Premier Issue

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The Nealon Report

Bridging advocacy, scientific, and government communities in the progress of cancer research

Eleanor O'Donoghue Nealon

NCI Dedicates Newsletter to Eleanor O'Donoghue Nealon

This premier issue of *The Nealon Report* is dedicated to Ms. Eleanor O'Donoghue Nealon, an advocate's advocate who built bridges among the cancer advocacy community, the scientific community, and the federal government. Although Ms. Nealon, the first director of the National Cancer Institute's (NCI) Office of Liaison Activities, passed away on October 22, 1999, she continues to be an inspiration to all of us who strive to maintain and broaden the relationships among these organizations.

As a cancer survivor herself, Ms. Nealon tirelessly engendered changes at the National Institutes of Health so that cancer patients could have an expanded role in the decision-making process at the NCI. At a time when the consumer advocate's voice was not as widely heard as it is today in the realm of scientific discovery, Ms. Nealon graciously persuaded many in the scientific community to open their minds, eyes, and ears to those who are affected by the work done at the NCI and in research laboratories across the United States.

As a result, consumer advocate representation in NCI activities has expanded over the past 6 years. Advocates now participate in all NCI advisory committees, working groups, progress and program review groups, clinical science peer review panels, and cancer center site visits. Each of these activities affects the direction of cancer research. For example, advocates look at the research conducted by the NCI and identify gaps in and future directions for key research areas such as clinical trials or breast and prostate cancer studies. In addition, cancer survivors and advocates are involved in a multitude of NCI program planning and implementation activities.

In 1997, Ms. Nealon led the efforts to establish the NCI Director's Consumer Liaison Group (DCLG), which is coordinated by NCI Liaison Activities. This group is the first all-consumer advocate advisory committee at the NCI and the NIH. The DCLG and NCI's Liaison Activities have served as models throughout the NIH and other federal agencies for consumer advocate involvement.

During her 18-year tenure at the NCI, Ms. Nealon was dedicated to helping cancer patients obtain the cancer information they needed and to understand the complexities of science and clinical trials. She held several key positions at the NCI including senior science writer for the NCI Director, and she directed NCI communications programs such as the NCI press office and the NCI's Cancer Information Service. Through the years, Ms. Nealon taught many of us that change *is* possible. Although it takes persistence and may take a long time, it is worth the effort and energy spent.

On a personal note, Eleanor embodied a compassionate, devoted personality. Her kindness, loyalty, sincerity, and integrity are sorely missed and will never be forgotten. Here's to you, Eleanor!

—K. Dionne

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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.

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5 New Advocates Selected for NCI's Director's Consumer Liaison Group

The NCI Director's Consumer Liaison Group (DCLG) has five new members who were selected by NCI Director Dr. Richard Klausner for terms that began on July 1, 2000. They are Barbara LeStage of Wrentham, MA; Pamela McAllister of Madison, WI; Henry Porterfield of Hinsdale, IL; Nyrvah Richard of New York; and Paula Simper of Palos Verdes, CA. They are the first members rotated into the 15-member consumer advocate advisory board since the group was established in 1997. For more information about the new members and the DCLG, including past meeting summaries and background information, visit the NCI's Web site at **www.cancer.gov** and click on "About NCI" to find the advisory boards and groups.

—E. Lee

NCI Creates User-Friendly Access to Its Web Site

Forget the acronyms. All you need to remember is **www.cancer.gov**—or even, simply **cancer.gov**. It's the NCI's new consumer-friendly URL for accessing the home page of the National Cancer Institute, conceived with you, the consumer, in mind. From the NCI's home page, you can access familiar resources such as publications from the NCI's Cancer Information Service, PDQ® and CancerNet®, and NCI clinical trials information from *cancerTrials*. The latest news from the NCI is available on **cancer.gov** as well as announcements about new programs and initiatives; information about funding opportunities, NCI-supported research, ongoing research activities at the NCI; and much more. Try it today—**cancer.gov.**

—K. Dionne

NCI Reorganizes Cancer Communications, Appoints Associate Directors

The National Cancer Institute has restructured and expanded its communications activities this year with the creation of an Office of Communications (OC). The new configuration is helping to integrate and coordinate all of the NCI's communication efforts. Five separate programs within the OC will focus on activities in the areas of Outreach and Partnerships, Media and Public Communications, Communications Coordination, Technologies and Services, and Cancer Information Products and Systems. Susan Sieber, Ph.D., is leading the new Office of Communications.

Elisabeth Handley is associate director for Outreach and Partnerships, which includes the Liaison Activities Branch (formerly the Office of Liaison Activities) headed by Elaine Lee, and the Health Promotion Branch. This program is responsible for developing, implementing, and evaluating national communications programs and fostering partnerships with professional and advocacy organizations and other government agencies.

The Communications Coordination program will include a Division Liaison group and a Topic Management group. The division liaisons will provide a direct link between the OC and the NCI's scientific divisions. The Topic Management group will ensure that the NCI is able to deal proactively with emerging scientific issues and will coordinate the Institute's responses so that they are clear, understandable, and culturally appropriate. Ms. Nelvis Castro is associate director of this program.

The Cancer Information Products and Systems unit will be led by Ann Thurn. This program incorporates the former International Cancer Information Center.

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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.

Lung Screening Study to Examine Spiral CT Scans

The NCI is currently conducting the Lung Cancer Screening Study with 3,000 current and former smokers. The year-long, $3 million study of spiral computed tomography (CT) scans is testing the promising but unproven technology for lung cancer screening. While the study will not determine if the scans save lives—the gold standard for any cancer screening test—it will gauge the feasibility of a larger, longer study designed to meet that goal.

How spiral CT scans work

Spiral CT uses X-rays to scan the entire chest in about 15 seconds, during a single breath-hold. Throughout the procedure, the patient lies still on a table. The table and patient pass through the CT machine, which is shaped like a donut with a large hole. The machine rotates around the patient and a computer creates images from the scan, assembling them into a 3-D model of the lungs. The amount of radiation absorbed during a spiral CT scan is comparable to that absorbed during a mammogram.

During September and October, six screening centers across the country recruited 500 people and randomly assigned them to receive either a spiral CT scan or a chest X-ray. Researchers are first determining the willingness of smokers and former smokers to participate in a randomized study. In addition, they will compare the lung cancer detection rate of each test; measure how much and what kind of medical followup is needed for positive or ambiguous results; and track how frequently participants receive spiral CT scans outside of the study.

This knowledge is crucial for the design of larger, more definitive studies, said John Gohagan, Ph.D., the NCI investigator heading the study.

Evidence from early studies suggests that spiral CT scans detect small lung cancers, often at the edges of the lungs. Whether finding these tumors actually saves lives, however, remains unknown. The only way to detect a survival advantage is in a large study in which people receiving the scans are tracked alongside a control group that does not get them; such research would be expensive, requiring tens of thousands of participants and 5 or more years. Thorough review of results from the Lung Screening Study will help researchers decide whether such a study is feasible.

The six participating centers are Georgetown University Medical Center/Lombardi Cancer Research Center (Washington, DC); Henry Ford Health System (Detroit); the University of Minnesota School of Public Health/Virginia L. Piper Cancer Institute (Minneapolis); Washington University School of Medicine (St. Louis); Marshfield Medical Research and Education Foundation (Marshfield, WI); and the University of Alabama at Birmingham.

Study participants are between ages 55 and 74, and have a history of long-term or heavy smoking; former smokers have quit within the last 10 years. People who have a history of lung cancer were ineligible.

Call the NCI's Cancer Information Service at 1-800-4-CANCER for more information about the Lung Screening Study or for information about quitting smoking or lung cancer.

Visit **www.cancer.gov** to view the full press release.

Chest X-rays May Detect Tumors With Limited Clinical Relevance

After tracking smokers for 20 years, a large study has confirmed that screening for lung cancer with chest X-rays does not save lives. The study, by Pamela Marcus, Ph.D., and colleagues from the NCI and the Mayo Clinic, Rochester, MN, which appeared in the August 16, 2000, *Journal of the National*

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From the Consumer Perspective

Written by the Alliance for Lung Cancer, Advocacy, Support, and Education

Research is the key. The National Cancer Institute has the opportunity to focus on reducing the death rate of lung cancer, the leading cause of cancer death for both men and women. More people die of lung cancer each year than breast, prostate, and colorectal cancers combined. We are told that the prognosis is so poor because 85 percent of those found to have lung cancer are diagnosed in the late stages of the disease, when the chances of a cure are very small.

Trust one who has gone through it. —Virgil, *The Aeneid*

At present, there is no screening test for lung cancer. Diagnoses of stage I lung cancer are usually incidental findings when patients are being tested for other problems. Therefore, the opportunity that the new low-dose spiral CT scan technique offers to those at increased risk of lung cancer is unprecedented. We urge the NCI to focus new resources on validating this technique and any others that are being researched as soon as possible. Lives are at stake!

Research must accelerate to improve the ability to detect lung cancer early, when it is potentially curable, and to improve patients' treatment and the quality of their lives. Lung cancer victims face issues that are specific to the diagnosis of lung cancer. The most difficult and far reaching is the stigma attached to this disease: "You have lung cancer—you must have smoked—therefore, you did it to yourself." Unfortunately, this stigma is based on ignorance and propagation by the tobacco companies. Another major difficulty is the fatigue associated with cancer and its treatments; it depletes the energy that patients so badly need for battling the disease. Someone worried about his next

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Screening

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breath cannot voice his concerns loudly enough to be heard by those who can change the status quo. More research *Cancer Institute*, reinforces original conclusions from the Mayo Lung Project published in the mid-1980s that X-rays at frequent intervals do not decrease the death rate from the disease. The analysis also points to a potential problem for any type of lung imaging: the detection of tumors that are not life threatening.

In their report, Marcus and her colleagues presented evidence that a substantial number of tumors detected between 1971 and 1983 in the 9,211 participating men turned out never to cause serious illness or death. In the absence of screening, the tumors would not have been found. Such over-diagnosis can lead to unnecessary worry or, more seriously, to expensive and risky biopsies or surgery.

These findings arrive in the middle of a debate over a newer screening technology, spiral computed tomography (CT) scans, and could slow enthusiasm for the scans until they are properly studied, she said. "A significant reduction in death rates is the gold standard for any cancer screening test. Our followup of the Mayo Lung Project shows that an intense regimen of chest X-rays in the 1970s and 1980s did not meet this standard. Likewise, until spiral CT scans are proven to save lives, they should not be recommended as a cancer screening test. The benefits of any screening test must outweigh the harm."

Visit **www.cancer.gov** for the full press release.

Lung cancer will be diagnosed in an estimated 164,100 people and claim 156,900 lives in the United States this year.

Consumer Perspective
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and compassion can provide the optimal treatment mandatory for all cancer survivors, including lung cancer survivors.

The Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE) has proclaimed November 2000 as national ***Lung Cancer Awareness Month.*** ALCASE is the only nonprofit organization in the country solely dedicated to helping people at risk for and living with lung cancer. For more information on our services or to obtain materials, call 1–800–298–2436 or visit our Web site at **www.alcase.org**.

Researchers Reaffirm Necessity of Phase II Trials for Nonsmall Cell Lung Cancer

Conference recommendations are posted on the NCI Web site
http://www.conference-cast.com/webtie/sots/sots.htm

According to recommendations made by leading researchers during the National Cancer Institute's State-of-the-Science conference on nonsmall cell lung cancer, phase III clinical studies still require feasibility and safety data from Phase II clinical trials.

During a 2-day workshop, where 80 of the nation's leading researches gathered to discuss their current research in nonsmall cell lung cancer and to identify future clinical research opportunities, scientists discussed whether phase II trials continue to be necessary and concluded that they are still a key component of the clinical trials process. Even though many of the new agents may be cytostatic rather than cytotoxic, participants in the conference felt that phase II trials are still important for evaluating critical endpoints such as time-to-progression and response, and for insuring that all of the toxicity issues have been examined and worked out.

State-of-the-Science workshops are part of the NCI's new framework for treatment clinical trials that bring together small groups of patient advocates with clinical and basic scientists from academia, industry, and the general community in a dialogue geared to identifying future clinical research opportunities.

Addressing the Question: "Why don't all Americans get the best available cancer care?"

The President's Cancer Panel (PCP) has begun a series of regional meetings to hear testimony from all 50 states to address the issue of inequality in cancer care. The first meeting was held in June in Omaha, NE. Additional meetings were held in September in Burlington, VT.; in October in Billings, MT; and in November in Nashville, TN. Future meetings will be held in January 2001 in California; March 2001 in New Mexico; and May 2001 in Washington, DC. By the end of the series of seven meetings, the panel will have received testimony from all 50 states. For more information, visit **www.PCPmeetings.org**.

NCI Reorganizes
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The NCI's major databases such as CANCERLIT® and PDQ®, and the CancerNet™ Web site, will be located and managed within this unit.

The Technologies and Services program includes the Information Resources Branch, the Web Design and Usability Branch, and a new unit for Emerging Technologies. An associate director has not yet been named for this program.

The NCI's public information activities will be served by the Media and Public Communications program. This group incorporates the NCI's public inquiries unit, the Mass Media Branch, and the Cancer Information Service Branch. This program has not yet named an associate director.

NCI Director Meets One-on-One With Scientific Organization Leadership

Recognizing the importance of open communication with the NCI's scientific audience, NCI Director Richard D. Klausner, M.D., each month invites the leadership of a professional society to discuss the needs of the organization and to share information that is pertinent to both the organization and the NCI. Together, NCI Deputy Director Alan S. Rabson, M.D., and the NCI's Office of Liaison Activities coordinate these meetings.

"The meetings are beneficial to both the NCI and the organizations," said Klausner. "They result in new collaborations, enhanced communication, and stronger working relationships."

—T. Clagett

Senior Consultant for Consumer Outreach Appointed

Yvonne Andejeski, M.D., has joined the National Cancer Institute (NCI) as a senior consultant for consumer outreach. She is working with Liaison Activities, where she oversees continuing and new projects and provides programmatic assistance. Such projects include efforts aimed at increasing public access to information and facilitating consumer inclusion throughout the NCI. She is focusing on the development of an application and a selection, training, orientation, and evaluation process designed to bring consumers into NCI activities. She is also interested in outreach to primary care providers.

Dr. Andejeski is a board-certified radiation oncologist at the Walter Reed Army Medical Center and serves as a Lieutenant Colonel in the U.S. Army. She is an active member of several cooperative groups and has served as a radiation oncology coinvestigator on several pediatric clinical trials.

Her experience with the advocacy community is extensive. She served as program director for the Department of Defense Breast Cancer Research Program in 1995, where she was the principal architect of the process to include breast cancer advocates in the first-level review of grant applications submitted each year. She also has led efforts to extend advocacy participation in other Defense Department programs, including the neurofibromatosis, prostate, ovarian, and lung cancer research programs. In addition, she directed a small consumer working group that standardized application processes, developed a minority outreach program, formalized a strong orientation program for scientific and advocacy participants, and created a quality improvement program.

—K. Dionne

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Available now from the National Cancer Institute

The Nation's Investment in Cancer Research
A Plan and Budget Proposal for Fiscal Year 2002

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