

PANCREATIC CANCER ACTION NETWORK

PANCREATIC CANCER FACTS 2016



THE PANCREATIC CANCER ACTION NETWORK CALLS ON THE 114TH CONGRESS AND THE ADMINISTRATION TO WAGE HOPE BY:

- Putting the National Institutes of Health (NIH) on a path of sustained growth by passing a final FY2017 budget package before the end of the calendar year that provides a minimum of a \$2 billion increase for the NIH and includes funding for the Cancer Moonshot to accelerate progress against this deadly disease.
- Allocating a portion of the Cancer Moonshot funds to research on our nation's deadliest cancers – the recalcitrant cancers that have five-year survival rates below 50 percent.
- Continuing to include pancreatic cancer in the Department of Defense Peer Reviewed Cancer Research Program and providing \$60 million, as recommended by the Senate Appropriations Committee.
- Completing work on a 21st Century Cures/Innovations for Healthier Americans Initiative legislative package that includes mandatory funding that supplements, not supplants, NIH annual appropriations.
- Joining the bicameral Congressional Caucus on the Deadliest Cancers.

PANCREATIC CANCER IS ONE OF THE DEADLIEST CANCERS

- In 2016, pancreatic cancer moved from the fourth leading cause of cancer-related death in the U.S. to the third, surpassing breast cancer.*
- Pancreatic cancer is the 11th most commonly diagnosed cancer in men and the ninth in women.
- It is estimated that in 2016, **53,070 Americans will be diagnosed** with pancreatic cancer, and 41,780 will die from the disease. Seventy-one percent of patients will die within the first year of diagnosis.
- Pancreatic cancer is the only major cancer with a five-year relative survival rate in the single digits, at just 8 percent.
- African-Americans have the highest incidence rate of pancreatic cancer, between 28 percent and 59 percent higher than the incidence rates for other racial/ethnic groups.
- While overall cancer incidence and death rates are declining, the incidence and death rates for pancreatic cancer are increasing. **Pancreatic cancer is projected to move past colorectal cancer to become the second leading cause of cancer-related death in the United States around 2020.**

PANCREATIC CANCER IS VERY AGGRESSIVE; THERE ARE NO EARLY DETECTION METHODS

- Because the pancreas is located deep within the abdomen, and because pancreatic cancer can progress very quickly from stage I (localized within the pancreas) to stage IV (metastatic disease) in an average of 1.3 years, it is critical to develop early detection tools.
- **At this time, there are no proven biomarkers, or clues detectable in the blood or other bodily fluids, that could indicate the presence of a pancreatic tumor.**
- **The vast majority of pancreatic cancer cases are diagnosed in late stage.** More than half of patients are diagnosed once the disease has metastasized. Only about 9 percent of cases are diagnosed when the disease is still confined within the pancreas.
- Symptoms — including abdominal or back pain, weight loss, jaundice, loss of appetite, nausea, diabetes and changes in stool — are often subtle and are generally initially attributed to other less serious and more common conditions.
- **The cause of the majority of pancreatic cancer cases is unknown.** For the few known risk factors (e.g., familial history, smoking, obesity), more research is needed to understand their direct relationship to the disease. The known behavioral factors only impact a minority of pancreatic cancer cases.

TREATMENT OPTIONS ARE EXTREMELY LIMITED; PATIENTS ARE UNDERTREATED

- While surgery (often the Whipple procedure) offers the best chance for survival, **fewer than 20 percent of pancreatic cancer cases are diagnosed early enough for surgical intervention.** Even with surgery, **the disease recurs in approximately 80 percent of these patients,** who die within five years of recurrence.
- For non-surgical candidates, chemotherapy — possibly with radiation — is typically offered but is not considered curative.
- Since 1974, only four drugs have been approved by the U.S. Food & Drug Administration (FDA) to treat pancreatic cancer: gemcitabine (Gemzar®) in 1996, erlotinib (Tarceva®) in 2005, albumin-bound paclitaxel (Abraxane®) in 2013 and irinotecan liposome injection (Onivyde™) in 2015. In 2011, a combination chemotherapy regimen called FOLFIRINOX was found to improve survival of metastatic pancreatic cancer patients. While these new treatments and combinations have recently been shown to extend the lives of pancreatic cancer patients, the improvement is small, and the vast majority of patients still rapidly succumb to their disease.

*The population-based statistics refer to all kinds of pancreatic cancer. Unless otherwise noted, all other facts refer to pancreatic adenocarcinoma as "pancreatic cancer."

- Many pancreatic cancer patients go untreated or undertreated by standard therapies. A study showed that **38 percent of patients received no treatment at all within one year of diagnosis**. Even among patients diagnosed with early stage disease, 27 percent received no treatment, and only 47 percent underwent surgery. African Americans have the highest rate of diagnosis but undergo fewer surgical resections than other racial groups.
- Although enrolling in a clinical trial is often the best option for pancreatic cancer patients, **only about 4.2 percent of patients participate in clinical trials**. While this percentage is within the national average for adult cancer patients (3-5 percent), it is not high enough, since the standard treatment options have limited effectiveness. A complicating factor is that according to a recent survey, **nearly half of pancreatic cancer patients' treating physicians did not tell them about clinical trial options**.
- **We don't necessarily need a higher number of clinical trials, but we do need better designed clinical trials**. Over the past 25 years, only 15 percent of the agents tested in pancreatic cancer phase III clinical trials have resulted in clinically meaningful advances for patients. Owing to the survival statistics and the fast progression of this disease, the number of pancreatic cancer patients available to participate in clinical trials is limited. In fact, a recent analysis showed that it would take approximately six years to fully accrue all the open clinical trials. One of the problems that must be addressed is that trials need to be designed to better match patient needs.

UNIQUE RESEARCH CHALLENGES REQUIRE SPECIFIC SOLUTIONS

- Around 95 percent of pancreatic tumors are driven by mutations in a gene called KRAS, which signifies a very aggressive and treatment-resistant tumor. Mutated KRAS has been dubbed "undruggable," although efforts are underway to devise targeted therapies.
- Pancreatic tumors are surrounded by more dense fibrotic tissue, known as the stroma, than are most other solid tumors. More research is necessary to decipher the role of the stroma in cancer progression and response to treatment.
- A 2016 study identified four subtypes of pancreatic cancer based on molecular changes, but more work is necessary to determine which treatments are best aligned with these patient characteristics.
- Solving these and other challenges requires more researchers and more resources focused on the disease, but the solutions will spur scientific advances in the entire field of cancer research.

THERE IS HOPE

In February 2014, the NCI released the "Scientific Framework on Pancreatic Adenocarcinoma," the first report required under the Recalcitrant Cancer Research Act of 2012. This critical framework, as well as the scientific framework on small-cell lung cancer released in July 2014 and others that will hopefully follow for other deadly cancers, will help provide the strategic direction needed to change patient outcomes in the nation's deadliest cancers, defined as those with a five-year relative survival rate below 50 percent.

The pancreatic cancer framework outlines four key research topics for pancreatic cancer: the role mutated KRAS plays in this disease, the link between diabetes and pancreatic cancer, biomarkers for early detection of pancreatic cancer and immunotherapy.

Since the release of the framework, the NCI has introduced several new grant mechanisms that are focused on these key objectives. One exciting project that the NCI has launched as part of this framework, the RAS Initiative, has the potential to increase the survival rate for pancreatic cancer as well as for the more than 30 percent of all other forms of cancer that are driven by RAS.

The Pancreatic Cancer Action Network is doing its part to help foster these promising areas by awarding more than \$28 million through our Research Grants Program since 2003. Grants have been awarded to 122 researchers at 51 institutions. The organization recently launched the Know Your TumorSM precision medicine initiative, aimed at translating research findings into clinical benefit by tailoring treatment options to the molecular profile of a patient's tumor. In 2015, we also introduced an online Patient Registry, a database that gives patients the opportunity to record and easily access the details of their disease experience, potentially generating insights that can lead to better patient outcomes.

WHAT WE ARE ASKING FROM CONGRESS

We applaud Congress for the historic NIH and NCI funding increases in FY2016 and applaud President Obama for calling for a Cancer Moonshot that has the potential to speed progress in developing new treatments and tools for the over 200 diseases we call cancer. We are also encouraged by the continued support that Congress gave to the Department of Defense's Peer Reviewed Cancer Research Program (PRCRP) in FY2016 and by its continued inclusion of pancreatic cancer. However, even with the FY2016 increases, the NIH budget is still nearly 18 percent below its FY2003 level, when accounting for inflation. Ten years ago, the NIH funded nearly one out of three grant applications; now, that number has dropped to about one in seven. Funding for the NCI has declined even more.

The fact that pancreatic cancer has surpassed breast cancer to become the third leading cause of cancer-related death and is expected to become second by 2020 only underscores the urgency of ensuring that the down payment Congress made on NIH and NCI funding is continued in FY2017 and beyond. Approximately 80 percent of all pancreatic cancer research funding comes from the federal government, and the NCI is the largest federal source of funding. Therefore, the NCI is a critical resource.

We cannot hope to have success in diseases like pancreatic cancer without putting the NIH and NCI on a path to robust, sustained growth. Furthermore, it will be difficult to leverage the opportunities that come out of the scientific framework developed as a result of the Recalcitrant Cancer Research Act without continuing the progress Congress started last year toward restoring NIH funding. We therefore urge Congress to fully fund the Cancer Moonshot so that we can capitalize on promising new initiatives and maintain momentum in ongoing pancreatic cancer research. We further ask that Congress continue to include pancreatic cancer in the DoD's PRCRP and provide \$60 million, as recommended by the Senate Appropriations Committee.

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CANCER
ACTION
NETWORK

National Office

1500 Rosecrans Ave., Ste. 200
Manhattan Beach, CA 90266

Government Affairs & Advocacy Office

1050 Connecticut Ave. NW, Ste. 500
Washington, DC 20036