

OUTREACH

VOLUME VII, ISSUE 4 - OCTOBER 2007

A Publication of the Pancreatic Cancer Action Network



Picture
Your World
Purple
See Page
5



Chairman of the Board's Message

Dear Friends of the Pancreatic Cancer Action Network:

Most organizations come to a point in their growth cycle when it is time to reevaluate their messaging and branding to make sure that it still reflects its core values. Due to our enormous growth and expansion over the last eight years, we felt it was important to appraise our situation and determine whether the current messaging and branding truly represent the multi-faceted organization that we are today.

Through our evaluation, we discovered that our audience is very diverse, and tends to view the organization very differently. For example, those who interact frequently with PALS see great value in the hope and sense of community that we provide, but many of them did not recognize or know of our advocacy work or research funding. Therefore, our mandate was to develop a new messaging platform and branding strategy that would accurately capture our passionate nature, while at the same time illuminate the organization's significant influence as a leader and dynamic force in the pancreatic cancer community.

Therefore, we are happy to report that the Pancreatic Cancer Action Network has officially restated its mission statement to reflect the comprehensive approach we take to fighting pancreatic cancer. This mission statement addresses all of our endeavors, which include funding research, providing patient support, generating community awareness and advocating for a cure. At the same time we have created a new logo and outreach campaign that speak to this comprehensive approach.

We will slowly be rolling out our new messaging and branding over the next year through our publications and website. We ask for your patience during the transition period. We look forward to sharing our new look with you in the months ahead!

It is with great enthusiasm that we approach Pancreatic Cancer Awareness Month in November. This year we will again ask you to RAISE YOUR VOICE! Please read inside this newsletter and visit our website about how you can RAISE YOUR VOICE during the month of November. Remember that when you pass on information about pancreatic cancer and the needs of the pancreatic cancer community to family, friends and colleagues, and they in turn pass it on to their family, friends and colleagues, you have exponentially raised awareness about the disease.

We are looking forward to working with all of you this November, because together, we are providing a stronger voice for patients and researchers. Thank you for being a part of our team!

Sincerely,

Jason Kuhn
Chairman of the Board

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Advocacy: Your Questions Answered

We know that many of you have participated in our Action Alerts and we greatly appreciate your help! For this issue of the newsletter, we wanted to give you a better understanding of why we send Action Alerts and why your response to each of them is critical!

What is an Action Alert?

PanCAN sends Action Alerts through our email system to volunteers who have indicated an interest in advocacy at key points in the legislative process when we need Members of Congress to hear from a large number of their constituents. The email will generally come from PanCAN's Government Affairs Department (advocacy@pancan.org) and will explain the reason we are issuing the alert and the action we want you to take. A typical Action Alert will direct you to the Advocacy portion of PanCAN's website (www.pancan.org/Public/take.html) through which you can send a letter to Congress in a few easy steps. The letters are designed to only take a few minutes

of your time, but can have a significant impact on our efforts to secure more federal research dollars for pancreatic cancer and help us find a cure!

I already contacted my Members of Congress. Why do I need to do it again?

First, please rest assured that your Senators and Representative are not at all bothered by you contacting them repeated times about issues that are important to you. In fact, your voice "counts" more if you contact them several times about an issue (preferably, over the course of the year, and not all in the same hour!). It may seem strange, but elected officials use the number of times a person has talked to them about a specific issue, and the number of people they have heard from, as measures of how important the issue is to the people they represent (their constituents). Ever heard of the saying that "the squeaky wheel gets the grease"? If you just contacted your elected officials once and never again about the need to

increase federal funding for pancreatic cancer research, they would figure that you weren't really interested and that they should focus on other issues.

Second, while many of the Action Alerts are on the same issue (e.g., federal funding for pancreatic cancer research), each alert is slightly different and has a slightly different message depending on where we are in the legislative process. See the box. A new funding bill gets introduced each year and given the way the policy process works, the issues that we encounter to try to increase funding for that year change over the course of the year.

There will be an Advocacy component of our November Awareness Campaign. Our goal is to have everyone who receives this newsletter participate!

Do you have a question about Advocacy that you'd like to learn more about? Send us an email at advocacy@pancan.org!

Annual Federal Funding Cycle



February:

President's Budget Request
The President drafts a 'suggested' budget for the year.

March – April:

Budget Resolution
Congress outlines and debates a spending blueprint. This blueprint is critical because it dictates how much money will be available for the appropriations bills and ultimately, for pancreatic cancer research.

May – September:

Appropriations Bills
Congress assigns dollars to the spending blueprint and provides specific funding levels for various programs. There are 12 separate appropriations bills. The one we focus on covers the Labor, Health & Human Services (HHS) & Education Departments. The Department of HHS includes the National Institutes of Health and the National Cancer Institute, which funds pancreatic cancer research. Note that while this process is supposed to end by September 30, the start of the government's new fiscal year, it can extend until December or beyond.

Your Opinion Counts!

Go to www.pancan.org/survey

Please go to www.pancan.org/survey and complete our online survey. It will only take a few minutes.

The results of this survey will help determine if our newsletter is meeting your information needs regarding all aspects of pancreatic cancer.

Your responses will remain confidential and your contact information will not be shared outside of PanCAN.

Please go to www.pancan.org/survey!

Thank you!





BnB Finder proudly supports pancreatic cancer and the Pancreatic Cancer Action Network



B&B Gift Certificates

BnB Finder.com Supports National Pancreatic Cancer Awareness Month

As part of BnB Finder.com's *Find a Cure Campaign*, from November 1 – November 30, BnB Finder.com will donate 5% back to PanCAN of the total gift certificate value from each *BnB Finder.com B&B Travel Gift Certificate* that's purchased online by a PanCAN supporter. To order Gift Certificates good at over 1,500 B&Bs visit www.TravelGiftCertificate.com. You must use the Key Code PANCAN when purchasing gift certificates during November for PanCAN to benefit from this exciting promotion.

Plus, make a reservation with any Inn participating in BnB Finder.com's *Find A Cure* promotion and mention their Pancreatic Cancer Awareness Month promotion when making your reservation, a percentage of your stay or a predetermined dollar amount will be donated back to PanCAN. Go to www.BnB Finder.com/PanCAN – to get all the details.



Raise your Voice! and Take Action this November!

November is National Pancreatic Cancer Awareness Month!

Have you ever noticed when you drop a stone into a pond it creates energy and movement that moves in circles radiating from the point of contact? You, your friends, family and colleagues can have the same impact when you RAISE YOUR VOICE this November in the fight against pancreatic cancer.

Tell everyone you know that November is National Pancreatic Cancer Awareness Month. Tell them that pancreatic cancer is the 4th leading cause of cancer death in the US. It receives the least amount of federal research dollars and receives little public attention. You, and everyone you know can be a powerful "stone in the pond" to change the way funding is distributed for pancreatic cancer research. You can raise public awareness and create hope for those affected by pancreatic cancer.

Here's all you have to do!

Take Action Today – Go to: www.pancan.org/raiseyourvoice to find the links for all the actions below.

- 1 Tell A Friend
- 2 Write to Your Elected Officials
- 3 Write to the editor of your local paper
- 4 Create a personal fundraising page
- 5 Picture Your World Purple on November 15
- 6 Make a donation today

Picture Your World Purple on November 15

Pancreatic cancer is the 4th leading cause of cancer death in the United States, but it receives the least amount of research funding and little public recognition. You can help change that.

- 1 On November 15th, Picture YOUR World Purple and join the fight to defeat pancreatic cancer. Go to www.pancan.org/PYWP and see a list of some creative ideas to get you started! Send a hi-res (300 dpi) file to volunteer@pancan.org. Imagination counts!
- 2 Tell us why you are raising your voice about pancreatic cancer. Be sure to include your city, state and the name of your group (office, school, family, etc).
- 3 Submission deadline is Wednesday, November 21, 2007. Your photo may be featured on the Pancreatic Cancer Action Network website or in our newsletter!

PRIZES

First Place	\$100 PanCAN Online Store gift certificate
Second Place	\$75 PanCAN Online Store gift certificate
Third Place	\$50 PanCAN Online Store gift certificate

Starting November 5, 2007, go to www.ebay.com/pancan for an opportunity to bid on silent auction items benefitting PanCAN.



Shop the 5th Annual Z GALLERY Shopping Week to Benefit PanCAN November 5th – 9th

Z Gallerie proudly supports the Pancreatic Cancer Action Network in memory of Shirley Zeidan. Z Gallerie will donate a portion of the proceeds from their retail and online stores made between November 5th and 9th. Visit www.zgallerie.com to find a store near you or purchase online.

TeamHOPE

PanCAN TeamHOPE affiliates educate their communities and raise awareness about pancreatic cancer. Affiliates are volunteer-based and host activities and events to help PanCAN fulfill its mission. If you are interested in events or volunteer opportunities, please contact us at volunteer@pancan.org or call us toll-free at (877) 272-6226.

PanCAN welcomes our newest TeamHOPE Coordinators!

Heather Raehl, TeamHOPE Arizona – Tucson

James Fisher, TeamHOPE California – Orange County

Jim Blackburn, TeamHOPE Colorado – Denver

Rose Blackburn, TeamHOPE Colorado – Denver

Claudia Cubillos, TeamHOPE Florida – Miami

Jane Miller, TeamHOPE Georgia – Savannah

Carla Bech Hansen, TeamHOPE New Hampshire

Elizabeth Fox, TeamHOPE North Carolina – Winston-Salem

Shena Hamel, TeamHOPE Rhode Island

Gregory Petrowicz, TeamHOPE Texas – Austin

Wendy Melara, TeamHOPE Virginia - Richmond

Kathryn Tenyer, TeamHOPE Wisconsin – Southeast

TeamHOPE Events

California

In its biggest year yet, the fifth annual **Walk through the Vineyards** in the beautiful Napa Valley raised almost \$45,000 for PanCAN! TeamHOPE Bay Area Affiliate Coordinator Michelle Monhart was assisted by a team of long-time Napa volunteers in planning this successful event. The walkers braved chilly morning temperatures to enjoy a scenic walk, a wonderful auction, and live music from young singer Adriana Kwicinski.

TeamHOPE Event Coordinator Justine Medeiros planned a **bingo night** for PanCAN at a West Hollywood restaurant on August 8. Guests enjoyed a lively game with celebrity bingo callers and great prizes. The event raised over \$2,000 and helped raise awareness of pancreatic cancer in the Los Angeles area.

TeamHOPE San Diego raised almost \$15,000 at its third annual **TeamHOPE Walk** on June 2! Over 100 walkers and runners from all over Southern California gathered at Rohr Park and enjoyed not only the brisk exercise, but also a large raffle and live music! The event grows each year and the team is already planning next year's walk.

Colorado



TeamHOPE Colorado - North's **Longmont Leap** was a great success in its first year. Through online fundraising and generous local sponsorships, the event raised over \$13,000 and brought together four survivors. *Pictured: Survivors Patti Kepler, Cindy Hannah, Nancy Peterson and Lilliemae Ortiz*

With a little help from mom Kathleen, twelve-year-old Koby McInnis raised over \$700 by coordinating a **bake sale** for PanCAN on June 8. By asking friends, family, and local businesses to participate, Koby surpassed her goals for her first fundraising event and set a great example for kids and adults alike!

Connecticut

The third annual **PanCAN Summer Jam** took place on June 23 at the Madison Surf Club. Guests enjoyed a waterfront evening of fun with friends, music, drinks, hearty appetizers and both live and silent auctions.

Georgia

TeamHOPE Savannah organized **Purple Day** and a bake sale, held at Memorial Health University Medical Center on June 7. Additionally, employees dressed in purple to raise awareness for pancreatic cancer.

Illinois

TeamHOPE Illinois-North participated in Six Flags Great America's **Coasters for A Cause** event on May 19. It was a gorgeous day and the group sold more than 500 tickets, raising \$4600.

Thanks to the 115 walkers, 145 "Web walkers," the children of Pope School, and the sponsors who took part in the 2nd Annual **Walk with the Dogs** on June 2 in Nashville! As a result of their generous support and enthusiastic participation, \$9,200 was raised for PanCAN.



The Kuna family hosted the **Striking Pins for Pancreatic Cancer** fundraiser on June 23 at their newest facility, Raymond's Bowl in Johnsbury. The event was in honor of Felicia Kuna, a nine-and-a-half year pancreatic cancer survivor. Diandra Asbaty, current QubicaAMF World Cup Gold medal holder, was kind enough to give bowling tips and sign autographs at the event. Three more pancreatic cancer survivors were also in attendance, adding to the celebration. More than \$5,000 was raised by the 79 bowlers who participated in the event. Special thanks to the Kuna family for their generosity and to PanCAN volunteers Kim Giovanni, Linda Szramiak and Valerie Powley for managing the event.

Iowa

Mike Scram ran the **Okoboji Marathon** and raised funds through his personal page at www.firstgiving.com/TeamTOOT. Runners enjoyed great weather and Mike raised over \$2,000.

Kansas

The fifth annual **Rod Rogers Memorial Golf Tournament** was another huge success, with almost \$26,000 going to PanCAN. The day began with rain and thunder, and although the clouds stayed around, the rain held back, making it a perfect day for golf. 153 golfers joined in the fun, along with 55 volunteers, and family and friends arrived from Texas, California, New York, Nebraska, Kansas and Missouri to help make the day special.

Massachusetts

On June 16, TeamHOPE Boston held the first-ever **Framingham 5K Road Race**. The event raised over \$18,000 for PanCAN and included participation from the local police and fire departments. The volunteers are already looking forward to holding the event next June.

Michigan

PanCAN supporters in Lyndon held a **pheasant hunt** on June 25 and raised over \$3,000.

Minnesota

A **benefit screening of the movie "The Eyes of Scott Robbins"** was held in Minneapolis June 7. "Eyes" is the fictional story of a television producer diagnosed with pancreatic cancer who films the last six months of his life. Director Jason Smith and Associate Producer David Ulrich spoke after the film, which raised

TeamHOPE Events cont.

over \$1,000 for PanCAN. Find out more about the movie at www.eyesofscottrobbins.com.

Missouri

Helen Jung's children, Melissa, Jim and Joe, held their second annual **Grandpa Schwartz Memorial Bike-a-thon** and raised over \$2,500. This event is in honor of their Grandpa Ron Schwartz and all of those who are fighting and surviving pancreatic cancer.

New York

Family and friends of Rudy Nunez held a fundraising event, **Remember Rudy**, on July 21. The event raised \$4,500 and donations to www.firstgiving.org/rudynunez continue to come in. Friends, family and guests enjoyed this event and look forward to honoring Rudy again next year.

On June 21 Rensselaer Honda held the 5th Annual **Tom Gorman Memorial Golf Tournament**, raising over \$10,000. This year's tournament was held at the Fairways of Halfmoon golf course and included lunch, dinner, a silent auction and 50/50 drawing.

Ohio

Elizabeth Schindler and her daughter held the **Ohio Dog Walk** in Coldwater to raise money and awareness for PanCAN. The event was inspired by the family's Bichon Frize, Gracie, who has been Elizabeth's constant companion since losing her husband Ron eight years ago to pancreatic cancer. Mrs. Schindler and her daughter sent letters to friends, family and members of the community who had also lost loved ones to pancreatic cancer. The event even garnered publicity from a local radio station, who interviewed Mrs. Schindler for a regular 30-minute program. Everyone who participated was given a packet of information about pancreatic cancer and enjoyed homemade "ribbon" cookies frosted with purple frosting.

The 3rd Annual **Mary Diaz & William Copeland, Jr. Memorial Tennis Tournament** was very successful this year. Held at the Ohio State University Stickney Tennis Center, the event has been growing every year, and this year was the biggest yet. Over 140 people were involved, with about 85 playing in the tournament. It is estimated that this year's event raised over \$60,000 - about double that of last year's tournament. Organizers are very pleased with the results of this year's tournament and hope that the money raised will help support PanCAN in all the things the organization is doing to help fight this horrible disease.

Pancakes for PanCAN in Dayton raised over \$4,000 for pancreatic cancer research. As a senior project, Sarah Finley teamed up with three classmates and the Golden Nugget Pancake

House in Dayton to raise awareness and funds for pancreatic cancer. The Golden Nugget Pancake House is owned and operated by the Thomas family, who like Sarah, lost a close relative to pancreatic cancer. Sarah spent much of her final high school term soliciting funds and raffle prizes for the event, which took place May 29-31. The event was so successful that the Golden Nugget requested Sarah conduct the fundraiser an additional day, June 3. Nearly 3,000 people visited the restaurant during the course of this event. Sarah and the Thomases plan to team up for another event this fall to keep the fight to find a cure alive.

TeamHOPE Cleveland held their 6th Annual **Race To Make a Difference For Pancreatic Cancer** on Saturday, June 16 in Bay Village. The event featured a 5K run and 2 mile walk. The event was a huge success, attracting over 620 participants and raising over \$80,000. Several pancreatic cancer survivors were also there to enjoy the festivities.

TeamHOPE Columbus raised over \$800 at the **Worthington's Treasures on the Green** event, and hope to top \$1000 with additional items being sold on consignment. Volunteers spoke with many people and distributed ribbons and bracelets.

The first-ever **WoodSticks & Strings** two-day concert event in Waynesville was great, despite bad weather. One night's shows had to be cancelled, but those that attended had a ball and can't wait until next year.



The third annual **Steve Speece Memorial Triathlon and Picnic** raised \$2,000 for PanCAN on August 11 in Youngstown. The event had a great turnout and event organizers were extremely pleased.

Oregon

Ash Trace and Chris Panagos embarked on a **cross-country bike ride** from San Diego, CA to St. Augustine, FL, on April 15. The pair logged almost 3,000 miles, raised \$14,000 and spread invaluable awareness! Ash and Chris documented their six-week journey on their blog rideforawareness2007.blogspot.com.

TeamHOPE Portland raised over \$800 and sold out of tickets for its first annual **PanCAN Night with the Portland Beavers** August 3! The announcer introduced Affiliate Coordinator Liz Potter as she threw the first pitch. The Portland Beavers also graciously allowed TeamHOPE to host an awareness table and the announcer reminded the crowd to stop by.

Pennsylvania

The third annual **Dale Pokorney 5K Walk/Run** was held on June 2 in Hermitage. The event is sponsored by the Dale Pokorney Foundation, which supports PanCAN as well as local initiatives. Besides giving half of the event's net proceeds to PanCAN, event organizers invited PanCAN representatives to attend the event and distribute information to help raise awareness of pancreatic cancer.

South Dakota

TeamHOPE South Dakota Affiliate Coordinator Peggy Kessler held the **5th Annual Brandon Scramble** on August 5. This popular summer event brought together 100 people for a great day of golf.

Tennessee



TeamHOPE Chattanooga raised over \$3,500 for an awareness event at a **Chattanooga Lookouts game**. Donnie Burns, a 2 and 1/2 year survivor, threw out the first pitch at the game.



Make sure you
visit the PanCAN Store
to get ready for
**Pancreatic Cancer
Awareness Month**
in November!

www.pancan.org/store

Pilot Grant Awardees

“This year PanCAN launched a new innovative Pilot Grant Award program. The goal of the program is to support innovative research grants for pancreatic cancer. The grants focus on important questions in basic science or clinical science that could lead to advances in early detection or new discoveries in treatment. Due to the current state of funding at the National Cancer Institute, funding for “innovative ideas” in the beginning stages is in peril. PanCAN’s Pilot Grant program ensures that the best new ideas can be developed and that important data can be generated, hopefully then allowing the grantees to get larger federal grants or private funding. The awards are \$60,000 each for one year and PanCAN is funding five of them this year. Please take time to read about their work and ideas in the article below. We are grateful to the scientific community for making pancreatic cancer research their focus, and we are humbled by the incredible generosity of our donors and volunteers who made these grants possible.” – Julie Fleshman, President and CEO



Pinku Mukherjee, PhD,
Mayo Clinic

Development of immune-modulating therapies delivered directly to the pancreatic tumor site

Current protocols for the treatment of pancreatic cancer are not as effective as we desire. Novel therapies such as cancer vaccines that target specific proteins only on the tumor present an attractive alternative with the expectation that this approach will cause fewer side effects and prevent metastasis and recurrence better than standard therapies. To prevent metastasis and recurrence, cancer vaccines must generate immune memory against these tumor-specific proteins. So far, this has not been possible because tumors have adopted ways to successfully escape recognition and killing by the immune cells. Several known agents that can reverse immune escape have previously been tested but with modest clinical responses because the agents were administered systemically and may have never reached the tumor site. Goal:

Our goal is to target these novel immune-modulating agents directly to the pancreatic tumor site using a tumor-specific MUC1-antibody as a carrier. Hypothesis: We hypothesize that a robust anti-tumor response along with a strong memory response will be generated when MUC1/KRAS-based vaccine is combined with novel immune modulating agents that are delivered directly to the pancreatic tumor site. To test the hypothesis, we have generated an appropriate animal model that develops spontaneous pancreatic cancer and appropriately mimics the human disease. These studies could form the basis for targeting other agents directly to the pancreas site. If successful, the results from these studies could help us develop a new combination modality for the treatment of localized and disseminated tumors.



Sunil R. Hingorani, MD, PhD,
Fred Hutchinson
Cancer Research
Center

Activated kras G12D and oncogene dependence in pancreatic cancer

Activating mutations in the *RAS* family are among the most frequently encountered oncogenic events in human malignancies. In pancreas cancer, KRAS mutations appear to be essential for disease initiation. It remains unknown, however, whether sustained mutant *KRAS* activity is required to maintain the preinvasive or invasive and metastatic stages of the disease. In other words, does oncogenic *KRAS* subvert and rewire intracellular signaling networks to create a situation of dependence or ‘addiction’ to its effects? If so, then the very event that endows the pancreatic cancer cell with its lethal abilities may also represent the means to its undoing. We have previously shown that targeted conditional expression of endogenous

Kras^{G12D} in progenitor cells of the murine pancreas induces the development of all three stages of preinvasive pancreas cancer lesions, termed pancreatic intraepithelial neoplasias (PanINs). These lesions can progress of their own accord, or can be hastened to progress in the setting of additionally targeted tumor suppressor gene mutations, to fully invasive and widely metastatic pancreatic ductal adenocarcinoma (PDA). We now propose experiments to establish whether physiologic levels of oncogenic *Kras* create a state of cellular dependence in vivo in faithful animal models of human PDA and rigorously demonstrate whether activated *Kras* represents a valid therapeutic target.



Christine Iacobuzio-Donahue, MD, PhD
Johns Hopkins

Using a genomic scale to identify the genes that play a role in the ability of pancreatic cancer to metastasize to other organs

We propose to use a novel technology called functional allelotyping to investigate those changes in gene expression that accompany the formation and spread (“metastasis”) of pancreatic cancer. Functional allelotyping is unique compared to other whole genome evaluation methods because it can detect abnormalities

of both DNA content and epigenetic control of gene expression in the same sample. Studies that focus on pancreatic cancer metastasis have the potential to greatly expand our understanding of the most lethal stage of this disease and identify novel areas for intervention.



Douglas Hanahan, PhD
University of California,
San Francisco

Assessing mechanisms and therapeutic potential of an aspartyle protease in pancreatic cancer

Our study is focused on the underlying mechanisms of pancreatic cancer which we believe can potentially have important implications for pancreatic cancer therapy. We are testing the hypothesis that Cathepsin E expression in neoplastic ductal epithelial cells of the pancreas serves to functionally promote carcinogenesis and is, therefore, an attractive therapeutic agent. We will test this hypothesis by crossing a Cathepsin E gene knockout mouse into the

pancreatic tumor model. We have also identified an FDA approved drug, Ritonavir, which inhibits Cathepsin E. Once we have identified a role for this enzyme in ductal carcinogenesis we will then evaluate the therapeutic potential of targeting this enzyme in improving disease prognosis. These tools will enable us to evaluate the effect of Cathepsin E loss on lifespan of tumor bearing mice and also the effects on the parameters of the tumor and its microenvironment.



Gloria Su, PhD
Columbia University
Medical Center

Activin signaling in the development of pancreatic cancer precursor lesions

Genetic engineered mice have been effective tools for cancer modeling and pathway studies. In our application, we propose to study activin signaling pathway in genetic engineered mice, because we have previously shown that activin signaling pathway is important for human pancreatic tumorigenesis and this tumor-suppressive pathway has not been investigated in vivo. Our preliminary data shows that the inactivation of activin pathway in combination with Kras oncogenic activation can lead to the development of mucinous cystic lesions in the pancreases of the mice. We

plan to utilize these mice to further our understanding of the tumorigenesis from non-invasive mucinous cystic precursor lesions to invasive cancer in human pancreases. By studying these genetic engineered mice, we hope to understand the predetermination of the three common precursor lesions, PanIN (pancreatic intraepithelial neoplasias), IPMN (intraductal papillary mucinous neoplasms), and MCN (mucinous cystic neoplasm), at the onset of pancreatic tumorigenesis.

The Summit on Pancreatic Cancer

The Pancreatic Cancer Action Network hosted the first Summit on Pancreatic Cancer August 2 – 5, 2007 in La Jolla, CA. The genesis of this meeting was to address the important questions for our community: Which approaches to studying the disease show the most promise in early detection or the development of therapeutics? Which are dead ends? Where are the gaps in understanding and how can we address them? And how can scientists at different institutions better coordinate their efforts to produce discoveries that have the greatest potential to benefit patients?

Finding answers to these questions is crucial if pancreatic cancer researchers are to achieve the kind of progress that has led to significant decreases in the morbidity and mortality rates of other forms of cancer. It is especially important at a time when advances in genetics, biotechnology, bioinformatics and other fields have transformed scientific understanding of cancer and laid the groundwork for more effective detection methods and treatments.

60 of the world’s leading pancreatic cancer investigators from the United States, the United Kingdom, Japan, and Spain, as well as other luminaries of the biological sciences assembled to tackle these challenging questions discussing, debating, and challenging one another. Presenters included (in order of presentation):

- Dr. Diane Simeone, University of Michigan – *Cancer Stem Cells*
- Dr. Steven Leach, Johns Hopkins – *Cell of Origin*
- Dr. Tony Hunter, Salk Institute – *Signaling*
- Dr. Neal Rosen, Memorial Sloan Kettering – *Mechanism Based Therapeutic Strategies*
- Dr. David Tuveson, Cancer Research Institute – *In Vivo Models*
- Dr. Dafna Bar-Sagi, NYU – *Ex Vivo Models*
- Dr. Thea Tlsty, UCSF – *Epigenetics*
- Dr. Michael Goggins, Hopkins – *Early Detection*
- Dr. Mariano Barbacid, NCIO – *KRAS Oncogenes and Pancreatitis, a Deadly Mix*
- Dr. Inder Verma, Salk Institution – *Oncogenesis and Inflammation*
- Dr. Ronald Evans, Salk Institute – *The Crossroads of Inflammation and Metabolism*
- Dr. Timothy Yeatman, Moffitt Cancer – *Exploiting Molecular Tools to Personalize Pancreatic Cancer Therapeutics*
- Dr. Ralph Hruban, Johns Hopkins – *Hunting for and Using Pancreatic Cancer Genes*

The outcomes of the conference will result in the publication of a White Paper (November 2007) to help guide the future of the research portfolio for PanCAN and to shape and inform the expanding research efforts of the National Cancer Institute. Our expectation at the outset was that given the caliber of the attendees and the energy and ideas being generated in advance of the meeting, 2 -3 “big ideas” would emerge outlining novel ways to approach early detection and/or therapeutics for pancreatic cancer. At the close of the meeting, we learned of 5 collaborations that were forming. Over the coming months, committee members and attendees will expand upon these ideas (bringing forward expertise that may be needed outside of the attendees) to develop innovative proposals.

In keeping with our mission to share information and expand ideas, we worked with Dr. Roger Bingham of The Science Network to capture this historic and important meeting sharing portions of with our community via webcast.

The meeting was convened by Dr. William Isacoff, Dr. Dafna Bar-Sagi, Dr. Geoff Wahl, Dr. Inder Verma, and Dr. Ron Evans.

Patient and Liaison Services (PALS)

PanCAN's Patient and Liaison Services (PALS) program offers information about treatments, clinical trials, symptoms and side effects, and support resources for patients and families. Call the PALS program at (877) 272-6226 or send a question by email to pals@pancan.org to learn more about the diagnosis of pancreatic cancer.

When you contact PALS, you will be connected one-on-one to a PALS Associate. Your PALS Associate has specific training in pancreatic cancer and can provide detailed information in a variety of areas – diagnosis, treatment, support resources, diet and nutrition, and symptom management. We encourage you to call PALS as many times as necessary to get the information you need throughout your diagnosis and treatment. Each time you contact PALS, you will be re-connected with your original PALS Associate for continuous case management.

The PALS program is now available in Spanish! Call PALS to speak with a PALS Associate in Spanish and to receive Spanish-language educational materials. The following booklets are available in Spanish: *An Overview of Pancreatic Cancer*, and *Diet and Nutrition: Nutritional Concerns with Pancreatic Cancer*.

¡El programa de PALS ahora esta disponible en español! Llame para hablarle a un socio de PALS en español y para recibir materia educativa en español. Los siguientes libros ahora están disponibles en español: *Información General del Cáncer de Páncreas y La Dieta y Nutrición: Preocupaciones Nutricionales Respecto al Cáncer de Páncreas*.

**Monday through Friday
8:00 am to 5:00 pm Pacific Time
Toll-free: (877) 272-6226
Email: pals@pancan.org**

Considering a Second Opinion

Each person's pancreatic cancer journey is unique; there is no predetermined path that a patient should follow. However, it is important to feel empowered and prepared to make informed decisions regarding treatment based on individual needs. Upon receiving a pancreatic cancer diagnosis, one of the first things to consider is getting a second opinion.

Why get a second opinion?

Just as it is normal to shop around for a house or car, it is acceptable for patients to seek multiple opinions to safeguard their health. A second opinion provides different perspectives and serves as a quality check. It is one way to confirm the pancreatic cancer diagnosis and to verify that all available treatment options have been offered and explained.

It is the patient's right to feel comfortable with the doctor who is responsible for his or her care. Doctors should not be insulted if their patients wish to seek second opinions. In fact, most doctors encourage it and can even offer names of other doctors to consult.

When to get a second opinion

There is no wrong time to seek a second opinion. Pancreatic cancer patients often find second opinions useful to confirm their diagnoses and decide on treatment plans.

To confirm the specific pancreatic cancer diagnosis, a second opinion from a gastroenterologist may be useful. A gastroenterologist is a medical doctor who specializes in the function and disorders of the digestive system, including the pancreas.

Once the diagnosis has been validated, a patient wants to find the best available treatment. Since doctors differ in their treatment styles, a second opinion can provide more complete information about both aggressive and conservative treatment options. Chemotherapy or other anti-cancer drugs may be prescribed and administered by a doctor who specializes in treating cancer, called a medical oncologist.

If surgery is an option, a pancreatic cancer patient should look closely at the surgeon's experience. Studies indicate that surgeons who perform large numbers of pancreatic surgeries have better outcomes.

How to find a doctor for a second opinion

It is important that a second opinion be obtained from a doctor who has experience treating people with pancreatic cancer. Oftentimes, these doctors are found at large cancer institutions. For pancreatic cancer patients who live in rural areas, travel may be necessary. While local hospitals can provide quality care, the physicians may not have as much experience in caring for people with pancreatic cancer. Large cancer centers employ more doctors who are familiar with pancreatic cancer and research involving the most current treatments.

In addition to asking the doctor to recommend someone for a second opinion, there are many resources to find pancreatic cancer specialists around the country:

- PanCAN's Patient and Liaison Services (PALS) program maintains a list of pancreatic cancer specialists around the country. While PALS Associates cannot recommend one doctor over another, they can provide callers with the names and contact information for doctors who see a large number of pancreatic cancer patients each year.
- Local hospitals often have patient referral services that provide lists of specialists at a specific hospital.
- The National Cancer Institute (NCI) provides information about doctors who practice at NCI-designated cancer centers. <http://www.cancer.gov/cancertopics/factsheet/NCI/cancer-centers>.
- The National Comprehensive Cancer Network (NCCN) allows users to search physicians and their specialties at their member institutions. http://www.nccn.org/physician_directory/SearchPers.asp.
- The American Medical Association (AMA) website offers a DoctorFinder option. <http://webapps.ama-assn.org/doctorfinder/home.html>.
- The American Society of Clinical Oncology (ASCO) allows the public to search for member doctors through its People Living with Cancer web site, www.plwc.org.
- The American College of Surgeons (ACS) provides a list of surgeons who are ACS members. http://web2.facs.org/acsdirect/default_public.cfm or (312) 202-5236
- The patient's insurance provider can provide names of cancer specialists who are covered in their network of doctors.

Considerations when seeking a second opinion

Some insurance plans require a second opinion. Others only pay for a second opinion if the patient requests it. A patient may seek a second opinion even if the appointment is not covered by health insurance if he/she can manage the cost.

If a patient is limited by travel, second opinion services exist that do not require an in-person meeting. Remote second opinion services may not be covered by the patient's insurance company. For more information on these services, contact a PALS Associate. See the sidebar on this page for contact information and hours.

Getting a second opinion is an important part of pancreatic cancer diagnosis and treatment. Valuable information is provided by speaking to multiple doctors before choosing a specialist to provide treatment. Patients who are confident in the doctors providing their care will feel more content with their health care experience.

Story of Hope and Inspiration

Jay E., Moraga, CA



Pancreatic cancer survivor and advocate, Jay E.

My pancreatic cancer was found purely by chance! My father died of an aortic aneurism in his seventies. The abdominal aorta is that portion of the aorta generally affected in that disorder. When I reached the age at which my dad died, I asked my internist whether I should be examined for a possible aortic aneurism. She agreed and arranged a CT scan for me. At the hospital, the capable young radiologist informed me that my aorta was fine, but that my pancreas looked "rather strange." I had no symptoms of pancreatic disease. A second CT scan confirmed the anomaly. I then gave the lady radiologist a large bouquet of roses! I was promptly referred for additional tests such as ultrasounds and biopsies.

Less than a week later, I was referred to an outstanding pancreatic surgeon. For 12.5 hours, she performed on me the full Whipple procedure for my Intraductal Papillary-Mucinous Neoplasm. After surgery, I was declared clear of malignant cells, and shortly thereafter, I was designated a survivor! It has been four years now, and I feel fine! Yes, there are complications of the Whipple, but I feel I have been blessed.

Also, I have been designated a survivor of squamous-cell carcinoma (about 24 years), and

prostate cancer (about 14 years). I believe that one must have the will to overcome the trials encountered in life. The day before I entered the hospital for Whipple surgery, I mailed two abstracts for talks to be given at professional societies during the spring months. Later, I gave those talks proudly! We must "put up the good fight," act promptly when the cancer is detected, and, of course, pursue means of early detection and treatments.

PanCAN offers fine supportive services towards such ends. They provided me with sound information. For example, they helped me find a first-class dietitian when I encountered serious digestive problems following the Whipple. More recently, PanCAN provided me once again with educational materials when my pancreatic enzyme production was insufficient. In turn, I have had the privilege of communicating with a number of individuals as a volunteer who speaks with others to provide hope and inspiration through the Survivor and Caregiver Network at PanCAN.

When young, I wrote the national plan for the new National Eye Institute, the NEI. I served twice on the National Advisory Eye Council. Separately, I helped start modern professional optometry in India (at Chennai, formerly Madras). This successful program and college have since been cloned, and today there are 7 added new colleges in India - all cooperating with ophthalmology. I served as Dean at Berkeley for 12 years, and upon the California Systemwide Health Sciences Committee. Thus, I have had fine opportunities to build educational and scientific programs and institutions!

In "retirement", I have dedicated myself to help others afflicted with pancreatic cancers.

We need orderly and quality growth of our scientific cohorts in order to provide early detection, prevention, and treatment of pancreatic cancers! Most critically, we must enhance our early detection of these diseases. And we must attract additional fine researchers and practitioners to our cause. These causes must be supported by distinguished centers for pancreatic research and teaching. Toward such ends, this year I served PanCAN as lobbyist, as a Survivor-Scientist at the AACR meeting, and I have encouraged young and enthusiastic students and their very fine teacher in a nascent pancreatic research program at Chapman University in Orange, CA. I have also personally donated to pancreatic research. To be more effective, I am continually seeking education about pancreatic cancers. And, above all, we must all work and plan together to achieve success.

10th Annual
An Evening With the Stars
Saturday
October 27, 2007
Make your reservations today!
(323) 904-4400 or go to:
www.pancan.org/ewts07

Caregiver's Corner: How to Help a Caregiver

The role of the caregiver is often a broad and challenging one. From taking care of a loved one's physical and emotional needs, to caring for daily matters, a caregiver may find that there is little time left in the day to take care of his or her own needs.

There are ways to help share in the process of caregiving that may remove some stressors in the caregiver's life. The following is a list of suggestions for assisting a caregiver:

Help a caregiver by offering concrete assistance. Examples of tasks you may want to offer are:

- Taking him/her to a dinner-and-movie night
- Preparing meals each week
- Helping to clean the house and do laundry

- Collecting pharmacy and grocery items
- Offering to research pancreatic cancer or other topics
- Offering your sincere desire to be his or her friend, to listen, stand by him/her, and understand how to participate in his/her life
- Helping with insurance or other paperwork
- Offering to take walks or join a yoga class with the caregiver

Some points that are NOT recommended for interacting with a caregiver are:

- Do not always talk about medically related issues. It may help the caregiver to talk or hear about other topics.
- Do not share your personal stories about people you know who have had cancer

and what they have done for it, unless the caregiver asks for that information.

- Do not hide or shy away from the caregiver. Let the caregiver know that you are there for him or her.
- Do not make light of the caregiver's worries and concerns. This is often done in a positive, loving attempt to reassure someone, but it can be perceived as insensitivity.

As caregivers are sometimes reluctant to reach out for support, it is important to reach out to them with your willingness to assist them. The above examples are a good place to start the process of outreach with the caregiver in your life.

For more information about helping a caregiver, please contact a Patient and Liaison Services (PALS) Associate toll-free at (877) 272-6226 or pals@pancan.org.

Pancreatic Cancer Symposium
An Event to Educate and Create Awareness
LOS ANGELES

Friday, October 26, 2007

Beverly Hilton Hotel
Beverly Hills, California

Symposium details and registration will
be available at www.pancan.org.

Just added

Sunny Days Ahead

A Network of Supportive Relationships

Meet with others who have lost their
spouses to cancer.

Saturday, October 27, 2007
9am - Noon

Beverly Hilton Hotel – Room TBA



National Headquarters:
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information, please cut and paste your address label from below and return it to:

Mailing List, PanCAN, 2141 Rosecrans Avenue, Suite 7000, El Segundo, CA, 90245.
We appreciate your help!

Calendar

Event Start Date	Event Name	City	State	Contact
10/7/07	TeamHOPE Walk - Maryland 2007	Bel Air	Maryland	Ken Cunzeman, kcunzeman@pancan.org
10/10/07	8th Annual Hank Granberry Charity Classic	Grapevine	Texas	Sarah Kewak, sarah.kewak@gsginet.com
10/13/07	3rd Annual Dave Thiele Memorial Golf Tournament	Scottsdale	Arizona	Christine Thiele, cthiele@msn.com
10/13/07	5th Annual Trail Walk/Run for Pancreatic Cancer	Morristown	Tennessee	Leslie Frantom, lfrantom@pancan.org
10/14/07	Toronto Marathon	Toronto	Canada	Elizabeth Carroll, ecarroll@pancan.org
10/14/07	TeamHOPE New Jersey - Picnic for PanCAN	Clark	New Jersey	Anne Travisano, atravisano@pancan.org
10/19/07	2nd Annual Wood D. Sink Memorial Open	Raleigh	North Carolina	Carol Birney, cbirney@pancan.org
10/20/07	Passion in Purple, Legacy of Life	Boca Raton	Florida	Allan Boshell, allan@fitdr.com
10/20/07	TeamHOPE 3rd Annual Stride for Hope	Wichita	Kansas	Michelle McWhorter, mmcwhorter@pancan.org
10/25/07	Light up the Night with Hope	St. Louis	Missouri	Susan Dertke Hendin, sdhendin@pancan.org
10/26/07	Pancreatic Cancer Symposium - Los Angeles	Beverly Hills	California	Mayra De Anda, mdeanda@pancan.org
10/27/07	An Evening with the Stars gala	Beverly Hills	California	Jill Gisselere, jgisselere@pancan.org
10/27/07	TeamHOPE Walk - Cape Cod 2007	South Yarmouth	Massachusetts	Nancy Harrison, pancanevents@comcast.net
10/27/07	6th Annual Ol' Country's Boot Scootin for PanCAN	Fort Worth	Texas	Virginia Griffin, vgriffin@pancan.org
10/27/07	1st Annual 5K Walk/Run for Pancreatic Cancer	Orlando	Florida	Diane Germ, dgermabc@aol.com
11/3/07	TeamHOPE Walk - Philadelphia 2007	Newtown	Pennsylvania	Christina Tabarrini, ctabarrini@pancan.org
11/4/07	Cups of Hope Tea Celebration	San Diego	California	Geneveve Bucsit, geneveve@cox.net
11/5/07	Baking for PanCAN	Terre Haute	Indiana	Kathy Cooper, kathy.cooper@rose-hulman.edu
11/8/07	TeamHOPE Tampa- Auction for Action	Tampa	Florida	Brad Jackson, bradwjackson@yahoo.com
11/10/07	Pancakes for PanCAN	Fort Wayne	Indiana	Sondra Skaggs, sondra.skaggs@verizon.net
11/10/07	Pancreatic Cancer Symposium - Houston	Houston	Texas	Mayra De Anda, mdeanda@pancan.org
11/11/07	TeamHOPE Atlanta Walk 2007	Atlanta	Georgia	Brittany Black, bblack@pancan.org
11/17/07	All In For A Cure Charity Poker Tournament	Altamonte Springs	Florida	Neil Belliveau, neil@tolmultimedia.com
11/18/07	PanCAN's Stride for a Cure Indoor Mall Walk	Albany	New York	Linda Eisenberg, leisenberg@pancan.org
12/1/07	TeamHOPE Walk 2007- In Memory of Wayne Remy	Lake Charles	Louisiana	Kristi Remy, wkremy@bellsouth.net
1/27/08	ING Miami Marathon and Half Marathon	Miami	Florida	Jaimi Nanko, jnanko@pancan.org