



## ***Division of Extramural Activities***

### **DCLG Supplemental Material**

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#### **NCI Selects First Members of New Director's Consumer Liaison Group**

The National Cancer Institute (NCI) has named 15 consumer advocates to the first ever Director's Consumer Liaison Group (DCLG). The DCLG will help develop programs and help set research priorities as well as find new ways to increase consumer representation at NCI, creating a forum for exchange between the cancer advocacy and scientific communities.

"It is my fervent belief that the communities NCI serves need to have a voice within the Institute," said NCI Director Richard Klausner, M.D. "It is also my belief that NCI needs -- and indeed cannot afford to do without -- all sources of ideas, knowledge, and wisdom that will assist it in making good decisions and setting priorities. I hope and expect that the DCLG will not only be a channel for consumers to voice their opinions and concerns, but a mechanism by which the NCI can obtain advice and feedback from the consumer community on a broad range of issues."

The members are (in alphabetical order):

Paula E. Bowen, Brooklyn, N.Y.	Ruth Chiang Lin, Short Hills, N.J.
Susan Lowell Butler, Alexandria, Va.	Gena H. Love, Albuquerque, N.M.
Manuel H. Castillo, Dayton, Ohio	Susan McCarthy, Vancouver, Wash.
Kerry J. Dewey, Missoula, Mont.	Daniel M. Moore, Jr., Decatur, Ill.
M. Venus Gines, Lithonia, Ga.	Lillouise Rogers, Chicago, Ill.
Felicia Schanche Hodge, Berkeley, Calif.	Susan K. Stewart, Highland Park, Ill.
Michael Katz, New York, N.Y.	Brad Zebrack, Ann Arbor, Mich.
Susan A. Leigh, Tucson, Ariz.	

DCLG members will serve three-year terms. The group will meet several times a year and directly make recommendations to the Advisory Committee to the Director, NCI. This committee consists of the director, NCI as chair; the chair of the National Cancer Advisory Board; and the chairs and co-chairs of the NCI Board of Scientific Counselors and Board of Scientific Advisors.

The three-fold purpose of the DCLG will be to:

- serve as a primary forum for discussing issues and concerns and exchanging viewpoints that are

- important to the broad development of NCI program and research priorities.
- help develop and establish processes, mechanisms, and criteria for identifying appropriate consumer advocates to serve on a variety of NCI program and policy committees.
- establish and maintain strong collaborations between NCI and the cancer advocacy community.

The 15-member DCLG is made up of people involved in cancer advocacy and who reflect the breadth and diversity among those whose lives are touched by cancer. They were selected from a pool of 136 candidates. All qualified candidates who were not selected may be asked in the future to serve the Institute in a variety of other capacities.

The 136 candidates for the group were asked to name the most pressing issues facing cancer patients today. The top four issues were: access to and availability of reliable cancer information; access to effective, high-quality treatment, including clinical trials; increased rehabilitation, psychosocial support, and other survivor concerns; and participation in setting research priorities.

The group's first meeting is slated for December. The DCLG is coordinated and supported by the NCI's Office of Liaison Activities, which is headed by Eleanor Nealon. "It is an exciting time at NCI," said Nealon. "The establishment of this new group will give consumer advocates a very visible presence and important voice in the Institute."

### **Composition of the Group and the Nomination Process**

The majority of the newly appointed DCLG members are cancer survivors, but family members of cancer patients and health professionals involved in cancer advocacy are represented. The cancer experience of the group includes prostate, breast, kidney, ovarian, cervical, lung, bladder, and brain cancer, Hodgkin's disease, leukemia, sarcoma, and myeloma. The group includes Asian American, Native American, Hispanic, African American, and non-Hispanic white persons, the young and old, men and women, and people from all geographic areas of the country, both rural and urban. The constituencies represented by the members include advocacy organizations that represent both specific cancers and all cancers.

The call for nominations went out in May 1997 and nominations had to be postmarked by Sept. 15, 1997 to be considered. The four-month call for nominations allowed information about the nomination process to reach local as well as national and regional candidates.

The nomination process and criteria for evaluating candidates was defined by a Planning Group composed of cancer advocates and NCI staff. The group met in March 1997 to assist in defining the initial role of the DCLG and to design the blueprint for the nomination and selection process. Eligible candidates had to meet two key requirements: they had to be involved in the cancer experience as a cancer survivor, a person affected by the suffering and consequences of cancer, or a professional/volunteer who works with survivors or those affected; and they had to represent a constituency, formally or informally, with which they communicate regularly on cancer issues and be able to serve as a conduit for information both to and from this constituency.

All eligible nominees were rated based on pre-established criteria: their cancer advocacy experience, ability to communicate effectively, ability to represent broad issues, ability to contribute to an effective group process, and leadership ability. Two letters of recommendation were required.

Attachment: **First NCI Director's Consumer Liaison Group Members**

For more information about cancer visit NCI's Website for patients, public and the mass media at [NCI's](#)

## FIRST NCI DIRECTOR'S CONSUMER LIAISON GROUP MEMBERS

**Paula E. Bowen**, a four-year survivor of kidney cancer, is from Brooklyn, N.Y. Bowen has been a member of the Board of Directors of the National Kidney Cancer Association since 1996. Her advocacy began, and continues, at the grass roots level. She was instrumental in reinvigorating the Association's New York Chapter by calling kidney cancer patients and finding out what kinds of programs and services they needed and wanted. She also helped formulate the mission statement for the Chapter. Those most typically afflicted with kidney cancer are older white males, approximately 100,000 nationwide with nearly one-third being medically underserved. Bowen, whose family is from Guyana, South America, says that one of her primary interests is extending her cancer advocacy outreach more deeply into urban areas where financial, economic and social constraints preclude access to medical centers of excellence. She feels strongly about the importance of getting good cancer information to the community and learning the viewpoints especially of underserved populations. She has also been very active politically to encourage insurance reform and the need for increased research funding.

**Susan Lowell Butler**, a three-year survivor of both ovarian and breast cancer, is from Alexandria, Va. Her cancer advocacy began during the course of her treatment when she found herself scrambling for information, struggling to manage the difficulties intensive treatment brings to the body and soul, and coping with her personal and professional life. She has chosen to focus her advocacy efforts on ovarian cancer. Butler is a founding member of the Ovarian Cancer National Alliance and a co-chair of the Ovarian Cancer Coalition of Greater Washington. Among her many other activities, she works closely with the women's community and is serving on the Steering Committee of the Council of Presidents of National Organizations, a coordinating council for leaders of more than 150 national women's organizations. Through her participation on an ovarian cancer Internet discussion group, she learned of a quilt being assembled by an ovarian cancer survivor from squares made by other ovarian cancer survivors. Butler realized that this "Ovarian Cancer Survivors Quilt" would make a terrific vehicle to bring ovarian cancer to the forefront of public consciousness. She organized an event at the National Institutes of Health that brought together a member of Congress, high level officials from NIH and NCI, several top NCI ovarian cancer specialists, and the women who created the quilt. This event received extensive publicity and the Quilt is now being displayed across the U.S. and internationally. Butler is also a member of the National Breast Cancer Coalition.

Although **Dr. Manuel Castillo** of Dayton, Ohio, is a surgeon and Medical Director at Samaritan North Cancer Care Center and Associate Professor of Surgery at Wright State University, he finds time to volunteer for a wide variety of activities to help cancer patients and their families. He also serves on the Board of Directors of the regional American Cancer Society as their Medical Advisor to Greene, Preble, and Montgomery Counties. While he lived in New York, in coordination with the local chapter of the Oncology Nursing Society, he helped to organize and obtain funding for Camp Fresh Horizon to provide summer activities for adults with cancer. Volunteers helped participants with their daily needs. Since coming to Ohio, he has established a weekend camp for adult cancer patients. Campers and family members can attend at a very low cost. At the present time he is trying to secure donated land near the center of the state which will become "Camp Samaritan." While in Puerto Rico, in conjunction with the American Cancer Society, he developed a club for cancer patients who have suffered disabilities as a result of surgery including those having laryngectomies and ostomies to contribute to their rehabilitation. Dr. Castillo is very concerned about the underserved minority populations in the community in which he serves and often secures services for cancer patients who cannot afford them. He also is working to bring cancer screening and messages about cancer control to high schools, nursing homes, and local clubs and churches. He is well known for his international commitment to the care of cancer patients.

**Kerry Dewey**, a 12-year breast cancer survivor, describes herself as a cancer survivor turned activist. From Missoula, Mont., she is a two-time survivor of breast cancer. Her first efforts were with the American Cancer Society's Reach to Recovery program where she eventually became a trainer. Between 1987 and 1991, she was active in the Breast Cancer Outreach Program (BCOP) in Portland, Oregon, where, in addition to many other activities, she developed and coordinated the BCOP's Male Call program, a men's peer-support network for the spouses, partners and/or male family members of women with breast cancer. After returning to Montana, Dewey started a breast cancer support group and in 1993 was a founding member of a local education group which came to be called the Breast Cancer Resource Network. She co-directed the work on the Montana Breast Cancer Resource Guide, a compilation of all resources available for breast cancer patients and their families that was completed in late 1996. Montana, as a rural state, has difficulties with dissemination of information about and access to resources for its constituents. Dewey contacted every hospital, mammography clinic, support group, prosthesis provider, cancer center and breast cancer organization in the state and got input from the multicultural Native American, Hmong, and Russian populations in Montana. This guide was the first statewide guide of its kind in the U.S., is free, and has a website. Dewey also is a founding member of the Montana chapter of the National Breast Cancer Coalition (NBCC). After completing Project LEAD, a science training program of the NBCC, Dewey became very active politically and helped research, draft and gather support for the Breast Cancer Protection Act passed by Montana in 1997. This legislation expands insurance coverage for mammograms, mandatory disclosure of all treatment options, and addresses other needs of women with breast cancer.

**M. Venus Gines**, is a five-year breast cancer survivor from Lithonia, Ga. She also has lost a family member to cervical cancer. She has been active in community work with the American Cancer Society (ACS), developing programs to increase awareness and cancer screening among the Hispanic community. Gines serves on the ACS Atlanta Division Board of Directors, Public Relations/Fundraising Committee, and on the Hispanic Cancer Awareness Coordinating Committee for the ACS Georgia Division. Her advocacy work has been directed at developing culturally appropriate programs and educational materials for Hispanic women and men, and some of her focus has been on the medically underserved with low literacy skills. For example, she developed ethnic-specific videos on breast, cervical and prostate cancers to educate migrant workers who have low literacy. She also collaborated with a number of organizations to host the first Hispanic Women's Health Fair in Atlanta, focusing on breast and cervical cancer education and screening. Gines is currently pursuing her master's degree in the Georgia State Women's Studies Graduate Program where she is researching cultural barriers to early detection for breast cancer among Hispanic women. Also, professionally she has worked as a flight attendant with TWA for 21 years. Gines is a member of the Hispanic Health Coalition of Georgia, the Latina Institute for Reproductive Health, and the National Breast Cancer Coalition (NBCC). She was the first Hispanic woman to graduate from NBCC's Project LEAD science training program and the first Hispanic patient representative on the Food and Drug Administration's Oncologic Drug Advisory Committee. Gines recently received the 1997 HOPE Award from the Intercultural Cancer Council at the 6th Biennial Symposium on Minorities, the Medically Underserved and Cancer for her work with the Hispanic community in educating the underserved and uninsured, and developing a unique ethnic-specific program to promote cancer screening.

**Felicia Schanche Hodge**, a 20-year survivor of epithelioid sarcoma, is an Associate Researcher at the University of California at Berkeley where she teaches American Indian health and social welfare policies. She is a former director of the Northwest Portland Area Indian Health Board, and a member of the California Cancer Information Service (CIS). Dr. Hodge is the founder and director of the Center for American Indian Research and Education (CAIRE) that supports research, evaluation, education, advocacy, policy development, planning, chronic disease prevention, and community service. This agency serves American Indians and Alaska Natives nationally. The advisory board of CAIRE is composed of tribal members from Indian agencies nationwide. Dr. Hodge uses this board to reach out to a wide group of tribes to advocate for Indian cancer control issues. Dr. Hodge has been concerned about the health of American Indians for the past 25 years and studies

behaviors which contribute to chronic health problems such as diabetes, heart disease, and cancer. Since 1982, she has been particularly interested in advancement of cancer awareness and research on cancer prevention and control (including smoking cessation and screening). One successful technique she uses to convey culturally appropriate screening and healthy lifestyle messages is the Talking Circle where people are brought together socially and receive information about cancer prevention. Dr. Hodge stresses that while she works with the Indian community, she does not conduct "helicopter research" (dropping in to collect data and leaving nothing behind). Instead, she is careful to bring the tribe's interest to the table, to consider their needs, and to provide training workshops in the community. As much as possible, she hires assistants from the local tribal groups, and created an internship program for Native Americans to spark their interest in cancer research.

**Michael Katz** is a seven-year myeloma survivor from New York City. He is on the board of the International Myeloma Foundation (IMF), an international organization serving more than 20,000 myeloma patients and family members. He has played an active role in expanding the scope of IMF patient and scientific programs and helping to raise funds for patient support programs and research. He supplements those activities by doing one-on-one counseling with patients and family members. Since becoming involved with the IMF, he has expanded his activities in many ways to have a progressively greater impact on the myeloma community, such as developing online information resources. These tools help patients learn about myeloma and get in touch with other patients, families and medical experts. For example, he personally developed the [IMF website](#), which shared the first Oncolink Editor's Choice award with the NCI's Physician's Data Query (PDQ) - a comprehensive cancer database containing information on cancer treatment, supportive care, prevention, and screening. His experience as an executive, expertise in computers and networking, and an engineering background have enabled him to quickly learn about the principles of hematology/oncology. Katz likes to help bridge the patient and scientific communities, providing for an exchange of ideas and a better mutual understanding. Recently, he conducted a survey of attitudes of myeloma patients about how they deal with their illness and about their interactions with the medical community. His other contributions to the myeloma community include authoring IMF patient handbooks, contributing a chapter to an upcoming myeloma textbook, and writing a regular column in "Myeloma Today," the IMF newsletter. He also serves as Chair of the Eastern Cooperative Oncology Group (ECOG) Patient Representative Committee. ECOG is a national group of cancer researchers.

**Susan A. Leigh** is a 25-year survivor of Hodgkin's Disease, a seven-year survivor of breast cancer, and three-year survivor of bladder cancer. Professionally, she is an oncology nurse living in Tuscon, Ariz. Among many cancer advocacy accomplishments, Leigh has been actively involved with the National Coalition for Cancer Survivorship (NCCS) since the initial meeting of cancer advocates that created the organization in 1986, and she is now the Immediate Past-President, a board position with NCCS. She continues to speak professionally to health care and consumer audiences both nationally and internationally about cancer survivorship, and interacts daily with cancer survivors to help them cope with their illness. Leigh is also actively involved in the Oncology Nursing Society (ONS) for which she created the Nurse Survivor's Focus Group and Survivorship Special Interest Group. She contributed to NCCS's Imperatives for Quality Cancer Care which addresses the physical and psychosocial late and long-term effects faced by many cancer survivors. Recently, she served on an Award's Committee for the 6th Biennial Symposium for Minorities, the Medically Underserved and Cancer. While her main area of work has been with adult survivors, she has also done some work in issues of childhood cancer. Furthermore, Leigh has written extensively on the topic of cancer survivorship, including articles and book chapters, and has been instrumental in attempting to define the semantics of survival from a survivor's perspective.

**Ruth (Zu-Kei) Chiang Lin, R.N., M.S., O.C.N.**, is an Oncology Clinical Nurse Specialist at Morristown Memorial Hospital in Short Hills, NJ. In her professional role, Lin trains oncology nurses, teaches and counsels cancer patients, works with social workers to coordinate the cancer support programs, conducts quality improvement projects in cancer care, and helps to supervise for the low income minority women in

breast and cervical cancer screening projects. She bridges her professional and advocacy roles by coordinating the American Cancer Society (ACS) "I Can Cope" program at Morristown Memorial Hospital. She expands her volunteerism by presenting "Early Detection of Breast Cancer" at various Chinese community sites (e.g., banks, Chinese schools, and various religious groups in Southern California) and serving as a liaison and translator for Mandarin and Taiwanese speaking cancer patients. While much of her focus is on the Chinese American population, she has worked extensively with different ethnic groups, incorporating their cultures into specific health care programs. A recent transplant to the east coast, Lin spent 10 years in the Los Angeles area working in oncology patient care, where she played a pivotal role in setting up culturally sensitive health care opportunities for the growing Asian population. Currently she is working with the ACS Chinese American Affiliate in New Jersey on women's cancer screening projects and patient teaching materials.

**Gena Love**, from Albuquerque, N.M., is an 18-year survivor of Hodgkin's Disease. Because she had been told that Hodgkin's disease was easy to cure, she did not become involved in support groups or try to learn about her disease, treatment, or long-term survival. However, less than three years after completing radiation therapy her disease recurred. Over the next seven years she had three more recurrences and multiple rounds of treatment that culminated in a stem cell transplant which led to a complete, sustained remission. During this time, she sought support from a group called "Living Through Cancer" (LTC). Over the next several years, she helped to facilitate the group which she describes as a healing and growing experience for her. For the last four years, she has been Director of Support Services for this cancer survivorship support and education group, now known as "People Living Through Cancer" (PTLC). The group serves a population that includes Asian Americans, Hispanics, African Americans, Native Americans, and non-Hispanic Whites from rural as well as urban and suburban areas. Love also serves on the advisory board of ENCOREplus/YWCA, a group that identifies low cost breast cancer screening and follow up services for women, and on the American Cancer Society Southwest Division Leadership Council and Breast Cancer Core Team. As Director of Support Services for PTLC, she has developed and implemented a cancer support training program known as "Cancer Survivorship: Together We Walk the Path." Through this program, Love trains and supervises volunteers in support groups. This program is now being adapted for "Cancer Survivorship in Indian Country" and is supported by funds from the Indian Health Services.

**Susan M. McCarthy** is Director for Planning and Program Development for the Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE) in Vancouver, Wash. She has a medical education with a focus on oncology, and has had daily, direct contact with lung cancer patients through her work at ALCASE for several years. ALCASE provides education and support to approximately 2,200 lung cancer patients from all walks of life and 1,700 health care providers nationwide. In her position, McCarthy is responsible for creating and maintaining all programs, including the ALCASE Hotline, the ALCASE Phone Buddies program, and *Spirit and Breath: A Newsletter for People Living With Lung Cancer*, the only lung cancer specific newsletter in publication. She was instrumental in developing Phone Buddies, a peer-to-peer support program where callers are matched with other survivors based on a number of factors. One of McCarthy's most successful projects was the creation of "invisible" ribbon lapel pins to symbolize the unseen and unknown lung cancer survivor population and to increase awareness of those living with lung cancer. Additionally, she has contributed to the [ALCASE website](#), the 1997 Workshop on Lung Cancer: Improving Outcomes for the New Millennium, and the design and development of a variety of print materials for lung cancer patients and health care professionals.

**Daniel M. Moore** is a five-year survivor of prostate cancer. He has family members who have experienced breast, cervical, skin, and brain cancers. In 1995, he started the Central Illinois US TOO! Prostate Cancer Support Group at Decatur Memorial Hospital, through which he works with the national US TOO! office. Moore's prostate cancer advocacy experience includes instituting a peer support training program for prostate cancer survivors and family members and writing a monthly newsletter. Moore is also a lawyer in Decatur, Ill., where he practices elder law. He combines his professional and advocacy roles when he makes

"house calls" to hospice patients to provide legal support and visits the senior center to provide pro bono legal assistance. He serves as a member of the Macon County Board of Health and as secretary to the senior division of the Human Service Agency Consortium, composed of agency representatives from hospitals, nursing homes, mental health centers and others. He was president of the Visiting Nurse Association for two years from 1994-1996. Furthermore, he was appointed by Governor Edgar to the State of Illinois Council on Aging, and he is immediate past chairman of the Illinois State Bar Association Elder Law Section Council. The members of the US TOO! Prostate Cancer Support Group live in urban and rural areas. Through his other committee and volunteer work, Moore has had the opportunity to assist medically underserved populations in the central Illinois area. A special honor was awarded to Moore when he was appointed by his Congressman Glenn Poshard to serve as a delegate to the 1995 White House Conference on Aging in Washington, D.C.

**Lillouise Rogers** is a 14-year breast cancer survivor from Chicago, Ill. During her early years of experience with breast cancer, she reached out to Y-ME National Breast Cancer Organization. As a result of the support she received from Y-ME, she vowed to devote the rest of her life to helping other women with this devastating disease. She is a hotline counselor and Assistant to the Director of Public Education for Y-ME at their headquarters in Chicago. Rogers conducts support sessions for breast cancer screening, leads a community support group on the south side of Chicago, the Y-ME Woodlawn open door support group, and is very active in taking the message of early detection to black churches and community groups. She describes her constituency as primarily African American breast cancer survivors of whom about 50 percent are medically underserved. She represents Y-ME in various professional forums, working with health professionals to sensitize them to the needs of a woman with breast cancer. She is also a national hotline trainer who provides technical support and education to Y-ME chapters which have created local hotlines in their communities. Rogers has participated in several national discussions of health care reform. For example, in 1994, she represented the American Public on "Good Morning America" with Hillary Clinton and expressed concern about whether or not the proposed Health Care Reform legislation would provide coverage for people with pre-existing conditions. Rogers knew from personal experience what it was like to lose her job and therefore her health care insurance and then be turned down for other health insurance because she was a breast cancer survivor. In addition, Rogers understands the fears all cancer patients have about chemotherapy, the fear of being out of control, and the need to be educated about their disease in order to make good choices about their health care.

**Susan K. Stewart** is a nine-year survivor of acute myelogenous leukemia (AML) from Highland Park, Ill. Shortly after her diagnosis, she received a bone marrow transplant. After recovering from her transplant, she created the *BMT Newsletter* (BMT formerly stood for bone marrow transplant, and is now Blood and Marrow Transplant). It was the first, and continues to be the only newsletter written by and for these transplant patients and survivors. The BMT Newsletter is sent to bone marrow and stem cell transplant donors, recipients, care-givers, and family members, most of whom live in the U.S. They are a diverse group from all racial backgrounds, and the newsletter also reaches some medically underserved blood and bone marrow donors and recipients. More than 200 cancer centers and bone marrow transplant centers also use the newsletter and/or a patient handbook also authored by Stewart. In addition, Stewart coordinates two services for prospective transplant patients. One is the "Patient-Survivor Link" service that links bone marrow and stem cell transplant candidates with survivors who have been through a similar transplant and/or similar diagnosis. The second is the "Attorney-Referral" service for patients having difficulty securing insurance coverage for these transplant-related expenses. She has helped develop videos for patients on post-transplant psychosocial issues, published articles, spoken at conferences, and developed a website to share [information about transplantation](#). To support her advocacy efforts, Stewart is a participant in *Partnerships in Patient Advocacy*, a forum coordinated by the Association of Community Cancer Centers (ACCC) that brings together advocates from leading cancer organizations to discuss joint efforts on issues of concern to cancer patients.

**Brad Zebrack, M.S.W., M.P.H.**, from Ann Arbor, Mich., is a 12-year survivor of Hodgkin's disease. About a year and a half after the end of treatment, he began a 11,000 mile bicycle tour around the United States to promote awareness about cancer survivorship. One reason for embarking on this bike trek, which he called "BikeAmerica: A Ride for Survivors," was to demonstrate to young adult cancer patients that a viable and productive life can still be achieved even after a diagnosis of cancer. Following completion of chemotherapy he became an American Cancer Society Volunteer and interested in social work. He is a former pediatric oncology social worker and serves on the board of directors of the National Coalition for Cancer Survivorship. He leads the local Cancer Survivors Network group which evolved out of "Town Hall Meetings" to meet community needs. Most of his work is with young adults with Hodgkin's disease and non-Hodgkin's lymphomas. He has published several articles on cancer survivorship and contributed to publications such as "The P.L.U.S. Program: A Project for Learning, Understanding and Support" which is an educational manual and program for patients. Zebrack is currently working on his Ph.D. at the University of Michigan and is interested in the psychosocial needs of long-term survivors of childhood cancers.