

*There Is Something More **You** Can Do To Help Fight Cancer: Consumer Advocates in Research and Related Activities*

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The National Cancer Institute (NCI) values the opinions of cancer survivors. It has long been a practice of the NCI to draw upon the experience of consumer advocates who bring the viewpoints of cancer patients to the NCI. Advocates are vital to the success of NCI programs and activities. In order to maintain and build on this dynamic relationship, the NCI has created a new program called Consumer Advocates in Research and Related Activities (CARRA). CARRA was established to encourage people affected by cancer to provide their viewpoint and ideas directly to NCI staff. The NCI can then incorporate this perspective into our programs and activities. CARRA members represent consumer advocates who are involved in cancer-related activities (such as support groups, cancer hot lines, or advocacy groups), many different cancer types, age groups, and ethnic groups from across the Nation. CARRA members are cancer survivors/patients, or first-degree family members/life partners, or individuals with 3 or more years of involvement in cancer-related activities. In addition to participating in NCI activities, CARRA members represent the opinions of their groups and play critical roles as two-way information links between their own communities and constituencies and the NCI.

Based on a combination of their skills and interests as well as on NCI program needs, CARRA members, recruited in advance on an as-needed basis, are selected for

individual NCI activities. In order to continue their valuable contributions, advocates who were already involved or have been involved in NCI programs and activities were given the opportunity to be “grandfathered” into the CARRA program by NCI staff members.

CARRA members make a 3-year commitment to participate in the program through one or more activities from home and/or in the Washington, D.C., metropolitan area and to represent the viewpoint of other cancer survivors or their family members.

Look for more information in an upcoming issue of *The Nealon Report*. Information on the program may also be obtained by calling 301-594-3194 or online at liaison.cancer.gov/CARRA.

—Nina Ghanem

Review of Research Progress Helps to Guide Direction for Disease-Specific Areas

Which scientific resources will help neuroscientists unlock the mysteries of brain tumor development? What is required to develop desperately needed early detection strategies for pancreatic cancer? How can we discover effective ways to encourage Americans to undergo colorectal cancer screening? These are the type of

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THE NEALON REPORT

Official Newsletter of NCI Liaison Activities

The Nealon Report is dedicated to Ms. Eleanor O'Donoghue Nealon, first director of the NCI Office of Liaison Activities. Ms. Nealon passed away in 1999 from breast cancer.

Editor-in-Chief

Kristie S. Dionne, M.A.

Editorial Board

Yvonne Andejaski, M.D.
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Kristie S. Dionne, M.A.
Tracy Kilmer Clagett, M.A.
Laurie Rosenberg, M.P.H.
Keisha Martin
Nina Ghanem

Contact Information

Liaison Activities
National Cancer Institute
6116 Executive Boulevard
Room 3068A, MSC 8324
Bethesda, MD 20892-8324
Tel: 301-594-3194
Fax: 301-480-7558
E-mail: liaison@od.nci.nih.gov

NCI Web site: www.cancer.gov

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Research Progress

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questions addressed by the National Cancer Institute's Progress Review Groups (PRG), our primary vehicle for planning cancer site-specific research.

Each review group consists of 21 to 30 prominent members of the scientific, medical, and advocacy communities. We ask them to outline and prioritize a national research agenda for a particular cancer type. Participants draw on a number of sources, including the Institute's research portfolio and input from experts and consumer advocates who participate in a comprehensive roundtable meeting. The final product of the PRG is a report that outlines the research priorities and resources that are necessary and must be addressed to make progress against the type of cancer under discussion. The Institute uses these reports to chart its course for future site-specific programs and activities. Reports are widely distributed to the research and advocacy communities.

The Institute has planned an ambitious future through 2003 for progress review groups that will cover the most common cancer types. For more information about these groups and to read completed group reports, visit <http://planning.cancer.gov>.

See page 4 for a timetable of current and future PRGs.

—C. Nichols and K. Nagy

From the Consumer Perspective

Written by Kathy Giusti

Multiple Myeloma Research Foundation

On January 12, 1996, I was diagnosed with multiple myeloma. I was 37 at the time and devastated to learn this blood cancer was incurable, leaving me with an average life expectancy of 3 years. The more I read, the

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Consumer Perspective

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worse I felt. There was so little awareness and funding for this disease.

The December 2000 Leukemia, Lymphoma, Myeloma Progress Review Group (PRG) roundtable meeting reminded me just how much has changed in a short period of time. First, the NCI's commitment to blood cancer research became obvious. The Institute made it clear that since non-Hodgkin's lymphoma and multiple myeloma are two of the fastest growing cancers in the United States today, it needs to develop a plan to improve the survival rates of patients with these diseases. Second, there was a commitment from the pharmaceutical companies and biotech firms that attended to identify and pursue new therapeutic compounds in lymphoma, leukemia, and multiple myeloma. This industry support is critical since the research that is focused on less commonly occurring cancers yields lower financial gain than the research that is focused on more prevalent ones. Third, advocacy groups representing blood cancers and leading thinkers representing research on lymphoma, leukemia, and multiple myeloma were brought together to work side by side, pursuing common interests, sharing goals, and identifying the priorities in studying all blood cancers.

As president of the Multiple Myeloma Research Foundation, I communicate with tens of thousands of patients and family members who can sense the energy that the Leukemia, Lymphoma, Myeloma PRG has engendered. Collaboration with the NCI, academia, advocacy organizations, pharmaceutical companies, and biotech firms will help us master the biology, identify the targets, screen the compounds, and offer new options to patients quickly. This is the shared goal of every individual who dedicates his or her time to this important project.



Information Resources

NCI's Cancer Information Service

1-800-4-CANCER (1-800-422-6237)

TTY: 1-800-332-8615

The Cancer Information Service (CIS) is a nationwide information and education network for cancer patients and their families and friends, the public, and health professionals. The CIS can provide information from the NCI's PDQ® (Physician Data Query) database. This toll-free number connects English- and Spanish-speaking callers all over the country with the office that serves their area.

NCI's Web Site

www.cancer.gov

This NCI home page provides links to *CancerNet*® for NCI materials for health professionals, patients, and the public; *cancerTrials* for cancer clinical trials information; and the NCI's online publications locator and ordering service.

CancerMail

This service includes NCI information about cancer treatment, screening, prevention, and supportive care via computer E-mail. To obtain a contents list, send an E-mail with the word "help" in the body of the message to cancermail@icicc.nci.nih.gov.

CancerFax®

This service provides cancer information by fax. To use CancerFax®, dial 301-402-5874 from the telephone on a fax machine and listen to the recorded instructions to receive a faxed list of available documents and instructions for having documents faxed to you.

Timetable for Current and Future Progress Review Group Meetings

Progress Review Group (PRG) Meeting	PRG Planning Roundtable	PRG Release	Report Response	NCI-PRG Meeting
Brain Tumor	Mar 2000	Jul 2000	Nov 2000	Mar 2001
Pancreatic Cancer	May 2000	Sep 2000	Feb 2001	Jun 2001
Leukemia, Lymphoma and Myeloma	Aug 2000	Dec 2000	Apr 2001	Aug 2001
Lung Cancer	Jan 2001	Apr 2001	Aug 2001	Dec 2001
Gynecologic Cancers	Feb 2001	Jun 2001	Oct 2001	Feb 2002
Kidney and Bladder Cancer	Jul 2001	Nov 2001	Mar 2002	Jul 2002
Stomach/Esophageal Cancer	Nov 2001	Mar 2002	Jul 2002	Nov 2002
Liver/Bile Duct Cancer	Feb 2002	Jun 2002	Oct 2002	Feb 2003
Skin Cancers	Jun 2002	Oct 2002	Feb 2003	Jun 2003

Office of Cancer Survivorship Thrives at the NCI

*Written by Julia H. Rowland, Ph.D.
Director, Office of Cancer Survivorship*

There is no greater proof of the progress we've made than the more than 10 million Americans who have survived cancer. Many have special psychological, physical, and health care counseling needs that we are only beginning to understand. Some face recurrence of their illness. Some can't get health insurance.

On October 27, 1996, during a formal ceremony in the Rose Garden of the White House, former President William J. Clinton spoke those words to announce the November 1 opening of the Office of Cancer Survivorship (OCS) at the National Cancer Institute. The creation of OCS was a direct outgrowth of impassioned advocacy

within the survivorship community, championed by articulate spokespersons like Ellen Stovall of the National Coalition of Cancer Survivorship and the visionary leadership of NCI Director Dr. Richard D. Klausner. With the establishment of the OCS, the NCI formally recognized the growing population of cancer survivors and their unique, poorly understood needs. It provided a focus for the support of research that yields a clearer understanding of and ultimate prevention or reduction of adverse physical and psychosocial outcomes

associated with cancer and its treatment. The NCI also made a commitment to educate health care professionals and consumers about issues and practices critical to attaining the highest level of well-being for cancer survivors and their loved ones.

In the 4 years since the OCS was established, the National Institutes of Health's spending on research to examine the impact of cancer on posttreatment survivors has increased from approximately \$6.6 million to \$32.4 million. Meanwhile, the OCS has grown from carrying just one part-time employee to five full-time staff members. A Web site has been created at dcccps.nci.nih.gov/ocs to help researchers and the public track the OCS's success and activities.

Today, the number of individuals in the United States with a history of cancer is estimated at over 8.9 million. We are gathering information about these people and research about the problems they face once treatment ends, and are looking at the value of psychosocial and behavioral interventions on reducing the cancer burden they bear and on improving health outcomes both for cancer survivors and for their families. We're also examining

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From the NCI Director's Consumer Liaison Group

Written by Michael Katz, DCLG Chair

Eleanor Nealon was a woman of extraordinary creativity, commitment, and infectious exuberance. Never were these qualities more evident than when she and Rick Klausner set out to constitute a diverse group of advocates who could provide consumer perspectives on issues confronting the Director and the Institute. They realized their vision with the formation of the NCI Director's Consumer Liaison Group (DCLG).

Assembling 15 people from vastly different cancer experiences and backgrounds created a group that has been characterized by proactive high energy that drives discussion and initiates change both inside and outside the NCI. In turn, the leadership and staff input that the Institute has contributed has helped spark lively, substantive debate and invaluable opportunities to become more effective advocates.

Over the past 3 years, the DCLG has collaborated with the NCI on numerous projects, including a genetics primer, clinical trials system redesign, accrual, education, and a patient-friendly informed consent template. The Group also worked with the NCI to create three new entities; one of these, the Extraordinary Opportunity

for Cancer Communications, was formed at the request of Dr. Klausner and utilized Eleanor Nealon's unmatched mix of caution, diplomacy, and brass to review key NCI communication functions. Eleanor provided invaluable guidance and leadership at the same time that she was dealing with the ravages of end-stage metastatic breast cancer. Her commitment spurred us to reach deeply into the Institute and out to our constituencies to deliver practical, real-world perspectives and recommendations. We will not soon forget the image of Eleanor overflowing with pride as she watched the DCLG share its findings and recommendations with the staff.

Most recently, DCLG worked with the NCI's Liaison Activities office to design the new Consumer Advocates in Research and Related Activities (CARRA) program. This year, we hope to recruit 150 people who will be available to participate in NCI activities over time. In addition to CARRA, five new advocates join the DCLG each year.

As we look forward, the DCLG will continue to address survivorship, health care disparities, quality of care, clinical trials, advocacy involvement, NCI branding, communications, and Web site design.

Information and application materials for the DCLG and the CARRA program can be obtained by contacting NCI Liaison Activities at 301-594-3194.

NCI and Urologic Society Cosponsor First Annual Meeting

On December 2 and 3, 2000, the National Cancer Institute and the Society for Urologic Oncology (SUO) cosponsored their first joint annual meeting. The conference was held at the NIH in Bethesda and brought together over 300 participants. They included scientists, urologic surgeons, medical and radiation oncologists, and advocates to

discuss state-of-the-art practices of medicine and research in prostate, kidney, and bladder cancers as well as strategies in urologic oncology.

Specific topics addressed included molecular diagnostics, immunotherapy, and cancer genetics. General topics included cooperative group clinical trials and research funding opportunities at the NCI. During his keynote address, NCI Director Dr. Richard Klausner spoke of a continued

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Clinical Trials Corner: Over 65? Barriers to Clinical Trials Are Falling

Most cancer patients are age 65 or older, but only about 25 percent of those who take part in clinical trials falls into this age group. What keeps older patients out of trials? Barriers include health problems other than cancer—"comorbidities" such as heart disease or poor kidney function—but additional roadblocks may be psychological

or socioeconomic. Now, one of the financial barriers to trial participation is coming down. Last June, the White House announced that Medicare would begin to cover routine patient care costs such as office visits and tests associated with clinical trials. It will also pay for the administration of experimental drugs and for supportive care such as anti-nausea drugs.

Updates on Medicare's new policy are available at www.hcfa.gov/coverage/8d.htm.

—Carolyn McNeil

Office of Cancer Survivorship

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resources that may be helpful to survivors in communicating their followup needs and concerns to their health care providers. The next few issues of *The Nealon Report* will be used to share OCS information with you.

Meeting

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need for research and dissemination of cancer information at the community level.

The Society's second annual cosponsored meeting is scheduled for November 30 through December 2, 2001, at the NIH. Please direct any questions regarding the meeting to Teresa Burdette in the Urologic Oncology Branch, NCI, at 301-402-6505.

—Laurie Rosenberg

NCI Liaison Activities
Office of Communications
6116 Executive Boulevard
Room 3068A, MSC 8324
Bethesda, MD 20892-8324
Tel: 301-594-3194
Fax: 301-480-7558
E-mail: liaison@od.nih.nci.gov

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