



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

June 13, 2001

The Honorable John McCain
241 Senate Russell Office Building
Washington, D.C. 20510

The Honorable Edward Kennedy
315 Senate Russell Office Building
Washington, D.C. 20510

The Honorable John Edwards
225 Senate Dirksen Office Building
Washington, D.C. 20510

Dear Senators McCain, Kennedy and Edwards:

On behalf of cancer patient advocates, health care professionals and research organizations, the undersigned organizations thank you for your vital leadership in introducing a Patients' Bill of Rights that provides comprehensive coverage for routine patient care costs in clinical trials. Notably, your legislation covers all high quality clinical trials, not just those sponsored by government funding agencies. As cancer drug development is increasingly undertaken by the pharmaceutical and biotechnology industries, it is essential that their trials be accessible to cancer patients, and your legislation will achieve this result. In addition, your bill provides a workable definition of "routine patient care costs" that will enable implementation to proceed expeditiously.

One of the primary objectives of advocacy by the cancer community over the past decade has been assured coverage of routine patient care costs in clinical trials. Last year, the Medicare program acted pursuant to executive memorandum to extend coverage to all trials conducted under the auspices of either government funding agencies like the National Institutes of Health (NIH) or the regulatory oversight of the Food and Drug Administration (FDA). If such a policy is appropriate for the Medicare program, surely it should be a guaranteed right for patients under private health plans.

Recent reports in the scientific and popular press have highlighted the impressive advances in development of cancer drugs that are both more effective and less toxic than traditional treatments. People with cancer should have early access to these investigational drugs, as well as investigational devices, in the context of high quality clinical trials. Without a comprehensive coverage provision, patients will continue to be at the mercy of health plans' inconsistent approach to this issue. For this reason, we strongly support the clinical trials provisions contained in S. 283 and look forward to their eventual enactment.

The 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.
Association of American Cancer Institutes
Cancer Care, Inc.
Cancer Research Foundation of America
The Children's Cause, Inc.
Coalition of National Cancer Cooperative Groups, Inc.
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
Ovarian Cancer National Alliance
Pancreatic Cancer Action Network
Susan G. Komen Breast Cancer Foundation
US TOO! International, Inc.
The Wellness Community
Y-ME National Breast Cancer Organization

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