NATIONAL CANCER INSTITUTE
DIRECTOR′S CONSUMER LIAISON GROUP
DoubleTree Hotel, Rockville, MD
Summary of Meeting
October 15-17, 2001

The meeting of the NCI Director=s Consumer Liaison Group (DCLG) was convened at 8:10 a.m., October 15, 2001, at the DoubleTree Hotel, Rockville, Maryland.

DCLG Members

Ms. Barbara K. LeStage, Chair
Ms. Vernal Branch
Ms. Susan Butler
Ms. Kathy Giusti
Mr. Michael Katz
Ms. Paula Kim
Ms. Ruth Lin
Ms. Gena Love
Mr. Christopher Pablo
Ms. Karen Packer
Mr. Henry Porterfield
Ms. Nyrvah Richard
Mr. Doug Ulman
Dr. Brad Zebrack

Speakers

Dr. Alan Rabson, Acting Director, NCI
Ms. Tracy Clagett, Advocacy Program Manager, Liaison Activities Branch, OC, NCI
Ms. Elisabeth Handley, Director, Outreach and Partnerships, Office of Communications, NCI
Ms. Mary McCabe, Acting Director, Office of Communications, NCI
Ms. Margo Michaels, Office of Education and Special Initiatives, NCI
Ms. Cynthia Morgan, Office of Ethics, NCI
Mr. Frank Jackson, Center to Reduce Cancer Health Disparities
Ms. Susan Scherr, National Coalition for Cancer Survivorship
Dr. Joanne Lynn, Director, RAND Center to Improve Care of the Dying
Ms. Sarah Singer, Patient Care Manager, Leukemia and Lymphoma Society

Other NCI Staff

Ms. Jill Bartholomew, Deputy Director, Office of Communications, NCI

NCI Liaison Activities Staff

Ms. Elaine Lee, Executive Secretary, NCI, Director’s Consumer Liaison Group
Dr. Yvonne Andejeski
Ms. Tracy Clagett
Ms. Nina Ghanem
Ms. Brooke Hamilton
Ms. Keisha Martin
Ms. Julie Tu
Dr. Marianne H. Alciati, Consultant, Management Solutions for Health, Inc.

CALL TO ORDER AND OPENING REMARKS

Ms. Barbara LeStage called the meeting to order and determined that a quorum was present. She reviewed the rules governing confidentiality and conflict of interest. She asked DCLG members and other participants to introduce themselves and describe their experiences with cancer and advocacy.

REPORT OF THE DIRECTOR

Dr. Alan Rabson, Acting Director, NCI, reported that the Department of Health and Human Services (HHS) was operating on a war footing because of the threat of bioterrorism. NIH, like CDC and FDA, has been mobilized. Ironically, he began his own career in 1952 as a member of the Epidemic Intelligence Service at CDC, planning defenses against germ warfare. He spent 46 years at NIH under eight directors, and was appointed Deputy Director to Dr. Klausner.

Dr. Rabson recognized the contributions of Mr. Michael Katz who served as the first chair of the DCLG after it was chartered. Between 1998 and the present, Mr. Katz led the DCLG through several key activities including development of a genetics primer "*Understanding Genetic Research and Population- Based Studies*," a review of NCI's revised informed consent document and review of selected NCI communication programs.

Dr. Rabson said that he expects the DCLG and NCI to continue to carry out their missions despite the departure of Dr. Klausner. It is uncertain when a new director will be appointed and who might be named since NCI's Director is a presidential appointment. Names of a number of highly qualified individuals have been submitted. He expects that a new director will be appointed soon. He reported that several other senior managers have retired from NCI.

The FY 2002 budget is going forward steadily. The House supported the President=s budget but the Senate (led by Senators Specter and Harkin) increased the amount of money. At present NIH is operating under a continuing resolution.

In response to questions, Dr. Rabson said that Dr. Klausner is leaving to become president of the Case Institute of Science and Technology, funded by the founder of America Online. Dr. Klausner retains his laboratory at NCI, however, and is a Aspecial volunteer@ available for consultation and special assignments. Ms. LeStage added that Dr. Klausner had invited her to address the Executive Committee on DCLG=s role and ideas. He said that although Dr. Harold Freeman=s appointment as Director of the Center for Reducing Cancer Health Disparities (CRCHD) has been held up, he is currently operating on a part-time basis with a skeleton staff.

ETHICS

Ms. Cynthia Morgan, Office of Ethics, NCI, briefed DCLG members on the ethics regulations that apply to them as Special Government Employees (SGEs). These include financial disclosures, prohibitions against bribes and gratuities, and conflict of interest rules (for example, lobbying HHS on matters before, or during, DCLG activities or reviewing a grant proposal from their own university). Members are not allowed to fundraise during the period of their employment (during DCLG meetings). In answer to questions, Ms. Morgan suggested that members consult the chairperson or executive secretary when there might be an appearance of conflict. Paid speaking engagements are allowed if not appearing as a member of DCLG or speaking for DCLG. Ms. LeStage added that it is only necessary to reveal stock holdings in biotechnology, medical, and pharmaceutical companies.

OUTREACH TO MINORITY AND UNDERSERVED POPULATIONS

Ms. LeStage explained that Dr. Zebrack had expressed concern about the lack of a Latino member of the DCLG. This led to a broader discussion of whether DCLG is sufficiently diverse in its membership, contacts, and activities. She asked members to review the current list of organizations that get mailings for DCLG and CARRA and urged them to add groups and individuals that would broaden the circle of communication. She said she had cross-referenced the DCLG list with the American Cancer Society=s list and identified a number of new groups. Similarly, members should suggest minority and ethnic media outlets that should receive NCI mailings and releases.

In response to questions, Ms. Tracy Clagett said that Privacy Act restrictions limit the disclosure of information about individual contacts from the organizations on the list. Ms. Susan Butler said that some of this information could be found online and that national organizations would pass the information along to local affiliates. Ms. Nina Ghanem said that LA currently sends hard copies to organizations on its mailing list, but she hopes to use to e-mail and web communications in the future in order to achieve broader distribution with the same budget. Recipients would be given the choice of receiving regular messages from the LA listserve.

Dr. Brad Zebrack pointed out that the goal was not just to build a database, but to establish relationships with all of these groups. Ms. Lis Handley said that NCI=s Office of Education and Special Initiatives and Center for Reducing Cancer Health Disparities are approaching these groups systematically to see if they are interested in such a system. Ms. LeStage asked if she should call specific organizations or attend their annual meetings to talk about DCLG and CARRA. She asked the Advocacy Involvement Working Group to report back on which organizations should be contacted and prepare a draft letter of general introduction from DCLG.

Mr. Frank Jackson, Center for Reducing Cancer Health Disparities, NCI, reported CRCHD is still awaiting the confirmation of Dr. Freeman, and a hiring freeze has prevented the hiring of key staff members, but the current staff was making steady progress. The Special Populations

Networks (SPNs) , created under the old Office of Special Populations Research, has awarded 17 grants to Investigators to establish community partnerships, including those with Asians, Samoans, Hawaiians, Native Americans, Latinos, African Americans, and rural populations. Mr. Jackson added that CRCHD had received valuable advice from DCLG members in the past and hopes to involve DCLG or CARRA in grant reviews, including one in December or January. He said that he would send an e-mail to SPN grantees asking for the names of community organizations. Ms. LeStage asked if LA was using the SPN grantee list to inform and involve advocates from these populations. Ms. Clagett said that SPN is partially represented in the LA database and has been used in CARRA mailings.

UPDATE ON CANCER COMMUNICATIONS EXTRAORDINARY OPPORTUNITY

Ms. Mary McCabe, Acting Director for the Office of Communications, NCI, explained that she was the Aco-champion,@ with Barbara Rimer, for "*The Nations Investment in Cancer Research. A Budget Proposal for Fiscal Year 2002*" Extraordinary Opportunity in Communication. She reviewed the stepwise design, implementation and evaluation of the initiative, which consists of communications tools (e.g., low-literacy, non-English), communications research (evidence-based strategies), and partnerships with public and private groups to broaden impact. This approach stresses a menu of communications choices to facilitate the dissemination of products and findings. Specific components (the required plan for this Extraordinary Opportunity) include the following:

- Data collection — Health Information National Trends Survey (HINTS) and HLID, survey designed to find out how people get information about cancer and health and who uses the NCI website
- Access and usability — several "digital divide" projects, including a partnership with Head Start, and continuing efforts to create a set of portals at *http://cancer.gov*
- Accelerating the pace of research C centers of excellence in communications research and the Community Clinical Oncology Program (CCOP)
- Menu of communications choices C clinical trials series, News Center Web-site, instant messaging, and low-literacy programs
- Improving dissemination C supplements to existing grants and new programs at the Transdisciplinary Tobacco Use Research Center.

In addition, NCI publishes *The Nealon Report,* a newsletter for advocates and patients, and sponsors the Eleanor Nealon Extraordinary Communicators Lecture Series. NBC reporter Katie Couric delivered the 2001 lecture.

In response to questions, Ms. McCabe said that there will be an ongoing need for DCLG=s help and feedback as these initiatives evolve, particularly the new Web portals and a planned series on survivorship. The DCLG members stated that they were interested in sponsoring a summit on the digital divide and how the NCI Web-site is used. Ms. McCabe said that this would be a good idea and might be convened after pilot projects are completed, as an input to the strategic plan.

WORKING GROUP PLANNING SESSIONS (1)

DCLG members broke out into two working groups, (1) Clinical Trials and (2) Cancer Survivorship. These groups were asked to generate an agenda of activities for the coming year, along with some idea of the budget that would be required to carry them out. LA staff assisted the working groups in their deliberations, and each group had a science writer to record the ideas and action items that emerged. Team leaders later reported on these plans to the full DCLG membership.

The meeting recessed at 4:30 p.m.

October 16, 2001

Ms. LeStage called the meeting to order at 8:00 a.m.

CONSUMER ADVOCATES IN RESEARCH AND RELATED ACTIVITIES (CARRA) UPDATE

Ms. Clagett introduced Ms. Julie Tu, a Technology Transfer Fellow in LA who assists her in CARRA activities. Ms. Clagett reported that NCI leadership continues to support the involvement of advocates in all clinical and population-based activities. LA=s role is to recruit new members to CARRA, match them with NCI activities, and identify new opportunities for advocate involvement and support NCI staff working with advocates. LA works with NCI staff to ensure that the role of CARRA participants is clearly defined, and it provides advocates with the orientation and background they need to serve meaningfully.

Ms. Clagett described the diversity achieved in the current group of CARRA members which consists of 147 members and 71 others that were Agrandfathered@ for a single three-year term. The latter are advocates who are already involved in NCI activities, and they will serve as mentors for new members. CARRA members represent 24 different cancers, including pediatric tumors, and come from 38 states and 2 territories. All major ethnic groups are represented, with approximately 30 percent minorities and 35 percent men. Members are allowed to select their own preferred role (communications or science) and to designate one or more areas of special interest. LA has prepared an online orientation package and has made mentors and staff available to answer specific questions. Dr. Zebrack is working with LA to develop an evaluation process for CARRA, which will be descriptive as well as focus on both process and outcome. Mr. Hank Porterfield has volunteered to be the DCLG liaison to CARRA.

In answer to questions, Ms. Clagett said that most candidates chose communications as their favored role, but many designated science as a second choice. It was clear from applications that many of them have practical experience with science. LA has received good feedback on advocacy participation in Progress Review Groups (PRGs) and review groups. Ms. Kathy Giusti suggested that special training might be needed for some science assignments, such as site visits and peer review, and that mentoring in these roles would be particularly important. Ms. Clagett invited DCLG members to review the CARRA training site and give feedback to LA. Ms. LeStage said that NCI conceives of DCLG as a "board of directors" for CARRA and will provide a monthly update on CARRA activities. It will be vital for DCLG members to respond to queries on their listserve.

Ms. Handley suggested that special training would help to build confidence, particularly with regard to terminology and procedures. Ms. Love suggested that there should be standards for CARRA participants, such as writing a report and Anot just sitting there.@ Ms. Giusti suggested that it might often be better for an advocate in peer review to start as a reader, and later become the second reader. Dr. Zebrack suggested that LA develop a Acheat sheet@ or *checklist* for CARRA reviewers, something to be included in their review packet. Ms. Clagett said that LA is working with NCI=s legal and ethics offices to sort out the confidentiality issues (many of them arising from participation in review groups) that must be resolved if CARRA members are to be able to communicate with one another or be included in a listserve. At present she can identify the organizations they primarily represent, but not individual names. Ms. Clagett is exploring options for making a list available. The CARRA members will serve a three-year term but may not be assigned a task immediately. NCI wants to establish open communication with CARRA members and the communities they represent.

WORKING GROUP PLANNING SESSIONS (2)

Members participated in two working groups, Advocacy Involvement or Health Disparities and Quality of Cancer Care. Team leaders reported to the full Committee.

DCLG BUSINESS

Ms. Lee announced that copies of the latest *Nealon Report* would be available soon. She apologized for the travel problems that some members had encountered prior to this meeting. Members should follow the instructions provided for each meeting since policies and procedures frequently change.

Ms. Lee reminded members that, when they are acting as members of DCLG, they should do so within the guidelines in the DCLG charter. For example, when an NCI component asks them to review a document or participate in a focus group, they should notify LA and Ms. LeStage before doing so. When there are press inquiries, DCLG will respond as a group through Ms. LeStage as chair. This will ensure that the DCLG speaks with a unified voice and is a useful way to identify differences of opinion among its members.

Ms. Lee also introduced Ms. Jill Bartholomew, the newly appointed Deputy Director for Communications, NCI. Ms. Bartholomew said that she came to NCI from the White House Drug Policy Office, and that she has a background in social marketing.

WORKING GROUP REPORTS

A representative of each working group presented a report to the DCLG.

Clinical Trials. Ms. Giusti reported that the Clinical Trials Working Group set a goal of *increasing accrual to cancer clinical trials.* The two greatest challenges to achieving this goal are the need to make trials widely available, and the need to increase consumer demand for trials. The working group to address these issues through two sets of activities:

1. Foster collaborations between NCI and outside coalitions to increase physician participation in clinical trials.
    - X Convene diagnostic workshops or interviews with the Clinical Trials Support Unit (CTSU), the Clinical Trials Cooperative Groups (CTCGs), and the National Coalition for Cancer Clinical Trials (NCCT)
    - X Develop a written report from the working group to DCLG that synthesizes the findings of these interviews and previous studies of problems in clinical trials
    - X Invite outside groups to comment on the draft report in a focus session during the DCLG meeting in April 2002
    - X Work with NCI, and the coalitions to develop a plan for implementing the resulting priorities

2. Build public awareness and patient knowledge to stimulate demand for cancer clinical trials by:
    - X Working with Ms. Margo Michaels, Office of Education and Special Initiatives (OESI) to maximize the effectiveness of clinical trials education materials (two or three members will attend CIS training sessions and report to the DCLG, and helping to disseminate these materials in their own organizations and other groups)
    - X Working with NCI and other advocacy groups to include clinical trials information in patient brochures
    - X Working with NCI, to assess the status of public service announcements about clinical trials
    - X Working with NCI to standardize the responses to patients seeking information about intramural clinical trials at NCI

Mr. Katz said that process issues are also involved, and these might be more difficult. Ms. Handley said that it was a good idea to ask the actual players where the needs are and to synthesize a common plan for addressing them. Ms. Kim said that the PALS project, a PanCan joint venture, is testing the use of a liaison or expediter to assist patients and make some of the initial calls to get them into clinical trials. Ms. Vernal Branch said that Dr. Harold Freeman used a similar mechanism in Harlem, calling it a Apatient navigator.@ Ms. Gena Love noted that it was not helpful to inform the patient of a trial if there was no follow-up, or if Medicaid or insurance wouldn't=t pay for it; she hopes the plan will also address the issue of reimbursement in the April meeting. Ms. Kim praised this double strategy as a way of developing the infrastructure for participation while simultaneously building consumer demand.

Survivorship. Ms. Kim referred members to the white paper on survivorship that was circulated at the last meeting. She said that the working group=s discussions had focused on four different phases or Atrajectories@ of survivorship, each with its own needs and issues: (1) immediate post diagnosis; (2) chronic phase; (3) post-treatment phase; and (4) end of life. Further research will be needed to refine and standardize these definitions. While a variety of groups provide services for the newly diagnosed, very little research or attention has been given to the other three areas. For this reason, the working group believes that DCLG should submit a proposal to NCI for an Extraordinary Opportunity in Cancer Survivorship, for The Office of Cancer Survivorship Bypass Budget, has submitted its own proposal, and the DCLG=s support can help to ensure favorable consideration.

The working group noted that there is very little research on long-term survivors, making this an area of opportunity for new research and programs. Similarly, there has been a lack of behavioral research on cancer survivorship, and the DCLG encourages NCI to address this lack by involving a larger pool of behavioral scientists in cancer research. The group, through the DCLG, also challenged NCI to provide disease-specific information and guidance on the needs of cancer survivors, such as mid- and long-term follow-up, continuity of care, and information for patients. For example, the "Facing Forward@ series lack a disease-specific focus. In the future, new materials should be prepared to address these. Ms. Michaels presented information on new materials being developed by OESI and OCS. The group also provided feedback to Ms. Michaels on the new Facing Forward series. The working group, through the DCLG, also suggested that NCI should convene a consensus conference and/or develop a best-practice statement on survivorship. Ms. Kim said that there is a role for NCI in providing survivorship training or internships for both advocates and behavioral scientists.

Ms. Love reported that the National Cancer Policy Board (established by the Institute of Medicine [IOM] in 1997 to address quality of care in cancer) held a meeting on survivorship the second week in October, and is eager to collaborate with DCLG on this topic. Mr. Ulman said that a lack of funding was constraining that group=s deliberations on definitions, measures, and standards of quality care. The DCLG agreed that the committee should submit a proposal for an Extraordinary Opportunity in Cancer Survivorship. Dr. Zebrack said that he would draft a proposal based on the language in the proposal in cancer communications. Ms. Clagett said that she would help to coordinate the effort.

Health Disparities and Quality of Care. Ms. Love reported that the working group suggested that there were more opportunities for advocate involvement in these areas than could be covered by the members of the working group, or indeed by all of DCLG. They therefore decided to identify a contact person for each opportunity and explore the possibility of using a CARRA member. Ms. Love reported that she had attended a Quality of Cancer Care Committee (QC3) meeting and that Dr. Robert Hiatt, who is leading NCI's efforts, is open to advocate participation in that activity.

In the area of health disparities, the working group suggested that cervical cancer in rural areas should be a particular focus. However, they understand that the Center for Reducing Cancer Health Disparities (CRCHD) is still under development and doesn't have a firm agenda or schedule of activities. They want to ensure that DCLG is in position to play an active role in this area as the Center for Reducing Cancer Health Disparities (CRCHD) evolves.

Advocacy Involvement. Dr. Zebrack reminded members that they resolved in April 2001 to strengthen relations between DCLG and other cancer advocacy organizations and to support CARRA. For the first topic, the working group will draft a letter for approval by the DCLG. This letter , to be signed by Ms. LeStage, will be tailored to each recipient. It will introduce the DCLG and invite them to work with the DCLG. This letter will be ready in two or three weeks and will be followed up by telephone calls and personal contacts. The working group hopes that these groups will see DCLG as a forum and voice for their concerns.

The working group is working with Liaison Activities to develop measures for evaluation of both the process and the outcome of the CARRA program. Dr. Zebrack indicated that there is a continuing role for DCLG in orientation and training for CARRA members, such as reviewing the orientation module on the OLA Web-site and preparing a Atip sheet@ on what CARRA members can expect as advocate representatives in NCI activities. Mr. Porterfield, who is the official DCLG liaison to CARRA, said that CARRA is a well-known success for which DCLG can take a lot of credit, and that the DCLG should continue to support and utilize CARRA members wherever possible.

Ms. Giusti raised several questions about the DCLG press release announcing new members. She noted that the DCLG was more than a channel for information and suggested using words in the DCLG charter. The DCLG is the voice of advocacy and advises the Director of NCI. She suggested that DCLG needs what a PR person would call a Arelaunch,@ using the original charter as the basis for the introduction of a stronger DCLG. Ms. LeStage agreed that the wording should be changed. Ms. Branch said that DCLG should try to get the ear of the new Director by making it clear what the group can contribute and how it could be useful to him or her. Various members suggested that the DCLG is more than a link to the advocacy community; it is NCI=s Athought partner@ and a source of information, contacts, and ideas. CARRA is the perfect example C the DCLG helped it to be established and now it will help it succeed.

The Working Group members then discussed what the next major project like CARRA should be for DCLG. Ms. Giusti suggested that it should be something that is important to both NCI and the cancer community, such as clinical trials, health disparities or NCI's Progress Review Groups (PRGs). Ms. Kim and Mr. Porterfield agreed that PRGs would be an important topic, but it was not clear how DCLG could contribute to this initiative. Ms. Love suggested that the proposed Extraordinary Opportunity on Cancer Survivorship might lead to something similar to a PRG, but focused on survivorship. Ms. Kim indicated that some in the advocacy community are concerned about the outcomes and follow-up on PRGs. The group decided that Ms. Kim and Ms. Giusti will draft a resolution of support for the DCLG, and LA will ask Ms. Cherie Nichols, Director of the Office of Science Policy and Assessment, who leads the PRG efforts to join a conference call to discuss the best ways for DCLG to support and promote this initiative. The next scheduled DCLG conference call will be on November 8 from 2 to 4 p.m., EST.

NEW BUSINESS

Ms. LeStage asked the team leaders from each working group to identify new opportunities for advocacy involvement, similar to the list that Ms. Love generated for Health Disparities and Quality of Care. Ms. LeStage will make assignments to these committees to ensure that everyone who wants to participate has a chance to do so. Ms. Kim suggested that one DCLG member could cover several meetings, if it would save on travel, but Ms. LeStage said that NCI staff has expressed a preference for continuity in advocacy representation. Ms. LeStage also requested that members who attend NCI activities submit reports, stressing the purpose and actions of each committee.

Ms. LeStage announced that some members of the DCLG, Ms. Packer, Ms. Lin, Mr. Ulman, and Ms. LeStage, recently provided their comments about NCI's proposed logo and tag line.

Ms. LeStage asked each member to complete an evaluation of this DCLG meeting, either before leaving or by e-mail, and to suggest agenda items for the April 2002 meeting. Ms. Nyrvah Richard said that she thought this had been the most constructive and productive DCLG meeting to date. However, she also asked that the minutes, or at least the action items and timeline, be distributed in a more timely fashion. Ms. Kim and Ms. Giusti suggested that DCLG should also do something to capture the experiences of departing members, rather than losing this important Ainstitutional memory.@

Mr. Katz suggested that it would be useful to have the Director remain in the meeting for longer than an hour, in order to interact with DCLG instead of just reporting to them. Ms. Lee suggested that it would be possible to ask the Director to remain for a special forum, and this would also attract the public to attend. Ms. Kim suggested that the forum on survivorship at this meeting, or the proposed forum on clinical trials at the next meeting, would be opportunities for this kind of extended interaction. Dr. Zebrack said that no one knows how soon NCI would have a new Director, but that it behooves DCLG to have a presentation ready for him, outlining its past accomplishments, present activities and future plans.

Ms. Ghanem presented a quick preview of the new LA website, which will be user-tested by advocates in November. Mr. Porterfield suggested that the website should link DCLG with CARRA. Ms. Ghanem assured him that there would be links.

The meeting recessed at 4:00 p.m.

October 17, 2001

Ms. LeStage called the meeting to order at 8:00 a.m. and welcomed Dr. Yvonne Andejeski.

GRASS ROOTS VIEWS ON SURVIVORSHIP: OPPORTUNITIES AND UNMET NEEDS

Ms. Kim welcomed those who had come to participate in the forum on survivorship, which she characterized as an opportunity to the issues, models and gaps in this important area of cancer research. She noted that the speakers represent the entire continuum of cancer survivorship, from diagnosis through treatment to the end of life.

Opening Remarks. Dr. Julia Rowland, Director, Office of Cancer Survivorship (OCS), NCI, said that her office is still developing accurate statistics on cancer survivors. One estimate, based on the Connecticut SEER database, suggests that there were 8.9 million cancer survivors in 1997. Another estimate said that there were 7.4 million survivors in 1998 who had been diagnosed in the past 20 years. Since many patients survive far longer than 5 years, it is clear that there are many Americans living with either a cure or a chronic condition.

OCS was established in June 1998 in recognition of the numbers and needs of cancer survivors. It uses the National Coalition on Cancer Survivorship definition, by which survivorship begins at the moment of diagnosis and continues until death. OCS has a very broad mandate to address the needs of patients and their families by preventing adverse events, improving quality of life, and providing a knowledge base for further improvements in treatment and care.

OCS currently has five full-time employees and a portfolio of $10 million in 134 grants funded by NCI, DOD, and other federal agencies. At present 48 percent of these grants are in breast cancer, and OCS would like to broaden its portfolio not only in terms of disease site but also in terms of ethnicity and age. (Dr. Rowland characterized survivorship research as comprehensive for pediatrics but lacking for those who are older than 55 years of age.) Seven areas have emerged as priorities for survivorship research:

- Descriptive epidemiological research
- Intervention research (including evaluation and dissemination)
- Family issues
- Economic issues (including patterns of care)
- Instrument development (especially in quality of life)
- Neglected groups (by site, ethnicity and/or age) and
- Training and education (to encourage careers in survivorship research)

Recent initiatives by OCS include (1) supplements to the CCOGs to study minority and underserved survivors populations, (2) Rapid Response Surveillance Studies of care and quality of life among survivors, (3) a research workshop on physical activity and cancer survivorship (rescheduled from October 2001 to January or February 2002), and (4) the biennial survivorship conference cosponsored by NCI and the American Cancer Society on June 2B4, 2002. Dr. Rowland expressed hope that DCLG would help to organize a Atown meeting@ during that conference. Related NCI initiatives of interest to survivors include the following:

- Cancer Care Outcomes Research and Surveillance Consortium (CanCORs), seven extramural centers focusing on outcomes research in lung and colon cancer over a period of five years
- Cancer Outcomes Measurement Working Group (COMWG), an intramural group that will report its findings to the Quality of Cancer Care Committee in spring 2002
- Centers of Excellence in Cancer Communications Research (CECCRs), a concept that will be proposed to the Board of Scientific Advisors on November 16, would provide $50 million over five years to study improvements in cancer communications

Dr. Rowland closed by identifying a number of hot topics in survivorship research. One is the area of evolving late effects of treatment, including cognitive fatigue (Achemobrain@), cardiac problems, menopause, and osteoporosis. Another is the search for interventions that improve the quality of life as well as the length of life. She alerted participants to look for a shift in *paradigm*, away from the medical or disability focus on negative impacts, and toward the search for positive impacts. This paradigm shift will create the need for new tools to evaluate positive outcomes, such as greater emphasis on self-reports. Finally, there will be a growing emphasis on the resilience of cancer survivors and their needs as a community.

Cancer as a Chronic Disease. Ms. Scherr described the educational and outreach programs of the National Coalition on Cancer Survivorship (NCCS), which addresses all cancers in both sexes. NCCS programs and products, all of them free, include the following:

- *Survival Tool Box,* a training program for oncology nurses and oncology social workers, developed with support from Genentech and available on audiotapes and, just released, on CD-ROM

- *Cancer Keys for Survival,* a training program for cancer patients on issues such as personal needs, communicating with doctors, patient=s rights, insurance, and employment
- Seminars on cancer survivorship delivered through NCCS chapters
- Several teleconferences and Webcasts, including one on workplace issues in January 2002
- A scholarly paper on the psychosocial aspects of cancer (one finding was that even when support services are available, few patients make use of them)
- *Cancer Survivor Almanac,* the one NCCS product that is not free

Ms. Sarah Singer, patient care manager of the DC chapter of the Leukemia and Lymphoma Society (LLS), pointed out the differences between patients with curable cancers (e.g., non-Hodgkin=s lymphoma with 80 percent cure rate) and patients slow-growing, treatable cancers (e.g., chronic lymphocytic leukemia with average 14 years survival). The former are survivors living with a cure, while the latter are survivors living with cancer as a chronic disease. The priorities for these survivors are, first of all, maintaining optimum health, but also developing a philosophy of life with cancer, whether spiritual, philosophical, or social.

The Leukemia Lymphoma Society addresses these needs through public education and advocacy that provides survivors with information and hope. Information includes pamphlets, a help line and a speakers= series that allows survivors to Abear witness.@ Leukemia Lymphoma Society programs include First Connections, Cancer Keys, cancer walks, and financial and social services. Ms. Singer identified the following areas as needs that are often unmet:

- Health insurance to cover sperm banking and egg collection for patients who want families, portability of health insurance, financial assistance for out-of-pocket costs, and educational assistance for the children of cancer survivors
- Employment concerns (fatigue, alternative employment, and self-employment)
- Children with cancer (teacher attitudes, cognitive and learning problems, fatigue, and the long-term effects of treatment)

Post-Treatment Issues. Ms. Richard described the survivorship programs of Self Help for Women With Breast or Ovarian Cancer (SHARE), a nonprofit organization that provides support for women and their families who have been affected by breast or ovarian cancer. SHARE=s central philosophy is self-help and peer support from providers who’ve been there, covering the entire spectrum from diagnosis through treatment to survival or and bereavement. Telephone hotlines are available in English and Spanish to deal with the emotional, mental, and social needs of survivors, spouses, and children. SHARE also addresses spiritual needs though yoga, meditation, art therapy, and alternative and complementary medicine. These programs give survivors a valuable opportunity to give back to the community.

Ms. Richard reported that much of the demand for these services is in the area of post-treatment support, answering questions that have to do with, AWhat now?@ She said that there is no manual for life after treatment, and no formal support network for these survivors. SHARE tries to address their needs by letting them know that it=s all right to have questions or be confused, and by providing educational programs and support groups, sorted by disease and age, that address what to expect and how to deal with others. Because Apost-treatment@ can mean chronic disease and end of life, SHARE also provides recurrence and metastatic support groups. Advocacy activities are an important outlet for the survivors, because those who have gone through it want to address it and help others.

Ms. Richard identified a number of unmet needs for post-treatment survivors. For one thing, most medical teams don=t prepare patients for post-treatment symptoms such as “chemo brain” and neuropathy. Quality of life after treatment depends on close monitoring and long-term follow-up, but health insurance can be a problem if the survivor changes doctors, loses coverage, or must pay for post-treatment care. In addition, there in no guidance on how to use alternative and complementary treatments, and no standards for costing or insurance coverage. Training is also an issue for SHARE, since many of its volunteers go back into treatment or die.

End of Life. Dr. Joanne Lynn, director of the RAND Center to Improve Care of the Dying, urged the DCLG to recommend that NCI pay greater attention to end-of-life issues. Increasingly, cancer is becoming a disease of the old, and among the elderly a cancer that is not prevented, or cured in the first round of treatment, will prove fatal. Research has taught us how to extend life, but it hasn’t focused on how to live well when faced with pain, seizures, cachexia, and depression. Or rather, we know how to treat these symptoms, but the treatment is not delivered consistently. What is needed, increasingly, is hospice-level care for months or years, rather than days or weeks.

Dr. Lynn presented three pressing reasons for NCI to fund additional research on these end-of-life issues: a large number of cancer patients are surviving for a long time; we already know a lot about how to care for the dying; and there is an important role for research and education in applying what we know more broadly and more consistently. Several studies have already established the outlines of a research agenda, including clinical studies (e.g., shortness of breath), delivery studies (strategies that work), and quality of care studies.

Dr. Lynn insisted that the comprehensive cancer centers must address these topics, and NCI must help to force them to do so, or the next generation of oncologists will still not know how to provide appropriate care. To accomplish this, those centers would have to stop doing all their research at the subcellular level, they would have to reach out to older patients (the average research subject is 15 years younger than the average cancer patient), and they would have to develop system-wide standards and practices. Such change is needed immediately, because the number of patients dying of cancer will double in the next 20 years, and society has a responsibility to make the end of life better for these patients. These results are achievable in three to five years, not 20 years, if society makes a commitment to pursue them.

In answer to questions, Dr. Lynn explained that 100 years ago, most people died young and suddenly, from causes such as accidents, infectious diseases, or the complications of childbirth.

The new paradigm of dying old and slowly, from chronic conditions, is a relatively new phenomenon that was not foreseen in the design of medicine. The transition from living to dying may no longer be a short one, and medicine needs a new paradigm or language of mixed management C contingent care, early pain management, and other palliative measures that are as appropriate for some cancers as they are for heart and lung failure. However, our culture has no model for Aextended death@ and caregivers have no stories to learn from. The necessary standards and practices are researchable, just as they were in obstetrics; we fail to address the needs of the dying, not because we don=t know how, but because there are gaps and inconsistencies in the system.

Ms. Butler suggested that those who are advocates for cancer patients have a responsibility to talk about death, as well as life. Mr. Porterfield said that doctors don=t prepare a cancer patient for death, but rather hold out the hope of a miracle cure. Dr. Lynn said eliminating cancer would not eliminate death, and that 50 percent of those over 85 already need assistance with daily living and will die of dementia. The goal should be to have a good life, even if that life is only a few months longer. Ms. LeStage offered Jacqueline Kennedy Onassis as a good model: she did what her doctors asked, but at the end she=d had enough and went home to die on her own terms. Dr. Lynn suggested that if oncologists were required to follow their patients into death, and their families into bereavement, they would see things differently and change the way they treat their patients. Asked for the four programmatic areas of greatest need, Dr. Lynn identified symptom relief, caregiver support, service delivery models, and training (there is a 50-percent shortage of nurses of all kinds).

New Extraordinary Opportunity. Ms. Kim reviewed the results of the DCLG survivorship survey and asked if it might be the pilot for a larger study that would validate these results and provide guidance for OCS. She spoke to Dr. Jon Kerner about using his Aconcept mapping@ software to analyze responses if the survey were repeated on a larger scale. Among the findings of this survey: the 1990s saw an explosion of advocacy groups, the older groups have a responsibility to share what they've learned, there is considerable agreement about which survivorship issues are most important, and there is an important role for NCI in validating past research, funding new research, and disseminating the results.

Dr. Rowland identified several areas in which OCS needs input from DCLG. One is dissemination C given that a lot of information is already available, what mechanisms should NCI use to put that information in the right hands? What new publications or information materials should NCI provide, is there a need for a central repository, and how should we evaluate and assess the available publications? Another area is validating the term Asurvivorship@ itself C is it acceptable to patients and physicians? What sites or communities are missing from OCS= current portfolio, and how should these gaps be filled? Finally, OCS could use DCLG=s help in organizing a town hall meeting at the survivorship conference in June 2002.

Dr. Rowland said that OCS submitted a proposal for an Extraordinary Opportunity in Cancer Survivorship, and that she would welcome DCLG=s endorsement or even a separate proposal on the same topic. She said that, according to NCI guidelines, an Extraordinary Opportunity should be a broad area of science with great potential for discovery, a frontier that could become the foundation for future research and applications, an opportunity to accelerate the pace of research and discovery, and an implementable plan with milestones that addresses all cancers. The four necessary elements of a proposal are a goal, a statement of recent advances, the elements of a plan, and a statement of why this opportunity should be pursued now rather than later.

Dr. Rowland explained that OCS was created to fill the gap in post-treatment care, originally beginning five years after treatment; this has now been reduced to two months after treatment but C due to organizational boundaries within NCI C OCS could not address diagnosis or treatment. Similarly, OCS did not originally encompass the end of life but has been pushed toward it by the QC3 initiative. Dr. Rowland asked if this should be called Asupportive care@ rather than Asurvivorship.@ Mr. Ulman said that this was a chance to broaden the definition of survivorship.

Several DCLG members indicated that they preferred to submit a separate proposal that explicitly included everything from diagnosis to end of life C Aa house of our own,@ as Ms. Kim put it, Aand a bigger house at that.@ Ms. Branch suggested that the proposal call for research on cultural issues and recurrence, and that treatment be tailored to the individual patient. Ms. Butler suggested a statement of the goal: *ATo improve the quality of supportive care and outcomes for cancer patients from diagnosis to end of life.@* Other members suggested the following as Arecent trends@ that support the need for this initiative:

- Availability of new and improved treatment options
- Demographic changes (aging population)
- New information from the Human Genome Project (markers, risk management)
- Improvements in screening, detection, and early diagnosis
- Patients living longer with disease
- Consumer activism, advocacy, demands for information and advice
- Need to counteract bad information on the Internet
- Managed care and changes in the economics of medicine and insurance

Dr. Rowland suggested that several ongoing NCI programs could be leveraged for greater information, such as the Special Populations Networks, Early Detection Network, and SEER database. Dr. Zebrack indicated that the answer to Awhy now@ is the opportunity cost of not doing so, measured in loss of life and diminished quality of life for cancer survivors. Dr. Rowland added that the Extraordinary Opportunity in Cancer Communications had spawned the HINTS survey, a population based investigation of how individuals get health information; perhaps this initiative could include a HINTS-S survey of how people get information about survivorship issues. There is a need to coordinate all the information that=s already in the pipeline and apply it to survivorship. She also agreed that research products could include standards of care, current practices, dissemination of new practices.

Ms. Kim indicated that DCLG would use its own proposal for the Extraordinary Opportunity in Cancer Communications as a model for this new proposal. Dr. Rowland said that she would be glad to review the model, and that OCS would return to DCLG in future, regardless.

ADJOURNMENT

Ms. LeStage thanked all the participants for a very productive forum and meeting. The meeting adjourned at 1:00 p.m.

__________ Date	________________________ Chair, Director=s Consumer Liaison Group
__________ Date	________________________ Executive Secretary, Director’s Consumer Liaison Group

ACTION ITEMS

October 15B17, 2001

- Liaison Activities (LA) will prepare slides and other materials about DCLG and CARRA and will provide other assistance to members in preparing presentations about these groups
- The DCLG Working Group on Health Disparities and Quality of Cancer Care will draft a letter to be approved by the DCLG for Ms. Barbara LeStage's signature. It will introduce the role and functions of DCLG to minority and underserved health organizations as a first step in establishing relations with them
- Liaison Activities will coordinate with Center to Reduce Cancer Health Disparities (CRCHD), Cancer Information Service (CIS), the Office Education and Special Initiatives (OESI), and others to identify new organizations for the LA database
- DCLG members will suggest new organizations and individuals to be added to the LA database
- Mr. Frank Jackson, CRCHD, will send an email to SPN grantees asking for the names of minority and underserved health organizations to be added to the LA database
- Dr. Brad Zebrack will draft a proposal for an Extraordinary Opportunity in Cancer Survivorship, based on the DCLG proposal in cancer communications
- Ms. Tracy Clagett will coordinate efforts between the Working Groups on Quality of Care and Survivorship in developing a proposal for a new extraordinary opportunity
- The DCLG will submit a proposal for an Extraordinary Opportunity in Cancer Survivorship
- Mr. Hank Porterfield will prepares a monthly update on CARRA activities for the DCLG listserve
- Liaison Activities will invite Ms. Cherie Nichols to join a DCLG conference call on the subject of PRGs
- Ms. Paula Kim and Ms. Kathy Giusti will draft a resolution of support for the PRG process for consideration by the whole DCLG
- The DCLG will submit a proposal for an Extraordinary Opportunity in Cancer Survivorship
- The DCLG will prepare a presentation for the new NCI Director, outlining the groups past accomplishments, current activities and future plans
- The DCLG will invite the Director to remain or return for the forum on clinical trials, tentatively planned for the April 2002 meeting
- Departing DCLG members will record their experiences and advice for new members
- DCLG members will submit additional agenda items for the April 2002 meeting
- Liaison Activities will attempt to distribute meeting minutes, action items, and timelines in a more timely manner

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