



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

July 24, 2000

Nancy-Ann Min DeParle
Administrator
Health Care Financing Administration
Department Health & Human Services
200 Independence Ave., S.W.
Room 314-G B HHH Bldg.
Washington, D.C. 20201

Dear Ms. DeParle:

We write to you as representative leadership of the cancer treatment, research, support, and advocacy community to ask that you once again become personally involved in the implementation of the President's Executive Memorandum announced on June 7, 2000. The Executive Memorandum was intended to resolve an issue that had been of longstanding concern to us--i.e., the question of Medicare reimbursement for routine patient care costs for beneficiaries enrolled in clinical trials. The announcement was made after the White House expressly promised representatives of the community that the Administration's initiative would cover all phases of clinical trials and would include not just government-sponsored trials but also those sponsored by the private sector. The White House also represented that this agreement was reached only after consultation with both the Health Care Financing Administration (HCFA) and the National Institutes of Health (NIH).

The community has now met three times with HCFA staff and seen some progress, but no firm resolution of implementation efforts. Recently, additional scheduled meetings have been postponed and not rescheduled. In the absence of these meetings, we are hearing from a variety of concerned parties that efforts to dilute and diminish the scope of coverage promised in the President's announcement are underway. These reports raise questions about the resolve of the Administration, and specifically HCFA, to honor the promises made to the cancer community. It was on the basis of those promises that we stood with a bipartisan group of Senators and Representatives to issue press releases and praise publicly the Administration for its action. And it was those promises that led to favorable coverage for President Clinton and Vice President Gore in national television and print media. If those promises are not fulfilled, some will believe that the public record should be corrected.

To clarify our position, we will not be satisfied with coverage of clinical trials that does not cover, as represented, all phases of clinical trials and privately-sponsored trials as well as those that are government-sponsored. These issues have been reviewed time and again over the years, have resulted in state-by-state coverage of all phases of cancer clinical trials, and, in our view, were thankfully resolved for Medicare by Executive decision of the President. The cancer community wants to know, does HCFA now stand in opposition to that decision?

At the last meeting with HCFA staff, the community was promised a final decision consistent with our understanding of the Executive Memorandum no later than mid-September. We expect HCFA to honor that commitment, but, based on recent events, the cancer community questions the agency's willingness to meet that deadline or to abide by the President's promises.

The Cancer Leadership Council (CLC) is next meeting September 7. We are inviting you and your staff, as well as key officials of NIH and the Food and Drug Administration (FDA), to explain the position of the Administration on this issue of utmost importance to people with cancer.

With respect and in appreciation for your leadership on these matters, we thank you in advance for your personal intervention so that bureaucratic resistance to implementing the good intentions of the Administration does not thwart the reasonable expectation of hundreds of thousands of Medicare beneficiaries living under a diagnosis of 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.
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:

The Honorable William Jefferson Clinton, President of the U.S.
The Honorable Albert Gore, Vice President of the U.S.
The Honorable Donna Shalala, Secretary, HHS
Ruth Kirschstein, M.D., Acting Director, NIH
Jane E. Henney, M.D., Commissioner, FDA
The Honorable Connie Mack
The Honorable John D. Rockefeller
The Honorable Nancy L. Johnson
The Honorable Benjamin L. Cardin
The Honorable Ken Bentsen
The Honorable Henry A. Waxman