



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

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September 12, 2000

The Honorable J. Dennis Hastert  
Speaker of the House  
H-232 The Capitol  
Washington, D.C. 20510

Dear Mr. Speaker:

As representatives of the cancer patient, survivor, provider and research communities, the undersigned organizations are writing to thank you for your commitment to pass a Patients' Bill of Rights this year. The cancer community has a well-known interest in the clinical trials provision. As negotiations continue, we urge your support for a strong provision that includes access to those trials privately sponsored by the pharmaceutical, biotechnology and medical device industries.

Privately-funded trials are among those most sought after by people with cancer because they feature the exciting new technologies that may offer the most hope of extending survival or improving quality of life. There quality cannot be questioned as they are under review by the Food and Drug Administration (FDA).

It is worth noting that the Health Care Financing Administration (HCFA) has just issued a proposed National Coverage Decision that extends coverage of clinical trials under Medicare not only to government-sponsored research but also to trials by industry that proceed under an investigational exemption from FDA. This administrative decision was reached after the President issued an Executive Memorandum instructing that Medicare cover such trials, both those publicly funded and those funded by the private sector. If this scope of coverage is available for Medicare beneficiaries, we believe it unquestionably is appropriate for those enrolled in private health plans.

If the universe of privately-sponsored clinical trials is omitted from coverage, the Congress will have done only half of the job that is needed to address the concerns of cancer patients — and others with serious or life-threatening diseases — about access to potentially life-extending clinical trials. As you proceed with deliberations over the Patients' Bill of Rights, your support for this critical enhancement will be greatly appreciated.

#### **Cancer Leadership Council**

Alliance for Lung Cancer Advocacy, Support, and Education  
American Cancer Society  
American Society of Clinical Oncology  
Association of American Cancer Institutes  
Cancer Care, Inc.  
Cancer Research Foundation of America  
The Children's Cause, Inc.  
Coalition of National Cancer Cooperative Groups  
Colorectal Cancer Network  
Cure For Lymphoma Foundation  
International Myeloma Foundation  
Kidney Cancer Association  
The Leukemia & Lymphoma Society

Multiple Myeloma Research Foundation  
National Alliance of Breast Cancer Organizations  
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  
Pancreatic Cancer Action Network  
The Susan G. Komen Breast Cancer Foundation  
US-TOO International, Inc.  
Y-ME National Breast Cancer Organization

cc:

Patients' Bill of Rights Conferees