

Advocacy and pancreas cancer: a new world

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The role of nonprofit organizations is evolving. The goal and mission of the National Pancreas Foundation (NPF) has been to improve the life of the patient with pancreatic diseases. For the past twenty years, the NPF has been working to accomplish this goal through a variety of programs and strategies.

The NPF has been on the forefront in bringing physicians and scientists together to collaborate on research and to establish guidelines for diagnosis of all forms of pancreatic diseases. The NPF hosts an annual Fellows Symposium to increase the number of young researchers committed to the field of pancreatic disease and to establish a network of mentors and researchers. This annual meeting remains one of our most important programs. By engaging young physicians and researchers and teaming them up with world-class mentors, we encourage them to enter and remain in the field of pancreatology. Bringing the best young minds to this field will have long term impact on the lives of our patients. Because the NPF is involved in all diseases of the pancreas, the Fellows Symposium is able to bring together fellows and mentors in the field of gastroenterology, surgery and oncology and including pediatric and adult disease settings. The goal is to ignite early cooperation among these fellows and leaders in the field to better understand pancreas biology and how diseases develop and are treated. For almost twenty years, the NPF awards seed grants to promising research projects in the field of pancreas disease. We are the only foundation to support research in all of these areas: pancreatic cancer, acute pancreatitis, chronic pancreatitis and pediatric pancreatitis.

The NPF helps educate the patient community by providing information through our extensive animation program, patient education events, website and social media.

Using animation and physician and patient testimonials, the ‘Animated Pancreas Patient’ helps patients and families understand complex medical terminology, disease states, procedures, and clinical implications. This is an easily accessible web resource for anyone seeking information on acute pancreatitis, chronic pancreatitis, pancreatic cancer, risks associated with various procedures, and the benefits of diagnostic and therapeutic pancreatic endoscopy, endoscopic ultrasound (EUS), fine needle aspiration (FNA) and endoscopic retrograde cholangiopancreatography (ERCP). The ‘Animated Pancreas Patient’ project has been tremendously successful and posters have been present at Digestive Disease Week (DDW) and the American Pancreatic Association (APA) Annual Meeting illustrating this program and its successes in educating patients and caregivers and encouraging them to contact their physicians with questions. The NPF now hosts patient education events across the country. These events bring together physicians, social workers, nutritionists, pain management experts and others to help the patients understand how to best cope with diseases of the pancreas and to better their quality of life. The newly-designed website provides an array of information for patients, caregivers, and providers. Topics include tools for diagnosis, treatment options, and nutrition. We continually add content and encourage input from our patient and physician communities.

Now the time has come where we have to do more for our patients and caregivers. The quality of life for patients with pancreatic disease has not dramatically improved. In 2016, the NPF established NPF Centers for pancreatitis and pancreatic cancer. These centers at premier healthcare facilities focus on multidisciplinary treatment of pancreas diseases, treating the “whole patient” with the emphasis on optimal outcomes and an improved quality of life for the patient. For people coping with pancreas cancer, there are

inconsistencies in the level of care they receive. The NPF Center designation will help facilitate the development of high-quality, multidisciplinary care approaches for the field. The centers will also seek to advance research and lead the way for heightened awareness and understanding of pancreas cancer among community physicians, allied health professionals, patients, families and the general public. The approval process for NPF Centers is rigorous. Applicant institutions were subject to an auditing process to ensure that each participating institution met the criteria that were developed by a task force comprised of invited subject matter experts and patient advocates. The criteria includes having the required expert physician specialties such as oncologists, pancreas surgeons, and interventional radiologists, along with ancillary support services such as a pain management service, psychosocial support and social workers.

The NPF recently launched the National Patient Registry for Pancreatic Diseases (NPR). The NPR is a national research study database used to track the health and treatments of people with pancreatic diseases. The NPF pioneered this registry to support treatments and research dedicated to all pancreatic conditions. The primary goal of the NPR is to capture data reported by healthcare providers and patients to better understand pancreatic diseases, the effectiveness of current treatments, and the quality of life for patients affected by pancreatic conditions. The NPR collects information from healthcare providers and patients through a secure web-based portal. This effort enables the partnering medical facilities and researchers from across the country to share de-identified aggregate data that will be used to support evidence-based medicine and provide hypotheses for further prospective evaluation. Unlike other patient registries, the NPR also provides patient-participants the opportunity to report their personal disease experiences through its online Patient Portal by completing surveys about their medical history, family history, diagnosis,

symptoms, treatments, overall well-being. It empowers participants to become more proactive in their health care to help improve the quality of their lives. The NPR will be paramount to the development and acceleration of research dedicated to pancreatic diseases, as well as finding the most effective therapies to help patients combat these disorders.

What is next for advocacy and improving the quality of life for the patient with pancreas cancer? The NPF advocates for increased research funding for pancreas diseases from both the public and private sectors. We work with government, for profit and nonprofit organizations, and the biopharmaceutical industry to improve the level of awareness, interest, and investment in research for these diseases. Presently, research in pancreatic disease is moving forward but not quickly enough. Often, new drugs have the possibility of adding only months to the patient's life. We need to find other ways we can enhance this research. Is it partnering with the National Institute of Health to increase their funding potential? Is it working with the U.S. Department of Defense to expand its program on pancreatic cancer? Or is it coming up with a completely novel approach? How do we get more patients to sign up for clinical trials? Will our registry help researchers better understand the quality of life of the patient with pancreas cancer when they are not on clinical trials? Do the clinical trials improve their QOL? What is happening to the patient being treated in the community? These are some of the areas that nonprofit organizations such as NPF are focused on today.

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Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

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