C L C CANCER LEADERSHIP COUNCIL

A PATIENT-CENTERED FORUM OF NATIONAL ADVOCACY ORGANIZATIONS ADDRESSING PUBLIC POLICY ISSUES IN CANCER

STATEMENT OF THE
CANCER LEADERSHIP COUNCIL
ON
FY 2001 APPROPRIATIONS
FOR THE NATIONAL INSTITUTES OF HEALTH
SUBMITTED TO THE SENATE APPROPRIATIONS SUBCOMMITTEE
FOR LABOR, HEALTH AND HUMAN SERVICES,
AND EDUCATION
APRIL 2000

The Cancer Leadership Council (CLC) is a forum of national advocacy organizations addressing public policy issues in cancer. CLC participants include organizations representing patients and their caregivers. We are pleased to have this opportunity to submit comments to the Subcommittee regarding funding for the National Institutes of Health (NIH), including the National Cancer Institute (NCI). We are particularly concerned about clinical cancer research and have recommended special actions that must be taken to protect clinical research and ensure that basic research findings are rapidly translated into improved therapies.

FY 2001 NIH FUNDING

The CLC commends the Subcommittee for its leadership in securing substantial increases in funding for NIH in FY 1999 and FY 2000 and ensuring steady progress toward a goal of doubling the NIH budget between 1999 and 2003. Because of the commitment of the Subcommittee to biomedical research, NIH has experienced a period of predictability and stability in its funding, and the research enterprise has benefitted greatly.

The CLC wholeheartedly supports increasing NIH funding by 15 percent in FY 2001, a boost that is necessary to ensure movement toward the year 2003 funding goal. We also urge that Congress fund the NCI according to the Bypass Budget, or at a level of $4.1 billion. The Bypass Budget outlines promising research opportunities that could be funded if NCI receives that level of funding. CLC believes that important cancer research projects are being abandoned because of funding constraints, and Congress could ensure that good science is funded if it meets the Bypass Budget funding recommendation.

COVERAGE FOR CLINICAL TRIALS

In order to move basic research findings to the patient bedside, they must be tested in clinical trials. The optimal clinical trials system is one that enrolls patients promptly and tests therapies rapidly to answer questions about the best possible treatments. Unfortunately, there are a number of barriers that prevent individuals from enrolling in trials and therefore slow the clinical trials process.

CLC and others in the cancer community have worked diligently to remove barriers to patient enrollment in clinical trials, and our efforts have focused on guaranteeing that third-party payers reimburse the routine patient care costs of those enrolled in cancer clinical trials. In this Congress, we are seeking passage of the Medicare Cancer Clinical Trials Coverage Act and inclusion of a clinical trials coverage provision in the Patients' Bill of Rights.

Although Medicare and other third-party payer policies are not in the jurisdiction of the Subcommittee, they are vitally important to the health of the clinical research effort. If researchers face obstacles to enrolling patients in clinical trials due to real or perceived difficulties in reimbursement, the speed and efficiency of clinical trials will be adversely affected and the translation of basic research findings into new therapies will be slowed.

The CLC urges your support for efforts to guarantee third-party reimbursement for those enrolling in cancer clinical trials. This coverage is a necessary component of the biomedical research enterprise and is of utmost concern to cancer patients and their caregivers.

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CLINICAL RESEARCH STUDY SECTION

In the past, CLC has asked the Subcommittee to direct NIH to revise the peer review process to ensure that cancer clinical research proposals receive a fair evaluation. Cancer clinical research proposals have historically been reviewed by basic researchers, and several advisory groups to the NIH have concluded that this results in inequitable review of clinical research because basic researchers are not well versed in clinical research and the challenges associated with it.

This Subcommittee previously directed NIH to alter its peer review process, and the NIH finally responded by establishing a Clinical Oncology Research Special Emphasis Panel. This panel represented a significant advance because it provided for the review of clinical cancer research proposals by clinical researchers. Regrettably, the Center for Scientific Review (CSR) has indicated that it will reinstitute a system in which basic researchers will review clinical research. We urge you to direct the NIH to retain the Special Emphasis Panel and abandon plans for a system in which cancer clinical research will again be reviewed by basic researchers.

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The CLC is pleased to have the opportunity to submit comments to the Subcommittee. This panel's steadfast advocacy for biomedical research is very important to the CLC, and we lend our enthusiastic support to your efforts to enhance NIH funding. We request your special consideration of our proposals to protect and foster clinical cancer research.

Cancer Leadership Council

Alliance for Lung Cancer Advocacy, Support, and Education
American Cancer Society
American Society of Clinical Oncology
Cancer Care, Inc.
Cancer Research Foundation of America
The Children's Cause, Inc.
Cure For Lymphoma Foundation
Coalition of National Cancer Cooperative Groups, Inc.
Colorectal Cancer Network
Kidney Cancer Association
The Leukemia & Lymphoma Society
Multiple Myeloma Research Foundation
National Coalition for Cancer Survivorship
National Patient Advocate Foundation
National Prostate Cancer Coalition
North American Brain Tumor Coalition
Oncology Nursing Society
Ovarian Cancer National Alliance
The Susan G. Komen Breast Cancer Foundation
US-TOO International, Inc.
Y-ME National Breast Cancer Organization