in the advocacy community that NCI's desire to work with the patient community is sincere. The DCLG should serve as one vehicle for patients and groups to have their questions answered and make their ideas known to the NCI.

Ms. Branch asked how to identify CARRA members from a particular region. LA can provide this information on CARRA members who are willing to be so identified.

Mr. Katz asked whether NCI staff is following the directive to involve CARRA members in their activities. Ms. Clagett does not have the data to answer this question, but suspects that some staff does not understand the program yet. LA is engaged in several internal promotional activities to reach staff. Mr. Katz suggested raising this issue at an Executive Committee meeting and pointing out that Dr. von Eschenbach agreed with the directive to use CARRA members.

Dr. Zebrack suggested that the large amount of work to be done by some of the DCLG's working groups might provide an opportunity for CARRA members to participate. They can participate as ad hoc consultants as can others who might have needed expertise.

VI. Role And Membership Of The DCLG

Action Items. Ms. LeStage listed future DCLG activities identified so far at the meeting:

- Create a response to the *Time* article as a group.
- For Dr. von Eschenbach:
 - Discuss the future role and composition of the group
 - Discuss how the DCLG should operate as an interface between NCI and the broader advocacy community
 - Help NCI look at survivorship issues in a more integrated way
- Determine the role of the DCLG–CARRA liaison
- Provide comments on the CRP—this can be done individually, but a more effective strategy is to submit all of the group's comments jointly
- Help publicize <http://cancer.gov>

Role of the DCLG. Since the remaining founding members of the DCLG will soon be completing their terms, Ms. Kim suggested that the group should take this opportunity to address issues related to the role and composition of the DCLG. DCLG members agreed that the group is not as effective as they would like it to be and postponed working group discussions to address these issues.

One area of concern is the number of working groups. Ms. Kim noted that all of the working groups are very busy. Ms. Richard added that some working groups are finding that the issues they are addressing are no longer specific to any particular working group. With five experienced members leaving the DCLG, the working groups are left with few members and many responsibilities, and some efforts are being duplicated. Ms. LeStage noted that the working groups help her to organize DCLG activities. However the DCLG organizes itself, it needs many people to take on additional responsibilities.

Ms. Gena Love asked Ms. LeStage to summarize her discussions with Dr. von Eschenbach about the DCLG's role. Ms. LeStage replied that they agreed that the DCLG has not been as effective as it could be. They discussed the possibility of including different kinds of people in the group. Dr. von Eschenbach admitted that in trying to determine where the different pieces of the NCI fit together, he was not sure where the DCLG fit. Ms. LeStage responded that the DCLG serves more of an infrastructure role and reaches out to groups that would not otherwise have a way to communicate their perspectives to the NCI. Mr. Katz agreed with Ms. LeStage that the DCLG needs working groups and must be able to distribute the workload. But the DCLG may not always need the same working groups, and it should be able to create working groups at one

meeting that exist only until the next meeting. At the end of each meeting, the group should take stock of which groups it still needs.

Although working group planning sessions were scheduled next, the DCLG decided to break up into two groups to discuss the following questions:

- If you created an advocacy group to advise the NCI, how would you construct it?
- What would its role be?

After the group reconvened, a representative of each group summarized the discussions.

Ms. Kim reported on the deliberations of Group 1. This group agreed that the role of the DCLG is to offer the consumer advocate perspective on the development and delivery of NCI services in pursuit of its mission. DCLG members should be selected according to established criteria. The DCLG should meet face to face more frequently and be part of the Director's inner circle.

The reporter for Group 2, Mr. Katz, listed three roles for the DCLG:

- Bring the advocacy view to NCI programs (On specific issues, where appropriate, the DCLG should develop an advocacy perspective and make recommendations to the NCI in partnership with the NCI and advocacy organizations.)
 - Serve as working members in NCI program planning, implementation, and review activities (For example, DCLG members should have an ongoing role in the group that is evaluating the PRGs.)
 - Serve as a resource for NCI programs requiring quick feedback from a core group of seasoned advocates
- Ensure advocacy involvement in and awareness of NCI programs, including CARRA, provide outreach to advocacy groups and the community and develop partnerships with the advocacy community
- Make recommendations to the NCI Director as a federally chartered advocacy group.
 - Respond to specific requests from the NCI Director
 - Bring issues to the attention of the NCI Director based on DCLG members' interactions with the NCI and the advocacy community in performing the first two roles

Group 2 emphasized that the DCLG needs a permanent, full-time advocate in LA to help the group structure its work and manage its relationship with the NCI. Ms. LeStage noted that the DCLG neglected to ask Dr. von Eschenbach when a new, permanent LA director would be hired. Mr. Katz mentioned the importance of preserving the DCLG's grassroots and underserved voices, which are not represented by the major advocacy organizations. The DCLG also should ensure that, in addition to a mix of "heavy hitters" and grassroots representatives, it recruits members with different tools. All of these proposals have budget implications.

Ms. LeStage pointed out that the suggestions of the two groups are quite similar. For example both groups mentioned the need for a consumer or advocate perspective at the NCI, and Mr. Katz's group listed ways in which this could be accomplished. Both groups also referred to the DCLG's ability to identify emerging needs. Finally, Mr. Katz's group listed the need for the DCLG to ensure advocacy involvement in and awareness of NCI programs.

DCLG Membership. Both groups agreed on the importance of diversity in the DCLG and the desire for representatives of different organizations, regions, ethnic groups, and ages.

Dr. Weiss suggested that DCLG members also represent a range of gender, sexual orientation, and special populations. Ms. LeStage was concerned that if the group tries to recruit such a diverse membership, it will focus too much on diversity and lose the ability to recruit people with appropriate leadership skills. Ms. Giusti added that recruiting the best people requires the knowledge that the job is important, which in turns requires that the DCLG truly be a voice to the Director and have a place in the Director's office.

Ms. Love suggested that one way to preserve the group's diversity is to recruit people who are not necessarily leaders, but who have the potential to become leaders. Ms. Richard suggested that 3 years is a relatively short time to develop leadership skills. DCLG members should begin mentoring new members early in their appointment on so that they can become leadership roles in the working groups.

Mr. Ulman noted the concern expressed by several members that the group does not have sufficient time or people to do its work. The group must either scale back its role or increase its membership and budget.

Ms. LeStage asked if DCLG members' terms should be longer than 3 years. Ms. Kim pointed out that 5- or 6-year terms are standard on other boards.

Ms. LeStage asked whether 15 members are enough for the DCLG. Several members suggested that 20 would be a more appropriate number.

Working Groups. Ms. Kim suggested that the projects addressed by each working group should not be limited to a specific number as long as they define their projects and are able to undertake them successfully. Ms. LeStage added that an individual member rather than a working group can address some tasks, and that not every member needs to serve on more than one.

Meeting Frequency. A majority of DCLG members indicated that the group should meet face to face three times a year. Ms. Branch suggested that an extra meeting would help ensure continuity of the responsibilities of those who are rotating off the DCLG.

Mr. Ulman was concerned about adding an annual meeting when the NCI Director is only able to meet with this group for such a short time. Dr. Weiss pointed out that these meetings are "where the work happens." Ms. Kim added that even though Dr. von Eschenbach could only spend a limited amount of time with the DCLG this time, this need not set the tone for future meetings. If the DCLG can redefine itself into a more effective group that meets the Director's goals, it will receive more time with the Director.

Ms. LeStage pointed out that even though the DCLG might not always have access to the Director, it will have access to members of his office. If the group met three times a year, the Director might only come for a short period to each meeting, but if he could not attend, others from his office would represent him. Dr. Alan Rabson, a member of Dr. von Eschenbach's inner circle, promised to attend as many DCLG meetings as possible and to share the results of this meeting with Dr. von Eschenbach.

Workload. Ms. Richard reminded the group that if the DCLG takes on more members and meets more frequently, this does not mean that its members should take on more work. Last year, the DCLG identified a list of priorities and suggested those appropriate for DCLG members as well as those appropriate for CARRA members. It did not prioritize these activities.

Mr. Porterfield stated that the DCLG has activities that were not always well thought through. Too many activities have been identified as high priority. Ms. Elisabeth Handley agreed that the DCLG should focus on a more narrow set of issues might help it to have more impact.

Communications. Dr. Weiss suggested that the DCLG respond to Dr. von Eschenbach's interest in the delivery of information to the DCLG's constituency. Ms. LeStage agreed, explaining that Dr. von Eschenbach was excited about the DCLG's efforts to build a relationship with advocacy organizations through the letter. The DCLG has helped LA expand its list of consumer advocates. This list now includes CARRA members and groups with which the DCLG can communicate and from which it can obtain feedback.

Time Response. Dr. Weiss suggested that the DCLG offer its own response to the *Time* magazine article and identify people willing to talk about their experiences as part of this response. Mr. Katz suggested coordinating the DCLG's effort with that of the NCI.

Ms. LeStage supported the proposal to develop a response from the DCLG but explained that Dr. von Eschenbach would really like the DCLG to respond on behalf of several hundred advocacy organizations in the future. Mr. Katz suggested that each DCLG member sign the response on behalf of the organizations they represent. The DCLG could also contact CARRA members and other organizations by e-mail to solicit their participation. Ms. LeStage would like to develop relationships so that the DCLG has a network of organizations from which to request input on future issues. Mr. Katz suggested that if the DCLG were in the Director's office, it would have more visibility with the advocacy community.

Dr. Weiss and Mr. Katz volunteered to draft a response to the *Time* magazine article by the end of the next day. Dr. Weiss suggested sending an e-mail to all CARRA members to ask those who have participated in clinical trials to consider a response as well.

Health Disparities. Dr. Weiss suggested preparing a position paper on the health disparities issues because so many people focus on racial differences when disparities actually arise from socioeconomic factors. The paper could identify programs at NCI addressing health disparities. Ms. Richard emphasized that in identifying action items, the DCLG must do the research to find out what mechanisms are in place and what the DCLG can do that the NCI can support. In addition, DCLG members must always keep in mind the impact of these new opportunities on their workload.

Ms. Lee noted that LA can help collect responses from outside organizations for analysis by DCLG members. Mr. Katz mentioned an earlier communications effort in which LA collected information sent by the members.

VII. Recess

The meeting recessed at 5:00 p.m. on April 22, 2002.

April 23, 2002

Ms. LeStage called the meeting to order at 8:34 a.m. on April 23, 2002.

VIII. Response To The *Time* Magazine Article

Ms. Handley suggested that the DCLG decide whether to submit its response to the *Time* magazine article on behalf of the DCLG or the NCI. A response from the DCLG on behalf of the NCI Director would require a resolution, and be cleared through appropriate channels at NCI. A response from the DCLG could not be submitted on NCI DCLG letterhead, and it would have to indicate that it is from DCLG members and not NCI or the U.S. government. Ms. Claire Benfer, NCI Committee Management Officer, further clarified this option. The DCLG can write a letter expressing the views of its members, but not as a federal advisory committee. Ms. LeStage can sign this letter as Chair of the DCLG, but the letter must specify that these are the views of the group and do not represent the views of the NCI.

Ms. Giusti was concerned that *Time* might not know who the DCLG is. Ms. LeStage agreed that the letter would have to provide some information on the DCLG. Mr. Porterfield suggested that the letter give credit to the NCI for setting up the DCLG and showing that it seeks the viewpoint of patients.

DCLG members agreed that the group should directly to the magazine and not as a resolution to the Director. Mr. Katz suggested sending an e-mail to the CARRA list asking for statements from those who have participated in clinical trials and are willing to be quoted. He thought this could be accomplished quickly.

After additional consultation with Ms. Benfer, Ms. Handley reported that DCLG members might finalize the response after this meeting, and then vote by e-mail to approve the final version of the response.

Ms. Handley suggested that staff in the OC or the press office help “punch up” the text of the response. Dr. Weiss will e-mail her draft response to the DCLG listserv, incorporate the feedback, and send it to the OC for its feedback. Ms. Handley will make sure that the letter is reviewed expeditiously before passing it on to Drs. Von Eschenbach and Rabson for their comments. Dr. Weiss offered to distribute the letter that evening and asked for a response from DCLG members within a day.

Mr. Katz pointed out that, however *Time* responds, it will not repair the damage done by this article. He urged the DCLG to work with Ms. Bartholomew and others to identify a reporter that would do a balanced, fair story on clinical trials. The DCLG could tell the reporter that it has many quotes available. These quotes will probably not be available soon enough to include in the DCLG’s response to *Time*, but they could be used for the next step.

Ms. LeStage suggested that the DCLG not try to contact CARRA members for quotes for this letter. However, it should send CARRA members a copy of the letter and encourage them to write to *Time* on their own. The CARRA members could also be encouraged to let the DCLG know if they had a positive experience with clinical trials because the DCLG will try to arrange

for a follow-up story and have a reporter contact them for an interview. Ms. Branch stated that several CARRA members have already sent letters to *Time*.

Ms. Handley suggested that the Clinical Trials Working Group address how to obtain more favorable press for this issue. Ms. Kim said that this is part of communications and strategy, a much broader topic within the DCLG.

Mr. Katz proposed the following motion, which was seconded by Ms. Love:

The DCLG recommends that the group send a letter to *Time* magazine in response to its recent article on clinical trials, after DCLG members and the NCI approve the letter.

The motion passed unanimously.

IX. Clinical Trials Primer

Mr. Katz provided an introduction to the NCI Cooperative Group system of clinical trials. Clinical trials offer access to new, potentially better treatments, serve as the vehicles by which new treatments can be proven safe and effective to join the standard of care, and advance the science and bring better treatments. In 2001, the NCI's nine clinical trial Cooperative Groups in the United States brought together 8,000 investigators in 1,500 institutions with more than 26,000 patients in approximately 370 trials. This represents about half of all cancer accruals to clinical trials in the United States.

The NCI Cooperative Groups are known for their high scientific standards, and they focus on questions that might not be commercially significant but have an impact on the standard of care. The focus of the Cooperative Groups is the scientific question to be answered rather than the potential commercial value of the answer.

Privately funded trials typically involve a single institution or a small number of institutions. An investigator develops a protocol, which is reviewed by the hospital or cancer center institutional review board (IRB). Once the protocol is approved, it is open for accrual. The Cooperative Groups develop protocols that can be opened at as many as 1,000 institutions. However, the protocol development and approval process is very complex. Cooperative groups submit their protocol to the NCI and, if a new drug is involved, the U.S. Food and Drug Administration. The protocol is then distributed to the IRBs of all of the participating institutions for review before being activated at those institutions. One to two years are typically required for a protocol to be released to institutions for IRB review and activation. Every 6 months, 20 to 30 new protocols typically open up.

The NCI clinical trials system is implementing recommendations made by Clinical Trials Review Group headed by Dr. James Armitage in 1997. NCI created the Clinical Trials Implementation Committee in 1998 to implement the Armitage report recommendations. This committee decided to address four components:

- Focus resources on the best science
- Enhance efficiency and streamlining
- Increase accrual and broaden access to patients and physicians

- Provide adequate compensation to participating investigators and clinicians.

The committee recommended four pilot projects. The **Cancer Trials Support Unit** will consolidate much of the groups' redundant infrastructure into a new, central structure that streamlines several functions. The pilot projects also will make all trials more broadly available through a central access point. Funding will be more closely linked to performance. The intergroup registration system will be centralized, so that people in the groups can register for other group trials. A Central Institutional Review Board (CIRB) will replace the local reviews or permit local IRBs to conduct more expeditious reviews. The remaining pilots included **State of the Science conferences** to determine which questions should be addressed and **Concept Evaluation Panels** to develop protocols for the trials.

The DCLG's Clinical Trials Working Group and the Patient Advisory Board (PAB) of the Coalition of National Cancer Cooperative Groups have initiated a dialogue between the NCI/Cooperative Group advocates and the NCI/Cooperative Group leadership on the status of the pilot projects and the transition. Both groups are gathering input from grassroots organizations and NCI/Group leadership on the status and progress of the NCI Clinical Trials Redesign pilot projects. Representatives of the DCLG and the PAB will meet to discuss their findings.

Ms. Lin asked about the NCI's computer tutorial for healthcare professionals (available at <http://cme.nci.nih.gov>). Dr. Jeff Abrams replied that the human subjects protection course is available to all investigators and anyone interested in clinical trials on the Web site. Currently, this course is a one-time requirement, but this might change. Ms. LeStage recommended this course to other DCLG members.

Mr. Porterfield congratulated Mr. Katz and the Clinical Trials Working Group for this "extremely important work for the DCLG."

Dr. Abrams distributed a list of NCI Web sites. DCLG members and other patient advocates can obtain access to the members-only information on the Cancer Trials Support Unit Web site (<http://www.ctsu.org>) by e-mailing a request for access.

X. Update From The Office Of Education And Special Initiatives

Overview of the Office of Education and Special Initiatives (OESI). Dr. Charmaine Cummings provided an update on cancer education strategies and programs in the OESI.

NCI's goals for education are to:

- Enhance knowledge of new technologies and treatments in cancer care
- Increase the number of individuals from all ages and backgrounds, and of health care providers participating in clinical trials through education
- Enhance the quality of patient care through education

The OESI's mission is the development and implementation of education programs and products over the entire cancer continuum. The OESI coordinates clinical trial issues across the Institute and is responsible for the clinical trials portal of <http://cancer.gov>. Target audiences include patients and families; survivors, advocacy groups, and the public; and health care professionals.

New programs and products for 2001–2002 include:

- A pain kit for low-literacy individuals in pain that includes a video
- Updated booklets, including *Young People with Cancer*
- New Spanish-language publications

Clinical Trials Education Series. The OESI recently developed a new clinical trials education series that includes:

- Two levels of self-study booklets
- Three PowerPoint slide programs that cover the information in the self-study booklets
- Two videos—an introduction to clinical trials, and a video to help patients and families make decisions about participating in clinical trials
- Two culturally sensitive Spanish and English low-literacy brochures
- An interactive resource guide to help community groups learn about cancer and spread the word about clinical trials
- A trainer's guide for cancer education in general

The OESI is disseminating these products through healthcare professional societies, advocacy groups, and health care service organizations. The OESI has trained the Cancer Information Service trainers and partnership staff to use the materials.

Dr. Cummings distributed copies of the basic self-study workbook on cancer clinical trials, which includes slides for groups. The booklet is written for a lay audience but is being used to orient oncology unit staff on who have little background or experience in clinical trials. The self-study booklet may also help the health care provider, such as the referring physician or nurse, who does not have a very deep knowledge of clinical trials. This booklet includes the information in the basic booklet as well as additional materials, including a case study. The majority of the materials developed by OESI are available in both PDF and html format from <http://cancer.gov>

In response to a question from Ms. Kim, Dr. Cummings explained that her staff plans to participate actively in promoting the materials at meetings with partners, beyond simply setting up a booth. They are also developing some ads and will present the materials to groups of physicians and nurses. The OESI will conduct a seminar on how to use the materials, and it has invited representatives and advocates from the Cooperative Groups. The Oncology Nursing Society is piloting a system to use the booklet online for a continuing medical education (CME) course for nurses.

Several of the DCLG members' organizations are using the materials and linking the program to their Web sites. Other organizations are helping evaluate the program. Dr. Cummings urged DCLG members interested in using the materials with their organizations to contact her office, which can expedite larger orders and provide technical assistance.

Dr. Cummings listed the following future initiatives:

- A gap assessment to determine what is needed, especially in patient and family education and family products
- Products or programs to address end-of-life and palliative care issues

- A tutorial on incorporating clinical trials into the practices of referring physicians, nurse practitioners, nurses, and investigators who are new to clinical trials
- A genetic testing booklet
- Information on biotherapies for patients
- More low-literacy materials and Hispanic materials

Ms. Giusti asked how the OESI measures its success. Ms. Cummings replied that the office tracks the number of requests for materials and visits to the clinical trials section of <http://cancer.gov>. The office also works with a consultant to develop an evaluation system that will measure all process data, numbers of hits, and organizations receiving the materials. OESI has also formed partnerships to collect evaluation data on whether the products are effective.

Ms. Branch suggested that OESI send evaluation cards out with its materials. Ms. Cummings explained that OESI has done this to some extent. However, very few people, perhaps one or two percent, return the cards. Ms. Margo Michaels explained that Office of Management and Budget regulations preclude the OESI from sending out certain types of questionnaires, but other organizations can do this for the OESI. Dr. Cummings added that the OESI conducted focus groups with physicians and nurses to collect some qualitative data before starting this project. Ms. Giusti suggested that if all of these efforts are changing attitudes and behaviors.

Dr. Weiss asked what proportion of people entering clinical trials belong to minority populations. Ms. Margo Michaels explained that the percentages of minorities participating in treatment trials are proportional to their representation in the general population. However, the participation rates in prevention trials are low.

Ms. LeStage stated that the DCLG would be happy to help in any way that it can. The group believes that it can be most effective if it is involved from the planning stages of the project to provide the consumer perspective, and hopes to be involved as the OESI moves forward. Dr. Cummings promised to continue to involve the DCLG in the development and implementation of OESI products.

Facing Forward Series. Ms. Michaels distributed copies of flyers promoting the *Facing Forward* cancer survivor series, which was developed in close collaboration with the Office of Cancer Survivorship.

Since few resources exist for survivors, families, and friends for the time after treatment is completed, the OESI decided to develop four new products that address what to expect following the end of cancer treatment. These products include resources, ways to get involved, information for health care professionals, and information for family members. Many DCLG members were involved in developing these materials. *Life After Cancer Treatment* is in press now and will be ready at the end of this month. *Ways You Can Make a Difference in Cancer* will be published in 2002, and publications for health professionals and for family members will be available in 2003.

Life After Cancer Treatment addresses physical issues, psychosocial issues, social relationships, and practical matters. The book includes an extensive list of resources. Ms. Michaels informed DCLG members that only organizations on the official NCI list are included in the book.

Ways You Can Make a Difference in Cancer addresses ways to become involved with the cancer community. The publication was developed because survivors wanted to identify ways to help individuals become involved with them as advocates or volunteers. This new book directs people to become involved by thinking about their skills, interests, time, and what they can do in their own communities.

DCLG members participated in the internal review and pretest interviews. They can also review the new materials. Ms. Michaels sent a list to Ms. Kim of products her section is working on for survivors. Ms. Michaels would love to have each of the DCLG members' organizations partner with the OESI to disseminate and evaluate these products. Press kits were sent to all DCLG members on this series, and Ms. Michaels asked for feedback.

Ms. LeStage suggested that DCLG members directly contact Ms. Michaels if they want to involve their organization.

XI. DCLG Composition

The Working Group sessions scheduled for Tuesday morning were deferred until a later date and the members resumed their discussions related to the role and composition of the DCLG.

Mr. Katz suggested that the DCLG provide input to the Director about what it is seeking in future group members. DCLG members are legally barred from seeing any of the applications or from being involved in the selection process. But Ms. Giusti pointed out that DCLG members can meet with those who select members and list the areas in which the group is deficient. Ms. LeStage pointed out that if people with the right expertise do not apply, they will not be available for participation in the DCLG.

Ms. Lee said that the process is too far along to change this year, but it might be changed in the future if the DCLG so recommends. Ms. Handley added that the nominations for this year have already been reviewed and a slate of candidates is ready for the Director's review. The people who apply to the DCLG might not reflect the skills needed for the DCLG's revised role. The group will have to determine how to attract such people. Ms. Giusti suggested that the DCLG establish a nominating committee to help the Director choose those with the best qualifications.

Ms. LeStage explained that traditionally, the Director has been given the final names from the selection process. However, this year Dr. von Eschenbach asked to see a list of all of the candidates. Ms. LeStage has discussed with Dr. von Eschenbach the kinds of people she believes would be helpful. The interview questions may need to be revised; one question asks whether the individual can contribute 12 days a year, the amount specified in the charter, but members actually contribute much more time than that. Ms. Lee said that this process was set up to make sure that this group did not turn into an "old boys network," where people nominate their friends and the group becomes inbred. The process continually brings in new people who can learn about the NCI and develop the skills needed to be effective on the DCLG. Ms. Richard pointed out that DCLG members have a responsibility to nurture and recruit people in the community that they work with who are potential future leaders of the DCLG.

Recommendations to Change the DCLG Charter. Ms. Lee explained that the DCLG's charter expires on August 17. If DCLG members want to change the charter, now is the time to

make their recommendations to the Director of NCI. Ms. Kim suggested that several DCLG members join Ms. LeStage in presenting the group's suggestions for changes to its charter to Dr. von Eschenbach. Ms. LeStage pointed out that the previous day's discussions address much of what is in the charter and can be used as the basis for the group's proposal. Ms. Handley explained that changes to the charter must be approved at several levels. DCLG members should not deliver a "lengthy white paper" that will prevent the charter from being renewed in time. Instead, the group should quickly make specific recommendations about the issues of concern, such as the number of members and the frequency of meetings.

According to Mr. Katz, the DCLG must make sure that DCLG members will grow by taking on activities that are challenging and beyond their current capabilities. If members only review and react, they will not grow. Another priority is to assign appropriate tasks to the group so that people want to spend time on those tasks. This will help DCLG members grow in capability.

Mr. Porterfield reminded the group that Dr. von Eschenbach indicated that he wants committees, which are useful to him and NCI. The DCLG should devote more attention to carrying out its charge to reach out to cancer patients and their families. Mr. Porterfield expressed his willingness to spend as long as necessary to make sure that the group selects important tasks to address.

At this point in the meeting, several DCLG members left the room to develop draft recommendations for the group's approval. After this group returned, the DCLG discussed specific changes to the charter.

Ms. Branch proposed the following motion, which was seconded by Ms. Richard:

The DCLG recommends that the text of its charter be changed from "The Committee shall consist of 15 members" to "The Committee shall consist of 20 members."

The motion passed unanimously.

The DCLG discussed whether language should be added to the charter specifying that in selecting new members for the group, consideration be given to diversity. However, the charter already includes a statement to this effect.

Ms. Branch proposed the following motion, which was seconded by Mr. Porterfield.

The DCLG recommends that the text of its charter be changed from "Members shall be invited to serve for overlapping terms of up to three years" to "Members shall be invited to serve for overlapping terms of up to four years."

The motion passed unanimously.

Ms. Handley advised that the DCLG explain to the Director why it is making these changes. The group should explain what the taxpayers will "buy" for the extra amount they will spend to implement these changes.

Ms. LeStage suggested that the group specify the number of teleconferences it should hold per year in addition to face-to-face meetings. The teleconferences offer DCLG members a chance to report on their activities and hold them to their commitments.

Mr. Porterfield proposed the following motion, which was seconded by Ms. Branch.

The DCLG recommends that the text of its charter be changed from, “Meetings of the full Committee shall be held not less than two times a year, at the call of the Chair” to “Face-to-face meetings of the full Committee shall be held three times a year, and teleconferences of the full Committee shall be held six times a year, at the call of the Chair.”

The motion passed unanimously.

Ms. Lee suggested that the DCLG not limit itself by specifying how often its working groups should meet. However, she expressed concern that the DCLG application process does not give a realistic expectation of the time requirement for a DCLG member. Applicants should be informed of the working group responsibilities of DCLG members.

The budget in the charter is calculated according to a formula and is based on the number of meetings, types of projects, and number of members.

Ms. Butler proposed the following motion, seconded by Ms. Giusti:

The DCLG recommends that the text of its charter be changed from:

...The National Cancer Institute Director’s Consumer Liaison Group (DCLG; also referred to as “Committee”) assists in developing and establishing processes and criteria for identifying appropriate consumer advocates to serve on a variety of NCI program and policy advisory committees; serves as a primary forum to discuss issues and concerns and exchange viewpoints that are important to the broad development of NCI program and research priorities; and establish and maintain collaborations between the NCI and cancer advocacy community to reach common goals.

to:

...The National Cancer Institute Director’s Consumer Liaison Group (DCLG; also referred to as “Committee”) assists in developing and establishing processes and criteria for identifying appropriate consumer advocates to serve on a variety of NCI program and policy advisory committees; provides the patient/advocacy perspective to the Director of the National Cancer Institute; provides recommendations to the Director of the National Cancer Institute in response to specific requests from the Director and in response to the needs of the advocacy community; and establishes and maintains strong collaborations between NCI and the cancer advocacy community to reach common goals.

Ms. Giusti explained that the DCLG members who drafted the proposed revision thought it critically important that Dr. von Eschenbach inform the DCLG of issues he needs the group to address. But the DCLG must also be the eyes and ears of the advocacy community, so that the group can inform Dr. von Eschenbach when the NCI is not meeting their needs.

Ms. Packer asked why the text on “serves as a primary forum” was omitted. Ms. Giusti replied that the DCLG really wants to provide specific recommendations, rather than serve as a forum. Dr. Zebrack clarified that serving as a forum is a way to accomplish the goal of providing recommendations.

The motion passed unanimously.

The DCLG’s name can be changed even after the charter is approved.

Ms. Lee will make the proposed changes into the charter and distribute the resulting draft charter to all DCLG members for their review. Ms. LeStage will appoint a small group to join her when she meets with Dr. von Eschenbach to discuss the proposed changes.

Ms. Lee pointed out that anyone named to the DCLG before the charter changes are made will serve only 3 years, because they applied under this assumption. Anyone who joins the group after the charter is changed will serve 4 years.

XII. Recognition of Departing DCLG Members

Ms. LeStage announced that this would be the last meeting of five of the original DCLG members: Ms. Susan Butler, Mr. Michael Katz, Ms. Ruth Lin, Ms. Gena Love, and Dr. Brad Zebrack.

Ms. LeStage thanked the departing members for their “yeoman’s service” on behalf of the DCLG, the Director, and the NCI. The group owes them an enormous debt of gratitude for what they have done. Ms. LeStage presented each departing member with a certificate of appreciation, and she and Ms. Lee described the departing members’ many accomplishments during their DCLG tenure.

Ms. Lee stated that the office still provides a link between all DCLG members, past and present, and will try to keep all of the addresses current. Perhaps a listserv or some other vehicle can be developed to keep the “DCLG emeritus” members posted, because the group does not want to lose their valuable experience and insight.

XIII. Orientation For New Members

Ms. Packer referred DCLG members to the draft orientation agenda for new DCLG members. Ms. Packer and Ms. Nina Ghanem made minor changes to the orientation program on the basis of evaluation sheets provided by DCLG members. The overall orientation is approximately 15 minutes shorter, and the tour has also been shortened.

According to Ms. LeStage, new members would like more information about the working groups to prepare them for the October meetings. Ms. Packer said that this has been added to the

orientation. Ms. Ghanem added that each working group chair will now produce a one-page description of their group, and more time will be spent describing the groups and their function in the DCLG.

The new members will also receive a manual of basic procedures, including how to submit expenses and make travel reservations, whom to contact for certain types of questions, and sample forms. Ms. Lee drafted this handbook, which will be distributed to all DCLG members for their review. Ms. Love suggested that the handbook include brief explanations of acronyms.

Ms. Love also suggested that even though the number of speakers has been reduced, NCI groups with whom the DCLG works should have an opportunity to provide a brief overview of what they do, how they fit into the Institute, and how DCLG members can work with them.

Ms. Packer added that the draft orientation plan now includes a 15-minute question-and-answer session with Dr. von Eschenbach.

Mr. Porterfield asked about the timing of the orientation session. Ms. Packer explained that it will be held in July 2002. Mr. Porterfield asked why the orientation will not be held during the same week as the next face-to-face meeting, which would save money. Ms. Ghanem explained that providing the orientation in July will allow new members to participate in both the August teleconference and the October meeting.

XIV. New Business

Ms. LeStage distributed the agenda for the May 9 teleconference, which will take place from 2:00 to 4:00 p.m. Eastern time, and announced that the following teleconference will be held on July 29. She asked DCLG members to review the list of possible dates for future teleconferences and face-to-face meetings and indicate the dates on which they will be available. Those who could not complete the forms at this meeting were asked to fax the forms back as soon as they returned home.

Ms. Handley asked when the third face-to-face meeting would occur, if this recommendation is approved. Ms. LeStage suggested that the three meetings be spread out as much as possible. Perhaps the first meeting could be held in March or even February, although the weather in February can make travel difficult.

DCLG members were also instructed to submit their reimbursement claims within 5 days of this meeting.

Ms. LeStage asked for volunteers to comment on the CRP Web site. Anyone who decides to provide comments should let Ms. LeStage know, so that the response can be sent from the DCLG instead of the individual.

XV. Future DCLG Working Groups

Ms. Kim stated that having only 15 members makes it difficult for the working groups to be effective. With so many experienced members leaving the DCLG, each working group has perhaps one experienced member left. It takes a while for new members to adjust to their new

responsibilities and feel at all comfortable chairing a working group. The issue of continuity is also a concern. Ms. Kim suggested consolidating the working groups into two that address broad areas, although each group would work on very focused projects.

The recent work on survivorship is an example of the DCLG being stretched too thin. Each of the Survivorship Working Group members has a vested interest in survivorship and the intention to contribute significantly to its work. But the members simply did not have enough time to put together the responses to the group's call for advocate perspectives on survivorship. The resulting product probably does not reflect the group's best possible work.

Ms. Giusti reminded DCLG members that Dr. von Eschenbach focused a great deal on moving from the bench to the bedside, and how to make this happen quickly.

Ms. Kim suggested the following working groups:

Clinical Trials and PRGs

Survivorship

Another group, but perhaps not a working group, should address communications issues such as defining the DCLG and developing a system that will enable the DCLG to react quickly to cancer issues. Ms. Richard reported that at their last meeting, the Quality of Care and Health Disparities Working Groups had identified areas that they needed to work on and/or assign point people. However, because the Center for Health Disparities is not operational, DCLG work in health disparities is impossible. Moreover, with Ms. Love and Ms. Lin rotating off the DCLG, the two working groups have very few members left. Separating this group into two working groups is therefore premature. Ms. Richard suggested that she and Ms. Branch serve as co-chairs of a single Quality of Care/Health Disparities Working Group. If the Center for Health Disparities is up and running by the October DCLG meeting, the working group can revisit the possibility of splitting into two groups at that time.

Ms. Kim agreed that this was not the right time for the DCLG to address health disparities. Moreover, this issue can be built into the two working groups she has proposed. An additional group should focus on process issues, such as setting up a process for responding to the *Time* article.

Ms. Giusti supported Ms. Kim's proposal for two large working groups. She said that almost all of the DCLG's projects fall under survivorship or clinical trials. But clinical trials are only part of what should be addressed by the group that focuses on getting drugs to people. Advocacy should be part of everything that the DCLG does, so a separate advocacy working group is not necessary. If Ms. Clagett needs someone to help with CARRA issues, Ms. Giusti would be willing to volunteer. Moreover, some CARRA members could help the working groups as ad hoc consultants or even working group members.

Ms. Love suggested that the DCLG identify priority areas first before creating working groups, instead of creating working groups and fitting the group's priorities into those groups.

Mr. Porterfield agreed that the current working groups should be eliminated. The letters that Ms. Kim received demonstrate that people have a poor understanding of survivorship, which refers to everything that occurs after an individual develops cancer. Mr. Porterfield encouraged the DCLG to continue the clinical trial activities initiated by Mr. Katz. Although Mr. Chris Pablo will chair

the DCLG's efforts on clinical trials, Mr. Katz will continue to participate in the evaluation of the NCI's Cooperative Group program through his involvement in other activities at the NCI and his membership in the Patient Advisory Board.

Ms. Branch stated that neither quality of care nor health disparities falls under clinical trials or survivorship. Ms. Kim responded that the cancer survivorship group could address quality of care, which crosses the continuum from diagnosis through active treatment and beyond.

Ms. Richard reviewed the group's activities in the last 6 months and noted that the working groups have used the same methods to respond to different issues. The DCLG should "stop thinking in terms of working groups and start thinking in terms of priorities." Many of the issues addressed by the Clinical Trials Working Group are closely related to survivorship issues. The DCLG should define two broad areas that will overlap to some extent, and separate tasks.

Ms. Giusti expressed concern that current DCLG members might be more likely to work on survivorship than the clinical trials process, which is difficult to understand. Ms. Handley stated that Mr. Katz's work relates to institutional reforms to make it easier to conduct clinical trials. The Cooperative Groups system is very complex but does not require scientific knowledge to understand. The group could also address many other areas of clinical trials, such as the fact that more women are enrolled in breast cancer than ovarian cancer trials. Ms. Handley reminded the group that the Director had told them that the two areas under consideration by the group are priorities for him. So it makes sense for these to be the group's priorities.

Mr. Katz said that these two priorities will not translate into action unless the DCLG has projects to do or issues to address. At each meeting, members working on projects should have the opportunity to gather together and bring the group up to date. The number of breakouts would differ from meeting to meeting. Conference calls can also be scheduled among small numbers of DCLG members who are working on discrete projects. The DCLG should focus its organization around projects and point persons instead of basing its activity in its working groups.

Ms. Kim pointed out that Mr. Katz's project is very specific and has a goal, tangible steps, and projected outcomes. The project is far reaching in its attempt to change the process and the system. But it represents one small component of the clinical trials issue. For example, the *Time* article also falls within clinical trials. Responding requires a strategy that involves outreach and advocacy.

Ms. Giusti suggested that a small group of DCLG members write a business plan that will explain the reasons for the proposed changes to the group's charter and discuss other issues such as the importance of returning LA to the Director's office. She agreed to chair this group. She asked DCLG members to inform her about the issues that they see as pressing to the DCLG, the Director, and the advocacy community. She will incorporate these into the plan which presented to the DCLG as a whole for approval.

Ms. LeStage reminded the group of Dr. von Eschenbach's excitement at the idea of more active communication between the DCLG and the broader advocacy community. Ms. Giusti noted that the Advocacy Involvement Working Group had discussed this issue and had planned a summit of advocacy groups. But if the two proposed groups are formed, they could start by surveying as many advocacy organizations as possible to make sure that the DCLG is addressing their issues.

Ms. LeStage emphasized that reaching out to the advocacy community on an ongoing basis is a priority. The advocacy community needs to know who the DCLG is and vice versa.

Ms. Love pointed out that the five new DCLG members will have many ideas on how the DCLG can do its job better. Instead of asking the new members about their interests, the DCLG should orient the new members in DCLG's current areas of interest.

Ms. Giusti suggested asking Dr. von Eschenbach to identify 10 priorities that he would like the DCLG to address, and then surveying the advocacy communities about those priorities. Dr. Weiss suggested that the DCLG survey the advocacy community first, before showing their priorities to Dr. von Eschenbach. Mr. Katz said that the DCLG has tried to determine the focus areas of the NCI Executive Committee. Ms. Kim suspects that the PRGs are one of those areas. Communication is clearly another important area, including strategy, outreach, and advocacy.

Ms. Giusti believes that a top priority for Dr. von Eschenbach is for new drugs to reach patients as quickly as possible. Two ways to accomplish this are through clinical trials and PRGs. Ms. Giusti is familiar with the issues of one PRG, and the DCLG might be able to collect valuable feedback from the advocates involved in each of the PRGs.

Ms. LeStage specified that survivorship includes quality of care and quality of life. Another area, "bench to bedside," includes clinical trials and drug development. A final area is communication, which includes strategy, outreach, advocacy, and inreach. Every topic that the DCLG wants to address probably fits into one of these. Dr. Weiss pointed out that communications, like advocacy, underlies everything that the DCLG does.

A group of people should be assigned to develop and design the DCLG's philosophy and projects for each category. Ms. Giusti emphasized the importance of communications for clinical trials, especially to determine whether they make a difference. Also, a group of individuals should help determine whether the <http://cancer.gov> Web site is effective.

Ms. LeStage summarized the group's next steps. Ms. Giusti will lead a small work group (possibly to include Ms. Kim, Mr. Katz, and Dr. Zebrack, as well as Ms. LeStage) that will draft a business plan for the DCLG to justify changes to the charter. Ms. LeStage hopes this small group will accompany her to the meeting with Dr. von Eschenbach to discuss the group's findings. LA will distribute a draft of the revised charter within the next week. Mr. Porterfield emphasized the importance of responding quickly to Ms. Giusti once she distributes her group's draft business plan.

Mr. Katz said that the DCLG must not spend its next face-to-face meeting discussing process and structure. Instead, the group should start thinking about who from the DCLG will report on the work they have done with the NCI and advocates. Ms. Handley also suggested the group bring back the results of what members are doing and invite the relevant people from the NCI to attend. Showing results at meetings will help the DCLG build credibility and relationships within the NCI. Ms. Handley listed two good, recent examples: the forum on survivorship and the forum on reducing health disparities.

XII. Adjournment

The meeting adjourned at 3:23 p.m. on April 23, 2002.

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

Attachments:

Roster

Reports Cited:

Armitage Report

Facing Forward

Life After Cancer Treatment

Ways You Can Make a Difference in Cancer

A complete set of handouts are available from the Executive Secretary.

DCLG ACTION ITEMS

April 22–23, 2002

- DCLG members will help promote the CRP as a resource by, for example, linking to the CRP Web site from their organizations' Web sites, including drop-in articles about the CRP in their newsletters, and distributing CRP rolodex cards at their meetings.
- DCLG members will provide Ms. LeStage with any feedback for the NCI on the design and usefulness of the CRP Web site.
- The DCLG will discuss the possibility of establishing partnerships between nonprofit groups and the NCI to implement some of the PRG goals.
- The DCLG will find out what has and has not worked well in the PRGs from the advocacy perspective.
- Mr. Porterfield will provide feedback to the CARRA members who submitted responses to the Survivorship Working Group.
- Dr. Weiss and Mr. Katz would draft a response to the *Time* magazine article by the end of the day on April 23. DCLG members were to respond to the draft within 1 day and vote by e-mail to approve the response. Dr. Weiss was to send the final response to LA for review by the NCI before submission to *Time*.
- The DCLG will distribute a copy of the DCLG's letter to CARRA members and encourage them to respond to the *Time* magazine article on behalf of the organizations they represent. CARRA members will also be encouraged to let the DCLG know if they had a positive experience with clinical trials so that they could be interviewed for future positive articles on clinical trials.
- DCLG members interested in using the new clinical trial educational materials with their organizations should contact the NCI Office of Education and Special Initiatives.
- DCLG members will provide feedback to Ms. Michaels on the Facing Forward series of materials.
- DCLG members interested in having their organizations promote the Facing Forward series will contact Ms. Michaels.
- Ms. Kim will share the list of upcoming OESI projects with Ms. LeStage.
- Ms. Giusti will chair a small group of DCLG members that will write a business plan to explain the reasons for the proposed changes to the group's charter and discuss other issues addressed at this meeting, such as the importance of returning LA to the Director's office. This group will join Ms. LeStage when she meets with Dr. von Eschenbach to discuss the proposed changes.
- Ms. Clagett will insert the proposed changes into the charter and distribute the resulting draft charter to all DCLG members for their review.
- Ms. Lee will distribute the draft DCLG handbook to all DCLG members for their review.
- DCLG members will provide their availability for future DCLG teleconferences and meetings either at this meeting or by fax immediately upon their return from the meeting.
- DCLG members must submit their reimbursement claims within 5 days of this meeting.

