

The Patient Navigation Outreach Program

Submitted by:

**Pancreatic Cancer Action Network
2141 Rosecrans Avenue, Ste. 7000
El Segundo, CA 90245
(310) 725-0025**

TABLE OF CONTENTS

Content	Page
Executive Summary	1
Introduction	2
Statement of Need	3
Organization Description	5
Project Description.....	9
Overall Strategy	9
Goals and Objectives.....	9
Target Audience	10
Tactics	11
Project Management.....	14
Key Staff and Partners	14
Publicity	16
Timeline	17
Evaluation	18
Sustainability.....	20
Budget and Narrative	21
References	22
Appendix A: Leadership Teams.....	24

EXECUTIVE SUMMARY

Pancreatic cancer is the fourth leading cause of cancer death and will claim the lives of more than 35,000 Americans this year. Diagnosis is made most often in late stages of the disease, when surgical removal of the tumor is impossible (American Cancer Society, 2009). Available treatments aim to palliate symptoms. Of all the cancers, receiving this diagnosis is most daunting for patients and caregivers.

The Pancreatic Cancer Action Network was founded in 1999 to change the course of history for pancreatic cancer. The organization's Patient and Liaison Services (PALS) program was specifically designed to meet the urgent information and health system navigation needs of pancreatic cancer patients and their caregivers.

The Pancreatic Cancer Action Network's PALS program will lead the proposed *The Patient Navigation Outreach Program*, which aims to ensure that patients and their caregivers have access to up-to-date information about the disease, are aware of and are connected to needed resources and services, and are equipped and empowered to make informed decisions about their care and treatment. The proposed project will be implemented over 2.5 years and has a budget of \$1,036,592. The Palette Fund is partnering with the Pancreatic Cancer Action Network on this project and will fund fifty percent of the project budget in the amount of \$518,000. The remaining funding for the project is respectfully requested from additional partners.

Health care professionals not only play a critical role in the care of pancreatic cancer patients, but also are uniquely positioned to refer these patients and caregivers to needed resources and support services. Therefore, the outreach project will focus on equipping the health care community with the information, tools and resources they need to effectively work and intervene with this important and growing population.

The proposed project involves a multi-faceted approach that is designed to ensure that:

1. health professionals appropriately consider pancreatic cancer when making a diagnosis;
2. where a diagnosis of pancreatic cancer is confirmed, health professionals make appropriate referrals to experienced pancreatic cancer specialists;
3. pancreatic cancer patients and caregivers are referred to PALS and receive the education, support and services they need to successfully navigate the fragmented health service system.

The potential impact of this outreach project is a profound positive effect in the lives of pancreatic cancer patients and their caregivers.

INTRODUCTION

The Pancreatic Cancer Action Network respectfully requests funding over 2.5 years to support *The Patient Navigation Outreach Program*, a national patient and caregiver navigation project that aims to provide guidance, information and support to individuals diagnosed with pancreatic cancer and their loved ones. The overall project budget is \$1,036,592. The Palette Fund is partnering with the Pancreatic Cancer Action Network and will fund fifty percent of the overall project budget in the amount of \$518,000. The remaining funding for the project is respectfully requested from additional partners. The project aims to ensure that these patients and their loved ones receive timely and needed support to effectively navigate the fragmented health system, are aware of and are connected to needed resources and services, have access to up-to-date information about the disease, and are equipped and empowered to make informed decisions about their care and treatment.

The project recognizes that health care professionals not only play a critical role in the care of pancreatic cancer patients, but also that they are uniquely positioned to refer these patients and caregivers to needed resources and support services. It also recognizes that there is significant variability in health care professionals' experiences and expertise with pancreatic cancer. The project aims to improve their understanding and capability to effectively work with pancreatic cancer patients and their caregivers.

The projects builds on the success of the Pancreatic Cancer Action Network's Patient and Liaison Services (PALS) program and is designed to augment its existing services and expand its reach and penetration to ensure that more patients, caregivers, and professionals benefit from the program.

The proposed program is well aligned with the mission and capabilities of the Pancreatic Cancer Action Network and it is enthusiastically supported by its Board of Directors, Medical Advisory Council, and Scientific Advisory Board.

STATEMENT OF NEED

In 2009, more than 42,000 Americans will be diagnosed with pancreatic cancer (American Cancer Society, 2009). Though this number represents a relatively small portion of the 1.4 million cancer diagnoses in the U.S. annually, the exceptionally high mortality rate makes this cancer especially problematic and a significant public health concern. Given that this disease disproportionately affects older age groups and that the total population is aging, if past trends continue we can expect the incidence and prevalence of pancreatic cancer to increase in the future.

Lack of navigational resources for patients and caregivers

Prior to the launch of the Pancreatic Cancer Action Network's Patient and Liaison Services (PALS) program seven years ago, pancreatic cancer information for patients and caregivers was difficult to locate or completely absent. Established resources like the American Cancer Society and the National Cancer Institute typically provided general cancer information with little specifics about pancreatic cancer diagnosis, therapies, surgical procedures, nutrition and other specific symptom management. No pancreatic cancer organization other than the Pancreatic Cancer Action Network offers comprehensive navigational services and education for patients and caregivers.

Interviews with patients and caregivers during the development of the PALS program revealed that patients and caregivers who searched the internet or asked their health professionals for resources often felt frustrated, isolated and disappointed. Some families reported simply sacrificing treatment to get personal affairs in order because they did not have access to quality, accurate information about the options and support available.

Delay in diagnosis and treatment

Two problems persist for pancreatic cancer patients and caregivers with regards to time delays:

- 1) Significant delay in receiving accurate diagnoses.
- 2) Significant delay between diagnosis and commencement of treatment.

Particularly for pancreatic cancer, these delays can have substantial negative impact on patient outcomes. (Picozzi et al, 2009)

Delays in diagnosis and commencement of treatment may be attributed to:

- 1) Limited knowledge of physicians regarding pancreatic disease and diagnosis.
- 2) Limited knowledge of physicians regarding appropriate medical referral patterns and resources for the patient with pancreatic cancer.
- 3) Fatalistic attitudes of physicians and other health professionals regarding pancreatic cancer treatment.

Treatment by non-specializing hospitals and physicians

Furthermore, patients with pancreatic cancer may receive treatment from non-specializing physicians or hospitals who may have limited or no knowledge of recent treatment information. According to a study published by Chang et al in 2009, less than half of pancreatic cancer patients are being referred to high-volume (specializing) centers.

A study by Bilimoria et al in 2007 described a striking underuse of pancreatectomy (a surgical procedure used to remove pancreatic tumors) in the United States. The study points out that nearly 40% of pancreatic cancer patients with early stage disease did not have surgery to remove their tumors because surgery was not offered by their physicians. Furthermore, patients who were over the age of 65, African American, low-income, less educated or received treatment at low-volume (non-specializing) community hospitals were even less likely to be offered a surgical treatment option.

A 2008 study by Pawlik et al likewise demonstrated significant variations in clinical care for pancreatic cancer patients and the importance of seeking care with specializing physicians and facilities. The study was specifically designed to compare the treatment recommendations that patients received from the Multidisciplinary Pancreatic Cancer Clinic at Johns Hopkins with previous recommendations they received from other institutions. The results showed that reviews by the multidisciplinary expert team improved treatment plans for a significant number of patients. In fact, the treatment plans recommended by another institution were changed for about one in four patients. Evaluations by the team of pancreatic cancer experts indicated some patients did not have true pancreatic masses; several had metastases that were previously undetected; others who were previously offered surgery were found to have unresectable disease; and still others who had been advised that their tumors were unresectable were found to be acceptable surgical candidates.

Treatment of patients by non-specializing physicians may be attributed to many of the same reasons for delays in diagnosis and commencement of treatment:

- 1) Limited knowledge of physicians regarding pancreatic disease and diagnosis.
- 2) Limited knowledge of physicians regarding appropriate medical referral patterns and resources for the patient with pancreatic cancer.
- 3) Fatalistic attitude of physicians and other health professionals regarding pancreatic cancer treatment.

The poor prognosis of this disease is compounded by lack of navigational resources for pancreatic cancer, lack of awareness and access to options, and delays in diagnosis and treatment. Patients and caregivers are left isolated, frustrated, and with poor outcomes from treatment. The ultimate result is a very low survival rate. The bottom line for this year is that more than 35,000 Americans will die from pancreatic cancer (American Cancer Society, 2009).

ORGANIZATION DESCRIPTION

Founded in 1999 by three visionaries as a small 501(c)(3) non-profit patient-based advocacy organization, the Pancreatic Cancer Action Network understands the many challenges that patients and their caregivers face in the fight against pancreatic cancer.

With our national headquarters in Los Angeles, California, and a Government Affairs office in Washington, DC, the organization fulfills its mission through a nationwide network of people dedicated to working together to advance research, support patients and create hope for those affected by pancreatic cancer.

In just ten years, we have evolved from a staff of one with an annual budget of \$200,000 to a nationally recognized organization that operates with an annual budget of over \$10 million and 54 staff and nearly 2,000 volunteers supporting 70 affiliates across the country. Throughout this time, the organization has been led by President and CEO, Julie Fleshman, and its growth and success is a testament to her leadership and vision. Moreover, while there is an ongoing infusion of staff and volunteers with new skills and new ideas, there is very little staff turnover and many of the earlier staff and volunteers continue to work passionately for the organization.

Mission

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 raises money for direct private funding of research and advocates for more aggressive federal research funding of medical breakthroughs in prevention, diagnosis, and treatment of pancreatic cancer. We fill the void of information and options by giving patients and caregivers the reliable, personalized information they need to make informed decisions. Finally, the organization helps support individuals and communities all across the country work together to raise awareness and funds to find a cure for pancreatic cancer. We create a sense of hope and community so no one has to face pancreatic cancer alone.

Goals

The Pancreatic Cancer Action Network's goals are to give pancreatic cancer patients a fighting chance for survival by working in a comprehensive way to meet the following urgent needs:

1. Supporting patients and giving them options with top-notch, evidence-based, comprehensive information and resources.
2. Increasing federal and private funding to advance research programs that create breakthroughs in the understanding, treatment and prevention of pancreatic cancer.
3. Funding innovative research that expands the current portfolio of pancreatic cancer research leading to more options for patients.
4. Encouraging early career scientists to make pancreatic cancer their research focus.
5. Encouraging collaboration and partnerships across the government and private sector, connecting researchers, scientists and healthcare professionals—thereby producing faster results for patients.

6. Sharing our knowledge and increasing our effectiveness by increasing outreach with all partners including patients, health professionals, donors, volunteers, corporations, other pancreatic cancer organizations/foundations and government officials.
7. Sustaining and expanding our network of volunteers and donors to help people make a real difference on this disease through leadership, volunteerism, advocacy and community outreach.
8. Educating and creating awareness and activism in the general public about pancreatic cancer.

Programs

The Pancreatic Cancer Action Network has three core programs:

- 1) Patient and Liaison Services (PALS)
- 2) Research
- 3) Community Outreach

1) Patient and Liaison Services (PALS)

Patient and Liaison Services (PALS) addresses the needs of pancreatic cancer patients and caregivers by providing *one* place to call for quality pancreatic cancer specific information and resources. Patients and families access the PALS program via a nationwide, toll-free telephone number or online via the internet or email. Upon contacting PALS, the patient or caregiver is connected one-on-one with a trained, dedicated PALS Associate. PALS Associates typically have at least a college or graduate degree in the medical and/or health fields, and represent diverse cultural and ethnic backgrounds. They are highly attuned to the people and community being served. Their principal role is to provide guidance, support and information that is customized to meet patient and/or caregiver needs. The goal is to help pancreatic cancer patients and caregivers navigate the fragmented health system and make informed and timely decisions. PALS Associates provide guidance and personalized information about the disease, treatment options available, specialists, clinical trials, support groups, nutrition and much more.

Evidence-based and reviewed by medical experts

The philosophy of the PALS program is to provide patients and caregivers with credible, reliable, evidence-based information on diagnosis, treatment options, supportive care and resources. To this end, the content of the PALS program and all educational materials are reviewed by the Pancreatic Cancer Action Network's Medical Advisory Council. Volunteer members of the Medical Advisory Council are leading pancreatic cancer clinicians, including surgeons, medical oncologists, radiation oncologists, gastroenterologists, nurses, and registered dietitians.

State-of-the-art information

PALS Associates are armed with the latest evidence-based published information about pancreatic cancer diagnosis, treatment, nutrition and symptom management. To ensure that the PALS Associates maintain current knowledge, staff members attend continuing medical education sessions, read peer-reviewed journals and participate in educational in-services led by health professionals.

PALS has a comprehensive library of print and online educational tools for patients and caregivers. The print library is made up of more than 70 fact sheets and six (6) booklets: *Overview of Pancreatic Cancer* (English and Spanish), *Diet and Nutrition* (English and Spanish), *Clinical Trials for Pancreatic Cancer*, and *Hospice: End-of-Life Care for Pancreatic Cancer*. Extensive educational content is also available on our website.

Furthermore, PALS organizes and convenes the Pancreatic Cancer Symposia for patients and caregivers in cities across the United States. These free, intensive educational workshops feature, and provide attending patients and their caregivers the opportunity to meet and talk with, leading local and national healthcare professionals that specialize in pancreatic cancer.

Free, customized education packets are prepared for all patients and caregivers who contact PALS. Packets are mailed via USPS Priority Mail within 24 hours of the contact, in order to meet the urgency felt by patients and caregivers.

Clinical trials

The PALS program maintains a database of IRB-approved pancreatic cancer clinical trials. PALS staff continuously and regularly contact physicians, cooperative groups, and pharmaceutical companies to obtain up-to-date specifics about their clinical trials. Information about these trials is loaded into a database and personalized searches are performed for individual patients and caregivers. Results from the personalized searches are sent in print or electronic format so that patients can discuss the trials with their physicians. The PALS clinical trials database is updated weekly, significantly more often than www.clinicaltrials.gov and other online searchable clinical trials tools, to ensure that we provide patients with timely, accurate information. Any IRB-approved pancreatic cancer trial may be included in the database free of charge.

Peer-to-peer support resources

Often, patients and caregivers are seeking support and encouragement from others facing the same disease. The PALS Survivor and Caregiver Network provides peer-to-peer matches for both patients and caregivers so that they have ready access to someone to talk with who has had similar experiences. Furthermore, PALS Associates are equipped with details on other support groups and telephone and online support resources for patients and caregivers.

Continuous case management

Patients and caregivers are encouraged to contact PALS as many times as necessary to get the navigational resources and information they need throughout their journeys with this disease. With each call, the individual is re-connected with the original PALS Associate for continuous case management. Furthermore, there is never a charge for the call or any of the information or educational literature provided.

2) Research

We fund a robust research program using a peer-reviewed system administered through the oldest and largest cancer organization in the world, the American Association for Cancer Research. Our goal is to fund innovative research, grow the number of researchers directly working on this disease, foster collaboration across disciplines and institutions, and act as a facilitator in the research community to expedite scientific progress that benefits patients. To

date, the Pancreatic Cancer Action Network has funded nearly \$5 million in research grants. Our 2010 grants program is underway and once funding decisions are finalized this figure will increase to over \$7 million.

Since the federal government has more dollars for cancer research than any private entity, we augment private research funding with aggressive advocacy for increased federal dollars for pancreatic cancer. With a strong presence in Washington, DC, we actively take our fight to Congress by continually educating elected officials about the need for increased spending for pancreatic cancer research. Our advocacy efforts have contributed to a \$70 million increase in National Cancer Institute funding for pancreatic cancer research, climbing from \$17 million in 1999 to \$87 million in 2008.

The Pancreatic Cancer Action Network has worked with Congress to develop the first-ever substantive legislation that will lead to the creation of a federally supported strategic plan and increased resources for pancreatic cancer research. The legislation, called the *Pancreatic Cancer Research and Education Act* (H.R. 745), was introduced in the 111th Congress on January 28th, 2009 by U.S. Representatives Eshoo (D-CA) and Brown-Waite (R-FL).

3) Community Outreach

The Pancreatic Cancer Action Network is powered by active affiliates in more than 70 cities across the country. Our affiliates comprise hundreds of dedicated and passionate volunteers who help us fulfill our mission. Affiliate volunteers work as teams to raise awareness about PALS and our other services and activities, host local events, educate the public through health fairs, and provide valuable information about the disease to hospitals, clinics and healthcare professionals. They also help us to further our goals by engaging their local media, and by alerting their elected officials about the urgent need for scientific progress in the area of pancreatic cancer. In 2008-2009, a total of 396 volunteer-driven events were held across the country. Through their efforts, we were able to distribute over 1,000 informational packets to health care professionals in their communities.

PROJECT DESCRIPTION

The Pancreatic Cancer Action Network proposes *The Patient Navigation Outreach Program*, an extensive outreach project aimed at increasing awareness and use of its Patient and Liaison Services (PALS) program, ensuring that patients and caregivers have timely, accurate disease information and can successfully navigate the healthcare system.

Overall Strategy

The overall strategy of this outreach project is founded on the recognition that health professionals play a crucial role with patients and their caregivers, and are well positioned as a referral resource. It also recognizes that there is significant variability in the accuracy and quality of care that patients receive depending upon the knowledge and skills of their health care team. Consequently, this project focuses on equipping the health care community with the information, tools and resources they need to effectively work and intervene with pancreatic cancer patients and caregivers.

When physicians provide information and resources to their patients and encourage their patients to participate in decision-making processes about treatment, patients, especially women and those in minority groups, are empowered and report a higher quality of life (Maly et al, 2008). Moreover, educational outreach interventions have shown to improve proper diagnostic evaluation in cancer patients (Myers et al, 2004).

Goals and Objectives

The proposed project involves a multi-faceted approach that is designed to:

1. Ensure that health professionals appropriately consider pancreatic cancer when making a diagnosis;
2. Ensure that where a diagnosis of pancreatic cancer is confirmed, health professionals make appropriate referrals to experienced pancreatic cancer specialists;
3. Ensure that pancreatic cancer patients and caregivers are referred to PALS and receive the education, support and services they need to successfully navigate the fragmented health service system.

Plans are to achieve these goals by building the services and resources of PALS and by enhancing the role of health professionals as a referral resource so that more patients and caregivers use and benefit from the program.

The objectives of the project are measurable and focus on usage, knowledge and other behavioral impacts of the program, particularly as related to psychosocial support and awareness and access to timely and appropriate treatment and care. Specific objectives include:

- Increase patient and caregiver contacts to Patient and Liaison Services (PALS) by 8% in FY 2011 (10,040 total contacts) and 8% in FY 2012 (10,843 total contacts).
- Increase educational materials orders from health professionals by 12% in FY 2011 (1,124 total orders) and an additional 12% in FY 2012 (1,259 total orders).

- Increase health professionals' referrals to PALS, as demonstrated by 20 % of contacts to PALS program who report being referred by a health professional.
- Improve knowledge levels of patients, caregivers and health professionals about pancreatic cancer and available care and treatment options.
- Improve patient, caregiver and health professional perceived and actual ability to connect and communicate with medical decision-makers in the health care system.
- Reduce feelings of isolation and hopelessness amongst patients and caregivers.
- Reduce delays in diagnosis of pancreatic cancer by general practitioners.
- Improve medical referral patterns and reduce delays in treatment for patients with pancreatic cancer.

Target Audience

The primary target audience for this outreach project is health professionals, and specifically:

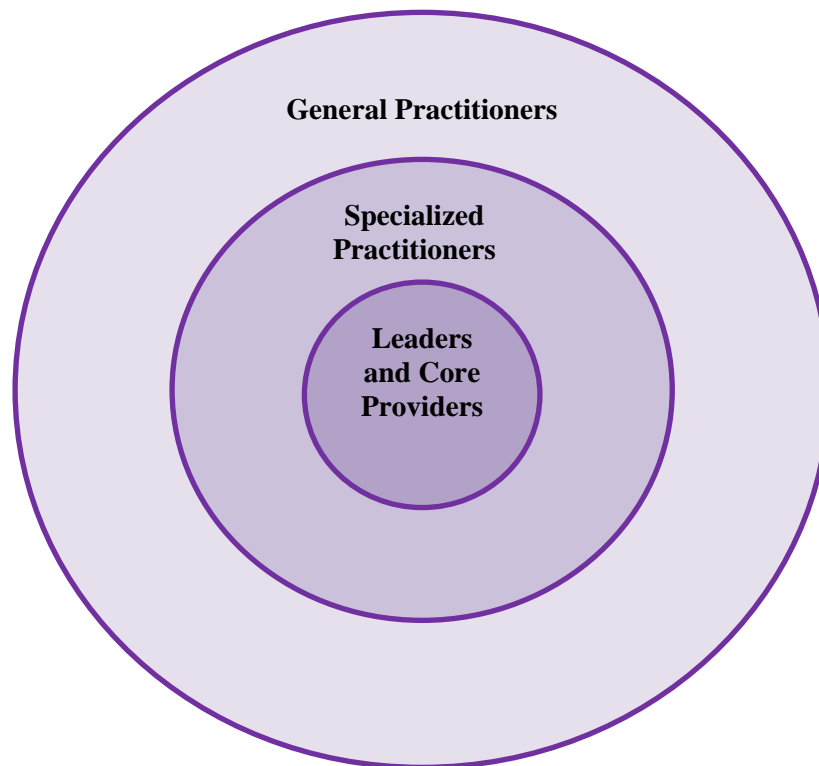
- Gastroenterologists
- Surgeons
- Oncologists
- Radiation Oncologists
- Nurses
- Social Workers
- Dietitians
- Primary Care Physicians
- Patient Advocates
- Hospital-based Patient Navigators

The health professional audience is vast and thus distinct methods are planned for three groups identified as having varying levels of expertise about pancreatic cancer and the PALS program:

- 1) **Leaders and Core Providers:** Includes physicians, researchers and other allied health professionals who participate on the Pancreatic Cancer Action Network's Medical Advisory Council (MAC) and Scientific Advisory Board (SAB). Also part of this group are other physicians and other health professionals who care for large numbers of pancreatic cancer patients and are well-informed about the organization's programs. Members of this group are highly knowledgeable with regards to diagnosis, treatment, and medical referrals for patients with pancreatic cancer.
- 2) **Specialized Practitioners:** Includes physicians and allied health professionals who likely care for significant numbers of pancreatic cancer patients. Many have considerable knowledge of pancreatic cancer diagnosis, treatment and medical referrals, but may not be familiar with the patient and caregiver navigational resources available through PALS.

- 3) **General Practitioners:** Includes primary care physicians, community oncologists, and allied health professionals who *very occasionally* diagnose and treat people with pancreatic cancer. Most lack sufficient knowledge of the disease for timely and accurate diagnosis or treatment. Many are unfamiliar with appropriate medical referrals, or are unwilling to make appropriate referrals due to persistent fatalistic attitudes toward pancreatic cancer treatment. Most are unlikely to be aware of patient and caregiver navigational resources available through PALS.

Based on a theory of radiating impact, some tactics of this project will involve Leaders and Core Providers reaching out to Specialized Practitioners and in turn, Specialized Practitioners reaching out to General Practitioners. This model incorporates the utilization of experts to educate peers, an approach with demonstrated efficacy in the medical field.



Tactics

Distinct outreach tactics will be employed with each level of health professional (Leaders and Core Providers, Specialized Practitioners, General Practitioners), with messaging crafted to meet the educational needs of the target audience.

As an overview, Leaders and Core Providers need reminders to provide PALS as a navigational resource for patients and caregivers; Specialized Practitioners need diagnosis and medical referral information, as well as PALS resources; and General Practitioners need symptom and diagnosis information, medical referral information, and PALS resources.

Tactic 1: Develop and distribute educational materials.

ACTION: Develop three (3) educational videos.

ACTION: Develop six (6) print marketing/educational materials.

ACTION: Develop education and resource package for health professionals; contains the necessary materials for health professional to share with patients and caregivers.

ACTION: Design and acquire educational exhibit displays for use at conferences.

Methods for distribution of educational materials

METHOD: Conduct outreach by mail. Send education and resource packages to Leaders and Core Providers; obtain health professional society membership lists and research provider directories; perform direct mail of PALS materials.

METHOD: Conduct in-person outreach. Exhibit organization at national conferences, local/regional conferences and health fairs; utilize trained volunteers for cost-effectiveness; promote organization through unique opportunities at national health professional conferences; visit local hospitals and institutions in conjunction with symposia; coordinate individual volunteer visits to health professionals.

Tactic 2: Implement wide-reaching media campaign.

In addition to direct distribution of education and outreach materials, this project will employ an awareness campaign to reach a broad spectrum of the General Practitioners through larger media outlets. The campaign messages will be formed with the expertise of the Pancreatic Cancer Action Network's Marketing and Communications department and our partner communications firm, Neimand Collaborative. With repeated exposure to disease symptoms and the organization's name and brand, we aim to enhance awareness of pancreatic cancer and name recognition of the Pancreatic Cancer Action Network and *The Patient Navigation Outreach Program*.

ACTION: Create attention-grabbing print advertisement.

ACTION: Produce video public service announcement (PSA) on PALS.

ACTION: Produce radio announcements on the topic of educational symposia for patients and caregivers.

-Air radio announcements on local radio stations in Symposium cities.

ACTION: Develop and distribute press release announcing awareness campaign to media outlets.

ACTION: Develop strategy to promote awareness campaign to health care professionals through social networking media.

ACTION: Utilize the Pancreatic Cancer Action Network website to announce and promote awareness campaign.

ACTION: Partner with professional societies and organizations with wide reach, to promote awareness campaign to health professionals.

PROJECT MANAGEMENT

Anitra Engebretson, Director of Patient and Liaison Services (PALS) will provide executive level oversight of the project. During her four years in the PALS program, Anitra has built an in-depth knowledge of all aspects of PALS operations. She is responsible to the President and CEO for the quality and performance of the PALS call center, educational library, clinical trials database, health professional outreach, and Symposium series. Furthermore, Anitra works in close collaboration with the Medical Advisory Council to ensure medical accuracy of the program's information and resources.

The **PALS Manager of Outreach** will be responsible for day-to-day management of the project. This position reports to the Director of PALS and is accountable for all aspects of outreach related to PALS. The PALS Manager of Outreach will draw upon her significant experience in health related outreach, including a considerable smoking cessation outreach effort on behalf of the National Cancer Institute of Canada. The PALS Manager of Outreach will serve as the facilitator for internal staff collaborations between PALS, Marketing and Communications, and Community Outreach (volunteer program).

Should a grant be awarded for this project, a new position of **PALS Outreach Specialist** will be created. The PALS Outreach Specialist will report to the Manager of Outreach and will be responsible for analyzing PALS contacts and health professional order data, creating training and guidance outlines for volunteer outreach efforts, and maintaining health professional records in the organization's database. The Outreach Specialist will be primarily occupied with the implementation of this outreach plan.

Furthermore, PALS will require additional **PALS Associates** to field an increased volume of contacts as a result of effective outreach tactics. One new PALS Associate will be hired per year.

Key Staff and Partners

Key staff from other departments within the Pancreatic Cancer Action Network will contribute significantly to the successful execution of this outreach project.

Lisa Gilmour, Director of Marketing

Lisa brings more than 20 years of experience in the area of strategic marketing and planning, marketing programs and marketing communications from the high tech industry. Prior to joining the Pancreatic Cancer Action Network, Lisa worked for Symantec Corporation, one of the largest and most successful high tech companies. While there, she developed marketing software programs targeted to healthcare professionals as solutions when working within the parameters of Health Insurance Portability and Accountability Act (HIPAA) regulations. Lisa's passion to create effective marketing and communication programs to help raise national awareness about this disease stems from the loss of her brother to pancreatic cancer in 2002.

Michelle Duff, DPT, Director of Research and Scientific Affairs

Michelle served nearly seven years as the Director of Patient and Liaison Services (PALS) & Medical Affairs before transitioning into Research and Scientific Affairs. Together with her team, Michelle built the structure and strategy for the PALS program and established the

program as a credible source of evidence-based information for patients and caregivers. In her eight years with the Pancreatic Cancer Action Network, Michelle has developed widespread connections in the medical/scientific community. She maintains membership in numerous oncology professional societies and participates in other senior level oncology leadership and advisory committees.

An outreach project of this scope requires specialized expertise from partners.

Neimand Collaborative, a small communications firm with superb experience in the area of health messaging, will serve as our primary partner for the development of the media campaign. **Rich Neimand, President and Creative Director of Neimand Collaborative**, has a wealth of experience marketing to the medical community with a current client list that includes AdvaMed, National Association of Public Hospitals, National Health Council, Wyeth Pharmaceuticals, National Family Planning and Reproductive Health Association, and the Kidney Cancer Association. Rich's expertise will help guide large portions of this outreach project to healthcare professionals and will ensure branding and messaging consistent with the mission of the Pancreatic Cancer Action Network.

The Pancreatic Cancer Action Network has a record of productive partnerships with multiple professional societies, including the American Society of Gastrointestinal Endoscopy, the Oncology Nursing Society, the Association of Oncology Social Work, and the American Association for Cancer Research. We will again call upon our partners within these organizations for the successful implementation of this outreach project.

PUBLICITY

The Pancreatic Cancer Action Network recognizes that the awarding of a grant for *The Patient Navigation Outreach Program* would provide an outstanding opportunity to increase public awareness of the work being done by our organization and all of the project partners. Should a grant be awarded, a publicity plan will be developed and shared with all of the partners. Some of the key elements that are anticipated include:

- Media release announcing the grant and *The Patient Navigation Outreach Program* (for print and electronic media)
- Website announcement of grant award (est. 36,000 hits per month)
- Article in our *Outreach* newsletter (est. 80,000 circulation)
- Announcement in our annual report (2,100 circulation)
- Interim media releases announcing newly developed products and services (as appropriate)
- Acknowledgement of grant award in newly developed videos and print materials, and presentations

TIMELINE

The following general timeline illustrates major milestones for the project. Staff managing this project will refer to a more detailed project timeline for day-to-day implementation.

Year One (FY 2010)

Six Months ending June 2010:

Develop initial announcements and press plan regarding partnership between the Pancreatic Cancer Action Network, The Palette Fund, and other partners.

Create attention-grabbing print advertisement.

Develop four of six proposed print marketing/educational materials.

Design and acquire educational exhibit displays for use at conferences.

Develop and distribute press release announcing awareness campaign to media outlets.

Year Two (FY 2011)

Six Months ending December 2010:

Develop remaining two of six proposed print marketing/educational materials.

Develop one of three educational videos.

Develop education and resource package for health professionals.

Produce radio public service announcements on the topic of educational symposia for patients and caregivers.

Six Months ending June 2011:

Develop second of three educational videos.

Produce video public service announcement (PSA) on PALS.

Year Three (FY 2012)

Six Months ending December 2011:

Develop remaining one of three educational videos.

EVALUATION

Careful monitoring and evaluation of the project tactics and outcomes will take place on an ongoing basis to ensure that the project remains on track and that objectives are being met. The assessment tools that will be developed and used will provide rapid and frequent feedback to help navigate potential obstacles and problems and successfully steer the program forward. The PALS program already includes an evaluation component that focuses on quality assurance measures. Plans are to enhance and augment these systems in order to ensure that appropriate and meaningful quantitative and qualitative data are generated and analyzed.

The evaluation will be based on data obtained from written surveys, interviews, and discussion groups with the various stakeholders, including patients, caregivers, healthcare professionals and PALS Associates. Key data collection instruments will include:

- contact and inventory reports maintained by PALS Associates to monitor number and type of contacts received and follow-up actions, including specific information and materials that were requested and sent;
- post card surveys that will accompany each educational packet that is sent to assess satisfaction with the assisting PALS Associate and resources requested—responses will help identify the most useful components of the PALS program and where improvement is most needed;
- follow-up surveys with clients to determine if and how the provided information and resources were actually used and contributed to disease diagnosis, and decisions and experiences with care and treatment;
- annual written surveys and one-on-one interviews with a sample of patients, caregivers and health professionals to obtain in-depth feedback about the program's process and outcomes;
- quarterly surveys (submissions are anonymous) and discussion groups with PALS Associates to obtain feedback on their experiences and recommendations for improvement;
- post-symposia/education session written questionnaires and discussion forums to examine participant frequency, satisfaction and perceived value of the attended activity.

The evaluation tools will be multidimensional and will assess opinions about the individual components of PALS, its specific resources and tools, and how they are used and impact decision making and care. Moreover and importantly, they will also identify unmet needs and voids in services and resources, and provide recommendations and guidance on how we may further improve the program to ensure that it is a best practice navigation system.

We recognize that in a comprehensive evaluation, PALS clients would be compared with non-clients to assess differentials in demographics, knowledge and experiences. It is possible and likely that clients are a selective group and differ in characteristics from the broader pancreatic cancer community. These differences can account at least in part for the differences they experience in care, treatment, and their overall journey with the disease. The evaluation will

explore this issue and make some preliminary comparative conclusions relating to knowledge levels of the disease, timeliness of diagnosis, time between diagnosis and treatment, and experiences and satisfaction with care among patients and caregivers served by PALS and not served by PALS. We will work with our Medical Advisory Council, Scientific Advisory Board, and other senior advisors to recruit participants to survey who have not been involved with PALS.

SUSTAINABILITY

The Patient Navigation Outreach Program will have significant and lasting impact on the pancreatic cancer community, including patients, caregivers and health professionals. After successful implementation of the proposed project, the targeted health professionals will better recognize and diagnose pancreatic cancer, will refer pancreatic cancer patients to specializing practitioners, and will recognize the importance of referring patients and caregivers to the PALS program.

Throughout the span of the program, careful and rigorous evaluation of all outreach efforts will be conducted in order to monitor effectiveness and to guide strategy. Additionally, *The Patient Navigation Outreach Program* will be incorporated into the Pancreatic Cancer Action Network's overall strategic plan and will undergo equivalent thorough evaluation and be held to the high standards of all projects implemented as part of the organization's overall strategy.

At the end of the project timeline, we will conduct final evaluations of each of the specific outreach efforts to determine overall impact and compile lessons learned. It is expected that data and outcomes generated through this project will substantiate the need for targeted education and outreach efforts to health professionals and the need for evidence-based patient and caregiver navigational resources and pancreatic cancer information. We anticipate continuation of the most successful strategies and will use general operating funds and seek subsequent project funding for these efforts. We would seek continued commitment from The Palette Fund and other current partners. Other potential funding sources include individual donors, foundations, and corporations, particularly those with interest in health and nutrition.

Furthermore, we will work to create future cost effective strategies that maintain health professionals' disease knowledge and awareness of the PALS navigational resources achieved through *The Patient Navigation Outreach Program*.

BUDGET SUMMARY

Applying Organization: Pancreatic Cancer Action Network
Project Title: The Patient Navigation Outreach Program
Project Director: Anitra Engebretson
Financial Officer: Rena Hayami
Organization's Fiscal Year: July 1 **To** June 30

Beginning and Ending dates of requested funding: January 1, 2010 **To** June 30, 2012

	1st Year Project Budget	2nd Year Project Budget	3rd Year Project Budget	Total Project Budget
	From:	From:	From:	
	1/1/2010	7/1/2010	7/1/2011	
	To:	To:	To:	
	6/30/2010	6/30/2011	6/30/2012	
PERSONNEL Costs				
Salaries	\$22,500	\$88,675	\$134,335	\$245,510
Taxes, Benefits & Recruiting	\$3,370	\$16,985	\$27,220	\$47,575
Personnel Subtotal	\$25,870	\$105,660	\$161,555	\$293,085
NON-PERSONNEL Costs				
Media	\$0	\$169,790	\$227,643	\$397,433
Conferences/meetings	\$9,500	\$76,465	\$76,465	\$162,430
Education and Outreach Materials	\$30,968	\$81,351	\$59,290	\$171,609
Shipping/Postage	\$595	\$5,650	\$5,790	\$12,035
Non-personnel Subtotal	\$41,063	\$333,256	\$369,188	\$743,507
GRAND Total				\$1,036,592
FUNDING from The Palette Fund				(\$518,000)
TOTAL Amount Remaining				\$518,592

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APPENDIX A

LEADERSHIP TEAMS

National Board of Directors

Comprised of committed individuals with exceptional expertise in business, higher education, fundraising, legislation and legal issues.

Jason Kuhn, Chairman of the Board

- President and CEO of Direct Automotive in Tampa, Florida
- Director of Florida Automobile Dealers Association
- Lost his father to pancreatic cancer

Stephanie R. Davis, JD, MA

- Senior intern at the California Family Counseling Center in Encino, California
- Lost her mother, maternal aunt, grandmother, mother's maternal cousin and paternal uncle to pancreatic cancer

Tim Ennis, Immediate Past Chairman

- President and CEO of Montondo's Seafood, Inc.
- Member of Town of Lockport planning board
- Member of Lockport Memorial Hospital Board of Directors
- Member of Dale Association Senior Citizen Board
- Member of the Partners in Pride Program with the Lockport School District
- Co-Chairman of the Lockport Memorial Hospital Modernization Project
- Past member of the Town of Lockport Zoning Board
- Lost his wife to pancreatic cancer

Julie M. Fleshman, JD, MBA, President and CEO

- Graduate of Santa Clara University School of Law and Leavey School of Business
- Became the Pancreatic Cancer Action Network's first full-time staff person and Executive Director in April 2000.
- Appointed as President and CEO by the Board of Directors in July 2004
- Under Julie's leadership, the organization's advocacy and grassroots efforts have led to a 400% increase in federal funding for pancreatic cancer research and the organization has funded researchers from around the country.
- Lost her father to pancreatic cancer

Stevan Holmberg, MBA, DBA

- Professor in the Kogod School of Business at American University in Washington, DC
- Chair of the Management Department
- Former Acting Dean of the Kogod School of Business
- Lost his wife to pancreatic cancer

Peter Kovler

- Director of the Marjorie Kovler Philanthropic Fund
- Chairman of the Board of the Blum-Kovler Foundation

- Chairman of the Board of the Center for National Policy
- Founder of Chicago's Kovler Center for Victims of Torture
- Lost his mother to pancreatic cancer

Laurie MacCaskill

- One of the founding board members of the Aspen Center for Integral Health
- Volunteers with The Colleagues in Los Angeles
- Chairman of the National Committee for the Performing Arts with the Kennedy Center in Washington, D.C.
- Pancreatic cancer survivor

Jai Pausch

- Previously led the Carnegie Mellon School of Computer Science Web team as the Director of Electronic Publications
- Previously served as Outreach Coordinator for the University of North Carolina at Chapel Hill Department of Computer Science
- Lost her husband to pancreatic cancer

Scientific Advisory Board

Provides advice, scientific expertise, and leadership to the Pancreatic Cancer Action Network with regard to the research and scientific program goals and initiatives of the organization. Comprised of leading pancreatic cancer researchers from institutions across the United States.

Dafna Bar-Sagi, PhD, New York University
Chair, Scientific Advisory Board

Teri Brentnall, MD, University of Washington

Michael Hollingsworth, PhD, University of Nebraska Medical Center

Ralph Hruban, MD, Johns Hopkins University

Elizabeth Jaffee, MD, Johns Hopkins University

Craig Logsdon, PhD MD, Anderson Cancer Center

Margaret Mandelson, PhD, Fred Hutchinson Cancer Research Center

Gloria Petersen, PhD, Mayo Clinic

Margaret Tempero, MD, University of California, San Francisco

David Tuveson, MD, PhD, Cambridge Research Institute/CRUK

Selwyn Vickers, MD, University of Minnesota

Geoffrey Wahl, PhD, The Salk Institute

Medical Advisory Council

Advises the organization on specific medical and clinical aspects of pancreatic cancer as it relates to our programs. Includes clinicians who specialize in the care of people with pancreatic cancer.

Mark Talamonti, MD, Evanston-Northwestern Healthcare
Chair, Medical Advisory Council

Jordan Berlin, MD, Vanderbilt-Ingram Cancer Center

John Cameron, MD, Johns Hopkins University

Marcia Canto, MD, Johns Hopkins University

Christopher Crane, MD, MD Anderson Cancer Center

Jason Fleming, MD, MD Anderson Cancer Center

Julie Meddles, RD, LD, The Ohio State University Medical Center

Mary Mulcahy, MD, Northwestern University

Maria Petzel, RD, LD, CNSD, MD Anderson Cancer Center

Vincent Picozzi, MD, Virginia Mason Medical Center

Mark Pochapin, MD, Jay Monahan Center for Gastrointestinal Health