



Division of Extramural Activities

DCLG Supplemental Material

November 1997
U.S. DEPARTMENT OF
HEALTH AND HUMAN SERVICES
National Institutes of Health

From the Director, NCI

Preface

The Director's Consumer Liaison Group Planning Group Members

- Consumer Advocates
- National Cancer Institute

Table of Contents

- Envisioning the DCLG
 - Background
 - Purpose and Operations of the DCLG
 - Initial Steps in Developing the DCLG
- Designing the Blueprint
 - Role of the Planning Group
 - The Design Process
 - Results
 - Issues and Challenges
- From Blueprint to Reality
 - Promoting Nominations
 - The Nomination Process
 - Screening and Scoring of the Nominees
 - Selecting the Final Candidates
- The Face of the Director's Consumer Liaison Group
 - Members of the First NCI Director's Consumer Liaison Group
 - Profiles of the DCLG Members
 - Key Issues of Concern
 - The Importance of the DCLG
 - In the Words of the DCLG Nominees

From the Director, NCI

The experience of cancer is all too common in today's society, and the suffering it causes is incalculable. Individuals who have been affected by cancer can bring wisdom and insight that are

crucially important to our research efforts at the National Cancer Institute (NCI). The Director's Consumer Liaison Group is a powerful new entity-made up entirely of consumers-through which we hope to tap that wisdom and insight. The DCLG is a landmark initiative that will bring together consumer advocates and scientists on a regular basis to address key issues in cancer research. By virtue of its own work, and by facilitating the broader participation of other consumer advocates in various NCI activities, the DCLG will ensure that those who experience the burden of cancer also help to shape the course of our efforts to eradicate this disease.

The DCLG will not only provide a rich source of ideas and viewpoints for NCI, but it also will give the cancer advocacy community an opportunity to provide input in the planning of programs and our future directions. It is my belief that the communities NCI serves need to have a voice within the Institute. It is also my belief that NCI needs-indeed, cannot afford to do without-all the sources of ideas, knowledge and wisdom that can assist it in making good decisions. For this reason, I hope and expect that the DCLG will be a channel for consumers to voice their opinions and concerns and serve as a mechanism by which the NCI can obtain advice and feedback from the consumer community on a broad array of issues. These issues range from clinical trials and cancer genetics to early detection and public information, and their number and complexity can be expected to grow as the pace of discovery continues to accelerate.

The charge to the DCLG is broad, and we will work together with its members to develop it. Their commitment is crucial for the group's evolution, and their talents, leadership and perspectives will certainly contribute to its success. Developing the processes and systems necessary to perform the DCLG functions will largely be its responsibility and will evolve over time. We also owe a debt of gratitude to the splendid work of the DCLG Planning Group, which designed the foundation of the DCLG.

Today we are at the starting point, and the task for the initial DCLG is to set the direction for a unique advisory body that will effectively represent its constituency- the community of those affected by cancer-and that will become an increasingly valuable source of advice for NCI. I look forward to this dynamic new partnership and offer my full support for its success.

Richard Klausner, M.D.
Director, National Cancer Institute

Preface

The past year has been an exciting time as we have undertaken the development of the Director's Consumer Liaison Group (DCLG)-a unique effort to increase consumer advocate involvement in a wide range of the National Cancer Institute efforts. With the active participation of the cancer advocacy community, we have created an outstanding team that will bring the voice of cancer patients and others affected by cancer directly to the Institute to work with us to meet the needs of the cancer community.

It is impossible to overstate the enormous contribution made by the DCLG Planning Group. Their intelligence and insight, their willingness to work hard and cooperatively, and their gracious acceptance of their role as planners rather than as members of the initial DCLG were crucial to the progress we have made.

The DCLG is a totally new initiative for which there was no template. It consists of 15 consumer advocates who reflect the diversity among those whose lives are affected by cancer. NCI will bring

together these advocates from across the country to directly interact with the scientific community at NCI on a wide range of programs and issues. The DCLG will form a new junction between science and the advocacy community, providing a two-way communication channel, helping to institutionalize consumer advocate representation on NCI committees and working groups, and serving as a wonderful new vehicle for fresh views, advice, and recommendations on NCI programs and priorities.

While one can only speculate about the eventual scope and outcomes of its efforts, there is every reason to believe that the DCLG will not only prove a success, but will become a model of consumer advocate involvement that may be of interest to other agencies and organizations. Certainly a great deal of groundwork has been laid from which other groups might benefit. That experience is outlined briefly in the pages that follow. This report serves as a record of the crucial contributions and commitment of the Planning Group in designing the blueprint for the DCLG.

With the initial developmental steps complete and the first members of the DCLG appointed, we now enter a new stage of activity. It promises to be equally challenging and exciting, and we will continue to need the input and support of many people to make the DCLG as strong and robust as possible. As for the members of the DCLG Planning Group, they surely know that they have my heartfelt thanks for the excellent job they did, and that I will continue to depend upon them for their wise counsel and support.

Eleanor Nealon
Chair, DCLG Planning Group
Director, Office of Liaison Activities
National Cancer Institute

The Director's Consumer Liaison Group Planning Group Members

Consumer Advocates

Kathryn Adams, Vice President
Cure For Lymphoma Foundation
Diane Blum, M.S.W., Executive Director
Cancer Care, Inc. Elizabeth Clark, Ph.D., President
National Coalition for Cancer Survivorship
Sharon Green, M.H.A., Executive Director
Y-Me National Breast Cancer Organization
Elmer Huerta, M.D., M.P.A., Member
Intercultural Cancer Council
Karen Eubanks Jackson, Founder and National President
Sisters Network, Inc.
Peggy McCarthy, M.B.A., Executive Director
Alliance for Lung Cancer Advocacy, Support and Education
Jane Reese-Coulbourne, M.S., Ch.E., M.B.A., Executive Director
National Breast Cancer Coalition
Susan L. Weiner, Ph.D., Chair
North American Brain Tumor Coalition
COL (Ret) James E. Williams, Jr., M.S., S.P.H.R., Board of Directors

US-TOO International, Inc.

National Cancer Institute

Leslie G. Ford, M.D., **Division of Cancer Prevention and Control**
Ruthann Giusti, M.D., **Division of Cancer Epidemiology and Genetics**
Brian Kimes, Ph.D., **Division of Cancer Treatment, Diagnosis and Centers**
Mary McCabe, R.N., **Division of Cancer Treatment, Diagnosis and Centers**
Eleanor Nealon, **Office of Liaison Activities, Chair, Planning Group**
Susan Sieber, Ph.D., **Division of Cancer Epidemiology and Genetics**
Chris Thomsen, **Office of Cancer Communications**

Table of Contents

ENVISIONING THE DCLG

Background

There has been an appreciation for the contribution that consumer advocates make to the work of the National Cancer Institute. Their role in decision-making at the Institute has grown in recent years as cancer advocacy groups have become better organized and more proactive on behalf of their interests and concerns and as NCI's mechanisms for obtaining and utilizing their input have been expanding. For example, the Office of Liaison Activities (OLA) was recently established as a central point of contact and NCI link to cancer advocacy organizations, strengthening NCI's relationships and cooperation with these groups. At the request of NCI Director Richard Klausner, M.D., a key initiative of this Office has been the development of the Director's Consumer Liaison Group (DCLG). As envisioned, this group will help develop programs and set research priorities as well as find ways to increase consumer representation at NCI and provide a forum for exchange of views between the cancer advocacy and scientific communities.

Consumer representatives of advocacy organizations participate regularly in a variety of NCI committees, including the National Cancer Advisory Board (NCAB) as well as many special purpose committees or groups formed by various units within the Institute. Until recently, however, the pool of consumer advocates known to NCI and serving on those committees has been relatively small. With the establishment of OLA, this pool began to expand, and the nomination process for the DCLG has resulted in the identification of a larger number of additional, appropriate consumer advocates who have indicated their willingness to be called upon for service in a variety of activities at the NCI. The DCLG will be asked to help develop further mechanisms to identify additional consumers who can be invited to represent at NCI the voice of the many and diverse individuals whose lives are affected by cancer.

Purpose and Operations of the DCLG

The DCLG is composed of 15 consumer advocates selected by the NCI Director from nominations received from the cancer advocacy community. Members will serve 3-year terms.

Ongoing communication and collaboration between NCI and the consumer advocacy community is a dynamic process, and the role of the DCLG is expected to evolve over time. The three-fold purpose of the DCLG is to:

- Help develop and establish processes, mechanisms, and criteria for identifying appropriate consumer advocates to serve on a variety of program and policy advisory committees responsible for advancing the mission of the NCI
- Serve as a primary forum for discussing issues and concerns and exchanging viewpoints that are important to the broad development of NCI programmatic and research priorities
- Establish and maintain strong collaborations between NCI and the cancer advocacy community to reach common goals

It will be incumbent upon the DCLG both to help set its agenda and to develop strategies for accomplishing its work. These strategies are expected to include two or three meetings yearly, supplemented as necessary by the more intensive efforts of subgroups charged with specific tasks and by communication via mailings, teleconferences, or website. Initial tasks projected for the DCLG include:

- Reviewing the process used in identifying initial DCLG members to provide input regarding the selection process for future DCLG members
- Developing mechanisms and criteria, in partnership with NCI, for use in identifying appropriate consumer advocates to participate in a variety of NCI program and policy advisory committees
- Serving as a link between NCI and consumer advocacy organizations

In addition to collaborating with NCI on a variety of projects, the DCLG will provide valuable perspective and viewpoints on current NCI programs and challenging issues, and will help NCI in planning programs and setting research priorities. In all these efforts the members of the DCLG will be seeking and reflecting input from their constituencies and relaying information back and forth between those constituencies and NCI. Findings and recommendations of the DCLG will go directly to the Advisory Committee to the Director (ACD) of NCI. The NCI Office of Liaison Activities will coordinate and support the DCLG. Eleanor Nealon, OLA's Director, will serve as the DCLG's Executive Secretary.

Initial Steps in Developing the DCLG

The NCI Director, Dr. Richard Klausner, recognized the need for and value of expanded consumer advocate participation in NCI program and policy development and, in the fall of 1996, directed the OLA to work to establish the DCLG as a mechanism for accomplishing this. Informal discussions conducted by the Director of OLA with representatives of key advocacy groups confirmed initial support for the DCLG. OLA held internal planning meetings with a group of key NCI staff from various divisions and they agreed on the need to form a Planning Group that would itself represent the consumer advocacy community as well as NCI. The Planning Group would help define the initial role of the DCLG, criteria for individual members, and the characteristics of the group as a whole, and would design a process for identifying and evaluating potential members. NCI staff guided the development of the Planning Group and agreed that the majority of its members should be consumer advocates. Consumer advocates were defined as:

survivors of cancer or anyone who has been affected
by the suffering and consequences or risk of cancer.

This definition was broad; it encompassed families and friends of cancer patients, health care providers, and community workers dealing with cancer issues, as well as those who had been diagnosed with cancer. Health professionals were included in recognition of the fact that many of

them actively support the cancer advocacy community and play advocacy roles.

Criteria for membership on the DCLG Planning Group were established for both NCI and consumer advocate members.

NCI members of the DCLG Planning Group were required to:

- Represent broad programmatic knowledge of NCI's research mission and activities
- Have broad knowledge of or experience with the issues and concerns of the cancer advocacy community

Consumer advocate members of the DCLG Planning Group were required to:

- Be knowledgeable about the research mission of the NCI (and preferably have some experience in dealing with NCI procedures)
- Be effective planners, able to think "globally" rather than focusing on a specific cause-related issue
- Have a balanced perspective (as perceived by the NCI and the advocacy community)
- Represent, as a group, a range of cancer sites
- Be demographically and culturally diverse, as a whole
- Represent or be involved with a cancer-related advocacy or voluntary organization (such organizations must: 1] be national in scope or otherwise broadly based, with an identified (authorized) representative; 2] share common goals with the NCI mission and programs; 3] be nonprofit (or for-profit educational); and 4] support a rigorous scientific process and method in investigation of new approaches to cancer prevention, detection/diagnosis, and treatment)
- Not currently serve on any NCI-chartered board or committee

The NCI staff also recommended that, in order to avoid real or perceived conflict of interest, members of the Planning Group should not be eligible for membership on the initial DCLG, although other members of their respective organizations would be eligible to serve.

Using these criteria, and working from a list of potential Planning Group members compiled with wide NCI input, 10 consumer advocates were identified and selected by the NCI Director. These 10 consumer advocates, along with the 7 NCI staff already participating in DCLG planning efforts, comprised the DCLG Planning Group. Their names and affiliations are shown on the following page.

DESIGNING THE BLUEPRINT

Role of the Planning Group

The DCLG Planning Group activities began almost immediately upon appointment of its members in December 1996. Their first task was to review a draft proposal on the initial role of the DCLG. The Planning Group provided substantive comment on this proposal and clarified their own role. Once revised to reflect Planning Group input, this proposal provided the conceptual basis for the planning process.

The Planning Group next focused their efforts on designing the blueprint by which the DCLG would be created. Their mission was to help define the initial role of the DCLG, the criteria for members, and categories for the group as a whole, and to design the screening, scoring, review, and nomination process. The Planning Group's success would be largely due to the commitment of its members and their determination to work together to bring the DCLG to fruition. Teleconferences were held

initially, and a two-day meeting was set for March 1997.

The Design Process

OLA prepared the Planning Group for a productive meeting. Planning Group members received a number of materials in advance of their meeting, including background information on NCI and its committees, information about existing models of consumer involvement in use by other federal agencies, and suggestions from the broader cancer advocacy community about eligibility criteria and categories for DCLG members.

A limited number of models was identified that used policies and procedures relevant to the tasks of the DCLG Planning Group. Although no complete templates were found, some elements of these models are reflected in the process adopted by the Planning Group for nominating and evaluating candidates for the DCLG. The models for consumer involvement that were reviewed included:

- U.S. Army Medical Research, Breast Cancer Research Programs
- U.S. Food and Drug Administration, Reinventing the Regulation of Cancer Drugs
- National Cancer Institute, Southwest Oncology Group

A Federal Register notice and an OLA mailing to national cancer advocacy and voluntary organizations outlined the proposed purpose of the DCLG, described the role of the Planning Group, identified the time and location of the Planning Group's March meeting, and invited input from "advocacy or voluntary organizations related to cancer" that might be useful for accomplishing the meeting's objectives. Input received in response was provided to the Planning Group. All these efforts not only contributed to the Planning Group's decision-making, but helped to promote awareness of the plans for the DCLG and the call for nominations.

On March 13 14, 1997, the DCLG Planning Group met for a day and a half to accomplish the following tasks:

- Identify a screening process for selecting a pool of candidates who met or exceeded basic eligibility requirements for DCLG membership
- Identify criteria (qualifications) for use in assessing individual nominees for the DCLG
- Identify a scoring and review process that would involve using the criteria to evaluate the nominees for the DCLG
- Identify categories that would define the characteristics of the DCLG as a whole
- Identify a nomination process that would encourage an adequate pool of candidates with multicultural diversity nominated from the cancer advocacy community who were likely to be qualified and motivated to serve on the DCLG

The process for accomplishing all of these tasks in a compressed time period relied heavily on the use of accumulated background materials, premeeting teleconferences and assignments completed by the Planning Group members, and an expert facilitator with an in-depth knowledge of NCI and familiarity with the issues and concerns of the cancer advocacy community. The NCI Director presented his vision of the DCLG to the Planning Group. He demonstrated the importance NCI attaches to establishing better two-way communication between the scientific community at NCI and the consumer advocate community, and the value NCI places on the views of that community.

Results

Results of the Planning Group's work are summarized below, and their implementation discussed in

Part Three of this report.

Eligibility Requirements for Individual Members. Eligibility requirements were minimum requirements for participation in the DCLG. A member of the DCLG had to:

- **Be involved in the cancer experience: a cancer survivor, a person affected by the suffering and consequences of cancer (i.e., a parent or family member), or a professional/volunteer who works with survivors or those affected**
- **Represent a constituency with which s/he communicates regularly on cancer issues and be able to serve as a conduit for information both *to and from* his/her constituency**

Another essential membership requirement was a commitment to participating in the DCLG; however, unlike the other eligibility requirements, this one was not to be used as a basis for initial screening of nominees, but assessed as part of the more in-depth evaluation of candidates.

The Planning Group decided not to establish any minimum requirements for education or facility with the English language, and directed that questions relating to education, language, or employment history not be included on the application. Such questions were judged to have no direct bearing on a candidate's qualifications to serve on the DCLG and might well discourage nominations of candidates who could bring other important qualities to the DCLG. Candidates would, however, be evaluated on their ability to communicate effectively.

Criteria for Evaluating Individual Candidates. Nominees meeting the eligibility requirements related to experience with cancer and representation of a constituency were to be further assessed based on the following criteria:

- Cancer advocacy experience
- Ability to communicate effectively
- Ability to represent broad issues, think "globally"
- Ability to contribute to an effective group process
- Leadership ability

Characteristics of the DCLG as a Whole. The Planning Group felt strongly that not only must individual members meet the criteria outlined above, but the DCLG as a group should reflect the breadth and the diversity of the cancer advocacy community. The following group characteristics were recommended:

- Multicultural diversity
- Representation of a broad mix of cancer sites
- Representation of the medically underserved
- Men and women
- A range of organizations (local/regional and national)
- Age diversity
- Geographic diversity (including rural/urban mix)

The Planning Group also urged NCI to make every effort to ensure that racial/ethnic diversity was reflected in the DCLG, striving to identify qualified candidates representative of special populations.

Screening, Scoring and Review Process.

- **Screening.** All nominees would be screened to determine if they met the eligibility

requirements for experience with cancer and representation of a constituency. Those who did not meet these requirements were not eligible to serve as members of the DCLG.

- **Scoring.** A numeric scale was to be used to score all eligible nominees according to the established criteria, based on information provided in the nomination package. The content of this nomination package is outlined later in this report.
- **Assessing the nominee pool.** All eligible candidates were to be evaluated based on their scores.
- **Telephone follow-up with candidates.** As a supplement to the written nomination, follow-up conversations with some highly qualified candidates would be held to elaborate on information provided in the formal nomination and clarify the candidates' understanding of the role of the DCLG.
- **Preparing the final slate of candidates.** After the final evaluation of the candidates' qualifications, a list of candidates would then be presented to the Director, NCI, who would select the 15 DCLG members.

Nomination Process

Sources of nominations. Nominations could come from organizations or individuals. Self-nominations were to be accepted.

- **Content of the nomination package.** The nomination package should include information provided both by the candidate and by others who could attest to the candidate's qualifications to serve on the DCLG. Specifically, this information should document 1) the extent to which the candidate met the eligibility requirements and the criteria established by the Planning Group, and 2) characteristics relevant to achieving the broad mix of individuals sought for the DCLG as a whole.
- **Call for nominations.** To encourage nominations from a diverse community of cancer consumer advocates, a broad range of groups would receive the announcement of the DCLG and the call for nominations, including grassroots, regional, and national organizations. A variety of materials that these groups could use to disseminate the call for nominations to their members should be prepared and distributed.
- **Time frame for implementing the nomination process.** The call for nominations should last for at least three months. The deadline for receipt of completed nominations was set for September 15, 1997.

Issues and Challenges

Good preparation was key to the successful Planning Group meeting. The development of a comprehensive blueprint required the group to address a number of complex issues. A few of the key issues which were discussed follow:

Defining "The Cancer Experience." One of the eligibility requirements on which virtually all Planning Group members agreed was the requirement that DCLG members be involved in "the cancer experience." How to define this term for purposes of assessing candidates for the DCLG was one of the first issues addressed at the Planning Group meeting. A number of different groups were identified who might qualify as having the cancer experience:

- Personal survivors of cancer
- Parents of children with cancer
- Family members of cancer patients
- Health professionals with a strong record of cancer advocacy

- Consumers who were cancer advocates but not personal survivors

In the final analysis, the Planning Group was concerned that the use of a narrow, highly exclusionary definition might arbitrarily exclude potentially strong candidates. They chose instead the following broad definition of someone who was involved in the cancer experience:

A cancer survivor, a person affected by the suffering and consequences of cancer, or a professional/volunteer who works with survivors or those affected.

Defining a "Constituency." In addition to the requirement that candidates be involved in the cancer experience, the Planning Group agreed that candidates must be identified with a constituency in order to be eligible for the DCLG. How to define that constituency was not immediately clear. Did it mean that a candidate must be an officer in an advocacy organization? Did candidates have to have *any* affiliation with an advocacy organization? While it appeared likely that the majority of candidates would have formal links to such an organization, the Planning Group recognized that exceptions were possible and, once again, chose to be inclusive in their definition: a candidate was required to represent a constituency (formally or informally) and had to be able to demonstrate that he or she communicated regularly with that constituency on cancer issues and was able to serve as a conduit for information both *to and from* that constituency.

Achieving Diversity. Perhaps the most challenging issue that confronted the Planning Group was how to achieve appropriate diversity within the DCLG. They wanted to ensure multicultural representation among the 15 DCLG members, along with other important characteristics; e.g., gender and age diversity, representation of a range of cancer sites, and types of organizations. Alternative approaches to achieving this diversity were discussed at length. The Planning Group would have preferred to stipulate that at least one-third of DCLG members belong to a racial/ethnic minority. However, NCI could not implement this because federal law precludes selection of individuals based on race. The Planning Group urged NCI to make efforts to ensure that racial/ethnic diversity would be reflected in the DCLG. They also developed a strategy for promoting the call for nominations that would reach diverse groups, prompting nominations from African Americans, Asian Americans/Pacific Islanders, Hispanics, and Native Americans as well as non-Hispanic whites.

The Blueprint. With two exceptions, the recommendations of the Planning Group became the blueprint for conducting further steps in the development of the DCLG. One of those exceptions related to the role of the Planning Group in the selection process. Their charge had been to help define the initial role of the DCLG and to define the criteria for individual members, the characteristics of the group as a whole, and the screening, scoring, and nominations processes. However, they were also interested in going beyond their original charge and participating in some review and assessment of individual candidates and in sending forward a list to the NCI Director for selection. While NCI recognized that the Planning Group had much to contribute to the assessment process, ethical concerns about perception of conflict of interest and problems of fairness of process precluded their involvement in the selection process. The issue of concern was public perception of bias when an individual from one organization is asked to evaluate the work or attributes of either members of his/her own organization or an individual from another organization competing for a limited number of appointments.

In another area, federal law precluded mandating multicultural diversity on the DCLG in the specific manner initially proposed by the Planning Group. Nonetheless, NCI was committed to seeking and finding the best qualified candidates from all population groups, including minorities and the medically underserved. A promotion plan for the DCLG nominations, developed by OLA in

conjunction with the Planning Group, successfully reached a large number of diverse and highly qualified candidates. Results of the Planning Group meeting provided the basis for a fair and objective assessment of all candidates and resulted in a DCLG with all the strengths and dimensions of diversity that the Planning Group hoped to achieve.

Planning Group members received input and were involved throughout the implementation of their blueprint. For example, they reviewed the proposed nomination package and guidelines for scoring candidates before they were finalized.

Identifying Issues for the DCLG. In addition to designing the blueprint for the DCLG, the Planning Group identified a number of issues that they wanted to pass on to the DCLG for possible consideration:

- Accessing quality cancer information
- Promoting behavioral approaches to cancer control
- Increasing participation in clinical trials
- Assessing NCI consumer publications
- Accessing cancer treatment under managed care

The Planning Group also suggested that NCI call upon the expertise of all the qualified DCLG candidates for various NCI activities, whether or not they were selected for the DCLG. NCI concurred and developed a mechanism to do this.

FROM BLUEPRINT TO REALITY

The NCI Office of Liaison Activities implemented the process established by the Planning Group for identifying and assessing candidates to serve on the DCLG. The time frame from the conclusion of the Planning Group meeting to the preparation of a final list of candidates to be forwarded to the NCI Director was approximately 7 months.

Promoting Nominations

The major objectives of OLA efforts to promote nominations were 1) to attract candidates who were well qualified to serve on the DCLG, as measured by the criteria established by the Planning Group, and 2) to obtain diversity and balance within the Group. Promotional efforts needed to reach a broad range of groups, including many that might not be reached through NCI's most commonly used communications channels. OLA, with the Planning Group, developed a promotion plan to call for nominations during a period which lasted approximately 4½ months—from May 1997 to September 15, 1997.

Mailings to Organizations and Individuals. A number of mailing lists were identified that targeted key audiences for the promotion, including minority and multicultural groups. A package of promotional materials was developed, including articles of varying length for placement in organization newsletters and a form for requesting the nomination package. A number of organizations placed announcements about the call for nominations in their newsletters. About 1,900 promotional packages were mailed, and additional lists were prepared for use in the event of a poor response to the first wave of mailings and other promotional efforts. These were not needed. While large-scale media campaigns were not employed, a few media-related strategies were used.

Electronic Promotion. Announcements about the formation of the DCLG and the call for nominations were placed at three different NCI websites. Both a description of the DCLG and the

request form for the nomination package were available from these sites.

Targeted Media Promotion. Information appeared in the *Journal of the National Cancer Institute* and "The Cancer Letter," a weekly newsletter with broad circulation in the cancer community.

Presentations and/or Exhibits at Meetings. A number of meetings were identified where information about the DCLG call for nominations was distributed in the spring of 1997, including the 6th Biennial Symposium on Minorities, the Medically Underserved & Cancer, the Oncology Nursing Society, and the National Breast Cancer Coalition. A brochure was created specifically for use at the Biennial Symposium. Fact sheets were distributed at the other meetings.

Other Promotional Strategies. Notices were circulated internally at NCI via electronic mail and to a variety of NCI committees and working groups. The NCI's Cancer Information Service (CIS), with a national network of offices, was asked to spread the message to its local and regional partners. A notice also appeared in the Federal Register. The call for nominations resulted in more than 900 requests for the nomination package, and about 100 of the requests came through the NCI websites.

The Nomination Process

The nomination package consisted of several items designed to collect the information which the Planning Group specified should be obtained on each candidate.

- A **letter** written by the candidate that summarized cancer advocacy experience and accomplishments, and other relevant experiences that s/he considered important to DCLG membership.
- A **nomination form** that provided data regarding the characteristics of the candidate, including name, address, age, sex, and ethnic group. This information is subject to the Privacy Act. Since the time frame for conducting the nomination process did not provide sufficient time to get approval from the Office of Management and Budget for a new form, the existing NIH consultant form was adapted. Sections of this form requesting information not required for DCLG nomination were crossed out.
- An **Agreement to Keep Information in NCI Database** that indicated whether candidates consented to NCI's retaining information in their nomination package for use in demographic analysis and reports (excluding personal identifiers) and/or selection for service on NCI groups or advisory committees.
- Two **letters of recommendation.**

NCI recorded data on all requests for the nomination package, including information reflecting the characteristics of diversity being sought for the DCLG. In this way, diffusion of the promotion to key target audiences was monitored. About 6 weeks before the deadline for submitting nominations, all those who had requested nomination packages but had not yet submitted them were sent a reminder.

Screening and Scoring of the Nominees

Each candidate was assessed according to the eligibility requirements and criteria established by the Planning Group. This assessment process was designed in conjunction with the Planning Group and conducted by contractors to OLA along with OLA staff.

Consistent with the recommendations of the Planning Group, each nomination was screened and scored by two trained contractor staff. A quality control evaluator monitored the screening and scoring process, answered questions, and resolved problems. As a further quality control check, OLA

staff reviewed the nomination packages and scoring sheets for all candidates.

Screening (Assessing Candidate Eligibility). Only nominees meeting the following eligibility requirements were further assessed as candidates for the DCLG. A member of the DCLG was required to:

- Be involved in the cancer experience: a cancer survivor, a person affected by the suffering and consequences of cancer (e.g., a parent or family member), or a professional/volunteer who works with survivors or those affected.
- Represent a constituency (formally or informally) with which s/he communicates regularly on cancer issues, and be able to serve as a conduit for information both *to and from* his/her constituency.

Since the Planning Group had concluded that DCLG candidates did not have to formally represent an identifiable cancer advocacy organization, it became incumbent upon such candidates to define the constituency they represented and clarify their role with that group. Scorers assessed whether these eligibility requirements were satisfied. If one or both scorers had questions about a candidate's eligibility, OLA staff determined eligibility status.

Scoring (Applying the Criteria to Eligible Candidates). Nominees meeting the eligibility requirements were then scored on the five criteria established by the Planning Group, using the numerical scoring system also established by the Planning Group. As in the screening process, the nominee was reviewed and scored by two trained staff. The five criteria were measured based on the following definitions:

- **Cancer advocacy experience.** While all candidates meeting the eligibility requirements had experience in cancer advocacy, this criterion spoke to the quality of that experience. Its assessment involved an examination of the candidate's track record of specific accomplishments. At the direction of the Planning Group, it was assigned greater weight than the other four criteria.
- **Ability to communicate effectively.** This criterion encompassed such qualities as the ability to communicate ideas clearly, comprehend and articulate the issues likely to be addressed by the DCLG, be a good listener, and interpret information and communicate it back and forth between the DCLG and his or her constituency.
- **Ability to represent broad issues.** Members of the DCLG had to be able to think "globally," to step back from only their personal experience or association with a specific disease and to consider issues from the perspective of the broader cancer advocacy/consumer community.
- **Ability to contribute to an effective group process.** Effective functioning of the DCLG would depend upon the ability of group members to be cooperative, constructive, flexible, and innovative.
- **Leadership ability.** While members of the DCLG were not required to hold a formal leadership position within a cancer advocacy organization, they had to have leadership skills. They had to be credible and respected within their constituency, able to command attention and amplify that constituency's voice, and willing and able to take initiative.

Selecting the Final Candidates

After the deadline of September 15, 1997, a total of 136 candidates for the DCLG were screened and scored using the eligibility requirements, preestablished criteria, and the policies and procedures described above. Follow-up telephone conversations with highly qualified candidates were conducted by both an OLA staff member and a contractor to supplement the information obtained from the

written nomination. OLA staff reviewed the qualifications and attributes of highly qualified candidates from which the Director of NCI selected the final 15 DCLG members. Selection was made in early November.

As the Planning Group suggested, information will be retained on all qualified candidates who expressed an interest and willingness to be considered for future roles with NCI whether or not they were selected for the initial DCLG. This roster of qualified individuals will be an important resource for calling upon consumer advocates to provide advice and input to the Institute in a variety of activities now and in the future.

THE FACE OF THE DIRECTOR'S CONSUMER LIAISON GROUP

The 15 members of the first NCI Director's Consumer Liaison Group, announced November 6, 1997, reflect the face of cancer patients and advocates across America. They are intelligent, thoughtful, highly motivated, and dedicated to their constituencies- impressive evidence that the process designed to select them worked extraordinarily well. They will bring the concerns, issues, and ideas of the cancer advocacy community to the NCI and serve as an ongoing conduit of information from NCI to their constituents and back again to NCI.

The majority of the newly appointed DCLG members are cancer survivors, but family members of cancer patients and health professionals who are involved in cancer advocacy are also represented. They have had experience with many different forms of cancer, and represent broad constituencies, including the National Coalition for Cancer Survivorship and the American Cancer Society, as well as organizations that focus on specific cancers. The cancer experience of the group includes prostate, breast, kidney, ovarian, cervical, lung, bladder, and brain cancer, Hodgkin's disease, leukemia, sarcoma, and multiple myeloma.

There is wide multicultural diversity among DCLG members, including African American, Asian American/Pacific Islanders, Hispanic, Native American, and non-Hispanic white. Both the old and the young, men and women, and all geographic areas of the country-including rural and urban-are represented. Members also bring to the table the issues of the medically underserved from Eastern metropolitan areas and the South, across the Midwest to the rural Western states.

Members of the First NCI Director's Consumer Liaison Group with links to Profiles of the DCLG Members:

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.	

Key Issues of Concern

As part of the nomination process, the DCLG candidates were asked what they considered the three most important issues facing cancer patients today. The issues mentioned most frequently were the

following:

- Access to reliable, understandable cancer information
- Access to effective, quality cancer treatment (including clinical trials)
- Increased rehabilitation, psycho social support, and other survivor issues
- Increased involvement of the advocacy community in setting research priorities and building an understanding of what advocates can contribute in the scientific arena
- Improved technology for cancer prevention, detection, and screening, and education of the public about healthy behaviors in these areas that would lead to economic and health benefits for all
- Concerns about legal issues such as patient privacy and confidentiality, implications of genetic testing, job discrimination, and loss of insurance
- Adequate supportive services for children with cancer

These issues, as well as those identified earlier by the Planning Group, are guiding the development of the agenda for the first DCLG meeting in December 1997, and are expected to be the focus of much of the DCLG's efforts in the months and years to come.

The Importance of the DCLG

DCLG nominees were also asked why they thought the DCLG was important and why they wanted to serve on this consumer advocacy group. Their responses to both questions were closely linked:

- The DCLG provides a new opportunity for NCI to benefit from the voice of consumer advocates in an ongoing and formal way
- Members of the DCLG will be able to clarify misperceptions about the scope of NCI's activities and communicate an accurate picture of those activities to their constituencies
- The DCLG will encourage the cancer advocacy community to work together and with the scientific community as a unified group
- It will make consumer advocates a decision-making partner in policy development, allowing them to influence the direction of cancer research and help set research priorities
- By increasing NCI's understanding of consumer issues and needs, the DCLG may impact on the quality of care that cancer patients and survivors receive, and improve the quality of life for those affected by cancer
- The DCLG empowers advocates to be more effective, two-way conduits of important cancer information
- The DCLG will bring to NCI the special skills and expertise of consumer advocates on issues such as representation of the medically underserved, third-party insurance coverage, informational materials for cancer patients and their families, and the needs of special populations
- It will unify the work of advocates from different constituencies, rejuvenating and motivating them to better serve their communities, bringing them valuable information and new hope from NCI

IN THE WORDS OF THE DCLG NOMINEES

The following examples from DCLG nominees express their interest in serving on the DCLG and its importance to them.

“Part of the social contract that we must have in order to have a strong and healthy community is to assure that public policy is created in an atmosphere of collaboration with those people whose lives will be most affected by those policies.”

“All people with cancer—those who are receiving therapy, are on maintenance therapy, are in remission, are experiencing recurrences or second malignancies, are considered cured, or are dying of their disease—no matter what their stage of survival, need representation to voice their issues, concerns, and needs.”

“My ultimate goal is to give my constituency hope.”

“I would like to serve in hope of making life better for those who follow; until such time as there is a cure, I truly believe I have a responsibility to make the road easier for others to travel.”

“The NCI has a global impact on the quality of patient care and the direction of research efforts into all types of cancer. The opportunity to play even a small part in that work is very exciting and certainly worth the investment of what I’ve come to realize is our most precious commodity—time.”