

**NATIONAL CANCER INSTITUTE
DIRECTOR-S CONSUMER LIAISON GROUP
Doubletree Hotel, Rockville, Maryland**

**Summary of Meeting
April 16-18, 2001**

The NCI Director-s Consumer Liaison Group (DCLG) convened for its meeting Monday Tuesday and Wednesday, April 16-18, 2001 in the Madison Room, Doubletree Hotel, Rockville, Maryland. The meeting, which began at 8:30 on all three days, was open to the public. Mr. Michael Katz presided as Chair.

DCLG Members

Mr. Michael Katz, Chair
Ms. Susan Lowell Butler
Ms. Kerry Dewey
Dr. Felicia Schanche Hodge
Ms. Barbara K. LeStage
Ms. Ruth Lin
Ms. Gena Love
Dr. Pamela McAllister

Mr. Daniel Moore
Mr. Henry Porterfield
Ms. Nyrvah Richard
Ms. Lillouise Rogers
Ms. Paula Kim (Simper)
Ms. Susan Stewart
Dr. Brad Zebrack

Speakers

Dr. Richard Klausner, Director, NCI
Dr. Marianne H. Alciati, Consultant, Management Solutions for Health, Inc.
Dr. Marcia Carlyn, Consultant, United Information Systems, Inc.
Dr. Mark Chesler, National Board Member, Candlelighters Childhood Cancer Foundation
Dr. Harold Freeman, Director, Center for Reducing Cancer Health Disparities, NCI
Ms. Karen Jackson, Executive Director, Sisters Network, Inc.
Ms. Gena Love, Member, DCLG
Dr. Grace Ma, Director, Asian Tobacco Education and Cancer Awareness Research Initiative
Mr. Hank Porterfield, Member, DCLG
Ms. Ellen Stovall, President, National Coalition for Cancer Survivorship
Dr. Brad Zebrack, Member, DCLG

NCI Liaison Activities Staff

Ms. Elaine Lee, Executive Secretary, DCLG
Dr. Yvonne Andejeski
Ms. Tracy Clagett

Ms. Christine Ghanem
Ms. M.. Kathleen Joyce (Consultant)

Ms. Keisha Martin
Ms. Laurie Rosenberg

CALL TO ORDER AND OPENING REMARKS

Mr. Michael Katz called the meeting to order and determined that a quorum was present. He reviewed the rules governing confidentiality and conflict of interest.

REPORT OF THE DIRECTOR

Dr. Richard Klausner reported that NCI continues to support high priority cancer research despite stresses arising from a budget freeze, which was lifted in December, as well as the ongoing hiring freeze. The former has held up the launch of new programs; the latter has prevented the hiring of new personnel to manage those programs. He is currently working on testimony in preparation for the FY 2002 budget cycle.

Burden of Cancer. This year's report on the burden of cancer, jointly produced by NCI, the Centers for Disease Control and Prevention (CDC) and the American Cancer Society (ACS), will soon be released. It notes that overall cancer mortality is down, particularly because of gains against breast and prostate cancers and among African American males. However, incidence or mortality is up for other cancers (including non-Hodgkins lymphoma, melanoma, and esophageal and hepatocellular cancer), representing 13 percent of the total burden. NCI has expanded its SEER database to cover 36 percent of the U.S. population, with overrepresentation of African American, non-Mexican Latino, American Indian, rural, and poor populations. These improvements will support more detailed analysis of the burden of cancer and rapid response studies, as well as diffusion and dissemination of results to state health agencies and professional societies. Cancer maps on the NCI Web site are also becoming more useful and user-friendly.

STI-571. There has been considerable media attention to STI-571, an exciting new treatment for chronic myelogenous leukemia (CML) that provides a glimpse of what is to come in targeted molecular therapies. A complete change in how we define, diagnose, and treat cancer. In this case, 51 of 57 CML patients went into complete remission, with few side effects. STI-571 shows promise against a number of other cancers, and recent changes in the clinical trials system are allowing NCI to begin a number of additional studies. In the future, the limiting factor in cancer therapy will not be the discovery of new drugs, but rather the ~~Ac~~credentialing of molecular targets. NCI received 175 applications in the first 12 months of funding for the discovery and validation of molecular targets, and was influential in convincing the pharmaceutical company to develop STI-571.

The DCLG Role. Accrual to clinical trials goes rapidly when these promising results are publicized. The DCLG has helped NCI to raise the awareness and expectations of the community, and NCI's job would be far more difficult without this engagement and feedback from its partners. Dr. Klausner noted that he likes the concept of the DCLG working groups who can work closely with NCI program staff. He is looking forward to discussion of the functions, priorities, and operations of the DCLG.

Discussion and Questions . In response to a question about the benefit of STI-571, Dr. Klausner stated that STI-571 represents a paradigm shift in what drug discovery and development have been to date. Also, we don't yet know whether this drug will save lives, or whether it will be effective in the last stage of CML. NCI is addressing these questions in collaboration with the researchers. Dr. Klausner will provide the DCLG with the number and type of clinical trials that are under consideration.

The DCLG members reminded him that there had been the same kind of excitement about herceptin a few years ago, leading to grave concerns about availability and anger at the difficulty of getting into clinical trials. They predicted that there will be a similar outcry when the news of STI-571 becomes more widely known. Dr. Klausner agreed that it is important not to oversell these preliminary results, and to point out how much work remains to be done. NCI has promoted earlier discussions between researchers and manufacturers, urging the drug company to increase production. In addition, STI-571 is easier to produce than herceptin.

The Identity project is proceeding to promote NCI as the go-to source for credible cancer information. In response to a question about the public's reliance on information provided by the American Cancer Society (ACS), Dr. Klausner stated that NCI's efforts are not in competition with ACS, which uses NCI information. Dr. Klausner reminded DCLG members that NCI has a mandate to disseminate information about the results of the research the Institute supports to maximize access to and use of cancer information by the public, consumers, patients, survivors and health professionals. He noted that ACS and others may not always give credit for the information to NCI. The DCLG members agreed NCI should receive credit for the research it funds and the information it provides. They encouraged NCI to find ways grantees and those who use information NCI provide could better acknowledge such support. NCI requires grantees to identify NCI as the source of funding, when they publish, but information provided by the Institute is in the public domain. DCLG members urged NCI to cooperate with ACS and other groups to keep duplication to a minimum. Dr. Klausner reported that, based on his reception at the World Economic Forum, NCI's public reputation is secure overseas. He remains frustrated by the limited public awareness of NCI and its activities at home, even among NCI grantees.

CONSUMER ADVOCATES IN RESEARCH AND RELATED ACTIVITIES (CARRA) UPDATE

Dr. Yvonne Andejaski reported that the CARRA discussion would be divided in two parts: scoring and evaluation first, and balance and interaction on later. She reported that the CARRA Web site has received 30,000 hits, over 1,100 applications have been requested, and over 100 applications have been received to date, with many more expected over the next week. The postmark deadline is April 16. NCI will use a contractor to handle the scoring and evaluation of candidates.

Scoring. Dr. Marcia Carlyn explained that when applications are received, they are first screened for completeness and eligibility. Those that satisfy the requirements are entered into a database. Each qualifying application will be scored independently by three reviewers (one DCLG member and two NCI staff) using approximately 30 questions that reflect the seven selection criteria in three areas of expertise: advocacy skills, cancer interest, and communication skills. Candidates must receive a minimal acceptable score in each area.

Dr. Klausner noted that NCI has a mandate to disseminate information about the results of the research the Institute supports to maximize access to and use the cancer information by the public, consumers, patients, survivors, and health professionals.

In response to questions, Dr. Carlyn explained that candidates should represent a formal constituency (not just a family member with cancer), but that scorers would look for a range of participation, from local to national. The scoring scheme was not designed to favor the most experienced applicants. The DCLG members discussed the advantages of assigning different weights based on the track chosen by the applicant, science or communication. The DCLG members recommended that no weighting be done.

Orientation. Dr. Marianne Alciati gave an overview of the draft CARRA orientation modules. Modules include Roles and Responsibilities of CARRA Members, Types of NCI Activities (CARRA members will participate in); How CARRA Members Are Selected to Participate; General Information about NCI; and Support for NCI Staff. These modules will be Web-based initially with possible development of a printed orientation planned for the future. Dr. Alciati asked for feedback from the DCLG members about the content. They suggested several changes in terminology, such as **A**constituency@ rather than the more restrictive **A**group,@ and **A**consumer advocate@ rather than **A**lay representative.@ Ms. Tracy Clagett reported that field-testing had revealed some confusion about the meaning of **A**consumer advocate,@ by which NCI usually means patients, family, and others affected by cancer who represent a constituency. There are many points in the text where more can be done to make it clear that advocates have a valid, and valuable role to play in NCI activities. Members also noted that the modules were confusing and difficult to navigate. Dr. Alciati said that finding aids and other navigation tools will be included in the final web version. She asked that discussion focus on larger themes and issues; she invited DCLG members to send their detailed comments and corrections to her via email.

Discussion and Questions. In their detailed comments on the orientation module, DCLG members indicated that the 16 bullets under **A**roles and responsibilities@ were too dense, and that the preferences were not mutually exclusive. They wanted more information about travel, such as where advocates might go. They also suggested that pictures and examples would help to clarify several points. Under **A**peer review,@ they felt that there was inadequate attention to the power and importance of the peer review process, and that it would be useful to include examples of cases where advocate input made a difference in the result of the peer review process. Many of the terms, concepts, and categories will

require further clarification. When other modules are added, the whole might be overwhelming. Too many hyperlinks might be confusing and frustrating. The help modules are clear, but there is too much overlap and repetition. There will be mechanisms for feedback. Dr. Andejaski pointed out that Liaison Activities plans to establish a CARRA listserv which could serve as a guide for members and a mechanism for them to share information about the activities.

DCLG members expressed concern for the workload that this product would place on mentors; new participants should be urged to read the background information before contacting their mentor. More importantly, there are several places where the importance of consumer advocates should be rewritten from the advocate's point of view. Members were pleased to see that there is an ombudsman for dealing with NCI staff who aren't receptive, but they wonder what provision there would be to deal with CARRA members who aren't working out, or for unwilling members to withdraw from the program. Members felt that the completed modules should be tested for usability and content as soon as possible, preferably with a private logon site while the package is still under development.

**PROMOTING NCI/ADVOCACY PARTNERSHIPS
TO ELIMINATE HEALTH DISPARITIES:
THE NUTS AND BOLTS OF ADVOCACY ORGANIZATIONS**

Dr. Brad Zebrack reminded members that NCI had asked for ways in which the DCLG could help with NCI's challenge to reduce health disparities in cancer. He also pointed out that the ultimate goal should be to *eliminate* those disparities. The purpose of this session was to introduce NCI staff to the activities of advocacy organizations that are relevant to that effort. Dr. Zebrack expressed his hope that the discussion would lead to action steps by which advocacy groups and NCI could help one another reduce disparities.

Introduction. Dr. Harold Freeman suggested that the war on cancer, launched by the National Cancer Act of 1971, has been primarily a research war, and that much remains to be done in terms of delivering on what researchers have discovered. Despite considerable progress since then, there remain certain populations that bear an unequal burden of cancer. Discovering the causes of these disparities is not only a scientific challenge, it is a moral and ethical imperative.

The President's Cancer Panel, in six regional hearings over the past 17 months, has identified the following issues with regard to cancer care:

- C Financial barriers, notably 43 million uninsured and millions more who are under insured
- C Language and communications barriers
- C Lack of information and knowledge about cancer prevention, diagnosis and care
- C Systemic issues arising from the complexity of the health care system
- C Geographic barriers, particularly the long distances that some patients must travel to get care

President Clinton recognized the issue of health disparities in January 1998, and Congress responded by creating the new National Center on Minority Health and Health Disparities. NCI has created its own Center for Reducing Cancer Health Disparities (CRCHD). The CRCHD includes both a research division, which includes the pre-existing Office of Special Populations Research, and a policy division, which will be responsible for bringing the results of CRCHD-funded research to policymakers and the public. Dr. Freeman believes that consumer advocates have already had a major impact on the direction of biomedical research, and he welcomes the DCLG's input on the three issue areas that he believes are the drivers of cancer health disparities:

- \$ Financial status C Poverty is related to poor living conditions and lack of information, risk-taking behavior, and lack of contact with preventive health care and early treatment.
- \$ Culture C Communication and belief systems are the prisms through which poverty acts to influence behavior.
- \$ Social injustice C Historical injustice influences the present status of American Indians and African Americans, and there is growing evidence of *racialism* in health care. For example, African Americans are less likely to have curative surgery for lung cancer, and are therefore less likely to survive.

The CRCHD will look at racialism in access, treatment, and outcomes. It will also look at the other issues in hopes of understanding the problem in its totality, and of discovering the dimensions in which it can be solved.

Overview on the Cancer Advocacy Movement. Ms. Ellen Stovall described the history and evolution of the cancer advocacy movement, which began with the Candlelighter's Childhood Cancer Foundation in 1970 and the Y-ME National Breast Cancer Organization. Her own organization, the National Coalition for Cancer Survivorship (NCCS, founded in 1986), has a board of 26 directors, half of whom are cancer survivors, as is one-third of the staff. This is a characteristic that distinguishes survivors groups C founded of, by, and for people with cancer C from other organizations such as the American Cancer Society and the various professional and scientific societies with an interest in cancer. Several other groups were founded in the 1980s, and the 1990s saw an explosion of new groups, including three 501(c)4 advocacy groups that are permitted to do unlimited lobbying for survivor issues: the National Breast Cancer Coalition (possibly the most active and effective of the groups), the North American Brain Tumor Coalition, and the National Prostate Cancer Coalition. Several new groups are emerging with a focus on research rather than lobbying.

These groups use the terms Apatient@ and Asurvivor@ interchangeably, and their original purpose was to provide information and support to patients and their families. The most important issues in their current advocacy campaigns are (1) access to quality care, (2) research oversight, (3) patient protection, (4) reimbursement for care, and (5) research funding. They would like to see the creation of a center for cancer drug evaluation at the Food and Drug Administration (FDA). Reimbursement for oral drug treatment is an emerging issue for the future, as more drugs like STI-571 come on line. These groups

try to operate as honest brokers, but they need to be alert to conflicts of interest. The pharmaceutical companies are their friends and contributors, but their first loyalty must be to patients and their families. Advocacy groups must work together to influence policy in Washington, where only a united effort will bring success.

Working with Communities. Dr. Mark Chesler stated that health disparities reflect the inequalities of our political and economic system. Race, class, and privilege are barriers to equal access, both in the United States and abroad: cure rates are 70 percent at home, but only 25 percent in the Third World. They are also barriers to cooperation and collaboration, as can be seen in the tensions between patient advocates and the bureaucracies of medicine, cancer groups, and research agencies. Table 1 summarizes the major differences between the parents of children with cancer and the professionals with whom they must interact.

Table 1. C Major Differences Between Parents of Children with Cancer and Professionals Working with These Parents and Children

DIFFERENCE	PARENT	PROFESSIONAL
Function and status	Service recipient Relatively powerless Medical visitor	Service provider Relatively powerful Medical home team/host
Knowledge base	Experiential wisdom Personal Particular Uncredentialed	Academic expertise Technical General Legitimate/credentialed
Interests and accountability	Children Particular child Child and family	Career or profession Children in general Medical community
Mindset/emotional state	Emotional closeness/ expression	Emotional distance/ caution
Job and family concerns	Family internal to illness Job external to illness	Family external to illness Job internal to illness

SOURCE: Adapted from Chesler and Chesney, 1995, p. 206.

Similar differences exist between cancer organizations and parents= organizations, and these differences can lead to tension and conflict on specific issues. For this reason, coalition-building requires acknowledgment of these differences and respect for the independence of each organization. There must also be respect for the different sources of knowledge, as well as differences in power and status. In some cases, that is, Aexperts@ must cede leadership to those who might otherwise defer to them. The

structure of a therapeutic alliance should pull groups together to pursue the common goal of finding a cure and providing a normal life for children with cancer.

PERSPECTIVES OF ADVOCACY ORGANIZATIONS

National Groups. Mr. Henry Porterfield pointed out that the American Cancer Society has 1,700 offices throughout the United States and over 2,000 employees. By comparison, Y-ME has only seven chapters but also operates on a nationwide basis. His own organization, US TOO! International, was founded by prostate cancer survivors and their wives, and it still operates on an almost totally volunteer basis. It has grown because of the dedication of its regional directors, who help local volunteers to establish and build new chapters. US TOO! collaborates with Y-ME in publishing the *Hot Sheet*, a newsletter that emphasizes enrollment in clinical trials. It also collaborated with NCI in publishing an information booklet, *Your Choices for Prostate Cancer*, that has gone through several printings. The national organization has also published a step-by-step guide for setting up local support groups. In these ways, volunteer groups can raise public awareness and build political support for cancer research.

Local Groups. Ms. Gena Love described the activities of People Living Through Cancer (PLTC), which was founded by Ms. Catherine Logan and four other survivors. PLTC is an all-volunteer organization that provides free services to address the unmet needs of their community. As a grassroots organization, the group acts as the guardian of the culture and wisdom of survivorship. PLTC is a 501(c)3 organization with an annual budget of \$300,000 and a staff of 200 volunteers. Its mission is to help patients make informed choices and improve the quality of their lives. For the past two years it has been the primary source of cancer support and information for the 30,000 cancer survivors in the state of New Mexico.

New Mexico is a large, rural state with a low per-capita income and large minority populations (51 percent Latino, American Indian, or African American). Rural delivery and special populations are challenges. PLTC has established a mechanism to provide funding for women in breast and cervical cancer screening who lack the money to access follow-up care. It sponsors a Cancer Leadership Council that meets twice a year to share experiences and seek solutions for common problems. Ms. Love is particularly proud of PLTC's role in recruiting, training, and supporting leaders from under represented populations. The principal challenge is raising money, particularly funds that will support PLTC's mission, but other challenges are to create diversity, develop culturally sensitive programs, and collaborate with its agency partners. She believes that NCI's Special Population Networks are a step in the right direction, and she hopes that they seek additional opportunities to collaborate with grassroots organizations. Recruitment to clinical trials and dissemination of information are two areas of special opportunity.

Minority/Underserved Groups. Ms. Karen Jackson described Sisters Network, Inc., whose mission is to increase attention to the impact of breast cancer on African American women. It operates through personal networking and by seeking and sharing resources. Ms. Jackson founded the

organization in Houston in 1994 with only 15 members; today there are 2,000 members in 15 chapters, including several in the Caribbean, but only two paid staff. Sisters Network has a Web site, but it disseminates most of its information through door-to-door canvassing, community organizations, and church-based programs. Local chapters are independent of the national organization, which provides guidance in setting up new chapters.

Sisters Network collaborates with several groups in disseminating information and recruiting African American women to clinical trials. Their members receive advocacy training through ACS and other groups. The challenges for this group are (1) developing leadership and programs, (2) obtaining funding (annual budget \$150,000), (3) getting recognition (which helps in competing for funding), and (4) fighting the fear factor that prevents African American women from talking about breast cancer and seeking early detection and treatment. Their national slogan is **Stop the Silence**. They have statewide billboards in Illinois, and they have placed articles in a number of magazines. Ms. Jackson urged NCI to tailor its programs to the communities they target.

HOW THE SPECIAL POPULATIONS NETWORKS REACH OUT

Dr. Grace Ma described the outreach activities of the Asian Tobacco Education and Cancer Awareness Research Initiative (ATECAR), one of 18 Special Population Networks funded by NCI's Office of Special Populations Research. ATECAR operates in the Philadelphia and southern New Jersey region, with the goals of increasing knowledge, changing attitudes and behaviors, and reducing high-risk behaviors in the Vietnamese, Chinese, Cambodian, and Korean communities. They recently began year two of a five-year program designed to (1) collect information, (2) design and implement interventions, (3) develop infrastructure and training, and (4) evaluate research. ATECAR will partner with the Fox Chase Cancer Center for the conduct of clinical trials.

The program has been successful in developing an Asian Community Cancer Coalition, with support from 15 local agencies and a number of church and community groups. It provides \$500 as seed money for pilot projects to develop posters and plays that promote tobacco awareness and cancer prevention. It has developed targeted curricula for adolescents, adults, and professionals, in four different languages. It reaches out through articles in Asian-language newsletters and local community events, such as health fairs and New Year's banquets. These efforts must combat targeted tobacco advertising in Asian newspapers and misconceptions about smoking and cancer. They commonly advertise the availability of information through 1-800-4CANCER. Training programs are evaluated through pre- and post-testing and three-month follow-up; coalition-building is evaluated through annual surveys.

Discussion and Questions. DCLG members suggested that local health agencies still aren't very good in dealing with cancer, and that advocacy groups can help them to be more effective. American Indian groups haven't been particularly successful in communicating and cooperating with NCI, and they might need the services of other, more experienced advocates to be more effective. In many cases, one good story can influence policymakers far more powerfully than volumes of dry statistics; more needs to

be done to put those stories before Congress. This approach may be anecdotal, but if you have enough anecdotes they become evidence.

Local support groups can be effective in promoting prevention and screening, but are less effective in ensuring that patients receive follow-up care. Advocacy groups can help to create navigation systems in minority communities, but this won't help when the nearest clinic is 200 miles away. Dr. Klausner had pointed to the disconnect between discovery and delivery, but delivery lies outside NCI's purview. Dr. Freeman said that access and affordability are the principal barriers to quality cancer care, and that CRCHD will be able to ask research questions that have compelling policy implications. By informing and educating policymakers, it can lead them to the right conclusions about health care delivery. Advocacy groups can help NCI in this effort by bringing forward those compelling anecdotes and by promoting population-based studies as a central component of NCI's research portfolio. The DCLG should urge NCI to be more aggressive in pursuing the information and education parts of its mission, as well as research dissemination.

The meeting was recessed at 5:10 p.m.
Tuesday April 17, 2001.

DCLG INTERNAL FOCUS

Mr. Katz called the meeting to order at 8:30 a.m. Ms. M. Kathleen Joyce explained that the focus of the day's meeting would be on the internal operation of the DCLG: enriching members' ability to work together, creating effective operational processes, determining points of influence, and refining the DCLG's goals and plans. She led a short team-building exercise, from which the members concluded that successful group activities demand creativity, cooperation, division of labor, openness to change, and a willingness to abandon bad ideas in the face of experience.

Dr. Andejaski suggested that the same qualities would be valuable in building the DCLG, which needs a new structure to match its accumulating functions. Drawing analogies to Sarah Susanka's *Not So Big House*, she urged members to begin with a foundation based on the five critical goals outlined by Dr. Klausner in October 2000:

- \$ Develop and formalize substantial relationships with national cancer advocacy groups and their constituencies;
- \$ Involve consumers in NCI processes like review, planning, workshops, and working groups, especially for special projects and critical issues;
- \$ Act as CARRA Board of Directors;
- \$ Set precedents, criteria, and expectations for consumer advocate involvement at NCI; and
- \$ Develop a new set of remarkable relationships, both personal and professional.

However, she also urged them to think stretch their imaginations.

The DCLG members indicated the central issue should not be their internal teamwork but rather their interactions with external groups. They suggested that a turnpike or nervous system might be a better metaphor than a house; their goal was to facilitate communication and participation from groups that represent people with cancer. There was considerable debate about whether the larger national advocacy groups actually want to have the DCLG between them and NCI. Some outsiders perceive the DCLG as a public relations tool of NCI, and the DCLG needs to define and communicate its true function. For example, those large national groups don't need help, but small local groups do; should the DCLG's focus be on these new, excluded, or isolated groups, rather than the usual suspects? The meeting broke into smaller working groups to identify the characteristics of successful organizations.

When the group reconvened, Mr. Katz suggested that they now focus on the DCLG's own goals and functions, and allow a structure to emerge from function. As a set of ground rules, he suggested that they focus on working on things that are important, participating in decision-making forums, leveraging NCI resources, producing quality work, having a tangible impact, following up on recommendations and initiatives, and giving and providing feedback. He also reiterated Dr. Klausner's five priorities for the DCLG:

- \$ Advocacy involvement C Get more people involved in a meaningful way in NCI activities;
- \$ Cancer survivorship C Identify the full spectrum of short- and long-term needs of all cancer survivors and ways in which NCI can address those needs;
- \$ Clinical trials promotion C Increase participation in clinical trials, and improve their quality, timely completion, and impact;
- \$ Health disparities C Help NCI reduce or eliminate health disparities in cancer outcomes through research and communication initiatives; and
- \$ Quality of cancer care C Help NCI improve the overall quality of cancer care through research and communication initiatives.

In the discussion that followed, and in working group sessions during the afternoon, the group identified specific projects, activities, and initiatives by which the DCLG can pursue and accomplish these goals. After the working groups reported back to the entire DCLG, members were given an opportunity to vote for the projects and activities that should have the highest priority. The goal of this exercise was to prioritize and focus the attention of the DCLG on the most important activities among the numerous activities that it might pursue. The results of this discussion and voting are presented in Table 2.

NOTE: The 15 DCLG members were asked to vote for the nine activities that deserve highest priority, so the highest number of votes possible for any given initiative was 15. Priority #4 received 10 votes, but members did not indicate a preference for a specific initiative or activity.

Table 2.C Priorities, Initiatives, and Activities for The DCLG

Priority #1C Advocacy Involvement (get more consumers involved in NCI activities)

- \$ Communicate with the broader advocacy community (14 votes*)
- \$ Launch and support CARRA, a work in progress (12)
- \$ Participate in various forums inside NCI (8)
- \$ Participate as DCLG members in forums outside NCI (1)
- \$ Attract and integrate new members into the DCLG (0)

Priority #2C Health Disparities (help NCI reduce/eliminate disparities in cancer outcomes)

- \$ Help identify research priorities supporting CRCHD's programs by gathering input from outside NCI and participating in NCI forums (12)
- \$ Identify areas where advocates can best participate actively in the research process (12)
- \$ Gather and make use of survivor stories to reach populations and policy makers (3)

Priority #3C Clinical Trials Promotion (increase participation in, and improve the quality, timely completion, and impact of, cancer clinical trials)

- \$ Develop communications tools to increase public awareness of and receptivity to cancer clinical trials (11)
- \$ Help with the continuing evolution of the clinical trials system (10)
- \$ Develop tools and incentives to improve awareness and participation by health professionals (6)
- \$ Improve availability of clinical trials across all populations (geographic, racial, ethnic, cultural, age) (0)

Priority #4C Quality of Care (help NCI improve the overall quality of cancer care through research and communications initiatives) (10)*

- \$ Identify areas for advocate involvement
- \$ Develop core process and outcomes measure for assessing quality of cancer care
- \$ Enhance quality of care research within the restructured clinical trials systems
- \$ Help build a knowledge base of best practices to improve quality of cancer care
- \$ Improve the quality of cancer care by strengthening cancer communications

Priority #5C Cancer Survivorship (identify the full spectrum of needs for all cancer survivors and ways in which NCI can help address those needs)

- \$ Working with NCI and the advocacy community, develop research priorities, participate actively in the research process, and disseminate practical information (8)
- \$ Gather first-hand input from survivors to synthesize issues and develop recommendations for NCI and the advocacy community (4)
- \$ Develop compelling survivor stories that put a face on cancer and on research priorities, and that would be of use to survivors and as a communications tool to the broader public and policymakers (3)

The DCLG members agreed that working groups will consult their staff champions and then confer by teleconference, after which they would put together white papers, activity lists, work plans, and (where possible) resource needs for each of these five priority areas. Those champions, in conjunction with

LA, can advise on what activities are possible, and which are already underway elsewhere. Staff identified the following NCI Champions and LA Facilitators for each area:

- \$ Advocacy involvement C Dr. Yvonne Andejaski
- \$ Cancer survivorship C Dr. Julia Rowland, Dr. Yvonne Andejaski
- \$ Clinical trials promotion C to be determined, Dr. Yvonne Andejaski
- \$ Health disparities C Dr. Harold Freeman, Ms. Tracy Clagett
- \$ Quality of cancer care C Dr. Joseph Lipscomb, Ms. Tracy Clagett

OPERATIONAL PROCESSES

Succession Planning for Chair. Mr. Katz reviewed the duties that he had been called on to perform during his term as chair. These included working with the DCLG members and NCI staff; providing counsel and direction to members; leading meetings; overseeing working groups and ad hoc efforts; serving on the Advisory Committee to the Director; and serving as a point person to outside organizations. He also presented alternatives for the eligibility, term of office, transition, and selection process for his successor. Dr. Klausner has assured him that the DCLG charter would be revised, as required, to accommodate the group's preferences in each of these questions, including extending the term of service and increasing the number of members. It was agreed in advance that Mr. Katz should serve for one year as chair emeritus, to ensure the initial transition, and that the new chair would be selected by Dr. Klausner guided by the recommendations from DCLG members following the April meeting but before June 30, 2001.

In the discussion that followed, members pointed out that a one-year term would expand the pool from nine to 15 eligible candidates, while adhering to the current term expirations would reduce the pool to five candidates. A one-year term would allow more people to serve as chair, while a two-year term would give the chair more time to learn the job and follow up on initiatives. Several members thought that it would be useful to have a vice chair, either elected or appointed. Final decisions on these matters were to be deferred to April 18th.

The meeting was recessed at 5:10 p.m.

Wednesday April 18, 2001

CARRA UPDATE (CONTINUED)

Mr. Katz called the meeting to order at 8:45 a.m.

Balancing CARRA Membership for Diversity. Dr. Carlyn reported that, at last count, LA had received 298 CARRA applications, including 42 individuals who would be grandfathered. They anticipate a final pool of 150 members plus the grandfathers. To ensure that this is a diverse group that represents the cancer experience in the United States, the pool of candidates could be balanced according to the following variables:

- C Cancer type
- C Cancer age group (pediatric, young adult, adult, elderly)
- C Applicant=s race or ethnicity
- C Applicant=s age group (young adult, adult, elderly)
- C Applicant=s gender
- C Applicant=s geographical area (Northeast, Mid-Atlantic, Southeast, Midwest, Central, West)
- C Rural or non-rural area

Dr. Carlyn asked the DCLG, as stakeholders representing the advocacy community, to indicate how they would prioritize these variables. The members asked whether any candidate would be excluded as a result of these variables, and whether it wouldn't be better to take the best candidates and then see what groups are missing. One member indicated that sexual preference was just as important as gender; another suggested that region or even race/ethnicity was less important than rural/urban; a third said that these categories wouldn't catch all underserved groups. Ms. Elaine Lee indicated that, based on LA=s experience with DCLG candidates, the vast majority of high-ranking candidates will be white female breast cancer survivors. Members noted they would prefer good balance among the best candidates. NCI staff said that there would be no rigid slots or quotas but the Institute would ensure diversity by selecting the members from the qualified candidates. When asked for a show of hands, DCLG members indicated the following priorities, with little difference among the last four:

- \$ Cancer type
- \$ Race/ethnicity
- \$ Rural/urban
- \$ Cancer age group
- \$ Applicant=s age
- \$ Geographic region
- \$ Applicant=s gender

How The DCLG Will Interact with CARRA Members. Dr. Andejaski indicated that CARRA should function as a mechanism for gathering and disseminating information to a wide range of cancer organizations. LA has a mailing list of 250 groups, but these are primarily larger national groups.

CARRA members will be able to reach more of the advocacy community. LA plans frequent updates on CARRA and dissemination of news from NCI to CARRA members. The DCLG members suggested that these releases should be tailored for local outlets, or as Adrop-ins@for newsletters, in order to reach grassroots groups. Candidates not chosen for the network might be included in this dissemination. The Advocacy Involvement Working Group asked to review the letter to be sent to those who are not selected.

OPERATIONAL PROCESSES (CONTINUED)

Mr. Katz returned to the topic of succession, reviewing the alternatives for term, timing, and process. The DCLG unanimously approved the following: 1) the office of the chair be two years; 2) term of service of the newly elected chair be extended by two years, if necessary, in order to permit a two-year term of office; and 3) the new chair will take office on July 1, 2001, and that the current chair serve as chair emeritus until June 30, 2002.

The DCLG members suggested the following process by used in appointing the next chair. The DCLG members will submit nominations before May 1 to Andrea Collins in NCI Committee Management, either by telephone at 301-496-5708 or by email at <*acollins@mail.nih.gov*>. Self-nomination is permitted. Mr. Katz will contact those nominated to determine their willingness to serve and to answer any questions they might have. LA will schedule a teleconference, during which the candidates will make a short statement and answer questions. Candidates will be allowed to submit a position paper by email to members who are unable to join the teleconference. Ballots will be mailed to Ms. Lee, the Executive Secretary of the DCLG by June 30. A simple majority is required, and a runoff will be held as necessary. It was moved and seconded that the DCLG adopt this schedule and procedure; passed unanimously. Mr. Katz and Dr. Andejaski will meet with Dr. Klausner to inform him of these decisions.

This process will for naming a new chair will be suggested to Dr. Klausner. The nomination process for chair will proceed after he approves it.

Branding. The NCI Branding Activity is currently being reviewed by the NCI Executive Committee. Mr. Katz reported that NCI feels that it hasn't gotten answers from the DCLG on the questions it posed in the memo of December 14, 2000. The NCI branding activity is currently being reviewed by the NCI Executive Committee. The DCLG members agreed to send their comments to Ms. Kerry Dewey before May 15; she will consolidate them and relay them to Dr. Susan Sieber in the Office of Communications. Ms. Dewey invited new members of the DCLG to join her working group, which will be losing two of its three members on June 30. Mr. Katz indicated that he wanted to see the materials and be involved in decisions.

Chain of Command. Mr. Katz reported that there has been some confusion about who speaks for the DCLG and its working groups. He indicated that NCI should contact him, or the new chair, if there is an issue involving the performance of a working group. They should also contact the working group chair.

The DCLG members discussed the process for selecting a vice chair—runner-up, special election, random selection, or selected by the chair? When the question came to a vote, a majority of members said that the chairman should select the vice chair, and that this individual should be considered an alternate or chair pro tem rather than an official replacement. This process depends on the approval of Dr. Klausner.

Priorities. Mr. Katz reviewed the results of the voting for priorities and initiatives, which are presented in Table 2. He will distribute this information to members in Acrobat PDF format, and LA will transcribe the flip charts and send copies to the working group chairs for use in preparing their white papers, which they should circulate to their members before submitting them. Ms. Dewey suggested that the white papers be included in the orientation materials for new DCLG members. Mr. Katz asked that the DCLG hold another teleconference with LA after the white papers are prepared.

Committee Participation and Working Groups. Mr. Katz reviewed the schedule of upcoming meetings and asked for volunteers to represent the DCLG. There may be a second slot for The DCLG on the Central IRB Committee; Mr. Daniel Moore is the current representative, but it is unclear if he will retain this post when he leaves the DCLG. Seven DCLG members are needed for CARRA scoring; volunteers should contact LA before May 1. There is a need for a representative to the Special Populations Working Group (SPWG); Dr. Felicia Schanche Hodge will attend the meeting on April 23, and Ms. Nyrvah Richard would like to know the dates of future meetings. Ms. Love would like to be considered as an alternate for SPWG.

At present there are eight DCLG Working Groups: Advocacy Involvement, Clinical Trials, Quality of Care and Health Disparities, Survivorship, DCLG Operations, Web Site, Branding, and Extraordinary Opportunities. Members agreed that there was no further need for the DCLG Operation or Web Site working groups, and they will be abolished. There was no agreement on splitting Quality of Care and Health Disparities in two; this will be left to the members of that working group.

The meeting was adjourned at 12:00 noon.

	Chair, Director's Consumer Liaison Group
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	Executive Secretary, Director's Consumer Liaison Group
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ACTION ITEMS
April 16B18, 2001

- \$ LA will provide DCLG members with a complete list of the expanded clinical trials currently under consideration for STI-571.
- \$ LA will investigate the possibility of having Dr. Michelle Christian do a presentation on the STI-571 trials and results, perhaps at the October meeting.
- \$ All of the Working Groups will assist NCI in identifying **Acompelling stories@**that illustrate the need for and value of specific services and programs.
- \$ The DCLG working groups will consult with their NCI staff **Achampions@**and **Afacilitators@**to address which initiatives are possible and which are already being addressed.
- \$ The DCLG working groups will develop white papers (by May 15), prioritized lists of projects and initiatives, detailed work plans, and (where possible) resource requirements for each of the five priority areas (by June1).
- \$ LA will compile a central list of NCI publications, in existence or in development.
- \$ The DCLG will review LA's advocacy mailing list, with a view to expanding it and advising LA whether or not the best contact are being used.
- \$ The Advocacy Involvement Working Group will put together a plan to maintain contact with small, local advocacy groups.
- \$ The Advocacy Involvement Working Group will review the CARRA letter to be sent to unsuccessful candidates.
- \$ DCLG members will submit nominations before May 1 to Andrea Collins in NCI Committee Management, either by telephone at 301-496-5708 or by email at <acollins@mail.nih.gov>.
- \$ Mr. Katz will contact those nominated to determine their willingness to serve and to answer any questions they might have.
- \$ The DCLG will hold a teleconference around May 15 during which the candidates could make a short statement and answer questions. Candidates will be allowed to submit a position paper by email if members are unable to join the teleconference.
- \$ The DCLG will vote by closed mail ballot to Committee Management, not later than June 30.

- \$ Mr. Katz and Dr. Andejaski will meet with Dr. Klausner to inform him of the DCLG's decisions with regard to the chair's term of office and term of service.
- \$ The DCLG members will review the Abranding@ memo of December 14, 2000, and send their comments to Ms. Kerry Dewey before May 15; she will consolidate them for relay to Dr. Susan Sieber.
- \$ Mr. Katz will distribute priority and initiative information to members in Acrobat PDF format.
- \$ LA white papers will transcribe the flip charts and send copies to the working group chairs for use in preparing their white papers.
- \$ Working Group chairs will circulate white papers to their members before they are submitted.
- \$ LA will include the white papers in the orientation materials for CARRA members.
- \$ The DCLG will hold another teleconference with LA after the white papers are prepared.
- \$ LA will find out whether Mr. Moore will retain his seat on the Central IRB Committee, and whether there will be a second seat for the DCLG.
- \$ DCLG members will volunteer for CARRA before May 1; a total of seven are needed.
- \$ LA will find out the dates of upcoming SPWG meetings and whether it will be possible for both Dr. Hodge and her replacement to attend future meetings.

