



Rewriting the Future for Pancreatic Cancer Patients

BY ANITRA ENGBRETSON AND NICOLE LISE FEINGOLD, MA

November is National Pancreatic Cancer Awareness Month, so it's a perfect time to shine a much-needed spotlight on the fourth-leading cause of cancer death in the U.S., and to tell you about the Pancreatic Cancer Action Network (pancan.org).

The Pancreatic Cancer Action Network is the organization rewriting the book on how to fight a deadly disease. In the 16 years since our founding, we've focused on attacking pancreatic cancer on all fronts. Early on, we put into place a strategy that includes funding private research, advocating for increased federal research funding, providing support to patients, and raising awareness in communities nationwide through the voices and activities of thousands of passionate volunteers who have joined the fight.

Using this comprehensive approach—and bolstered by our dedicated supporters, who are just as determined as we are to advance progress against the disease—we've fueled a national pancreatic cancer movement. In fact, our rallying cry, “Wage Hope,” speaks to the need to take unprecedented action: to change the statistics and rewrite the future for pancreatic cancer patients. That's because despite the progress being made, the five-year survival rate for pancreatic cancer remains in the single digits at just seven percent. Although survival has increased since our efforts started (it was 5 percent in 1999), a recent study we conducted showed that pancreatic cancer will surpass colon and breast cancer to become the second leading cause of cancer-related death in the U.S. by 2020.

But we are working to change these dire statistics. Our goal: to double pancreatic cancer survival by 2020. It's an ambitious goal, and it won't be easy to achieve, but patients deserve nothing less.

Patient Central

One of our proudest achievements is becoming a trusted and important resource for pancreatic cancer patients. We encourage anyone diagnosed with pancreatic cancer to contact Patient Central, our one-to-one service that connects patients—and their caregivers—to valuable information about the disease, clinical trials, treatment options, and support resources. Our highly trained and compassionate Patient Central Associates are available without cost by phone or email, and they provide free information, resources, and hope to approximately 11,000 people each year. We feel honored to provide this service so that patients and their families can make informed decisions about their treatment and care.

The level of personalized patient support that we provide allows us to represent the patient's voice through all of our programs, and it also gives us the opportunity to implement innovative and cutting-edge initiatives. Armed with the patient's voice, we are able to drive change from the bottom-up, rather than from the top-down. We believe that is our greatest strength, and it enables us to have the most lasting impact on changing the course of history for this disease.

This month, we will serve our 100,000th individual since the program started in 2002.

But to meet our goal of doubling survival by 2020, we need more patients and caregivers to contact Patient Central. We are extremely grateful for the healthcare professionals who help us reach them.

A Gateway to Progress in Research

As of 2011, an average of only 4.5 percent of pancreatic cancer patients nationwide were enrolling in clinical trials. This low enrollment rate slows progress toward new diagnostic tools and treatments. To that end, we encourage all patients to consider clinical trials as a treatment option. In fact, one of the most important aspects of Patient Central is our ability to help patients access relevant, current clinical trial information through our new online Clinical Trial Finder: clinicaltrials.pancan.org. This free tool provides patients, caregivers, and healthcare professionals around-the-clock access to the most comprehensive and up-to-date database of pancreatic cancer clinical trials in the U.S. As we sat down to write this column, approximately 155 pancreatic cancer clinical trials were underway, and it would be very difficult for any oncologist to know about all of them. Our resources allow patients and healthcare professionals access to all possible options.

Clinical trial consideration isn't only important for each patient—it's critical for the pursuit of knowledge that can lead to new research advances. A clinical trial may be a patient's best option and researchers need patients to participate in trials in order to learn about new possible drugs for patients in the future.

Of the patients who connect with our Patient Central Associates to find a clinical trial, 14 percent enroll in a clinical trial—almost three times the national average. This is accelerating research. But we want to do more.

Powerful Knowledge. Personalized Treatment.

The need to expedite progress, and also ensure that patients quickly find the right treatment for them, is the reason we created Know Your TumorSM (pancan.org/section-facing-pancreatic-cancer/know-your-tumor), our personalized medicine service. Know Your Tumor was designed to help double pancreatic cancer survival by increasing the number of patients enrolling in clinical trials by building on the success of our Patient Central program and empowering them with information that assists with treatment decisions.

By participating in Know Your Tumor, patients and their healthcare professionals receive coordinated assistance with facilitating tissue collection and molecular testing. At the end of the process, patients and their physicians receive an expertly-reviewed report that contains the molecular test results and a list of potentially relevant treatment options.

While there is no guarantee that the biomarkers identified in the testing process will be actionable for guiding treatment, this process can give healthcare professionals potentially helpful information about their patients. Currently, nearly 50 percent of reports have revealed an actionable finding, meaning the information gained has the



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potential to impact treatment choices by identifying options that may have value in treating the patient's specific tumor.


This information may be extremely valuable to a patient as they choose a treatment to pursue and enroll in a clinical trial identified for their situation. Additionally, the fields of precision medicine and targeted therapy are growing, and Know Your Tumor will contribute vital information as it relates to better understanding their potential importance in pancreatic cancer.

These are just a few of the exemplary services we provide to pancreatic cancer patients and families. To learn more about Patient Central, Clinical Trial Finder, Know Your Tumor, and other services, please contact us at patientcentral@pancan.org. We are waiting to speak with you!

Rewriting the Story of Pancreatic Cancer

It's a revolutionary time for the pancreatic cancer scientific community, with great

expectations for significant progress in treating this daunting disease. We are proud of our progress against this disease so far. We also are keenly aware that it would not have been possible without the power of our passionate and relentless supporters.

The Pancreatic Cancer Action Network is the organization rewriting the book on how to fight a deadly disease. We invite you to join us in writing the next chapter in the fight—not only for today, but for future generations. Together, we will end pancreatic cancer as we know it. 

Anitra Engebretson is director of Clinical Initiatives and Nicole Lise Feingold, MA, is director of Patient Services for the Pancreatic Cancer Action Network. For more information about the Pancreatic Cancer Action Network or to join our movement to Wage Hope, visit pancan.org or call 877.272.6226. Because when we Wage Hope together, we make progress.