

OPEN

# Inaugural Meeting of North American Pancreatic Cancer Organizations

## *Advancing Collaboration and Communication*

Barbara J. Kenner, PhD,\* Julie M. Fleshman, JD, MBA,† Ann E. Goldberg, BA,\* and Laura J. Rothschild, MBA\*

**Abstract:** A meeting of North American Pancreatic Cancer Organizations planned by Kenner Family Research Fund and Pancreatic Cancer Action Network was held on July 15–16, 2015, in New York City. The meeting was attended by 32 individuals from 20 nonprofit groups from the United States and Canada. The objectives of this inaugural convening were to share mission goals and initiatives, engage as leaders, cultivate potential partnerships, and increase participation in World Pancreatic Cancer Day. The program was designed to provide opportunities for informal conversations, as well as facilitated discussions to meet the stated objectives. At the conclusion of the meeting, the group agreed that enhancing collaboration and communication will result in a more unified approach within the field and will benefit individuals diagnosed with pancreatic cancer. As a first step, the group will actively collaborate to participate in World Pancreatic Cancer Day, which is planned for November 13, 2015, and seeks to raise the level of visibility about the disease globally.

**Key Words:** pancreatic cancer, neuroendocrine tumors, nonprofit organizations, collaboration, communication, World Pancreatic Cancer Day

(*Pancreas* 2015;44: 1178–1184)

A meeting of North American Pancreatic Cancer Organizations planned by the Kenner Family Research Fund and Pancreatic Cancer Action Network was held on July 15–16, 2015 in New York City. The meeting was attended by 32 individuals from 20 nonprofit groups from the United States and Canada. The objectives of this inaugural convening were to share mission goals and initiatives, engage as leaders, cultivate potential partnerships, and increase participation in World Pancreatic Cancer Day (WPCD). The program was designed to provide opportunities for informal conversations, as well as facilitated discussions to meet the stated objectives.

### MISSION GOALS AND INITIATIVES

The meeting began with a brief presentation by each organization in which they described their mission and current initiatives. The groups varied in size, resources, and primary focus; however, many were founded by individuals who were personally touched by adenocarcinoma or neuroendocrine pancreatic cancer, either by having the disease or losing a family member or close friend. Hearing the personal stories was inspirational and

empowering for the participants, and an acknowledgement that many caring people are working for a common cause.

The missions of the nonprofit organizations are wide-ranging and address multiple areas of need. A number of groups primarily provide research funds to young investigators and established researchers in the areas of early detection and treatment. Other organizations are advocacy oriented, leading efforts in education and building awareness among the general public, clinicians, medical institutions, and government agencies about pancreatic cancer, the availability of treatment options, and the critical need for additional funding. Several organizations have established national patient registries and patient hotlines for referral sources while other groups support fellowship programs and clinical trial initiatives. Others focus on planning, producing, and hosting educational conferences, workshops, and seminars for patients and their families, and members of the research community. Finally, several groups provide critical financial assistance to patients and their families while undergoing treatment. Approaches to fundraising were as unique and multi-faceted as the organizations themselves, including golf tournaments, walks, runs, marathons, cycling events, basketball tournaments, galas, luncheons, and symposiums, as well as direct solicitation of the general public.

More specific information about each organization is included in this article under the section entitled *2015 North American Pancreatic Cancer Organizations Directory*.

### Engagement as Leaders

To gain further understanding of the skills necessary to lead a nonprofit organization, Ruma Bose, president of Chobani Foundation ([www.chobani.com/foundation](http://www.chobani.com/foundation)) and Chobani Ventures facilitated a workshop based on what she learned while volunteering with Mother Teresa. Ms. Bose coauthored the international best-selling book, *Mother Teresa, CEO: Unexpected Principles for Practical Leadership*<sup>1</sup> which has been translated into multiple languages and describes Mother Teresa's management and leadership principles. Ms. Bose expertly guided the group through several exercises that highlighted the importance of aligning one's personal values to the goals of the organization. Other skills that exemplified Mother Teresa's approach to effective leadership included the necessity of facing challenge directly, and the need for a clear vision and open communication. Ms. Bose stressed that developing a well-defined message and targeted focus on branding is important to success. She encouraged the engagement of all stakeholders including funders, policy makers, academics, and non-governmental organizations in creating the message. The meeting participants were challenged to engage as leaders in order to amplify the message about pancreatic cancer and to make a difference in the survival of individuals diagnosed with the disease.

### Cultivating Partnerships

Corinne Rieder, Ed.D., past president, John A. Hartford Foundation ([www.jhartfound.org](http://www.jhartfound.org)) and Christina Spellman, Ph.D., executive director of The Mayday Fund ([www.maydayfund.org](http://www.maydayfund.org))

From the \*Kenner Family Research Fund, New York, NY; and †Pancreatic Cancer Action Network, Manhattan Beach, CA.

Reprints: Barbara J. Kenner, PhD, Kenner Family Research Fund, 39 East 78th Street, Suite 501 New York, NY 10075 (e-mail: [drbkenner@kennerfamilyresearchfund.org](mailto:drbkenner@kennerfamilyresearchfund.org)).

The authors declare no conflict of interest.

Copyright © 2015 Wolters Kluwer Health, Inc. All rights reserved. This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially.

engaged the group in a conversation about the benefits their organizations have experienced through partnering on various projects. Dr. Rieder and Dr. Spellman maintained their success in partnering was due to 3 shared principals: (1) a commitment to collaboration; (2) a commitment to a single, focused mission; and (3) a commitment to strategic planning and project evaluation. The lessons they learned over multiple years of partnering were also helpful to the group. They advised that it takes time and hard work to form a successful partnership, and that staff and board support is essential. Similarly, partnerships are most effective when formed with outstanding people who are “where you are.” Finally, they emphasized that nonprofits partnering with government agencies can be an important way to leverage resources.

### Call for Action: World Pancreatic Cancer Day

Julie Fleshman, global chairman of WPCD, relayed to participants the opportunities available for leadership and partnering in making this day successful. The inaugural World Pancreatic Cancer Day was launched on November 14, 2014. The WPCD is a 1-day social media campaign that brings awareness to pancreatic cancer by starting an online global conversation about the disease. The campaign was conceptualized at a meeting in Zurich, Switzerland, attended by pancreatic cancer patient advocacy organizations from the United States, Canada, and Europe. A volunteer Steering Committee was formed representing 6 organizations and 8 countries. The campaign goals for the first year were to generate awareness of WPCD among pancreatic cancer organizations and their respective networks, create a brand, launch a website, generate social interest, and engage users by giving them simple calls to action. In the first year, there were 30 partnering pancreatic cancer organizations representing nineteen countries that participated. The day was considered a success with the WPCD's Facebook page reaching over 850,000 people, tweets reaching over 970,000 potential impressions on Twitter, the website counting 7,500 unique visitors, and the video receiving over 11,000 views.

This year's World Pancreatic Cancer Day ([worldpancreaticcancerday.org](http://worldpancreaticcancerday.org)) is planned for November 13, 2015. The campaign will be expanded to include opportunities for organizations to participate online leading up to WPCD and on the day itself. A public relations plan will also be put in place and tools will be provided to all partnering organizations so that groups can reach out to their local media. Participants were enthused to learn about WPCD and inspired to take part. Everyone agreed that a priority for advancing pancreatic cancer outcomes is creating overall awareness about the disease, and that WPCD is an opportunity to work together to elevate the cause to new heights around the world.

### Setting Priorities and Next Steps

Building on the focus of leadership and partnering, the participants worked together in small groups to identify priorities and next steps. Several themes emerged. The first priority is to recognize opportunities for collaboration. Improved communication on both a micro and macro level is the second priority. It is important that there be a unified message and an increased awareness of pancreatic cancer. The general public requires additional information regarding risk factors and symptoms, and the medical community through professional societies will benefit from educational tools to aid in diagnosis and treatment.

Steps to achieve these goals include formalization and branding of the North American Pancreatic Cancer Organizations, establishing a structure for the group, hosting an annual meeting, participating in World Pancreatic Cancer Day, and potentially funding collaborative initiatives. The benefits of sharing

organizational resources and creating a common database of resources were also discussed.

### Impressions

The inaugural meeting of North American Pancreatic Cancer Organizations provided an opportunity for participants to hear passionate personal stories and learn how pancreatic cancer has changed the lives of so many. To describe their reactions to the term pancreatic cancer the participants used words such as deadly, sadness, and lethal. But there was also a sense of hope, opportunity, and encouragement throughout the meeting, as participants realized they had common goals and were energized by the support and enthusiasm generated. The face-to-face interactions, open forum, carefully selected speakers, and facilitated brainstorming helped participants appreciate that there is strength in collaboration and by improving communication, patients and their families, as well as researchers and the medical field will feel heard and supported by the nonprofits of North American Pancreatic Cancer Organizations. As a first step, this group will actively collaborate to build awareness of World Pancreatic Cancer Day.

### 2015 North American Pancreatic Cancer Organizations Directory

The organizations listed here graciously provided their information for this first edition of the Directory. This should not be considered an exhaustive list of organizations, and there may be other nonprofits that either did not respond or were not known at the time of the Directory's publication.

ALLIANCE OF FAMILIES FIGHTING PANCREATIC CANCER  
[www.affpc.org](http://www.affpc.org)

Theresa Dukovich, Executive Director

[theresa@affpc.org](mailto:theresa@affpc.org), 800.704.9080, Ext. 101

Kendra Haywood, Board President and Director of Fundraising

[kendra@affpc.org](mailto:kendra@affpc.org), 917.584.8595

The mission of the Alliance of Families Fighting Pancreatic Cancer (AFFPC) is to take a united and pivotal role in changing pancreatic cancer treatment by empowering patients with personalized options for better survival and quality of life.

#### Key Initiatives

The AFFPC supports the following research projects and activities initiated by the Pancreatic Cancer Center at Beth Israel Deaconess Medical Center, a Harvard Medical School teaching hospital, to improve the lives of patients and families affected by all stages of pancreatic cancer:

- Improved care for patients suffering from pancreatic cancer
- Personalized treatment by going beyond the “one-size-fits-all” approach
- A laser beam focus on quality of life
- Empowering patients and families to make informed choices
- Assessing new technologies for treating patients with pancreatic cancer
- Discovering the first-ever clinical biomarker to diagnose and treat pancreatic cancer

CARING FOR CARCINOID FOUNDATION

[www.caringforcarcinoid.org](http://www.caringforcarcinoid.org)

[info@caringforcarcinoid.org](mailto:info@caringforcarcinoid.org)

617.948.2514

The mission of Caring for Carcinoid Foundation is to fund research to discover cures and more effective treatments for carcinoid,

pancreatic, and related neuroendocrine cancers. The foundation is committed to timely identification and funding of projects with the most potential for positive outcomes, collaboration with aligned organizations and private foundations, and support for a diversified portfolio of basic and clinical projects.

#### Key Initiatives

- US \$2 million Immunotherapy Initiative—testing the potential of immune-based therapies to provide breakthroughs for patients with neuroendocrine tumors
- Bringing Peptide Receptor Radionuclide Therapy (PRRT) to the United States and Improving Safety/Effectiveness—opening a randomized clinical trial of PRRT in the United States and funding another clinical trial of a different PRRT
- Education/Resources—providing 4 annual educational conferences, an e-newsletter with the latest in research and treatment information, and a website with a doctor database, patient group information, and information on all funded research projects, as well as discoveries in the field

#### CRAIG'S CAUSE PANCREATIC CANCER SOCIETY

www.craigscuse.ca

Stefanie Condon-Oldreive

Founder/Director of Craig's Cause Pancreatic Cancer Society

stefanie@craigscuse.ca

902.827.5811

Kate Elliott, Executive Assistant

kate.elliottk8@gmail.com

902.478.3956

The mission of Craig's Cause Pancreatic Cancer Society is to provide information and support to those with pancreatic cancer and their families; to create awareness and educate both the general public and health professionals about the disease; and to raise research funds leading to earlier detection and better treatments and quality of life for patients.

The society was incorporated in 2007 after Craig Schurman Condon lost his life to pancreatic cancer, 8 weeks from diagnosis. In 2012, Craig's Cause received its charitable status.

#### Key Initiatives

- To work collaboratively with other like-minded organizations
- To hold signature fundraising events, to sustain our mission goals
- To distribute educational materials

#### FLORIDA PANCREAS CANCER COALITION, INC.

www.flpcc.org

Patrick F. McLaughlin

pfmcl@comcast.net

904.392.8115

The mission of Florida Pancreas Cancer Coalition is to invest in world class, pancreatic cancer research, and to provide support to Florida programs and initiatives. The Coalition also works closely with oncologists and surgeons at Florida's premier cancer centers.

#### Key Initiatives

- Raise funds for research and grants in the areas of early detection, treatment, and finding a cure for pancreatic cancer by hosting events, such as the Annual Celtic Open Golf Tournament
- Support and educate pancreatic cancer patients, their families and friends with support groups and other programs
- Educate and inform the medical community in the care, treatment, latest science and clinical trials by hosting educational meetings such as the 2015 Florida Summit on Pancreas Cancer

#### GRIFFITH FAMILY FOUNDATION

www.griffithfamilyfoundation.org

Cathy Griffith

cathy@griffithfamilyfoundation.org

814.937.1082

The mission of the Griffith Family Foundation is to find a cure for pancreatic cancer, offer hope to those in need, connect patients, families and communities, fund research, and raise awareness of the necessity for a new direction for innovative research and treatment plans. It provides support for pancreatic cancer research at Beth Israel Deaconess Medical Center/Harvard Medical School. The Foundation was founded in memory of Greg Griffith by his wife, Cathy, and their 2 sons, Jordan and Jamie.

#### Key Initiatives

Through the Foundation's campaign, Sideline Cancer, it hosts numerous fundraising and community-building events for high school and college students which include:

- Fundraiser dinners
- Basketball tournaments
- Tee Off for a Cure golf tournaments
- Memorabilia auctions
- Sideline Cancer with Santa
- New Year's Eve Believe Spectacular

#### HIRSHBERG FOUNDATION FOR PANCREATIC CANCER RESEARCH

www.pancreatic.org

Agi Hirshberg, Founder

ahirshberg@pancreatic.org

310.473.5121

Founded in 1997, Hirshberg Foundation was the first national, nonprofit organization dedicated to advancing pancreatic cancer research, providing financial aid, information, resources and support to pancreatic cancer patients and their families.

The mission of the Hirshberg Foundation is to:

- Find a cure for pancreatic cancer in honor of the thousands of people diagnosed with this disease
- Create a premier Pancreatic Cancer Center to meet all needs of pancreatic cancer patients with the most advanced treatment options
- Serve as a patient support reference source for patients and their families
- Fund projects and programs designed to improve patient care, treatment and pancreatic cancer survival rates
- Unite generations through physical fitness participation, while creating public awareness

#### Key Initiatives

- International Seed Grant Research Program
- Pancreatic Tissue and Data Bank at UCLA
- Educational Symposium for patients and families
- Patient financial assistance
- Patient Resources: Pancreas booklet, Roadmap Program and caregiver workbook

#### THE JOSEPH C. MONASTRA FOUNDATION FOR PANCREATIC CANCER RESEARCH

www.jcmfoundation.org

Grace Saunders, President

gracemsaunders@yahoo.com

216.534.0842

The mission of The Joseph C. Monastra Foundation is to engage in charitable, educational and scientific efforts, including

funding research, scientific endeavors and other activities directed at the eradication of cancer, specifically pancreatic cancer.

#### Key Initiatives

- Support early detection research at John Hopkins Medical Institution/Sol Goldman Pancreatic Cancer Research Center and Emory University that includes genetic analysis of single pancreatic cancer cells and defines the molecular changes that underlie the events that lead to invasion in pancreatic cancer
- Fund research which improves diagnosis, classification, and clarification of the molecular mechanisms of pancreatic cancers and focuses on the genetics and biological determinants of familial pancreatic cancer risk
- Further promote advocacy and awareness through social media
- Host fundraising events—Signature Event: ArtCAN ([www.jcm-artcan.org](http://www.jcm-artcan.org))

#### KENNER FAMILY RESEARCH FUND

[www.kennerfamilyresearchfund.org](http://www.kennerfamilyresearchfund.org)  
Barbara Kenner, PhD, Founder  
[drbkenner@kennerfamilyresearchfund.org](mailto:drbkenner@kennerfamilyresearchfund.org)  
212.585.3697

Kenner Family Research Fund (KFRF) was established in memory of Peter Kenner and is committed to supporting the development of an early detection protocol for pancreatic cancer. KFRF efforts are focused on outcomes that will positively impact the time of diagnosis, length of survival, and quality of life for individuals diagnosed with pancreatic cancer.

#### Key Initiatives

- Facilitate collaboration through conferences and conversations with professionals whose diverse expertise and perspectives support a strategic plan for early detection. KFRF, in collaboration with the American Pancreatic Association, planned and organized the inaugural Early Detection of Sporadic Pancreatic Cancer Summit Conference
- Encourage innovation through initiatives and publications that challenge current thought and methods. Recent publications include Early Detection of Sporadic Pancreatic Cancer: Strategic Map for Innovation, Early Detection of Sporadic Pancreatic Cancer: Summative Review, and 2015 Directory of North American Pancreatic Cancer Organizations
- Promote pioneering research initiatives that demonstrate potential for achieving the fund's vision. KFRF currently supports research at Mayo Clinic and Memorial Sloan-Kettering Cancer Center

#### LUSTGARTEN FOUNDATION

[www.lustgarten.org](http://www.lustgarten.org)  
[kkaplan@cablevision.com](mailto:kkaplan@cablevision.com)  
516.803.2304; Toll-free 1.866.789.1000

The Lustgarten Foundation is America's largest private foundation dedicated to funding and advancing scientific and medical research related to the diagnosis, treatment, prevention, and cure of pancreatic cancer. Since its inception in 1998, the Foundation has contributed more than US \$110 million to more than 200 research projects at nearly 60 medical and research centers worldwide.

#### Key Initiatives

- Increase funding and support of pancreatic cancer research into the biological mechanisms and clinical strategies
- Facilitate and enhance the dialogue among members of the medical and scientific communities about basic and clinical research efforts

- Educate the public about pancreatic cancer through awareness campaigns and fundraising events
- Provide informational support for pancreatic cancer patients, their families, and friends. Because of Cablevision's support of the Foundation, 100% of every dollar donated goes directly to pancreatic cancer research. The Lustgarten Foundation and Cablevision are also partners in the curePC public awareness campaign (<http://www.curePC.org>).

#### THE NATIONAL PANCREAS FOUNDATION

[www.pancreasfoundation.org](http://www.pancreasfoundation.org)  
Matthew Alsante  
Executive Director  
[malsante@pancreasfoundation.org](mailto:malsante@pancreasfoundation.org)  
1.866.726.2737

The National Pancreas Foundation (NPF) provides hope for those suffering from pancreatitis and pancreatic cancer through funding cutting edge research, advocating for new and better therapies, and providing support and education for patients, caregivers, and health care professionals. NPF hosts events and workshops.

#### Key Initiatives

- Developing approved NPF Centers which provide the multidisciplinary treatment of pancreatitis
- Creating a National Patient Registry in pancreatic cancer and pancreatitis that has a patient portal and physician/EMR-entered data
- Funding and advocating for pancreas research
- The Animated Pancreas Patient program featuring animations and expert interviews on pancreatitis, pancreatic cancer, surgery, and endoscopic procedures.

#### NATIONAL PANCREATIC CANCER FOUNDATION

[www.npcf.us](http://www.npcf.us)  
Rhonda Hatfield  
[Rhonda@npcf.us](mailto:Rhonda@npcf.us)  
800.859.6723, Ext 3

The mission of the National Pancreatic Cancer Foundation is to provide unwavering support to those afflicted and affected by pancreatic cancer through 4 core programs:

- Direct Financial Assistance
- Early Detection Research
- Patient Advocacy
- Educational Awareness

#### Key Initiatives

- To provide direct financial assistance to those in treatment for pancreatic cancer
- To create awareness and funding for early detection research

#### NEUROENDOCRINE CANCER AWARENESS NETWORK

[www.netcancerawareness.org](http://www.netcancerawareness.org)  
Bob Wahmann, Executive Director  
[bob@netcancerawareness.org](mailto:bob@netcancerawareness.org)  
516.781.7814  
NCAN was formerly the Carcinoid Cancer Awareness Network Inc.  
866.850.9555

NCAN's mission is to heighten the awareness of neuroendocrine cancer by hosting conferences, charitable events, local meetings, direct mail, and access to a toll free support line. NCAN is committed to providing financial assistance, information and

merchandise to other charitable groups in support of their efforts to improve the quality of life for neuroendocrine pancreatic cancer patients and their families. They actively pursue funding to support their initiatives by hosting fundraising events and seek contributions from private and institutional donations.

#### Key Initiatives

- 2015 Regional Patient Conference Series on Long Island, NY; in Phoenix, AZ; Dublin, OH; and Minneapolis, MN
- 2016 National NET (Neuroendocrine Tumor) Patient Conference
- 2015 Support Group Leaders' Seminar
- Presence at American Society of Clinical Oncology and American Society of Clinical Oncology Gastrointestinal Cancers
- Initiate dialogue with the American Cancer Society

#### NIKKI MITCHELL FOUNDATION

www.nikkimitchellfoundation.org  
Rhonda Miles, President  
Rhonda@nikkimitchellfoundation.org  
Info@nikkimitchellfoundation.org  
615.982.6802

The Nikki Mitchell Foundation is dedicated to the support of research for the early detection and cure of pancreatic cancer. Nikki Mitchell Foundation funds the most promising research while maintaining a focus on public awareness and patient support. The Foundation places a special emphasis on prevention and patients' preferences in determining their own care.

#### Key Initiatives

- Understand patients' concerns, needs, and motivations
- Identify promising research and the scientists behind it
- Capture the key trends in research and establish their legitimacy and promise
- Support the establishment and application of developments in the prevention of pancreatic cancer

#### NORTH AMERICAN NEUROENDOCRINE TUMOR SOCIETY

www.nanets.net  
Kari Brendtro, Executive Director  
kari@nanets.net  
360.314.4112

The mission of the North American Neuroendocrine Tumor Society (NANETS) is to improve the management of neuroendocrine tumor (NET) disease through increased research and educational opportunities. Established in 2006 by a group of health care professionals dedicated to advancing the field of NET disease management, NANETS has sponsored 7 international symposia, 11 regional conferences, and published consensus guidelines in 2010 and 2013.

NANETS awards young investigator research grants to inspire the inquisitive spirit of discovery crucial to building scientific momentum, and to create mentoring opportunities for upcoming physicians with established experts.

#### Key Initiatives

- Annual NET symposium which includes an allied healthcare track, young investigator and poster sessions
- Regional educational conferences
- Development of cooperative projects that help to expand joint research efforts and protocols
- Provision of relevant scientific developments to its membership and site visitors

#### PANCREATIC CANCER ACTION NETWORK

www.pancan.org  
info@pancan.org  
Toll Free: 877.272.6226  
Phone: 310.725.0025

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. The organization accomplishes its mission through a comprehensive strategy that includes funding private research grants, aggressively advocating for more federal research funding, providing patient services, and educating the public about the disease.

#### Key Initiatives

- Double survival for pancreatic cancer by 2020
- Increase government and private research funding
- Increase the clinical trial enrollment rate
- Promote Know Your Tumor to drive clinical trials that are based on real patients and their tumors

#### PANCREATIC CANCER ALLIANCE

www.pancreaticalliance.org  
info@PancreaticAlliance.org  
508.873.3600

The mission of the Pancreatic Cancer Alliance is to support pancreatic cancer research and care at the University of Massachusetts Medical School and UMass Memorial Cancer Center in Worcester; and to support patients and their loved ones in the battle against pancreatic cancer.

#### Key Initiatives

To raise funds to further pancreatic cancer research and treatment efforts for the medical and research communities at UMass Medical School and UMass Memorial Cancer Center for programs that include:

- Providing startup money for researchers developing drug trials
- A fellowship program to train the next generation of surgical residents in the pancreatic cancer field
- Heightening public awareness of pancreatic cancer by sponsoring educational symposia and fundraising events that highlight pancreatic cancer
- Creating patient kits for newly diagnosed patients that provide comprehensive information about the disease and treatment options
- Helping to educate patients and medical professionals about pancreatic cancer

#### PANCREATIC CANCER CANADA

www.pancreaticcancercanada.ca  
Laurie Ellies, Co-founder and Acting Executive Director  
laurieellies@pancancanada.ca  
416.919.9943

Pancreatic Cancer Canada is committed to improving pancreatic cancer survival and creating hope through awareness, education, patient support, research into early detection and treatment, and advocating for increased funding.

#### Key Initiatives

- Education – expand the Educational Series and introduce a diet and nutrition webinar series
- Patient Support—launch a pancreatic cancer information service
- Research—hold the second Annual Innovative Research Grant Competition; continue to work toward creating a Canadian Pancreatic Cancer Research Strategy; PCC recently convened a

cross-section of researchers to identify a direction for pancreatic cancer research and explore collaborative, coordinated efforts to address gaps in research capacity and fund the most promising programs

- Awareness—involve more communities across Canada in World Pancreatic Cancer Day and in their 2 national awareness campaigns: “Purple Lights” and “Pansies for Pancreatic Cancer”
- 10th Anniversary Kick-Off

#### PROJECT PURPLE

[www.run4projectpurple.org](http://www.run4projectpurple.org)

Dino Verrelli, Founder and Chairman

[dino@run4projectpurple.org](mailto:dino@run4projectpurple.org)

203.414.2716

Elizabeth Mauldin, [elizabeth@run4projectpurple.org](mailto:elizabeth@run4projectpurple.org)

Diana Brancato, [Diana@run4projectpurple.org](mailto:Diana@run4projectpurple.org)

203.714.6052

The mission of Project Purple is to raise awareness and funding for a cure of Pancreatic Cancer by bringing people together through various running events, including the New York, Boston, and Chicago Marathons. The goal is to help find a cure, as well as to improve the quality of life for those currently suffering from the negative effects of the disease.

#### Key Initiatives

- Research Grants—distributing funds to select medical research facilities specializing in pancreatic cancer, as well as funding research conducted by individual researchers and fellows
- Patient Financial Aid—providing individuals diagnosed with pancreatic cancer and their families with relief from medical and living expenses
- Scholarships—awarding financial assistance to high achieving university students at all levels, whose lives have been adversely affected by pancreatic cancer

#### ROLFE PANCREATIC CANCER FOUNDATION

[www.rolfefoundation.org](http://www.rolfefoundation.org)

Lynda Robbins, Executive Director

[Robbins5000@aol.com](mailto:Robbins5000@aol.com)

[info@rolfefoundation.org](mailto:info@rolfefoundation.org)

312.726.7766

The mission of Rolfe Pancreatic Cancer Foundation is to serve as a catalyst for the early diagnosis and ultimate cure of pancreatic cancer and to provide support for patients and their loved ones.

#### Key Initiatives

- Advance the development of early detection by supporting research to develop a diagnostic test for pancreatic cancer in its earliest stage, when it is most treatable
- Fund medical research at leading clinical and academic centers by raising money for top-tier research institutions that will attract more scientists dedicated to pancreatic cancer research. Relative to other cancers, the number of scientific investigators with a demonstrated focus on pancreatic cancer is limited
- Provide resources for pancreatic cancer patients and their loved ones—the Rolfe Foundation provides quick and easy access to people and places for support.

#### RON FOLEY PANCREATIC CANCER FOUNDATION

[www.ronsrun.org](http://www.ronsrun.org)

Barbara Foley, Founder, President and Board Member

[barbara@ronsrun.org](mailto:barbara@ronsrun.org)

860.521.0500

Jennifer Loughran, Executive Vice President and Board Member

[jenniferloughran@att.net](mailto:jenniferloughran@att.net), 860.521.0500

The mission of the Ron Foley Foundation is to:

- Raise funds for medical research for more effective treatment of pancreatic cancer
- Promote public awareness of the pain, suffering, and loss caused by pancreatic cancer so that early detection will become a widely shared priority
- Provide direct financial aid to those suffering from pancreatic cancer and their families

#### Key Initiatives

- Continue to raise funds for pancreatic cancer medical research, medical symposia, public education and patient assistance through Ron's Run for the Roses, an annual Kentucky Derby day gala, and other fundraising opportunities
- Expand the Foundation's Ron's Rescue Fund, a donor-restricted fund dedicated to providing financial aid to patients and their families
- Increase public awareness by sponsoring a speaker series on pancreatic cancer featuring medical and research specialists and expanding existing public education seminars and medical symposia

#### SKY FOUNDATION, INC.

[www.skyfoundationinc.org](http://www.skyfoundationinc.org)

Sheila Sky Kasselmann

[info@skyfoundationinc.org](mailto:info@skyfoundationinc.org)

248.978.9845

Sky Foundation is dedicated to raising funds to advance research and increase awareness for the early detection and treatment of pancreas cancer. The Foundation supports mostly Michigan-based researchers at the University of Michigan and Karmanos Cancer Institute/ Wayne State University. It has provided more than US \$900,000 in seed grants which supplement government funding for scientists working on innovative approaches in prevention and early detection. Founded in 2008 by Sheila Sky Kasselmann, a pancreas cancer survivor, the Foundation's efforts are patient-focused with the goal of bringing hope to pancreatic cancer patients and their families.

#### Key Initiatives

Raise funds and build community by holding events that include:

- Family-oriented sports outings and get-togethers hosted by Sky Foundation's Young Professionals Group
- The Women's Event
- Hospital Tours
- Annual Luncheons
- Panel Discussions

#### WHIPPLE WARRIORS

[www.whipplewarriors.com](http://www.whipplewarriors.com)

Ronda Ayala

CEO and Founder

[whipplewarriors@hotmail.com](mailto:whipplewarriors@hotmail.com)

331.256.7807

The mission of Whipple Warriors is to support, educate and bring awareness to the needs of the Whipple patients regardless of the reason for their surgery. The Neuroendocrine Cancer Awareness Network and Pancreatic Cancer Action Network offers their patients the opportunity to become Whipple Warrior members on their web sites.

#### Key Initiatives

- Member conferences
- Raising awareness through patient-to-physician brochures

- Education through documents created by medical professionals
- Advocacy by working with university physicians to discuss the long-term effects of the Whipple surgery

#### WINGS OF HOPE FOR PANCREATIC CANCER RESEARCH

www.wingsofhopepcr.org  
 Maureen A. Shul  
 Mashul1010@aol.com  
 720.733.0491, 303.378.8868

The mission of Wings of Hope is to raise awareness and fund pancreatic cancer research at the University of Colorado Cancer Center.

Wings of Hope was founded in 2012 by Maureen Shul, after losing her brother and mother within months of one another to pancreatic cancer. One year later, the University of Colorado Cancer Center and the Foundation established a formal partnership to collaborate their efforts. In 2015, Wings of Hope created the first endowment for pancreatic cancer research at the University of Colorado Cancer Center.

#### Key Initiatives

- Host events to raise funds and support patients and their families
- Establish the first support group at the University of Colorado Cancer Center for pancreatic cancer patients and their families
- Raise awareness and funding for collaborative pancreatic cancer research
- Continue to grow nationally with donations, grants, and presentation requests now coming from across the country

#### ZETZ FAMILY PANCREATIC CANCER RESEARCH FOUNDATION

www.zetzfamilyresearchfund.org  
 Victoria Boyd  
 Executive Assistant  
 admin@zetzfamilyresearchfund.org  
 510.244.9619

The sole purpose of the Zetz Family Research Foundation is to seek out and provide funding to the most promising and cutting edge studies and projects working toward understanding and finding a cure for pancreatic cancer.

#### Key Initiatives

- Create awareness of research performed at the clinical level once a patient is diagnosed with pancreatic cancer
- Design a DNA donation program that is user friendly and immediately available to the patient, caregiver, and clinicians
- Provide support and funding to the National Familial Pancreatic Tumor Registry at Johns Hopkins Pancreatic Cancer Center to

cover costs of materials, collection, and transportation of pancreatic cancer DNA from diagnosed patients

- Connect pancreatic cancer patients with organizations that meet the changing needs of affected families

#### ACKNOWLEDGMENTS

*Participants in the 2015 meeting of North American Pancreatic Cancer Organizations were Pam Acosta Marquardt, Pancreatic Cancer Action Network; Matt Alsante, The National Pancreas Foundation; Sarah Banks, Hirshberg Foundation For Pancreatic Cancer Research; Joel Beetsch, Celgene Corporation; Kari Brendtro, North American Neuroendocrine Tumor Society; Stefanie Condon-Oldreive, Craig's Cause Pancreatic Cancer Society; Theresa Dukovich, Alliance of Families Fighting Pancreatic Cancer; Laurie Ellies, Pancreatic Cancer Canada; Kate Elliott, Craig's Cause Pancreatic Cancer Society; Julie Fleshman, Pancreatic Cancer Action Network; Barbara Foley, Ron Foley Pancreatic Cancer Foundation; Anne Glauber, Lustgarten Foundation; Ann Goldberg, Kenner Family Research Fund; Catherine Griffith, Griffith Family Foundation; Rhonda Hatfield, National Pancreatic Cancer Foundation; Kendra Haywood, Alliance of Families Fighting Pancreatic Cancer; Ron Hollander, Caring for Carcinoid Foundation; Jane Holt, The National Pancreas Foundation; Kerri Kaplan, Lustgarten Foundation; Barbara Kenner, Kenner Family Research Fund; Audrey Kurlan-Marcy, Pancreatic Cancer Alliance; Jennifer Loughran, Ron Foley Pancreatic Cancer Foundation; Sandy Pearl, Pancreatic Cancer Canada; Laura Rothschild, Kenner Family Research Fund; Maureen Shul, Wings of Hope for Pancreatic Cancer Research; Sheila Sky Kasselman, Sky Foundation, Inc.; Diane Tonelli, Pancreatic Cancer Alliance; Dino Verrelli, Project Purple; Sidney Walker, Florida Pancreas Cancer Coalition, Inc.; Bob Wahmann, Neuroendocrine Cancer Awareness Network; Maryann Wahmann, Neuroendocrine Cancer Awareness Network; Grace Zetz, Zetz Family Pancreatic Cancer Research Foundation. Planning Team members were Barbara Kenner, Ann Goldberg, Laura Rothschild of Kenner Family Research Fund; Julie Fleshman and Deanna Courtney of Pancreatic Cancer Action Network. The North American Pancreatic Cancer Organizations meeting was made possible through contributions from Celgene and Pancreatic Cancer Action Network. Ann Goldberg served as project director and editor and Laura Rothschild as editor of The 2015 North American Pancreatic Cancer Organizations Directory. Funding for the Directory was provided by Kenner Family Research Fund.*

#### REFERENCE

1. Bose R, Mother Teresa FL CEO. *Unexpected Principles for Practical Leadership*. San Francisco, CA: Berrett-Koehler Publishers; 2011.