



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

July 15, 2008

The Honorable Arlen Specter
711 Hart Building
United States Senate
Washington, D.C. 20510

Dear Senator Specter:

The undersigned organizations, representing cancer survivors, researchers, and physicians, are writing to share our views about the resources and strategies that will be required to cure cancer. We understand that you have asked a number of cancer organizations for advice about the resources necessary for the fight against cancer. Although our coalition did not receive a direct inquiry, we write to share our opinions about the campaign to cure cancer.

Many of our individual organizations were founded with the specific mission of curing cancer, and we remain dedicated to that aim. We are therefore buoyed by your focus on this ambitious goal. However, we have increasingly found that the effort to cure cancer is a multi-faceted one that must include not only an aggressive basic, translational, and clinical research program but also must ensure that Americans have access to screening tests, early diagnostic tools, and the best cancer care available, including survivorship care. An initiative to find a "cure" must combine the most outstanding research program possible with the most stellar system of care possible.

We recommend that a renewed and revived cancer program include the following elements:

- *Basic research.* A core element of an initiative to cure cancer is a basic research program that is aggressively supported, ensures that deserving new research grants are appropriately funded, and guarantees that outstanding projects receive continuation funding in order to realize their full potential. It is important that groundbreaking research projects be supported, and it is also critical that researchers be reassured that the National Institutes of Health grants program is adequately funded so that it can support their quality research efforts. Unless the federal government sends this clear message, researchers will leave academic research for other fields of endeavor. Absent firm action, we are at risk of losing a generation of talented researchers and allowing our cutting-edge basic research program to deteriorate.

- *Translational and clinical research.* A translational and clinical research program must be fully supported in order to eliminate the current roadblocks delaying translation of basic research into new therapies. Sustaining a viable translational and clinical research program will require that cancer centers, cooperative groups, the community clinical oncology program, and the entire infrastructure for translational and clinical research at the National Cancer Institute (NCI) be supported at the level that those entities identify as necessary to support and encourage cancer therapeutic development. Other promising mechanisms for translational and clinical research, including the Specialized Programs of Research Excellence (SPOREs), have shown early promise, and they should be funded at reasonable levels if their promise is to be achieved.
- *Access to clinical trials.* Clinical trials are the engine for development of new therapies, yet the system in the United States is showing significant stresses and strains. Immediate action should be taken soon to address the several problems facing the clinical trials system. The infrastructure for clinical research described above must be appropriately funded. Achieving a sufficient level of support will require substantial increases in the payments that researchers with NCI grants receive for enrolling patients in trials. Moreover, the NCI rate of per-patient payment for enrollment in trials must be boosted as trials become more expensive in an age of testing and developing targeted therapies. In addition to enhancing payment for the research costs associated with clinical trials, the barriers to payment for routine patient care costs for those enrolled in clinical trials must be addressed. Medicare has a policy for coverage of the routine patient care costs incurred by those enrolled in trials that has had a positive impact on the enrollment of seniors in clinical trials. The Medicare coverage standard should be adopted and implemented by private and other public payers.
- *Access to screening tests.* The infrastructure for providing uninsured and underinsured individuals breast and cervical cancer screening services is in place, yet the funding has never been adequate to meet the need. In addition, the current screening program does not include colorectal cancer screening services. We recommend that the current cancer screening program be expanded to meet the need for breast and cervical cancer screening services, and that Congress support incorporation of colorectal cancer screening and treatment services into that program as rapidly as possible and make additional screening services available when recommended by public health authorities.
- *Access to care.* Some of the organizations who are signatories to this letter have documented the significant problems that Americans face in obtaining quality cancer care. Many Americans are diagnosed with cancer very late because of their limited access to health care – the result of lack of insurance or lack of adequate insurance – and they receive inadequate care even when they are diagnosed. The disturbing findings about the substantial barriers to cancer care persuade us that a reinvigorated program to cure cancer must include program elements to guarantee that all Americans have access to the best possible care that is available at the time of diagnosis and that they continue to receive care appropriate to cancer survivorship. A cure will never be realized if Americans do not receive cancer care when they need it. We now understand that individuals who are diagnosed with cancer may experience late and long-term effects of

cancer and cancer treatment, and survivors must have access to comprehensive, coordinated, and long-term survivorship care that addresses the transition from patient to survivor.

We offer our recommendations for your consideration and as a complement to other advice you have been provided. The comprehensive approach we recommend – combining a reinvigorated research program and access to cancer screening and care upon diagnosis – would require an aggressive fiscal commitment. We believe that the cancer research program could be responsibly doubled in short order, and that a comparable commitment could be made to ensuring access to quality cancer care.

We are mindful of the current budget situation and the odds against a rapid infusion of funds into cancer research and care. However, a dedicated and sustained effort to cure cancer deserves no less commitment from the American people and their leaders.

Cancer Leadership Council

American Cancer Society Cancer Action
Network
American Psychosocial Oncology Society
American Society for Therapeutic
Radiology & 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
Kidney Cancer Association
Lance Armstrong Foundation

The Leukemia & Lymphoma Society
Lymphoma 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
Susan G. Komen for the Cure Advocacy
Alliance
Us TOO International Prostate Cancer
Education and Support Network
The Wellness Community

cc: The Honorable Tom Harkin