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# It's Time for a Death Defying Strategy: Support the Pancreatic Cancer Research & Education Act (S. 3320/H.R. 745)

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

- Pancreatic cancer is one of the deadliest cancers and is one of the few cancers for which survival has not improved substantially in nearly 40 years. In fact, pancreatic cancer is the only one of the top 10 cancer killers that still has a five-year survival rate in the single digits.<sup>1</sup>
- The number of new pancreatic cancer cases and the number of deaths caused by pancreatic cancer are increasing

   not decreasing. Most alarmingly, the expected number of new pancreatic cancer cases is projected to increase by 55% between the years 2010 and 2030.<sup>2</sup>
- 94% of those diagnosed with pancreatic cancer die within the first five years because there are no early detection tools or effective treatments for this disease. Given the research discovery timeline, it is unlikely we will have the tools required to manage 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 to make progress on this deadly killer.

### We Need to Step Up the investment in pancreatic cancer research

- Currently, the NCI allocates just 2% of its \$5 billion annual budget for pancreatic cancer research.
- There is no question that when researchers are properly funded, research advances follow:
  - While in 2009 NCI funded approximately 8,700 research grants, contracts and intramural research projects across all forms of cancer, only 471 (approximately 5%) were relevant to pancreatic cancer.<sup>3</sup>
  - Further, NCI currently funds significantly fewer pancreatic cancer researchers at any funding level compared to the other top five cancer killers. In 2009, only 334 pancreatic cancer researchers were funded, compared to 1,558 breast cancer researchers, 838 prostate cancer researchers, 835 lung cancer researchers and 820 colorectal cancer researchers.<sup>3</sup>
- Less than 2% of the NCI's 2009 awards for early-career and established investigators (K, F and T awards) had
  relevance to pancreatic cancer. Even more troubling, NCI reduced the total funding allocated for these important
  awards from their 2008 level.<sup>3</sup>
- Given the lack of funding for pancreatic cancer research, senior scientists from other areas of biomedical and cancer research do not have the incentive to apply their knowledge to this disease.
  - Out of the researchers who received NCI funding specifically for pancreatic cancer research, only 32 received funding totaling \$500,000 or more, a level appropriate for senior scientists. By comparison, this level of funding was awarded to 240 researchers in breast cancer, 108 in prostate cancer, and 110 in colorectal cancer. The positive survival trends in these other cancers strongly suggest that these larger grants are necessary to further progress and attract investigators.<sup>3</sup>

# We Need a Unique and Targeted approach to studying this disease

- Pancreatic cancer tumors are different than many other tumors. The cellular make-up of the tumors is different and therefore, specialized research techniques must be applied.
- Numbers are also an issue. An estimated 43,140 Americans will be diagnosed with pancreatic cancer in 2010 compared to 209,060 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, scant pancreatic cancer tissue is available for research.
- Additionally, many patients who might 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.

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

S. 3320/H.R. 745 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 comprised of pancreatic cancer research experts, early career pancreatic cancer investigators, and a pancreatic cancer advocate.
- The NCI-directed 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 Deadliest Cancers

A new five-year grant pilot project would be created at the NCI specifically for research into the deadliest 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

Nearly 40 years is too long to wait for true progress. We need Congress to act to ensure that sufficient NCI funding is available to further research progress for all types of cancer, including pancreatic, and to put in place a strategic plan that addresses the research needs for pancreatic cancer. *The Pancreatic Cancer Research & Education Act* calls on NCI to focus on improving outcomes for cancers with poor survival rates. It is a vehicle for ensuring that we invest our scarce research dollars in the areas where progress is most needed.

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

- Co-sponsoring the Pancreatic Cancer Research & Education Act (S. 3320/H.R. 745).
- Ensure that the NCI has predictable and sustainable funding that also allows for progress in diseases like pancreatic cancer by providing \$5.79 billion for the NCI in FY 2011.

<sup>&</sup>lt;sup>1</sup> American Cancer Society. Cancer Facts & Figures 2010. Atlanta: American Cancer Society; 2010.

<sup>&</sup>lt;sup>2</sup> 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.

<sup>&</sup>lt;sup>3</sup> Source: NCI Funded Research Portfolio, http://fundedresearch.cancer.gov (Accessed May 2010). Funding statistics exclude "Extramural Support" and payments with no grant mechanisms specified because they represent NCI administrative costs, not research, as well as projects with ≤ \$1 in NCI relevant funding because they are insignificant. .