

Testimony of the  
**Pancreatic Cancer Action Network, Inc.**  
**(PanCAN)**

2141 Rosecrans Avenue, Suite 7000, El Segundo, CA 90245

Submitted to the  
**Labor, Health and Human Services and Education Subcommittee  
of the House Appropriations Committee**

**By Julie Fleshman, President & CEO, PanCAN, on March 31, 2006**

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Dear Chairman Regula and Colleagues:

On behalf of The Pancreatic Cancer Action Network (PanCAN), I thank you for this opportunity to present written testimony to the Labor, Health and Human Services, and Education Subcommittee of the House Appropriations Committee.

PanCAN was founded in 1999 to focus national attention on the need to find the cure for pancreatic cancer. We provide 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 thirty individuals, and ninety "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.

**Background on Pancreatic Cancer**

Every 17 minutes, someone in the United States dies from pancreatic cancer. It is the 4<sup>th</sup> leading cause of cancer death in the United States. The facts on pancreatic cancer are striking:

- Over 33,730 Americans will be diagnosed with pancreatic cancer in 2006, and 32,300 will die from this disease.
- The 99% mortality rate is the highest of any cancer.
- There are no early detection methods.
- The average life expectancy after diagnosis with metastatic disease is just three to six months.

Yet, despite these statistics, pancreatic cancer receives the least amount of research funding from the federal government of all major cancers. Federal funding for pancreatic cancer research totaled roughly \$66 million in Fiscal Year 2005 (FY 05), a mere 1% of the National Cancer Institute's (NCI's) \$4.825 billion dollar research budget. While good progress is being made in

early detection, research and treatment programs for some cancers, **this is clearly not the case for pancreatic cancer.**

Pancreatic cancer is the deadliest cancer for one reason: the limited federal funding opportunities which discourage researchers from pursuing pancreatic cancer as a focus. There are less than 15 fully-funded researchers nationwide who are specifically dedicated to this disease. The combination of few dollars and few researchers means there has been very little scientific progress.

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 Cancer Research, Prevention and Treatment Programs.**

Pancreatic cancer is the country's fourth leading cause of cancer death, killing over 33,730 people annually, yet it remains severely under-funded when comparing National Cancer Institute (NCI) funding levels for the top five cancers based on mortality. The NCI spent a reported \$66 million on pancreatic cancer research in Fiscal Year 2005, yet the other four top cancers (in mortality) are funded at levels at least four times this amount. Further, the discrepancy in funding has existed for many years, only compounding this inconsistency.

PanCAN supports the highest possible funding increase that Congress can provide for the NIH and the NCI in Fiscal Year 2007 (FY 07). With additional funding for both the NIH and the NCI, new research grants can be awarded to fulfill the research goals identified by the NCI as essential to combating this disease. PanCAN is a member of the "One Voice Against Cancer" (OVAC) coalition which is comprised of more than 50 cancer advocacy organizations that have come together to support our common goal: increased federal funding for cancer research, prevention and training programs that are funded through the NIH, NCI and Centers for Disease Control and Prevention (CDC).

PanCAN wholeheartedly endorses OVAC's proposed FY 07 funding requests that seek a 5% increase for both the NIH and NCI. We urge you to provide a minimum of \$29.7 billion for the NIH in FY 07. Within these funds, we ask that the Subcommittee provide a minimum of \$5.034 billion for the NCI, in order to keep progress moving forward for cancer research.

Separate testimony submitted to the Subcommittee by OVAC reiterates the need for additional federal funding for biomedical research: "The tremendous investment our nation has made in the NIH has reaped remarkable returns and set the table for a period of unparalleled innovation in the fight against cancer and other diseases. For FY 2007, OVAC joins with the broader public health community and urges Congress to provide \$29.7 billion for the NIH. This is the minimal level of funding that will allow the NIH to maintain the current pace of discovery and innovation."

PanCAN also supports the NCI Director's Professional Judgment Budget, which calls for a total of \$5.9 billion for the NCI in FY 07. Those within the agency and very knowledgeable of the

research being conducted by the NCI have developed this plan and accompanying budget that seeks to investigate the most promising research available to the community at this time. *We urge the Committee to do all that it can to support investments in biomedical research that will save lives. At a minimum, we urge the Committee to support a funding increase of 5% above last year's level for the NCI, which would bring the agency's FY 07 funding level to \$5.034 billion. This funding level would provide an additional \$240 million to at least keep the existing level of research at the NCI moving forward at a stable pace and thus protect the current number of investigator grant awards from significant cuts.*

## **2. Ensure that Pancreatic Cancer Research is Not Compromised as the NCI Shifts its Focus from Disease Specific Research to More Global Science Initiatives:**

Last year, PanCAN requested that the Committee oversee implementation of the short, medium, and long-term strategies as identified in the Pancreatic Cancer Progress Review (PRG). The PRG has been in place since September 2002 and yet, four years later, few of these strategies have been implemented. *For this reason, PanCAN urges the Committee to require the NCI to implement, in FY 07, all of the outstanding strategies as identified in the NCI implementation plan for pancreatic cancer PRG recommendations.*

Through conversations and meetings with NCI leadership, we've learned about the shift in the NCI's focus on research. Disease specific science is being shelved in favor of sexier initiatives in the areas of nanotechnology, genomics, and the development of a biospecimen repository.

As the NCI moves its scientific agenda forward in these three areas, PanCAN is concerned that critical resources will be taken away from the significant investments that have been made in research related to early detection, diagnosis and treatment protocols for specific cancers. Other cancers have achieved significant declines in their respective mortality rates after early detection protocols have been developed. Since there is no such tool for diagnosing pancreatic cancer early in its development, the mortality rates remain high, and tens of thousands of patients are lost each year. As the advocacy community for pancreatic cancer patients, we feel that the NCI cannot justify any reductions in funding for pancreatic cancer research until significant reductions are achieved in the mortality rate for this cancer.

*PanCAN urges the Committee to obtain assurance from the NCI that the cornerstone research of the agency will not be diminished as these new scientific initiatives are pursued. Further, PanCAN urges the Committee to direct the NCI to develop a written report that specifically details how these three major scientific initiatives will specifically advance pancreatic cancer research and submit this report to the Committee by April 1, 2007.*

## **3. Support Selected Opportunities for Advancement of Pancreatic Cancer Research to Capitalize on the Initial Investment of Disease Specific Research.**

- Identify genetic factors, environmental factors, and gene-environment interactions that contribute to pancreatic cancer development.

- Achieve a more complete understanding of the biology of the normal pancreas and the development of pancreatic adenocarcinoma and use this knowledge to improve prevention, early detection, and treatment interventions.
- Develop nationwide tissue and data repositories, molecular profiling resources, and bioinformatics tools for pancreatic cancer research. Use these resources to develop prevention and early detection interventions that are based on molecular features of pancreatic cancer.
- Establish models for the study of environmental factors, gene-environment interactions, chemoprevention, chemotherapy, radiation therapy, vaccines, and imaging to improve understanding of pancreatic cancer risk, prevention, diagnosis, and treatment.
- Identify and develop surveillance and diagnosis methods for early detection of pancreatic cancer and its precursors.
- Develop and establish sustained, expanded training and career development efforts in pancreatic cancer research and care to build a comprehensive, multidisciplinary research community focused on this disease.

### **Closing**

Mr. Chairman, the scientific community – through research – is making great progress in combating cancer. More people are surviving cancer today than any other time in history. Unfortunately, these achievements are not extended to the vast majority of pancreatic cancer patients. We urge you to provide America’s world-renowned research enterprise with the funding levels necessary for investigators to continue to work their magic and develop screening protocols, effective treatments and therapies that will one day lead to the eradication of all cancers – including pancreatic. To quote Congressman Clay Shaw (R-FL), a cancer patient, “When you approach the finish line, you don’t walk...you run!” If the United States truly seeks to move forward with its ambitious goal to stop pain and death from cancer by 2015, it is imperative that federal research programs be adequately funded to achieve this goal. On behalf of the 33,730 patients diagnosed with pancreatic cancer in 2006, I urge you to support increased funding for cancer research, treatment and prevention programs in your FY 07 bill.