

Translational Genomics Research Institute

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Kirsten's Legacy

THE POWER OF 1

PAGE 8



Michael Bassoff

A LOOK INSIDE...

Dear Friends,

At TGen, we recognize the **power of one**.

How one person, one family, one company can make a difference for thousands, possibly millions, of others. Even TGen's research focuses on the **power of one**, as many of our faculty study a single patient's unique genetic signature to guide that individual's course of treatment.

In this issue, you'll read the inspiring story of Kirsten Pasquinelli Sandstrom's valiant fight against adrenocortical carcinoma (ACC) and of her family's commitment to honor her memory through a contribution that enabled TGen to be the first in the world to use whole genome sequencing to spell out the DNA code of an ACC patient's tumor. In this way, the **power of one** woman led one family to better inform the care of others facing this rare and devastating cancer.

The **power of one** was again the focus when TGen faculty, collaborating with physicians at the Mayo Clinic in Scottsdale, used whole genome sequencing to help inform treatment options for a patient with a rare type of pancreatic cancer. One patient's unique genome sequence resulted in a precision treatment plan for that patient.

Globally, the **power of one** team of collaborative scientists from TGen, the Technical University of Denmark (DTU) and Northern Arizona University (NAU) identified the source of last year's cholera outbreak in Haiti, where the intestinal disease killed more than 6,000 people and sickened nearly 300,000.

Finally, perhaps no one understands the **power of one** better than Roger Magowitz, TGen's tireless pancreatic cancer advocate, whose battle cry is "If not me, then who?" On Page 4, you'll read how Roger's leadership led to a commitment by Mattress Firm Corporation to join TGen in support of its efforts to end pancreatic cancer.

I hope you will consider your own **power of one** and the impact that you could have on a single patient, or perhaps thousands of others, by financially supporting TGen's work at whatever level and in whatever way is comfortable for you. If you cannot make a gift at this time, I have outlined some of the easiest ways to plan a future gift on our back cover.

On behalf of everyone at TGen, I'd like to say thank you for helping us make a difference, one life at a time.

Michael Bassoff

A handwritten signature in dark ink, reading "Michael Bassoff". The signature is fluid and cursive, written in a professional style.

President, TGen Foundation

Translational Genomics Research Institute

TGEN TODAY



Cover Story Page **8** — Pasquinelli Sandstrom families establish AAC fund

On the cover - Kirsten Sandstrom

Photos of Kirsten and the Sandstrom family are courtesy of Deb Schwedhelm photography

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About TGen

The Translational Genomics Research Institute (TGen) is a non-profit organization dedicated to conducting groundbreaking research with life changing results. Research at TGen is focused on helping patients with diseases such as cancer, neurological disorders and diabetes. TGen is on the cutting edge of translational research where investigators are able to unravel the genetic components of common and complex diseases. Working with collaborators in the scientific and medical communities, TGen believes it can make a substantial contribution to the efficiency and effectiveness of the translational process. TGen is affiliated with the Van Andel Research Institute in Grand Rapids, Michigan. For more information, visit: www.tgen.org

One Man's Genome, One Man's Treatment

TGen teams with Mayo Clinic in one of the first uses of whole genome sequencing to inform patient care



Although in its infancy, many scientists and clinicians believe that whole genome sequencing (WGS) holds great promise as a therapeutic decision making tool, much the way X-rays became a powerful tool for informing diagnosis and treatment of a wide spectrum of diseases in the early 1900's.

Unlike the X-ray, however, which provides a contrasting image, WGS provides a macro view of an individual's complete genome — spelling out the DNA code of all 3 billion chemical bases— in both its healthy and disease state. And similar to the X-ray, as the technology develops and the costs drop, this ultra-DNA analysis may soon become a standard part of treatment, rather than an exception.

One of the first clinical uses of WGS occurred earlier this year when TGen scientists and physicians at the Mayo Clinic in Scottsdale used this advanced research technique to help inform treatment options for a patient with pancreatic cancer. Mayo physicians led the clinical aspects of the research, while TGen performed the sequencing.

"Whole genome sequencing provides the deepest look ever into the human genome," said TGen's Dr. John Carpten, whose lab led the sequencing effort. "By gathering more information we increase our probability to identify an 'Achilles heel', or treatment option, not previously recognized by more conventional approaches."

Other sequencing techniques —

such as genome-wide association studies — are less expensive tests, but examine only selected portions of DNA. Whole genome sequencing looks at the entire genome, giving scientists the most comprehensive view of the potential genetic origins of disease.

Even though scientists previously sequenced the whole genomes of several individuals in recent years, the TGen-Mayo teams believe theirs is one of the first successful applications of WGS performed in support of the medical care of a cancer patient enrolled in a clinical trial.

By comparing the tumor DNA to the patient's normal DNA, researchers found genetic changes (mutations) that could be important in helping inform doctors about how best to plan the patient's treatment.

While the TGen-Mayo sequencing occurred as part of an ongoing research project, it signals a major step toward implementation of WGS and informing clinic treatment options. And much like the X-ray, it illustrates the power of science and medicine interacting toward improved patient benefit.

"The long-term hope is that physicians will leverage this information to inform decisions about patient care in cancer, and beyond," said Dr. Carpten.



Dr. John Carpten

TRACKING DOWN CONTAGIONS

TGen tests can help stop real-world epidemics



Dr. Paul Keim

The types of high-security laboratories and halls of national and international health organizations depicted in this year's movie thriller *Contagion* are familiar territory for TGen researchers Dr. Paul Keim and Dr. Lance Price.

Dr. Keim, Director of the TGen Pathogen Genomics Division, and Dr. Price, Director of TGen's Center for Microbiomics and Human Health, work in the real world to hunt down microbes that could cause epidemics.

Using whole-genome sequencing, they recently teamed up with the Technical University of Denmark (DTU) and Northern Arizona University (NAU) to pinpoint the source of last year's cholera outbreak in earthquake-ravaged Haiti, where the intestinal disease killed more than 6,000 people and sickened 300,000.

TGen staff used cutting-edge technology to spell out the billions of chemical bases in DNA, providing the strongest evidence yet that peacekeepers from Nepal, where cholera is widespread, brought the disease to Haiti.

In a study published August 23 in a new online journal *mBio* and titled "Population Genetics of *Vibrio Cholerae* from Nepal: An identical clone in Nepal and the Haitian outbreak," researchers confirmed the source of the cholera, and — perhaps more importantly — suggest how to prevent such outbreaks in the future.

Dr. Keim, senior molecular biologist on the study, said methods he helped pioneer during the FBI investigation of the 2001 anthrax letters case and today's greatly diminished costs for whole genome sequencing make it possible to apply this powerful technology to new and critical public health challenges.

Dr. Price, an associate professor at TGen and co-author of the new study, said the investigation into the source of Haitian cholera could help prevent such outbreaks in the future.

"This effort validates the power of advanced molecular tools in investigating outbreaks of this nature," Dr. Price said. "The goal now should be finding ways to prevent such outbreaks, perhaps through screening prior to deployment. This study is not about placing blame, it's about preventing such disasters in the future."

Researchers confirmed the source of the outbreak by comparing the DNA of 24 cholera samples (the bacterium *Vibrio cholera*) from five different districts in Nepal with 10 samples of cholera from Haiti. All 24 samples from Nepal matched the samples from Haiti. Some of the samples, the report said, "were almost identical."

Dr. Keim was in Europe in recent weeks, talking with international health officials about how tests developed by TGen could help prevent such international disease outbreaks.



Dr. Lance Price

MATTRESS FIRM NAMES TGEN CHARITABLE PARTNER OF CHOICE

Nationwide bedding retailer supports TGen's efforts in pancreatic cancer research

When Steve Stagner (below), President and CEO of Mattress Firm, first met with TGen pancreatic cancer research advocate Roger Magowitz, he knew very little about the disease. Magowitz, a bedding industry veteran who had lost his mother to the disease, felt Mattress Firm would make an ideal supporter and partner of TGen. It didn't take long for Stagner to realize that a TGen-led alliance of the world's foremost scientists, physicians and advocates in the fight against pancreatic cancer was a cause worth supporting.

At Mattress Firm, charitable giving was about more than making leadership feel good; it was about social responsibility to customers, employees, vendors and the communities Mattress Firm serves. That is why in April, Stagner announced that Mattress Firm had developed the Mattress Firm Foundation, and that TGen's pancreatic cancer research would become its charitable partner of choice.

"Mattress Firm's support of TGen's research and clinical efforts to defeat pancreatic cancer provides our employees the opportunity to change lives and raise awareness of this devastating disease with every customer interaction," said Stagner.

Shortly after developing the Foundation, Mattress Firm launched its national alignment with TGen's pancreatic cancer research efforts at its more than 700 stores nationwide.

"Not only will we participate in local and national events to raise funds that support the research at TGen, but we will also use opportunities to educate our customers and communities about

pancreatic cancer and the TGen's research efforts. Awareness is the key to progress, and we have the opportunity to make a significant impact in our lifetime," Stagner said.

TGen's pancreatic cancer national advisory committee member Jai Pausch praised Stagner and the Houston-based mattress retailer. Pausch became a national advocate for pancreatic cancer following the death of her husband, Randy, a Carnegie Mellon professor and author of the bestselling book, *The Last Lecture*.

"As an advocate who understands how devastating pancreatic cancer can be for patients and their families, I applaud Mattress Firm's commitment to

TGen, and their effort to bring much needed resources and attention to our fight," Pausch said.

Stagner said he hopes that Mattress Firm's support of TGen will multiply and do for pancreatic cancer research and scientific discovery what the Susan G. Komen for the Cure organization has done for breast cancer.

"We have the opportunity to get involved and engaged with our communities, and impact the lives of over 44,000 Americans who are diagnosed with pancreatic cancer each year," Stagner said.

Pancreatic cancer is the nation's fourth leading cause of cancer death, and the only one of the 10 most deadly cancers with a survival rate in the single digits. Nearly 75 percent of the estimated 44,000 Americans diagnosed annually die within the first year: only 6 percent survive longer than five years.

According to Dr. Daniel D. Von Hoff, TGen's Physician-In-Chief and one of the world's leading authorities on pancreatic cancer, early detection of pancreatic cancer is non-existent, the survival rate remains low, and federal funding is a trickle for a river of need.

Less than 2 percent of the National Cancer Institute's federal research budget supports pancreatic cancer research.

"Discoveries directly follow funding, and pancreatic cancer receives little in comparison to the percentage of lives it takes," said Dr. Von Hoff, who leads a team from 45 institutes around the world who form the backbone of TGen's efforts. "Having the commitment of Mattress Firm will elevate TGen's efforts, and the monies raised will allow us to aggressively pursue the underlying



"MATTRESS FIRM'S SUPPORT OF TGEN'S RESEARCH AND CLINICAL EFFORTS TO DEFEAT PANCREATIC CANCER PROVIDES OUR EMPLOYEES THE OPPORTUNITY TO CHANGE LIVES."

— Steve Stagner



genetic causes of the disease and drive an unprecedented number of new therapeutic approaches to patient care.”

Donations to TGen enable the international team of physicians to move quickly on promising new clinical therapies.

Specifically, the funds enable scientists and clinicians to: identify diagnostic biomarkers as drug targets; identify and improve new agents that affect the activity of those targets; and evaluate new agents and take the most promising ones to clinical trials for patients in advanced stages of pancreatic cancer.



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— Jai Pausch

Simmons Bedding raises more than \$150,000

Simmons Bedding Co., makers of Beautyrest mattresses, raised more than \$157,000 recently for TGen and its pancreatic cancer research.

Simmons raised the funds during a promotion in which the company donated \$50 to TGen for every Simmons Beautyrest dual floor sample sold nationwide April 6-17 at nearly 700 Mattress Firm stores. The amount far exceeded the promotion’s \$100,000 goal.

“To be able to raise the amount of money we did in less than two weeks is inspiring,” said Steve Stagner, Mattress Firm’s President and CEO. “This is a cause that has affected several of our employees and that passion to make a difference really shines in our culture.”

In April, Mattress Firm announced that it named TGen its “charitable partner of choice,” specifically funding TGen’s pancreatic cancer research.

And in July, Mattress Firm announced fundraising efforts for TGen’s pancreatic cancer clinical trials.

On Dec. 3, Stagner will serve as Honorary Tournament Chairman for the 9th annual Seena Magowitz Celebrity Golf Classic (see Page 15) at the landmark Arizona Biltmore resort in Phoenix.

As many as 288 golfers will help support a TGen-led research initiative, which includes more than 40 institutes worldwide dedicated to finding a cure for pancreatic cancer, the nation’s fourth leading cause of cancer death.

Make a Difference

The TGen Foundation directs the philanthropic endeavors of TGen and drives its initiative in conjunction with the leadership of a pancreatic cancer national advisory council.

Your gift directly supports physicians and researchers in their efforts to cure pancreatic cancer, which is the most lethal — and yet underfunded — of all cancers.

You also can help raise awareness throughout your community and raise money by organizing fundraising events or engaging corporate partners.

To learn more about TGen’s efforts and to find out how you or your organization can become involved, please visit helptgen.org.

Representatives of foundations, corporations and major contributors may contact the TGen Foundation at 602-343-8411 or via e-mail at foundation@tgen.org.

Adrenocortical Carcinoma – ACC – Lab

Dr. Michael Demeure

Dr. Kimberly Bussey

Left to right:

Kaiti Schwartz, Research Associate II
Claire Linnehan, Graduate student at
Midwestern University

Lauren Morast, Helios Scholar
Dr. Kathryn Coan, Research Resident



Left to right: Dr. Michael Demeure, Kaiti Schwartz, Claire Linnehan, Lauren Morast, Dr. Kathryn Coan, Dr. Kimberly Bussey

THE TALES A SEQUENCE MAY TELL

First Whole Genome Sequencing of ACC Tumors Provides New Information

For too many years, patients diagnosed with adrenocortical carcinoma (ACC) had few treatment options and, sadly, even fewer physicians with experience treating the disease.

ACC is rare: less than 2 individuals in 1 million are susceptible. When the numbers are that low, few federal or philanthropic dollars flow toward studying the causes or finding a cure. That means fewer advances in diagnoses or therapeutic treatments.

At TGen, Drs. Kimberly Bussey and Michael Demeure hope to change that.

The latest advances at TGen began the day Dr. Demeure met Gary Pasquinelli, a

Yuma, Arizona, businessman and father of Kirsten Sandstrom, a young woman diagnosed with ACC.

Dr. Demeure had already worked closely with ACC survivor, Troy Richards, who was instrumental in establishing TGen's ACC program. Richards has actively raised dollars for ACC research through the Advancing Treatment for Adrenal Cancer (ATAC) fund. This program helped bring ACC research out of the dark ages and into the 21st century.

Shortly after Kirsten lost her battle with ACC, Pasquinelli donated \$1.5 million and joined forces with Troy to further TGen's ACC research program.

Pasquinelli's donation is allowing TGen scientists and clinicians to conduct the first whole-genome sequencing of ACC patients. This offers new insight into the possible causes of this extremely rare and aggressive form of cancer by identifying all 3 billion chemical DNA bases of ACC tumors. Researchers compare the cancer DNA to a patient's normal DNA to discover what's different; what mutations might cause the disease.

Drs. Bussey and Demeure lead a team of scientists and clinicians who, for the first time, have already completed the first whole genome sequencing of two ACC tumors.

How the Genetics of ACC Will Drive Therapeutic Decisions

ACC, which forms in the adrenal glands that sit atop the kidneys, grows rapidly and yet often goes undetected inside the abdominal cavity until its advanced stages. The adrenal glands produce hormones needed to deal with stress, fight infection and maintain normal body functions, such as blood sugar and blood pressure.

The letter-by-letter analysis provided by whole genome sequencing will allow researchers to identify genetic differences, and then leverage that information toward targeted and improved therapies.

“The rarity of ACC has limited therapeutic development for decades,” said Dr. Bussey, Co-Director of TGen’s ACC Research Program. “Our hope is that the information we obtain from whole-genome sequencing will enable us to pinpoint the abnormalities of this tumor, see what it tells us about its biology, and in turn, use that information against the disease in a clinical setting.”

With the sequence analysis in hand, the next step is prioritizing a list of potential therapeutic targets:

a protein whose activity is modified by a particular drug, which leads to a desired therapeutic effect.

Because researchers have not found mutations in genes commonly associated with cancer, they have turned their attention to cellular pathways, which are a series of chemical reactions that occur within a cell.

BY IDENTIFYING THE CELLULAR PATHWAYS BEST SUITED FOR TARGETED THERAPIES, WE SHOULD BE ABLE TO DRAMATICALLY IMPROVE THE OUTCOME FOR PATIENTS WITH ACC

“By identifying the cellular pathways best suited for targeted therapies, we should be able to dramatically improve the outcome for patients with ACC,” Bussey said. “At a minimum, we should make ACC a manageable disease and ideally, a curable cancer.”

Currently, the primary drug used for

ACC patients is mitotane, a chemical relative of DDT, which the U.S. banned as an insecticide in 1972. Mitotane chemotherapy, while effective on about 1 in 4 tumors, also causes DNA damage.

“Whole-genome sequencing is the only way you can begin to understand how the tumor is repairing its DNA,” Bussey said.

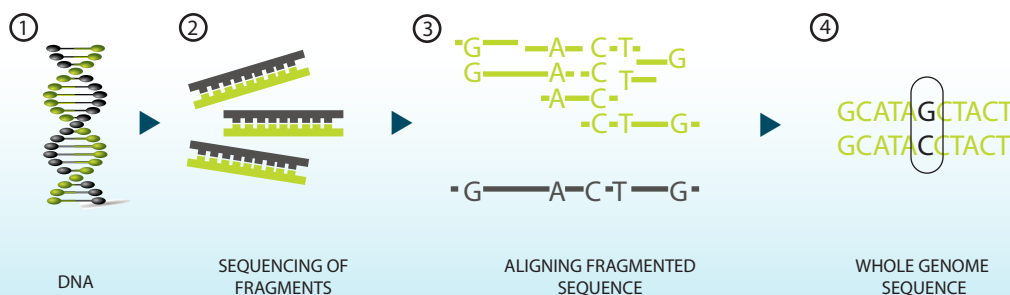
Today, with two of six planned sequences complete and a third underway, Dr. Demeure, an endocrine surgeon at Scottsdale Healthcare and Director of TGen’s Rare Cancer Program, views this accomplishment as a major step toward understanding ACC.

“It’s a great start,” said Dr. Demeure. “The information we glean from this effort will, without doubt, prove valuable.”

Plans are currently underway to initiate grant requests to support the sequencing of 36 additional genome sequences.

“Long term,” said Dr. Demeure. “The additional characterization of patient samples, particularly at the sequence level, will help us fully understand ACC biology and apply that knowledge to clinical practice.”

How Whole Genome Sequencing Works



Step 1: Patient DNA is extracted from healthy and disease tissue.

Step 2: DNA sample is broken into short fragments, allowing for faster sequencing.

Step 3: The sequence of all the fragments are then aligned against a reference genome.

Step 4: The aligned fragments are then compared (healthy vs. disease) to find those areas where differences (mutations) occur.

THE POWER OF

Pasquinelli-Sandstrom family establishes Kirsten's Legacy, to focus on ACC



ONE

research

To all those who knew her, Kirsten Pasquinelli Sandstrom was an extraordinarily caring and loving woman. As a wife, mother, daughter and friend, Kirsten displayed a level of grace and selflessness that lifted the hearts of her family and lent them strength as she herself endured a 21-month struggle with Adrenocortical Carcinoma (ACC) a rare and aggressive cancer of the adrenal glands that in the end, claimed her life.

Throughout her ordeal, as was Kirsten's way, she also served as a source of inspiration for others dealing with ACC, people whom she met while undergoing treatment or on-line via CaringBridge, a Web site that connects people experiencing similar health challenges.

Having touched the lives of all those she came in contact with —families, caregivers and researchers hoping to learn from her illness— her family saw an opportunity to help others while honoring Kirsten's memory.



Her parents, Gary and Barbara Pasquinelli of Yuma, Arizona, gifted \$1.5 million to TGen toward the establishment of Kirsten's Legacy, a program to drive much needed ACC research and clinical care advancements, and move new treatments quickly to the benefit of ACC patients. The Pasquinelli's made their donation as a challenge gift to help encourage others to support ACC research. TGen also established a Kirsten's Legacy website as a central resource for all things ACC related.

"From early childhood, you could tell she was genuinely concerned about others," Gary Pasquinelli said about his daughter, whose ACC diagnosis came in July 2008. "As was typical of her, she didn't question 'Why me?' She didn't despair. She didn't drown in self-pity, and seek consolation from everybody.

On the contrary, she consoled us."

Barbara Pasquinelli said that, even though ACC is a rare disease, it is her family's hope that research breakthroughs at TGen will not only benefit ACC patients, but will also have applications for other types of cancer.

Today, Kirsten's Legacy funds the first whole-genome sequencing of ACC patients, a study designed to offer new research insights by identifying the 3 billion chemical DNA bases of ACC tumors. Researchers hope that by comparing the cancer DNA to a patient's normal DNA they'll discover what's different: in short, the changes at the DNA level that might cause the disease, and chemical pathways that will enable improved treatment, perhaps even a cure.

"Our hope is that TGen's efforts surrounding ACC will have utility and benefit on other types of cancer as well," Barbara said.

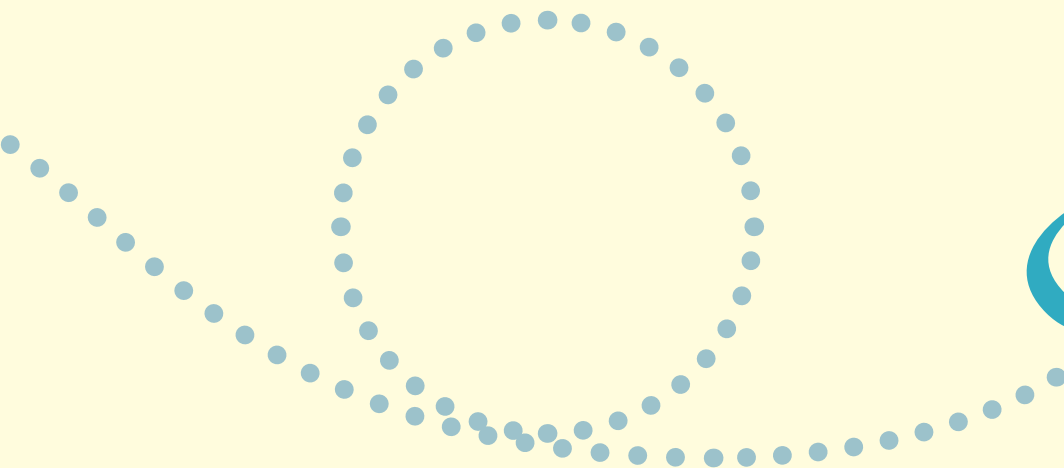
And she doesn't want ACC patients and their families to struggle in the wake of a loved-one's diagnosis when they seek even basic information about this disease.

"We had such trouble finding information on ACC that we want the Kirsten's Legacy website to be an information center, a place where you can get substantial information about ACC without having to go through what we went through," Barbara said. "We hit roadblock upon roadblock, and every doctor told us something different."

In contrast, Gary said, the TGen staff consistently went the extra step to counsel and assist Kirsten and her



The Sandstrom family: Ed and Kirsten with sons, clockwise from left, Jake, Bailey and Holden



family at every turn in her treatment, boosting Kirsten's already indomitable fighting spirit.

"The legacy of that fighting spirit, it lives on genetically in her children and her family. But we want it to live on at TGen, too, through their research, to let others have that hope and that fighting spirit, to have their courage renewed. There are some very brilliant, passionate people working at TGen to end this disease," Gary said.

Kirsten's husband, Ed Sandstrom, also praised the staff of TGen, especially Kirsten's surgical oncologist, Dr. Michael Demeure, Dr. Raoul Tibes and patient care specialist, Joyce Schaffer.

"At TGen, the doctors showed so much care and concern and knowledge about such a rare and unique disease. That gave Kirsten hope, and they gave our family hope," Ed said. "Time and again, they put the well-being of the patient and family above all else. They were authorities on the subject when there was so little information out there."

The difficulty in learning of a cancer diagnosis is described in vivid detail in a school essay by one of Ed and Kirsten's three sons, Bailey:

"I asked in a cautious voice, 'What's wrong, Dad?' He told us to sit down with him and said, 'Mom is really sick, and the doctors say she has cancer.' My heart skipped a beat. I was still wondering if he said this right. Could that even be possible? When I looked around the room, everything was

fuzzy and I could not see anything. It was then that I heard my innocent little brother, Jake, ask, 'What's cancer?' At that moment, I knew he would feel unimaginable pain far worse than what Holden (Bailey's twin) and I were currently feeling. I knew that we all wanted to hug our Mom and never let go."

Kirsten's family wants to help ease that pain for others.

BY FUNDING THIS RESEARCH, KIRSTEN'S FAITH AND COURAGE LIVE ON THROUGH THE SUCCESSES I KNOW TGEN WILL ACHIEVE

"We felt so lost and so unsure of what to do," Ed said. "We want to make sure there is hope. We want to support families working through that initial shock of an ACC diagnosis, to provide a resource that will provide some peace of mind."

Gary's voice trembles when he recalls the courage, faith and fortitude with which Kirsten addressed her illness.

Following a scan that showed a particular drug had failed, Kirsten immediately turned to her husband and said, "Eddie, I'm so sorry this didn't work," Gary recalled. "She wasn't worried about herself as much as how the bad news affected her husband."

When Kirsten visited hospitals for chemotherapy, she went out of her way to bring treats for the nurses, Gary said. "She became the caregiver. Because of her attitude, she brought a lot of cheer and smiles into that unlikely place, the chemo ward, where they were really needed."

In making their gift, Gary and Barbara believe their daughter's legacy of caring lives on at TGen.

"We're impressed," they said, "not only by the scientific expertise, but because the people are so passionate about what they are doing. To us — and to Kirsten— that's an essential quality. Sure they've got the science and the big computers, but what's most impressive is the genuineness and care of all we've met."

The Pasquinelli's recalled how much Kirsten expressed her trust in God. "She said, 'You know Mom and Dad, I'm not afraid to die. I know where I'm going. I know God loves me. I know there's a heaven and I'll go wait for you guys.'"

Gary said he believes that Kirsten's faith and courage are reflected in the work at TGen.

"What we hope to do at TGen through Kirsten's Legacy is this: She doesn't have to be physically alive for her faith and courage to be contagious, to give others hope. By funding this research, her faith and courage live on through the successes I know TGen will achieve. And in turn, those successes will give others with ACC a chance."

Luxembourg appoints President Trent as Trade Counselor



Dr. Jeffrey M. Trent

Dr. Jeffrey M. Trent, TGen's President and Research Director, has been appointed Foreign Trade Counselor of Luxembourg in the United States.

cancer, a highly aggressive form of this cancer that disproportionately affects African-Americans.

Komen recently called for proposals from teams of physicians and scientists called Promise Grants, multi-million dollar, multi-year, collaborative grants aimed at answering the most difficult questions in breast cancer and translating their findings into outcomes that will impact patient care.

Only three teams were selected for funding for this highly competitive program. One of the team leaders is TGen President and Research Director Dr. Jeffrey Trent. The other two are Dr. Pat LoRusso of the Karmanos Cancer Institute in Detroit, and Dr.

Executive Board of the 45-member international Pancreatic Cancer Research Team.

PCRT is a network of clinical trials sites organized under TGen Drug Development (TD2) and provides the research backbone of our efforts to wipe out pancreatic cancer.

"PCRT is now more than 8 years old and is growing and becoming a major force for pancreatic cancer treatment across the nation and across the globe, especially as we branch into Europe," Dr. Ramanathan said.

TGen Physician-In-Chief Dr. Daniel D. Von Hoff also is a member of the PCRT Executive Board.

into place, we are making steady progress in the development of diagnostic and prognostic biomarkers for lung, colon, breast and pancreatic cancer as well as other diseases," said Dr. Petritis.

Dr. Weiss heads international lung cancer consortium



Dr. Glen Weiss

Dr. Glen Weiss, who holds joint appointments at TGen and at the Virginia G. Piper Cancer Center at Scottsdale Healthcare, is the new Chief Medical Officer of an international lung cancer research consortium.

In this new position, Dr. Weiss heads the Cancer Research and Biostatistics-Clinical Trials Consortium (CRAB-CTC), a Seattle-based cooperative research network, created by a group of preeminent lung cancer investigators. It represents more than 10 institutes worldwide dedicated to funding and facilitating clinical trials, thereby providing lung cancer patients with newly developed therapeutics as quickly as possible.

"Our Consortium's explicit mission is to organize and accelerate the clinical development of new agents for the treatment of patients with lung cancer," said Dr. Weiss, an Assistant Professor of TGen's Cancer and Cell Biology Division and Director of Thoracic Oncology at Virginia G. Piper Cancer Center Clinical Trials, a TGen partnership with Scottsdale Healthcare.

TGEN IN BRIEF

Dr. Trent has been a leader in promoting cooperation in science, technology, and economic development between Luxembourg and the United States. He has played a pivotal role in building the Luxembourg personalized medicine infrastructure, including the Integrated Biobank of Luxembourg and the lung cancer research and development projects with the Luxembourg National Health Research Center (CRP-Sante).

"I'm honored by this appointment and look forward to continuing to support the efforts to develop the biomedical knowledge-based workforce in Luxembourg," said Dr. Trent.

TGen breast cancer research benefits from \$3.5 million Komen award

TGen is part of a team of medical investigators receiving a \$3.5 million grant from Susan G. Komen for the Cure to study triple-negative breast

Max Wicha of The University of Michigan Comprehensive Cancer Center. Other centers collaborating on this project include the Van Andel Research Institute (VARI) in Grand Rapids, which is TGen's affiliate, and the Baylor College of Medicine in Houston.

Dr. Ramanathan named chairman of PCRT



Dr. Ramesh Ramanathan

Dr. Ramesh K. Ramanathan, Clinical Professor and Deputy Director of TGen's Clinical Translational Research Division, is the new Chairman of the

TGen Proteomics is named Center of Innovation



Dr. Konstantinos Petritis

TGen's Center for Proteomics is moving forward with collaborations that position it to be an international leader in using proteomics for biomarker discovery and verification.

In August, Massachusetts-based Waters Corporation, one of the world's largest developers of analytical technologies, recognized TGen's Center for Proteomics, headed by Dr. Konstantinos Petritis, as a Waters Center of Innovation, one of fewer than 20 such centers worldwide.

"With the infrastructure we've put

TD2 recognized for economic development of Arizona biosciences



Dr. Stephen Gately

TGen Drug Development (TD2) won a Fast Lane award from the Arizona BioIndustry Association (AZBio) for promoting the economic development of Arizona biosciences.

TD2, a subsidiary of TGen, provides world-class clinical and regulatory expertise to biopharmaceutical companies using cutting-edge technology to minimize the risks in cancer drug development. TD2 works to shorten the development cycles for anti-cancer agents and improve their success rates.

"TD2 is at the forefront of helping pharmaceutical companies navigate the regulatory system to get the safest, most effective compounds as quickly as possible to the patients who need them," said Dr. Stephen Gately, President and Chief Scientific Officer of TD2.

"This award not only recognizes the good work of TD2, but is reflective of all the advancements of TGen, and of our collaborators."

Since 2002: jobs in Arizona's bioscience industry grew 32 percent; the number of bioscience and related firms including research, manufacturing, testing, medical labs, and healthcare delivery systems grew 28 percent; and research partnerships with the National Institutes of Health (NIH) increased 65 percent. Arizona bioscience organizations now generate \$21 billion in annual

revenues and \$765 million in state and local taxes.

"Organizations like TD2 and their partners ensure that we keep advancing healthcare at an ever increasing rate," said Joan Koerber-Walker, President and CEO of AZBio.

Gene found that might lead to kidney failure



Dr. Johanna DiStefano

A gene called PVT1 may help reduce the kidneys ability to filter blood, leading to kidney disease, kidney failure and death, according to a study published by TGen researchers in the online scientific journal *Public Library of Science (PLoS) ONE*.

The TGen team found PVT1 expression levels increased up to 5-fold in response to hyperglycemia, or high blood sugar, a condition that often accompanies diabetes. But by knocking down or reducing the expression of the PVT1 gene, TGen researchers lowered the amount of proteins associated with the excessive accumulation of extracellular matrix (ECM) in glomeruli, part of the basic filtration unit of kidneys.

"The goal of this study was to identify possible molecular mechanisms by which PVT1 may contribute to the development and progression of diabetic nephropathy in mesangial cells," said Dr. Johanna DiStefano, the study's senior author and Director of TGen's Diabetes, Cardiovascular and Metabolic Diseases Center.

New drug effective in blocking skin cancer

A new drug is effective in preventing new basal cell carcinomas in patients with an inherited predisposition to the disease.

These patients with basal cell nevus syndrome develop large numbers of basal cells, which can become locally invasive or metastatic, according to a discussion presented by TGen's Physician-In-Chief Dr. Daniel Von Hoff at the 102nd annual meeting of the American Association for Cancer Research (AACR).

Dr. Von Hoff and his team at the Virginia G. Piper Cancer Center Clinical Trials at Scottsdale Healthcare found that the drug, vismodegib (GDC-0449), a hedgehog pathway inhibitor, was effective in shrinking advanced invasive or metastatic basal cell carcinomas.

TGen receives \$50,000 for rare breast cancer study



Dr. Heather Cunliffe

The Inflammatory Breast Cancer Research Foundation (IBCRF) has awarded \$50,000 to TGen to discover the genetic causes of this rare and most deadly form of breast cancer.

Unlike other types of breast cancer, Inflammatory Breast Cancer (IBC) is very often

misdiagnosed, and rapidly progresses to an advanced stage, said Dr. Heather Cunliffe, Head of TGen's Breast & Ovarian Cancer Research Unit.

"No one knows what causes IBC and what drives the aggressive nature of this disease," Dr. Cunliffe said. "You can wake up one morning and out of the blue your breast will be twice its normal size, red and inflamed with full blown Inflammatory Breast Cancer."

TGen graduate students each receive \$50,000 from Salt River Project

Two Arizona university graduate students working at TGen have each received \$50,000 grants from the Salt River Project (SRP).

Jolene Bowers, a Research Associate III at TGen's Pathogen Genomics Division in Flagstaff, and Brooke Hjelm, a Research Associate in TGen's Neurogenomics Division in Phoenix, are each the recipients of \$50,000 awards from SRP's Arizona Graduate Student Support Program.

This program promotes the recruitment, development and retention at TGen of high quality graduate students from Arizona universities, and highlights TGen's commitment to the training and career development of Arizona's future scientists and technical innovators.

"Our partnership with TGen stretches back to its very first days and we are proud to continue supporting the important work being done by its staff and by graduate students from Arizona universities," said SRP General Manager Mark Bonsall.

Visit www.tgen.org/news for more.



WAYLON FUND HITS THE RIGHT NOTE IN SEEKING END TO DIABETES

Waylon Jennings, who lived much of his storied career in Arizona, at times led a difficult life, and it only got harder when he developed diabetes.

Like a lot of songwriters, his personal challenges led to redemption and fueled the emotional power of his music. But in 2002, at age 64, he died of complications related to diabetes.

Now, his legacy is powering a new initiative at TGen aimed at finding new treatments and someday a cure for diabetes, a growing threat to the nation's health that already afflicts nearly 26 million Americans.

Jessi Colter and Shooter Jennings, the late country music legend's wife and son, worked with TGen to establish the Waylon Fund for Diabetes Research.

"We now have a chance to honor the man who loved his country, his family and cared so much for his community, by helping to speed the development of new treatments for those suffering from this terrible disease," said Jessi Colter.

Waylon Jennings bucked the Nashville corporate establishment, pushing for creative freedom that led to his "Outlaw" collaborations with the likes of Johnny Cash, Kris Kristofferson and Willie Nelson. He is famous for songs like *Good Hearted Woman*, *Luckenbach*

Texas, and *Mammas Don't Let Your Babies Grow Up to Be Cowboys*, and also for the theme song to the popular *The Dukes of Hazard* television show.

Now, his "kicking down the doors" style of music will infuse the Waylon Fund for Diabetes Research, supporting state-of-the-art investigations into the genetic and genomic origins of diabetes in an effort to produce better treatments and give patients better quality of life.

"I am honored to put Waylon's name behind TGen's diabetes research efforts. I have met the researchers and am confident that donations in Waylon's memory are an investment that will lead to better ways of preventing and detecting the disease," said Jessi Colter.

Just as his Outlaw genre spearheaded the crossover appeal and re-popularization of country music, the Waylon Fund will enable TGen to challenge conventional ideas and discover novel ways of attacking diabetes.

"TGen is extremely grateful to the family of Waylon Jennings, who have so generously allowed his name to be the inspirational centerpiece of this promising new research effort," said TGen Foundation President Michael Bassoff.

All contributions to the Waylon Fund will be put to work immediately to speed the development of new treatments by enabling TGen researchers to conduct comprehensive genomic, or DNA, analysis of diabetes, using the latest technology.

Dr. Johanna DiStefano, Professor and Director of TGen's Diabetes, Cardiovascular & Metabolic Diseases Division, leads a team of researchers focused on the genetic factors that cause or contribute to complications due to Type I and Type II diabetes. Under Dr. DiStefano's direction, TGen's team of scientists has important work underway in five areas of diabetes research: heart disease, diabetic nephropathy, obesity, liver disease, and individualized treatment strategies.

From Dr. DiStefano's most recent work, which replicates findings and characterizes a cellular pathway that contributes to diabetes through changes in gene expression, to the discovery of genes and genetic markers that contribute to our overall body of knowledge surrounding diabetes and its associated complications, TGen is at the forefront of today's diabetes research.

UPCOMING TGEN FOUNDATION EVENTS



November 6, 2011

On the Run

6th annual stepNout Run/Walk/Dash
Kiwanis Park, Tempe, Ariz.

You, your family and friends can make a commitment to wipe out pancreatic cancer by joining us for the 6th annual stepNout Run/Walk/Dash. Activities include a change drive, silent auction and awards. Registration begins at 7 a.m. on race day. Register online in advance. Join a team. Sponsor a runner. Make a donation and help us wipe out pancreatic cancer, one step at a time.

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Visit www.helptgen.org for more information on these events.

December 3, 2011

Philanthropy on the Fairways

9th annual Seena Magowitz
Celebrity Golf Classic

Arizona Biltmore, Phoenix, Ariz.

Join us at one of the premier charity golf tournaments in Arizona, supporting pancreatic cancer research at TGen. Registration begins at 6 a.m on December 3. Activities include silent auction and 19th Hole luncheon and awards ceremony.

December 10, 2011

2nd Annual James R. Machnicki Golf Benefit

Sun Village East, Mesa, Ariz.

Join us on the greens as we tee off in support of pancreatic cancer research. Activities include raffle, BBQ luncheon & awards.

January 15-22, 2012

Classic Cars on the Block

Scottsdale, Ariz.

The 41st annual Barrett-Jackson Auction at WestWorld in Scottsdale, the world's largest auction of collector automobiles, will benefit TGen's colon and prostate cancer research through the Barrett-Jackson Cancer Research Fund at TGen. Craig Jackson, Chairman and CEO of Barrett-Jackson Auction Company LLC, established the fund in honor of his father, Russ, and brother, Brian.

This year, more than 83,000 Americans will lose their life to colon and prostate cancer, but with your support TGen scientists and physicians can accelerate the development of new diagnostic tests and therapies, and help save lives.

Connections, challenge pledge, drive unTEAL A Cure fundraiser



Foster and Lynn Friess continue ovarian cancer research support with \$79,000 matching gift

Every cause has its supporters. For unTEAL A Cure, a fundraising effort backing ovarian cancer research at TGen, philanthropists Foster and Lynn Friess (upper right) are true champions.

Ovarian cancer — represented by the color teal — is a highly aggressive disease that strikes 21,000 American women each year. It is the fifth-leading cause of cancer death among women in the U.S., claiming the lives of nearly 14,000 women annually.

Thanks to the Friesses, the second annual unTEAL A Cure 5-kilometer race more than doubled its initial fundraising goal of \$75,000. Through a matching gift challenge, the Friesses donated an additional \$79,000 to the event held March 6 at Tempe's Kiwanis Park, pushing the total raised to more than \$179,000.

The Friesses, of Jackson, Wyoming, and Scottsdale, Arizona, learned of the unTEAL effort through Judy Jost of Cave Creek, Arizona, Foster's personal assistant. In 2007, Judy's 22-year-old daughter, Taryn Ritchey, passed away from ovarian cancer.

"We believe we can win the battle against this disease," said Foster Friess. "The progress made by TGen in terms of understanding the genetic causes of ovarian cancer provides hope for all those involved with unTeal A Cure."

The Friesses challenge spurred the 800 participants in this year's event — including 22 ovarian cancer survivors — to redouble their efforts, knowing that every dollar counts when it comes to funding research. Their efforts paid off.

A Personal Connection

For Christal Gustafson of Scottsdale, unTEAL A Cure co-chair, the connection hit closer to home. She wants to stop ovarian cancer, which afflicted her mother, Calista Rea of Jefferson City, Missouri.

"The day my mom was diagnosed with stage four ovarian cancer, she promised me she would fight," said Gustafson. "She held her promise to the bitter end. Now it's my fight, and I'll fight for prevention, effective diagnosis, and to find for a cure. I want to prevent this cancer from touching the lives of my nieces and future granddaughters."

Funds raised through this year's unTEAL A Cure event support groundbreaking research aimed at translating scientific discoveries into improved clinical care and enhancing the quality of life for ovarian cancer patients.

"Thanks to many concerned, generous contributors, the research conducted by TGen faculty brings us closer to the day when women worldwide will no longer fear ovarian cancer," said TGen Foundation President Michael Bassoff. "We are grateful to Mr. and Mrs. Friess and the hundreds of people who joined with them to support TGen research, and make a difference for the nearly 21,000 women diagnosed with the disease each year."

To learn more about TGen's ovarian cancer research and how you can get involved, please visit our website at www.helptgen.org/ovariancancer.





Kelly Kinney always admired her brother Bret Conners' love of the outdoors and his passion for living a full and energetic life.

Bret's adventures across the Southwest and beyond led him to ski steep black-diamond slopes in Aspen, hike the red rocks of Sedona, race boats on the Colorado River, and deep-sea fish off the coast of Mexico.

Shortly after Bret turned 49, however, his life took a fateful turn.

A trip to the doctor revealed Bret had pancreatic cancer. Considered the most deadly of all cancers, and nearly always detected in its advanced stages, only 25 percent of pancreatic cancer patients survive more than a year. Through courage, a positive attitude and persistence, Bret beat the odds: he survived three and half years before losing his battle in early 2009, leaving behind his wife of 25 years and their three sons.

His sister Kelly, a resident of Toledo, Ohio, credits TGen's clinical trials program with providing Bret those extra years. Shortly after his passing, Kelly began searching for a way to honor Bret's memory, as well as help others facing their own battle with pancreatic cancer.

"I've always found comfort in nature," Kelly said. "So I thought of growing hope by providing resources for both continued research and additional clinical trials."

Kelly's idea was to sell small potted flowers, a concept truly unique in its approach, but one that seemed a fitting tribute to her brother. While not an easy concept to sell, Kelly persisted.

After several nursery retailers turned her down, Kelly eventually found a receptive ear in an owner whose own life had felt the impact of pancreatic cancer: she had lost her mother to the disease. The owner put Kelly in touch with the area's Maumee Valley Growers and soon after 16 affiliated northwest Ohio greenhouse retailers chose to participate.



Sowing the Seeds of Hope

With her newfound partners, Kelly initiated Plant Purple-Grow Hope to honor Bret's life. The growers and nurseries selected "denim shock wave petunias" as the campaign's flower of choice, because they are easy to care for and their purple hue matches the color symbolizing pancreatic cancer awareness.

During May and June, Plant Purple-Grow Hope participants set aside 50 cents for every 4.5-inch purple petunia pot sold. The funds raised support TGen's pancreatic cancer research. The attention the cause drew raised awareness about this deadly disease, which receives less than two percent of all federal research dollars for cancer.

"We are delighted to be the first grower organization in America to partner with TGen in support of this important cancer research," said Joe Perlaky, Program Manager for the Maumee Valley Growers.

Kelly and her partners are currently planning next year's event, and have hopes that a "shock wave" of purple flowers will eventually roll across America in support of scientific research to end pancreatic cancer.

"Bret lived a full and energetic life," said Kelly. "To him, every day was an adventure, an opportunity to experience new things, and enjoy every moment. My hope is that this program draws on that energy and truly makes a difference in defeating pancreatic cancer."

To launch a Plant Purple-Grow Hope program in your community, please contact Erin Massey at the TGen Foundation at 602-343-8470 or emassey@tgen.org.



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PLANNED GIVING 101

TGen is pleased to offer a wide-variety of ways you can make planned gifts that will help you meet your philanthropic goals.

The simplest type of planned gift is a bequest. You might also consider naming TGen as a beneficiary of your life insurance policy. Another simple giving vehicle that will benefit you as well as TGen is a charitable gift annuity, which will provide you with an income for life.

Bequests

A bequest is perhaps the most widely used form of planned giving. Most of us are familiar with the need to make a will, but according to an AARP survey, 40 percent of Americans (2 out of 5 over the age of 45) do not have a will. It is important to have a will for many reasons, including the appointment of guardians for minor children, the distribution of assets according to your wishes, and the ability to make a legacy gift to your favorite charity. Whether it's an unrestricted gift to support the general charitable purposes of your

favorite non-profit, or a restricted gift to benefit a certain program at the institution, your gift will be greatly appreciated by the organization and help it carry out its important work.

Life Insurance

It couldn't be simpler, though many individuals have not considered this easy way to leave a lasting charitable legacy. All you need to do is to name your chosen 501(c)(3) organization as a beneficiary on your life insurance beneficiary designation form. You can select the percentage that you want the organization to receive as either an original or contingent beneficiary. It is important to review your life insurance beneficiary designations from time to time, especially should your marital status change, or should you have a new baby, or if your minor children are now comfortably on their own. The next time you do so is the perfect opportunity for you to name a charitable beneficiary and ensure your support of an organization that is special to you.

Charitable Gift Annuities

Given the current low interest rates paid by banks on CDs, now is the time to consider a charitable gift annuity that will pay you (and/or you and a joint beneficiary) an income for life followed by a gift of the remaining funds to establish your legacy at TGen. TGen has partnered with Arizona Community Foundation (ACF) to administer its gift annuity program. The recently published rate of return for a person 78 years of age is 7 percent, which is a significant rate of return in today's environment. Upon the donor's passing, ACF holds the charitable gift annuity as an endowment to benefit TGen in perpetuity.

Please contact the TGen Foundation regarding these beneficial ways of making a gift that has lasting value for you and for TGen.

To learn more about TGen's planned giving program, please call 602-343-8411, or e-mail at Foundation@tgen.org.