



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

March 14, 2000

HAND-DELIVERED

To PBR Conferees

The Honorable

Washington, D.C. 20515

Dear Representative:

The undersigned organizations advocate on behalf of people with cancer, their caregivers and not-for-profit organizations that fund cancer research. For cancer patients, there is no more important provision in the Patients' Bill of Rights than the requirement of coverage of routine patient care costs for persons enrolled in cancer clinical trials. Only through support of clinical research—including required payment for routine patient care costs—will patients have access to potentially life-extending cutting-edge therapies, and society as a whole will make progress against cancer, a major source of morbidity and mortality in this country.

Over the course of the past few years, the Congress has made and thus far honored a commitment to double the budget of the National Institutes of Health as a way to take advantage of the many opportunities now presented by biomedical research discoveries. This investment will be optimized only if the health care system does its part so that research discoveries will be translated into clinical applications that will reach patients. The responsibility of health plans is to honor insurance contracts by covering routine patient care costs. We emphasize that these costs—including such matters as the usual physician and hospital charges and routine diagnostic tests—are normally borne by third-party payers, and the fact that they are incurred in the context of a clinical trial does not relieve payers of their obligation. If the clinical trial is permitted to excuse payers from responsibility for covering these routine costs, the payers will receive a great windfall and patients will be deprived of the value of their insurance.

While we are very supportive of cancer clinical trials coverage and appreciative of those who have championed it, it is important to note that covering only government-sponsored trials, such as those emanating from NIH, will address only half the problem. It is estimated that trials sponsored by NIH and other government agencies include no more than about half of all new cancer therapies. The other half are in trials sponsored by industry. Not infrequently, it is these industry-sponsored trials that offer the new agents so desperately sought by cancer patients. The review to which these industry-sponsored trials are subjected by the Food and Drug Administration is at least as rigorous medically, scientifically and ethically as those reviewed by NIH or other funding agencies. Complete relief requires that coverage be extended to industry-sponsored cancer clinical trials reviewed by FDA.

As you enter deliberations over a final Patients' Bill of Rights, we speak for more than 8 million cancer survivors in urging you to include a provision requiring coverage of routine patient care costs for those enrolled in high-quality cancer clinical trials, whether sponsored by government funding agencies or by industry after review by FDA. In doing so, you will be enhancing the quality of care for people with cancer while also ensuring that medical progress against this terrible disease will continue.

Cancer Leadership Council

Alliance for Lung Cancer Advocacy, Support and Education
American Cancer Society
American Society of Clinical Oncology
American Society for Therapeutic Radiology and Oncology, Inc.
Cancer Care, Inc.
Cancer Research Foundation of America
Coalition of National Cancer Cooperative Groups, Inc.
The Children's Cause, Inc.
Colorectal Cancer Network
Cure For Lymphoma Foundation
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
Ontology Nursing Society
Ovarian Cancer National Alliance
Pancreatic Cancer Action Network
Susan G. Komen Breast Cancer Foundation
US-TOO International, Inc.
Y-ME National Breast Cancer Organization

cc:
Patients' Bill of Rights Conferees

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PATIENTS' BILL OF RIGHTS (PBR) CONFEREES

The Honorable Bill Archer
The Honorable Michael Bilirakis
The Honorable Thomas J. Bliley, Jr.
The Honorable John A. Boehner
The Honorable John D. Dingell
The Honorable Nancy L. Johnson
The Honorable Frank Pallone, Jr.
The Honorable Charles B. Rangel
The Honorable John B. Shadegg
The Honorable Fortney H. Stark
The Honorable James M. Talent
The Honorable William M. Thomas
The Honorable Ernest Lee Fletcher
The Honorable William L. Clay, Sr.
The Honorable Robert E. Andrews
The Honorable Porter J. Goss
The Honorable Marion Berry
The Honorable Christopher J. Dodd
The Honorable Michael B. Enzi
The Honorable William B. Frist
The Honorable Phil Gramm
The Honorable Judd Gregg
The Honorable Tom Harkin
The Honorable Kay Bailey Hutchison
The Honorable James M. Jeffords
The Honorable Edward M. Kennedy
The Honorable Barbara A. Mikulski
The Honorable Don Nickles
The Honorable John D. Rockefeller