



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

June 30, 2009

Dear Member of Congress:

The undersigned cancer organizations commend your commitment and substantial effort to drafting a health reform measure to meet the goals of expanding coverage to uninsured Americans while enhancing health care quality, reducing costs, and protecting consumer choice. Cancer patients, health care providers, and researchers routinely confront the significant problems that occur when cancer patients do not have adequate insurance or when there are lapses in the quality of the care they receive. We support reform to provide all Americans consistent access to quality health care.

- *Include insurance market reforms in any reform plan.* We are pleased that the major reform proposals under consideration would guarantee issue of coverage and eliminate pre-existing conditions limitations. These market reforms are critical for cancer patients, who often find they are “uninsurable” after their diagnosis or can only obtain inadequate insurance at an insurmountable price.
- *Protect consumers from annual and lifetime insurance limits.* We applaud Congress for proposing protections from annual and lifetime insurance limits. Cancer is a chronic disease for many, and as a result many patients face a lifetime of cancer treatment. It is increasingly likely that cancer survivors will confront insurance caps and as a result be forced to make very difficult decisions about the care they will receive and how to pay for it.
- *Eliminate cost-sharing requirements for prevention and screening services.* Congress has demonstrated its commitment to improved access to and utilization of prevention care and screening services by recommending the elimination of cost-sharing requirements. We strongly support this reform, along with efforts to strengthen the “Welcome to Medicare” physical examination. To ensure that new preventive and screening technologies are rapidly incorporated into practice, health plans should be required to cover these services according to evidence-based guidelines, including those issued by the US Preventive Services Task Force and other appropriate organizations.

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- *Protect important coverage standards.* Cancer advocates have worked steadily for more than a decade to ensure that third-party payers cover the routine patient care costs incurred in clinical trials. The Medicare clinical trials coverage policy has been in place since 2000, and more than half of the states have enacted clinical trials coverage laws. These coverage standards ensure that cancer patients can receive their care in clinical studies, providing them access to all treatment options and ensuring that the pace of clinical research is not slowed by reimbursement issues. The availability of third-party payment for routine patient care costs will be critically important for the smooth functioning of clinical trials, a key element of a comparative clinical effectiveness research effort. We strongly recommend that reform legislation provide that clinical trials coverage requirements and other consumer protections that have been enacted by the states will remain in effect.
- *Include patient advocates and medical professionals in any advisory panel with responsibility for defining the benefit package.* Cancer patient advocates and health care professionals providing cancer care should be included in the benefits package advisory panel. The work of defining a benefits package should not be left solely to government officials, health plan officials, and health economists without patient and provider input. Patients and health care providers bring important expertise and experience to inform benefit design and ensure that the benefit package reflects the needs of patients. The advisory panel should also have procedures for public participation and to permit rapid revision of the benefit package, if medical evidence supports such changes.
- *Use demonstration project authority to test new systems for providing and reimbursing cancer care.* We are pleased by the strong Congressional interest in testing new systems for providing and paying for quality health care, including special emphasis on enhancing the coordination of care and improving the tools of patients and health care providers for better decision-making. We urge the investigation and evaluation of patient-centered models of cancer care that would encourage patient participation in treatment decision-making. A patient-focused system of care would include among its features written plans for care at the beginning of active treatment and at the initiation of survivorship monitoring and care.

We look forward to working with you and the Obama Administration to advance health reform legislation.

Sincerely,

Cancer Leadership Council

American Cancer Society Cancer Action Network
American Psychosocial Oncology Society
American Society for Radiation Oncology
Bladder Cancer Advocacy Network
Breast Cancer Network of Strength
C3: Colorectal Cancer Coalition
Cancer Care
The Children's Cause for Cancer Advocacy
Coalition of Cancer Cooperative Groups
International Myeloma Foundation
Lance Armstrong Foundation
The Leukemia & Lymphoma Society
Lymphoma Research Foundation
National Coalition for Cancer Survivorship
National Lung Cancer Partnership
National Patient Advocate Foundation
North American Brain Tumor Coalition
Ovarian Cancer National Alliance
Pancreatic Cancer Action Network
Prevent Cancer Foundation
Sarcoma Foundation of America
Susan G. Komen for the Cure Advocacy Alliance
Us TOO International Prostate Cancer Education and Support Network
The Wellness Community