

**National Institutes of Health
National Cancer Institute
Director-s Consumer Liaison Group
Summary of Meeting
October 17-18, 2000**

The NCI Director-s Consumer Liaison Group (DCLG) convened Tuesday and Wednesday, October 17 and 18, 2000, in Conference Room E1/E2, Natcher Conference Center, National Institutes of Health (NIH), Bethesda, Maryland. The meeting, which began at 8:30 on both days, was open to the public. Mr. Michael Katz presided as Chair.

DCLG MEMBERS

Mr. Michael Katz, Chairperson
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 (absent)
Ms. Lillouise Rogers (absent)
Ms. Paula K. Simper
Ms. Susan Stewart (present by telephone,
10/17, 1 p.m.-3 p.m.)
Dr. Brad Zebrack

NCI SPEAKERS

Dr. Richard Klausner, Director, NCI
Mr. Michael Katz, Chair, DCLG, International Myeloma Foundation
Ms. Elaine Lee, Chief, Liaison Activities Branch and Executive Secretary, DCLG
Dr. Marianne Alciati, Consultant, Liaison Activities Branch, NCI
Dr. Yvonne Andejaski, Program Director, Liaison Activities Branch, NCI
Ms. Kathy Joyce, Consultant, Liaison Activities Branch, NCI
Dr. Susan Sieber, Director, Office of Communications, NCI
Dr. Anne Thurn, Associate Director, Cancer Information Products and Services,
Office of Communications, NCI
Dr. Julia Rowland, Director, Office of Cancer Survivorship, Division of Cancer Control and
Population Sciences, NCI
Dr. Joe Lipscomb, Chief, Outcome Research Branch, Applied Research Program,
Division of Cancer Control and Population Sciences, NCI
Dr. Jon Kerner, Associate Deputy Director, Research Dissemination and Diffusion,
Division of Cancer Control and Population Sciences, NCI

NCI LIAISON ACTIVITIES STAFF

Ms. Elaine Lee (Executive Secretary)
Dr. Yvonne Andejaski
Ms. Tracy Clagett
Ms. Laurie Rosenberg
Ms. Keisha Martin

Ms. Sabrina Reed

OCTOBER 17, 2000

CALL TO ORDER AND OPENING REMARKS

Mr. Michael Katz called the meeting to order, determined that a quorum was present, and welcomed all in attendance. He reviewed the rules governing confidentiality and conflict of interest. The meeting began with short introductions of the new DCLG members. Mr. Katz noted that this meeting marks the first that time the DCLG has met with new members as terms ended for some of the board's initial members.

REPORT OF THE DIRECTOR

Dr. Richard Klausner, Director of NCI, gave a detailed report outlining his vision for the DCLG. Dr. Klausner emphasized the importance of the DCLG, which is entering its fourth year. Dr. Klausner's remarks looked back over the past three years and then forward to what the DCLG and NCI together should strive to accomplish. He reminded the DCLG that their role within NCI was to help the Institute develop a new set of relationships with people who experience cancer. Dr. Klausner also emphasized that the DCLG should:

- \$ Find productive ways to involve consumers in NCI processes and decision making by helping to identify appropriate advocates and assisting with training and orientation
- \$ Assume special projects, similar to the review of selected communications programs.
- \$ Develop strong two-way links to consumer advisory community
- \$ Assess, measure, and monitor involvement of NCI with consumer groups and advocates to gauge involvement in special projects and other critical issues needing advocate involvement

He told the DCLG that NCI needs its help with daily operations related to advocates and outlined his areas of priorities for the DCLG:

- \$ advocate involvement processes
- \$ quality of cancer care
- \$ health disparities
- \$ clinical trial promotion
- \$ cancer survivorship

He said that the DCLG's efforts to gain a better understanding of clinical cancer trials should continue to be a goal for the group. The DCLG should set ambitious, realistic goals, and a system should be established to monitor progress. Such a system should have a clear list of priorities and objectives from which to work. Liaison Activities staff will serve as a resource for carrying out these activities. Finally, Dr. Klausner promised that NCI would carefully consider their recommendations in these areas.

Discussion and questions. Mr. Katz asked about the DCLG's purpose and charge, and

focused on how members should interact with their communities in relation to what happens in the bi-annual meetings. One key question is "How Do We Act in The Community?" Dr. Klausner responded by saying the Institute expected DCLG members to act and not just transmit information, and DCLG members should take the initiative to lay out consumer advocate objectives clearly. The members also pointed out the lack of public knowledge about NCI and the DCLG. Dr. Klausner acknowledged that certain information needed to be streamlined, so that its public can get a better idea of what NCI does. In addition the DCLG noted that there were issues surrounding clinical trials, which served as barriers to participation.

OFFICE OF COMMUNICATIONS REORGANIZATION

Dr. Susan Sieber reported that the reorganization of the NCI's Office of Communications (OC) is nearly complete, including a realignment of three existing offices. Since its official establishment in May, the Office's top priority has been staffing for a deputy director and five Associate Director positions. Dr. Anne Thurn is the new Associate Director of Cancer Information Products and Systems. Ms. Elisabeth Handley will serve as the Associate Director for Outreach and Partnerships. Candidates for the position of the Deputy Director and for the Associate Director for Technologies and Services are being interviewed. In addition, the Office has focused its efforts on ordering OC activities into the five major program areas.

PROGRESS IN COMMUNICATIONS

Dr. Thurn described recent activities in Cancer Information Products and Systems (CIS). CIS focuses on delivery, content, and promotion mechanisms used to deliver cancer information. These include "Cancer Fax" (1-800-624-2511), which now accepts calls from any phone; wireless access, which is under development; and Cancer Voice that will allow voice recognition and text to speech conversion. Dr. Thurn reported that NCI is now training information specialists to handle questions in real time. A pilot program of Internet instant messaging is also being developed. Dr. Thurn asked for the DCLG's help in beta testing instant messaging. Also under development is a customized clinical trials search model for Internet access. This model will allow groups to tailor their search of the Internet to specific consumer and advocate groups and identify pilot projects. Because new legislation in that state allows for third-party payers to cover patient participation in trials, PDQ now includes all New Jersey clinical trials. In the future, the site will expand to include trials that are reimbursed by Medicare. Future plans also include the installation of a "What's New on CancerNet" page, where users can sign up to receive e-mails of updates and new links. The goal is to make it easy for people to find us and to tailor the site to specific consumers and patients.

OFFICE OF CANCER SURVIVORSHIP

Dr. Julia Rowland described the mission of the Office of Cancer Survivorship (OCS), which was formed to address the unique needs of the large number of individuals now surviving cancer for long periods of time. She described the emerging areas of cancer survivorship

research and suggested that the DCLG members visit the OCS Web site at <http://dccps.nci.nih.gov/ocs/> for further information. She outlined the goals of OCS as follows:

- \$ To enhance length and quality of survival for all cancer patients
- \$ To provide a focus for the support of research that will lead to a clearer understanding of, and the ultimate prevention or reduction in adverse physical, psychosocial, and economic sequellae associated with cancer and its treatment
- \$ To educate health care professionals who work with cancer survivors about issues and practices critical to the optimal well being of their patients. This educational commitment extends to both cancer survivors and their families.

She posed some questions for the group.

1. Can DCLG members help identify educational information or resources about cancer survivorship that the OCS might include on their web site or develop in collaboration with NCI's Office of Communications, the advocacy community or other agencies?
2. Can DCLG members help the OCS to identify priority areas for survivorship research? (e.g., Request for Applications (RFA) formulation, peer-review, advisory group membership)?
3. Are there key policy issues that the DCLG members think are pertinent to the survivorship community that our research should address or support (e.g., development and use of long-term follow-up guidelines, tax incentives for caregivers, Medicare coverage for clinical trials related to treatment of late effects)?
4. What role might DCLG members play in helping to highlight or disseminate evidence-based findings on important survivorship issues to the cancer patient's advocacy community as well as the health care delivery community?
5. What role might the DCLG play in supporting or facilitating Town Hall Meetings should the OCS decide to hold these?
6. How can the OCS help identify or link interested and qualified consumers and advocates to serve on the DCLG (e.g., web site information)?
7. How can DCLG members help NCI staff remain current on the activities of advocacy groups that affect health policy and congressional action?

Because patients and survivors wonder how they can get involved in their communities and help others who have received similar diagnoses, the OCS is working with the Office of Communications to address this issue. Dr. Rowland asked if the DCLG could help in compiling a booklet that informs survivors about opportunities for **A**giving back[®] and **A**getting involved.[®]

Discussion and Questions. Mr. Katz stressed that the main issue is to get the information out into the community and that there are many mechanisms to achieve this goal. Dr. Rowland emphasized that ongoing survivorship efforts need to be a two-way street. The NCI needs DCLG input on what concerns survivors have that research can address. At the same time, the DCLG needs to provide the NCI with opportunities to take this science back out into the

consumer community. NCI needs consumer advocates to provide input on current topics such as the Patient's Bill of Rights. Mr. Katz wondered if the office would be willing to send representatives to speak with support groups around the U.S. Dr. Rowland said they may be willing to promote the office, inform patients and survivors about ongoing research, and hear comments from the support groups.

QUALITY OF CANCER CARE COMMITTEE

Dr. Joe Lipscomb reported on NCI's challenge to better understand what constitutes the Quality of Cancer Care (QOC). This initiative is a major concern nationwide as described in "Ensuring the Quality of Cancer Care" report from the Institute of Medicine's National Cancer Policy Board, and is presented as one of eight Director's Challenges in the forthcoming Fiscal Year 2002 Bypass Budget. Dr. Lipscomb defined quality of care as the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge (based on the IOM definition from 1990).

The overall goal of the QOC Initiative is to enhance the state of the science for defining, monitoring, and improving The Quality Of Cancer Care. NCI's Quality of Care Plan will be carried out in conjunction with the Department of Health and Human Services and in cooperation with other federal agencies. Potential roles for advocates include helping to develop core process and outcome measures for assessing the QOC, strengthening the methodological and empirical foundations of QOC assessment, enhancing quality of care research within the restructured NCI clinical trials program, enhancing and strengthening the quality of cancer communications, and ensuring that Federal decision making on cancer care is informed by the best available scientific evidence about quality measures and assessments.

A goal of the QOC Initiative is to examine each major form of cancer and to develop core endpoint measures for assessing outcomes that matter to patients and other decision makers. Such outcomes include:

- \$ survival
- \$ health related quality of life
- \$ satisfaction with care
- \$ economic burden

Efforts toward this goal include investigations about whether existing endpoint measures adequately gauge cancer's impact on vulnerable populations. These efforts will also help to build a comprehensive assessment of progress to date and identify state-of-the-art approaches to instrument evaluation and development. DCLG members and other advocates can help develop core measures by serving on a Cancer Outcomes Measurement Working Group, which will carry out components of the evaluation and make recommendations to NCI. Other activities may include developing a Program Announcement for investigator-initiated studies in basic outcomes research, such as how modern measurement methodologies can be applied to cancer endpoint assessment, and developing a national-level cancer data system that monitors the impact of existing evidence-based guidelines, identifies disparities in access to high-quality cancer care, and reassesses whether existing quality benchmarks actually lead to improved outcomes. One example is the five-year, \$40 million effort, now underway (CanCORS) to study the impact of the of targeted interventions on patient-centered outcomes to investigate dissemination of state-of-the-art therapies in the community, examine modifiable risk factors, and analyze disparities in quality cancer care. Ultimately, all these efforts will help NCI disseminate information about best practices to patients, providers and payers. Another plan is to create Cancer Communications Centers of Excellence, which will focus on quality of care issues and develop tools for making informed discussions.

HEALTH DISPARITIES

Another NCI challenge is to identify and remove those barriers that prevent the benefits of research from reaching all populations, particularly those who bear the greatest disease burden.

Dr. Jon Kerner described NCI's plans for responding to this challenge. The goal is to understand the causes of health disparities and develop effective interventions to reduce them. This parallels the goals of "Healthy People 2010" to increase the quality and years of health and life, and eliminate health disparities. Dr. Harold Freeman, NCI's new Associate Director for the Center to Reduce Cancer Health Disparities within the Office of the Director will lead these efforts.

Some health indicators for cancer-related disparities include physical activity, obesity, tobacco use, responsible sexual behavior, environmental quality, and access to health care. NCI's challenge to eliminate health disparities is being driven by profound advances in biomedical science, which have led to increased longevity and improved quality of life, except in poor and underserved communities. NCI's challenge is to consider the consequences of racism inherent in racial classifications that have been associated with fewer social, educational and economic opportunities; greater exposure to stress and unsafe environments; and reduced access to quality health care. Health disparities have historically been based on racial and ethnic differences that may not have a scientific basis.

Dr. Kerner described a proposed NCI reorganization that includes an Office of Special Populations Research that reports to the Center to Reduce Cancer Health Disparities. He then outlined a five-year strategic plan that includes the following objectives:

- \$ Expand fundamental cancer control, epidemiology, and population research to further clarify the determinants of cancer-related health disparities
- \$ Support intervention research in prevention, early detection, treatment, and communications that may reduce cancer-related health disparities
- \$ Strengthen training and education in health disparities research and increase the number of competitive minority scientists working in cancer control science
- \$ Expand our capacity to define and monitor cancer-related health disparities
- \$ Expand the channels for research diffusion and dissemination, and foster collaborations with allied agencies and organizations, to facilitate the translation of research evidence into practice

In addition, a Web site, www.healthdisparities.nih.gov, will be launched.

Dr. Kerner asked for the DCLG to identify areas, within these objectives, where members may be involved. He also challenged NCI to move ahead with requesting additional funding for implementation of the above plans with a preliminary goal of 2010 for establishment and action.

Discussion and Questions. Mr. Katz asked how DCLG members can be a part of the planning and discussion to help break down the health disparities in cancer care. The DCLG discussed possible advocacy roles in helping patients in poor and underserved communities to gain access to care, screening, and services for better cancer health care. Dr. Kerner responded that Guidelines for such roles are now being developed and are welcomed by the new Office of Special Populations Research and the Center to Reduce Cancer Health Disparities.

DEVELOPMENT OF A PROCESS FOR ADVOCATE INVOLVEMENT AT NCI

Dr. Yvonne Andejaski presented a framework for the proposed structured process for advocate involvement at NCI. The Consumer Advocates in Research and Related Activities (CARRA) program includes development of a recruitment plan and an application, screening and selection guidelines, and developing orientation programs for advocates. Dr. Marianne Alciati, a consultant to NCI, is helping with this effort. Over the summer, Liaison Activities worked with the DCLG Advocacy Involvement Working Group to develop a strategy for establishing this new program. To help develop a process, the following activities were conducted:

- \$ Interviews with advocates who have participated in NCI activities
- \$ Interviews with NCI staff who have involved advocates in their activities
- \$ A workshop to determine best practices for involving qualified advocates; including representatives from advocacy groups, other organizations who involve advocates, and NCI staff

Report of Advocate and Staff Interviews

Between June and August 2000, 21 advocates and 20 NCI staff were interviewed by Liaison Activities staff using a questionnaire developed in concert with the DCLG. Dr. Andejaski

presented DCLG members with the outcomes of these interviews. Advocates were involved in 57 different activities over the past five years, which included site visits, program review groups, peer review, PDQ review board and working groups. Some advocates were involved in multiple activities at NCI. For almost half of these activities, advocates perceived their roles to be providers of the patient perspective. However, these advocates thought they were limited in their ability to give feedback. Although many advocates interviewed had no clear-cut expectations about their participation, they did believe that their input would be worthwhile and that they could influence funding decisions and therefore benefit their constituent organizations. Furthermore, many advocates said that they felt welcomed at NCI, that they felt they made a difference, and that their experience was respected. NCI staff members thought that advocates provided a patient and family perspective and an ability to focus scientists and clinicians on what was important to their consumers. NCI staff usually identified advocates from a wide variety of areas, sometimes directly from an advocacy group.

Some concerns about advocate inclusion that were raised by NCI staff and included: advocate agendas that are not revealed until late in the process; concern that advocates will distract from the science; communication issues; and informal selection of advocates for activities. The desire on the part of the advocate to please a scientist can also hinder the process. Overall, advocates and staff members agreed that the process of putting the scientists and advocates together was so new that it is still a work in progress. These interviews provided valuable information about consumer involvement at NCI, such as:

- \$ Current activities involving consumer advocates
- \$ The need for adequate definitions of consumer advocate roles and expectations
- \$ Consumer advocate and NCI staff skills that contribute to effective involvement
- \$ The importance of consumer advocates that can represent a constituency/group
- \$ The need for appropriate training and orientation for all participants
- \$ The importance of feedback about participation

REPORT FROM CAR WORKSHOP

Following the interviews, the NCI convened the Consumer Advocates in Research (CAR) Workshop in September 2000. The workshop involved NCI staff, and governments as well as non-government organizations who sponsor and support cancer research. Participants worked over the course of two days to identify best practices for including consumer advocates in large programs that fund and /or evaluate cancer research.

The workshop participants discussed ways to screen and select CARRA pool members. They also talked about criteria including: eligibility, consumer advocate responsibilities, roles and tracks of involvement, term of service and compensation for involvement.

The workshop participants recommended that in order to meet the eligibility requirements recommend, the advocate must:

- \$ be a cancer survivor, *or* first degree family member *or* individual with more 3 or more years of

- substantial demonstrated involvement in cancer-related activities
- \$ demonstrate ability to represent the perspectives of a constituency
- \$ demonstrate interest in extending your personal knowledge about cancer and cancer issues
- \$ have the ability to read and write English
- \$ have at least a high school education or GED
- \$ be nominated by an advocacy group

Draft Proposal of the Process For Recruitment, Application Screening, Selection, and Orientation of Advocates and Small Group Discussions

Building on these information-gathering activities, the NCI and the DCLG have developed Consumer Advocates in Research and Related Activities (CARRA), a process for involving advocates across the full spectrum of NCI activities. By establishing accessible, user-friendly processes for involving consumer advocates and supporting NCI staff, the CARRA program seeks to remove obstacles to involvement and ensure a fair and open process.

NCI's program was formed to provide a clear focus for program development and to ensure accountability for program outcomes. Two CARRA program goals have been established:

- \$ ensure opportunities for consumer advocates to work with the NCI in establishing research priorities and designing and implementing cancer programs
- \$ foster an organizational atmosphere that values the contributions and perspectives of consumer advocates

Dr. Alciati presented a draft proposal for the CARRA program. She noted that a large group of advocates would allow NCI officials to involve advocates in a variety of activities. Approximately 450 consumer advocates will serve in the program at any single point in time. It is estimated that approximately 100-150 consumer advocates will be selected from the program to participate in NCI activities each year. The purpose of maintaining this network will be to ensure that consumer advocates are readily available to work with NCI in establishing program priorities, designing and implementing program activities. Dr. Alciati also stressed the need for balance. The program will have a diverse group of advocates representing different cancer sites, age groups, genders, ethnic groups, educational levels, and geographic regions.

Guiding Principles

To provide clear direction about how program goals are to be achieved, guiding principles were established at the workshop. These principles reflect NCI's commitment to the inclusion of consumer advocates and the value it places on their unique perspectives.

The program should:

- \$ Involve consumer advocates in developing and refining NCI's procedures for involving consumer advocates
- \$ Foster an understanding of, and show value for consumer advocates' perspectives and

contributions

- \$ Routinely evaluate, and as necessary, modify CARRA activities and procedures

Program procedures must:

- \$ Reflect NCI's stature as a national agency that is accountable to the public
- \$ Balance the needs of NCI staff, scientists, clinicians, and consumer advocates
- \$ Be fair, open and impartial
- \$ Ensure that all activities and the roles of all participants in activities involving consumer advocates are clearly defined
- \$ Ensure that all participants are educated about their own and each other's roles.

Liaison Activities will coordinate this program and has developed draft plans for all the steps of the process. Staff will notify applicants of the receipt and completeness of their applications. A three-person review team, comprised of at least one DCLG member and one scientist, will consider each application. Applicants will be evaluated according to established criteria such as advocacy experience, communication skills, and interest in research. Issues raised about the application process include:

- \$ Application instructions that address a tendency to work only on activities related to their own disease-specific areas but should encourage applicants to think more broadly and select other areas of interest
- \$ Preferences toward those who have not had an opportunity to serve
- \$ The role of the DCLG in reviewing the applications

Consumer Advocate Responsibilities

While specific requirements, such as reviewing education materials or participating in meetings, may differ from one activity to the next, consumer advocates' roles across activities have common requirements. Regardless of the activity, the primary responsibility of consumer advocates will be to provide the perspective of patients and their families and share the patient experience. Both scientists and advocates will be expected to treat all participants with respect and consideration for their viewpoint.

SMALL GROUP DISCUSSION

Following Dr. Alciati's presentation, DCLG Members divided into small discussion groups to discuss various aspects of the CARRA process and to develop recommendations to be presented at the October 18 session. The groups were as follows:

- \$ Eligibility Requirements for the CARRA program
- \$ Recruitment for the CARRA program
- \$ Screening Applications for the CARRA program
- \$ Scoring Applications and Selection to the CARRA program

- \$ Balance across the CARRA program
- \$ Matching NCI needs to consumer advocates interests

The meeting was recessed at 5:00 p.m.

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Mr. Katz welcomed the DCLG members to the second day of the meeting.

SMALL GROUP DISCUSSION

Ms. Kathy Joyce, a consultant for Liaison Activities, led the DCLG members in a discussion of the recommendations of each of the working groups.

Eligibility Requirements

The group proposed the following requirements. Candidates must

- \$ Be cancer survivor, first degree family member, or individual with 3 or more years of substantial demonstrated volunteer involvement in cancer related activities
- \$ Demonstrate ability to represent the perspectives of a constituency
- \$ Demonstrate interest in extending personal knowledge about cancer and cancer issues
- \$ Ability to read and write English
- \$ Be nominated by an advocacy group **OR** be self-nominated
- \$ Submit supporting letters of recommendation (do this regardless of how nominated)

DCLG members expressed concern that the description of cancer experience proposed would not be inclusive enough and recommended the language used above. The members defined family as parent, sibling, spouse, child or partner.

Recruitment

The DCLG Members recommended that the focus be inclusive and involve new people in the cancer advocacy community. Development of a comprehensive advocate mailing list is key. A mass marketing campaign was suggested. Groups to contact include: the American Association of Retired Persons and the Veterans Administration. Various press stories and posters should be placed throughout the U.S. in oncology facilities. It is important for the promotion to go beyond the usual organizations that interact with NCI. A tiered approach was suggested.

Screening Applications

DCLG members recommended that the three-member screening panel should include a senior-level NCI official, a member of the DCLG, and a representative of Liaison Activities.

Acknowledgment of receipt of application and notification of any missing elements is necessary.

Advocates in the program should be asked regularly about their desire to remain in the program. The three-step evaluation approach proposed by NCI was approved.

Scoring and Selection

DCLG agreed with the following criteria:

- \$ Constituency: Experience representing the perspective of a constituency and the ability to think beyond one's own cancer experience
- \$ Involvement: leadership skills, commitment, and enthusiasm
- \$ Level of interest in cancer and issues: formal training, familiarity with science and/or health communications, and commitment to learning about cancer
- \$ Communication skills: presentation, vocabulary
- \$ Participatory Skills: cooperative spirit, initiative
- \$ Overall suitability score

The program should include a diverse group of advocates, as set forth in criteria by Dr. Alciati. It was suggested that incentives, such as an advocate newsletter and a program promoting the organizational structure of NCI, be offered. They also recommended that advocates who already participate in NCI activities may be grandfathered into the program.

Balance

DCLG recommended the following criteria:

- \$ Diversity (age, sex, race, ethnicity)
- \$ Cancer site (e.g., breast, prostate, colon, etc.)
- \$ Consumer advocate role (mentor, general cancer, cancer-specific)
- \$ Content focus (science vs. communications)

Discussion and Questions. DCLG members urged NCI to include pediatric cancer advocates in the program and to drop the requirement of holding a high school diploma or GED from the application to include more minority advocates, particularly Native Americans, who might be excluded from participation.

Matching NCI Needs to Consumer Advocate Interest

The DCLG members agreed with the proposal that applicants identify/rank the roles they wish to play and the track they prefer. This will help Liaison Activities match advocates with the appropriate qualifications to NCI programs.

The following roles will be used:

- \$ Mentor: Consumer advocate with previous experience participating in NCI activities who provides guidance and support to less experienced advocates
- \$ General Cancer Advocate: Consumer advocates who represents the perspective of cancer patients regardless of type of cancer
- \$ Cancer-specific advocate: Consumer advocates who represents specific perspective of individuals with a particular type of cancer.

Advocates will choose between one of the following tracks:

- \$ Science: Specific scientific issues require some understanding of basic scientific terminology for consumer advocates who will be working with scientists.
- \$ Communications: Communications and outreach issues may require some understanding of communications and outreach issues and familiarity with the internal and cultural sensitivities.

The DCLG members discussed the overall recruitment and involvement effort. The entire process for recruitment, application, screening, selection, and orientation of advocates. Mr. Katz stressed the importance of a dialogue between DCLG members and senior-level NCI officials. Mr. Katz urged that the process not be presented to the CLC until a firm commitment to select advocates from the CARRA program is made by NCI. In response, Dr. Andejaski agreed to meet with Dr. Klausner and raise the issue of commitment to use CARRA members in NCI activities.

WORKING GROUPS UPDATES

Clinical Trials Working Group

Susan Butler summarized the activities of the Working Group since the April 2000 meeting. She emphasized that the group recommends media training for DCLG members. They have been working with Jane Reese-Coulbourne on the clinical trials training program. The program is still under development and will be ready to review in the near future. The Office of Education and Special Initiatives is planning to make it available on the web and possibly as a compact disc. Ms. Butler will be meeting with the Cancer Leadership Council to seek collaboration with them. Some issues still remain to be resolved related to clinical trials promotion. If a massive effort to promote trials is launched, the system must be prepared to meet the needs of patients wishing to enroll in trials. There needs to be an understanding of what are reasonable expectations and a navigation system to help people find the right trials. The DCLG should work to establish bridges between NCI and others.

Advocacy Involvement Working Group

Dr. Zebrack noted that activities of the working group have focused on developing the CARRA Program and on establishing the National Health Advocates in Cancer Listserv. Dr. McAllister reminded the DCLG that a similar listserv, Patient Advocates In Research (PAIR) already exists serving a similar audience.

Quality of Cancer Care/Health Disparities Working Group

Ms. Love stated that the activities of the group were related primarily to working with Drs. Lipscomb and Kerner on the presentations for this meeting.

NCI Branding Working Group

Ms. Dewey reported that the NCI Branding (Identity) process continues to move forward. Interviews

with NCI staff and with people outside NCI are complete.

Communications Extraordinary Opportunity Working Group

Mr. Katz reported that the committee had not met.

DCLG Operations Working Group

The working group helped develop an orientation for new members and a draft of the annual report.

NCI Website Working Group

Mr. Katz reported that because of the continued reorganization of the NCI Office of Communications and the reassignment of the web responsibilities, the working groups had deferred action.

NEW BUSINESS

Mr. Katz announced the launch of The National Health Advocates in Cancer listserv, which was established by consumer advocates from the cancer community. This listserv was developed to create a virtual community where advocates could exchange ideas and help each other work effectively with scientists, clinicians, and other health professionals. The listserv represents the interests and viewpoints of its creators and does not necessarily represent the viewpoint of the NCI or the Federal government. NHAC listserv participants are expected to include advocates, advocacy organizations, scientists, clinical investigators, and institutions that work with advocates. If you are interested in joining the listserv, go to <http://myeloma.org/nhac> for more information.

Ms. Dewey reported on the President's Cancer Panel Meeting held in Billings Montana. She attended this meeting as a representative of the DCLG. She stated that she thought this was a very good venue for hearing from the people of the states of Montana, North Dakota, South Dakota, Wyoming, Idaho, and Wisconsin regarding their access to good quality cancer care. She mentioned there were barriers related to the rural nature of these states, which results in patients having to travel long distances for care. The next two meetings will be held in Los Angeles (February 1-2, 2001) and Albuquerque (March 8-9, 2001). DCLG members in those regions are encouraged to attend.

Ms. Elaine Lee, Executive Secretary for the DCLG presented the Draft Annual Report for the DCLG member's consideration. The DCLG members approved the report with revision to include the activities with professional societies, the Special Populations Working Group, and acknowledgment of Ms. Eleanor Nealon's contributions in establishing the DCLG.

The meeting was adjourned at 12:00 noon.

Date

Michael Katz
Chair, DCLG

Date

Elaine Lee
Executive Secretary, DCLG

ACTION ITEMS

- \$ Dr. Thurn asked for the DCLG's help in beta testing instant messaging.
- \$ Dr. Julia Rowland asked for the DCLG help in the following:
 - S Can DCLG members help identify educational information or resources about cancer survivorship that the OCS might include on their web site or develop in collaboration with NCI's Office of Communications, the advocacy community or other agencies?
 - S Can DCLG members help the OCS to identify priority areas for survivorship research? (e.g., Request for Applications (RFA) formulation, peer-review, advisory group membership)?
 - S Are there key policy issues that the DCLG members think are pertinent to the survivorship community that our research should address or support (e.g., development and use of long-term follow-up guidelines, tax incentives for caregivers, Medicare coverage for clinical trials related to treatment of late effects)?
 - S What role might DCLG members play in helping to highlight or disseminate evidence-based findings on important survivorship issues to the cancer patient's advocacy community as well as the health care delivery community?
 - S What role might the DCLG play in supporting or facilitating Town Hall Meetings should the OCS decide to hold these?
 - S How can the OCS help identify or link interested and qualified consumers and advocates to serve on the DCLG (e.g., web site information)?
 - S How can DCLG members help NCI staff remain current on the activities of advocacy groups that affect health policy and congressional action?
 - S Dr. Rowland asked if the DCLG could help in compiling a booklet.
- \$ Dr. Lipscomb asked for the DCLG to identify potential roles for advocates including:
 - S helping to develop core process and outcome measures for assessing the QOC
 - S strengthening the methodological and empirical foundations of QOC assessment
 - S enhancing quality of care research within the restructured NCI clinical trials program
 - S enhancing and strengthening the quality of cancer communications
 - S ensuring that federal decision making on cancer care is informed by the best available scientific evidence about quality measures and assessments
- \$ Dr. Kerner called for the DCLG to identify areas within the QOC objectives, where members may be involved.
- \$ Ms. Martin will schedule the next DCLG teleconference for December, 2000
- \$ Ms Martin will mail Dr. Alciatis and Dr. Andejaski's slides to the DCLG members
- \$ Ms. Clagett will schedule the next Health Disparities and Quality of Care Working Group Teleconference
- \$ Ms. Clagett will work with Dr. Anne Thurn and the DCLG members to develop a way to promote the use of PDQ and Desktop NCI icons to the advocacy community
- \$ Dr. Andejaski will discuss the issue related to NCI's use of CARRA network members in activities issue with Dr. Klausner

- \$ Dr. Andejaski will schedule a meeting with the Cancer Leadership Council to discuss the CARRA program
- \$ Dr. Andejaski and Ms. Clagett will assist the DCLG in establishing the Survivorship Working Group
- \$ Dr. Andejaski and Ms. Clagett will begin discussions with Anne Thurn about an advocacy role in reviewing Patient Summaries
- \$ Ms. Clagett will work with the DCLG and LA staff to develop Power Point presentations for the DCLG members to use to address the following:
 - S What is the DCLG?
 - S What are the major issues at the NCI?
 - S What are the critical issues in Clinical Trials including treatment, tissue banking, behavioral sciences, epidemiology
- \$ Dr. Andejaski, Ms. Lee and Mr. Katz will begin to develop a process for DCLG Chair succession and election
- \$ The April 2001 DCLG meeting will include discussions of the following:
 - S Operational issues for the DCLG
 - S Office of Communication Functional areas
 - S Bypass Budget
- \$ Present the outcome of the workshop to the DCLG members for their recommendations in October 2000.

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