

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

March 29, 2001

The Honorable Deborah Pryce U.S. House of Representatives 221 Cannon House Office Bldg. Washington, D.C. 20515

Dear Representative Pryce:

On behalf of the patient advocate, professional and research organizations that comprise the Cancer Leadership Council (CLC), we applaud your leadership on the important issue of cancer clinical trials. Specifically, we greatly appreciate your introduction, together with Representatives Maloney, Myrick and Bentsen, of H.R. 967, the Access to Cancer Clinical Trials Act of 2001.

Cancer strikes one in every two American men and one in every three American women. In the United States, one in every four deaths results from cancer. There is no greater public health threat, and any measures that advance progress against the disease are welcome. The cancer community understands that reductions in morbidity and mortality from cancer will be achieved only through carefully designed and conducted clinical trials, and legislation that ensures patient access to trials is sorely needed, both for the benefit of individual patients and in service to the public health.

The best example of the potential benefits of greater participation in clinical trials is childhood cancer, where remarkable strides have been made against the most common cancers through routine enrollment in clinical trials. It is surely no accident that some of the greatest progress against cancer has been made in a setting in which up to 80% or more of patients are enrolled in trials.

On an individual basis, many people with cancer seek to participate in clinical trials because they believe investigational therapy may be their best option, especially in the case of cancers that have no curative treatment. Unfortunately, many health plans routinely deny patients the ability to enroll in clinical trials, thus depriving them of the value of their health insurance at the time they are most in need. Your legislation will prohibit this practice and in so doing will help to improve cancer care not just for the individuals involved but for all of us who look forward to better cancer treatments through clinical trials.

We understand that a similar provision covering all serious and life-threatening disease is included in versions of the Patients' Bill of Rights legislation. However, your legislation is the most comprehensive effort yet to provide complete coverage of cancer clinical trials, and, should there be no Patients' Bill of Rights enacted in this session of Congress, H.R.967 will provide a ready opportunity to address this important consumer protection issue without further delay.

Again, thanks very much for your efforts on this bill and on all the many initiatives you have undertaken on behalf of people with cancer.

Cancer Leadership Council

Alliance for Lung Cancer Advocacy, Support, and Education American Cancer Society American Society of Clinical Oncology American Society for Therapeutic Radiology & Oncology, Inc. 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 The Wellness Community US TOO! International, Inc. Y-ME National Breast Cancer Organization

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