



PANCREATIC CANCER ACTION NETWORK

# OUTREACH

VOL IX ISSUE 1 FEBRUARY 2009



**COMMEMORATING THE  
TENTH ANNIVERSARY OF THE  
PANCREATIC CANCER ACTION NETWORK**

**ADVANCE RESEARCH. SUPPORT PATIENTS. CREATE HOPE.**

# CHAIR'S MESSAGE

## A DECADE OF INSPIRING HOPE



Dear Pancreatic Cancer Action Network Friends:

The new year brings with it tremendous excitement for all of us at the Pancreatic Cancer Action Network as we celebrate the organization's 10th anniversary. We could not have reached this milestone without the time, commitment and donations of our many supporters around the country.

These contributions, whether given in time spent volunteering, donations, or both, help advance research, support patients and create hope for those facing pancreatic cancer. This valued support enables us to maintain the programs and services upon which the pancreatic cancer community has come to depend.

When our three founders—Pamela Acosta Marquardt, Paula Kim and Terry Lierman—started the organization in February 1999, they were inspired by a future free from pancreatic cancer. Their passion and fortitude to change the course of history for a disease that now takes nearly 35,000 lives a year energized individuals nationwide to become involved.

From those beginnings as a start-up nonprofit, we have grown into the only national organization fighting pancreatic cancer in a comprehensive way. An important goal has been to increase both private and public funding for research into the disease. Since 2003, we have funded 38 promising researchers around the country. In addition, through our dynamic Government Affairs program, based in Washington, DC, concerted advocacy efforts have resulted in an increase in annual federal funding for pancreatic cancer research of more than \$55 million.

Another critical goal has been to offer patients and families information and resources about the disease. To that end, we have provided more than 35,000 patients, family members, caregivers, health professionals and others with the most up-to-date and thorough educational and disease-specific information at no charge through our highly regarded Patient and Liaison Services (PALS) program. PALS now serves as a model for other cancer organizations nationwide.

Finally, we know awareness is key to increasing research dollars. Our community outreach efforts have grown from just a few volunteers initially to more than 75 affiliates across the country today. They are supported by thousands of other committed volunteers who raise money through local events, distribute educational materials to health professionals, contact members of Congress and constantly work to raise the visibility of pancreatic cancer.

This year, we will build upon past successes as well. We will continue promoting RAISE THE CURE, an unprecedented campaign to significantly raise both public and private research dollars for pancreatic cancer. And *The National Plan to Advance Pancreatic Cancer Research Act*, the first substantive legislation dedicated to improving pancreatic cancer research, will be reintroduced in Congress in 2009.

We salute you for your dedication to our cause and invite you to celebrate with us as we acknowledge the considerable progress that has been made. As we rededicate ourselves to fighting this disease, we hope you will continue with us as we work to serve everyone affected by pancreatic cancer.

Sincerely

A handwritten signature in black ink, appearing to read 'JK'.

Jason Kuhn  
Board Chair

### BOARD OF DIRECTORS

Jason Kuhn, Chair, Tampa, FL  
Stephanie R. Davis, JD, MA, Secretary,  
Sherman Oaks, CA  
Tim Ennis, Boca Raton, FL  
Julie Fleshman, JD, MBA, President & CEO,  
Los Angeles, CA  
Stevan Holmberg, DBA, Potomac, MD  
Cynthia Stroum, Founding Chair, Seattle, WA

### SCIENTIFIC ADVISORY BOARD

Dafna Bar-Sagi, PhD, Chair, New York University  
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

Mark Talamonti, MD, Chair,  
NorthShore University HealthSystem  
Jordan Berlin, MD,  
Vanderbilt-Ingram Cancer Center  
Barbara Burtness, MD,  
Fox Chase Cancer Center  
John Cameron, MD, Johns Hopkins University  
Marcia Canto, MD, Johns Hopkins University  
Christopher Crane, MD,  
MD Anderson Cancer Center  
Betty Ferrell, PhD, RN, City of Hope  
Jason Fleming, MD,  
MD Anderson Cancer Center  
Julie Meddles, RD, LD,  
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  
William Traverso, MD,  
Virginia Mason Medical Center

# DEVELOPING BETTER THERAPEUTICS FOR PANCREATIC CANCER

by **Adrienne D. Cox, PhD, and Channing J. Der, PhD**

*Drs. Cox and Der are faculty members at the Lineberger Comprehensive Cancer Center, School of Medicine, University of North Carolina at Chapel Hill.*



Why is pancreas cancer so difficult to treat successfully, and what can we do about it?

A Scientific Summit hosted by the Pancreatic Cancer Action Network on August 2-5, 2007 in La Jolla, Calif., brought together key research community members to discuss recent advances in the field, define the key questions, and determine needed resources.



Sadly, not all patients' tumors respond to current therapeutic approaches. It is unclear whether this lack of response is due to unique features and characteristics of the disease, or if more knowledge about the properties of pancreatic cancer would enable the

development of drugs that attack it effectively. While improving early diagnosis would certainly have an enormous positive impact, Summit participants agreed that a critical issue is how to develop more effective drug treatments.

Most conventional anticancer drugs function by killing any cells that are dividing rapidly, whether they are cancer cells or normal cells. In contrast, "targeted therapies" work by acting against specific molecular targets that are especially important for properties of the tumor cells that promote growth or spreading of the cancer. Therefore, understanding what drives the complex biology of pancreatic cancer is critical to making progress in developing new therapies.

At the 2007 Summit, researchers held a lively debate over the identity of the molecular targets that are the most critical in enabling pancreatic cancer to grow, and whether these targets are in fact "druggable"—that is, whether drugs can be developed to block them effectively in patients. For example, abundant evidence exists that the KRAS oncogene (a cancer-causing gene) is an important target. However, it has been difficult to develop inhibitors for this gene because of its biochemical properties. Are there better, perhaps indirect, ways to develop effective anti-KRAS therapies?

In a recent issue of *Science* magazine (Volume 321, #5897, pp. 1801-1806), researchers reported on the results

of a comprehensive study that examined all the genes altered in 24 pancreatic cancers. This study confirmed that KRAS is mutated in essentially all patients, and also confirmed important defects in several other known pathways.

Some interesting questions remain. If these are not good targets, then how should we identify, select and validate new ones? Of the multitude of new and powerful technologies that may be applied, which ones represent the best use of our time and money?

A critical need is for better cell culture and animal models for accurately identifying ahead of time which drugs will work in patients. There is great optimism that new mouse models of pancreatic cancer will help to solve this problem, but much work remains to be done. For more accurate predictions, we may well need better models that more closely mimic the specific complexities of pancreas cancer biology.

A rigorous and extensive evaluation of existing mouse models remains to be done, but such studies are very expensive. Nevertheless, prompted in part by discussions at the Summit, some investigators (including the authors of this article) are beginning to conduct such research on a small scale.

An important and urgently needed resource for this effort would be a centralized but multi-institutional tissue bank. Such a collection of patient tumor and normal tissues, as well as blood samples, would provide a powerful source of information on the presence, absence or alterations in potential biomarkers, especially when these analyses are correlated to various other parameters about the course of a patient's disease and treatments. The Pancreatic Cancer Action Network is currently exploring the possibility of creating a shared biospecimen resource, called the Completely Annotated Pancreas Tumor Repository (CAPTURE) Project.

With so many exciting and important avenues in need of investigation, it is clear that our research is limited not by our ideas, but by our resources. The Pancreatic Cancer Action Network is working closely with top researchers to help develop the infrastructure and support the research to get the answers to these important questions. ✨

# A LOOK BACK WITH LONGTIME ADVISOR DR. TONY HOLLINGSWORTH

*Tony Hollingsworth, PhD, professor at the Eppley Institute, University of Nebraska Medical Center, has served on the Pancreatic Cancer Action Network Scientific Advisory Board since its inception in 1999, and served as the board's first chair from 2005 to 2008. As the Pancreatic Cancer Action Network celebrates its 10th anniversary, we asked him to share his thoughts regarding the growth and development of the organization and the evolution of research into this disease.*



## **How did you become involved with the Pancreatic Cancer Action Network?**

I was involved with two other groups shortly before the Pancreatic Cancer Action Network was founded. One was the Progress Review Group (PRG), in which I played a role along with several other researchers. The

other was the Pancreas Cancer Think Tank, which my fellow Scientific Advisory Board member Margaret Tempero, MD, put together. This was a group of people who got together to talk about the state of the science regarding the disease and what needed to be done. The Pancreatic Cancer Action Network came to fruition right after that period of time.

Because several of us were engaged in dialogue about these things, I was approached to become part of the organization early on. I was asked to be part of the Scientific Advisory Board when it was being put together and I agreed to do that wholeheartedly. These times were the formative stages in determining exactly what the organization would be doing, so it was an exciting time to become involved.

## **What do you believe the Pancreatic Cancer Action Network represents for the research community?**

I think it has had a significant impact in the research community. First of all, it has raised awareness about the dismal funding situation. Also, there have now been many active advocacy efforts in Congress and the National Institutes of Health (NIH) to keep pancreatic cancer front and center as much as possible. I think that's made a difference. By keeping the NIH's "feet to the fire," it has forced them to make sure that there were initiatives in place to ensure adequate consideration is given to the pancreatic cancer research community.

Perhaps as significant, or maybe even more so, has been the idea of funding Career Development Awards. These awards came at a time when the field was growing, but also at a time when we needed something to encourage young people to commit themselves to this field of research.

I think the true impact of these awards cannot be measured. One could try to quantify them in terms of the increase in numbers of people in the field. The effect of having more people working in the field is palpable in the research community. This is the sort of thing that one can look back on over ten years and see an impact. It's something that I expect will continue to have an impact over the next 50 years. All the younger people the Pancreatic Cancer Action Network has funded will stay in the field and will continue to get funded. We'll see significant contributions from them in the future. I think we're really at the beginning. Ten years is a nice benchmark, but it's really just the beginning of what the ultimate effect will be.

## **How does it feel as a senior investigator to see some of the junior researchers come into the field and be presented with these opportunities?**

The pancreatic cancer research community was present when I started out, but it was much smaller. There were opportunities to be mentored by some of the senior investigators, but I had to be in the right place at the right time in order to tap into that. I think these structured award mechanisms bring people together at more regular intervals. The second thing that is perhaps more important is that younger researchers aspire to secure these awards. They want to get them. It's a feather in their cap. And they are disappointed if they don't get one. If you have something worth aiming for, then more people will aim for it.

## **In your opinion, what have been some of the most significant scientific discoveries in the field of pancreatic cancer during the past ten years?**

The debate engendered by the formation of the PanIN (Pancreatic Intraepithelial Neoplasia) lesions has been a significant advance. The fact that people are investigating these pre-malignant lesions and trying to understand the process by which acquisition of mutations and other changes contribute to cancer is significant. I'm not saying that all of the theories about PanIN progression are correct. But the debate has been very healthy and very good.

A second thing that has been significant is the discovery of molecular alterations that occur during the progression of pancreatic cancer. There are a number of them that have been classified by many different groups, perhaps capped recently by the whole genome sequencing effort undertaken at Johns Hopkins University. I don't think that job is done, but it's a start.

More recently, I think it's significant that we are now focusing on the differentiation of adenocarcinoma from other forms of pancreatic cancer and other pre-malignant forms. There is a debate about IPMNs (Intraductal Papillary Mucinous Neoplasms) and cystic lesions in the pancreas, and the ability to differentially diagnose these and decide how they should be treated. This debate helps to propel research forward.

**What have you enjoyed most about serving as a member of the Scientific Advisory Board?**

I have enjoyed seeing the growth of the career development program and seeing the Pancreatic Cancer Action Network develop so that it has the ability to sponsor these grants. It has also been a pleasure to be a part of the many symposia around the country that the organization hosts for patients and their families. Patients have benefitted from these and certainly the research community has benefitted as well from having such close contact with these patients. It's a pleasure for the researchers to meet survivors in the context of the various local events that the organization hosts. These meetings add a large measure of humanity to our research efforts. ✨

# KEEP THE MEMORY ALIVE



**These inspirational pages represent a wonderful way to pay tribute to your loved one while heightening awareness and funding for pancreatic cancer.**

**Create an online tribute page for someone special and give others the opportunity to support the mission of the Pancreatic Cancer Action Network.**

**To create your own page, go to [www.firstgiving.com/keepthemoryalive](http://www.firstgiving.com/keepthemoryalive)**

**To learn more, contact our Donor and Corporate Relations Department at 877-272-6226.**



# GOVERNMENT AFFAIRS UPDATE

## EXCITING 2009 LEGISLATIVE PRIORITIES ANNOUNCED

*Thanks to the hard work of our volunteers and supporters, we have made important progress to ensure that pancreatic cancer becomes a higher priority at the national level. Now that the 111th U.S. Congress has convened, several new opportunities and challenges lie ahead. Our priorities in 2009 are outlined below. To learn more, go to our Take Action web page at [www.pancan.org/public/Take.html](http://www.pancan.org/public/Take.html).*

### **1. The National Plan to Advance Pancreatic Cancer Research Act**

This important bill, introduced in the U.S. House of Representatives in 2008 by Representatives Anna Eshoo (D-CA) and Ginny Brown-Waite (R-FL), is the first-ever substantive legislation focusing on pancreatic cancer research. The bill will be reintroduced in Congress' new session this year. Our immediate focus will be to get more members of the U.S. House of Representatives to sign on as co-sponsors for the bill, providing the National Cancer Institute with the tools necessary to make true progress on pancreatic cancer research. We have a long road ahead of us to get this bill signed into law, but we can do it if we have the help of all of our supporters across the country. To find out how you can help, visit our "Take Action" page.

### **2. Federal Appropriations**

Did you know that the federal government is the largest funder of medical research? The Pancreatic Cancer Action Network has a long history of successfully pushing the federal government to increase its funding of cancer research and, specifically, pancreatic cancer research. We will continue these efforts this year by advocating for a 15 percent per increase in the budget for the National Cancer Institute as outlined by President Obama during his campaign. We will also lobby to ensure a higher percentage of these funds are allocated specifically for pancreatic cancer research.

### **3. A Comprehensive Cancer Bill**

The Pancreatic Cancer Action Network has been working with Senators Ted Kennedy (D-MA) and Kay Bailey Hutchison (R-TX) to develop comprehensive cancer legislation to reform all aspects of cancer research and care. In particular, we have pulled together our peers representing organizations addressing the most lethal cancers to advocate for a new targeted research program focusing on such cancers.

### **4. A Cancer Trust Fund**

Recognizing new sources of funding are needed to stimulate additional research into pancreatic cancer, the Pancreatic Cancer Action Network is working with Representatives Brian Higgins (D-NY) and Steve Israel (D-NY) on legislation to establish a national fund for cancer research, a portion of which would be used to fund investigations into pancreatic cancer and the other most-lethal cancers. Such legislation would create better funding for cancer research at more consistent levels and protect investigations that might be interrupted during economic downturns due to emergency funding cuts.

Enactment of these priorities can make a significant impact in the fight against this disease. Success, however, depends upon the support of advocates like you. Visit [www.pancan.org/public/Take.html](http://www.pancan.org/public/Take.html) today to become involved in these lifesaving efforts. ✨



# JOIN US FOR THE THIRD ANNUAL ADVOCACY DAY

## MARCH 30 - 31, 2009 IN WASHINGTON, DC

To register, go to [www.pancan.org](http://www.pancan.org)

Please join us and other supporters from across the nation to tell Congress that pancreatic cancer **MUST** become a higher national priority. We'll arrange for you to visit with your members of Congress and give you tools to become an effective advocate. To learn more, register, or find out how you can participate if you can't travel to Washington, DC, go to [www.pancan.org](http://www.pancan.org).

# CLINICAL TRIALS OFFER HOPE

Patients who enroll in clinical trials have access to new treatments that may offer better results than standard treatment. Participation in a clinical trial also advances pancreatic cancer treatment, since data gathered may help researchers develop more effective therapies for future patients.

Treatments in clinical trials may consist of entirely new drugs, a new combination of existing drugs not yet used in the treatment of pancreatic cancer, promising alternative or complementary treatments, surgical interventions, radiation, lifestyle changes, or some combination of the above.


Considering participation in a clinical trial is a decision to be made by patients, their loved ones and their physicians. The effectiveness of the current treatment, the new treatment(s) being offered through the trial, the length of the study, and study location are all important factors that must be assessed.

During most cancer trials, patients receive at least the recognized standard of care for their tumor type; in other words, placebos, commonly known as sugar pills, will not be used in place of treatment. Patients may be asked detailed questions about their experiences with the experimental therapy and tested to assess the response of the tumor to the treatment. They can choose to leave the trial at any time.

New therapies must go through three phases in a clinical trial before they can be approved by the FDA for widespread use. Before trials involving patients begin, however, the new treatment(s) being offered must show promise against pancreatic cancer in laboratory and pre-clinical studies.

Phase I clinical trials are small studies primarily concerned with the safety and dosing of the treatment. Phase II trials include a larger group of patients; safety is still assessed, but the response of the tumor to the experimental treatment is critically measured. The correlation between treatment administration and tumor response is what researchers aim to understand in this phase of clinical trials. Phase III trials are conducted on a large scale, testing several hundred patients. These trials are randomized, which means patients are divided into two groups. This allows researchers to compare the efficacy of the new treatment with the current standard of care.

All phases of clinical trials must be completed before a new treatment is considered for standard use. Clinical trials provide an important link for patients to receive the most appropriate care for their pancreatic cancer. Moreover, clinical trials provide vital information to researchers and much-needed hope for patients now and in the future.

To learn more about clinical trials, or to receive a list of clinical trials in your area, please, contact a PALS Associate toll-free at 877-272-6226 or e-mail [pals@pancan.org](mailto:pals@pancan.org). 

## PANCREATIC CANCER PHASE III CLINICAL TRIALS CURRENTLY ENROLLING PATIENTS DIAGNOSED WITH PANCREATIC ADENOCARCINOMA

TRIAL TITLE	TRIAL SPONSOR
Aflibercept Compared to Placebo in terms of Efficacy in Patients Treated with Gemcitabine for Metastatic Pancreatic Cancer	Sanofi-Aventis/Regeneron Pharmaceuticals
Larotaxel Compared to Continuous Administration of 5-FU in Advanced Pancreatic Cancer Patients Previously Treated with A Gemcitabine-Containing Regimen (PAPRIKA)	Sanofi-Aventis
Phase III Trial of Weekly ABI-007 (Abraxane) Plus Gemcitabine Versus Gemcitabine Alone in Metastatic Pancreatic Adenocarcinoma	Abraxis BioScience
A Study of TNFerade™ Biologic with 5-FU and Radiation Therapy for First-Line Treatment of Unresectable Locally Advanced Pancreatic Cancer	GenVec

# CELEBRATING 10 YEARS OF PROGRESS IN THE FIGHT AGAINST PANCREATIC CANCER

From our beginning as a start-up nonprofit to our role today as the only national organization fighting pancreatic cancer in a comprehensive way, the Pancreatic Cancer Action Network has experienced extraordinary growth during the past decade. As we celebrate our 10<sup>th</sup> anniversary this month, join us in remembering some highlights in our storied history.

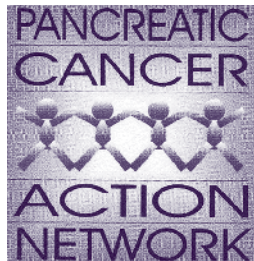
## 1998



Michael Landon, Jr., is interviewed at the first gala.

- ★ Pam Acosta Marquardt recruits volunteers on the Johns Hopkins University online network dedicated to pancreatic cancer to plan a fundraising event.
- ★ Held at the Beverly Hills Hotel, the inaugural An Evening with the Stars gala raises an impressive \$165,000.

## 1999



The first logo

- ★ Staffed solely by volunteers, the Pancreatic Cancer Action Network (PanCAN) is incorporated by founder Pam Acosta Marquardt and co-founders Paula Kim and Terry Lierman.
- ★ PanCAN's revenues reach \$225,000.
- ★ The organization's Scientific Advisory Board is established.
- ★ First state proclamation issued to recognize November as Pancreatic Cancer Awareness Month.

## 2000



A dozen survivors are acknowledged at the first Pancreatic Cancer Symposium.

- ★ PanCAN's first full-time staff member, Executive Director Julie Fleshman, is hired.
- ★ The first PanCAN office opens in Torrance, Calif.
- ★ The first pancreatic cancer symposium is held in Los Angeles.
- ★ PanCAN supporters participate in the inaugural One Voice Against Cancer (OVAC) advocacy days in Washington, DC, to push for increased research funding.

## 2006



Survivors gather at the 2006 Pancreatic Cancer Symposium in Los Angeles.

- ★ The Washington, DC, Government Affairs office opens.
- ★ First international affiliate launches in Japan.
- ★ PALS hosts three pancreatic cancer symposia.
- ★ TeamHOPE identifies five core volunteer roles for each affiliate, hosts 161 events and raises \$1.7 million.
- ★ The grants program funds six researchers.
- ★ Nearly \$4.7 million is raised from nearly 104,000 gifts.

## 2008

- ★ Randy Pausch, PhD, testifies before Congress on behalf of the Pancreatic Cancer Action Network about the urgent need for more federal research dollars.
- ★ *The National Plan to Advance Pancreatic Cancer Research Act* is introduced in Congress. The bill is the first substantive piece of legislation supporting pancreatic cancer research.
- ★ RAISE THE CURE fundraising campaign launches.
- ★ PALS lists more than 110 pancreatic cancer trials in its database.
- ★ A total of 35,000 patients and family members now served through PALS, which also hosts six symposia annually.
- ★ Community Outreach holds 321 events and raises \$3.6 million.
- ★ A total of 11 substantial research grants are funded.
- ★ Nearly \$7.6 million is raised from more than 207,000 gifts.

## 2007



**PANCREATIC CANCER ACTION NETWORK**  
ADVANCE RESEARCH. SUPPORT PATIENTS. CREATE HOPE.

The current logo

- ★ New logo and brand launch to reflect the organization's leadership position in the pancreatic cancer community.
- ★ A total of 25,000 patients and families served by PALS.
- ★ PALS begins to offer services in Spanish, publishes six booklets and hosts five symposia.
- ★ Community Outreach (formerly TeamHOPE) holds 261 events and raises \$2.6 million.
- ★ A total of 12 new research grants are awarded.
- ★ The Pancreatic Cancer Action Network hosts first Scientific Summit on Pancreatic Cancer in La Jolla, Calif.
- ★ First annual Pancreatic Cancer Advocacy Day is held in Washington, DC, with 160 participants from across the country.
- ★ More than \$7.3 million is raised from more than 146,000 gifts.





## 2001



PanCAN members advocate in Washington, DC.

- ✦ PanCAN leaders meet with National Cancer Institute staff and members of Congress to advocate for increased funding for pancreatic cancer research.
- ✦ Team Hope officially launches with the creation of a volunteer toolkit.
- ✦ Nearly \$754,000 is raised from nearly 4,000 gifts.

## 2002



Ralph H. Hruban, MD, Scientific Advisory Board member

- ✦ PanCAN relocates to a larger office space in El Segundo, Calif., and the online store moves from the home of volunteer and store founder Marsha Garil to the new headquarters.
- ✦ Ralph H. Hruban, MD, and colleagues define pre-cancerous lesions in the pancreas as Pancreatic Intraepithelial Neoplasia (PanIN). The discovery represents a turning point in pancreatic cancer research.
- ✦ The Patient and Liaison Services (PALS) program launches and lists more than 50 trials in its clinical trials database.
- ✦ Team Hope establishes 40 affiliates nationally, raises nearly \$364,000 during the year.
- ✦ First NCI Specialized Programs of Research Excellence (SPORE) grants for pancreatic cancer are funded.
- ✦ More than \$1.3 million is raised from nearly 12,500 gifts.

## 2003



Julie Fleschman, President and CEO, and David Tuveson, MD, PhD, research grant recipient

- ✦ Four researchers receive awards, marking the start of the grants program.
- ✦ PALS publishes its first educational booklet.
- ✦ Team Hope raises more than \$500,000.
- ✦ David Tuveson, MD, PhD, and colleagues characterize the first mouse model that closely mimics human pancreatic cancer.
- ✦ Nearly \$1.6 million is raised from nearly 23,400 gifts.

## 2005

### PanCAN

The second logo

- ✦ Pancreatic cancer symposia increase from one annually to two per year.
- ✦ A total of 10,000 patients and family members served by PALS.
- ✦ Team Hope establishes 70 affiliates nationwide, holds 120 events and raises more than \$1.6 million.
- ✦ Four more researchers are funded through the grants program.
- ✦ PALS lists 100 trials in its clinical trials database.
- ✦ Erlotinib (Tarceva®) is approved by the FDA to treat pancreatic cancer in combination with gemcitabine (Gemzar®).
- ✦ Nearly \$3.3 million is raised from almost 70,000 gifts.



Celebrants gather at the PanCAN fifth anniversary party.

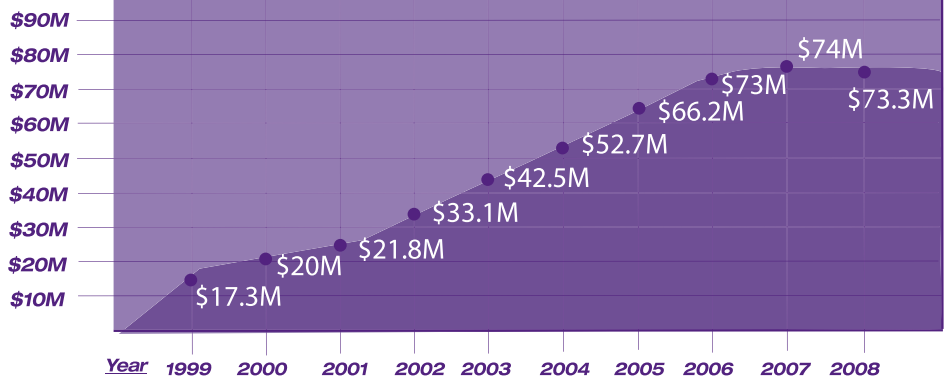
## 2004

- ✦ Grants program funds two more researchers.
- ✦ PALS formalizes its Survivor & Caregiver Network and publishes three educational booklets.
- ✦ The Pancreatic Cancer Research Map is created to connect researchers studying the disease.
- ✦ The PanCAN Medical Advisory Council is formed.
- ✦ More than \$2.3 million is raised from more than 42,000 gifts.

## BIG BOOSTS IN RESEARCH DOLLARS

Since the Pancreatic Cancer Action Network was formed in 1999, federal funding for research into the disease has increased dramatically.

Funding \*



\* Annual federal funding for pancreatic cancer research, in millions

## JOIN THE SURVIVOR AND CAREGIVER NETWORK AND SUPPORT OTHERS

Are you a pancreatic cancer survivor or currently caring for a pancreatic cancer patient and would like to lend support to others? The Survivor and Caregiver Network is a group of volunteers who communicate with other patients and caregivers by phone or e-mail as a source of support, hope, and inspiration.

To join the Survivor and Caregiver Network and share your experiences as a volunteer, please contact Megan Moffitt toll-free at 877-272-6226 or by e-mail at [mmoffitt@pancan.org](mailto:mmoffitt@pancan.org).

To connect with a current volunteer in the Survivor and Caregiver Network, you may contact a PALS Associate toll-free at 877-272-6226 or email [pals@pancan.org](mailto:pals@pancan.org) ✨

### ABOUT PATIENT AND LIAISON SERVICES (PALS)



Our Patient and Liaison Services (PALS) program offers information about pancreatic cancer, treatments, clinical trials, side effect and symptom management, diet and nutrition, as well as support resources,

including a peer-to-peer matching network, for patients and families facing pancreatic cancer. To learn more, or to order a complimentary educational packet, call a PALS Associate.

El programa de PALS esta disponible en español.

#### **Patient and Liaison Services (PALS)**

**Monday - Friday**

**7AM - 5PM Pacific Time**

**Toll-free: 877-272-6226**

**Email: [pals@pancan.org](mailto:pals@pancan.org)**

## SYMPOSIA OFFER EDUCATIONAL OPPORTUNITIES

The Pancreatic Cancer Symposia are a series of educational events held around the country for patients and their family members affected by the disease. The symposia, which are offered free of charge, bring together the nation's top oncology professionals in the field of pancreatic cancer with those facing the disease to share information about diagnosis, treatment, diet and nutrition and more.

Information about upcoming Pancreatic Cancer Symposia appears in the ad below. To learn more about these events, go to [www.pancan.org](http://www.pancan.org). ✨

### UPCOMING SYMPOSIA

**ATLANTA, GA**

**SATURDAY, MARCH 14, 2009**

**PHILADELPHIA, PA**

**SATURDAY, APRIL 4, 2009**

**SEATTLE, WA**

**FRIDAY, MAY 1, 2009**



*A total of 63 pancreatic cancer survivors join in camaraderie at the 2008 Pancreatic Cancer Symposium—Los Angeles, held on November 14, 2008 at the InterContinental Hotel.*



# A STORY OF HOPE AND INSPIRATION

By Maija E., Bellevue, Wash.



*Pancreatic cancer survivor  
Maija and her husband, Al*

I celebrated a joyfully anticipated retirement in December 2005, looking forward to spending much of the winter skiing in Sun Valley and having fun with friends. During our 10-hour drive to Sun Valley in January, I complained to my husband, Al, that our next SUV needed to have more comfortable seats for long drives. I just couldn't get my back in a comfortable position. In the coming weeks, I found myself popping ibuprofen more frequently to treat the discomfort I felt in my back and chest. This "remedy" remained in place for several months.

In late spring, I commented to my internist that the lingering discomfort was perhaps caused by a sports injury. He felt it would be prudent to determine whether my theory was correct. An ultrasound led to further tests; by mid-August, at age 52, I was diagnosed with unresectable pancreatic cancer.

A laparoscopy followed and confirmed that some spots on the liver were simply "birthmarks," allowing radiation of the pancreas to be part of an aggressive five-and-a-half week treatment protocol. The other components consisted of a 24/7 chemo pump, other treatment shots three times weekly and a second chemotherapy infused once a week. This treatment is considered intense, but I weathered the fatigue by taking tips from my cat, Sniglet. Naps are luxurious, and it's okay to be lazy. Nausea was not a significant issue due to prescribed anti-nausea meds. Constipation became an issue late in the treatment.

The resulting anorexia was more of a problem for my caregivers, Al and my dear friend, Jan. I didn't feel like drinking water or eating. They felt compelled to scheme about ways to get me to eat anything! I lost 20 pounds. Weighing 117 pounds with my 5'8" frame was not an ideal look.

I didn't realize that a complete exfoliation of the soles of my feet would be a surprise benefit. They became tender, the skin peeled off, and one month following my treatment, I had smooth baby-soft skin. My oncologist said he wouldn't charge for the "spa" treatment!

A less palatable side effect was an odiferous infection of my fingernail beds, followed by some nails falling off. Not a good look, but one learns that there could be worse consequences.

Six weeks after completion of treatment, the CT scan revealed that the tumor had shrunk by 80 percent. By February 2007, the subsequent CT scan could no longer detect the tumor. Now I was on a nine-month combination chemotherapy protocol.

The predictable hair loss was counteracted with synthetic wigs. Never a "bad hair day"...Erin, Skye and Mandy were always at their best. That is, until I fried Mandy one night when removing a tart from an oven. By the way, the wigs came with names (contrary to what a lot of people thought). With good fortune, I managed to feel well during the entire chemotherapy treatment, and resumed hiking, playing tennis and working out. Life was good in 2007.

Alien Tumor (or A.T., as a friend named him) packed his little suitcase and moved north, to a lymph node above my clavicle, in October 2007. Since I had responded well to the chemoradiation on the first round, it was determined to apply a similar approach for a six-week period. I asked my oncologist if I could ski with the re-installed PICC line and the chemotherapy pack ("dog on a leash"). He didn't think that was a winning idea. I had visions of his concern... chemo spewing forth on the slopes of Mt. Baker. Nonetheless, I decided to ski (with friends forming a protective barrier of "security" around me). I was happy, it worked just fine, and I brought photos of "The Infusiastic Skier" to share with my medical team.

I've been on "work release" from treatments since the end of January 2008! I also have the greatest appreciation for my dear friends, who created the *Celebration of Hope* fundraising gala in Seattle! It goes to show where one individual's idea may lead. By the time we have our third annual gala in May, we will have netted more than \$500,000 to support the mission of the Pancreatic Cancer Action Network. ✨

## TEN YEARS WITH THOUSANDS OF DEVOTED SUPPORTERS

The phenomenal growth of the Pancreatic Cancer Action Network over the past decade would not have been possible without the hard work of thousands of dedicated volunteers. These efforts deserve special recognition.

In 2008, many volunteers in cities nationwide helped organize 373 events, raising more than \$4.2 million. Many of these volunteers are members of affiliates, or groups of volunteers that represent the Pancreatic Cancer Action Network in their respective communities. Today, more than 75 affiliates raise money and awareness for the Pancreatic Cancer Action Network through a multitude of events and other activities. Over the past ten years, our affiliates have raised more than \$12.1 million (gross). Many fun and diverse fundraisers, such as pillow fights, bake sales, tennis tournaments and trail runs, are organized by supporters who want to make a difference in the lives of those facing pancreatic cancer. ✨

### **Kaiser Permanente San Francisco 5K**

February 3, '08 San Francisco - nearly \$62,000

### **5th Annual Walk for a Cure**

February 24, '08 Greendale, Wis. - nearly \$47,000

### **Walk for Judy**

March 8, '08 Tampa, Fla. - nearly \$16,000

### **Paws for Pancreatic Cancer**

April 12, '08 Houston, Texas - nearly \$11,000

### **A Celebration of Hope**

May 3, '08 Seattle, Wash. - nearly \$306,000

### **PurpleStride Cleveland 2008**

June 21, '08 Bay Village, Ohio - more than \$88,000

### **Outdrive Pancreatic Cancer**

June 30, '08 Annandale, N.J. - more than \$58,000

### **Diaz & Copeland Memorial Tennis Tournament**

July 11, '08 Columbus, Ohio - more than \$64,000

### **PurpleStride Island Run**

August 9, '08 Stone Harbor, NJ. - nearly \$53,000

### **Pick Up the Pace for Pancreatic Cancer**

August 17, '08 Allison Park, Penn. - more than \$116,000

### **PanCAN Links for a Cure**

August 25, '08 West Bloomfield, Mich. - nearly \$89,000

### **3rd Annual Golden Gallop**

September 6, '08 Golden, Colo. - nearly \$69,000

### **PurpleStride Central Ohio 2008**

September 13, '08 Ohio - more than \$31,000

### **PurpleStride Portland 2008**

September 13, '08 West Linn, Ore. - nearly \$29,000

### **Scranton Links for a Cure**

September 20, '08 Penn. - more than \$50,000

### **PurpleStride Long Island 2008**

September 21, '08 Holtsville, N.Y. - more than \$45,000

### **PurpleStride Maryland 2008**

October 12, '08 Bel Air, md. - nearly \$167,000

### **7th Annual Ol' Country's Boot Scootin'**

October 18, '08 Fort Worth, Texas - nearly \$26,000

### **Light Up the Night With Hope 2008**

October 22, '08 St. Louis, Mo. - nearly \$93,000

### **PurpleStride Orlando 2008**

October 25, '08 Orlando, Fla. - nearly \$34,000

### **PurpleStride Philadelphia 2008**

November 1, '08 Newtown, Penn. - nearly \$215,000

### **Jazzed for Hope**

November 1, '08 Madison, Wis. - more than \$93,000

### **Stride for a Cure**

November 2, '08 Albany, N.Y. - nearly \$52,000

### **2nd Annual Auction for Action**

November 6, '08 Tampa, Fla. - nearly \$59,000

### **PurpleStride Atlanta 2008**

November 15, '08 Atlanta, Ga. - more than \$131,000

### **PurpleStride Lake Area 2008**

December 6, '08 Lake Charles, La. - nearly \$23,000 raised

**We are deeply grateful to all of those who have given their time, money and resources to support us. The Pancreatic Cancer Action Network would not exist without your unending support and boundless energy.**



## SET THE PACE FOR PROGRESS

**JOIN THE PANCREATIC CANCER ACTION NETWORK RUNNING TEAM**

**KONA MARATHON AND HALF MARATHON / JUNE 28, 2009**

**REGISTER AT [WWW.PANCAN.ORG/KONAMARATHON09](http://WWW.PANCAN.ORG/KONAMARATHON09)**

## GROWING OUR DEDICATED AFFILIATE NETWORK

Events are an ideal way to raise money and bring people together, but what happens after they are over? In order to make progress, we need to ensure that pancreatic cancer remains at the forefront of people's consciousness. Such efforts may require as much work as the event itself.

Pancreatic Cancer Action Network affiliates, composed entirely of volunteers, aim to fill the gap between events by educating their communities about our cause year-round. Not only do they fundraise in more than 75 cities across the country; they also disseminate information, work with local media and provide a community for those who are affected by the disease.

Although affiliates are not support groups and do not provide the same information as our Patient and Liaison Services (PALS) program, they offer a safe place for those who are newly diagnosed, have a loved one with pancreatic cancer or have lost someone to the disease. For many people, just having others around who know what they're going through can provide a huge boost of confidence. Some affiliates partner with other local support groups, such as our Phoenix, Ariz., affiliate. Affiliate meetings are held at The Wellness Community, and the affiliate promotes the support group offered by the center.

Working with organizations that serve pancreatic cancer patients may be an important part of an affiliate's outreach strategy. In Detroit, Mich., for example, affiliate members participate in seminars offered by Beaumont Hospital, Royal Oak to teach medical professionals about the latest options available to pancreatic cancer patients. In Tampa, Fla., affiliate members host one of their fundraising events at the H. Lee Moffitt Cancer Center & Research Institute and frequently distribute information about our PALS program there.

Educating patients and medical professionals about their options is crucial, but government funding is critical to advancing research. To that end, volunteers build relationships with their elected officials, share their stories and urge them to support increased cancer research funding. With the launch of *The National Plan to Advance Pancreatic Cancer Research Act*, advocacy efforts have become even more integral to our comprehensive strategy. Our affiliate in York, Penn., has done a wonderful job of developing a relationship with their local congressman, Representative Todd Platts, who has played a vital role in our advocacy efforts by co-sponsoring the federal proclamation to declare November as National Pancreatic Cancer Awareness Month for the last eight years.

No matter what the focus of each affiliate is, the most important part of their work is to maintain a presence for our organization in their respective communities. Thanks to our dedicated volunteers, we're able to reach more people than we could with just our staff alone. It's because of our volunteer network that we're able to have so much success in funding our grants, garnering the support of members of Congress, and reaching affected individuals. Our affiliate volunteers are an integral part of our success. ✨

## EXCITING SPRING EVENTS

This spring, we will host some of our most notable fundraising events of the year. On May 2, we expect more than 1,000 supporters to join us for PurpleStride Chicago 2009. Last year's event attracted more than 800 walkers and raised nearly \$400,000, so we are excited about the event's anticipated growth. To register, please visit [www.pancan.org/purplestridechicago09](http://www.pancan.org/purplestridechicago09).

The third annual *A Celebration of Hope* gala will also be held on May 2 in Seattle. The event, scheduled on the day after our local patient symposium, has raised more than \$500,000 since its inception. This spectacular gala will be hosted by KING-5 News investigative reporter Susannah Frame and will include silent and live auctions and top-notch entertainment. To purchase tickets online, go to [www.pancan.org/seattlegala](http://www.pancan.org/seattlegala).

Finally, the St. Supery Vineyards & Winery in Napa Valley, Calif., will provide a picturesque backdrop for the 6th annual Walk Through the Vineyards, scheduled for June 13. Last year's event raised more than \$95,000. This year, the goal is to top \$100,000. To register, visit [www.pancan.org/vineyardwalk09](http://www.pancan.org/vineyardwalk09). ✨

## WELCOME TO OUR NEW AFFILIATE COORDINATORS

Pancreatic Cancer Action Network affiliates educate their communities and raise awareness about pancreatic cancer. Affiliates are volunteer-based and host activities and events to help us fulfill our mission. If you are interested in volunteer opportunities, please contact us at [volunteer@pancan.org](mailto:volunteer@pancan.org) or call us toll-free at 877-272-6226.

Please join us in acknowledging our newest affiliate coordinators:

**Terri Bertoli**  
Colorado – Pueblo/Colorado Springs

**Becky Sargent**  
Tennessee – Nashville

**Jay Stern**  
Oklahoma – Oklahoma City



# PANCREATIC CANCER COMMUNITY HEROES RECOGNIZED AT 11TH ANNUAL AN EVENING WITH THE STARS GALA

Bathed in a purple glow, the Beverly Wilshire Hotel served as a spectacular setting on November 15th when more than 700 supporters gathered in Beverly Hills, Calif., for the Pancreatic Cancer Action Network's 11th Annual An Evening with the Stars gala.

During the memorable evening, six individuals were recognized with three of the charity's most prestigious awards in recognition of their notable contributions to the pancreatic cancer community:

### **Jeffrey Zaslow, *The Last Lecture* co-author and *The Wall Street Journal* columnist The Spirit of Hope Award**

Along with the late beloved Carnegie Mellon University professor Randy Pausch, PhD, Zaslow inspired millions

worldwide through the publication of their internationally bestselling book, *The Last Lecture*. One of the evening's most touching moments occurred during Zaslow's award presentation, when Jai Pausch spoke about her life since her husband's passing from pancreatic cancer in 2008.

### **The Tabach-Bank family (Brad, Jordan, Casey and Lauren) The Emily Couric Public Service Award**

Honored in recognition of their outstanding commitment to advancing pancreatic cancer research, the Tabach-Bank family joined the Pancreatic Cancer Action Network in March 2008 to support Advocacy Day, sharing their own story of loss with Congress. Their involvement serves as a touching tribute to family matriarch Jeannie Tabach-Bank, who passed from the disease in 2005.



From left, Brad Tabach-Bank, Lauren Tabach-Bank, Jeffrey Zaslow, Patrick Soon-Shiong, MD, Jai Pausch, Casey Tabach-Bank and Jordan Tabach-Bank



From left, Jeffrey Zaslow, Roger Magowitz and Jeanne Magowitz



Eight-year pancreatic cancer survivor Sandra Martin



Some of the organization's founding volunteers join Jai Pausch (third from left) at the event. From left, Ellen Zeltmann, Marsha Garil, Pausch, Connie Baker, Marilyn Myrow and Barbara Johnson



Pancreatic cancer survivor Carolynn Kiel, left, and her daughter, Stacy Robson



From left, Margaret Tempero, MD, Meg Mandelson, PhD, Richard Tempero, MD, Dafna Bar-Sagi, PhD, and Sunil Hingorani, MD, PhD



From left, Janet Zucker, Patrick Soon-Shiong, MD and Jerry Zucker

### Patrick Soon-Shiong, MD, noted research scientist and medical visionary The Medical Visionary Award

A noted research scientist and surgeon, Dr. Soon-Shiong has devoted his career to developing next-generation technology to enhance the medical care of patients facing life-threatening diseases, including cancer, diabetes and heart disease. His research has been recognized with numerous national and international awards.

#### OTHER EVENING HIGHLIGHTS

In addition to feting the honorees, supporters were introduced to 18 of the organization's 2007 and 2008 grant recipients by Geoff M. Wahl, PhD, a member of the Scientific Advisory Board. In total, 23 grants were awarded during the two-year time period, funding projects that deal with critical issues in pancreatic cancer including disease biology, etiology, early detection and treatment.

For the second year, actor and comedian Joel McHale served as the evening's emcee. McHale, who is the popular host of E! Entertainment Television's *The Soup*, shared his personal story of how his life has been touched by pancreatic cancer and why the work of the Pancreatic Cancer Action Network means so much to him.

"The gala was a wonderful success, and we took great pride in recognizing all of our incredible honorees as well as the promising researchers who are working diligently to bring an end to pancreatic cancer," said Julie Fleshman, Pancreatic Cancer Action Network President and CEO. "The funding raised during the evening is critical to furthering our mission, and we are deeply appreciative of all of the donations raised through the event." ✨

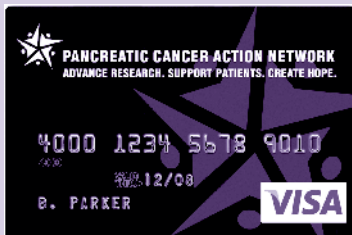


Angus and Jolina Mitchell, the son and former wife of hair industry legend Paul Mitchell, who died of pancreatic cancer in 1989

**SAVE THE DATE**

**AN EVENING  
WITH THE STARS  
12<sup>TH</sup> ANNUAL GALA**

**LOS ANGELES  
OCTOBER 17, 2009**



### MAKE A STATEMENT WITH OUR NEW CREDIT CARD

By opening a Pancreatic Cancer Action Network Visa credit card, your everyday purchases can work harder and help raise much-needed funds to advance research, support patients and create hope for those facing pancreatic cancer. The Pancreatic Cancer Action Network receives \$50 for every new account that is ACTIVATED within 90 days of an approved application. The Pancreatic Cancer Action Network also receives 0.3 percent of all net retail transactions. **There is no annual fee.** Visit [www.pancan.org/visa](http://www.pancan.org/visa) for more information and to apply for the card today.



**PANCREATIC CANCER ACTION NETWORK**  
**ADVANCE RESEARCH. SUPPORT PATIENTS. CREATE HOPE.**

2141 Rosecrans Ave., Ste 7000, El Segundo, CA 90245

Non-Profit Org  
 US Postage  
 PAID  
 Torrance, CA  
 Permit No.473



## SHOP PURPLE IN 2009

Add the latest apparel, fashion accessories, and home and office accents to your awareness collection by purchasing items from the Pancreatic Cancer Action Network Store.

[WWW.PANCAN.ORG/STORE](http://WWW.PANCAN.ORG/STORE)

# CALENDAR OF EVENTS

DATE	EVENT NAME	CITY, STATE	CONTACT
2/1/2009	Kaiser Permanente Half Marathon & 5K	San Francisco, Calif.	Michelle Monhart, mmonhart@pancanvolunteer.org
2/15/2009	Austin Marathon and Half Marathon	Austin, Texas	Greg P, gregp@pancanvolunteer.org
2/22/2009	Mardi Gras Party	Roanoke, W.Va.	Annette Santilli, asantilli@pancanvolunteer.org
3/7/2009	Run Across Kansas	Topeka, Kan.	Danny Miller, danrdanny@gmail.com
3/14/2009	Pancreatic Cancer Symposium	Atlanta, Ga.	Mayra DeAnda, mdeanda@pancan.org
3/14/2009	4th Annual Elizabeth I. Negos Walk for Hope	San Diego, Calif.	Lily Villaverde, lvillaverde@pancanvolunteer.org
3/30 & 31/09	Advocacy Day 2009	Washington, DC	Kate Geyer, kgeyer@pancan.org
4/5/2009	Pick Up the Pace Benefit Dinner	Clarion, Penn.	Danielle Orr, tdukovich@pancanvolunteer.org
4/14/2009	Pancreatic Cancer Symposium	Philadelphia, Penn.	Mayra DeAnda, mdeanda@pancan.org
4/26/2009	PurpleStride Austin 2009	Leander, Texas	Mandy West, awest@pancanvolunteer.org
5/1/2009	Pancreatic Cancer Symposium	Seattle, Wash.	Mayra DeAnda, mdeanda@pancan.org
5/2/2009	3rd Annual <i>A Celebration of Hope</i>	Seattle, Wash.	Marie Gunn, mgunn@pancanvolunteer.org
5/2/2009	PurpleStride Chicago 2009	Chicago, Ill.	Maureen Feck, mfeck@pancanvolunteer.org
5/3/2009	Nazareno Regalbuto Memorial Walk	Sewell, N.J.	Lisa Regalbuto Santelli, lisa.regalbuto.santelli@comcast.net
5/9/2009	PurpleStride Ormond Beach 2009	Ormond Beach, Fla.	Laurie Sterbens, laurie.sterbens@yahoo.com
5/30/2009	Dinner Cruise for A Cure	Warren, R.I.	Shena Hamel, shamel@pancanvolunteer.org
6/1/2009	Links for A Cure	West Bloomfield, Mich.	Amy Ruckle, amyruckle@gmail.com
6/13/2009	7th Annual Walk Through the Vineyards	Napa Valley, Calif.	Michelle Monhart, mmonhart@pancanvolunteer.org
6/27/2009	PurpleStride Cleveland 2009	Bay Village, Ohio	Teresa Young, tyoung@pancanvolunteer.org
6/28/2009	Kona Marathon and Half Marathon	Kailua-Kona, Hawaii	Satel Patel, spatel@pancan.org