



Waiting 30 years for improved survival rates is too long: Support the Pancreatic Cancer Research & Education Act

We're Not Making Progress on pancreatic cancer and the consequences are deadly

- Pancreatic cancer is one of the most deadly cancers and is one of the few cancers for which survival has not improved substantially in the past 30 years.¹
- The number of new pancreatic cancer cases and the number of deaths caused by pancreatic cancer are increasing – not decreasing. In 2009, the expected number of new pancreatic cancer cases is projected to increase by 12%² and is projected to increase by 55% by the year 2030.³
- 95% of those diagnosed with pancreatic cancer die within the first five years² because there are currently no early detection tools or treatments for this disease. Given the research discovery timeline, it is unlikely that we will have the tools available to deal with the significant projected increase in expected cases unless we take dramatic action now.
- The National Cancer Institute (NCI) does not currently have a strategic plan for making progress on this deadly killer.

We Need to Step Up the investment in pancreatic cancer research

- Currently, the NCI allocates less than 2% of its nearly \$5 billion annual budget for pancreatic cancer research.
- There is no question that researchers and research advances follow the funding:
 - While in 2008 NCI funded approximately 8,725 research grants, contracts and intramural research projects across all forms of cancer, only 459 (approximately 5%) were relevant to pancreatic cancer.⁴
 - Further, NCI currently funds 327 pancreatic cancer researchers at any funding level, compared to approximately 1,600 breast cancer researchers, 913 prostate cancer researchers, 884 lung cancer researchers and 878 colorectal cancer researchers.⁴
- Less than 4% of the NCI's 2008 grants focused on young investigators (K, F and T awards) that had at least some component that supported pancreatic cancer research.⁴
- Given the lack of funding for pancreatic cancer research, senior scientists from other areas of biomedical and cancer research are not incentivized to apply their knowledge to this disease.
 - Out of the researchers who received NCI funding specifically for pancreatic cancer research, only 38 received funding totaling \$500,000 or more, a level appropriate for senior scientists. By comparison, this level of funding was awarded to: 273 researchers in breast cancer, 129 in prostate cancer, and 121 in colorectal cancer. The positive trends in these other diseases strongly suggest that these larger grants are necessary to further progress and attract investigators.⁴

We Need a Unique and Targeted approach to studying this disease

- Pancreatic cancer tumors are different than many other tumors. The make up of the cells is different and the way that research must be conducted is different. For example, researchers cannot conduct research on primary pancreatic tumors and must instead use cell lines.
- Numbers are also an issue. Approximately 42,470 Americans will be diagnosed with pancreatic cancer this year compared to the 194,280 who will be diagnosed with breast cancer.
- Due to the wide geographic dispersion of relatively few pancreatic cancer patients, few individual medical centers treat a sufficient numbers of patients to conduct statistically significant research.
- Furthermore, because few patients qualify for surgery and most patients die quickly after diagnosis, little pancreatic cancer tissue is available for research.
- Additionally, many patients who would consider participating in clinical trials are too sick to do so or die before they can enroll.
- These are challenges that can be overcome, but they require a concerted effort by NCI to develop a specific strategic plan to address these and other challenges in pancreatic cancer research in addition to an infusion of targeted research funding.



The *Pancreatic Cancer Research & Education Act* is the solution

This bill would allow us to make true progress on pancreatic cancer by better targeting research, developing a cadre of committed scientists, promoting physician and public awareness, and requiring accountability for these efforts. The legislation is based on the *National Plan to Advance Pancreatic Cancer Research*, a report developed by the Pancreatic Cancer Action Network's Scientific Advisory Board in 2008. Key components of the bill include:

Developing a Strategic Plan for Pancreatic Cancer Research

- The bill does not dictate how the NCI should conduct pancreatic cancer research. Instead, it calls for a strategic plan to be created under the direction of the Health & Human Services (HHS) Secretary and in consultation with the Directors of the National Institutes of Health (NIH), the NCI, and the Centers for Disease Control and Prevention (CDC), as well as a new Interdisciplinary Pancreatic Cancer Coordinating (IPCC) Committee comprising pancreatic cancer research experts, young pancreatic cancer investigators, and a pancreatic cancer advocate.
- The comprehensive annual strategic plan would detail the needs for the conduct and support of pancreatic cancer research and awareness activities during the upcoming fiscal year. To improve accountability, it would be submitted to the HHS Secretary and published on the agency's website.
- At the end of each year, the Secretary would submit an annual report to Congress that identifies the steps taken to implement the recommendations in the strategic plan.

Establishing a Cancer Research Incubator Pilot Project for the Highest Mortality Cancers

- A new five-year grant pilot project would be created at the NCI specifically for research into the most deadly cancers, defined as those with five-year survival rates below 50%. The initial phase would include pancreatic cancer and potentially other cancers that meet the criteria. Following the initial phase, the Secretary would submit a report to Congress evaluating the program and making recommendations for continuation and/or expansion into other deadly cancers.

Strengthening and Expanding Centers of Excellence for Pancreatic Cancer

- The legislation builds on a program created by Congress in the 1990s specifically for breast and prostate cancer called the Specialized Programs of Research Excellence (SPORE). The program was expanded in the last several years to not only provide increased opportunities for research into these cancers, but to also offer some limited research opportunities for pancreatic and other cancers.
- The legislation calls for the designation of at least two additional pancreatic cancer SPOREs.

Promoting Physician and Public Awareness

- The legislation calls for the NIH and CDC to work with patient advocacy organizations to develop a primary care provider education program on pancreatic cancer and a communication tool kit for patients.

What We Are Asking from Congress and the Administration

Thirty years is too long to wait for progress. We need Congress to act to both ensure that sufficient NCI funding is available to further research progress for all types of cancer, including pancreatic, and that there is a strategic plan in place that addresses the research needs for pancreatic cancer. *The Pancreatic Cancer Research & Education Act* is not a disease-specific bill, but is an outcome-specific bill and a vehicle for ensuring that we are investing our scarce research dollars in the areas where the most progress is needed.

The Pancreatic Cancer Action Network calls on the 111th Congress to give current and future pancreatic cancer patients a fighting chance by:

- Co-sponsoring the *Pancreatic Cancer Research & Education Act*.
- Supporting increasing NCI's funding to \$6 billion for FY 2010.

¹ Jemal A, Siegel R, Ward E, Hao Y, Xu J, Thun MJ. Cancer Statistics, 2009. *CA Cancer J Clin*. 2009.

² American Cancer Society. *Cancer Facts & Figures 2009*. Atlanta: American Cancer Society; 2009.

³ Smith BD, Smith GL, Hurria A, Hortobagyi GN, Buchholz TA. Future of Cancer Incidence in the United States: Burdens Upon an Aging, Changing Nation. *J Clin Oncol*. 2009.

⁴ Source: NCI Funded Research Portfolio, [http://fundedresearch.cancer.gov/?jsessionid=FB49DCB558B4DF37E3BCE75656E49F6C\(4/18/09\)](http://fundedresearch.cancer.gov/?jsessionid=FB49DCB558B4DF37E3BCE75656E49F6C(4/18/09)). Funding statistics exclude "Extramural Support" since these funds are for NCI administration and not research, and projects receiving < \$1 in funding.