

**Director's Consumer Liaison Group
National Cancer Institute
2002 Annual Report
October 2001 through September 2002**

INTRODUCTION

Formation

Believing that individuals affected by cancer have wisdom and insight to offer to the National Cancer Institute (NCI), Dr. Richard Klausner, then Director of the NCI, envisioned a new group focused on bringing together cancer care consumers, advocates, and NCI scientists to address key issues in cancer research. In 1997, Dr. Klausner created the Director's Consumer Liaison Group (DCLG) and directed that the Office of Liaison Activities (OLA) provide it with guidance and support. The first all-consumer advisory group at the National Institutes of Health, the DCLG became a federally chartered advisory committee in 1998, and functions to ensure that those who experience the burden of cancer also help to shape the NCI's efforts to eradicate the disease.

Mission

While the methods of achieving its goals are evolving, the DCLG mission has remained clear since its formation. The purposes of the DCLG are to:

- Assist in developing and establishing processes, and criteria for identifying appropriate consumer advocates to serve on a variety of program and policy advisory committees,
- Serve as a primary forum to discuss issues and concerns and exchange viewpoints that are important to the broad development of NCI program and research priorities,
- Provide recommendations to the Director, NCI, in response to specific advice and requests from the Director, NCI, and to the needs of the cancer advocacy community,
- Establish and maintain strong collaborations between NCI and the cancer advocacy community to reach common goals.

Membership

The DCLG reflects the diversity of those whose lives are affected by cancer. Members include cancer advocates and survivors, family members, and health care professionals. The survivors include individuals with a variety of cancers, both pediatric and adult, long-term survivors, and those whose diseases are considered incurable. Each member represents a constituency of people affected by cancer, and these constituencies are as diverse as the group members themselves.

DCLG members come from grassroots organizations in small rural communities, cancer-specific foundations, large national organizations, statewide agencies, and organizations

dedicated to minorities and other underserved segments of the cancer community. Some members work at the local, state, or national level to create or change existing cancer care policies. Others focus on providing individual assistance and support to people coping with cancer. Each DCLG member brings a unique focus and contribution to fulfilling the mission of the DCLG. Together, this ambitious and visionary group strives to represent America's 8.9 million cancer survivors, their families, and professionals dedicated to providing quality cancer care.

For more information on the DCLG please go to the DCLG web site at:
<http://deainfo.nci.nih.gov/advisory/dclg/dclg.htm>.

HIGHLIGHTS OF 2002

Extraordinary Opportunity for Cancer Survivorship Research

In 2002, the DCLG proposed that NCI make cancer survivorship research a focus and a priority within its budget. In October of 2001, members of the DCLG convened a forum entitled, *Grassroots Views on Cancer Survivorship: Opportunities and Unmet Needs*. The forum highlighted models of effective programs and identified common areas of opportunity for future research initiatives. Representatives from several survivorship organizations shared their perspectives with NCI staff on the challenges of cancer survivorship. Using information obtained at the forum and from an informal survey of DCLG constituency groups, the DCLG crafted and submitted *Cancer Survivorship Across the Continuum*, a proposed Extraordinary Opportunity (EO) for Investment within the Director's bypass budget (*The Nation's Investment in Cancer Research: A Plan and Budget Proposal for Fiscal Year 2004*). [Extraordinary Opportunities for Investment are areas of discovery that build upon the most important recent developments in knowledge and technology and hold promise for making significant progress against all cancers.] The DCLG's proposal was combined with others submitted on the same topic and accepted as the *Cancer Survivorship: Improving Treatment Outcomes and Quality of Life* Extraordinary Opportunity. The stated goal of this EO is to "reduce the adverse effects of cancer diagnosis and treatment and optimize outcomes for cancer survivors and their families". The DCLG will continue to work with the NCI Office of Cancer Survivorship as it develops and implements its survivorship plan.

Feedback on Cooperative Groups Clinical Trials Redesign Report

Scientific research is uncovering important insights into the causes of, and cures for cancer. Clinical trials, an important part of the research process, help move basic scientific research from the laboratory to treatments for people. In 1998, the NCI Clinical Trials Implementation Committee, a body of key stakeholders in NCI's clinical trials system, developed a set of implementation steps to redesign the system to overcome barriers to patient-oriented interventional treatment research. Still in transition, this redesign will ultimately impact every cancer patient, advocate, and cancer care provider. Seeing an important opportunity to fulfill its mission to "[s]erve as a primary forum to ... exchange viewpoints that are important to the broad development of NCI program and research priorities," the DCLG decided to seek feedback on the redesign's four pilot projects. Working in partnership with the Patient Advisory Board (PAB) of the Coalition of National Cancer Cooperative Groups, a report was written on the Cooperative Groups Clinical Redesign effort. This was a unique

and challenging attempt to bring both the NCI and the Cooperative Groups together to openly discuss and examine the successes and challenges within the redesign program. As a result of this report, the NCI, Coalition, PAB, and DCLG are working cooperatively to track the progress of the redesign and to assist with communication efforts about the redesign both within the Cooperative Groups and to cancer advocacy groups around the country.

Strategic Planning for the Future of the Director's Consumer Liaison Group

As the leadership of NCI changed in 2002, the DCLG began to re-examine its role within the Institute, past accomplishments, and future direction. In close consultation with the new Director of the NCI, Dr. Andrew von Eschenbach, and the staff of OLA, the DCLG formed a working group to help set clear priorities and goals for the Group as it moves into its sixth year.

With the agreement of the DCLG, the Future of the DCLG Working Group met with Dr. von Eschenbach on September 12, 2002, and recommended that the DCLG conduct a quantitative survey of the advocacy community. The purposes of the survey are to:

- Identify priority areas that both the advocacy community and NCI leadership support.
- Enhance NCI's database of advocacy organizations by collecting information on the organizations, including contacts and key areas of focus and potential outreach.
- Develop a process for ongoing communication with the advocacy community.
- Assess perceptions of the DCLG and NCI, and their priority areas. The survey will establish a baseline against which the DCLG's progress can be measured over time.

The working group also proposed that at least some future DCLG members have expertise in the priority areas that will be identified in the survey and agreed to by NCI.

OTHER DCLG ACTIVITIES THAT ADVANCED ITS MISSION

CARRA Program: The DCLG provided assistance in the creation in 2001 of the Consumer Advocates in Research and Related Activities (CARRA) program, and continues to guide its implementation and refinement. DCLG members work with research and policy champions at the NCI to identify opportunities for advocate involvement. The DCLG worked with the OLA to create a framework, based on matching the skill and perspective of the advocate with that required by the NCI activity, for the appropriate selection of skilled advocates to serve in those opportunities. Currently, the DCLG is participating with other stakeholders in the development of a CARRA evaluation program, which will include gathering information from CARRA members and NCI staff regarding their assessment of the efficacy and appropriateness of the advocates' participation. The DCLG is also involved with others in creating a pilot CARRA training program to better prepare advocates for participation in NCI peer review activities.

As evidence that the value of the CARRA program has grown, requests for advocate involvement from NCI continue to increase. From September 2001 through September 2002, NCI staff requested CARRA member participation in 101 activities, a four-fold increase in the average annual number of requests the OLA received for advocate participation prior to the creation of the CARRA program. The NCI Director's commitment to the CARRA program is expected to further increase the use of this unique and valuable resource.

For more information visit the CARRA web site at:

<http://liaison.cancer.gov/CARRA/index.html>.

Other Advocacy Involvement: When appropriate, the DCLG also helps to identify other advocates for specific activities within the NCI. Sometimes a request is made by the NCI for a representative of a specific subset of the cancer community from which no advocate has been previously identified. When neither a CARRA nor DCLG member will suffice, the DCLG works with OLA staff to identify, inform, and prepare individuals meeting the desired profiles. These advocates can then provide the perspective of their particular community or constituency, considered integral to the NCI's program or initiative. At the completion of their assignments, the advocates report back to the DCLG on their participation and any future opportunities for advocates within that particular NCI initiative.

In 2002, the DCLG identified advocates for the NCI's newly opened Center to Reduce Cancer Health Disparities (CRCHD) and the Cancer Outcomes Measurement Working Group (COMWOG) of the Quality Cancer Care Committee. Advocate participation in these activities impacted the development of future NCI-directed programs and recommendations. For example, because Hispanic women suffer disproportionately from cervical cancer, the DCLG identified a Hispanic survivor of gynecological cancer to attend the CRCHD's meeting, on *Reducing Health Disparities in High Cervical Cancer Mortality Regions*. This advocate was able to relate her perspective on barriers to cervical cancer screening among Hispanic women. The DCLG also helped identify advocates for the COMWOG in 2002. These individuals provided the patient's perspective on different disease-specific outcome measurement tools, and overall, to the standardization of evaluations to assess the final status of persons completing treatment for cancer.

DCLG Participation with Key Cancer-Related Boards, Committees, and Workgroups:

Since the inception of the DCLG, NCI staff and researchers have become increasingly receptive to including the advocacy community in the planning and implementation of new initiatives. Consequently, the DCLG now has a seat at the table of a number of key cancer-related committees, within and outside of NCI, and participates in several important projects. Members of the DCLG are included because of their ability to relate the concerns of their particular constituency, as well as provide the global perspective of all members of the cancer community. These abilities help the DCLG achieve its primary goal and ultimate contribution, and this presence continues to grow.

- Delivering the advocacy community's perspective at the highest level of cancer policy development, the DCLG provided representation to meetings of the National Cancer Advisory Board (National Cancer Institute), National Cancer Policy Board

(Institute of Medicine), and the National Quality Forum (non-profit membership organization).

- Within the NCI, the DCLG provided cancer consumer and advocate input through regular representation to the Advisory Committee to the Director, Central Institutional Review Board, Bypass Budget Planning Group, Health-related Quality of Care Intergroup Working Group, Clinical Trials Transition Team, Cancer Outcomes Measurement Working Group of the Quality of Cancer Care Committee, Center to Reduce Cancer Health Disparities, and the Communications Opportunity Leadership Team.
- Additionally, DCLG members have provided the consumer perspective by participating in the following conferences: *Physical Activity and Cancer Survivorship* (NCI), *Assessing Clinical Significance for Quality of Life Measures in Oncology Research* (Mayo Clinic), *Cervical Cancer Round Table and Think Tank* (NCI), *Digital Divide-Patient/Doctor Relationship* (NCI), the AACR Scientist↔Survivor Program, and *The Effects of Racism on Cancer Care Delivery* (NCI).

Through its increasing visibility, the DCLG is helping to make those who create cancer policies and direct cancer programs more aware of and interested in the needs and views of those who are most affected by these initiatives.

Cancer Communications: DCLG members also participated in the development of a number of key NCI communication and training products. The DCLG provided input and feedback on the development of the Clinical Trials Education Series, the NCI web site, the OLA web site, and the CARRA website. DCLG members reviewed the Cancer Progress Report, materials for Native American audiences, and the Office of Education and Special Initiatives' *Facing Forward*, a major new education series for cancer survivors. DCLG members also serve on the Editorial Board for the production of the *Nealon Report*, the OLA newsletter on cancer research for advocates, scientists, and government.

In addition to advising NCI in the development of new cancer materials, DCLG members are actively promoting, distributing, and demonstrating materials in their communities and through their networks in newsletters, press releases, listservs, websites, and in-person presentations. They are also including news and hyperlinks from the NCI in their advocate publications and websites including the *Living Through Cancer Journal* (New Mexico), the *New Mexico Cancer Connection*, *The Group Gazette* (Iowa), www.breastcancer.org (100,000 monthly hits), www.multiplemyeloma.org, www.cancernm.org, and many others.

Reaching Out to the Cancer Advocacy Community: As representatives of the NCI, DCLG members make presentations to the cancer advocacy community at national, regional, and community-focused conferences and meetings. These appearances serve to make the public aware of the resources and programs at the NCI, as well as the NCI's interest and commitment in acquiring a better understanding of the needs and opinions of the cancer community. This year, DCLG members were invited to present at the Resiliency Across the Lifespan Survivorship Conference, the First Annual New Mexico Cancer Survivors Retreat,

the Patient Advisory Board of the Coalition of National Cancer Cooperative Groups, and the First Annual National Native American Cancer Survivors' Conference. The DCLG believes these presentations are an important mechanism for informing the public, not just about the resources of the NCI, but also about increasing opportunities for new advocates to participate in activities at the Institute. This form of outreach is particularly vital to underserved and minority communities who are also underrepresented in advocacy organizations and within the advocacy opportunities at the NCI.

LOOKING TO THE FUTURE

This past year has been one of change and new beginnings for our nation, the NCI, and for the DCLG as well. As a relatively new player on the NCI scene, the Director's Consumer Liaison Group is slowly becoming interwoven into the fabric of the Institute. Members provide their unique perspective to many NCI committees, working groups, and boards. Their participation has impact from the highest levels of decision-making to the particulars of improving informational publications and web sites. DCLG members work in close collaboration with the Institute's Director, Center directors, researchers, and staff, and these collaborations are beginning to yield substantive results within the NCI and the larger cancer community.

The future of the DCLG holds many challenges including: identifying optimal mission, goals, structure, support, and processes; facilitating ongoing communication with the cancer advocacy community; recommending a member selection strategy; and identifying overlaps and gaps with the efforts of other cancer advocacy organizations. Current efforts are underway to accommodate and anticipate the challenges and changes. With the approval of the DCLG and Dr. von Eschenbach, the Future of the DCLG Working Group and NCI are conducting a quantitative survey of the cancer advocacy community. The survey will identify the cancer advocacy community's priorities and help the DCLG and NCI address them effectively. NCI has retained a contractor that will field the survey in March and present a final report in May. After meeting with the DCLG, the working group will discuss future DCLG priorities and member selection strategies with Dr. von Eschenbach and other NCI leadership.

The DCLG is positioned to be the voice of the cancer advocacy community within the NCI. It looks forward to maintaining and developing additional positive relationships with the leaders of both the advocacy community and the NCI's Offices and Centers. As the DCLG, in collaboration with the Director of the NCI, completes its strategic planning, it will become positioned to move with clarity and determination into the next year, with enthusiasm, vision, and success.

**NCI Director's Consumer Liaison Group
Roster 2001-2002**

Ms. Barbara K. LeStage, Chair
American Cancer Society
Term Ends: 2003

Ms. Vernal H. Branch
Y-ME National Breast Cancer Organization
Term Ends: 2004

Ms. Susan Lowell Butler
Ovarian Cancer National Alliance
Term Ends: 2003

Ms. Kathy Giusti
Multiple Myeloma Research Foundation
Term Ends: 2004

Mr. Michael Katz
International Myeloma Foundation
Term Ends: 2003

Ms. Paula Kim
Pancreatic Cancer Action Network, Inc.
Term Ended: 2002

Ms. Ruth Lin, AOCN
American Cancer Society
Term Ends: 2003

Ms. Gena Love
People Living Through Cancer, Inc.
Term Ends: 2003

Ms. Karen Packer
Marshalltown Cancer Resource Center
Term Ends: 2004

Mr. Christopher Pablo
Asian and Pacific Islander National Cancer
Survivor Network
Term Ends: 2004

Mr. Henry Porterfield
Alliance for Prostate Cancer Prevention
Term Ends: 2003

Ms. Nyrvah Richard
Self Help for Women with Breast or
Ovarian Cancer (SHARE)
Term Ends: 2003

Mr. Doug Ulman
Lance Armstrong Foundation
Term Ends: 2004

Dr. Marisa Weiss
breastcancer.org
Term Ends: 2003

Dr. Brad Zebrack
National Coalition for Cancer Survivorship
& Candlelighters Childhood Cancer
Foundation
Term Ended: 2002