

## Patient Advocate Corner

### Pancreatic Cancer Action Network: Advance Research, Support Patients, and Create Hope



*Julie Fleshman, JD, MBA*

*By Julie Fleshman, JD, MBA*

When my father, Jim Fleshman, was diagnosed with pancreatic cancer in 1999, this disease had no public visibility. My dad was given few options for treatment and was told to go home and get his affairs in order. My family felt devastated and alone—there were no organizations to turn to for information on the disease or to seek advice and support.

Shortly after his death, I was looking for answers as to why no efforts were underway to increase the treatment options and survival of pancreatic cancer. It was then that I discovered the Pancreatic Cancer Action Network, founded in 1999 by a group of people who had also lost loved ones to this disease. I was lucky to get involved with these amazing people and I began volunteering with them. Fortuitously, I was given the opportunity to dedicate my career to serving the pancreatic cancer community when I was offered the first full-time staff position at the organization.

Pancreatic cancer is the fourth leading cause of cancer death in the United States, and 75% of patients will die within 12 months of diagnosis. My dad died within 4 months. The number of Americans diagnosed with pancreatic cancer has steadily increased during the past 10 years; in 2008, nearly 38,000 Americans were diagnosed with the disease, and more than 33,000 succumbed. Unfortunately, the sobering statistics remain much the same as they were 10 years ago, but the scientific landscape for pancreatic cancer is changing. There is a tremendous amount of momentum in the scientific community to make progress against this disease.

Importantly, in the last decade, the Pancreatic Cancer Action Network has served thousands of pancreatic cancer patients and their families. We want people to know there is hope and there are resources available to help face this disease.

Our Patient and Liaison Services (PALS) program fills the void of information by providing patients and caregivers with high-quality, reliable disease information. All services and educational materials are provided free of charge. Patients and families can be connected with a trained PALS associate by calling (877) 272-6226 or e-mailing [pals@pancan.org](mailto:pals@pancan.org). PALS associates provide patients and their families with the most current information to help make informed decisions, including information about the disease, treatment options, clinical trials, specialists, support groups, diet and nutrition, and much more. PALS associates can perform personalized

eligibility searches in our clinical trials database to match patients to clinical trials taking place around the country.

Through the PALS program, the Pancreatic Cancer Action Network also has the Survivor and Caregiver Network, a group of dedicated survivor and caregiver volunteers willing to share their experiences and answer questions about their journeys with the disease. For patients and their families, speaking to others who have gone through similar experiences with pancreatic cancer can make a world of difference.

In addition to the patient services we provide, the Pancreatic Cancer Action Network funds research and advocates for increased federal research dollars for pancreatic cancer. We help to speed advances in pancreatic cancer research through our research grants program, which is designed to stimulate innovative research on the disease and increase the number of scientists working in this field. Since launching the program in 2003, the organization has funded 38 research projects around the country. With the commitment of funds for 2009, that number may reach nearly 50.

Through our advocacy efforts on Capitol Hill and locally, we encourage legislators to make pancreatic cancer research a priority. In January 2009, our community took an important step forward when The Pancreatic Cancer Research and Education Act (H.R. 745) was introduced in the U.S. House of Representatives. This historic initiative marks the first major piece of legislation that addresses the astounding mortality of pancreatic cancer.

Our community outreach network of volunteers supports the mission of the organization by working in neighborhoods across the country to raise both awareness about pancreatic cancer and the funds to find a cure.

We understand the many challenges facing those affected by pancreatic cancer. We understand what family members and caregivers are experiencing. We also know there is reason for hope: more research funding is available, more scientific research is underway, information for patients and families exists, and a community of volunteers is taking action. The Pancreatic Cancer Action Network ensures that no one need face this disease alone.

To learn more about the programs and services of the Pancreatic Cancer Action Network, please visit [www.pancan.org](http://www.pancan.org) or call (877) 272-6226.

*Julie Fleshman, JD, MBA, is the president and CEO of the Pancreatic Cancer Action Network. Under her leadership since 2000, the Pancreatic Cancer Action Network has grown to more than 50 employees with offices in Los Angeles, CA, and Washington, DC.*

DOI: 10.1200/JOP.0924502