

Building Community-Based Support: Fostering Hope for Pancreatic Cancer Survivorship

A Request for Funding to:
LIVESTRONG, Lance Armstrong Foundation
2201 E. Sixth Street
Austin, Texas 78702

PANCREATIC CANCER ACTION NETWORK



Photo Credit: Pan Act

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Executive Summary

The Pancreatic Cancer Action Network has three main goals: advance research, support patients and create hope. No one should have to face pancreatic cancer alone, and we work to ensure that pancreatic cancer patients and their families get the support they need. We focus on addressing the need for more community-based support groups, for both patients and caregivers.

Knowing your mission, we believe that you are a great match for the program we want to implement. We share the goal of creating more community-based initiatives that cater to promoting patients' physical, mental and spiritual wellness. We want to start a pilot project in Pittsburgh, PA, which will be a 24-hour support center for pancreatic cancer patients. The center will house patients traveling to receive medical care as well as local patients. All clients will have access to on-call nurses for 24/7 assistance; separate counseling sessions for patients and caregivers to attend to their different needs; a non-denominational chapel for spiritual support; and a pain-relief therapy spa. The goal of the program is to provide a more nurturing and comforting environment for the patients, so they can focus on hope and begin to believe that they can survive.

We developed a list of goals and objectives that we think will best meet this need in the Pittsburgh area. Our first goal is to provide a community support program for pancreatic cancer patients and their caregivers in the Pittsburgh area, catering to their physical, mental and spiritual needs. The objectives for meeting this goal are rent space in the Hillman Cancer Center, conduct the services, connect patients with resources in the area, and evaluate program success by surveying clientele every 3 months. Our second goal is to create awareness for pancreatic cancer and educate the local community. The objectives for this goal consist of the following: hire staff members and provide training on how to educate the community about pancreatic cancer; host public informational sessions once a month, as well as private informationals for groups that would like to schedule their own sessions; create partnerships with local universities and libraries to help spread awareness; and evaluation of program awareness by mailing questionnaires and surveys out to the local community every 3 months.

With your help, we will have the chance to bring this support group directly into the Pittsburgh community and foster the hope patients and caregivers need to survive. Then, hopefully with your support, this pilot project will be adopted in our affiliate chapter areas across the nation.

Background Statement

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. We help raise awareness and funds to ultimately find a cure to defeat pancreatic cancer. We work to create a strong sense of hope and community so that no one has to face pancreatic cancer alone.

History

- In 1996, founder Acosta Maurquardt learns her mother has pancreatic cancer and immediately researches the disease
- She soon realizes the lack of resources that exist in the community for pancreatic cancer patients and their families.
- In 1998, Maurquardt decides to organize a fundraiser to help with the development of an early detection research lab for pancreatic cancer run by a professor at John Hopkins University Medical Center.
- The event raises more than \$165,000, which leads to immediate exposure.
- A New York attorney who had both parents die from pancreatic cancer volunteers his services so that Maurquardt could establish 501(c)(3) status (see Appendix A for 501 (c) (3) status).
- Terry Lierman, a politician on Capitol Hill in Washington, DC, gets involved in the cause because he, too, had lost his father to pancreatic cancer. As the second founder, he plays a crucial role in the organization's political affairs.
- At their first meeting together, Maurquardt and Lierman decide on the name, Pancreatic Cancer Action Network.
- Paula Kim, who also lost her father to pancreatic cancer, becomes the third founder because she heads the organization of the first national office.
- In February 1999, the Pancreatic Cancer Action Network incorporates.

Location and Staff

Headquarters is located in El Segundo, California, and the Government and Affairs office established a presence in Washington, DC. Our organization functions under Julie Fleshman, President and CEO (see Appendix B for full bio and resume), a national Board of Directors, a Scientific Advisory Board, Medical Advisory Council, and the dedication of a full-time staff.

Programs and Services

Our national programs focus on five target areas:

- Create hope through research. We fund innovative research because we are committed to gaining better treatments and ultimately finding a cure for pancreatic cancer.

- Create hope through advocacy. We take an aggressive approach in our efforts to increase federal funding for pancreatic cancer research.
- Create hope through patient services. We give information to pancreatic cancer patients about the latest research and treatment options through highly trained and knowledgeable staff members, who work in our PALS (Patient and Liaison Services) program. No one should have to face pancreatic cancer alone.
- Create hope through volunteerism, awareness and action. We support our many affiliate chapters across the country (75) and the volunteers who lend their help to host events and give time to advocate for our cause.
- Create hope through generosity. We appreciate the financial support of many donors and corporations that believe in our vision and are willing to provide support for our comprehensive approach to fight against pancreatic cancer. In Fall 2009, we worked with Tempur-Pedic through our National Corporate Champion Program; in order to raise awareness and money for our organization, they created a special edition Tempur-Pedic Teddy Bear that was cobranded with our logo. (For a full list of our donors and corporate partners, see Appendix B)

Highlights in Research, Funding, and Support

- Our advocacy efforts have led to an increase in the National Cancer Institute's funding for pancreatic cancer research, from \$17 M in 1999 to \$89 M in 2009 (500% increase)
- Since our beginning, we have funded \$7.2 M in research grants.
- More than 35,000 patients and their families have received reliable information from our PALS program

Even with the strides our organization makes every day towards keeping hope alive and finding a cure for pancreatic cancer, there is still so much more work to be done.

Statement of Need

Story

About a year ago, in the East Liberty section of Pittsburgh, Stella Wilson struggled to care for her 94-year-old father, while simultaneously caring for her eldest sister, Dee Wilson, who had been struck with pancreatic cancer. As the only able-bodied person in the house, Stella also had to cook, clean, and manage the home. She didn't have much support from other family members, because they were scattered across the country and had homes to manage themselves. As a retired veteran of the U.S. Army, Stella was the only one in the family who could be Dee's caregiver.

Stella stayed up with Dee day and night. She watched Dee writhe in pain, beg for more medication, and squeeze her hand in agony. Stella felt so helpless as Dee stared up at her in disbelief that the cancer was slowly stealing her life. Several

times a week, on two and a half hour trips, Stella transported Dee back and forth to the hospital for chemo. Dee had even endured surgery to see if doctors could remove her cancer. Unfortunately, when the surgeons began the operation, they realized there was nothing more they could do. The cancer had already spread to Dee's liver and other parts of her body. So, they sealed her back up and sent her home to live out her last few months without any hope.

Stella had to be strong, not only for her sister Dee, but also for her father who had to watch his eldest daughter physically deteriorate before his eyes. He knew that she was entering the final stages of the disease and would soon precede him in death. At night, while they slept, Stella would cry, and in the morning, she would get up and fight through another day. There was no one there to support Stella, to hold her hand, to counsel her through it all, or to simply allow her to rest and take a break. She struggled to keep the hope alive, so that Dee could feel a sense of support and positivity. Dee needed to be surrounded by a support system so that she could feel that there was a chance she could beat this disease and live a healthy life.

Need

There are many family members of pancreatic cancer patients who are in Stella's position right now. They often have no place to take their sick relatives, so that they can take a break, and they have nowhere where they can go to get counseling on how to deal with being a caregiver. Currently, in the Pittsburgh area there aren't any large community-based initiatives that foster hope in pancreatic cancer patients and their families. They are often led to believe that they are helpless and to accept that their disease will be terminal. There are not enough local support centers for people in Dee and Stella's situation.

Facts

There is a great need for support centers due to the amount of people who are diagnosed with this disease and the statistics on the low survival rates. The American Cancer Society estimates that in the U.S. alone, in 2010, "**about 43,140 people (21,370 men and 21,770 women) will be diagnosed with pancreatic cancer.**" Out of those who are diagnosed, "**about 36,800 people (18,770 men and 18,030 women) will die of pancreatic cancer.**" Pancreatic Cancer has the highest mortality rate of all major cancers, because 94% of pancreatic cancer patients will die within five years of diagnosis, which means that only six percent (6%) will survive more than five years and **75% of patients die within the first year of diagnosis.** The survival rate for pancreatic cancer is alarmingly low, yet in 2009 it received the least amount of funding from the National Cancer Institute (NCI) budget, which was only two percent (2%). Our research has also shown that pancreatic cancer is one of the few cancers for which the survival rate has not improved substantially over 40 years.

Exposure and Education

Gaining a local community-based support group in any city will not only help the patients and loved ones, but will also increase awareness about pancreatic cancer and be a place where residents can attend informational sessions to learn about the disease. So, a community-based center in a city like Pittsburgh would serve to nurture and care for those who are immediately affected, while simultaneously being an educational center for people who may not know about the disease.

Existing Community-Based Programs for Patients

We are aware of community-based programs that do exist to meet some of the needs we have described, such as the American Cancer Society's Hope Lodges. These are places that house patients at a lower cost as they travel around the U.S. for medical treatments. There are also several Wellness Community programs, which provide in-person care and support for cancer patients throughout the country, however, the only one in Pennsylvania is in Philadelphia. We would like to build our program, on some of the same concerns as these existing programs, but we will be the only community-based initiative in Pittsburgh that is specifically for pancreatic cancer patients. This is not an attempt to isolate anyone, but to foster a greater sense of community and hope amongst patients who are being told they may only have a few months to live and no hope exists for them.

We believe this program will be the first step to bringing hope directly into the local community. We want our clients to talk about their concerns through counseling, receive physical care, and focus on their spiritual needs. All of these services will be implemented with hopes that receiving mental, emotional, and physical support will increase survivorship and recovery rates of patients. This will, in turn, foster more hope within their loved ones and caregivers and ease some of the stress that they feel.

Goals and Objectives

Goal 1: To provide a community support program for pancreatic cancer patients and their caregivers in the Pittsburgh area to cater to their physical, mental and spiritual needs

Objectives

1. Build the space in the Hillman Cancer Center and open the program to the Pittsburgh community
2. Start programs and services, which will include lodging rooms, group counseling sessions, non-denominational chapel services, pain relief spa treatments for patients, and a 24-hour staff
3. Connect patients with resources and other support groups that may be in the area
4. Conduct surveys and questionnaires to evaluate program success every 3 months.

Goal 2: To create awareness for pancreatic cancer and educate the local community

Objectives

1. Hire qualified staff and provide training on how to educate the public about pancreatic cancer
2. Host public informational sessions once a month, as well as private informationals for groups that would like to schedule their own sessions
3. Reach out to local universities, libraries and other places to help spread awareness for the disease
4. Mail questionnaires and surveys to the community every 3 months to get opinions on the center and to see if they are know about us and what we do

Program Description

Beneficiaries

This program benefits two main parties: 1) pancreatic cancer patients and 2) caregivers, who are usually loved ones. This program will help local Pittsburgh patients and their caregivers, as well as patients who may be travelling to the area to receive medical treatment at local hospitals.

When it comes to contacting beneficiaries, we will work with the Hillman Cancer Center and other resources to contact patients in the area. We will use our national marketing and PR team to advertise through our website and national initiatives.

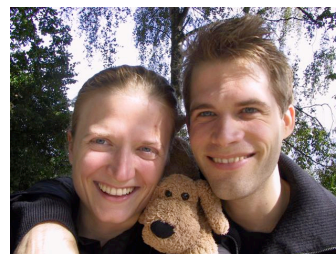
Exhibit 1:



Pancreatic cancer survivor James Moore and his wife.

Photo credit: Ceedz

Exhibit 2:



Caregiver Keri Hakan with her husband who survived pancreatic cancer.

Photo credit: C.m.keysers

Schedule

We will open our program in the Hillman Cancer Center's unused space on the top floor. We will work with them and UPMC to recruit the best nurses, healthcare providers, counselors, and massage therapists who are familiar with caring for

cancer patients. Next, training consultants will be contacted to provide proper training for the informationals. Our national marketing and PR team will publicize the opening of our first community-based program in Pittsburgh, PA. The local affiliate chapter, which mainly focuses on fundraising and volunteerism, will also publicize this new center that caters to patients and caregivers. The staff at the local affiliate chapter will help with contacting local patients in the area and telling them about our program.

After the recruitment, training, and PR period, we will open the doors to patients, caregivers and the community. As soon as we receive inquiries and responses from patients and caregivers, we will begin with the counseling sessions and pain-relief spa treatments. When patients are travelling into town for medical treatment at local hospitals, we will have the lodging areas available. Instead of paying for expensive hotel rooms, they will be able to stay at the center. Loved ones that are accompanying them will also be able to stay at our center.

Timeline

Activity	1 st quarter	2 nd quarter	3 rd quarter	4 th quarter
Rent space in Hillman Cancer Center	X			
Hire staff members and consultants	X			
Provide training for staff	X			
PR grand opening and services		X	X	X
Conduct programs and services (counseling, lodging, pain-relief treatments, etc.		X	X	X
Create partnerships with local universities		X	X	X
Conduct evaluation of services for clientele				X
Conduct evaluation of informationals for community				X

Staff

Our Project Administrator will be Theresa Dukovich, whose vision was to open a community-based program for pancreatic cancer patients to have somewhere to turn to for help. She is director of the Pancreatic Cancer Action Network, Pittsburgh Affiliate Chapter. She wanted to be involved with this local initiative and has agreed to oversee the entire project. Ms. Dukovich will ensure that all other staff members receive the proper training to provide the proper services. (See Appendix C for resume)

The Project Director will be Jeff Conway, who is a staff member at the local affiliate chapter. He is passionate about this program and wants to expand his involvement beyond volunteerism. He will carry out the daily tasks and oversee the staff at the site. Conway's duties include being at the site on a daily basis and supervising the operations. He is to communicate with Dukovich and be the liaison for the clients and the rest of the staff. (See Appendix C for resume)

The staff members under the Project Director will consist of counselors, pain-relief massage therapists, 24/7 on-call nurses, community outreach members, and a secretary for Jeff Conway. Five counselors will be responsible for conducting group sessions for the patients and caregivers. Three pain-relief therapists will work to give treatments to patients upon their request. Five nurses will be on-call 24/7 in case of patient emergency, and they will be there to provide medical care, if needed, or give medical advice. The community outreach members will be a mixture of paid staff and volunteers, who will be responsible for running informationals and working with the Hillman Cancer Center and local universities to promote our cause. Conway's secretary will answer phones, keep records, do all miscellaneous tasks and greet clients. (See Appendix C for resumes)

Our Board of Directors will consist of three patients, community leaders from UPMC and the Hillman Cancer Center, donors, and a local pancreatic cancer researcher. They will be responsible for program evaluation and making sure that the program is actually meeting our goals and objectives as well as our clients' needs. (See Appendix D for resumes)

Consultants

Our first consultant will be a construction company that will build the lodging rooms, bathrooms, spa area, chapel, and main office. We will also need training consultants to come in and teach the staff about how to treat the patients and best cater to their needs. The consultants (who will be volunteers) will run the informationals twice a month and answer any questions from community members. We will hire a CPA to see that we are meeting our budget needs and spending money efficiently. (See Appendix E for full list of consultants)

Collaborators

The Hillman Cancer Center is our primary partner because we will use their space and they will provide 45% of our capital and human resources; they will also help with contacting clients. UPMC is also providing support with human resources and contact information for patients. Local universities will help promote awareness about pancreatic cancer by allowing us to host marketing programs on their campuses. (See Appendix E for full list of collaborators)

Supplies

For our lodging areas, we will need beds, sheets, desks, towels, and robes. The spa area will also need towels, robes, and slippers. The spa area needs massage tables, sinks, and working stations for the massage therapists. The main office will need desks, chairs, shelves and basic office supplies. We will also need benches and chairs in the main lobby for clients to sit in while waiting for the office workers, or to be signed in. The counseling rooms will need round tables and chairs for the support-group sessions. The same rooms will be used to host the informationals. These rooms need to have tech support, PowerPoint capabilities etc. Tech consists of a microphone and podium, as well as a pull-down screen and projector. We also need forms and educational materials for the informationals. We will need phones and computers in the main office and in the study room, which will be available to guests who stay in the lodging area. Meals and refreshments are needed for clients who come to the community programs.

Sustainability

Our program will sustain on the funds you provide us, and we will seek funds from other sources. We will continue to build our partnerships with local universities, the Hillman Cancer Center, and UPMC in hopes that these will lead to fundraisers and further awareness of our cause. This project is not only impactful in the Pittsburgh community and its surrounding area, but it will serve as a model program that can be emulated in other cities across the country. As a national body, we hope to partner with our other affiliate chapters across the country to implement the services provided at this Pittsburgh center.

Program Evaluation

Collecting Data

Our evaluation will be based on utility and feasibility. We will conduct both internal and external evaluations.

1. Board of Directors

The Board of Directors will be responsible for conducting a formative internal evaluation. They will meet once every three months to determine whether or not we are reaching our goals. This meeting helps us make any necessary changes to our strategy.

2. Surveys

Our clients will receive surveys at the end of counseling sessions to give feedback to our counseling staff. The frequency of these surveys will be left to the discretion of the counseling staff. Surveys will also be mailed to clients' homes every three months, so they can provide feedback on our services. All surveys will be anonymous and confidential.

3. Interviews

We hope to conduct ten interviews. We will give clients confidentiality forms to fill out for their protection and privacy.

4. External Evaluation

After these qualitative results are collected, an external evaluation team will conduct a summative external evaluation. They will do data analysis based on more quantitative results of how many clients we have; how well we are reaching patients in the area; and how many of those are actually using our services, along with retention rates. The bulk of our evaluation will occur in the fourth quarter of the program implementation. After the evaluation team collects the quantitative data, they will be responsible for analyzing all data collected so far.

Disseminating Results

After the evaluation team performs data analysis and the results are available, the Project Director and his selected team of staff members will meet with the evaluation team to determine the best way to publish the results. Some of our options include posting an annual report, with charts and graphs, on our national website, and including videos with the interviews on our website. Through our partnerships with UPMC, the Hillman Cancer Center, and local universities, we hope to have our results posted on their websites and print material as well. The information sessions that we hold for the public will also function as sessions to disseminate results of the evaluation, so that the community knows where we are in completing our goals.

Budget

Personnel Costs

Salaries and Wages

<u>Title</u>	<u>% of time</u>	<u>Salary</u>
Project Administrator	10%	\$25,000
Project Director	80%	\$20,000
5 Counselors	80%	\$19,000
3 Pain-Relief Therapists	60%	\$17,000
5 Nurses	90%	\$15,000
Secretary	100%	\$13,000
Fringe Benefits	35%	\$38,150
Consultants		
Corman Construction	80%	\$100 per sq. ft. (250 sq. ft. total)
Staff Training Consultant	70%	\$15,000
CPA	75%	\$20,000
Sub-total Personnel		\$207,150

Non-personnel Costs

Space

Rent for Space in Hillman Cancer Center \$1,500 per mo.

Furniture

Rent of existing desks, tables and chairs \$500 per mo.
 Additional chairs, and tables \$300
 6 Desktop Computers (provided by headquarters)
 10 Beds \$1,500
 3 Massage Tables \$1,200

Communication

Phone Lines (provided by headquarters)

Insurance

Renter's Insurance \$360
 Omissions and Error Insurance \$6,000

Travel

(no anticipated travel)

Consumable Supplies

Office Supplies	(donated by Office Max)
Towels	\$200
Meals/Refreshments	\$2,000 per mo.

Project Supplies

Projector	\$200
Podium	\$80
3 Microphones	\$60
Disposable Slippers	\$100
Robes	\$200
Bed Linen	\$1,000
Forms/Educational Materials	(provided by headquarters)

Audit and Evaluation Costs

Surveys and Questionnaires	(provided by headquarters)
Evaluation Consultant Team	\$20,000

Printing/copying \$300 per mo.

Sub-total Non-personnel \$35,300

Total Cost **\$242,250**

Conclusion

In order to get this project started, we need your help. Your grant of \$242,250 will allow us to rent a space to create this community-based initiative for pancreatic cancer patients and caregivers in Pittsburgh, PA. With your help, this program will not only serve the Pittsburgh residents, but also the surrounding areas and those who are traveling into the area for medical purposes.

We know you understand how important it is to create a better sense of hope by helping those affected by pancreatic cancer on a mental, physical, emotional, and spiritual level. Your money will also help educate more people about this deadly disease and to increase awareness for government funding. Creating this pilot project will spark the existence of many community-based support groups around the country and our national organization will have even more awareness and support. You will support our goal to advance research, support patients, and create hope.

In conclusion, we ask that you consider this proposal. Together, we can create a support system for pancreatic cancer patients and give them the tools they need to focus on survivorship.

Appendices

Appendix A.....	501 (c) (3) Certification Letter
Appendix B.....	Julie Fleshman Full Biography and Resume
Appendix C.....	Project Director, Project Administrator and Staff Resumes
Appendix D.....	Board of Directors Resumes
Appendix E.....	Full Lists of Consultants and Collaborators

References

Pancreatic Cancer Action Network. www.pancan.org (Mission, History, Descriptions of Programs, Services, Research, and Partners)

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