

**Testimony of the
Pancreatic Cancer Action Network, Inc. (PanCAN)
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**Submitted to the
Labor, Health and Human Services and Education Subcommittee
of the House Appropriations Committee**

**By Ms. Julie Fleshman
President & CEO
PanCAN
on April 15, 2005**

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Dear Chairman Regula and Colleagues:

Every 17 minutes someone in the United States dies of pancreatic cancer. This year, over 32,180 Americans will be diagnosed with pancreatic cancer and 31,800 will die from this disease. The 99% mortality rate for pancreatic cancer remains the highest of all cancers, and the average life expectancy is three to six months after diagnosis with metastatic disease. There are no early detection programs, effective treatments or cures for pancreatic cancer. At a time when so much progress is being made in medical research, extremely few options exist for pancreatic cancer patients. Additional medical research is necessary to develop treatments and a cure for this disease.

The Pancreatic Cancer Action Network (PanCAN) was founded in 1999 to focus national attention on the need to find the cure for pancreatic cancer. PanCAN provides public and professional education that embraces the urgent need for more research, effective treatments, prevention programs, and early detection methods. PanCAN is the first and only national patient based advocacy organization specifically focused on pancreatic cancer. We now have a full time staff of 19, and 82 volunteer "Team Hope" affiliates in communities across the country, comprised of thousands of volunteers who seek to increase awareness about this disease, raise funds, and voice their concern that there is a desperate need to find a cure for pancreatic cancer.

Let me begin by stating that recent polls indicate that the American public supports increased Federal funding for medical research. In February, the Trust for America's Health (TFAH) released the results of a poll on America's Top Health Concerns and Emergency Preparedness (see www.healthyamericans.org) from a survey conducted this past January. The results show that 37% of Americans rank cancer as their top individual health concern. TFAH further notes that in 2003, the federal government spent 92 percent of its health dollars on diagnosis and treatment of disease, and eight percent of its health dollars on researching causes and preventing disease. The poll also indicated that over 70 percent of Americans support increasing the share of federal dollars going to health prevention rather than health care.

According to the National Institutes of Health (NIH), cancer cost our national almost \$190 billion in 2004, including \$69.4 billion for direct medical costs. Our national research investment has laid the foundation for a period of unparalleled success. With a sustained commitment from Congress, the goal of eliminating cancer death and suffering by 2015 can be made a reality. For these reasons, I encourage you and the Committee to provide significant increases in funding for the NIH, National Cancer Institute (NCI) and Centers for Disease Control and Prevention (CDC) for Fiscal Year 2006 (FY 06).

Challenges for Pancreatic Cancer

There are many factors that lead to pancreatic cancer's ranking among the deadliest cancers. First, there are **less than 10 fully-funded researchers nation-wide who are specifically dedicated to this disease.** Second, there are **limited funding opportunities for researchers who want to study this disease.** The combination of few dollars and few researchers means there has been very little scientific progress. As federal dollars for pancreatic cancer research increases, so will the number of investigators committed to this disease. **While the Federal government has increased the level of funds provided for pancreatic cancer research over the years, the overall funding level is extremely below the levels provided for the other top four highest cancers in mortality (see attached chart).**

PanCAN has outlined opportunities below for the federal government to take specific actions to facilitate progress in combating this disease.

1. Provide Adequate Funding Increases for the NIH and NCI in FY 06.

PanCAN joins its colleagues in the “One Voice Against Cancer” (OVAC) coalition in urging Congress to include a minimum funding of \$30.1 billion for the NIH in FY 06. This reflects an increase of \$1.7 billion or 6% above the FY 05 funding level and will allow the agency to account for biomedical inflation and also have additional funds available to start new research programs.

PanCAN and OVAC also support a minimum funding level of \$5.21 billion for the NCI for FY 06. This reflects an increase of \$386 million or 8% above FY 05. PanCAN and OVAC recognize the fiscal challenges facing policymakers in FY 06, and for this reason are advocating for a funding level for the NCI which is below the \$6.17 billion that was requested in the NCI's Professional Judgment Budget.

Deadly diseases like pancreatic cancer need new research programs that will investigate the causes of these illnesses. New research programs are needed for pancreatic cancer so that real breakthroughs can be made in identifying and developing treatments for this disease. Furthermore, we need to continue the momentum that has been started by doubling the NIH budget from FY 98- FY 02 so that true scientific discoveries can be made for all cancers. Continuing funding at essentially the same pace is only helpful for diseases with large research programs already in place; it does next to nothing for diseases that need to significantly expand their research programs.

2. Create a Sustained Mechanism to attract Early and Experienced Investigators to this Field of Pancreatic Cancer.

In Fiscal Years 2002 and 2003, the NCI increased the paucity of the pancreatic cancer research field through its program of a 50% formalized extended payline for grants that were 100% relevant to pancreatic cancer. In FY 02 alone, this extended payline resulted in three new-R01 grant awards. For the FY 03 grant cycles, NCI discontinued the extended payline mechanism. At the end of FY 03, NCI retroactively applied the extended payline. The community appreciates the fact that this decision resulted in the awarding of four new R-01 grants, however, the inconsistent pattern of starting, stopping and re-starting the initiative dilutes the confidence of the research community to commit their research careers towards pancreatic cancer and limits their ability to appropriately respond.

According to the advocacy and scientific communities, this was one of the single most important initiatives to attract both young and experienced investigators to develop careers in pancreatic cancer ever done. We commend NCI for its leadership in helping to develop the field of pancreatic cancer research through this initiative, however, ***we urge the NCI continue the 50% formalized extended payline for grants that are 100% relevant to pancreatic cancer.*** This policy would be most effective if the NCI would implement this policy for a significant period of time. For this reason, we recommend that the Committee urge the NCI to extend this policy for a 10 year period (from FY 06 – FY 15). A sustained multi-year effort will attract early and experienced investigators to the field of pancreatic cancer so we can build a critical mass of scientists focused on this disease.

3. Implement the Short, Medium and Long-Term Strategies as Identified in the Strategic Plan for Addressing the Recommendations of the Pancreatic Cancer Progress Review Group.

In February, 2001, the NCI released the Pancreatic Cancer Progress Review Group (PRG), a national agenda for the research needed on pancreatic cancer. A year and a half later (in September, 2002) the NCI then released the “Implementation Plan for Addressing the Recommendations of the Pancreatic Cancer Progress Review Group.”

Over four years later, the NCI has yet to implement many of the short, medium and long-term strategies as identified in the NCI implementation plan for the pancreatic cancer PRG. ***For this reason, PanCAN urges the NCI to move forward in FY 06 to implement all of the outstanding strategies as identified in the NCI implementation plan for the pancreatic cancer PRG recommendations.***

4. Implement Rapid Case Ascertainment for Tracking Pancreatic Cancer Patients.

Most pancreatic cancer patients die within three to six months of being diagnosed. Unfortunately, traditional NCI research protocols compile a database of patients over several years for large studies. This is a problem with pancreatic cancer patients, as 99% of the patients are no longer alive to provide information to the researchers attempting to identify environmental and genetic factors, and gene-environment interactions that may have contributed to the development of the disease.

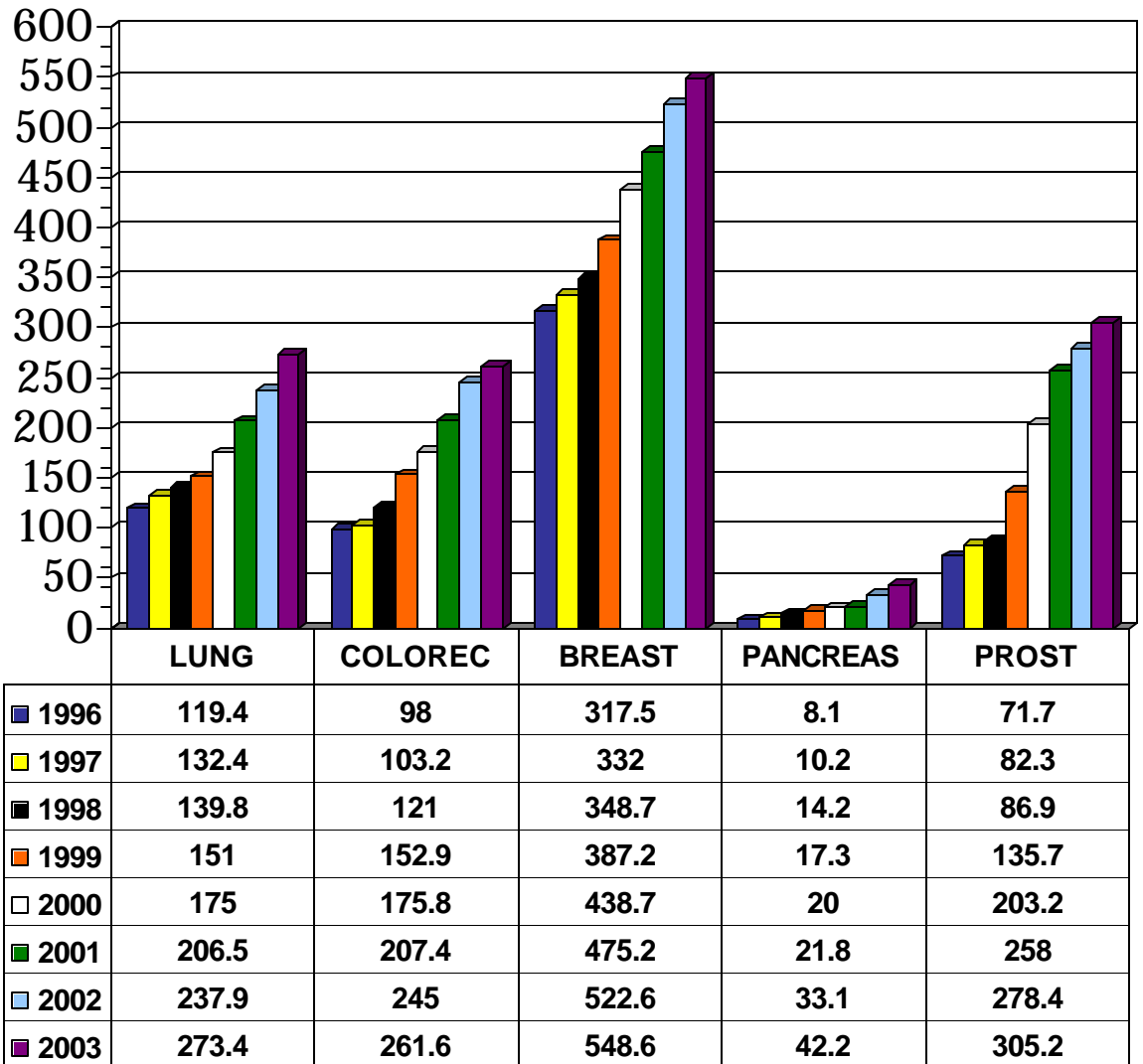
We urge the NCI to develop and implement methods for rapid case ascertainment. Such methods may include immediate electronic reporting from pathology, radiology, and laboratory medicine departments, which would provide information on new patients in a timely manner. ***PanCAN urges that new “ultra-rapid methods” for case ascertainment must be developed, tested and implemented so that pancreatic cancer patients can be contacted immediately.***

Mr. Chairman, cancer will strike one out of every two men and one out of every three women in the United States. This year alone, cancer will claim the lives of more than 560,000 Americans, including 31,800 people with pancreatic cancer.

The United States is a wealthy nation with an annual budget that totals over 2.5 trillion dollars. We have the power to find a cure for cancer and put a stop to the over half million deaths that it causes every year. As you finalize the FY 06 Labor/HHS/Education Appropriations bill for FY 06, I urge you to include the funds necessary for the outstanding researchers and investigators to do all that they can to manage and ultimately cure this disease. Thus, I urge you to provide a minimum of \$30.1 million for the NIH and a minimum of \$5.21 million for the NCI

Additional funds for the NIH and NCI are necessary so that adequate funds can be provided for pancreatic cancer research programs to bring the funding levels on par with the funding levels provided for other top cancers. Adequate funding is necessary to provide hope for the 31,800 individuals diagnosed with pancreatic cancer, the fourth leading cause of cancer death in the United States this year. Help us replace helplessness with hope.

National Cancer Institute
 Overview 1996 to 2003
FUNDING FOR TOP FIVE CANCERS IN MORTALITY



Totals FY 96-03	1.435b	1.364b	3.370b	0.167b	1.421b
2003 Mortality	157,200	57,100	39,800	30,000	28,900

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