Deadly pathogens are no match for

DR. ANTHRAX

PAGE 6
Thanks to a collaborative partnership with the Arizona Community Foundation (ACF), TGen is now pleased to offer our donors the opportunity to make planned gifts through the use of charitable gift annuities.

ACF has been a philanthropic leader in Arizona for more than 30 years, and TGen and ACF are privileged to share the leadership of some of the same individuals who serve on both organizations’ Boards. We are honored to work with ACF and provide our generous supporters with yet another way to benefit TGen.

I hope you will read the article on Page 17, which further outlines this effort and provides additional information about the particular benefits of gift annuities. If you have questions regarding charitable gift annuities or other planned gifts, including bequests, please feel free to contact me, Denise A. McClintic, J.D., LL.M., Associate Vice-President, TGen Foundation, at 602-343-8611 or at dmclintic@tgen.org.
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
Getz’s gratitude to Mayo, his expertise in banking and finance, his evolving interest in furthering the frontiers of medicine — and his connections to Arizona at a time when Mayo was expanding to the Grand Canyon State — eventually led to 16 years of service on Mayo Clinic’s national Board of Trustees, his final four as Board Chairman.

Meantime, as Chairman of the Globe Corporation — a diversified real-estate development and investment group — Bert Getz splits his time between Chicago, where Globe started, and Scottsdale, where the company makes its headquarters today.

His many business interests have included the one-time Arizona Bank, known for its distinctive “Dawn of a New Day” Katchina logo. Arizona Bank eventually merged into today’s Bank of America.

Getz also helped found the Arizona Community Foundation, which has grown since 1978 into a $471 million enterprise that donates millions annually to nearly 3,500 non-profit organizations, educational institutions and government agencies in Arizona and across the nation.

His leadership and interest in business and medicine also led Getz to become the founding chair of Mayo Clinic Leadership Council in Arizona.

So, when TGen founders looked around for someone with strong Arizona connections, who could also help forge alliances with Mayo, Getz was a natural choice.

“I believe in scientific collaborations. I think you can avoid a tremendous amount of duplication of effort and resources,” Getz said of his interests in tying TGen to Mayo and other key collaborators, such as Arizona’s three state universities. “The faster we can bring these science advances to the market, the better off everybody is going to be.”

As one of the founding members of the TGen Board of Directors, Getz has championed many of TGen’s most significant actions, including...
the establishment of TGen Drug Development (TD2) and other TGen operations next to the Mayo Clinic in Scottsdale.

Former Phoenix Mayor Skip Rimsza, another founding TGen Board Member, said that without Getz’s business savvy, it is doubtful that TGen would ever have been created.

“Bert was a visionary from the private sector, and without his support, I don’t think we could have made TGen happen,” Rimsza said. “He was critical to getting us over the top. At the time, there were no guarantees that TGen would turn out as wonderfully as it has.”

Getz also was a strong backer of what he calls TGen’s most significant decision: Forging an alliance and affiliation agreement with the Van Andel Research Institute (VARI) in Grand Rapids, Mich., a move that he says will bolster TGen’s financial position. Having attended the University of Michigan, Getz used his college connections to help ensure that the TGen-VARI scientific merger would be advantageous to both parties.

“Without question, Bert Getz has been one of the foremost champions of patients and TGen’s ability to provide patient benefit,” said Dr. Jeffrey Trent, TGen’s President and Research Director. “Because of Bert’s business acumen, his presence on the TGen Board has provided the institute with extremely competent guidance since

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**Taking a tour with Bert**

**Globe Corporation headquarters: A family museum**

Visiting the Scottsdale headquarters of the Globe Corporation is like taking a tour of a museum, actually multiple museums.

Original western art lines the lobby and main hall, including a silver engraved leather saddle adorned with small golden bullheads. A giant chessboard sports opposing armies of Kachinas.

On the walls of the boardroom are life-size portraits of members of the Getz family, including one of George Fulmer Getz Sr. — complete with hat and cane — who founded the Globe Corporation in 1901 in Chicago as a coal distribution company.

Over the decades, the company evolved, achieving success in manufacturing, banking and finance. Today, it is a diversified investment company, concentrating on real estate, asset management and private equity.

One room at the headquarters contains Getz family memorabilia. There's a collection of dozens of Mickey and Minnie Mouse carvings, including Mickey and Minnie Kachina dolls.

The walls of the break room are lined with the blue and white porcelain Christmas dishes issued every year since 1908 by Denmark’s Royal Copenhagen Manufactories.

Turn a corner and a floor-to-ceiling bookcase contains every bound copy of National Geographic magazine since the National Geographic Society began in January 1888 — considered one of the few such complete collections in the world.

In the office of the founder’s grandson, Chairman Bert A. Getz, stands a 3-foot-high Talavai, or dawn, Kachina, once used as the logo for Arizona Bank, later part of Bank of America.

Near his desk hangs an original oil painting by artist LeRoy Neiman of hockey great Robbie Furek.

Getz reaches for a National Geographic map of Antarctica as he explains the penguins that adorn his tie, designed by his wife, Sandy. He points to an area on the edge of the frigid continent, a more than 300-mile-long stretch of frozen shoreline identified as the Getz Ice Shelf. It is named for his father, George Fulmer Getz Jr., who helped furnish the seaplane used in 1940 by explorer Admiral Richard E. Byrd. A letter of thanks from Admiral Byrd hangs on the office wall.

Bottles of Getz Ice Shelf water line a bookcase shelf.

Bert Getz visited Antarctica in 1994, taking dozens of slide photos, especially of penguins, which he displays during an annual lecture he gives to 8-year-old students of All Saints’ Episcopal Day School in Phoenix, a ritual he started for his grandchildren.

“I’ve been very fortunate,” Getz said.

One Getz-inspired collection is not in Scottsdale, but in Phoenix’s Papago Park. The Hall of Flame Museum of Firefighting houses more than 90 fully restored pieces of antique firefighting apparatus. The National Historic Fire Foundation, formed in 1961 by George Fulmer Getz Jr., runs the museum.

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I envision many of TGen’s discoveries leading to successful commercial applications and new companies.
Dr. Scott Jewell envisions a time when the number of patients contributing biospecimens available to scientists at TGen and the Van Andel Research Institute (VARI) would exceed 1 million.

And the subsets of biological samples — blood and tissue, especially from cancer tumors — would run into multiple millions.

But even more important than the number of samples, Dr. Jewell said, is how — over time — TGen-VARI will develop new ways for those samples to benefit the process of discovery.

“More important than the number of samples is the structure to make them valuable and useful,” said Dr. Jewell, recently appointed Director of the newly established, inter-institutional Program for Biospecimen Science (PBS). “One major goal would be that, as time transpires, significant accomplishments towards new findings in the treatment of patients’ disease will result.”

Dr. Jewell is also a Professor and Deputy Director for Research Resources at TGen and VARI. In that capacity, he will focus on the development and improvement of best practices for biospecimen collection, processing, storage and distribution through biospecimen research.

The PBS will have a central office and a biorepository at VARI in Grand Rapids, Michigan, but also will combine resources developed at TGen in Phoenix under Dr. Galen Hostetter, Associate Investigator in TGen’s Integrated Cancer Genomic Division.
Dr. Jeffrey Trent, President and Research Director of TGen and VARI, recently told a meeting of all employees that the PBS program is a key example of the integration of the two research institutes.

PBS at VARI consists of nearly 1,000 square feet of office, 1,800 square feet of biopsy repository space, and 3,200 square feet of laboratory space. In addition, VARI has nearly 18,000 square feet of build-out space for the future expansion.

Special technologies for the PBS program include: high-throughput nucleic acid isolation technology, which uses differing chemistries for the isolation of RNA and DNA in fluids or tissues; RNA quality spectrophotometers; digital imaging microscopy; tissue microarray technology; genomic microarray technology; histology laboratory services; and specialized software for the management, documentation and annotation of biospecimens.

Recruited from Ohio State University, where he earned his master’s and doctoral degrees in experimental pathology and immunology, Dr. Jewell most recently served as OSU’s Director for the Human Tissue Resource Network, and Associate Director of the OSU Comprehensive Cancer Center’s Biorepository and Biospecimen Resource. Dr. Jewell’s accomplishments include the management, operation, and successful refunding from the National Cancer Institute for the Cooperative Human Tissue Network at OSU.

Dr. Jewell also serves as President of the International Society for Biological and Environmental Repositories (ISBER), which is the leading international forum for technical, legal, ethical and managerial issues at biorepositories. Among the lessons learned while leading ISBER, Dr. Jewell said: “Significant accomplishments can be attained when dedicated people work together with a common purpose.”

In announcing his appointment, Dr. Trent said that Dr. Jewell would work directly with research faculty to build out the program, aligning his expertise in tissue procurement and biorepository management for both basic and translational research.

“With the addition of the PBS, under Dr. Jewell’s direction, we will have established the foundation for a cutting-edge program to support clinical care in the age of precision medicine,” Dr. Trent said.

“Dr. Jewell also will serve an important leadership role in establishing initiatives that will broaden the scope of research within TGen-VARI, including development of key collaborations and partnerships within the West Michigan medical community,” Dr. Trent said.

In the future, Getz envisions many of TGen’s discoveries leading to successful commercial applications and new companies that then could plow a portion of their profits back into research at TGen.

He also foresees businesses moving to the Phoenix area because of the biomedical synergies created by TGen.

“TGen needs to continue to use its advances in medicine to form joint ventures that can commercialize products, and eventually bring back to TGen some funding that can lead to other new discoveries,” Getz said. “We should benefit by that.”

And it is his hope that discoveries made by TGen will not only help treat patients who develop diseases, but that major new discoveries will help diseases from occurring in the first place. “What I would like to see is to do more in prevention,” Getz said.
Anthrax.

The word alone induces a shiver and conjures images of untenable crimes. And while most people would choose the safety of distance, Dr. Paul Keim has spent his career in close proximity to the deadly spores. A Professor at TGen and Regents Professor at Northern Arizona University (NAU), Dr. Keim hopes to gain insight not only into how anthrax works and how to prevent others from using it as a weapon, but how to catch the perpetrators once they have committed a crime.
As Director of TGen’s Pathogen Genomics Division in Flagstaff, Dr. Keim supervises a team of scientists investigating the genetic and genomic origins of human disease caused by often-deadly microbes, including plague, E. coli and Salmonella, as well as anthrax.

Dr. Keim’s interest in anthrax started in the 1990s when a colleague from the Los Alamos National Laboratory in New Mexico, working on international biological-weapons treaty compliance, told Dr. Keim about his work in trying to do DNA analysis.

“I took a look at it and said, ‘Boy, there are better ways to do that. Let me help you out.’ Before you knew it, I took over the project.” said Dr. Keim, who at the time was already a specialist in studying the genomes of different organisms.

Today, Dr. Keim is the Cowden Endowed Chair in Microbiology at NAU, where he also is Director of NAU’s Microbial Genetics & Genomics Center, a program that works with numerous government agencies to help thwart bioterrorism and the spread of pathogen-caused diseases.

In addition to his work at TGen and NAU, Dr. Keim has served on the federal government’s National Science Advisory Board for Biosecurity (NSABB) for the past five years. As a member and acting chairman, he helped draft national guidelines for blunting bioterrorism that could elevate ethical standards and improve the quality of scientific research.

Formed in the aftermath of the 2001 anthrax attacks — when anthrax spores were sent through the mail, killing five people and sickening 17 — the NSABB consists of 25 experts from government, academia and private business who assess issues of biosafety in life sciences research and advise government agencies, all the way to the White House.

Dr. Keim’s lab was involved in the investigation of the 2001 anthrax attacks from the beginning. Imagine the highly guarded military flight into the Flagstaff airport that rushed anthrax samples from the U.S. House and Senate buildings to Dr. Keim’s laboratory for analysis. At the time, the FBI didn’t have a biosafety Level 3 lab. Dr. Keim’s lab became the major repository for anthrax samples gathered for comparison by the FBI from across the globe.

As one of the world’s leading authorities on anthrax, Dr. Keim over the years has been quoted in dozens of national and international publications, from The Washington Post to the science journal Nature.

His work supporting the FBI’s investigation of the 2001 anthrax attacks very recently thrust Dr. Keim back into the national limelight. Numerous news organizations sought his reactions to the February 15 release of a National Research Council (NRC) review of how the FBI handled the 2001 inquiry.

Some news organizations focused on what were described as lingering doubts about the strength of genetic testing that linked the anthrax-infested letters to a flask of lethal bacteria belonging to Bruce E. Ivins. According to The Washington Post, the U.S. Justice Department closed the probe last year after concluding that Ivins, an Army researcher who killed himself in 2008 as investigators closed in on him, had single-handedly prepared and mailed the anthrax spores, terrorizing the nation just after the Sept. 11, 2001, attacks.

But Dr. Keim said the NRC’s report amounts to a general endorsement of the FBI’s scientific approach.

“This NRC report is a qualified endorsement of the science in the FBI investigation,” said Dr. Keim. He praised the NRC review, which was requested by the FBI after a number of experts questioned the FBI’s scientific methods.

“I think the committee did a great job. It’s one of the most comprehensive accounts of the investigation anywhere.”

The NRC committee concluded that the anthrax used in the attacks was genetically similar to anthrax in Ivins’ custody, but that did not conclusively prove it came from that source.

Dr. Keim said the NRC panel is not saying the FBI was wrong, only that the scientific evidence wasn’t as strong as the agency suggested.

“The FBI always said the scientific evidence wasn’t definitive,” said Dr. Keim, adding that the scientific investigation yielded information about how and where the anthrax was made and the probable source. “Nothing in the NRC report said the FBI was wrong. They said the evidence wasn’t as strong as the FBI was saying, and they’re probably right with that.”

The FBI analyzed 947 samples and found 8 with the same genetic signature, based on four mutations, as anthrax from flask RMR-1029, which was in Ivins’ custody at the U.S. Army Medical Research Institute for Infectious Diseases, the NRC report said. However, as many as 100 people, not just Ivins, had access to RMR-1029, Dr. Keim and others have said. “So, the science never provided a definitive identification of Ivins.” Instead, the FBI used other kinds of evidence in building its case, Dr. Keim said.

Some of the kinds of studies recommended by the NRC panel already are under way, Dr. Keim said, including one at his lab through a U.S. Department of Homeland Security grant to study the use of next-generation DNA sequencing as a forensic tool to identify anthrax strains.

In 2002 and 2003, at the time of the anthrax letters investigation, the sequencing, or spelling out, of the DNA evidence was done with an older, slower, more-expensive technology.

“Today, we’re applying next-generation sequencing of DNA to the mutation process that occurs when microbes are grown in culture,” Dr. Keim said. “Thanks to TGen, we can do those same studies in just days, instead of years, and for only thousands of dollars, instead of millions.”
TGen’s globalCure initiative is a worldwide effort to prevent and eventually cure pancreatic cancer.

This is a vicious and aggressive disease that takes the lives of more than 42,000 Americans each year — 235,000 people worldwide — making it the fourth leading cause of cancer death.

GlobalCure is a revolutionary approach that embraces a comprehensive array of cross-disciplinary groups in a coordinated effort to help pancreatic cancer patients in the near-term, and ultimately put an end to this devastating disease.

Strategically, the initiative seeks to boldly impact the lives of those affected by pancreatic cancer by first extending their life expectancy. TGen and its partnering research groups are aggressively seeking the underlying genetic causes of pancreatic cancer by pursuing an unprecedented number of new therapeutic approaches to patient care, and efforts to treat pancreatic cancer are advancing at an unprecedented rate.

Participants in globalCure, including TGen Physician-In-Chief Dr. Daniel Von Hoff, already are seeing positive results.

For example, Howard Young is an Atlanta businessman and pancreatic cancer patient whose treatment under Dr. Von Hoff has resulted in a remission of his disease.

“I do not understand exactly why I have pancreatic cancer, but I am blessed to know and be treated by Dr. Von Hoff and the extremely talented team at TGen. They saved my life and they will save the lives of over 235,000 people each year when we cure this cancer,” said Young, a member of the TGen Foundation Board of Directors and Chairman of the globalCure National Advisory Council.

TGen also is a leader in a globalCure alliance with the Pancreatic Cancer Research Team (PCRT), which includes leading pancreatic cancer scientists, physicians and researchers — armed with the most technologically advanced tools and resources — at 46 institutions around the world.

This united front is determined to develop revolutionary advances in treating and defeating this cancer though a better understanding of the underlying genetic causes of the disease.

PCRT members represent the world’s leading pancreatic cancer physicians and researchers. They enjoy one-of-a-kind flexibility in resource allocation, in the development of sophisticated clinical investigation techniques, and the rapid testing of promising new pancreatic cancer therapies in large patient populations.

Everyone involved with globalCure shares the passion to bring new advances to pancreatic cancer patients as rapidly as possible, providing the only coordinated effort in the world dedicated to rapidly translating research discoveries into new treatments and supportive care for patients with pancreatic cancer.

The globalCure alliance is focused on an all-out effort to identify the genes that may reveal a predisposition to getting the disease, and understanding the genetic changes contributing to disease progression and resistance to therapy.

Experiments that were impossible and impractical only a few years ago are now conducted every day, leading to earlier diagnoses and smarter treatments. In addition, the globalCure team is developing novel therapies, designing relevant clinical trials and
helping launch fundraising programs to support these activities.

Through its international partnerships with academic, clinical, and corporate entities, globalCure is part of an overall mission to turn laboratory discoveries into improved healthcare interventions, and do so more rapidly than ever.

As new understandings about the underlying genetic causes of the disease and its resistance to traditional treatments are made, globalCure will quickly communicate them to the medical community for the ultimate benefit of patients and their families.

By marshalling expertise and resources from around the world, globalCure aims to put an end to pancreatic cancer.

TGen’s Clinical Translational Research Division, led by Dr. Von Hoff, brings together researchers who work in laboratories and physicians who see patients. This complementary partnership allows physician-scientists to take discoveries made in the laboratory and apply them to the patients they see.

To learn more about globalCure, please visit www.gcure.org.

Driven by individuals such as Jai Pausch (bottom left), globalCure brings together various philanthropic efforts and a national advisory committee in support of researchers and clinicians such as TGen Physician-in-Chief Dr. Daniel Von Hoff (bottom right) in an effort to cure pancreatic cancer.
Before he died of pancreatic cancer in 2008, Randy Pausch was a visionary professor and cross-discipline pioneer in virtual reality computing at Carnegie Mellon University.

Following his diagnosis of pancreatic cancer, Pausch put together one of the world's most inspirational lectures, later issued as a New York Times best-selling book and as a documentary movie, called *The Last Lecture*.

Despite his illness, and perhaps somewhat because of it, Pausch told the story of his personal quest, and his exhortation to others, to live life to the fullest measure. In his final university lecture, titled *Really Achieving Your Childhood Dreams*, Pausch shared his most important life lessons about doing what matters, and encouraged his audience to achieve their dreams, as well.

Now, Randy's widow, Jai, continues to spread his message of hope and achievement. She is a national advocate for pancreatic cancer research who has wholeheartedly endorsed TGen's globalCure initiative and serves on the recently created globalCure National Advisory Committee.

"Randy was only 46-years-old when he was diagnosed with pancreatic cancer, the only major cancer with a single-digit survival rate. Nevertheless, he took stock of his treatment options and he went after the cancer as aggressively as he could," said Jai.

“I’ve decided to carry on for Randy by spreading the word about this horrendous disease.”

As part of the globalCure effort, two programs bear Randy’s name.

“Randy’s Friends” is an ever-expanding group dedicated to pursuing philanthropic donations, aiding community fundraising efforts in support of globalCure and raising public awareness of the fight against pancreatic cancer.

“Pausch Scholars” is a select group of globalCure pancreatic cancer specialists who — for the first time — will assess and analyze the massive accumulation of both scientific and patient data, as well as create forums for patients and their loved ones to share and discuss relevant information. This intense data mining should help accelerate meaningful breakthroughs in the early diagnosis, treatment and cure of pancreatic cancer.

"We cannot change the cards we are dealt, just how we play the hand." — Randy Pausch, 1960-2008, husband, father, professor and author of *The Last Lecture*
Magowitz and Young families contribute $1 million each in support of globalCure

From Atlanta to Scottsdale, two golf tournaments and two families in recent months have raised more than $2.6 million for globalCure.

Roger and Jeanne Magowitz of Scottsdale pledged $1 million, and Atlanta businessman Howard Young and his family also pledged $1 million.

Roger Magowitz is the founder of the Seena Magowitz Foundation. Howard Young is a pancreatic cancer survivor and a member of the TGen Foundation Board of Directors.

In addition to the individual donations, October’s inaugural Golf Atlanta charity golf tournament raised $105,000, and December’s 8th annual Seena Magowitz Golf Tournament raised nearly $500,000 towards the eradication of this most deadly of all cancers.

“I never knew it would feel so good to give a million dollars,” said Magowitz, whose mother, Seena, died of pancreatic cancer. The annual golf tournament in Scottsdale and the Seena Magowitz Foundation bear her name.

Howard Young, who chairs TGen’s globalCure National Advisory Council, said, “Our family is committed to finding a cure for pancreatic cancer. There are numerous institutions staffed with brilliant investigators that are also committed to this cause. It is our opinion that TGen and (Physician-In-Chief) Dr. Daniel Von Hoff have the skills, intelligence, facilities, and — most of all — determination to lead and achieve this goal to cure pancreatic cancer.”

Make a Difference

The TGen Foundation directs the philanthropic endeavors of TGen and is poised to drive the globalCure initiative in conjunction with the leadership of the globalCure 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 for globalCure.

To learn more about the globalCure effort and to find out how you or your organization can become involved, please visit gcure.org.

Representatives of foundations, corporations and major contributors may contact the TGen Foundation at 602-343-8411 or via e-mail at globalCure@tgen.org.
In early 2010, Ruth Marcellino of Grand Rapids, Michigan, spoke with Dr. Jeffrey Trent about the tragic loss of her 24-year-old granddaughter, Jessica.

Rarely does a week go by that Dr. Trent, President and Research Director of TGen and the Van Andel Research Institute (VARI), doesn’t hear a similar tale of loss. Stories such as Jessica’s are what drive the teams at both institutes by infusing a sense of urgency into their research and clinical efforts.

Jessica suffered from a rare but aggressive cancer called small cell carcinoma of the ovary (SCCO), which primarily affects adolescent girls and young women, ranging in age from 9 to 43. The average age for onset is 24.

“One of the problems with SCCO is the fact that it simply does not present itself. Jessica’s symptoms were headaches and occasional bloating. Certainly no one is looking for ovarian cancer in such a young woman,” said Ruth Marcellino.

Referral to a specialist and a subsequent PET scan indicated a pelvic mass. Surgery revealed a 12-pound tumor with signs of advanced metastases. Multiple rounds of chemotherapy and various drugs proved useless.

“When it became obvious that Jessica would lose her battle, we asked one of our pastors to visit her,” said Ruth Marcellino. “He asked her, if she could have any wish in the world what would it be. Her reply? ‘That my cancer might help others.’”

Jessica passed away five days later, only five months after diagnosis.

SCCO survival rates are extremely poor, even when diagnosed at an early stage. Researchers and clinicians don’t yet know what causes the disease or why it progresses so rapidly, and in nearly all cases the disease resists conventional treatments.

Jessica’s family and others are fighting back.

Today, Ruth Marcellino is part of a growing network of individuals affected by SCCO — survivors, family members and friends—who want to make a difference. Joining her are women like Judy Jost of Cave Creek, Arizona, who lost her 22-year-old daughter Taryn Ritchey, and Tom Benford of Peoria, Arizona, who lost his 31-year-old daughter Andrea Benford Theis.

Their stories helped prompt Dr. Heather Cunliffe, head of TGen’s Breast and Ovarian Cancer Research Unit, to initiate...
an SCCO study with
Dr. Trent.

The study came to the
attention of international
businessman and
philanthropist Foster Friess,
who donated $50,000 to
seed the SCCO research.
Friess, who splits his
time between Jackson,
Wyoming, and Scottsdale,
Arizona, learned about the
disease from Judy Jost, one
of his personal assistants.
SCCO, considered a rare
or “orphan” disease, draws
little federal funding, so
it takes a benefactor like
Foster Friess to make a
difference.

“The loved ones of
women taken by this rare
disease look to both TGen
and VARI investigators
for answers based on
evidence from new
research technologies.
Unfortunately, we know
very little about SCCO.
Through our research
we intend to discover
the consistent genetic
and biologic causes of
this disease and develop
effective ways to treat
it,” said Dr. Cunliffe,
the study’s Principal
Investigator.

VARI investigators joining
Drs. Trent and Cunliffe are
Dr. Brian Haab, head of
VARI’s Laboratory of Cancer
Immunodiagnostics,
and Dr. Kyle Furge, head
of VARI’s Laboratory of
Computational Biology.

“In addition to our
studies into a host of
common diseases, TGen
and VARI specialize in rare,
or orphan, cancers. We can
use our advanced genomic
technologies to better
examine the causes of rare
cancers like SCCO, and give
patients hope for better
outcomes in the future,”
Dr. Trent said.

The first goal of the
study is to collect SCCO
tumor and blood samples.
Patients, or their loved
ones, may find instructions
for study enrollment and
biospecimen donation at
www.tgen.org/scco.

TGen and VARI
researchers will examine
tumors and blood samples
using advanced genomic
approaches. They will
attempt to understand
the molecular forces that
likely drive the onset,
rapid progression and
drug-resistant nature of
the disease. Researchers
also will study how SCCO
diffs from more common
forms of ovarian cancer.

Ovarian cancer is
not detectable through
routine Pap smears, and
insufficient molecular
evidence exists — due
to SCCO’s orphan status
— to propose genomic-
based precision treatment.
Currently, the surgical
removal of both ovaries
and the uterus is the
standard treatment
in early-stage SCCO
patients. For late-stage or
recurrent tumors, multi-
agent chemotherapy and
radiotherapy show some
improvement in survival.
Sadly, nearly 3 in 4 SCCO
patients succumb to the
disease within one to
two years of diagnosis,
despite aggressive
chemotherapeutic
treatment regimens.

One survivor, 32-year-old
Melissa Gallagher, was first
diagnosed in 2005. She
attributes her survival to a
studied self-awareness of
her body and perseverance
with her doctors. Her
Persistence prompted them
to act quickly, surgically
removing what had been
an extremely fast-growing
tumor — suddenly the size
of a volleyball — from the
diminutive woman, who
stands less than 5 feet tall.

Melissa, who lives in
Long Island, N.Y., has
established hopeful yet
tragic relationships with
other SCCO victims
through her online
network. “Most everyone
I meet passes away within
months; it’s heartbreaking.
The disease is so rare that
those affected become like
family to one another.”
DNA methylation — a modification of DNA linked to gene regulation — is altered with increasing severity in a blood cancer called multiple myeloma, according to a study by Mayo Clinic and TGen.

And at specific points of DNA, "global hypomethylation," in which many genes lose the modification, may be associated with the step-by-step development of myeloma, according to a scientific paper published recently in the journal Cancer Research.

"This is the first study to show that hypomethylation occurs early in the development of multiple myeloma and increases through disease progression," said Dr. Bodour Salhia, a TGen cancer researcher and the paper’s lead author.

**New TGen technology reduces storage needs & costs for genomic data**

A new computer data compression technique called Genomic SQueeZ (G-SQZ), developed by TGen, will allow genetic researchers and others to store, analyze and share massive volumes of data in less space and at lower cost.

Created specifically for genomic sequencing data, the encoding method underlying G-SQZ and its software use are described in a paper recently published in the journal Bioinformatics.

Tests show that G-SQZ can compress data by as much as 80 percent while maintaining the relative order of the data and allowing for selective content access. This could save researchers and others millions of dollars worldwide.

Dr. Edward Suh, TGen’s Chief Information Officer, described G-SQZ as a significant breakthrough in storing and analyzing ever-increasing genomic sequencing data.

**TGen finds therapeutic targets for rare cancer in children**

The first study of Ewing’s sarcoma that screened hundreds of genes based on how they affect cell growth has identified two potential anti-

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**Standing Tall: A Father’s Lessons Through his Daughter’s Cancer**

Andrea Benford Theis was the oldest of three sisters who all played softball, all played outfield, and all shared a father who was their biggest cheerleader.

At Greenway High School in Glendale, Arizona, Andrea was not only part of the homecoming court all four years, but was the fastest girl in metro Phoenix in five different track events.

At Glendale Community College, Andrea was a 1995 First-Team National Junior College Athletic Association (NJCAA) All-American and played on the Gauchos’ 1994 national junior college championship women’s softball team. She also played for New Mexico State University, where in 1996 she was part of the All Big West Conference team.

She inspired her younger sisters – Carly, 21, a 2010 Helios Scholar at TGen now attending and playing for Loyola University in Chicago; and 18-year-old Katie, already an accomplished actress even though still a senior at Centennial High School in Peoria, to also play and excel in softball. But Andrea’s biggest challenge came when, at age 30, she faced a diagnosis of small cell carcinoma of the ovary (SCCO), an extremely rare and extremely aggressive cancer that strikes women in their youth. The average age at onset is only 24.

Her father, Tom Benford, remembers how being told that Andrea had cancer was like being struck by lightning.

The news of her cancer came on the heels of another disappointment: Andrea’s second miscarriage. Tom recalls being at the hospital with Andrea’s husband, Eric, when an ultrasound exam detected something wrong. After exploratory surgery, the doctor called Tom and Eric aside.

“I had my arm on Eric’s shoulder,” Tom said. “She (the doctor) said, ‘Andrea is doing fine. She’s just coming out of anesthesia, however…’ and I remember it seemed like that ‘however’ took three minutes to come out of her mouth. She said, ‘We did find cancer.’ It was like I was hearing an echo reverberating through the room. I never heard everything that she said. Eric – I could feel his shoulders slump. I could feel the wind go out of him. I could feel the wind come out of me. It was just like being struck by lightning.”

What started as a tumor the size of a pencil eraser grew in just 30 days to the size of a softball, Tom said. But Andrea, who after college worked in pharmaceutical sales, was determined to fight her cancer.

“I was amazed at how she could talk about it,” Tom said. “She was bubbly, enthusiastic. It was like an experiment to her. It was like she was doing research.” When Tom asked his daughter how she could remain so upbeat, Andrea explained, “Dad, suppose a year from now this thing gets me? I know...
cancer drug targets, according to a scientific paper by TGen published recently in the journal Molecular Cancer.

Ewing’s sarcomas are rare, but aggressive cancer lesions that occur most frequently in the bones of teenagers.

The authors discovered two protein kinases with important roles in the growth and survival of Ewing’s sarcoma cells. Cancer cells died when investigators stopped the normal function of the two protein kinases called STK10 and TNK2.

“RNAi-based phenotypic profiling proved to be a powerful gene target discovery strategy, leading to successful identification and validation of STK10 and TNK2 as two novel potential therapeutic targets for Ewing’s sarcoma,” said Dr. David Azorsa, a TGen Senior Investigator and the paper’s senior author.

TGen Drug Development Teams with Oncoholdings to Fight Cancer

TGen Drug Development (TD2) and Oncoholdings Inc., a Syracuse, N.Y.-based pharmaceutical company, announced a partnership agreement in January that could lead to the prompt development of new anti-cancer agents.

Under the agreement, TD2 — a subsidiary of TGen — will be the exclusive development partner for Oncoholdings’ oncology portfolio. The company plans to develop as many as 15 early-stage drugs over the next three years.

“We are extremely eager to put the scientific assets of Oncoholdings on the most expeditious and precise path, moving their drug compounds safely and effectively to benefit cancer patients who so desperately need better treatments,” said Dr. Stephen Gately, President of TD2 and a member of the Scientific Advisory Board of Oncoholdings.

TGen and Genomic Health Inc. discover genes affecting cancer drug

Genomic research could help doctors better target a drug widely used to treat colorectal cancer patients, according to a study by TGen and Genomic Health Inc., published in the February issue of Molecular Cancer Research.

However, a significant number of patients experience serious side effects, including prolonged damage to the nervous system, “creating an urgent need to identify genes that are responsible for drug sensitivity or resistance, which results in directing therapy to those most likely to benefit,” according to the study.

An interfering RNA screen of 500 genes — with 2,000 unique siRNA sequences — identified 27 genes that, when silenced, altered the sensitivity of colon tumor cells to oxaliplatin.

“Those 27 genes, whose loss of function significantly affect the effectiveness of oxaliplatin, may be promising therapeutic biomarkers for oxaliplatin,” said Dr. Holly Yin, head of TGen’s Cellular Genomics Collaborative Center in Scottsdale, and a co-author of the study.

that’s not going to happen. But, what if it did? Why would I want to go out with a bad attitude?”

Andrea’s positive attitude carried her throughout her illness. “I know there were days when she could barely walk, barely move,” Tom recalled. “I never saw a person with the will that she had. It carried through to our entire family. It carried through to her friends. I’ve had so many people tell me what a difference Andrea made in their lives.”

Following surgery to remove the tumor and after six months of chemotherapy, Andrea received what her father described as a clean bill of health. But 11 days later, the cancer returned.

“I was struck by lighting again when they told us the cancer was throughout her body,” Tom said.

“I could feel it resonate all through me. It was just like being shocked with electricity. But I never could show it.” The Benford family stoicism, their outward resilience even though they harbored inner doubts, became their method of coping with the disease.

“We talked about getting better, and what the next steps would be, and about her having kids,” Tom said. “I wouldn’t let anybody even think that we weren’t going to win this battle, even though all the time in my heart and my soul … I knew things weren’t going well.”

On April 3, 2006, at age 31, Andrea passed away, 11 months after her diagnosis. Nearly 750 people attended Andrea’s memorial service.

A longtime Arizona resident, Tom thought of his daughter’s plight through an analogy that was familiar to him. Outside Florida, Arizona has more lightning strikes than any other state. And Arizona has the world’s largest stand of ponderosa pines, a tree that — as it ages — becomes resistant to lightning strikes and fire.

“A ponderosa pine can be struck once, two, three times in its lifetime, and survive those strikes, and continue to grow, and stand tall, and be the guardian over the forest. Much like a ponderosa pine, I stand as the guardian of my family,” Tom said. “Standing tall” is how Tom thought of Andrea, of Eric, of himself and his entire family. Now he is completing a book about his family’s experiences, specifically about his father-daughter relationship with Andrea, titled Standing Tall.

“Standing Tall” came from everybody telling us, “We don’t understand how you possibly did this. You guys have stayed so much a family. You’ve never let this interfere with your lives. You’ve been positive. You’ve been focused. Andrea’s been that way. How did you manage to do that?” But no one knew what was going on inside of me,” Tom said.

Although the book was inspired by Andrea’s illness, Tom said, it also is about what it takes to get through any kind of life-changing crisis.

“Dads don’t tell stories very often. We’re supposed to be (stoic) all the time. I wanted people to know how this affects a man — what I went through — so that other dads who are faced with something like this … it will help them get through it,” Tom said. “Nothing could ever happen to me that’s worse than losing my daughter.”

Benford, part of a growing network of families affected by SCCO, said he hopes the new TGen-VARI study will draw information from the death of his daughter and other victims of SCCO that could lead to better treatments for this disease.
The 5th annual stepNout Run, Walk, Dash for Pancreatic Cancer Research raised more than $131,000, pushing the total amount raised since the event began in 2006 to nearly $500,000. The Nov. 7 race at Tempe’s Kiwanis Park drew nearly 1,000 participants from across the nation, plus more tents and more teams of racers than ever.

“Even with the economy, we were very, very pleased with the way people continue to give and support this effort,” said Roseanna Robinson Norman, the event chairman. “It’s incredible anytime you raise more than $100,000.”

Norman, who lost her husband, Michael, to pancreatic cancer, said the event would not be possible without the time and dedication of dozens of volunteers.

This year’s sponsors included: Blue Cross Blue Shield, Cadwell Memorial, Lewis & Roca LLC, Genentech, Phoenix Coyotes, MidFirst Bank, Lynn Yturri, and Jason Hope.

Norman, a member of TGen’s National Pancreatic Cancer Committee, said she wants StepNOut to become a happening that people circle on their calendars and mark as a “don’t miss” event. The 6th annual stepNout is set for Nov. 6, 2011, at Kiwanis Park.

Pancreatic cancer is the fourth leading cause of cancer death in the United States, with nearly 43,000 new diagnosis annually. An estimated 36,000 will die this year from the disease. There are no early detection methods available, so the cancer usually is not found until its advanced stages. As a result, fewer than 1 in 5 survive more than a year after diagnosis, making it one of the most aggressive and most deadly of cancers.

Mark Curtis, the co-anchor for 12 News who lost his mother to pancreatic cancer, served as the honorary chair and master of ceremonies.

TGen’s pancreatic cancer research is headed by world-renowned expert Dr. Daniel Von Hoff, TGen’s Physician-in-Chief and Director of TGen’s Clinical Translational Research Division.
Donations to research made easier
Arizona Community Foundation will administer Gift Annuities

A partnership with the Arizona Community Foundation (ACF) will make it easier for large donors to support TGen research. Donors who give $25,000 or more through a Charitable Gift Annuity to TGen will gain access to the investment management programs already administered by ACF, a statewide affiliation of donors, volunteers and organizations addressing community needs through charitable giving.

In exchange for their gifts to TGen, donors receive lifetime payments at a fixed rate of interest, depending on age and whether they contribute as individuals or spouses. For example, at recent rates, a single person, age 60, could receive 5 percent annual interest in lifetime payments, made annually, semi-annually, or quarterly, according to the donor’s needs.

Donors may designate their gifts to a specific area of biomedical research, or to research in general at TGen, which focuses on discovering the genetic origins of such diseases as Alzheimer’s, diabetes and many types of cancer.

“This partnership could provide a substantial boost for TGen, which already benefits from the expertise of exceedingly knowledgeable board members that our organization shares with the Arizona Community Foundation,” said Dr. Jeffrey Trent, TGen’s President and Research Director.

Bennett Dorrance, Chairman of DMB Associates, and Jerry Biggrove, Chairman and CEO of the Stardust Companies, are members of the TGen Foundation Board of Directors, and both are past chairmen of the ACF Board of Directors.

“The Arizona Community Foundation is pleased to partner with TGen to enhance planned giving options for their donors,” said Steven G. Seleznow, President and CEO of ACF. “TGen is conducting breakthrough research and, deservingly, has many generous donors who understand the importance of this work. Charitable Gift Annuities are a perfect option for donors to sustain TGen and its critically important activities well into the future, while also generating an income stream for themselves to meet their personal financial needs. ACF is proud to offer this innovative giving strategy.”

Charitable portions of gifts to TGen are tax deductible, and portions of annuity payments range in how they are taxed, with some portions potentially tax-free. For more information, contact: Kimberly C. Kur, J.D., ACF’s Senior Advancement Officer at 602-682-2025; or Denise A. McClintic, J.D., LL.M., TGen Foundation Associate Vice-President, at 602-343-8611 or dmcclintic@tgen.org.

Gifts to TGen through this program reside at ACF, which administers contributions as an endowment to fund designated research at TGen. Endowments help ensure the long-term sustainability of an organization by providing a permanent source of support.

Founded in 1978, ACF has $471 million in assets.

It awards millions of dollars each year to nearly 3,500 non-profit organizations, educational institutions and government agencies in Arizona and across the nation. Since inception, it has invested nearly $350 million in communities through grant and scholarship funding.

Upcoming TGen Foundation events

**Ovarian Cancer unTEAL a cure**
2nd annual unTEAL a cure Run/Walk/Dash • Kiwanis Community Park, 611 S. All-American Way, Tempe • March 6, 7:00 a.m.

Friends, families, corporate teams, runners, walkers, advocates and survivors are encouraged to pre-register, and will receive the 2011 Run/Walk/Dash t-shirt. Registration fees are $30 for adults. For fast and easy registration, visit www.tgen.org.

**Gourmet Dinner for Breast Cancer Research**
Cookin’ for a Cure at Eddie’s House, 7042 E. Indian School Road, Scottsdale • March 10, 6:00-9:00 p.m.

The Marilyn B. Gula Mountains of Hope Foundation is cookin’ up somethin’ special at Eddie’s House, a casual, private dining experience at Chef Eddie Matney’s restaurant. Chef Eddie’s menu includes open bar, featuring Su Vino Wines and Belvedere Pink Martinis, passed hors d’oeuvres, and a buffet dinner with special desserts and coffee. In addition to delicious food, celebrity guests, including baseball legend Joe Garagiola, are expected. All proceeds benefit breast cancer research at TGen. Tickets are $150 per person. More information: www.mountainsofhopefoundation.org.

**Pancreatic Cancer Research In Step**
6th annual stepNOut for Pancreatic Cancer Run/Walk/Dash • Kiwanis Community Park, 611 S. All-American Way, Tempe • November 6

Save the date, Nov. 6, for this year’s stepNOut event, where every step taken and each dollar raised will be used in the fight to prevent and cure pancreatic cancer. Register online in May.
For TGen, Phil Francis has been a supporter, a donor and most recently a partner. Now, the Executive Chairman of PetSmart Inc., is a member of the TGen Foundation Board of Directors.

“I come at it from the perspective of service. I think TGen is very important to the future of Phoenix and of Arizona. Anything I can do to help it be successful — and make an impact — would give me great pleasure,” Francis said.

TGen Foundation President Michael Bassoff said the appointment of Francis to the Foundation’s Board of Directors would add significantly to the Board’s collective business expertise.

Specifically, Bassoff said that Francis would boost TGen’s ability to transform scientific discoveries and turn them into practical applications.

In addition, Francis will provide business leadership in TGen’s groundbreaking studies of diseases and medical conditions that affect dogs.

“Phil’s commitment to TGen is second to none,” Bassoff said. “I can only imagine that his presence on the Board will assist TGen’s top-notch scientists in transforming new ideas into better ways to help patients.”

Personally, and through PetSmart, Francis has supported TGen for many years.

PetSmart last year pledged $500,000 towards the TGen-VARI Canine Hereditary Cancer Consortium, which is pursuing genomic research of dog DNA to help discover the origins of diseases — especially cancers — that affect dogs and people, too.

Francis said there are plans in the works at the more than 1,100 PetSmart stores across the U.S. and Canada to collect the DNA of dogs, most likely by sampling dog saliva using simple cheek swabs. Following owner consent, a cheek swab takes less than two minutes and is not harmful to the animals.

“I can bring the perspective of both a donor and a partner, in that TGen and PetSmart are doing work together on the dog genome, and how it might impact both dogs and humans. So, perhaps that combination would be somewhat unique on the Board,” Francis said. “I’m humbled by the opportunity, and I’m going to try not to screw it up.”