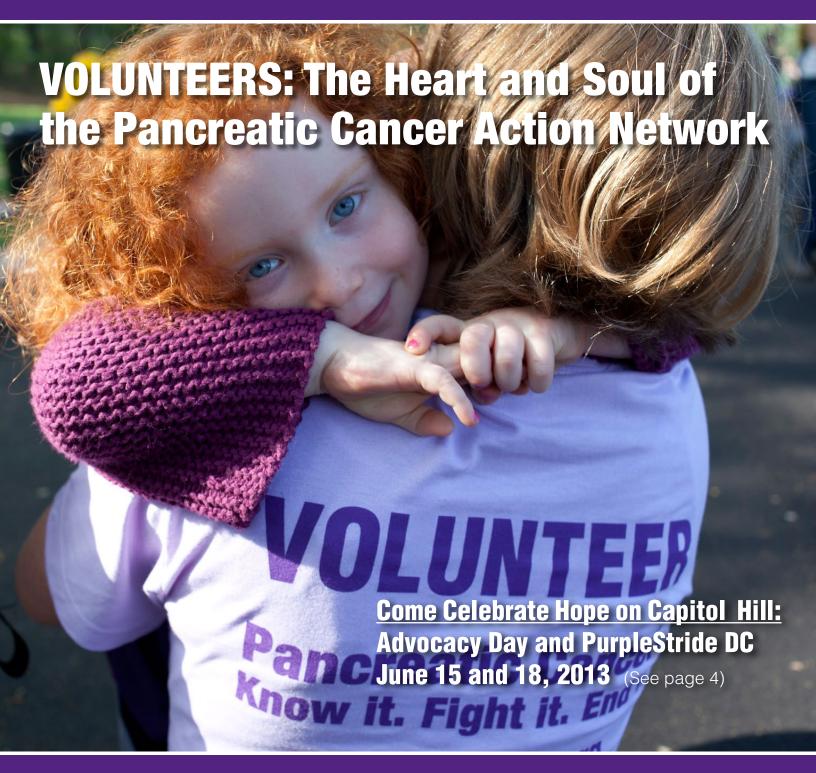


# OUTREACH

**VOL XIII ISSUE I SPRING 2013** 



### **CHAIR'S MESSAGE**

### **VOLUNTEERS CONTINUE TO DRIVE PROGRESS**



Since the Pancreatic Cancer Action Network was formed in 1999, we have led the way in transforming the pancreatic cancer community by heightening awareness of the disease nationwide, funding groundbreaking research, generating momentum within the pancreatic cancer scientific community, and developing comprehensive support services for all those affected by it.

Many of these accomplishments have been due to the innumerable contributions of our legions of volunteers, who we are proud to recognize during April, which is National Volunteer Appreciation Month. Throughout this issue of *Outreach*, we highlight how volunteers across the country are contributing to the fulfillment of our mission. We continue to be awed by the commitment of our volunteers and we are humbly grateful for everything they do.

If you are one of our thousands of volunteers, you are already aware of the unique rewards that come with volunteer service. The sense of camaraderie felt in joining others in supporting a common cause, opportunities to develop new skills, and the empowerment that comes from participating in a movement that is changing the course of history for a leading cancer killer all bring tremendous satisfaction. In coming weeks, we hope you will share your enthusiasm about the Pancreatic Cancer Action Network with your friends and family members and encourage them to visit <a href="mailto:pancan.org/volunteer">pancan.org/volunteer</a> to see all the volunteer opportunities available in their communities.

Volunteering is about the power of you. **You** can make an impact. Whether you have just a few minutes of time or are interested in a more extensive commitment, many options are available to volunteer to fight pancreatic cancer locally and nationally. <u>Opportunities</u> are available in nearly 90 communities nationwide. You can even support the cause from the comfort of your own home.

If you already serve as one of our dedicated and passionate volunteers, we remain deeply grateful for all that you do to enable us to fulfill our far-reaching mission. If you are considering a volunteer opportunity with us, we look forward to welcoming you into our family.

Sincerely,

Peter Kovler Board Chair

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### A "WARRIOR" GRANTEE USES A TROJAN HORSE TO FIGHT PANCREATIC CANCER



David A. Boothman, PhD

David A. Boothman, PhD, was delighted when he found out that he had been selected to receive a 2012 Pancreatic Cancer Action Network Innovative Grant, generously funded by the George & June Block Family Foundation. His application described an exciting and novel budding project under way in his laboratory.

Rather than attacking pancreatic cancer cells using a conventional chemotherapeutic drug or even a targeted drug aimed at blocking a particular protein signaling pathway, Dr. Boothman plans on taking more of a "Trojan horse" approach. His strategy is to exploit a particular enzyme, or active protein, that is selectively elevated within pancreatic cancer cells and trick that enzyme into sneaking an innocent-looking chemical compound into the cells.

While trying to get rid of the compound, the enzyme ends up making a toxic substance that effectively sterilizes the cancer cells. Part of the beauty of this approach is that normal cells elsewhere in the body, which express much lower levels of this particular enzyme, are spared and escape being killed by the compound.

When Dr. Boothman learned that a committee of pancreatic cancer specialists had chosen his project for funding, he was eager to embark on this scientific journey. However, he did not anticipate the personal and professional relationships that would be built after he received his grant. A Professor of Pharmacology at the University of Texas Southwestern Medical Center, Dr. Boothman was contacted by the Dallas-Fort Worth volunteer affiliate of the Pancreatic Cancer Action Network and invited to speak at a meeting shortly after his funded period began.

Dr. Boothman decided to take the experience one step further, and offered to give the volunteers a tour of his laboratory, in which all members of his lab participated. Moreover, he insisted on providing refreshments for all attendees, and was very accommodating and flexible even when he learned that the group would include nearly 40 people, many more than anticipated.

"What struck me the most about our evening with Dr. Boothman and his group was their enthusiasm for the work they are doing," Pancreatic Cancer Action Network volunteer and Dallas resident Virginia Holleman said. "It was very empowering for me to be there – and Dr. Boothman assured me it was just as empowering for all of his associates. It was really great to see that many people excited about doing research on pancreatic cancer and possible drugs." Dr. Boothman shared that his laboratory members were all energized after meeting the volunteers, and eager to know when they would get to interact again.



Dr. Boothman (center), with Pancreatic Cancer Action Network volunteers Jeffrey Ross and Brian Livingston, also participated in Advocacy Day 2012.

The Pancreatic Cancer Action Network's Innovative Grant is designed to attract experts from other fields to the study of pancreatic cancer, and our entire grants program strives to build and strengthen a close-knit community of researchers. Dr. Boothman truly epitomizes both of these goals by bringing a novel approach to combating pancreatic cancer and quickly becoming a great friend and advocate for the organization as well as the scientific and lay communities.

To learn more about Dr. Boothman and other research grant recipients' work, please go to <a href="https://www.pancan.org/grantsawarded">www.pancan.org/grantsawarded</a>.

Information about our 2013 grant recipients will be available in April.

Spring 2013 OUTREACH



### **MEET A GRANTEE**

### COSIMO COMMISSO, PHD: A YOUNG RESEARCHER WITH NOVEL IDEAS ABOUT UNDERSTANDING AND COMBATING PANCREATIC CANCER



Cosimo Commisso, PhD

In 2011, Cosimo Commisso, PhD, was awarded a Fellowship grant from the Pancreatic Cancer Action Network, generously funded by Cynthia Stroum in memory of her father, Samuel Stroum. From 2008 to the present, Dr. Commisso has been a postdoctoral fellow at New York University, working in the laboratory of Dafna Bar-

Sagi, PhD. Dr. Bar-Sagi is a current member and former chair of the Pancreatic Cancer Action Network's Scientific Advisory Board and a recipient of a 2008 Pilot Grant from the organization. Dr. Commisso graduated with high distinction from the University of Toronto and stayed there to pursue a PhD in the Department of Molecular Genetics.

Dr. Commisso's background in molecular genetics made him particularly interested in the changes that differentiate a cancer cell from a normal cell. He focused his proposal for the Fellowship grant on investigating K-Ras since this gene is known to be mutated in virtually all pancreatic tumors. The resulting mutated protein is thought to directly stimulate the growth and progression of the tumor through its action on the cell cycle machinery. However, Dr. Commisso hypothesized a novel mechanism by which mutant K-Ras may also exert its effects on the cell, via a process called macropinocytosis.

Macropinocytosis allows cells to bring in large volumes of fluid from outside the cell, and often, proteins are included. The proteins brought in from outside the cell provide nutrients and energy for the cell to continue its unregulated growth, promoting tumor progression. Dr. Commisso and his colleagues are now exploring whether this process can be reversed as a method to starve pancreatic cancer cells and stop them from growing. Moreover, one of the proteins that Dr. Commisso has shown enters the cell via macropinocytosis is albumin. Recent clinical trial results show that ABRAXANE, a chemotherapy drug that has been modified to be attached

to albumin, is effective in the treatment of pancreatic cancer. Scientists believe that macropinocytosis driven by mutant K-Ras could be responsible for facilitating entry of the drug into the cancer cells; further testing will examine that hypothesis.

Dr. Commisso commented that the research funding from the Pancreatic Cancer Action Network allowed him to "test novel ideas that would otherwise have been financially impossible." He also believes that this grant has "elevated the impact of [his] work, which will hopefully help [his] career in the long term."

Encouragingly, at the first American Association for Cancer Research (AACR) special conference focused on pancreatic cancer last June, Dr. Commisso was selected among hundreds of researchers to deliver an oral presentation of his

work. Moreover, he has recently submitted manuscript publication to one of the field's most prestigious scientific and journals, has received positive feedback. These milestones are critical an early-career researcher to achieve



Dr. Commisso addresses a gathering of scientists at an AACR meeting in 2012 (photo ©2012 AACR/Todd Buchanan).

professional advancement in a very competitive environment.

In addition to receiving research funding and important career development opportunities from the Pancreatic Cancer Action Network, Dr. Commisso has also interacted with organizational volunteers and community members on several occasions. In September 2012, he attended the Pancreatic Cancer Action Network's New York City PurpleLight Vigil, where he delivered a motivating speech to the hundreds in attendance.

We are excited to watch Dr. Commisso's progress in the coming years as he continues his research endeavors and contributes to knowing, fighting, and ending pancreatic cancer.



"Each year I am honored to pay tribute to my father by funding the annual Fellowship Award in his name. It brings me comfort to know how meaningful this award would have been to him, as it is to each new young investigator who receives it. Through this grant, my father's entrepreneurial spirit lives on and continues to create hope."

— Cynthia Stroum, Founding Chair Emeritus, Pancreatic Cancer Action Network Board of Directors

### FOLLOWING FIVE YEARS OF EFFORT, RECALCITRANT CANCER RESEARCH ACT SIGNED INTO LAW



On January 2, 2013, President Obama signed the *National Defense Authorization Act* into law, which included landmark legislation that will help advance pancreatic cancer research.

The <u>Recalcitrant Cancer Research Act</u> is the first-ever law dedicated to placing a greater focus on deadly cancers such as pancreatic cancer, and represents a historic milestone in the fight against the disease. Specifically, the bill requires the National Cancer Institute to create a long-term plan, or scientific framework, for pancreatic and other deadly cancers that includes evaluating its current efforts in studying the

disease and making recommendations on ways to accelerate progress and improve outcomes.

This is no small achievement considering the political environment in the 112th Congress a Congress that passed fewer bills than any other since the 1940s. In fact, of the nearly 10,500 bills introduced in both the House and the Senate (not including post office namings and resolutions) during the last Congress, only 193 became law (less than 2%).

So how did this particular

bill make it over the finish line? Mostly, because of YOU. Hundreds of supporters across the country became involved by creating awareness and asking Congress to pass the bill. In the five years since the bill was first introduced, you sent nearly 76,000 emails to Congress, attended over 1,300 meetings on Capitol Hill during Advocacy Days, and placed over 14,000 calls to Congress during the National Call-Ins. All of these efforts led to securing over two-thirds of the House and three-fifths of the Senate as co-sponsors of the bill in 2011-2012 – a remarkable feat on its own.

We have previously highlighted in this newsletter stories of advocates taking action to gain the support of members of Congress. Those stories and hundreds of others were what created the momentum needed and the impetus for Congress to act.

Whether you met with your members of Congress on Pancreatic Cancer Advocacy Day, sent an email through our Advocacy Action Center, called your representatives during the National Call-In, posted about pancreatic cancer on Facebook or Twitter, attended a Town Hall or district meeting, or wrote a letter to the editor of your local newspaper – YOU are the reason we succeeded. **Thank you!** 

### **BILL IMPLEMENTATION STEPS**

STEP 1	The National Cancer Institute (NCI) will convene two working groups to develop the scientific frameworks for pancreatic and lung cancers.
STEP 2	By July 2014, the NCI will complete the scientific frameworks for lung and pancreatic cancer (that contain information on the current status of research, identification of research questions, and recommendations for next steps).
STEP 3	Within 30 days of framework completion, the NCI must present the frameworks to Congress and post them on the Department of Health & Human Services' website.
STEP 4	The National Institutes of Health (NIH) must include in its biennial report to Congress the steps taken to implement the frameworks.
STEP 5	By 2019, the NCI must update the scientific frameworks to reflect current science.
STEP 6	By 2020, the NCI must submit a report to Congress on the effectiveness of the frameworks in improving the prevention, detection, diagnosis and treatment of lung and pancreatic cancer.

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### CELEBRATE HOPE ON CAPITOL HILL DURING COMBINED PURPLESTRIDE DC AND ADVOCACY DAY 2013



Advocacy Day 2012

The seventh annual Pancreatic Cancer Advocacy Day promises to be one of our best yet! We will celebrate passage of historic pancreatic cancer legislation, but more importantly, educate Congress about what they can do to ensure the bill is implemented quickly and show them that we are passionate about protecting critical cancer research funding. We have learned that when we educate members

of Congress about our issues, they listen and act.

Advocacy Day is the largest single gathering of people representing the full spectrum of those committed to fighting pancreatic cancer – patients, survivors, caregivers, family members, grassroots volunteers, researchers and healthcare professionals. Hundreds of participants come from all 50 states to learn about the disease, gain support, and meet with their elected officials. The event is empowering and vital to the success of pancreatic cancer researchers everywhere working to help find a cure. Comprehensive training is provided, so no previous experience is necessary.

This year, the event will be held on **June 17 and 18**, just two days after PurpleStride Washington, D.C. (June 15). Consider coming for the weekend and attending both events! To register or for more information, visit <a href="https://www.pancan.org/AD2013">www.pancan.org/AD2013</a>. Advocacy Day registration closes on **May 3**, or whenever capacity is reached, so reserve your spot today!

### **ADVOCACY IN 2013**

Now that the *Recalcitrant Cancer Research*Act has been signed into law, we will be monitoring its implementation closely and educating members of Congress about the new law and how implementation is going. It is also critical that we focus attention on preserving and protecting federal funding for the National Institutes of Health and the National Cancer Institute so that these federal agencies have the funds they need to create the scientific frameworks called for in the new law.

Federal funding for medical and cancer research has never been more at risk, so it is crucial that we remain engaged in this fight. To join this effort, please visit <a href="https://www.pancan.org/Advocate">www.pancan.org/Advocate</a>.

## **ADVOCACY DAY**June 17 and 18, 2013



Know it. Fight it. End it.

4 Spring 2013 OUTREACH

### **HELPING A CAREGIVER**

Serving as the caregiver of an ill person can be extremely rewarding. Many partners, family members or friends who have helped with caregiving find it very satisfying and would not have chosen any other option.



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

have little time left in the day to take care of his or her own needs. Therefore, caregivers may deal with feelings of stress, fatigue and frustration.

Because caregivers face significant responsibilities that are both physically and emotionally demanding, they often need support. As a friend of a caregiver, you may sometimes feel helpless. However, there are many ways to help with the process of caregiving that may alleviate some of the stressors in the caregiver's life. Help a caregiver by offering concrete assistance. Examples of tasks you may want to offer are:

- Offering to spend time with the patient so the caregiver can spend some time alone to take care of her/himself.
- Preparing meals for the caregiver's family.
- Picking up his/her kids from school or taking them to practices.
- Picking up prescriptions or driving the patient to doctor's appointments.
- Planning a fun activity for the caregiver make dinner plans with a close group of friends or go to a funny movie.
- Offering to take a long walk or join a yoga class with the caregiver.

The caregiver may take time to open up and share his or her

specific needs, so it is important to listen carefully and try to pick up on subtle or indirect ways that the caregiver may be asking for help. Caregivers are sometimes reluctant to reach out for support. You can remind your friend that he or she does not have to do it alone. Show them that you are willing to help.

It is equally important to recognize things you should avoid saying or doing while interacting with a caregiver:

- Do not always talk about medical-related issues. The caregiver will appreciate hearing about other things.
- Do not share your own personal stories of people you know who have had cancer and what they did for their cancer unless your friend asks for that information.
- Do not hide or shy away from the caregiver. Even though
  it is difficult to find the right words to say, just let him or
  her know that you are there to listen without judging.
- 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 received as being insensitive.
- Do not think that it is important that you have the right things to say. Communicating care, concern and love is one of the greatest gifts.
- Do not give directions about how the caregiver should express emotion.
- Finally, do not assume that little things do not matter.
   You may not receive immediate recognition for your assistance but the caregiver is appreciative of even the smallest efforts.

To find additional support resources for caregivers, contact the Patient and Liaison Services (PALS) program. Our PALS Associates can provide you with information about in-person, online and telephone support groups. You may also view our caregiver video.

### UPCOMING EDUCATIONAL OPPORTUNITIES

Learn about pancreatic cancer from experts in the field by registering for or attending one of our upcoming <u>educational programs</u>. NUTRITION MANAGEMENT FOR PANCREATIC CANCER WEBINAR
April 17 at 7pmET/4pm PT

PANCREATIC CANCER SYMPOSIUM San Francisco Bay Area, CA, May 10

UNDERSTANDING PANCREATIC CANCER SEMINARS
Baltimore, MD, March 21
Seattle, WA, June 7

### SHOULD YOU PARTICIPATE IN A PANCREATIC CANCER FAMILY REGISTRY?



not have any risk factors.

The exact causes of pancreatic cancer are not yet well understood. However, certain risk factors may increase the likelihood that an individual will develop the disease.

Research studies have identified the following as possible risk factors associated with pancreatic cancer: smoking, age

(individuals over 60), chronic or hereditary pancreatitis, ethnicity, long-standing diabetes, a diet high in red and processed meats, obesity and family history of the disease. Having one or more risk factors, however, does not mean an individual will develop pancreatic cancer. Some individuals who develop pancreatic cancer do

While only about 10 percent pancreatic cancers are considered familial. hereditary (inherited) factors are an important consideration for some families. An increasing amount of research is focused on the causes of and early detection for pancreatic cancer. In order to advance this knowledge, family, or genetic, registries have been established in hopes of finding common traits in families with multiple cases of pancreatic cancer.

Family registries are collections of data that can allow researchers to potentially identify other risk factors and/or genetic conditions associated pancreatic cancer. Family registries examine environmental factors, habits and/or history of pancreatic cancer along with the incidence of other cancers in the family. Researchers hope that discoveries among families with an increased incidence of pancreatic cancer will lead to improved understanding of this disease and to the development of better screening and early detection methods in the future.

Both patients and their family members may participate in most registries. Generally, participants are only required to fill out a questionnaire and provide medical records. However, in addition to the questionnaire, some registries may ask participants to provide blood or tissue samples for further genetic analysis.

Several institutions throughout the country currently keep active family registries. Requirements for participation vary among registries. Please contact a Patient and Liaison Services (PALS) Associate at 877-272-6226 or pals@pancan.org to obtain a list of current family registries, along with their contact information and criteria for participation. PALS Associates are available Monday-Friday 7 a.m. – 5 p.m. Pacific Time.

### FOUR NEW MEMBERS WELCOMED TO PANCREATIC CANCER ACTION NETWORK MEDICAL ADVISORY BOARD

The Pancreatic Cancer Action Network has named four new members to its Medical Advisory Board (MAB). The newest advisors are leading clinicians in the field of pancreatic cancer: Joseph M. Herman, MD, MSc, Johns Hopkins University; George A. Fisher Jr., MD, PhD, Stanford University; James Farrell, MD, Yale University; and Philip Agop Philip, MD, PhD, Karmanos Cancer Center.

The MAB includes clinicians who specialize in the care of people with pancreatic cancer. This board advises the organization on specific medical and clinical aspects of pancreatic cancer as it relates to our programs.

"I am pleased to welcome these distinguished leaders to our Medical Advisory Board. They bring a great wealth of expertise to the organization and their active participation will further strengthen our programs to support pancreatic cancer patients," said Julie Fleshman, President and CEO of the Pancreatic Cancer Action Network. "The role of the Medical Advisory Board is essential as the Pancreatic Cancer Action Network works to double the survival rate for pancreatic cancer patients by 2020.

"I also wish to acknowledge Dr. Mary Mulcahy of Northwestern University for her years of service and dedication. She recently became an emeritus Medical Advisory Board member," Fleshman added.

To see a full listing of our MAB membership, please turn to the inside cover page of this issue.









From left, Joseph M. Herman, MD, MSc; George A. Fisher Jr., MD, PhD; James Farrell, MD; Philip Agop Philip, MD, PhD

### A STORY OF HOPE AND INSPIRATION

By Merle W. Griffin, Clarkston, GA



Merle Griffin

On January 29, 2013, I celebrated 11 years of surviving pancreatic adenocarcinoma!

At the time of diagnosis, my symptoms were vague – lack of appetite, gas, bloating, a little stomach discomfort and I did not feel well in general. I saw my internist and had laboratory work done. Tests showed that my liver enzymes were abnormal. I saw my gastroenterologist two days later.

He performed an ERCP

and noted that the pancreatic and bile ducts were restricted. On January 21, 2002, a CT scan showed an undefined mass on the head of the pancreas. The gastroenterologist discussed the report and sent me to see the surgeon that he had already conferred with about my situation.

Then, on January 29th, I underwent an eight-hour Whipple procedure. I stayed in the ICU for eight days and on a surgical floor for nine more. My identical twin stayed with me during my recovery. She and I are retired registered nurses. I was discharged on my 44th wedding anniversary with a feeding tube and four drainage tubes in place, and extra nutrition was administered through a port. I gradually began to eat small amounts of food. This approach, combined with the tube and port feeding, helped me to not lose weight as many other cancer patients do.

In March of that year, I began chemotherapy which lasted for six weeks. Then in May I started chemoradiation planned for another six weeks. However, after three weeks of chemotherapy and 17 days of radiation, I was hospitalized for side effects. One night I decided that I would not continue the chemoradiation; it was just too much. The next morning, my oncologist said, "We (she and my gastroenterologist) have decided to discontinue the chemotherapy and radiation." I said, "Good because I made that same decision last night." After a long break, I was given six more infusions of chemotherapy.

I had a wonderful, caring support group including doctors, nurses, my husband, our daughter, my two sisters and friends.

I have joined the fight against pancreatic cancer by volunteering my time to help raise awareness and give support. Here in Atlanta, we have had seven 5K walks, now called PurpleStride Atlanta. My husband, our daughter and I have participated in all seven.

I have also communicated with several ladies who contacted me through the Pancreatic Cancer Action Network's Survivor and Caregiver Network. Most contacts are by telephone, notes and cards, but I did get to meet one lady and the son and daughter of another. The bonds we formed will be lasting. My husband and I also attend a pancreatic cancer support group meeting the first Thursday of each month to encourage those just diagnosed and in treatment.

Through the Pancreatic Cancer Action Network's Atlanta Affiliate, my husband and I attended Pancreatic Cancer Advocacy Day in Washington, D.C. in June 2012, where we met with our Senators and Representatives to encourage them to support research and education for pancreatic cancer. Legislation was recently signed into law for all recalcitrant cancers.

Most recently, in September 2012 we held our first PurpleLight Atlanta and I was asked to speak. I have also spoken at a local church support group for all cancers. By word of mouth, individuals will call to discuss my journey through this disease, treatment and recovery. Many prayers were said during my experience. I hope and pray that many more with this dreadful disease will survive, as I have been blessed.



The PANCHEATIG CANCER ACTION NETWORK is your source for information, resources and hope. Call our free Patient and Liaison Services (PALS) to be connected with one-on-one support that can help you make informed decisions.

CALL TOLL-FREE 877-272-6226



FIND HOPE HERE

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# PEOPLE plus

PASSION

The Power of

YOU

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It takes a very special person to agree to carry a child for another couple and requires an emotional as well as physical commitment. For Courtneylee Martinez, the experience also turned into an amazing journey.

Ever since she was young, Courtneylee felt a nurturing instinct. Knowing that some women could not bear children, she signed up to become a surrogate. She was matched with Kate Mazzola and her husband, Nain Gonzalez, to help them realize their dream of parenthood. In May 2011,

### A COMPASSIONATE OFFER TURNS INTO SO MUCH MORE

doctors transferred two embryos to Courtneylee. Like any expectant parents, Kate and Nain were thrilled and followed the pregnancy closely. It was a time of joy and hope that was sadly short-lived. Their worlds were turned upside down on June 30, 2011, when Nain was diagnosed with pancreatic cancer. He

fought strongly against the disease but passed away just six weeks before his daughter, Amara, was born.

Kate and Courtneylee grew closer through their shared joy at Amara's birth and their grief over Nain's death. One day, they saw a poster for PurpleStride Boston and decided to form a team to honor Nain. To say it was a memorable day would be an understatement. In honoring Nain's legacy, they found comfort and strength.

But Courtneylee did not stop there. "Once I started attending events for the Pancreatic Cancer Action Network, I knew this was the one cause I wanted to commit to," she said. She decided to dedicate her volunteer time to the organization and found her place with the Rhode Island Affiliate as the Education and Outreach Coordinator. She is now passionate about spreading awareness of the disease and recruiting others to become involved in the fight. "It's important for me to volunteer for this cause because it is a huge part of Kate and Amara's life," she explained. "I tend to be shy, but not about this cause. I am ready to bring it!"

Courtneylee and Kate remain close friends and are committed to putting an end to the disease that took Amara's father.



# PASSIO

**JULIE DETHERAGE** Indianapolis Affiliate Coordinator

**GWYNNE LUNDY** 

Nashville Affiliate Coordinator

"Our sister Gail had enormous zest for life. She did more in 50 years than most people do in a lifetime, from climbing mountains in Nepal to living her dreams every day. She was never one to ask, 'Can I?' Gail's question was always, 'How can I?' When she was only 20 years old, she moved from a small town in southern Indiana to New York City where she began living her dream in the fashion industry. She later owned her own clothing store, but that was not enough. She also earned her undergraduate degree and an MBA from Indiana University. She worked for one of the world's largest advertising agencies, and worked in Denmark for three years even though she never spoke Danish! Her only roadblock in life was when she was diagnosed with pancreatic cancer, but even then she didn't give up. Gail fought until the bitter end, always hoping that she

could live long enough for the next drug to be developed. We both know that Gail would have asked how she could do more for the fight. That is why we are Affiliate Coordinators. Our biggest accomplishments have been developing teams of volunteers and holding PurpleStrides in Nashville and Indianapolis. It is with her attitude in our hearts that we continue the fight in her honor and her memory."



# PASSIONATE STRIDERS

### you just have to **START**

**MARY JO MAHOWALD** 

PurpleRide Twin Cities participant & Twin Cities Advocacy Coordinator

"I lost my paternal grandparents and three aunts to pancreatic cancer, and then in 2002 the disease claimed my 52-year-old sister. It took me a little while to get involved; everyone has to go at their own pace. I attended my first PurpleRide Twin Cities in 2010.

"There is something very powerful about being in a place where everyone knows what you are feeling because they've been through it as well. PurpleRide was so well-run, I decided to get more involved in the organization. The fundraising part of PurpleRide is always exciting and rewarding to me. Most of my career was spent in dental sales where I learned that sales is just a numbers game: the more people you talk to, the greater support you find. It's amazing how many people have a connection. A woman I barely knew donated \$200! I always explain my personal connection, thank them immediately and personally via email for their donation, thank them again and tell them about PurpleRide, and keep them updated on any news about the disease throughout the year. I sent everyone news of the bill passing (the Recalcitrant Cancer Research Act) and I had people calling me crying because they were so touched and thrilled.

"They all know I am the Advocacy Coordinator for the Twin Cities Affiliate of Minnesota, so they appreciate knowing what is happening! It gives them a personal connection not only to me, but to the disease and what their donation can do. It's easy to ask people and typically easy for them to give. You just have to start; as a salesperson, I didn't sit in my car and wonder if the dentist would be too busy to see me, I just went right in. It's the same thing with fundraising; just ask and you will be amazed at the responses! I also believe that the organization is unique in that it really is a family. All of the affiliates are run by volunteers, all passionate about the cause, all knowing that whatever they do, they do out of love. With that behind you, you do begin to feel like anything is possible."

### **MATCHING UP WITH A**

### **COMPANY'S PASSION**

PurpleStrides across the country benefit from the contributions and sponsorships of many companies. Mattress Firm and its employees have taken their support to the next level. Mattress Firm's core values include trust, passion and growth, and its employees are directing their passion to the fight against pancreatic cancer. Several hundred employees from across the country turned out to participate in their local PurpleStrides. Jody Putnam, Regional Sales Director, joined PurpleStride DFW 2012 and had this to say about the experience: "We are excited to align with the Pancreatic Cancer Action Network in the fight against pancreatic cancer. PurpleStrides allow our associates to not only get involved on a local level, but ultimately help people across the country. Hundreds of our Dallas associates, specifically Whitney Ray, made it their personal mission to raise awareness and funds for the cause. I was overjoyed to see the team bring their passion and enthusiasm to this amazing event."

But the engagement doesn't stop there. Several hundred employees participated in the National Call-In as part of Advocacy Day last June. Stores have become event sponsors, and there's now a contingency of super-passionate employees who are rolling up their sleeves to volunteer for our

organization.

To date, Mattress Firm stores and about 400 of its volunteering employees have donated and/or fundraised more than \$30,000 for the cause. We are incredibly grateful for their contributions! To learn more about Mattress Firm and an opportunity for our supporters, click here.





### no personal connection, JUST DETERMINATION

"I don't have a personal connection to pancreatic cancer. I first became involved with the Pancreatic Cancer Action Network because I used to work for a company that sponsored a PurpleStride event. In 2011, I volunteered as a photographer for PurpleStride and was so drawn to the event and cause that I looked into how I could get more involved. I enjoy working with and helping people. It is a bonus that everyone I work with is so passionate. One of the highlights of this past year's event was when the DJ played the "electric slide" song and tons of people and families started dancing, smiling, clapping, laughing and just enjoying the moment. I had a family tell me that was their mother's favorite song (she recently passed from pancreatic cancer) and they were so happy to hear it. That will forever be a favorite memory for me because for a moment it seemed that everyone was celebrating the memories of their loved ones." - Shanté Nosir, Event Coordinator in Atlanta

### PASSIONATE CHAMPIONS



# PROFILE LEE RINGUETTE

Not many people can claim to have worn out a treadmill by walking, but Lee Ringuette can. Diagnosed with pancreatic cancer in 2000,

Lee, a 66-year-old sound engineer who lives in Los Angeles, underwent chemotherapy to shrink his tumor and then had a successful Whipple procedure. During his 36-day hospital stay, he started walking as part of his recovery – and hasn't stopped since! The support that Lee and his wife, Barbara, have given to the Pancreatic Cancer Action Network has been equally steadfast since they learned of the organization in 2005. Lee wishes the Patient and Liaison Services (PALS) program existed when he was first diagnosed.

"It would have been fabulous to travel this journey with PALS alongside of us every step of the way," he said. "To be able to connect with other patients and take advantage of the wonderful information and resources available through the program would have made this difficult road much easier to travel." Passionate about the organization's mission, the Ringuettes are also proud to have named the Pancreatic Cancer Action Network as a beneficiary in their will. "Most people just don't think about planned giving to help their favorite charities, so hopefully we can encourage others to do the same," Lee added.

### HELPING OTHERS CONNECT TO THE MISSION

Richard and Melanie Lundquist, owners of Continental Development Corporation, based in the Los Angeles area, are passionate about lending their support to fight pancreatic cancer. Thankfully, their family has not been personally touched by the disease, but they are deeply committed to changing the course for this illness. They have made significant individual and corporate financial investments in the Pancreatic Cancer Action Network and encouraged



Continental Development Corporation employees to get involved. Their contributions are pushing our mission forward and they also regularly use their connections in the community to spread awareness, open doors for the organization and champion the cause to individuals and corporations alike. "We believe strongly in giving back to the community and in supporting this cause. We encourage other companies to join us. We all need to work together to improve the survival statistics." Richard Lundquist said.

# ACTING QUICKLY AND WITH PURPOSE

Ali Schlosser did everything right. She ate nutritiously, exercised regularly and embraced a healthy lifestyle. It came as a shock when she was diagnosed with stage III pancreatic cancer. However, she refused to slow down. She merely shifted the direction of her passion. "When I learned about how little investment in research there has been for pancreatic cancer, and how far behind it is in finding a cure, particularly relative to more common cancers, I had to get more involved, beyond my own individual fight against the disease," Ali says. After battling the disease only a mere four and a half months, she has already planned, organized and executed a fundraising event in Corte Madera, California this past November, raising approximately \$9,200 for the organization. The Pancreatic Cancer Action Network's Third Party Events program enables individuals like Ali to take action locally - and quickly - to raise awareness and support for the fight against the disease.

### turn your PASSION

# into



### **HOME**

Become a fan of our Facebook page and follow @PanCAN on Twitter.

Advocate for research from your own computer! pancan.org/advocate

Designate the Pancreatic Cancer Action Network in your will. Email pmarquardt@pancan.org

Create an online Keep the Memory Alive or A Special Day web page to honor a loved one or a memorable event.

Establish a Named Legacy Fund. pancan.org/givehope



### in your **COMMUNITY**

Attend a meeting, join a committee or even take a leadership role in your local effort. pancan.org/volunteer

Serve on a PurpleStride event committee to help with logistics, sponsorship, entertainment and more!

Share your story by submitting a Letter to the Editor of your local newspaper. pancan.org/contactmedia

Plan a Third Party Events program like a fundraising dinner party or awareness day at work. pancan.org/hostevent

Join TEAMHOPE to run/bike/ swim/etc. to raise support and awareness for our mission.



### **PURPLESTRIDE**

Register to stride and fundraise for your local event!

Form a team of family and friends - the more people involved, the greater the awareness and support!

Ask your company to sponsor the event or create a team for PurpleStride.

Visit www.purplestride.org and click the "Share" button to spread the word.

> Learn more at www.purplestride.org



### WORK

Ask your employer to include a call for volunteers in the employee newsletter.

Check to see if your employer has a matching gift program.

Participate in your company's employee giving program via payroll deductions.

Ask your Human Resources department to add us to its workplace giving ballot.

Email donorrelations@pancan.org to learn more.

together we

KNOW IT. FIGHT IT.

### SPORTS LEGENDS HELP TO RAISE MORE THAN \$1 MILLION AT 15TH ANNUAL AN EVENING WITH THE STARS GALA



The Willard family (from left) Bryce, Weston, Greg, Laurie and Shelby gather before Greg accepts the Spirit of Hope Award at the gala.

Top names from the Southern California sports community gathered on October 20, 2012, to rally against a leading cancer killer when the Los Angeles Kings, the San Diego Padres/Padres Foundation and National Basketball Association (NBA) referee and pancreatic cancer survivor Greg Willard were honored at the Pancreatic Cancer Action Network's 15th annual An Evening with the Stars gala, held at the Beverly Wilshire Hotel in Beverly Hills, Calif.



Longtime Pancreatic Cancer Action Network friend, talented actor and comedian Joel McHale served as the evening's emcee, while Sean Kelly, a comedian and actor from Tru TV's hit show

San Diego Padres Manager Bud Black accepts the Nancy M. Daly Shining Star Award on behalf of the San Diego Padres/Padres Foundation. Storage Hunters, led the fundraising portion of the evening's program. An inspirational singing performance by *The Voice* contestant Chris Mann rounded out the entertainment for the evening.

Also on hand to lend their support to the cause were NBA legend and ESPN analyst Kurt Ramblis, Los Angeles Dodgers General Manager Ned Colletti, and *The Voice* contestant Erin Willett.

The inspirational event, which drew more than 450 supporters, grossed more than \$1 million. Net proceeds will be used to fund critical programs and research projects for the pancreatic cancer community. The gala's <u>Tribute Journal</u> shows the tremendous support displayed by sponsors.

"We were elated to join some of the most recognized names from the world of hockey, baseball and basketball, who all gathered to raise awareness and funding for pancreatic cancer," Julie Fleshman, President and CEO of the Pancreatic Cancer Action Network. "The participation of notable leaders in the sports world is important for growing our national movement."

Mark your calendar now. The 16th annual An Evening with the Stars gala will be held on October 19, 2013, again at the Beverly Wilshire Hotel.



Los Angeles Kings President and General Manager Dean Lombardi receives the Emily Couric Public Service Award on behalf of his team, winners of the 2012 Stanley Cup.



### **KEEP THE MEMORY ALIVE**

A wonderful way to pay ongoing tribute to your loved one while raising awareness and funding for the fight against pancreatic cancer.

www.keepthememoryalive.net



### CREATE A LEGACY GIFT

A legacy gift ensures that your estate will benefit countless lives affected by pancreatic cancer. To learn more about creating a bequest, or other planned-giving options, please contact Pamela Acosta Marquardt at pmarquardt@pancan.org or at 877-272-6226.

## OUR VOLUNTEERS INSPIRE US TO REACH NEW HEIGHTS EVERY DAY

We love to take every opportunity we can to show our gratitude and appreciation for our amazing volunteers!

Thank you for all you do for the pancreatic cancer



community and to move our critical mission forward.

We could never make the progress we have seen without the power of YOU!











