



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

June 20, 2007

Dear Senator/Representative:

The undersigned organizations, representing cancer survivors, physicians, and researchers, are writing to urge Congress to protect and foster the nation's cancer research infrastructure. The current system for investigating new strategies for the prevention, diagnosis, and treatment of cancer is under significant pressure, and the challenges to the system will be felt most acutely by the 10 million Americans living with cancer and the 1.5 million more who will be diagnosed with cancer this year. For all of them, the hope of surviving cancer and enjoying a high quality of life depends on research.

Funding for cancer research has been static, which translates to a decline in real terms. Of grave concern to cancer advocates is the impact of the budget on clinical cancer research. We have already observed the elimination of clinical trial enrollment opportunities, termination of research efforts directed at those cancers with the most limited early detection and treatment options, and an overall slowing of the pace of clinical investigation for all types of cancer. This is not an acceptable trend.

Cancer Clinical Research Infrastructure

The federal government has invested in cancer research for decades, a commitment that intensified after we declared War on Cancer and reached its pinnacle during the period from 1998 to 2003 when the entire National Institutes of Health (NIH) budget was doubled. Strong financial support for the National Cancer Institute (NCI) has yielded important benefits, including:

- Development of a cancer clinical trial cooperative group program that supports clinical trials to evaluate new cancer treatments, diagnostic tools, and preventive strategies.
- Support for 63 cancer centers located around the country that are specialized centers for research on the nature of cancer and improved therapies for all forms of cancer.
- Mechanisms to encourage and facilitate the participation of community oncologists in clinical trials, which ensures broad patient access to clinical trials and rapid dissemination of new treatment opportunities.
- Support -- both financial and scientific -- for a dynamic research community that has provided a supportive environment for established researchers and new researchers alike.
- Funding through special mechanisms -- including the Specialized Programs of Research Excellence (SPOREs) -- for translation of basic research findings into new therapeutic candidates.

The core of the cancer research system is the ability to efficiently test therapies to determine if they are safe and effective. Through the clinical trials system, we have realized incremental but important advances in treatment that are improving survival rates for many cancers and turning certain forms of cancer into a manageable chronic disease.

Recent Cancer Clinical Research Advances

Among the recent cancer research accomplishments are:

- ***The ability to identify molecular markers that predict prognosis.*** Research in the NCI cooperative groups has led to the identification of tumor characteristics that may predict the prognosis of patients with oligodendroglioma, a form of brain tumor, and research is yielding comparable information about patients with other forms of cancer, as well.
- ***Development of therapies that prevent cancer recurrence and improve survival.*** Federal funds were critical to the completion of a trial that concluded that trastuzumab (Herceptin) cuts breast cancer recurrence in half and increases survival and a trial that concluded that bevacizumab (Avastin) improves the survival of lung cancer and colorectal cancer patients. In addition, a recent cooperative group study in advanced prostate cancer patients found that radiation therapy after surgery resulted in a three-fold improvement in cancer-free survival.
- ***Improving strategies for the prevention of invasive breast cancer.*** The cancer cooperative groups played a critical role in identifying the role of hormonal agents in reducing the risk of invasive breast cancer.
- ***Identifying the genetic basis for familial clustering of pancreatic cancer.*** This research was undertaken through two SPOREs and PACGENE, a consortium of centers with pancreatic cancer experience. This consortium has also identified major risk factors for pancreatic cancer, including smoking.
- ***Enhancing the quality of life of cancer survivors through research on side effects of treatment and interventions to address late and long-term effects.*** Report from a major study of adult survivors of childhood cancers identified significant side effects from treatment and recommended enhanced, long-term follow-up medical care for these survivors.
- ***Turning certain forms of cancer into chronic disease.*** Cooperative group investigations concluded that maintenance use of Rituxan slows disease progression in those with advanced follicular lymphoma.

None of these important research advances would have been possible without the existence of the current system of cancer clinical research supported by federal dollars through NCI.

The Clinical Research System at Risk

The cancer clinical research enterprise is at grave risk because the federal cancer research budget has been static in years since 2003 or has suffered minor cuts in funding. But even a static budget is a reduced budget because it does not account for the biomedical research inflation rate.

Moreover, the climate of uncertainty about funding has already had a negative impact on clinical research.

In response to the current fiscal situation, some clinical research groups have already terminated trials that were slow to accrue patients; eliminated research efforts targeted to certain cancers, including brain tumors, head and neck cancer, sarcoma, and melanoma; curtailed certain tissue banking efforts; and delayed initiation of many trials. Other elements of the clinical research effort are also under stress. Cancer centers are being asked to do more with less, and SPORes remain under threat of streamlining or elimination. The weakening of these clinical research entities will have the effect of further slowing the pace of discovery of new treatments for cancer.

Especially troubling for the future is the fact that young cancer clinical investigators are leaving the field and students are declining to consider careers as clinical researchers. As the population ages and the burden of cancer intensifies, this is a very disturbing trend.

Recommendations of Cancer Advocates

Cancer survivors, physicians, researchers, and caregivers recommend several actions to protect cancer clinical research and the pace of cancer research.

- ***Boost NIH funding by 6.7 percent in FY 2008 and ensure that NCI receives an increase comparable to the overall enhancement in funding.*** This consensus recommendation from the biomedical research community will do no more than allow NIH to make up ground lost to biomedical research inflation since 2003 and match inflation in 2008. Comparable increases will be necessary in FY 2009 and FY 2010 to prevent further erosion due to inflation.
- ***Protect cancer clinical cooperative group funding.*** After successive decreases in funding since 2002, cooperative group funding has been stabilized at the FY 2006 level for FY 2007. For FY 2008 and beyond, an increase in funding is needed to restore lost infrastructure; alleviate the pressure to decrease accrual, delay or eliminate trials; keep pace with the rising costs of clinical research; and expand the trial portfolio to accommodate the ever growing number of new molecules and approaches to treat cancer patients. This recommendation is in keeping with the overall NIH funding proposal because it focuses on protecting the past federal investment in cancer research and preventing further deterioration in the pace of cancer clinical research.
- ***Restore funding to the Community Clinical Oncology Group (CCOP) Program.*** The CCOPs are funded through an NCI grant mechanism separate from the cooperative groups. The 61 CCOPs spread across the nation form the bulwark of community-based cancer clinical trial treatment and prevention research in urban and rural communities. The CCOPs have experienced annual budget cuts from FY 2004 to FY 2007, with the cuts in 2007 ranging from 5 to 8 percent. The CCOPs, which serve rural communities and underserved populations, must be provided funding in the future that is adequate to permit them to assist this diverse cancer patient community.
- ***Protect other elements of the cancer research enterprise, including cancer centers and SPORes.*** Important translational research initiatives will be interrupted or terminated if

SPOREs are eliminated. Moreover, the critical research mission of cancer centers, which are being asked to shoulder increased research responsibilities, will be disrupted if their funding remains stagnant.

CONCLUSION

For all of the above reasons, the undersigned groups encourage Congress to restore funding for these vital programs and make a commitment to ongoing support for them in the future.

Sincerely,

Cancer Leadership Council

American Cancer Society Cancer
Action Network
American Psychosocial Oncology Society
American Society of Clinical Oncology
American Society for Therapeutic
Radiology & Oncology
Bladder Cancer Advocacy Network
C3: Colorectal Cancer Coalition
Cancer Care
Cancer Research and Prevention Foundation
The Children's Cause for Cancer Advocacy
Coalition of Cancer Cooperative Groups
Fertile Hope
International Myeloma Foundation
Kidney Cancer Association
Lance Armstrong Foundation

The Leukemia & Lymphoma Society
The Lung Cancer Alliance
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
Sarcoma Foundation of America
Susan G. Komen for the Cure
Us TOO International Prostate Cancer
Education and Support Network
The Wellness Community
Y-ME National Breast Cancer Organization