



PANCREATIC CANCER ACTION NETWORK
ADVANCE RESEARCH. SUPPORT PATIENTS. CREATE HOPE.

Raise the Cure

***The National Plan to
Advance Pancreatic Cancer Research***

*Prepared by:
The Pancreatic Cancer Action Network
January 2008*

Pancreatic Cancer Action Network

Our Mission

The Pancreatic Cancer Action Network is a nationwide network of people dedicated to working together to advance research, support patients and create hope for those affected by pancreatic cancer.

How We Accomplish Our Mission

The Pancreatic Cancer Action Network is the only national organization creating hope in a comprehensive way through research, patient support, community outreach and advocacy for a cure. The organization raises money for direct private funding of research—and advocates for more aggressive federal research funding of medical breakthroughs in prevention, diagnosis and treatment of pancreatic cancer. The Pancreatic Cancer Action Network fills the void of information and options by giving patients and caregivers reliable, personalized information they need to make informed decisions. And, by helping individuals and communities across the country work together to raise awareness and funds to find a cure for pancreatic cancer. We create a sense of hope and community for those affected by pancreatic cancer.

Executive Summary

The Case: Pancreatic cancer is one of the deadliest and most aggressive forms of cancer. It will strike more than 37,000 Americans this year—and the toll from that strike is severe. In fact, it is one of the few cancers for which survival has not improved substantially over the past 25 years. While cancer death rates have generally declined in recent years, the number of deaths from pancreatic cancer has increased. Pancreatic cancer is the deadliest cancer: 75 percent of patients die within the first twelve months of diagnosis; the five year survival rate is less than five percent. If nothing is done to change the current trends, just five years from now, 185,850 more people will be diagnosed with pancreatic cancer, but only 10,000 of them will be alive to contribute to their families and society.

Despite these sobering statistics and the severity of the disease, the National Cancer Institute (NCI) has failed to make pancreatic cancer a research priority. In 2001, NCI developed *Pancreatic Cancer: An Agenda for Action*. Seven years later, only five of the action plan's 39 recommendations have been fully implemented. In the meantime, pancreatic cancer death rates have increased and have moved ahead of prostate cancer to become the 4th leading cause of cancer deaths. NCI currently devotes less than two percent of its budget resources to research on this disease. As a result, there are no early detection methods to find pancreatic cancer in its earliest stages and there are no effective treatment options.

The Solution: The National Plan to Advance Pancreatic Cancer Research

The Pancreatic Cancer Action Network has taken a leadership role in developing a plan of action to speed the cure for pancreatic cancer. Our Scientific Advisory Board, made up of the most prestigious pancreatic cancer researchers in the country and other members of the scientific community, developed ***The National Plan to Advance Pancreatic Cancer Research*** (“*The Plan*”). This plan, as outlined in this document, represents their professional judgment of what is necessary to mount a strong, sustainable program to make progress in pancreatic cancer. It recommends the following:

- Launch a Pancreatic Cancer Research Initiative (PCRI) at the NCI to promote prioritized research projects;
- Strengthen and expand Centers of Excellence for Research;
- Create a cadre of committed scientists;
- Establish a coordinating mechanism to keep the research focused and strategically managed; and
- Promote physician and public awareness of the disease.

The *National Plan to Advance Pancreatic Cancer Research* will require an investment of \$170 million to make true progress and create a sustainable scientific program for pancreatic cancer. If it is implemented and funded at the recommended levels, we will close the gaps and begin to be able to offer newly diagnosed patients true hope – a marked difference from where we are today. The Plan represents an urgent and necessary investment to overcome the disparity that has existed in funding pancreatic cancer research to date. The best way to make progress is to quickly bring federal funding for pancreatic cancer to a level that will allow research into key areas that could lead to an early detection tool and effective treatments. The thousands of Americans who are diagnosed each year with pancreatic cancer do not have the luxury of time. The solution is to implement and fund *The National Plan to Advance Pancreatic Cancer Research* now.

Pancreatic cancer is one of the deadliest types of cancer.

Difficult to diagnose and equally difficult to treat, pancreatic cancer is one of the deadliest and most aggressive forms of cancer.

1. Pancreatic cancer is so lethal because it is usually advanced by the time symptoms appear, and its cancerous tumors are especially resistant to chemotherapy and radiation. There are no early detection methods to find pancreatic cancer in its early stages.
2. While overall cancer death rates have declined in recent years, the number of deaths associated with pancreatic cancer has increased. In fact, pancreatic cancer is now the 4th leading cause of cancer-related deaths.
3. Each year, more than 37,000 Americans are diagnosed with pancreatic cancer; because there are no effective treatments, 75 percent of patients die within the first twelve months of their diagnosis; the five year survival rate is less than five percent.
4. In the years ahead, pancreatic cancer will likely claim substantially more lives and create even greater pressures on our health care system as the number of high-risk elderly continues to grow.

Despite the toll this disease takes in lives and human suffering, efforts to learn how to detect, treat or prevent pancreatic cancer are under-funded and under-researched.

1. Less than two percent of the NCI's annual budget—about \$74 million—is devoted to research on one of the deadliest forms of cancer.
2. Of the more than 5,000 research grants awarded annually by NCI in 2006, only 134 grants were categorized by the NCI as at least 50% relevant¹ to pancreatic cancer research.
3. In addition, fewer than 58 principal investigators² have multiple grants or a primary career focus on pancreatic cancer. Experienced scientists are turning to other fields of research and promising young investigators are opting for alternative career paths, shrinking the pipeline of future investigators and lessening the chances that groundbreaking research opportunities will be pursued.
4. Of the more than 160 cancer research centers supported by NCI, only three centers contain Specialized Programs of Research Excellence (SPORES) focused on pancreatic cancer research initiatives, none of which are fully funded by NCI.

¹ In the 2006 report, only 134 grants were characterized as “50% or more” in terms of their relevancy to pancreatic cancer. Only 108 grants (54% of the total pancreatic cancer portfolio) were characterized as 100% relevant to pancreatic cancer.

² The number of principal investigators was calculated by reviewing the Pancreatic Cancer Research Map grants made through the NCI, the Pancreatic Cancer Action Network, the American Cancer Society, and the Lustgarten Foundation from 2001 – 2007 and includes American, British, and German scientists with more than 1 grant.

5. Young investigators are being discouraged from pursuing careers in pancreatic cancer research. The K award system was developed by NCI for the purpose of training and supporting young investigators as they begin a field of study. In the last three years, only five K awards were made in pancreatic cancer. Further, pancreatic cancer research workforce needs will account for little in NCI's planned \$185 million effort to strengthen the cancer research workforce. It is estimated that pancreatic cancer will receive only 1½ percent of that sum, translating to a mere \$2.775 million. The Pancreatic Cancer Action Network, recognizing the urgent need to develop a cadre of committed pancreatic cancer scientists, has made funding young investigators a priority: they have committed to providing \$2.8 million by June 2008 to fund 28 young researchers through Career Development Awards. It is a start, but it is not enough.

We have a plan to conquer pancreatic cancer—it just needs to be implemented.

In 2001, the NCI released a report entitled *Pancreatic Cancer: An Agenda for Action*, followed 19 months later by a plan for implementing the report's recommendations. The product of a ten month effort, this report drew on the talents and expertise of more than two dozen of the top scientists and clinicians in the field to forge a national agenda for pancreatic cancer research. This group assessed the existing research portfolio, identified strengths and deficiencies in the scientific infrastructure that supports pancreatic cancer research, and laid out a detailed framework for mounting a robust, sustained and coordinated investment of resources.

Seven years after the release of NCI's Agenda for Action, only five of the report's 39 recommendations and tools have been fully implemented and/or created. In the meantime, 165,000 more Americans have lost their lives to pancreatic cancer.

By failing to follow through with concrete actions, opportunities to learn more on the causes and risk factors behind pancreatic cancer, and to develop early detection and treatment tools have stalled or been lost.

1. Of the top five cancers in terms of mortality, NCI devotes only \$74.2 million—less than two percent of its budget—to research on pancreatic cancer, the 4th leading cause of cancer deaths in the U.S., compared to \$584.7 million for breast, \$242.9 million for lung, \$244.1 million for colon, and \$293.2 million for prostate.
2. Only three research centers have been designated by NCI to receive SPORE grants to focus on pancreatic cancer, none of which have been fully funded.
3. There has been no concerted federal effort to educate physicians and the general public about the early signs of pancreatic cancer and the treatment options available to patients.
4. There is no coordinating mechanism in place to set priorities, develop research benchmarks and draw new researchers into this field of study.

Steps must be taken now to stop this killer.

To address these deficiencies, the Pancreatic Cancer Action Network has developed the *National Plan to Advance Pancreatic Cancer Research* that identifies research priorities, scientific infrastructure needs and workforce training requirements.

In August 2007, the Pancreatic Cancer Action Network convened the Pancreatic Cancer Research Summit, bringing together world renowned scientists in the field. Taking into account their recommendations as well as those laid out in the National Cancer Institute's 2001 report, the 2002 implementation plan and a June 2007 report by the National Cancer Advisory Board, PanCAN's Scientific Advisory Board set out to determine the minimum requirements to advance this research effort over the next two to three years. The following represents their professional judgment of what is necessary to mount a strong, sustainable program to conquer pancreatic cancer.

1. Launch a Pancreatic Cancer Research Initiative \$140 million

Pancreatic cancer continues to be under-funded and under-studied in both basic research laboratories and clinics. The disease's unique and especially deadly nature warrants a concerted effort by NCI to stimulate and foster basic, translational and clinical research.

Recommendation - To overcome this deficiency, NCI should launch a \$140 million Pancreatic Cancer Research Initiative (PCRI), to promote prioritized research projects focusing on:

1. Basic research to advance the understanding of the biology of pancreatic cancer, its natural history and the genetic and environmental factors that contribute to its development;
2. Expanded research on more precise diagnostic methods and ways to screen and detect pancreatic cancer in much earlier stages, including imaging technologies that can help identify early pre-invasive lesions and very small tumors and the use of serum markers; and
3. The launch of more innovative clinical trials testing targeted therapeutics and novel agents that will extend the survival of patients and improve their quality of life, including patients whose cancer has spread to other organs.

Recommendation - A team of scientists, recognized for their expertise in pancreatic cancer, should be assigned to function as an ad hoc "peer review" team for all pancreatic cancer-related grant applications that reflect pre-determined research priorities.

Recommendation - In order to help stimulate research, NCI should re-institute "exceptions" funding for grant applications whose primary focus is pancreatic cancer.

Recommendation - NCI shall submit an annual report to Congress identifying the steps taken to implement this research initiative, including a break-down of research grant awards by the National Institutes of Health (NIH) research institutes, and a summary of progress and deficiencies, and reasons for shortcomings, and a plan of remediation.

2. Strengthen and expand centers of excellence for research \$20 million

Centers of Excellence provide a vital staging area for optimizing research and patient outcomes, as well as facilitating the dissemination of knowledge to other scientists. Currently, NCI has designated only three Specialized Programs of Research Excellence (SPOREs) for pancreatic cancer—none of which have ever been fully funded. Designating more centers of excellence in pancreatic cancer would help achieve greater research productivity, more access to emerging technology and faster progress towards effective interventions.

Recommendation - In order to strengthen the pancreatic cancer research infrastructure and expedite progress on prevention, diagnosis and treatment, each of the three existing Pancreatic Cancer SPORES should be fully funded at \$3 million annually.

Recommendation - NCI should designate at least two additional SPOREs focusing solely on pancreatic cancer, and foster the creation of “satellite” centers to augment the work of the designated SPOREs.

3. Develop a cadre of committed scientists \$7 million

In addition to its lethal nature, pancreatic cancer is sufficiently distinctive in its origin and pathogenesis to warrant a targeted effort to increase the number of investigators focused solely on this line of research. While new dollars provided through the recommended PCRI ultimately will help draw more institutions and investigators to this field, steps should be taken immediately to increase the number of researchers focusing on this disease and to ensure an adequate pipeline of investigators in the future.

Recommendation - NCI and NIH should initiate programs for specialized training in pancreatic cancer for both Ph.D. scientists and clinician-scientists. Funding programs and award guidelines should be tailored so as to attract and retain the required scientific workforce, and NCI should work to persuade medical school and academic deans to adjust their institutions’ incentive structures to accommodate this program.

Recommendation - NCI and NIH should put in place grant mechanisms to attract talented scientists who have a track record of success in other forms of cancer.

Recommendation - Establish a fellowship program in pancreatic cancer research to foster clinical and translational research career development for scientists in the early stage of their career.

4. Establish a coordinating mechanism \$1 million

A goal-oriented, multidisciplinary effort of this nature should be closely coordinated and strategically managed. Overall priorities should be facilitated and regularly monitored; information gathered by patient registries and tissue banks should be uniform, of high quality, and readily accessible to others; and the successes and failures of various lines of research should be publicized throughout the pancreatic cancer research community so as to avoid duplication or missed research opportunities.

Recommendation - NCI should establish a mechanism of interdisciplinary coordination, composed of both federal and non-federal scientists, responsible for setting overall research objectives and benchmarks; facilitating and monitoring the flow of pancreatic cancer research applications, fostering special funding consideration for new investigators; enabling exception funding for applications meeting identified needs; and coordinating extramural and intramural research initiatives. This coordinating body should also be empowered to identify other potential funding sources, including the National Institute of Diabetes and Digestive and Kidney Diseases, The National Institute of Environmental Health Sciences, the National Center for Complementary and Alternative Medicine, the National Center on Minority Health and Health Disparities and the Common Fund.

5. Promote physician and public awareness \$2 million

Compared to other cancers, such as breast or colorectal cancer, there is no effective screening tool for diagnosing pancreatic cancer in its earlier, more treatable stages. Primary care physicians are in the best position to determine whether their patients may be predisposed to pancreatic cancer because of a family history or other factors, but physicians generally are unaware of the early signs of the disease.

Until an effective screening tool is developed, newly-diagnosed patients and their families face a short survival time and must make life-altering decisions rapidly and under tremendous stress. They must decide on a treatment option, determine which treatment setting realistically meets their needs, arrange for care-giving, resolve any insurance issues and learn how to cope with their fate.

Recommendation - NCI should develop a primary care provider education program that includes CME-accredited physician symposia as well as mailings to physicians' offices.

Recommendation - The Centers for Disease Control and Prevention and NCI, working collaboratively with the Pancreatic Cancer Action Network and other appropriate agencies should develop a communication toolkit for patients and their families that focuses on specific pancreatic cancer issues related to patient choices and patient care.

Summary of How the \$170 million Investment Would be Spent

Launch a Pancreatic Cancer Research Initiative	\$140 million
Strengthen and expand centers of excellence for research	\$20 million
Develop a cadre of committed scientists	\$7 million
Establish a coordinating mechanism	\$1 million
Promote physician and public awareness	\$2 million
TOTAL: \$170 million	

The *National Plan to Advance Pancreatic Cancer* is a significant but very urgent and necessary investment to overcome the gaps that have existed in funding pancreatic cancer research, which are preventing progress. The thousands of Americans who are diagnosed each year with pancreatic cancer do not have the luxury of time. The best way to make progress is to quickly bring federal research funding for pancreatic cancer to a funding level that will allow research into the key areas that could lead to an early detection tool or an effective treatment. We ask that Congress embrace our vision by dedicating \$170 million to the *National Plan to Advance Pancreatic Cancer Research*. We are asking Congress to help us *Raise the Cure*.

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