

OUTREACH

VOL XII ISSUE I SPRING 2012



THE FACES OF CLINICAL TRIALS



Read about their
experiences on page 6.

CHAIR'S MESSAGE

A FAR-REACHING \$1.4 MILLION GIFT



The year is off to a great start for us. Private funding for pancreatic cancer research received a momentous boost late last year when the Daniel and Janet Mordecai Foundation made a record \$1.4 million gift to the organization to fund part of the Pancreatic Cancer Action Network's 2012 Research Grants Program. The generous donation, made in memory of Daniel Mordecai, who passed from the disease in 2002, will fund five research grants this year, including one Pathway to Leadership award and four Career Development awards.

We are profoundly grateful for the benevolence shown by Mordecai Foundation President Janet Mordecai and her children, whose investment will make a substantial difference regarding research efforts into the disease for years to come. The foundation's gift is destined to have a major impact on our efforts to build a robust, comprehensive pancreatic cancer research community and fund critical research that can lead to early detection methods and better treatment options for those facing the disease. The additional investigations made possible through the funding could also move us closer to realizing our vision of doubling the pancreatic cancer survival rate by 2020.

In addition to helping build a robust pancreatic cancer research community and funding important research, we also strive to ensure that patients are aware of the latest research. To this end, we recommend that patients consider clinical trials when exploring their treatment options. Clinical trials could have a positive impact on an individual's treatment and will help speed scientific progress toward therapeutic breakthroughs for those who have yet to be diagnosed.

To emphasize the importance of clinical trials, we declared January as National Pancreatic Cancer Clinical Trials Awareness Month. This initiative allowed us to shine a spotlight on the need for increased patient participation in clinical trials. We have also dedicated this issue of *Outreach* to clinical trial awareness. As you read the articles, you will learn that clinical trials are an essential part of the research process and that increasing enrollment in them is also critical to our goal of doubling the survival rate by 2020.

As we start 2012, I want to thank you for all of your own efforts on behalf of the pancreatic cancer community and encourage you to remain engaged throughout the entire year as we move toward our goal of changing the course of history for the disease.

Sincerely,

A handwritten signature in black ink that reads "Peter B. Kovler". The signature is written in a cursive style.

Peter Kovler
Board Chair

P.S. I am pleased to announce that the Pancreatic Cancer Action Network has been recognized by Philanthropedia as one of the top ten outstanding cancer charities in the U.S. for 2011. Philanthropedia was recently acquired by Guidestar, a leading charity watchdog organization. To learn more, go to www.myphilanthropedia.org.

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OUR MISSION

The Pancreatic Cancer Action Network is a nationwide network of people dedicated to working together to advance research, support patients and create hope for those affected by pancreatic cancer.

BOARD MEMBERS, VICE PRESIDENTS ASSUME NEW LEADERSHIP ROLES

Noted philanthropists and key supporters **Jeanne Weaver Ruesch** and **Terrence Meck** recently joined the Pancreatic Cancer Action Network's National Board of Directors. In addition, **Jenny Isaacson** and **Lynn Matrisian, PhD**, assumed pivotal leadership roles as vice presidents on the organization's executive team.



Jeanne Ruesch

Jeanne, who lives in Chevy Chase, Maryland, is Chair of the Ruesch Family Foundation, a charitable entity in the Washington, D.C. region, that she founded in 2004 with her late husband, Otto J. Ruesch, who passed from pancreatic cancer that same year. Prior to the foundation's founding, she was the Executive Vice President and Chief

Operating Officer of Ruesch International, an international financial services company providing payment solutions for corporations worldwide.

Jeanne has served on numerous boards and advisory groups and presently serves as President of the National Symphony Orchestra at the Kennedy Center, as a member of the Kennedy Center International Committee, a Board member of Georgetown University Medical Center, and on the Executive Committee of the Center's *Doctors Speak Out* group. The Ruesch Foundation is the founding donor of the Otto J. Ruesch Center for the Cure of GI Cancers within the Lombardi Cancer Center at Georgetown University Medical Center.

She is affiliated with two corporate boards, serving as Chair of the Board of Directors of AUI Imports and as a member of the Bialek Environments Advisory Committee. Jeanne is also a member of *The Committee of 200*, a worldwide organization for entrepreneurial business women.

A resident of New York City, **Terrence** serves as the Executive Director of The Palette Fund, a private foundation that honors the legacy of his late partner, Rand Harlan Skolnick, who passed from pancreatic cancer in 2008. Through collaborative grant making and supporting programs that value human rights and education, the Palette



Terrence Meck

Fund, since its inception in 2009, has bestowed more than \$2.5 million in grants to nonprofits benefitting LGBT youth, patient navigation, and nutrition and wellness initiatives.

Terrence, who holds a B.A. in political science from Princeton University, also serves as President of real estate investment firm Intrinsic Capital. In addition, he serves on the boards of the Movement Advancement Project, the New York Zen Center for Contemplative Care, the Harold P. Freeman Patient Navigation Institute, the Threshold Foundation and God's Love We Deliver. From 2003 to 2008, Terrence and Rand co-owned The Raven Resort Properties in New Hope, PA, a business catering to diverse communities.

With more than 25 years of experience in fundraising, marketing and public relations, **Jenny** was named Vice President for Community Engagement in June of 2011. In her role, she provides overall management and strategic direction for the organization's Donor Relations, Corporate Relations and Community Outreach programs.



Jenny Isaacson

Hailing from Great Britain, where she graduated with honors from the University of East Anglia, Norwich, Jenny previously served as Vice President of Brand Marketing and Communications at the Starlight Children's Foundation, overseeing the foundation's fund development, corporate partnerships and cause-related marketing efforts, as well as helping direct the organization's visioning, strategic planning and brand marketing.

In January 2012, **Lynn** began serving as Vice President of Scientific and Medical Affairs, a position in which she



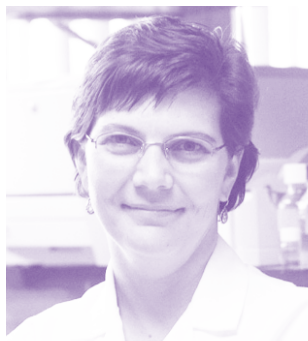
Lynn Matrisian, PhD

oversees the organization's Research and Scientific Affairs and Patient and Liaison Services programs. Previously, she served as professor and chair of the Department of Cancer Biology and Ingram Distinguished Professor of Cancer Research at Vanderbilt University, where she worked for 25 years. She earned her doctorate in Molecular Biology at the University of Arizona, completed her postdoctoral training in Strasbourg, France, and joined Vanderbilt's Department of Cell Biology as an Assistant Professor in 1986.

Highly regarded for her mentorship skills and expertise in the field of cancer biology, Dr. Matrisian is also a past president of the American Association for Cancer Research and has served as Special Assistant to the Director of the National Cancer Institute. ✨

MEET A GRANTEE

DIANE SIMEONE, MD: TACKLING PANCREATIC CANCER IN THE LABORATORY AND THE CLINIC TO BENEFIT PATIENTS



Diane Simeone, MD

Dr. Simeone received our Randy Pausch Family – Pancreatic Cancer Action Network – AACR Innovative Grant in 2010. She serves as the Lazar J. Greenfield Endowed Professor of Surgery and Physiology at the University of Michigan and as the Director of its Pancreatic Tumor Program.

In recognition of her outstanding reputation, Dr. Simeone has routinely been listed among the Best Doctors of America, Best Surgeons in America, and America’s Top Doctors for Cancer. She was recently inducted into the Institute of Medicine, and she is a Past President of the Society of University Surgeons and the American Pancreatic Association. She joined the Pancreatic Cancer Action Network’s Scientific Advisory Board in 2011.

As an undergraduate student at Brown University, Dr. Simeone majored in Neuroscience and enjoyed delving into various research projects in that area. During medical school at Duke University, when she focused her attention on surgery, she chose gastrointestinal surgery because it often provided an opportunity to “go in there and fix things, and make an immediate impact on the quality of people’s lives,” she said.

Unfortunately, surgery for pancreatic cancer is a complex procedure that is not often curative for patients. “We are deficient in our ability to improve outcomes, both surgically and scientifically, for pancreatic cancer,” she said. Consequently, she felt she could have the most impact in tackling the disease by working in both the operating room and the laboratory.

Her research project, funded by the Pancreatic Cancer Action Network Innovative Grant in honor of the Randy Pausch family, involves a clinical trial targeting pancreatic cancer stem cells (CSCs), which are considered the most

aggressive cells within a tumor and often grow, resist treatment, and spread, or metastasize, from the tumor to other organs.

After Dr. Simeone and her colleagues discovered CSCs in human pancreatic cancer, they found that the cells are particularly dependent on protein signaling involving the developmental pathway Notch. Notch signaling is ordinarily only active during the embryonic development of the pancreas and other organs, but absent from normal healthy adult cells. However, pancreatic CSCs reactivate Notch signaling, and require it for their growth and survival. Based on these observations, Dr. Simeone proposed developing a clinical trial to test a compound that blocks the activity of Notch.

She feels strongly that clinical trials should be based on robust, rigorous preclinical data (laboratory experiments). Ideally, she would like to test potential drugs in mouse models for pancreatic cancer, as well as human tissue samples of the disease, before using novel therapies to treat patients. She believes many drugs are tested in clinical trials without an adequate understanding of how they work and in which settings they might provide the most benefit. When her own clinical trial was stalled by unexpected setbacks, she opted to use the time to produce even more compelling preclinical data supporting the effectiveness of Notch inhibition in the treatment of pancreatic CSCs.

Dr. Simeone believes it is important to surround herself with a strong, diverse collaborative team of researchers. “The best way to achieve success is to get lots of types of input and come at the problem from multiple angles such as clinical, basic science, and drug development,” she said.

She encourages early career researchers to adopt this strategy, ensuring that basic scientists team up with clinicians, and vice versa. “The Pancreatic Cancer Action Network does a phenomenal job convening and growing an interactive research community, facilitating a greater exchange of ideas,” she said.

Dr. Simeone added that she is honored to be a part of the pancreatic cancer field, and feels positive about the community’s ability to make progress in the next few years. ✨



Jai Pausch

“We just need to give smart people the tools that they need to solve the problem (of pancreatic cancer).”

— Jai Pausch, National Board of Directors, Pancreatic Cancer Action Network

TWO "BASIC" SCIENTISTS PURSUE GOAL OF IMPROVING CLINICAL OUTCOMES



Drs. Bailey and Seeley receive our Pathway to Leadership awards at the 2011 American Association for Cancer Research Annual Meeting on April 5, 2011.

Since 2010, the Pancreatic Cancer Action Network has awarded Pathway to Leadership research grants to three highly promising early-career scientists in the mentored research phase of their careers, enabling their transition to research independence.

Researchers apply for this grant while they are working in the laboratory of a professor serving as their mentor, and then they establish their own labs during the

second part of the funded period. This timeframe represents a critical moment in the career of a young scientist, transitioning to running his/her own lab and committing to a research focus. Excitingly, the recipient of the inaugural Pathway to Leadership grant in 2010, Zeshaan Rasheed, MD, PhD, was recently promoted to Assistant Professor at Johns Hopkins University.

Jennifer Bailey, PhD, and E. Scott Seeley, MD, PhD, received the grants in 2011. Dr. Bailey finished her undergraduate and graduate studies at the University of Nebraska. Dr. Seeley completed his undergraduate studies at the University of Regina in Canada and Eastern Connecticut State University, then completed a joint MD/PhD program at Dartmouth Medical School. Currently, Dr. Bailey is a postdoctoral fellow at Johns Hopkins University and Dr. Seeley is a research and clinical fellow at Stanford University.

Although a continent apart, these exceptional young scientists tackle similar complex, biological questions in an effort to better understand the initiation and progression of pancreatic cancer. Both investigators have benefited from working with exceptional mentors who have deep-rooted connections to the pancreatic cancer community and our organization.

Dr. Bailey conducted her post-graduate studies in the laboratory of Tony Hollingsworth, PhD, a member and former chair of the organization's Scientific Advisory Board.

Currently, she is co-mentored by Steven Leach, MD, and Anirban Maitra, MD, a recipient of a 2004 Career Development Award and a Scientific Advisory Board member. Dr. Seeley works primarily with Max Nachury, PhD, the recipient of the 2009 Larry Kwicinski Career Development Award.

"It is a great testament to the success of our research grants program to see former recipients of early-career grants in a position to mentor future leaders in the field," said Pancreatic Cancer Action Network President and CEO Julie Fleshman.

Both Drs. Bailey and Seeley focus their research efforts on protein signaling necessary for the growth and survival of pancreatic cancer cells. Dr. Bailey studies the earliest cellular changes necessary to promote cancer formation by measuring the cells' response to expression of mutant K-Ras. Since K-Ras is the most frequently mutated protein in pancreatic tumors, she plans to use a novel mouse model to monitor the precise moment when mutant K-Ras is first expressed and observe resulting cellular changes. The ability to witness and potentially intervene in these extremely early events could have strong implications in the development of better methods to detect and treat pancreatic cancer.

Dr. Seeley examines the regulation of cellular protein localization and how this mechanism can impact the growth, movement and survival of cancer cells. For proper cellular signaling to occur, proteins need to be in the right place at the right time. Because of a tightly regulated process, a potential therapeutic strategy could interfere with cellular localization of critical proteins, leading to improperly located, nonfunctional proteins.

These types of creative studies delving into the biology of pancreatic cancer will serve as the foundation for future clinical trials leading to novel treatment and diagnosis options. Passionate, bright young scientists like Drs. Rasheed, Bailey and Seeley will be on the frontlines fighting this disease and advancing research for years to come.

In addition to providing critical research funding, the Pancreatic Cancer Action Network offers early-career grantees like them networking opportunities, allowing them to share ideas and progress and gain insight from experts in the field. Such collaborations represent an important component towards building a comprehensive pancreatic cancer research community. ✨

FROM CELLS TO MICE TO HUMANS: HOW LABORATORY RESEARCH TRANSLATES TO PATIENT BENEFIT THROUGH INNOVATIVE CLINICAL TRIALS

Modern clinical trials are designed to test novel drugs and combinations of drugs based on carefully evaluated scientific data generated in the laboratory. Better disease models for pancreatic cancer and a deeper understanding of the basic biology have led to the development of many promising clinical trials for pancreatic cancer. (For an example of such a trial, please see the story about Dr. Diane Simeone's research on page 2.) Another type of treatment option based on work in the laboratory is a family of drugs formulated to target a protein signaling pathway called hedgehog. To read a story about a patient under treatment with this type of compound, please see page 8.

When the research of Scientific Advisory Board Chair Dave Tuveson, MD, PhD was funded by his Pancreatic Cancer Action Network Career Development Award in 2003, he developed the first mouse model of pancreatic cancer that mimics the progression of human disease.

Previous experiments in the laboratory revealed the most commonly mutated genes in pancreatic cancer. Dr. Tuveson genetically engineered his mouse model so that it would be born with these mutations occurring specifically in the pancreas. Over time, the engineered mice developed pancreatic cancer, and showed weak responsiveness to the chemotherapeutic drug gemcitabine, the standard of care for pancreatic cancer patients. The results mirrored human patients' poor response rate to the drug.

Further analyses by Ken Olive, PhD (recipient of our 2011 Career Development Award funded by Tempur-Pedic® Retailers), conducted when he worked as a postdoctoral fellow with Dr. Tuveson, showed that the dense microenvironment surrounding the pancreatic tumor contributed to the resistance of the mice to gemcitabine. In fact, the microenvironment was so thick and impenetrable that the drug could not even make it to the cancer cells themselves.

When Drs. Olive, Tuveson and their colleagues looked

more carefully at the individual cells comprising the microenvironment, they found that a cell signaling pathway called hedgehog was abnormally activated. Hedgehog signaling is known to play an important role in the embryonic development of the pancreas and other organs, but is not supposed to be active in healthy adult cells.

Because of this observation, clinical trials are currently underway to test the combination of novel inhibitors of the hedgehog signaling pathway with other treatment options. Although early results with the first hedgehog inhibitor to be tested in pancreatic cancer patients were disappointing, other drugs are in trial to further examine this therapeutic strategy. The hope is that the hedgehog inhibition will break down some of the dense microenvironment surrounding the cancer cells, leaving them vulnerable to attack by chemotherapeutic drugs.

In this example, a clinical observation (that pancreatic cancer patients respond poorly to the chemotherapy drug gemcitabine) was recreated in an accurate mouse model of the disease. The mouse model provided insight into a potential mechanism for drug resistance (that the drug was not getting to the tumor), and analyses of the tissue specimens in the laboratory revealed activation of a pathway that can be therapeutically targeted. Together, these medical and scientific findings have led to a promising, strategic treatment option for one of the most difficult cancers to treat. Numerous other examples abound of elegant laboratory work informing the design and implementation of novel clinical trials aimed at treating pancreatic cancer. The Pancreatic Cancer Action Network encourages all patients to consider clinical trials when exploring treatment options.

Without clinical trials, patients will not have access to cutting-edge research and new and better treatment options for pancreatic cancer will not be developed. Encouraging patient participation in pancreatic cancer clinical trials is an extremely important part of the research process. ✨

PANCREATIC CANCER SPECIAL CONFERENCE SET FOR JUNE 2012

The American Association for Cancer Research (AACR) Pancreatic Cancer Special Conference will take place from June 18 to 21, 2012 in Lake Tahoe, Nevada.

The Pancreatic Cancer Action Network will proudly serve as the lead sponsor of the event and work with the AACR to offer an inaugural special conference completely focused on pancreatic cancer. Scientists and physician/scientists at various stages of their careers will have the opportunity to interact with experts in the field, fostering information-sharing, collaboration, and increased attention regarding the disease.

To learn more, go to www.pancan.org/AACRconference

ADVOCACY EFFORTS EXTEND BEYOND BILL PASSAGE



In addition to ensuring passage of the *Pancreatic Cancer Research & Education Act* and promoting awareness of the disease among government officials, the Pancreatic Cancer Action Network helps represent

the interests of pancreatic cancer patients in other ways. These include striving to ensure patients have access to clinical trials and working with government agencies like the Food and Drug Administration (FDA), the federal agency responsible for approving new drugs and medical devices.

The FDA uses “guidances” to tell manufacturers and other members of the drug and device industries what the agency expects in order for their drugs and (medical) devices to become approved. Recently, the Pancreatic Cancer Action Network submitted comments to the FDA to provide input on its draft guidance entitled, “In Vitro Companion Diagnostic Devices.”

In its draft guidance on which it sought comments, the FDA took the position that when manufacturers request FDA approval for a drug that is used in conjunction with a diagnostic

device, both the drug and the device must be approved at the same time. As an example, certain drugs are effective only in people whose tumors have a specific biomarker, such as crizotinib (Xalkori), a drug that was approved in 2011 for non-small-cell lung cancer. Researchers know this medication is likely to be effective only in people who have rearrangements in the anaplastic lymphoma kinase (ALK) gene. Under the draft guidance, if the FDA was considering approval of Xalkori today, a diagnostic device testing for the ALK gene would have to be approved at the same time.

The draft guidance is important for pancreatic cancer because it included a critical exception for drugs used to treat serious or life-threatening conditions for which there are no other good treatment options. Pancreatic cancer is classified as such a condition because of its five-year relative survival rate of just 6 percent and lack of effective treatments. Drugs or therapies developed to treat pancreatic cancer in conjunction with a diagnostic device or test can be exempt from this requirement and thus may come to market sooner. The Pancreatic Cancer Action Network submitted comments to the FDA strongly supporting this exception. To read our comments, visit www.pancan.org/FDAcomments. ✨

REGISTER TODAY FOR THE SIXTH ANNUAL PANCREATIC CANCER ADVOCACY DAY

Join hundreds of your fellow pancreatic cancer advocates from across the country on June 25 and 26, 2012, in Washington, D.C. for the sixth annual Pancreatic Cancer Advocacy Day. During the event, participants will meet with their members of Congress to share their stories about how the disease has impacted their lives and to push for passage of the *Pancreatic Cancer Research & Education Act*. Comprehensive training is provided, so no previous advocacy experience is necessary. The only requirement is enthusiasm about educating elected officials about pancreatic cancer, the organization, and the need for more federal funding for pancreatic cancer research.

To register for the event, go to www.pancan.org/AD2012. Since Advocacy Day is a very popular event and space is limited, early registration is encouraged. Registration will close on May 11, 2012, or whenever capacity is reached.

“Advocacy Day was emotional and inspirational, yet energizing for me. It was comforting to meet people who share a similar personal experience and passion for creating much-needed awareness for pancreatic cancer. I am very grateful for having had the opportunity to participate in such a tremendous event!”

-Diane Dudash-Dykes, Jacksonville, FL, 2011 Advocacy Day participant

PANCREATIC CANCER RESEARCH & EDUCATION ACT UPDATE

We are excited to announce that through the dedication and persistence of our grassroots advocates, we have now secured the support of more than half of the U.S. House (220 representatives) and nearly half of the U.S. Senate (43 senators) for the Pancreatic Cancer Research & Education Act (S. 362/H.R. 733)! To check if your members of Congress have co-sponsored the bill, go to www.pancan.org/senate and www.pancan.org/house. Now that we have reached this important milestone, we are pushing Congress to pass the bill out of the relevant committees and to bring it to the Senate and House floors for a vote. Please help us by attending Advocacy Day in June and by participating in advocacy-related action alerts!

PARTICIPATION IN A PANCREATIC CANCER CLINICAL TRIAL MAY BE RIGHT FOR YOU

Conducting clinical trials is critical to advancing progress in the fight against pancreatic cancer. Clinical trials are the only way for researchers to determine if new treatments are as effective and safe or better than current approved regimens for treating diseases like pancreatic cancer. Additionally, clinical trials provide patients with the opportunity to receive a promising drug or treatment.

By participating in an appropriate clinical trial, patients can have a positive impact on their own treatment and help speed scientific progress toward therapeutic breakthroughs for those who have yet to be diagnosed. In effect, enrolling in clinical trials is one of most significant ways patients can take an active role in advancing vital medical research in addition to helping themselves.



Michael Donnelly

Michael Donnelly, a 71-year-old father of three and grandfather of five who lives in Penfield, NY, knows firsthand about the benefits of participating in a trial. He entered one only a few months after his pancreatic cancer diagnosis in 2003. “Even after surgery, I knew I was facing a difficult disease, and my doctor told me that the best option for me was an investigational treatment through a clinical trial,” he said. Today, almost eight years later, Michael is working as a senior executive for a not-for-profit organization, enjoying golf, traveling and volunteering in his community.

Since every patient’s experience in a clinical trial will be different, anyone considering participating in one should carefully evaluate his or her options. Participants need to be informed and learn all they can about the trials so that they feel comfortable with their decision to enroll.

THE DECISION TO PARTICIPATE

Sue Kocis, a 55-year-old forest ranger from Sterling Heights, MI, knew she needed to research her trial thoroughly before making a decision. “I narrowed my search down to two trials, interviewed the clinical trial coordinator and the study doctors, then made my choice,” she said. “The trial coordinator is very dedicated and coordinates all my treatments, so I feel well cared for.”

After two months of participating in the trial, Sue is still excited to be part of it. “I close my eyes now and imagine the trial drugs and standard-of-care drugs working through

my body to eradicate any remaining cancer and zap it,” she said. “It’s reassuring.”

Clinical trials may offer many potential benefits and patients participate for a variety of reasons. Some hope that the treatment they will receive will be better than the standard treatment that is available. Patients may also be motivated by the opportunity to receive care from the top doctors and researchers who conduct trials at leading healthcare facilities nationwide.



Sue Kocis

OFFERING HOPE

A 70-year-old grandfather and architect who resides in Jacksonville, OR, Philip Schwimmer has been part of a trial since he was diagnosed with metastatic pancreatic cancer in 2010. “In my case, being part of a clinical trial has shown me the difference between thinking ‘outside of the box’ in terms of patient care and treatment, and accepting what was essentially a hopeless diagnosis,” he said. “My trial gave me the hope I needed to face my fears.”



Philip Schwimmer

Sue was also motivated by the possibility of a brighter future. “I knew I wanted to participate in a clinical trial because standard treatments still offer slim hope of a cure for me,” she added. “By participating, I feel like I ‘bought insurance’ and now have more hope that one of these days a cure can be found.”

TAKING A LOOK AT SIDE EFFECTS

Some patients are hesitant to participate in a trial because of concerns about possible side effects from an experimental treatment. However, all treatments may cause side effects. Therefore, choosing the standard treatment instead of a clinical trial does not mean there will be no side effects. In either case, the degree to which a patient experiences them can range from mild to severe.

“My trial coordinator reviewed the possible expected side effects with me and some have occurred,” said Sue, whose own side effects have been mild. “Since I was prepared, though, I am able to deal with the little inconveniences.”

(continued on next page)

In most cases, side effects are successfully managed with the help of the multidisciplinary team of healthcare professionals who often work on clinical trials, including physicians, nurses, social workers and dietitians. “The treatment I got was aggressive, and I did suffer from a number of side effects,” Michael said. “But throughout the trial, 10 or 11 different people, including specialists from different areas, were evaluating me and helping me deal with them.”

INFORMED CONSENT

Patients may also be concerned about their rights when participating in a clinical trial. One of the most important goals of those who conduct such trials is protecting patients’ rights. To ensure the well-being of all participants, a unique action plan called a protocol is used in each trial. The protocol ensures that the study is justified, safe for participants, and designed to answer research questions. A key component of protocols is informed consent.

Informed consent ensures patients receive complete information about a clinical trial prior to their participation

so that they understand their role and rights. During his own trial, Philip found informed consent reassuring.

“During the enrollment process, I was told that if I changed my mind, or if I felt the quality of my life was compromised by the treatment, I could quit,” he said. “Since I started the trial, I have lived for 13 months as opposed to the three months my physician initially gave me. If I had chosen standard cancer treatment for this disease, I might not be around.”

The Pancreatic Cancer Action Network understands the importance of clinical trials in the development of new treatment options for pancreatic cancer and encourages all patients to explore them when considering treatment options. Clinical trials are the only way to find more effective therapies to treat the disease.

We can help you find a clinical trial that may be right for you. To learn more, contact a PALS Associate toll-free at 877-272-6226 or email pals@pancan.org. ✨

PALLIATIVE CARE: ENHANCING QUALITY-OF-LIFE AND ADMINISTERING PRACTICAL CARE

Palliative care focuses on comfort, quality of life and a survivor’s total well-being during and after cancer-fighting treatments. Palliative care is meant to relieve the symptoms and side effects at any stage of living with cancer or other serious illnesses. Such care should be provided throughout the pancreatic cancer journey and can accompany cancer-fighting treatments.

Misunderstandings about the meaning of palliative care create a common challenge. Many people, including some healthcare professionals, think that palliative care is only given to people nearing the end of their lives. However, palliative care is appropriate at any time, regardless of prognosis. Pancreatic cancer survivors may experience pain, fatigue and other side effects that reduce their quality of life and they should ask for help. Survivors deserve to get the palliative

care they need throughout their journey.

Survivors should look to palliative care as a way to feel the very best that they can in every area of their lives. Survivors and their loved ones will be best equipped to deal with the challenges of their pancreatic cancer journey when their physical well-being and emotional attitude are strong. Total well-being enhances the quality of life of each survivor and should be considered by all members of the healthcare team.

The Pancreatic Cancer Action Network’s Patient and Liaison Services (PALS) recently published a booklet titled, “Palliative Care: Quality of Life and Practical Care in Pancreatic Cancer.” To receive a free copy of this booklet, or for help locating palliative care services, contact a PALS Associate toll-free at 877-272-6226 or email pals@pancan.org. ✨

CLINICAL TRIALS: A VITAL STEP IN MAKING PROGRESS

The Pancreatic Cancer Action Network recommends that all patients consider clinical trials when exploring treatment options.

The Pancreatic Cancer Action Network’s Patient and Liaison Services (PALS) program maintains a comprehensive database containing up-to-date information about pancreatic cancer clinical trials taking place throughout the United States. For a personalized clinical trials search or for other questions related to clinical trials, contact a PALS Associate toll-free at 877-272-6226 or email pals@pancan.org. PALS Associates are available Monday-Friday, 7am-5pm Pacific Time.

A STORY OF HOPE AND INSPIRATION

By Fred Wilhelms, Nashville, Tennessee



Fred Wilhelms with his first grandson, Charlie

In March 2011, I was diagnosed with metastatic pancreatic adenocarcinoma. As you're reading this story in *Outreach*, you are already familiar with most of what I could share because it follows the same path of so many other stories that have appeared in this magazine. It's a tale of fear, despair, hope, progress, setbacks and a never-ending fight. As I write this column, just before Christmas of 2011, I've been through all of that and I'm still in the middle of it. The fact that I am still in the middle of my pancreatic cancer journey is the part of my story that I want to share now.

After unsuccessful surgery in April to resect the tumor, my wife and I began a search for new ways to fight it. We weren't going to stop just because I still had cancer. Thankfully, I had built up a wonderful support circle of friends, family and cancer survivors who wouldn't let me quit, either. We began to explore clinical trials as an option.

We knew, with the dim prognosis I was given, that time was of the essence, but we made sure we found something that promised hope. Not just hope for me, and maybe not for me at all, but hope for the untold thousands who would follow me in this experience.

After a couple of weeks of searching, we found a clinical

trial using a drug known as "hedgehog inhibitor" that was just opening up. In fact, I was the first patient in the trial in my area. (To learn more about this therapeutic strategy, please see the story on page 4.) In June, I started the trial. The regimen was daily oral medication combined with regular chemotherapy one day a week, three weeks out of four. I have not experienced any real side effects from the trial, except for increased fatigue following the chemo sessions, which would probably be happening whether I was taking the test drug or not. I am pain free, with no nausea or other symptoms. I have a great appetite, remain in good spirits and stay as active as I was before the diagnosis.

The results have been encouraging, to put it mildly. Now I don't know, and neither does my oncologist, whether or not the trial drug is responsible. Neither of us know if I am getting the experimental drug or if I am getting standard treatment with a placebo (which is the same as receiving only the standard treatment). It could be the experimental drug. It could be the regular chemotherapy. It also could be the aggressively positive attitude I maintain with the support of my wife and friends. It could be the result of the prayer circles around the world who keep me in their thoughts.

It could be, and I'm betting it is, a combination of all that, but the result is really what matters. The cancer has not spread or grown since I started the trial. I am now well past the initial dire prognosis they gave me in March. As a result, I saw my daughter get married this past September and held my first grandson, Charlie. That's me with Charlie in the picture.

People say that when life hands you a lemon, make lemonade. That's usually good advice, but it wasn't going to work for me in beating my cancer. I needed more than lemonade, and the clinical trial gave me an opportunity to find more. Sometimes, even when life hands you a lemon, you have to keep looking for the champagne grapes. I did. And because I did, I can raise a toast to my fellow cancer survivors. ✨

PATIENT AND LIAISON SERVICES (PALS)



PALS offers comprehensive, high-quality information and resources to patients and families facing pancreatic cancer, including information about the disease, treatments, clinical trials, side effect and symptom management, diet and nutrition, and support resources. Contact a PALS Associate to answer your questions, receive personalized pancreatic cancer information or a free educational packet.

El programa de PALS esta disponible en español.

Patient and Liaison Services (PALS)

Monday - Friday, 7am - 5pm Pacific Time

Toll-free: 877-272-6226 | Email: pals@pancan.org

VOLUNTEERING FOR OUTREACH TO THE HEALTHCARE COMMUNITY

At a recent Education & Outreach volunteer committee meeting of the Pancreatic Cancer Action Network Twin Cities



Teri Larson, Education & Outreach Coordinator for the Twin Cities Affiliate, with her husband at an Awareness Night with the Minnesota Twins event, where she hosted a pancreatic cancer information table

Affiliate, Teri Larson was discussing the need to raise awareness about clinical trials when a pancreatic cancer survivor voiced a concern.

“He said he had beaten pancreatic cancer because he had received a proven course of treatment and he would hesitate to suggest that patients pursue anything else,”

Teri, the Twin Cities Education & Outreach Coordinator, recalls.

Then a remarkable thing happened. Fellow survivor Brenda Coleman quickly chimed in with a comment of her own: “Part of the reason you received that course of treatment was because of a clinical trial I participated in nine years ago that changed the standard of care,” she said. Her comments emphasize the extremely important role of enrolling in clinical trials.

It was a memorable moment, but one of many for Teri. In her role as coordinator, Teri hears from survivors in many venues. In addition to regularly hosting information tables at health fairs and conferences, she meets one-on-one with healthcare providers to share information about resources such as the Patient and Liaison Services (PALS) program, the Survivor and Caregiver Network and personalized searches for clinical trials.

Like many Education & Outreach Coordinators, Teri does not have a formal medical background. However, she did witness the progression of pancreatic cancer that took her mother in 2007; Teri herself is a survivor of Stage IV lymphoma. As a volunteer, she was initially hesitant about meeting with healthcare professionals but quickly overcame any uncertainty.

“One of my favorite things to do is to go into hospitals and clinics and talk to them about the organization,” she said. “Healthcare professionals are so receptive. They’ve had so little to offer their patients for pancreatic cancer and we are helping them provide hope.”

Emily Tedone, Education & Outreach Coordinator for the Phoenix Affiliate, recently gave a presentation about the organization to the Society of Gastroenterology Nurses Association regional meeting. “Afterward, 200 nurses just swarmed our information table! They were so grateful to finally have resources to direct their patients to,” she said. “Up until then, they hadn’t been doing much, because they felt there was nothing they could do.”


Emily lost her father to pancreatic cancer in 2008, but it wasn’t until 2009 that she began volunteering with her local affiliate. “I thought that once he passed, things would become easier, but it wasn’t until I began putting energy into the organization that I started to heal,” she said. “Looking back now, I realize how much volunteering helped me. The organization is so professional and supportive in how they treat their volunteers. I know if my dad had survived, he would have been involved, which makes it easier to know this is what I should be doing.”

Both Teri and Emily work full-time. Initially, their volunteer efforts required some juggling, but Emily, who oversees a committee of 15 Education & Outreach volunteers in Phoenix, shared that one of her most successful volunteers is a mom who can’t often make it to monthly affiliate meetings but frequently is out in the community talking with doctors and nurses.

Teri agrees. “One of the most important things we can do is just to be there. We provide a sense of community to help patients and their families know they are not alone. It can be hard; there are too many people with this diagnosis, but that can be motivating as well. I feel we are making a difference. I want to be part of this effort and this organization when we make that breakthrough; you can feel it coming,” she said.



Emily Tedone (left), Education & Outreach Coordinator for the Phoenix Affiliate, at Advocacy Day 2011 with her mother, Maria

Thanks to the work of Teri, Emily and volunteers nationwide, that momentum is palpable. To learn how you can become involved locally, visit www.pancan.org/volunteer. 

TEAM WALKING FOR WENDY TAKES ON THE COUNTRY



Team Walking for Wendy (here at PurpleStride New Jersey 2011) also had participants in PurpleStride Manhattan, Cleveland, South Florida and Houston, raising more than \$200,000.

participated in many fundraising walks, but when she was diagnosed with pancreatic cancer in December 2010, she and her family became involved on a whole new level.

Wendy had witnessed a close family friend pass away from pancreatic cancer, and she knew she was in for a fight, but she wanted her struggle to have an impact beyond her own experience.

When Wendy's daughter Heather suggested that they participate in PurpleStride Manhattan 2011, Wendy began making calls. "My mother always had a selfless way of doing things," Adam said. "She felt that whatever happened to her was going to happen, but she wanted to do everything within her power to make sure others in the future wouldn't have to endure the same suffering that she was experiencing. When

One of the most inspiring stories to come out of the 2011 PurpleStride season is that of Wendy Keil, her husband, Gordon, and her children, Adam, Sarah, Heather and Noah. Wendy, a breast cancer survivor, had

you're passionate about a cause, it's easy to ask people for their support."

The family's effort grew into a team of 130 supporters, who raised more than \$72,000 for the event. Not content to stop after PurpleStride Manhattan, the Keil family immediately set their sights on forming a team for the PurpleStride walks in Cleveland and New Jersey.

Although Wendy's health declined over the summer, her spirit remained vibrant. "It was clear we didn't have a lot of time left," Heather said. "But she was personally involved up until the end. She even went to a cancer support group at the hospital to recruit people for the walk." Sadly, Wendy lost her battle in September 2011, but her family and friends went on to raise more than \$100,000 at PurpleStride New Jersey, bringing the full year total to almost \$200,000.

However, the Keil family considers this just the beginning.

"Without a lot of planning, we had Walking for Wendy teams at PurpleStride Cleveland, South Florida and Houston this year," Adam said. "We've already looked at the calendar for 2012. We know people all over the country. We are planning to have at least 20 teams at next year's events."

"My mom would say to us, 'this isn't a club anyone wants to join, but now that we are here we need to have an impact,'" remembers Sarah. "That's what we intend to do."

To learn more about forming a team for an upcoming PurpleStride, visit www.purplestride.org. ✨

INAUGURAL ING NEW YORK CITY TEAMHOPE NATIONAL MARATHON TEAM MAKES SPECTACULAR DEBUT



Barbara Hannah-Grufferman, proud member of TEAMHOPE and New York Marathon finisher

Pancreatic Cancer Action Network. Inspired in part by team captain and New York Yankee pitcher David Robertson, participants raised more than \$231,000.

The ING New York City TEAMHOPE National Marathon Team comprised individuals of all different skill levels and backgrounds who shared a common goal: to end pancreatic cancer. Several runners also joined the effort as part of the

Manhattan provided a picture-perfect backdrop for the inaugural ING New York City TEAMHOPE National Marathon Team last November, when nearly 50 members ran in support of the mission of the

TEAMHOPE Individual Program.

"It was a great experience. David's guiding light was truly working overtime that day," said team member Sharon Wong-Lew. "If you ever choose to do one marathon in your lifetime, New York is the one! It's even better to run it to raise money for your favorite charity!"

Beginning as a grassroots effort in 2004, TEAMHOPE expanded into a National Marathon Team in 2008. In 2010, the Individual Program was added, offering flexibility in fund-raising goals and benefits, and providing runners and walkers around the country with a way to participate in the race of their choosing, whether it's a local 5K or a destination marathon with a team of family and friends.

Since its inception, TEAMHOPE has grossed more than \$1 million to advance research, support patients and create hope for the pancreatic cancer community. For race ideas and to learn more, visit www.iamteamhope.org and click "Learn More" about our Individual Program. ✨

UPCOMING PURPLESTRIDE EVENTS

PurpleStride fundraising and awareness walks and races help support the fight against pancreatic cancer. Dates listed reflect events scheduled from February 1 to June 30, 2012; however, new events are added frequently. Visit www.purplestride.org for more information on all 2012 PurpleStrides.

2/11/2012	PurpleStride Phoenix
4/21/2012	PurpleStride Kansas City
4/21/2012	PurpleStride New York City
4/28/2012	PurpleStride Chicago
5/6/2012	PurpleStride Rhode Island
5/12/2012	PurpleStride Los Angeles
6/2/2012	PurpleStride Milwaukee
6/9/2012	PurpleStride Omaha
6/9/2012	PurpleStride Indianapolis
6/9/2012	Walk Through the Vineyards (Napa, CA)
6/16/2012	PurpleStride Cleveland
6/16/2012	PurpleStride Scranton (PA)
6/16/2012	PurpleStride Washington, DC
6/24/2012	PurpleStride Denver
Date pending	PurpleStride Oklahoma
Date pending	PurpleStride Connecticut

ADDITIONAL SPRING EVENTS

Volunteers also host additional awareness events, fundraisers and volunteer meetings. Find one below or visit www.pancan.org/events for a complete list. New events are added every week!

2/4/2012	Awareness Night with the Missouri Mavericks
2/5/2012	Kaiser Permanente San Francisco Half Marathon & 5K Run
2/25/2012	Awareness Night with the Texas Stars
3/10/2012	Awareness Night with the Worcester Sharks (MA)
3/16/2012	Awareness Night with the Los Angeles Lakers
4/28/2012	PurpleLinks San Antonio
5/1/2012	Awareness Night with the Cincinnati Reds
5/7/2012	PurpleLinks Atlanta
5/31/2012	Awareness Night with the New Orleans Zephyrs
6/4/2012	PurpleLinks Detroit
6/9/2012	6th Annual Celebration of Hope, Seattle

For information on these and other events including local volunteer meetings, visit www.pancan.org/events.



PurpleLight Los Angeles, one of more than 50 held around the country in fall 2011



PurpleStride Savannah 2011



Survivor Ken Wardstrom (back row, center) a top fundraiser at PurpleStride Puget Sound 2011, surrounded by his team of family and friends



Volunteers Michelle Romanick (left) and Elena Piexoto celebrate at the end of a successful PurpleStride Portland 2011.

UPCOMING EDUCATIONAL OPPORTUNITIES

Learn about pancreatic cancer from experts in the field by attending one of our upcoming educational programs.

PANCREATIC CANCER SYMPOSIA: WASHINGTON, DC – SATURDAY, MARCH 10 | SAN FRANCISCO BAY AREA – FRIDAY, MAY 11

We will also be hosting several Educational Lectures throughout the country this Spring.

For up-to-date information and to register, visit www.pancan.org.

CULINARY MASTERS CONVERGE AT 14TH ANNUAL AN EVENING WITH THE STARS GALA, HELPING RAISE MORE THAN \$1 MILLION



Matt Bencivenga and Wolfgang Puck at the An Evening with the Stars gala

By his own admission, Matt Bencivenga, Chef and Managing Partner at Wolfgang Puck Catering, feels most at ease working tenaciously in a busy kitchen. However, the reserved culinary professional found himself on center stage on October 22, 2011, when he was honored with the Pancreatic Cancer Action Network's prestigious *Spirit of*

Hope Award at the 14th annual An Evening with the Stars gala, held at the Beverly Wilshire Hotel in Beverly Hills, Calif.

Renowned food industry legend Wolfgang Puck, actor Mindy Kaling from the hit television series "The



Mindy Kaling

Office", Pancreatic Cancer Action Network National Spokesperson Lisa Niemi Swayze, widow of Michael Landon and long-time supporter Cindy Landon, actor/producer and Academy of Motion Picture Arts and Sciences President Tom Sherak, and a multitude of Matt's colleagues from Wolfgang Puck Catering were among the more than 600 Pancreatic Cancer Action

Network supporters joining his family members and friends for the special evening.

Before presenting Matt with his award, Wolfgang shared amusing anecdotes about working alongside his longtime friend and business partner and professed his admiration for the work ethic as well as the good humor and bravery he showed as he faced his pancreatic cancer diagnosis.

Capping the memorable evening was a rousing and upbeat performance by legendary rockabilly artist Chris Isaak, whose band moved many gala attendees to dancing in the aisles of the hotel's ballroom.



Chris Issak (right) and a bandmate perform at the gala.

The inspirational gala grossed more than \$1 million, which will be used to fund critical programs and research projects for the pancreatic cancer community.

"This year, we were extremely pleased to honor Matt, who helped to make this year's gala a tremendous success," said Julie Fleshman, President and CEO of the Pancreatic Cancer Action Network. "The funds raised this year will enable us to help tens of thousands of people affected by the disease, as well as bring us closer to our goal of doubling the pancreatic cancer survival rate by 2020."



Matt and Sarah Bencivenga

Mark your calendar now for the 15th annual An Evening with the Stars gala, which will be held on October 20, 2012, again at the Beverly Wilshire Hotel. ✨



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.



TEMPUR-PEDIC® 'HUGS BACK' GIVING SURPASSES \$1 MILLION



From left, Mark A. Sarvary, President and CEO, Tempur-Pedic International; Pancreatic Cancer Action Network President and CEO Julie Fleshman and Rick Anderson, President, Tempur-Pedic, North America, Inc.

Tempur-Pedic International Inc. continues to lead the way for Pancreatic Cancer Action Network's corporate champions, having raised more than \$1 million to date for the cause since the inception of the Tempur-Pedic Hugs Back program in 2009.

As part of the 2011 program, Tempur-Pedic hosted its second annual November Rest Test campaign, which generated a \$10 donation for

the organization for every consumer who tested a Tempur-Pedic mattress at a participating authorized retailer. Thanks in part to campaign support by the organization's volunteers nationwide, the promotion was hugely successful.

The number of validated Rest Tests taken by consumers this year grew by more than 50 percent. Due to the campaign's

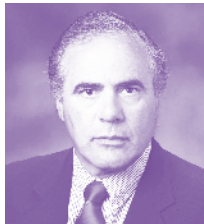
success, Tempur-Pedic will conduct an expanded version of the campaign in 2012.

"Tempur-Pedic is a forerunner in the corporate community in the fight against pancreatic cancer," said Julie Fleshman, Pancreatic Cancer Action Network President and CEO. "With their generous contributions, the company has made a bold investment in our goal to double the survival rate for pancreatic cancer by 2020."

"We are pleased to fund another Pancreatic Cancer Action Network research grant to move us closer to improving the survival rate and ultimately finding a cure," explained Rick Anderson, President of Tempur-Pedic North America, LLC. "We fully support the organization's comprehensive approach to combating this insidious disease. To that end, we are thrilled that with this year's award, we've been able to show our commitment to that approach by completing our support of the entire suite of research grants currently offered."

Monies raised throughout the year through Tempur-Pedic's efforts will fund a 2012 Tempur-Pedic Retailers – Pancreatic Cancer Action Network – AACR Innovative Grant. ✨

HONORING A CHERISHED FATHER'S LAST WISH



Roberto "Bobby" Friedman, PhD

Nick Friedmann's fund-raising efforts in memory of his father, Roberto "Bobby" Friedmann, PhD, who passed from pancreatic cancer in September 2011 at age 58, have surpassed even his own expectations. A Keep the Memory Alive page (www.fight4bobby.org) Nick created to support a Named Legacy Fund in his dad's honor has raised nearly \$44,000 to date, placing it among

the organization's most successful pages.

The outpouring of support from Dr. Friedmann's friends, colleagues and students at the University of Georgia, where he served as an educator for nearly 27 years, illustrates how beloved he was to all those who knew him.

Born in Montevideo, Uruguay, the elder Friedmann got the nickname Bobby at age 5 while attending an English preparatory school in his hometown. The moniker stuck even after he arrived in the U.S. in 1973 to attend the University of Kansas, where he earned a Bachelor of Science degree in Business and Economics, an MBA, and then a PhD in Marketing. In 1984, he was hired as an Assistant Professor of Marketing at the University of Georgia, where he eventually earned tenure as an Associate Professor.

In addition to individual donors, Nick credits local businesses in Athens and the University of Georgia as contributors to his fund-raising success. On November 21, 2011, he raised nearly \$9,000 through a benefit dinner and silent auction hosted by Athens's Taqueria La Parrilla restaurant. Donations of auction items from local businesses and franchises of national companies, including Outback Steakhouse and Chick-fil-A, boosted contributions.

A memorial service held at the University of Georgia's Performing Arts Center, planned by Dr. Friedmann himself, helped as well. "At the memorial, we set up a guest table with Pancreatic Cancer Action Network materials," said Nick, who manages a retail bank branch in Washington, D.C. "Because of widespread support we received from the university community, many opportunities were created for faculty, staff and students to donate."

Nick's mother, Liliana Jaso-Friedmann, PhD, a professor in the university's Department of Infectious Diseases, has been another major donor and supporter. "My mom, who is a 10-year breast cancer survivor, writes grant proposals to fund her own research," Nick said. "She has also reviewed grants for the National Science Foundation, the USDA and the National Institutes of Health, so she is keenly aware of the importance of federal funding to advance biomedical knowledge."

The family plans to continue their fund-raising efforts, including providing sponsorship for the 2012 PurpleStride D.C. Nick has also been working closely with the Government Affairs & Advocacy Office to help build support in Congress for the *Pancreatic Cancer Research & Education Act*. He will attend Advocacy Day in June as well.

The idea of supporting the Pancreatic Cancer Action Network occurred to the family when Dr. Friedmann was undergoing treatment at MD Anderson Cancer Center. "Later, when Dad was in hospice, he helped us choose it as the charity he wanted us to support. He was really impressed with both the mission and reputation," Nick said.

"Our family took this on to deal with our emotions about his death and to make a real impact in fighting the disease that took his life," he added. "We are proud to have helped fulfill one of his final wishes." ✨



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Register now for the
Sixth Annual Pancreatic Cancer Advocacy Day
 scheduled for June 25 and 26, 2012, in Washington, D.C.

To learn more and register, go to www.pancan.org/AD2012.

Registration will close on **May 11, 2012**, or whenever capacity is reached.



Right: Advocacy Day 2011

