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

MINUTES of the DIRECTOR'S CONSUMER LIAISON GROUP

September 24, 2003

The 25th meeting of the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG) was convened at 8:07 a.m., September 24, 2003, at the DoubleTree Hotel, Rockville, 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. Ruth Lin
Ms. Gena Love
Mr. Christopher Pablo
Ms. Karen Packer
Mr. Henry Porterfield
Ms. Nyrvah Richard
Mr. Doug Ulman (by telephone)
Dr. Marisa Weiss

Speakers:

Dr. Peg Anthony, Senior Vice President, ORC Macro
Ms. Carol Freeman, Principal, ORC Macro
Ms. Kathy Giusti, Chair, Future of the DCLG Working Group, DCLG
Mr. Michael Katz, DCLG
Ms. Barbara K. LeStage, Chair, DCLG
Mr. Larry Luskin, Senior Research Manager, ORC Macro
Dr. Edward Maibach, Associate Director for Strategic Dissemination, NCI
Ms. Cherie Nichols, Director, Office of Science Planning and Assessment, NCI

Other NCI Staff

Dr. Noreen Aziz, Program Director, Survivorship Research, Division of Cancer Control and Population Sciences
Dr. Ellen Feigal, Acting Director, Division of Cancer Treatment and Diagnosis
Dr. Roland Garcia, Health Scientist Administrator, Disparities Research Branch, Center to Reduce Cancer Health Disparities
Dr. Alan Rabson, Deputy Director

NCI Office of Liaison Activities Staff

Ms. Elisabeth Handley, Acting Director
Ms. Nancy Caliman, Executive Secretary, DCLG
Ms. Jamelle Banks, Fellow
Ms. Sarah Dash, Fellow
Mr. James Hadley, Advocacy Program Manager
Ms. Brooke Hamilton, CARRA Program Coordinator/Professional Societies Liaison

Ms. Jessica Horwath, Intern
Ms. Jane Jacobs, CARRA Program Manager
Ms. Keisha Martin, Program Assistant
Ms. Linda Ticker, Program Assistant

Other Guests
Ms. Paula Kim, Founder and President, Pancreatic Cancer Action Network

A sign in sheet listing all attendees to the meeting is available from the Executive Secretary.

I. OPEN—WELCOME AND SELF-INTRODUCTIONS

Opening Remarks. Ms. Barbara LeStage welcomed participants to the 25th meeting of the DCLG. She explained that at this meeting, DCLG members and NCI staff would focus on the future direction of the DCLG including: whether it should continue or be dissolved and, if it should continue, what the optimal mission and goals, structure, support, and processes for success might be. Ms. LeStage thanked the members of the Future of the DCLG Working Group—especially its chair, Ms. Kathy Giusti—for their long hours and hard work.

Meeting Objectives and Desired Outcomes. Ms. LeStage noted that one part of the day's discussion would focus on the results of a survey of cancer advocacy organizations. NCI, at the request of the DCLG, contracted with the firm, ORC Macro, to develop and field a survey of cancer advocacy organizations to obtain their opinions on the future role of the DCLG. Ms. LeStage expressed appreciation to Ms. Carol Freeman, Mr. Larry Luskin, and Mr. Matt Suljak of ORC Macro for their outstanding job on the survey.

The meeting agenda included discussions on:

- Areas of future focus,
- Primary roles,
- Future membership, and
- Operating procedures.

Based on these discussions, the DCLG would develop a set of recommendations about the future of the DCLG that the Future of the DCLG Working Group would present to NCI Director Dr. Andrew von Eschenbach on Tuesday, September 30, 2003.

Conflict of Interest Statement. Ms. LeStage reviewed the rules governing confidentiality and conflict of interest, and Ms. Nancy Caliman determined that a quorum was present.

Approval of Minutes of July 29, 2003, DCLG Meeting. The members unanimously approved a motion to approve the minutes of the July 29, 2003 DCLG meeting.

Introduction of Facilitator. Ms. LeStage introduced Dr. Peg Anthony of ORC Macro, who served as facilitator for the meeting. Dr. Anthony asked all participants to introduce themselves.

II. FUTURE OF THE DCLG

Summary of the Process, Findings, and Recommendations Along the Way. Ms. Giusti reviewed the process followed by the Future of the DCLG Working Group to develop recommendations on the future direction of the DCLG. The Working Group was formed following the April 22-23, 2002 face-to-face DCLG meeting. During that meeting, Dr. von Eschenbach asked the DCLG to help him determine the optimal role and direction for the DCLG. The Working Group was formed to make recommendations to the DCLG on whether the DCLG should continue and, if so, what its mission and optimal structure should be. The original members of the Working Group were Ms. Giusti, the Chair, Ms. LeStage, Mr. Mike Katz, and Ms. Paula Kim (who continued to serve after she left the DCLG). Ms. Gena Love was appointed to the Working Group in January 2003.

Ms. Giusti stated that the Working Group began its work by interviewing Ms. Ellen Stovall, President and C.E.O. of the National Coalition for Cancer Survivorship, about the early history of the DCLG. The Working Group then developed a qualitative interview guide and interviewed approximately 12 NCI staff members and 12 to 15 representatives of cancer advocacy organizations.

The qualitative interviews found that NCI staff were aware of the DCLG but had difficulty identifying examples of the group's effectiveness. Ms. Giusti said that NCI staff believed that the DCLG should understand NCI, focus broadly across all cancers, and bring ideas from the advocacy community to NCI. NCI staff identified three priority areas for the DCLG: clinical trials, survivorship, and research. Advocacy groups were less aware of the DCLG than NCI staff. They wanted the DCLG to bring their insights to NCI, and suggested the same priority areas for the DCLG as did NCI staff.

The Working Group met with Dr. von Eschenbach to share its findings on June 7, 2002. They suggested that the DCLG would be more effective if its members were incorporated into NCI planning at the earliest stages. Ms. Giusti said that Dr. von Eschenbach saw the DCLG's role as more tactical, such as reviewing NCI educational materials. Working Group members believed that Consumer Advocates in Research and Related Activities (CARRA) members could serve this role. Moreover, NCI staff were supportive of having DCLG members play a more strategic role than they had in the past. The Working Group then suggested to Dr. von Eschenbach that the DCLG conduct a survey of the advocacy community to identify its perceptions of NCI and the DCLG, enhance the OLA's database of advocacy organizations, and recommend a process for ongoing communication with the advocacy community. Dr. von Eschenbach approved the conduct of the survey.

The Working Group collaborated with ORC Macro to develop the survey instrument, which was fielded under NCI's generic OMB clearance for formative research. In order to comply with the generic OMB clearance, the survey was not permitted to collect data on the perceptions of the DCLG. Further, due to privacy considerations, ORC was not permitted to reveal identifiable information about the advocacy organizations to be included in the database. The resulting survey focused on respondents' familiarity with NCI and the DCLG and potential future directions for the DCLG.

Of the 152 advocacy organizations invited to participate in the survey, 80 (53%) responded. Most were small, grassroots organizations. In summary, they indicated that the DCLG should facilitate better collaboration between NCI and the advocacy community and serve in a strategic rather than a tactical role. The three most highly rated focus areas were clinical trials, survivorship, and research.

Ms. Giusti stated that during the meeting, the DCLG would review the implications of the survey results, integrate the survey findings with NCI's needs, and develop clear recommendations for Dr. von Eschenbach regarding the group's priorities, structure, and support. During the meeting with Dr. von Eschenbach, the following issues would need consideration:

- The future role of the Future of the DCLG Working Group,
- Facilitation of communication between advocacy organizations and NCI,
- How to build on the relationships with advocacy organizations that were initiated through the survey,
- Coordination with other NCI advisory groups,
- Database development and management, and
- A potential timeline for these activities and for a baseline survey on the DCLG.

III. RECOMMENDATIONS FOR THE FUTURE OF THE DCLG

NCI Director's Priorities. Ms. Cherie Nichols, Director of the NCI Office of Science Planning and Assessment, provided an overview of NCI's planning activities. She said that NCI has established a challenge goal: to eliminate the suffering and death due to cancer by 2015. The institute has identified seven initial strategic priorities to help achieve the challenge goal. These priorities are:

- Early detection, prevention, prediction;
- Strategic development of cancer interventions;
- Integrative cancer biology;
- Integrated clinical trials system;
- Overcoming health disparities;
- Molecular epidemiology: new approaches to understanding the causes of cancer; and
- Bioinformatics.

Other strategic planning initiatives that impact NCI are the Bypass Budget, Progress Review Groups (PRGs), the National Institutes of Health (NIH) Roadmap for Medical Research, and the Department of Health and Human Services (DHHS) priorities. The 2005 Bypass priority areas are investments in broad scientific areas, public health emphasis, research platforms, and research enablers. Ms. Nichols presented a diagram showing how the elements of the Bypass and the 2015 strategic plan might be coordinated. These two internal planning processes will be integrated for the 2006 Bypass Budget, and NCI would like the DCLG's assistance in this effort.

NCI is currently undergoing an internal review. It will formalize the linkages among all of its strategic planning processes. Staff members are working with a contractor to determine how the elements of all the processes link with one another. A tentative timeframe calls for the following: a draft plan to be distributed to NCI leadership at the branch chief level and above by the end of

September; these recommendations to be brought to the executive committee in October; a round of review by advisory boards, including the DCLG, in mid-November; the final document by April 2004.

Ms. Nichols asked the DCLG for advice on how advocacy organizations can best communicate with NCI. NCI made a commitment to bring these groups into the Bypass Budget planning process but when it sent chapters of the 2004 Bypass out for comment to 400 organizations, it received only 35 responses. Ms. Nichols expressed concern about the DCLG's view that NCI does not have a planning process and would like to discuss this with the group in the future.

Discussion. Ms. Giusti suggested that the DCLG could help NCI present the Bypass Budget plans in lay terms. The document may be overwhelming for many advocacy organizations, especially those that focus on communications and education rather than research.

Ms. LeStage clarified that the DCLG understands that NCI has many planning processes. But many NCI offices do not have a formal planning process. This makes it difficult for the DCLG to identify a role it could play in NCI's planning.

Ms. Nichols noted that the survey found that many advocacy organizations do not refer to the Bypass Budget in their work. She said that the document is used primarily by scientists and clinicians for their own strategic planning. Some have suggested a companion document for the lay public but Ms. Nichols expressed reluctance to begin developing many different documents for different audiences. However, a less complex version might be helpful to advocacy groups.

Mr. Katz suggested that NCI's 2015 strategic priorities include an indication of what NCI will accomplish in the next five years and how. This would make the plans more comprehensible. Ms. Nichols explained that the strategic priorities are part of a roadmap project at NCI that is attempting to determine which priorities should be addressed quickly and which will take longer. NCI is very aware that it cannot wait until close to 2015 to accomplish all of its priorities. Moreover, NCI has many good programs now that it will not abandon.

Mr. Katz suggested that Ms. Nichols identify questions concerning the Bypass Budget on which NCI needs input from the community. NCI could then obtain responses through a Web or telephone survey. For example, NCI might ask the groups to comment on whether NCI should reduce the number of clinical trials and focus on doing them faster. Many organizations simply do not know what NCI wants from them.

Ms. Nichols asked how advocacy groups that are not involved in research can give input on NCI research priorities. Ms. Susan Butler explained that although most advocacy groups do not do research, they "watch it like hawks." Virtually every organization has staff or knowledgeable advocates who are very engaged in following research in their areas.

Ms. Vernal Branch suggested that NCI identify the outcomes of its research for the community.

Ms. Paula Kim asked about the role of NCI's other advisory groups in developing the NCI roadmap. She also requested an update on the PRGs. Ms. Nichols explained that the National

Cancer Advisory Board's subcommittee on planning gives advice on the Bypass planning process. The Board of Scientific Advisors (BSA) serves a more conceptual role, helping to direct the science of NCI. NCI realizes that its advisory boards are good pulses of the community and will use them more productively in the future to obtain advice on the Bypass. Last year, all of the advisory boards, including the DCLG, were sent sections of the Bypass for comment.

Dr. von Eschenbach expects that the PRG process will involve the advisory boards. The PRG strategic planning process is proceeding parallel to NCI's strategic planning process and is not well integrated into those processes. NCI recognizes that it cannot fund all of the PRG recommendations and is trying to address this issue. For example, it is bringing together the main funders in prostate cancer to determine how to work jointly to support the initiatives in the prostate cancer PRG report.

Dr. Anthony suggested that DCLG members submit their remaining questions in writing to Ms. Nichols.

NCI Director's Priorities - Facilitating Collaboration. Dr. Ed Maibach, NCI's new Associate Director for Strategic Dissemination, noted that a major conclusion of the survey was that the DCLG should play a role in facilitating better collaboration between NCI and the cancer advocacy community. NCI is a large, highly decentralized agency and is therefore difficult for advocacy organizations to understand or navigate. The advocacy community is also a large and decentralized community. NCI has a sincere desire for dialogue with the advocacy community but has not been successful in creating mechanisms to facilitate this dialogue. Dr. Maibach defined dialogue as "being given a chance to express one's point of view and active listening, in alternating turns."

Dr. Maibach suggested that the DCLG play a pivotal role in

- Advising and collaborating with NCI to design mechanisms to facilitate true dialogue, and
- Serving as an "honest broker" to monitor and evaluate the process.

If the DCLG identified mechanisms that were effective in enhancing collaboration between NCI and the advocacy community, NCI could develop those mechanisms. The DCLG could then track how well those mechanisms were working. Specifically, the DCLG would assess the satisfaction of NCI and the advocacy organizations with the relationship. If the mechanisms did not work, the DCLG would help diagnose why and identify ways to fix the problems.

This focus would enable the DCLG to function at the strategic level and to play a role that is clear, distinct, and valuable to NCI and the advocacy community. By playing this role, the DCLG would also serve as a model for relationships with advocacy communities across NIH.

Discussion. Ms. Giusti characterized Dr. Maibach's proposal as being consistent with several comments made by Dr. von Eschenbach, who wants the DCLG to serve as a communication vehicle to the advocacy community. But the DCLG has indicated several times to Dr. von Eschenbach that it could better serve this role if its members were more involved in planning

processes early on. In order to communicate effectively, the group must understand the information that it is communicating.

Dr. Maibach said that he did not mean for the DCLG to serve as spokesperson for either NCI or the advocacy community. Instead, the group could design mechanisms to facilitate a broad exchange of viewpoints.

Ms. Gena Love asked how the role described by Dr. Maibach differed from the roles of the other advisory groups. She also wondered what the implications of this role would be for the DCLG's composition. Dr. Maibach differentiated between serving as a facilitator and a gatekeeper. The composition and process by which membership in the DCLG will be determined would be a very contentious issue if the DCLG serves as a spokesperson for NCI and the advocacy community. However, if the DCLG mission is to ensure that mechanisms exist for real dialogue between NCI and the advocacy community, then the membership becomes less contentious because members are not purporting to speak for anyone else. Typically, when a body speaks on behalf of other groups, those groups want a say in the membership of the body.

Results of NCI/DCLG Advocacy Survey. Mr. Larry Luskin reported that ORC Macro began the quantitative survey process with a series of qualitative interviews with NCI staff and advocacy organizations to help develop the survey content. The resultant quantitative survey was sent to 152 advocacy organizations, and ORC Macro analyzed the results from the 80 completed surveys received.

Most of the respondents were national or international in scope, and most focused on education and constituent information activities. Nearly all said that they serve patients and most also serve families. The respondents tended to be smaller organizations with small or no paid staffs. However, a few large organizations did participate.

Ms. Carol Freeman reviewed the survey results. More than half of the respondents suggested that the most valuable potential DCLG activity would be helping to facilitate better collaboration between NCI and the cancer advocacy community. Almost 70% agreed that the most beneficial activities for the DCLG to undertake would be strategic in nature, and not focused on implementation or monitoring. Respondents also indicated that research, clinical trials, and survivorship were the most important areas of activity for the DCLG. Dr. Marisa Weiss pointed out that health disparities and communication, which were also regarded as important activities by respondents, cut across the areas of research, clinical trials, and survivorship. Ms. Giusti explained that in the survey, the communications activity referred specifically to the activities of the NCI Office of Communications.

Ms. Freeman reported that respondents indicated that, within research, the most important activity would be to speed the development of promising agents. Within survivorship, the DCLG should help develop and disseminate new interventions, and participate on the survivorship extraordinary opportunity leadership team. Within clinical trials, the DCLG should work with NCI and the cancer advocacy community to increase the participation of patients in national trials.

Ms. Freeman concluded that, according to the survey results, the DCLG should:

- Concentrate its efforts in areas where it can help facilitate better collaboration between NCI and the cancer advocacy community;
- Identify activities that are strategic in nature;
- Focus on activities related to survivorship, research, or clinical trials where opportunities exist to facilitate collaboration and serve a strategic role; and
- Use the characteristics identified in the survey in its membership recruitment activities.

Discussion. Ms. Giusti noted that 47% of respondents disagreed that NCI is communicating how it sets its priorities, which might be an area of focus for the DCLG. Mr. Porterfield noted that respondents also disagreed that NCI effectively translates research into interventions, and that NCI's research is appropriately balanced. Ms. Giusti stated that advocacy organizations do a great job on education and communication but most cannot do research, so they count on NCI for that and watch its research activities very closely. Clearly, these respondents do not understand the Bypass Budget, or they would not disagree that NCI communicates how it sets its priorities. Ms. Kim pointed out that the Bypass Budget is designed for Congress, not the cancer advocacy community.

Ms. Kim wondered how the DCLG could enhance communications between NCI and the large number of advocacy organizations with small constituencies.

Ms. Giusti pointed out that many of the findings of the survey are positive. For example, advocacy organizations are very satisfied with many of NCI's communications vehicles, such as its website and 800-number.

Areas of Commonality - Small Group Discussions. Dr. Anthony asked DCLG members and NCI staff to form four small groups. Each group would spend 10 minutes discussing areas of commonality in the initial presentations of the meeting, and identify areas of greatest impact for the DCLG as it collaborates with NCI on various initiatives involving the advocacy community. Following their discussions, representatives of each group shared their group's conclusions.

Ms. Nyrvah Richard reported that instead of identifying common themes from the earlier discussions, her group identified key expressions that had been mentioned several times:

- Collaboration and dialogue: These terms had not been fully defined. Those who had mentioned collaboration appeared to have different definitions of the term, and it was not clear what should be communicated through dialogue.
- Discovery, development, and dissemination: It was not clear where the DCLG fits into this continuum in such a way as to produce the greatest impact.

Mr. Christopher Pablo stated that his group agreed that the voice of the cancer advocacy community should be heard at the beginning rather than later in NCI planning processes. For example, the DCLG should be involved at the beginning of the clinical trials process. The group also suggested that the activity areas of clinical trials and survivorship have commonalities that may make it possible to bridge these two issues. The group noted that palliative care had not been addressed and should be integrated into the entire treatment process, not solely at the end of life. Dr. Weiss added that survivorship and clinical trials overlap because people who survive

cancer want to know the long-term results of clinical trials. Clinical trials need to be designed to address endpoints other than survivorship, such as quality of life, as well as different reporting intervals. Ms. Butler added that the DCLG should not become the voice for the cancer advocacy community.

Dr. Ellen Feigal asked how the DCLG could reconcile the strategic role that it wants to play with the desire to be involved at the beginning of clinical trials, which is a tactical role. Ms. LeStage explained that NCI's seven strategic initiatives include redesigning the clinical trials system at NCI, and the DCLG needs to be involved in this process from the beginning at a strategic level. Other advocates could be involved at a tactical level in planning individual trials.

Ms. Giusti reported that her group noted that both DCLG members and NCI staff agreed that the DCLG should focus on clinical trials, research, and survivorship. A clear need exists for a conduit between NCI and the cancer advocacy community. A need also exists to bridge the gap between research and communication/education in the cancer advocacy community. Advocacy organizations find it difficult to understand what is going on in research and how to communicate about research to their constituencies.

Ms. Nichols pointed out that NCI tried to involve advocates early in its planning process when it sent out requests to the community at the formulation stage of its 2005 Bypass Budget, but it received very little response. She wondered if NCI is approaching the community with the appropriate communication tool. Ms. LeStage noted that the DCLG did provide extensive feedback for the 2005 Bypass process.

Ms. Butler suggested that advocacy organizations believe that the Bypass Budget document is in virtually final format by the time they see it. Many are also intimidated because the document is developed by scientists. NCI may need to consider new vehicles for dissemination. Ms. Nichols replied that the process was changed with the 2004 Bypass Budget so that the community saw a very early version of the document.

Ms. Love suggested that the response to Ms. Nichols's request might not be a good measure of NCI's efforts to involve advocacy organizations early in the process. In the survey, almost half of all respondents indicated that they did not refer to the Bypass Budget in their work. That might explain why so many organizations failed to respond to the request for feedback.

Mr. Katz explained that his group had discussed the exclusion of health disparities from the three priority areas of activity for the DCLG. The group also noted strong agreement that collaboration between NCI and the advocacy community was not working, and a disconnect between where NCI and the advocacy community thinks such collaboration would be helpful, such as in basic science. Collaboration within the advocacy community is probably more problematic than between NCI and the cancer advocacy community. The DCLG needs to be diverse and savvy enough to facilitate these collaborations. The group needs more tangible objectives for what an improved process would be and what it is trying to fix.

Mr. Katz clarified that the survey indicates that collaboration between NCI and the cancer advocacy community is not working, and this matched the perceptions of Mr. Katz's group.

Advocacy groups do not believe that NCI's actions reflect their priorities or that NCI is having an impact in certain areas. They do not understand the connection between research and clinical trials. Many advocates do not know what NCI does or what its impact is, and believe that NCI is not doing all it could. In contrast, NCI staff members believe that they are doing as much as they possibly can. Ms. Ruth Lin pointed out that minorities do not enroll in sufficient numbers in clinical trials. The advocacy community has made recommendations to address the situation but it is not clear how NCI has responded.

Dr. Roland Garcia stated that the DCLG could help NCI improve its image with the advocacy community. Many community and survivor groups view NCI and NIH as ivory towers of research. They do not do not believe that they can have an impact on NCI's planning.

Ms. Branch suggested that the DCLG propose new ways to involve the advocacy community, such as through consensus conferences for advocacy organizations. These conferences could be organized by the organizations and would communicate the outcomes of NCI funded research.

Dr. Weiss suggested that the DCLG identify the processes that have and have not worked well.

Three Key Issues for DCLG Involvement 2003-2005. Mr. Katz, Ms. LeStage, and Ms. Giusti presented proposals for the involvement of the DCLG in the areas of clinical trials, survivorship, and research. Each presentation included justification for involvement based on survey data, potential strategic, collaborative, and communicative activities, and measures for effectiveness.

Clinical Trials. Mr. Katz noted that the advocacy survey found that a majority of advocates believe that NCI is making clinical trials more widely available but 70% thought that the DCLG should work with NCI to increase participation and few think that NCI is collaborating well with the cancer advocacy community about clinical trials.

Mr. Katz stated that research does not benefit the patient until a clinical trial occurs. The system needs sufficient capacity so that all of the good ideas reach the bedside. Through discussions with NCI staff, Mr. Katz identified three potential roles that the DCLG could play in NCI's clinical trials process:

1. Building a more effective collaborative relationship. NCI needs to understand the advocacy community's perspective on what is and is not working. The DCLG could also document the full extent of advocate involvement and determine whether the right advocates are involved and are making an impact. In addition, the DCLG could identify the problems and propose potential solutions for enhancing collaboration between NCI and the cancer advocacy community.

2. Improving communications. The DCLG should work with NCI's Clinical Trials Support Unit (CTSU) to help improve the dissemination of trial menus and updates, and address problem trials. DCLG liaisons might serve on the CTSU and prevention trial patient advisory groups. Also, the DCLG could communicate with the advocacy community about the importance and benefits of prevention trials.

3. Providing a liaison for redesign/rationalization. One of NCI's 2015 strategic initiatives is to redesign the clinical trials system. Perhaps the tremendous amount of redundancy and waste in the system can be reduced. NCI staff is receptive to DCLG involvement in this process, and the DCLG can best contribute if it is involved early in the process. Several DCLG members know the clinical trials system from the grassroots level and could help make a difference in the long term.

Success of the DCLG's activities in clinical trials could be evaluated by repeating the advocacy survey annually. Ideally, the DCLG would improve advocacy contributions and communications, and will be productively involved in redesign/rationalization.

Survivorship. Ms. LeStage explained that the survey identified two potential areas within survivorship for DCLG involvement: (1) helping to develop and disseminate new interventions and best practice guidelines for follow-up care and monitoring of post-treatment survivors; and (2) participating in the new survivorship extraordinary opportunity leadership team.

Ms. LeStage discussed the DCLG's potential involvement in survivorship with Dr. Julia Rowland, Director of the NCI Office of Cancer Survivorship, who pointed out that strategic involvement in intervention and best practice guidelines would be difficult for the DCLG, because the interventions and guidelines are developed through extramural investigator-initiated research. The DCLG could help develop and disseminate related educational materials but this is probably a more appropriate task for CARRA. Dr. Rowland would, however, welcome two DCLG members on the survivorship extraordinary opportunity leadership team.

Ms. LeStage questioned whether the DCLG could make a unique contribution to survivorship, given that many other groups, such as the President's Cancer Panel, the National Dialogue on Cancer, the Centers for Disease Control and Prevention, and the National Coalition for Cancer Survivorship, are addressing this issue.

The DCLG can help improve collaboration between the advocacy community and NCI on survivorship by reaching out and soliciting input from the advocacy community and continuing its involvement with the President's Cancer Panel survivorship initiative.

The DCLG could also play a role in communication through monthly newsletter articles on NCI survivorship activities, President's Cancer Panel survivorship meetings, new survivorship clinical trials, and the results of completed survivorship trials. The DCLG might also hold a meeting in collaboration with the 2004 survivorship conference in Washington, DC. In addition, the DCLG needs to establish regular communications with advocates serving on other NCI advocacy boards.

The DCLG could measure its effectiveness in survivorship by measuring the success of the survivorship extraordinary opportunity and by repeating the advocacy survey annually to assess the cancer advocacy community's perception of the NCI's collaboration with them on survivorship issues. In response to a question from Ms. Butler, Ms. LeStage clarified that the DCLG had originally intended to survey the advocacy community on its perceptions of the DCLG but NCI's generic OMB clearance for formative research did not permit this. Therefore,

the DCLG still needs to collect this information to establish a baseline, and then repeat the survey annually.

Ms. Elisabeth Handley reported that when the Office of Liaison Activities (OLA) discussed the survey results with Dr. von Eschenbach, he was excited about the prospect of having the DCLG focus on survivorship. She said that Dr. von Eschenbach believes that the various groups involved in survivorship can infuse their knowledge and energies into one another. Ms. LeStage suggested that if survivorship were selected as a focus area for the DCLG, collaboration with these other groups would be essential.

Dr. Weiss suggested that survivorship, clinical trials, and research are connected and the DCLG should not try to work on each area discretely. Ms. LeStage agreed that a continuum exists, but each area was identified separately in the survey, is represented by a different office at NCI and has its own strategic planning process. Dr. Noreen Aziz noted that the NCI offices for clinical trials, survivorship, and basic research do work together. However, since survivorship is a relatively new science, much of the current research in this area involves case control or cohort studies, which will provide endpoints that can be incorporated at some future time into clinical trials. The success of clinical trials might not be the best measure of the progress of survivorship research.

Dr. Feigal suggested that the DCLG does not need to be constrained by NCI's separate offices because they do communicate extensively with one another. However it is challenging to identify the most appropriate contact for various purposes, and a navigation system would be helpful.

Research Priority Development. Ms. Giusti stated that the survey found that advocacy organizations believed that NCI is making progress reducing the cancer burden. However, they did not understand how NCI sets its research priorities. Further, advocates find it difficult to identify the appropriate persons at NCI to address their specific research issue.

Ms. Giusti suggested that, in the short term, two DCLG members could be integrated into the NCI research planning process. One would work with Ms. Nichols and her colleagues to identify appropriate opportunities for advocacy input and improve the response rate on the Bypass Budget. The second member could be involved in analyzing and communicating about the PRG process.

The DCLG needs to establish communications with the advocacy community. The DCLG could distribute a monthly e-mail message and a quarterly newsletter. It could also develop a website, perhaps on the NCI website, providing a layperson's perspective on the planning process at NCI with contact information for and descriptions of NCI staff members that advocacy organizations might wish to contact. The DCLG could also issue press releases with NCI explaining the planning process and incorporating quotes from advocates who participated in that process. Accomplishing these tasks will require a comprehensive database of advocacy organizations.

To address research issues at NCI, DCLG members need to be familiar with NCI, its research grant programs, and the PRG process. They also need strong communication skills and availability for meetings and other activities.

Ms. Giusti noted that public-private partnerships are a high priority for NCI. The PRG recommendations, for example, can only be implemented through public/private partnerships. In the longer term, the DCLG could help integrate public-private partnerships into the NCI planning process and portfolio. For example, the DCLG could identify advocacy organizations that could co-fund a research roundtable. A portfolio is needed to document how advocacy groups are currently working with NCI, as these groups could provide helpful advice.

Ms. Nichols pointed out that public-private partnerships are a component of the NIH Roadmap for Medical Research. Dr. von Eschenbach is one of two co-chairs of the Roadmap Public-Private Partnership Implementation Group. Dr. Feigal and Ms. Nichols are members of the group. Ms. Nichols suggested that if the DCLG developed a list of ideas for public-private partnerships, it could share this list with her or Dr. Feigal, who would then share the list with the NIH implementation group. Dr. Feigal agreed that public-private partnerships are an area of interest for NIH as a whole and could be a very active area of involvement for the DCLG.

Other Ideas and Discussion. Ms. Love recommended that the DCLG consider focusing on cancer health disparities. She noted that when asked how important it is for the DCLG to be involved in five areas – research, clinical trials, survivorship, health disparities, and communication -- health disparities tied at 89% with research and survivorship when responses of "Very Important" were combined with "Extremely Important". She also said that eliminating health disparities is a goal of the DHHS *Healthy People 2010* goal. As evidence of its importance to DHHS, the Department recently held a trans-HHS PRG on cancer health disparities that was run by NCI. She urged that the DCLG take a leadership role in this area because cancer disparities impact many aspects of research such as accruals to clinical trials and cancer treatment outcomes.

Ms. Butler suggested that cancer health disparities could be integrated into the other focus areas. Ms. LeStage said that the survey data found that clinical trials, survivorship, and research were a higher priority to cancer advocates and that CARRA members could take on some of the disparities-related activities such as helping to identify unmet information needs and optimal communication mechanisms for the underserved. She agreed that increasing access and accrual could be integrated into clinical trials.

Ms. Love stated that it could be argued that clinical trials could be integrated into survivorship and health disparities. She said that the DCLG should send a strong message to its constituencies that its goal is to eliminate cancer health disparities by 2010.

Dr. Garcia spoke about the unequal burden of cancer on minorities. Cancer health disparities affect the elderly, those who live in rural areas, and the poor as well as racial and ethnic minorities. These groups may not be represented on the DCLG or by advocacy organizations. The NCI Center to Reduce Cancer Health Disparities has a large task and it would welcome assistance from the DCLG. Dr. Garcia agreed with Ms. Love that cancer health disparities is different from the other areas of focus and if it is integrated into them, many important issues could be lost.

Ms. Karen Packer agreed that the DCLG should serve those who are not being heard. Her organization was recently asked to develop a model to disseminate information through one-on-one contacts with patients through small organizations. This might be an appropriate project for the DCLG.

Dr. Maibach noted that, in all of the priority issues discussed, effective mechanisms are lacking for requesting and listening to input, and reflecting what has been heard early and continuously. Dr. Maibach would like to identify mechanisms that would facilitate this kind of dialogue.

Ms. Butler said that many cancer advocacy organizations do not do a good job addressing health disparities because they are largely run by White middle class persons.

IV. PUBLIC COMMENT

Ms. Barbara Butler, a member of the NIH Director's Council of Public Representatives (COPR), asked whether NCI staff members have enough time to address the issues discussed by the DCLG. Ms. LeStage noted that because NCI staff members are so busy, the DCLG asked for their input on its suggested areas of focus to ensure that they would welcome DCLG participation in these areas. Dr. Feigal explained that whether NCI staff members have time to devote to these activities depends on the priority level of these initiatives. Receiving input from patients and community representatives is a high priority for NCI. NCI staff members are extremely busy and have a variety of different responsibilities. Ideally, the NCI would have more staff and more time to complete all of its tasks. But the activities of the DCLG are important.

Mr. Greg Bielawski, a CARRA member, expressed his appreciation for the hard work of the DCLG and NCI staff in trying to formulate a way for both groups to work together. He asked the DCLG to consider additional ways in which it can use the more than 200 CARRA members to carry its message, once that message is developed.

V. PRIORITY ISSUES OF FOCUS FOR THE DCLG

Dr. Anthony led the discussion on selecting priority issues of focus for the DCLG. Some members suggested that the DCLG's role needed to be clarified before it selected priority areas. Ms. LeStage and Ms. Giusti explained that the advocacy survey identified three key roles for the DCLG: involvement in helping to set NCI priorities (strategic), helping to facilitate better collaboration between NCI and the cancer advocacy community (collaborative), and communicating with the advocacy community about the DCLG's activities and impact (communicative).

Ms. Giusti clarified that "strategic" means helping develop priorities rather than, for example, responding to a brochure. A strategic role for the DCLG was contrasted in the survey with the more tactical and monitoring roles such as helping to implement or monitor the implementation of NCI strategies. Dr. Anthony suggested that collaboration could mean building consensus, identifying issues, and engaging members of groups.

Ms. Butler stated that the DCLG needed to know what role Dr. von Eschenbach would like the group to play. Ms. LeStage explained that the NCI director asked the DCLG to make recommendations regarding its future roles and activities. He will make a decision on the DCLG's future role after reviewing the DCLG's recommendations. Ms. Giusti added that the group would be unlikely to further define its three roles during this meeting, and should proceed to select its focus areas. Dr. Anthony suggested that since the group seemed to accept the three roles based on the survey data, it could define them further after the meeting.

Criteria for Selecting Areas of Focus. Dr. Anthony asked participants to list criteria that should be used to select the areas of focus for the DCLG. She explained that by agreeing to a set of criteria, the group would select its focus areas from a common point of view.

Dr. Weiss noted that the members of the DCLG are all active at NCI as individuals. Whatever projects they select as a group will not prevent them from continuing to serve in their individual capacities at NCI.

After discussion, Mr. Katz summarized the key criteria for focus areas for the DCLG:

- They should be of importance to the advocacy community and to NCI;
- By its involvement in the focus areas, the DCLG can bring value to NCI and the advocacy community;
- The activities that the DCLG engages in within the focus areas should be demonstrable and doable.

Ms. LeStage added that the focus areas should provide a unique role for the DCLG that does not duplicate what other organizations are doing.

Areas of Focus to Consider. Dr. Anthony asked the DCLG to consider four potential focus areas:

- Clinical trials,
- Survivorship,
- Research, and
- Health disparities.

Dr. Maibach suggested that the importance of collaboration between NCI and the advocacy community is clear but NCI lacks a good process for engaging the advocacy community early and throughout the course of initiatives and planning. This issue was not listed as a potential focus area and if it were not selected by the DCLG, NCI would nevertheless do its best to develop this process without the benefit of input from the DCLG.

The DCLG could play a unique role that is not being served by anyone else in helping design a good process that facilitates collaboration. Dr. Maibach also pointed out that the three roles of the DCLG—collaborative, strategic, and communicative—are closely related. Collaboration cannot occur without communication, for example, and if collaboration helps NCI make better decisions, it is strategic from NCI's perspective that it proceed with its planning with good input. At the same time, the advocacy community would be aware that a good mechanism exists whereby it can communicate its ideas. Dr. Maibach said that some advocacy groups are good at

communicating with NCI but there is no unified way to make the ideas of the entire community known to NCI. Dr. Maibach hoped that the DCLG would focus on how to create a collaborative process and become an honest broker for that process by monitoring its success. Dr. Anthony suggested adding strategic dissemination as a potential area of focus.

Mr. Katz said that strategic dissemination is an enormous area. He suggested that it could be related to the other areas of focus. For example, the DCLG could work on improving the process for obtaining input on the Bypass Budget, which affects the research planning process. This would be a tangible example of how the DCLG could accomplish strategic dissemination.

Ms. Kim suggested that the DCLG work with NCI to create and monitor a process to facilitate collaboration between NCI and the advocacy community. If the DCLG can accomplish this, it would lay the groundwork for everything else that the DCLG wants to do. This role would require support from Dr. von Eschenbach, who would need to direct NCI staff to work with the DCLG on developing the process.

Dr. Feigal noted that in order to collaborate, an area of mutual interest must be identified. The process is secondary to the substance, and someone needs to identify the substance.

Dr. Anthony asked whether strategic dissemination should be added to the list of areas of focus. Ms. LeStage suggested that strategic dissemination should be part of whatever the DCLG does in all focus areas it selects. She also suggested that regardless of the focus areas selected by the DCLG, DCLG and CARRA members could be assigned to work with Dr. Maibach on strategic dissemination.

Selection of Areas of Focus. The DCLG agreed to discuss the following focus areas:
1. Clinical trials,
2. Survivorship,
3. Research planning, and
4. Health disparities.

Dr. Anthony reminded the group that members had agreed on the following criteria for selecting areas of focus:

- Impact
- Importance
- Feasibility
- Demonstrability
- Unique role for the DCLG.

Each of the four potential focus areas had specific activities identified by the members of the Future of the DCLG Working Group:

- Clinical Trials:
    - Building a more effective collaborative relationship between NCI and the advocacy community;
    - Improving communication between NCI and the advocacy community;

  - Providing a liaison for clinical trials redesign process.

- Survivorship:
  - Participating on the leadership team for Extraordinary Opportunity in Survivorship;
  - Continuing to collaboration with the President's Cancer Panel;
  - Communicating about survivorship in DCLG newsletters and holding a DCLG meeting before or after the June 16-18, 2004 survivorship conference in Washington, D.C.

- Research planning:
  - Integrating two to three DCLG members into the NCI research planning process to bring insights of the cancer advocacy community to NCI;
  - Communicating with the advocacy community about NCI's planning processes;
  - Helping to integrate public-private partnerships into the NCI planning process and portfolio.

- Health Disparities
  - Increasing knowledge about, tools for, access to, and use of cancer communication tools for underserved populations;
  - Increasing access and accrual of underserved populations to state-of- the-art clinical trials;
  - Working with the Center to Reduce Cancer Health Disparities on areas that it identifies;
  - Developing a model to disseminate information through one-on-one contacts with patients through small organizations;
  - Following-up on the recommendations of the cancer health disparities PRG.

Dr. Anthony asked DCLG members to vote on the focus areas. The rank order of the focus areas was as follows:

1. Survivorship
2. Clinical trials
3. Disparities
4. Research planning

Dr. Anthony stated that research planning could be dropped. Ms. LeStage suggested that narrowing the areas of focus to two would be desirable to prevent overload for the DCLG. Another option was to present Dr. von Eschenbach with three options and ask him to choose two. Mr. Katz suggested that the DCLG present all three areas of focus to Dr. von Eschenbach, noting that one of these opportunities may be dropped once the group develops a more detailed plan for each area. Ms. LeStage reminded the group that future DCLG members will work on the focus areas, and current members should not prescribe what the future members should do.

Ms. Branch suggested that the DCLG show Dr. von Eschenbach the roles it will play within each area of focus. Ms. Love stated that she has not spoken to NCI staff about specific activities the DCLG could undertake with regard to health disparities. Ms. Richard offered to talk to Dr.

Freeman of the Center for Reducing Cancer Health Disparities and develop a document, similar to the documents for the other areas of focus, by Friday (9/26/2003) morning. Ms. Ruth Lin and Ms. LeStage offered their assistance with this task.

Strategic Dissemination. Dr. Weiss and Ms. Kim urged the DCLG to reconsider Dr. Maibach's invitation to help create and monitor a process for the involvement of advocates within NCI. They stated that it was an opportune time for the DCLG to be engaged in this effort because NCI is reviewing how advocates are involved in NCI divisions and offices. Dr. Weiss said that Dr. Maibach's proposal is relevant to the survey results because advocates want the DCLG's help in collaborating with NCI.

Dr. Maibach reiterated that the survey results indicated that the advocacy community places a high priority on the DCLG facilitating collaboration between NCI and the advocacy community. He said that Dr. von Eschenbach believes it would be "fantastic" if the DCLG could accomplish this. He emphasized that the DCLG would not speak for the advocacy community but would create mechanisms whereby the community could speak. Dr. Maibach noted that managing input from the advocacy community can be difficult and therefore NCI needs to design a process that is efficient and effective that will help NCI make the best decisions possible. The DCLG could serve as an honest broker in ensuring that the process is effective once it is implemented.

Ms. LeStage asked whether the DCLG would simply pass advocate input to NCI, or would advocates help decide what to do with the input. Dr. Maibach emphasized that he is not asking the DCLG to collect information and hand it over to NCI. Instead, he wants the DCLG to help design a process for dialogue with the advocacy community. Ms. LeStage stressed that once the process is designed, the DCLG will be most effective if it can be involved in deciding what to do with the information that is obtained. Dr. Maibach hoped that all NCI offices would support this kind of feedback on all initiatives.

Dr. Maibach stated that this activity would take place through several NCI offices, including the OLA. Initially, the DCLG could work on strategic dissemination in the three areas of focus it has selected. Once a good process is developed, multiple issues can be run through that process. This will teach NCI and the advocacy community how the process works and will prevent the need to develop a new process for every area of focus.

Ms. Branch suggested that strategic dissemination be a fourth area of focus for the DCLG. All four areas should be presented to Dr. von Eschenbach, who can decide which issues the DCLG should undertake. Ms. Richard supported the idea of making strategic dissemination part of the DCLG's role rather than an area of focus. Dr. Anthony summarized the group's discussion by saying that the DCLG agreed to include strategic dissemination in its presentation to Dr. von Eschenbach. Mr. Katz clarified that the DCLG will use the three areas of focus as pilot tests for the system that it will design and will then work toward a broader agenda.

Dr. Weiss further defined the agreement that the DCLG would assume a collaborative and strategic role in defining, designing, creating, and monitoring a process for involving advocates at NCI, and the areas of activity within NCI that the group believes deserve the highest priority

in representing advocates are clinical trials, health disparities, and survivorship. She also requested a job description and necessary skills for those who would participate in this process.

VI. ROLE OF DCLG ON BEHALF OF THE CANCER ADVOCACY COMMUNITY

The DCLG discussed its roles in the context of selecting areas of focus (see above summary).

VII. IMPLICATIONS FOR MEMBERSHIP, STRUCTURE, AND OPERATIONS OF THE DCLG

Dr. Anthony asked participants to divide into three sub-groups tasked with discussing the implications of the group's decisions regarding roles and areas of focus on membership, operating procedures, and budget. Each group spent 15 minutes discussing one of these areas.

Membership. Ms. Branch summarized the sub-group's conclusions on the qualifications of new DCLG members. These members will need:

- Expertise in the priority areas (this should be stated in the application form);
- Leadership in organizations or the community—members could be cancer survivors, caregivers, or health professionals;
- Knowledge in cancer;
- Good communication skills;
- Diversity—members should represent different areas of the country, ethnic groups, and ages; and
- Ability to focus broadly across all cancers.

In the future, a shorter timeline should be followed for advertising and receiving applications, and a more targeted approach should be used. Ms. LeStage explained that the 150 organizations that were invited to participate in the advocacy survey and a few websites should be targeted to receive information about DCLG membership recruitment.

Ms. Love asked about the importance of recruiting "different faces" to the group. Ms. Branch replied that her group had decided that the DCLG should recruit some representatives of grassroots organizations that have a large presence in their own communities even if these groups are not national in scope. Ms. Love clarified that some well-known cancer advocates serve on many advisory boards and, when the DCLG was originally formed, one goal was to recruit those who were less well known.

Dr. Weiss suggested that the group recruit individuals who have a large constituency that could serve as a distribution channel for information thereby increasing the DCLG's reach. Ms. Butler expressed concern that this would rule out many potential members and Dr. Weiss clarified that not all potential DCLG members need to have large constituencies.

Dr. Maibach added that future DCLG members should have a passion for the process of gathering input.

Operating Procedures. Dr. Weiss reported that this sub-group agreed that the DCLG should establish the following:

- A working group to create a system of communication and accountability for advocates at NCI. The members of this group must be very involved in a consistent way in the process.
- A system of regular interactions and feedback with the Office of the Director.
- A system of regular interactions and feedback with the advocacy community.
- An increased number of face-to-face meetings.
- Selection of members of working groups by vote.

Ms. LeStage asked if DCLG members would like to coordinate a face-to-face meeting with the survivorship conference to take place in the summer of 2004. Dr. Weiss replied that the group should schedule its meetings in conjunction with other meetings, such as those required for strategic dissemination, as this will create synergies.

Budget. Mr. Porterfield reported that the DCLG's budget should be sufficient to cover:

- Four face-to-face meetings plus two more in conjunction with conferences, such as the survivorship conference;
- Six conference calls for the entire DCLG;
- Six conference calls for each working group;
- OLA staff, administration, and clerical expenses.
- Consultants for logistics, program, and surveys; and
- Recruiting, analyzing, interviewing, and selecting new DCLG members.

Ms. LeStage suggested that instead of having six face-to-face meetings a year, the budget should include funds for DCLG members to attend other meetings. For example, the NCI divisions might not have the funds to pay for DCLG members to travel to Washington, so the DCLG budget should cover these expenses. Ms. Richard clarified that the budget sub-group was proposing four face-to-face meetings for the entire DCLG, and two additional meetings for individual DCLG members in their specific areas of focus.

Dr. Garcia asked how the DCLG will assess whether its work is successful, as this needs to be included in the budget. Ms. LeStage stated that the DCLG would require a baseline survey to assess perceptions, a significant budget item. Mr. Porterfield noted that this expense is included under consultants.

Dr. Maibach asked if the consultants' budget would includes the creation of mechanisms for soliciting feedback, such as the creation of a website. Mr. Porterfield replied that the consultants' item would include those costs.

Mr. Porterfield asked if the DCLG budget includes the budget for CARRA. Ms. Handley replied that CARRA has a separate budget. She added that NCI staff rather than consultants might be able to develop some of the communication vehicles that were discussed.

Dr. Weiss pointed out that the budget should include a system of communication with the director and another system for communication with advocacy groups. The database needs to be

enhanced for this latter purpose. Ms. Handley noted that OLA is working to enhance its current database of advocacy groups.

VIII. HOW WILL THE DCLG COMMUNICATE WITH AND INVOLVE THE CANCER ADVOCACY COMMUNITY?

Dr. Anthony asked the group to consider what it wants to communicate and to whom about the results of this meeting.

The DCLG agreed to send the survey executive summary and the results of the DCLG meeting to the 150 organizations that were invited to participate in the survey, CARRA members, NCI advisory boards, key NCI staff including Executive Committee members, division heads, and those interviewed by the Future of the DCLG Working Group, and NIH public liaison officers. Ms. LeStage suggested that the OLA develop a listserv of the organizations invited to participate in the advocacy survey so that the DCLG could continue to communicate with them.

IX. SUMMARY OF RECOMMENDATIONS AND NEXT STEPS

Ms. LeStage thanked Dr. Anthony for a "fantastic job under difficult circumstances." She also thanked the members of ORC Macro who worked with the Future of the DCLG Working Group so diligently for eight months. She thanked the members of the Working Group, the DCLG, and OLA staff for their work.

Ms. LeStage asked for a motion to approve the recommendations made during the course of the meeting. Ms. Branch made a motion that the DCLG accept the priorities and roles that it had selected by consensus, and that it accept the recommendations made for membership, operating procedures, and budget. The motion was seconded by Mr. Pablo and carried unanimously.

Ms. LeStage announced that the next step would be a conference call meeting for the Working Group on Friday (9/26/2003) when the group would review a written summary of the DCLG's recommendations. The group would turn that summary into a presentation to Dr. von Eschenbach to be given on Tuesday, September 30. Following the September 30 meeting, the Working Group would develop a cover letter to send with the survey results. At that point, the Future of the DCLG Working Group's tasks would be completed. Ms. LeStage thanked Ms. Giusti for the tremendous effort and talent she brought to her role as chair of the Working Group.

Ms. LeStage promised to communicate the results of the discussion with Dr. von Eschenbach to all DCLG members.

Ms. Caliman thanked the DCLG and the Working Group, on behalf of NCI, for their hard work and patience.

The meeting adjourned at 4:45 p.m. on September 24, 2003.

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

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

DCLG ACTION ITEMS

September 24, 2003

- By Friday morning, September 26, 2003, Ms. Nyrvah Richard will develop a plan to address cancer health disparities as an area of focus for the DCLG. This plan will incorporate the three priority roles of the DCLG, and will be similar in format to the plans for addressing survivorship and clinical trials. Ms. Ruth Lin and Ms. Barbara LeStage will assist in the preparation of this plan.
- The DCLG will develop a cover letter to distribute with the results of the survey of advocacy organizations.
- The DCLG will send the executive summary of the survey report to the 150 advocacy organizations that were invited to participate in the survey, members of NCI advisory boards, CARRA members, and NCI division heads and executive committee members. Those seeking more detail will be invited to request the full survey report.
- Once Dr. Eschenbach responds to the DCLG's recommendations regarding its future priority roles and areas of focus, the DCLG will communicate this response to the advocacy organizations.
- The Office of Liaison Activities (OLA) will create a listserv of the 150 advocacy organizations that were invited to participate in the survey.
- OLA will share the survey results with the public liaison officers of other NIH institutes.
- Ms. Barbara LeStage will communicate with all DCLG members about the results of the Tuesday, September 30 meeting between the Future of the DCLG Working Group and Dr. Eschenbach.
- The DCLG will attempt to hold a face-to-face meeting in conjunction with the survivorship conference in 2004.