



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

April 28, 2009

The Honorable Edward M. Kennedy
United States Senate
Washington, D.C. 20510

The Honorable Kay Bailey Hutchison
United States Senate
Washington, D.C. 20510

Dear Senators Kennedy and Hutchison:

The undersigned cancer patient, research, and provider organizations appreciate your commitment to legislation to revitalize the nation's cancer research effort and enhance access to quality cancer care. We look forward to working with you to ensure that the 21st Century Cancer Access to Life-Saving Early Detection, Research, and Treatment (ALERT) Act meets the pressing needs of those living with cancer and those who will be diagnosed this year and in the future.

We offer the following recommendations for modifications, additions, and deletions to the ALERT Act.

- *Ensure access to care in clinical trials without regard to type of insurance plan of the cancer patient.*

The ALERT Act provisions on clinical trial coverage would apply only to a portion of private health insurance plans and as a result would prevent many with cancer from considering care in a clinical trial. Access to care in a clinical trial should not depend on the nature of insurance coverage; instead, such coverage should be an integral component of any health care system. We urge substitution of the language of the Access to Cancer Clinical Trials Act (S. 488/H.R. 716), which applies to all private insurance plans, for the clinical trials language in the ALERT Act.

Substitution of the language of S. 488/H.R. 716 would address the potential problems created by the ALERT Act's prohibition of coverage of costs that are "necessitated solely because of the trial." This language will create uncertainty about third party coverage of routine care costs and as a result will discourage patients from trial enrollment. In contrast, S. 488 and H.R. 716 define covered costs with admirable clarity.

- *Encourage care planning for all cancer patients.*

We propose that the language of the Comprehensive Cancer Care Improvement Act (H.R. 1844) establishing a Medicare cancer care planning service replace the cancer care planning demonstration currently included in the ALERT Act. Providing all Medicare beneficiaries access to cancer care and survivorship planning honors the recommendations of the Institute of Medicine (IOM) for better coordination of cancer care. The demonstration project included in the ALERT Act would be implemented in only six sites and would take a number of years to implement and evaluate, a period of time during which most Medicare beneficiaries would be denied access to a standard of care repeatedly endorsed by the IOM.

- *Guarantee that those diagnosed with cancer through federally supported screening programs have access to cancer care.*

We commend your decision to provide access to care for those who are diagnosed through the colorectal cancer screening program. The experience with the National Breast and Cervical Cancer Early Detection Program underscored the serious problems that are created when individuals are diagnosed with cancer through a public screening program and are then unable to receive appropriate care. We urge you to resist efforts to remove from the ALERT Act the provisions that would help those diagnosed in the screening program obtain necessary care.

We recommend two changes in the language authorizing the colorectal cancer screening program. We propose that grantees be permitted some flexibility regarding the utilization of funds for outreach and education, at least in the early years of the program and subject to a justification that additional funds are need for those purposes. The authorization should also permit adjustment in payment rates for screening services, if technological changes justify such modifications. These issues can be addressed by incorporating the language of H.R. 1189, the Colorectal Cancer Prevention, Early Detection, and Treatment Act.

- *Ensure that the cancer research program reflects the diversity of cancer and cancer research.*

Although important strides have been made in the treatment of some types of cancer, for many others the pace of discovery and therapeutic development is slow and improvements in survival are limited. In addition, many survivors suffer serious late and long-term effects of their treatment. There remains a pressing need to improve treatments for all cancers, including by minimizing the side effects of treatment.

The research and development provisions of the ALERT Act should reflect the realities and difficulties of cancer research and the diversity of the scientific and clinical challenges of cancer research. The provisions of the bill requiring reports about grants for high-mortality cancers and low-incidence cancers will provide valuable information for assessing the cancer research program. We recommend greater accountability and transparency regarding all National Cancer Institute (NCI) investments.

- *Eliminate the reference to “complete recovery care.”*

We applaud the inclusion of provisions that acknowledge the psychosocial needs of cancer patients and that authorize programs to improve the delivery of such services. We recommend, however, that the phrase “complete recovery care” be replaced by the phrase “coordinated cancer care.” Although many cancer patients enjoy a long period of survivorship, few achieve “complete recovery,” which would seem to mean either cure or treatment without late and long-term effects. We recommend the wording change so the legislation and this provision more accurately reflect the current experience of most cancer survivors and the benefits of coordinated cancer care, including appropriate symptom management.

- *Invest in clinical research to ensure optimal translation of basic research findings into new and better therapies.*

We recommend that the ALERT Act be amended by the addition of provisions to strengthen the existing clinical trials infrastructure. This could be accomplished by authorizing payments to clinical researchers that are adequate to match the costs associated with enrolling patients in trials and by strengthening programs that encourage active participation of community oncologists in clinical research.

- *Achieve a Cancer Human Biorepository Network by utilizing new technologies.*

The language of the ALERT Act should clarify that the Cancer Human Biorepository Network will be a virtual network that would link existing biospecimen repositories into an interoperable system that would facilitate research. We believe that maximum collaboration of institutions and investigators could be achieved by structuring the network as a virtual one and utilizing technology to achieve interoperability in collection, storage, and sharing of biospecimens and data.

- *Develop the oncology workforce of the future.*

One of the most serious issues confronting the cancer community in the 21st century will be the inadequacy of the oncology workforce. It is projected that the workforce will be woefully inadequate to meet the needs of an aging population that already accounts for 60 percent of cancer diagnoses and will account for a larger portion in the future. The ALERT Act is silent on this issue, save a modest nurse education provision. Additional legislation will be necessary in the near future to address the supply, education, and distribution of oncology providers, including physicians and nurses.

We appreciate the opportunity to offer these recommendations regarding the ALERT Act and look forward to working with you on this legislation.

Sincerely,

Cancer Leadership Council

American Society of Clinical Oncology
American Society for Radiation
Oncology
Bladder Cancer Advocacy Network
Breast Cancer Network of Strength
C3: Colorectal Cancer Coalition
Cancer Care
Coalition of Cancer Cooperative Groups
International Myeloma Foundation
Kidney Cancer Association
The Leukemia & Lymphoma Society
Lymphoma Research Foundation

Multiple Myeloma Research Foundation
National Coalition for Cancer
Survivorship
National Lung Cancer Partnership
North American Brain Tumor Coalition
Ovarian Cancer National Alliance
Prevent Cancer Foundation
Sarcoma Foundation of America
Us TOO International Prostate Cancer
Education and Support Network
The Wellness Community

cc: Members of HELP Committee