

A female scientist with dark hair and bangs, wearing a white lab coat and blue nitrile gloves, is focused on her work. She is leaning over a piece of scientific equipment, specifically a microfluidic platform, which is housed within a fume hood. Two large, black, flexible ventilation hoses are visible, framing her face and the equipment. The background is a clean, laboratory setting.

# +notebook

VIRGINIA G. PIPER CHARITABLE TRUST

|

April 2009

THE DAWN OF  
PERSONALIZED  
MEDICINE



# notebook

## April 2009

*Piper Notebook* is a magazine published three times each year, April, July and November (annual report), by Virginia G. Piper Charitable Trust to inform the community about the work of the Trust and its grantees in Maricopa County, Arizona.

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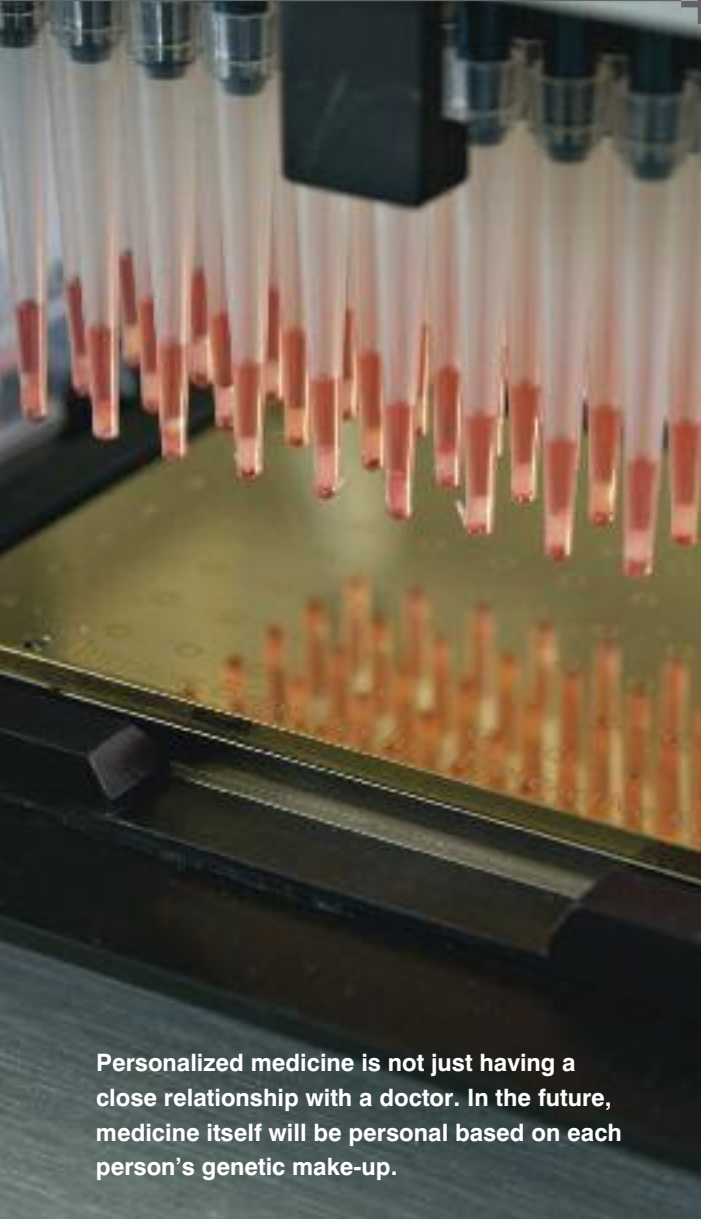
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## ON THE COVER AND LEFT

The Partnership for Personalized Medicine places Arizona institutions in the center of exciting new developments in the future of healthcare. A researcher at the Translational Genetics Research Institute (TGen), on the cover and below, prepares sensitive equipment to conduct proteomic analysis. The Biodesign Center at ASU, above left, uses gold plates for mass spectrometry in the search for biomarkers of disease.



**Personalized medicine is not just having a close relationship with a doctor. In the future, medicine itself will be personal based on each person's genetic make-up.**



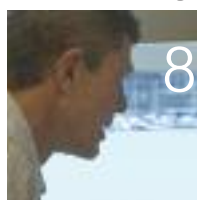
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# Of Note

BY JUDY JOLLEY MOHRAZ, Ph.D.  
President and CEO

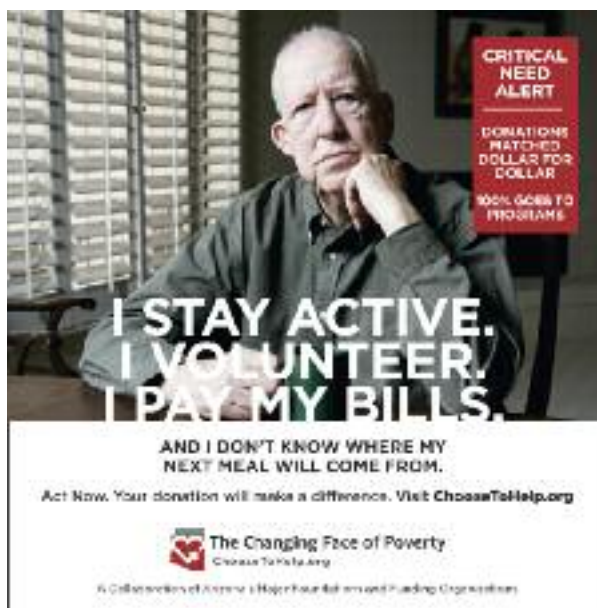


## **Now Versus the Future: Allocating Funds in a World of Possibilities and Immediate Needs**

This issue of the *Piper Notebook* comes at a time when job loss, reduced public services and economic decline are uppermost in our minds. Yet we know that if a family member or close

friend is critically ill, even the dismal reports of the financial crisis recede. What matters first is a loved one's health.

Balancing precious financial resources between long-term bets on major medical breakthroughs and more immediate community needs is the task of Piper trustees and staff, day in and day out. It is never an either/or proposition. Our goal is always to strategically invest in high impact initiatives that may not reap full benefits for years while preserving funds critical for pressing issues and shorter-term projects.



## **Basic Needs Collaborative**

Piper Trust was pleased to join nine other Maricopa County funding organizations in creating a \$1.3 million community relief fund to be matched via a statewide dollar-for-dollar campaign. One hundred percent of dollars raised will go to selected nonprofits due to the Lodestar Foundation covering all administrative costs. Give online at [ChooseToHelp.org](http://ChooseToHelp.org).



### **Partnership for Personalized Medicine**

In creating the Partnership for Personalized Medicine in concert with the Flinn Foundation, the Piper Trust has joined an international quest to use genetic and proteomic research to produce more targeted, accurate diagnosis and prevention of disease.

Arizona is an important center of breakthrough work in the new world of personalized medicine. Recently, Arizona State University recruited world-renowned proteomics scientist Josh LaBaer, M.D., Ph.D., from Harvard University to lead the Biodesign Institute's efforts in personalized diagnostics. Alan Nelson, Ph.D., pioneering cancer

scientist and biomedical entrepreneur, replaces Dr. George Poste, former head of ASU Biodesign who is now leading ASU's Complex Adaptive Systems Initiative.

This issue on personalized medicine introduces some of the recognized individuals at work on research that will over time change both treatment and reimbursement for state-of-the-art care. These stories cover diverse aspects of personalized medicine from reducing the cost of health care to targeting adult-onset diabetes and helping cancer patients with few remaining options. Guest author Lee Gutkind looks at the looming question of when family doctors working with average patients need to jump on board the personalized medicine express.

### **Everyday Hard Choices**

Every grant the Trust makes represents a hard choice—an investment of dollars that could be directed to a hundred worthy causes. We hope that just as a tight rope walker preserves balance, step by step, so Piper Trust, now celebrating its 10th anniversary, will maintain that critical balancing act: Looking toward the horizon while simultaneously recognizing immediate community opportunities and needs. \*

# The Partnership for Personalized Medicine

In late 2007, the Piper Trust and the Flinn Foundation announced an initiative to develop personalized diagnostics as part of the longer term goal of making Arizona a center for personalized medicine.

World-renowned scientist Dr. Lee Hartwell, 2001 Nobel laureate and director of Fred Hutchinson Cancer Research Center, leads the Partnership for Personalized Medicine. The initiative builds on the strengths of the Biodesign Institute at Arizona State University and The Translational Genomics Research Institute (TGen).

In its first year of operation, the Partnership for Personalized Medicine signed a partnership agreement with the Duchy of Luxembourg to focus research on lung cancer in a collaborative effort, thereby adding considerably to the foundations' initial \$45 million investment in the Partnership.

diagnostics and treatments, infectious disease and a healthy future for our planet. Biodesign Institute research includes a device to diagnose disease before symptoms appear; a vaccine against breast cancer that may also protect against other types of cancer; methods to produce safer, low-cost vaccines; and systems to rapidly identify and treat naturally occurring infectious disease.

## Fred Hutchinson Cancer Research Institute

At Hutchinson Center in Seattle, interdisciplinary teams of world-renowned scientists and humanitarians work

together to prevent, diagnose and treat cancer, HIV/AIDS and other diseases. Researchers, including three Nobel laureates, bring a relentless pursuit and passion for health, knowledge and hope to their work and to the world. Hutchinson Center researchers have made many of the world's most important medical research advances of the last three decades in transplantation, targeted cell treatments, prevention studies, new technologies and improved detection.

## The Translational Genomics Research Institute

TGen is a nonprofit organization dedicated to conducting groundbreaking research with life-changing results. Research focuses on diseases such as cancer, neurological disorders and diabetes. TGen, headquartered in Phoenix, is on the cutting edge of translational research where investigators are able to unravel the genetic components of



Biodesign Institute at Arizona State University



## Biodesign Institute at Arizona State University

Biodesign Institute at ASU in Tempe is multidisciplinary, combining expertise in biology, chemistry, physics, applied mathematics and engineering. Biodesign focuses on personalized



**Fred Hutchinson Cancer Research Institute**

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. \*

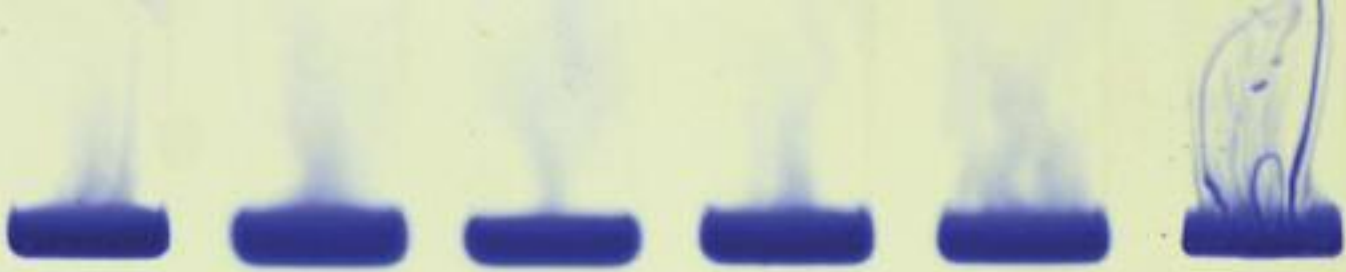
**The Partnership for Personalized Medicine aims to develop, test and validate personalized diagnostic tools for a wide range of diseases.**

The goal is to obtain approval for clinical use of diagnostic tests, which are reimbursable by insurance companies. The result of this effort is an entirely new approach to medicine that offers more accurate assessments of disease risk; better predictions of responses to treatment; safer, more effective treatments; and long-term savings in the cost of healthcare.



**The Translational Genomics Research Institute**



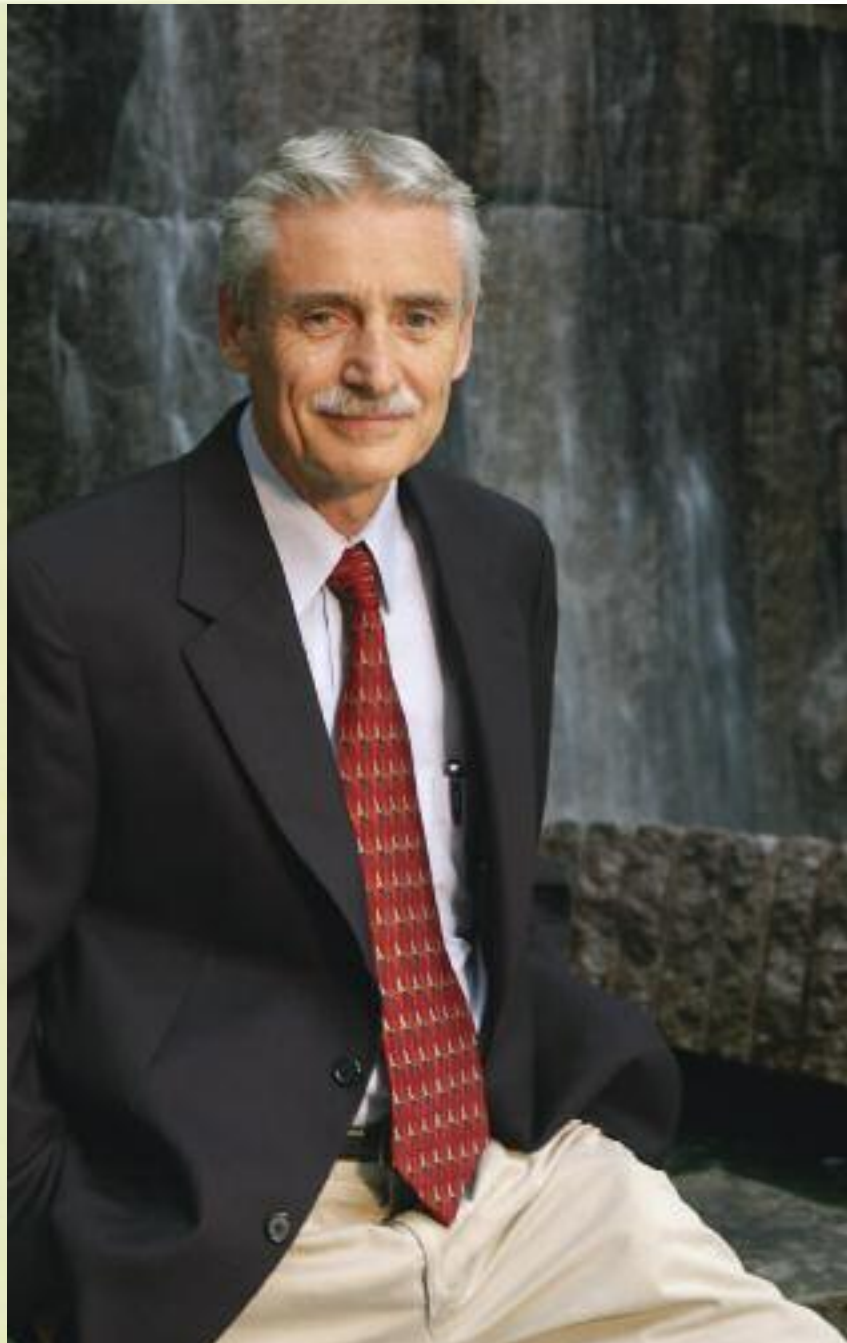


**Lee Hartwell, Ph.D.**  
**Fred Hutchinson Cancer  
Research Center**

Dr. Hartwell is president and director of Seattle's Fred Hutchinson Cancer Research Center. He concurrently serves as Research Professor of Genetics with the American Cancer Society and Professor of Genome Sciences at the University of Washington. For most of Hartwell's career, he studied genes that control cell division in yeast. Subsequently, many of these same genes have been found to control cell division in humans and often to be the site of alteration in cancer.

He chairs a national and international project, the Partnership for Personalized Medicine, to improve methods for discovering protein biomarkers for cancer and other diseases. He believes that the most efficient path to reduce mortality from cancer is to identify individuals at high risk for disease, detect cancer and other disease at an early stage when they can be cured, provide prognostic information and monitor therapeutic response.

Hartwell has received many national and international scientific awards, including the 2001 Nobel Prize in Medicine. Other honors include the Albert Lasker Basic Medical Research Award, the Gairdner Foundation International Award and the Alfred P. Sloan Award in Cancer Research.





## Q&A with Dr. Lee Hartwell, Chair of the Partnership for Personalized Medicine

**The Partnership for Personalized Medicine was created a year and a half ago. What have been key milestones during the startup?**

Our efforts have focused on building awareness of the Partnership for Personalized Medicine among potential partners around the world and on recruiting research personnel and assembling facilities.

We prepared a brochure and launched the Partnership concept at two Pacific Health Summit meetings. We have had discussions with high-level decision-makers from Luxembourg, Singapore, Korea, Japan and Australia. The Partnership launched one biomarker discovery project on lung cancer with the Duchy of Luxembourg in June 2008, and a second project is currently under discussion with Singapore.

We have recruited key personnel to head the economics section, Dr. Scott Ramsey, and the lung cancer biomarker project, Dr. Mandy Paulovich. Build-out of the facility is underway at TGen under the leadership of Dr. Cheryl Selinsky. In a much anticipated step, Biodesign Institute at ASU is bringing on Dr. Josh LaBaer, a proteomics leader, and his team from Harvard University.

**Have there been any surprises in ramping up the Partnership?**

Yes. We have come to realize the lack of cost-benefit analysis in healthcare. As a result, we have moved it up to be our number one focus in presenting the Partnership's case to new partners.

**The Partnership will concentrate its biomarker research efforts on specific diseases. What diseases will be the initial research focus and why?**

The Executive Committee has identified cancer, heart disease and diabetes as key areas of focus. Our partners also play an important role in picking

“DON'T PURCHASE GENERAL GENETIC TESTS. THEY ARE ALMOST ALL OF NO VALUE IN MAKING HEALTHY DECISIONS.”

Dr. Lee Hartwell, Ph.D.,  
Fred Hutchinson Cancer Research Center

the disease that they are interested in. The Luxembourg project, for example, is focused on lung cancer, and the potential Singapore project would be on heart disease.

**The average person has some information about personalized medicine and may want to purchase available genomic tests. What is your advice to healthcare consumers?**

Don't purchase general genetic tests. They are almost all of no value in making healthy decisions because most genetic variations associated with common diseases actually confer very small risk for disease. Lifestyle and environmental exposures are also important influences in health and well-being but are not reflected in genetic profiles.

**What about the doctors in patient care and how and when should they respond to advances in personalized medicine and begin to talk to their patients about it?**

There is already a lot of personalized medicine, particularly in cardiology with HDL and LDL testing and in cancer with mammography, colonoscopy and screening for cervical cancer. In the future, there will be even more. The biggest challenge is for doctors to understand the value of the tests. Many tests will be offered that should not be used, and it requires considerable familiarity with the research literature to understand this.

**What are the Partnership's goals for the next two years?**

Over the coming years, we intend to build a consortium of healthcare partners around cost-effective and evidence-based medicine as well as develop one or two more biomarker discovery projects. \*

# Can Personalized Medicine Really Affect the Cost of Healthcare?

It sounds too good to be true: Personalized medicine can lower the cost of healthcare.

“But it can, absolutely,” according to Scott Ramsey, M.D., Ph.D., head of the Cancer Technology Assessment Group at Fred Hutchinson Cancer Research Center in Seattle.

He notes that medicine to a large extent has focused on costly treatments that may be right for a very small percentage of patients. The new approach looks at gathering the greatest number of genetic profiles possible to more accurately assess risk of disease and make better predictions about patients’ responses to treatment.

Ramsey underscores that health systems around the world are facing horrific increases in the cost of healthcare. They want to adopt new technologies but don’t have money to invest in extensive research and development.

The answer: Determine cost effectiveness before developing technologies.

“Cost effectiveness studies of diagnostic tests like CAT scans and blood tests are not new,” said Ramsey. “What is different now is doing the cost analysis before a test is launched. An expensive test lacking value that is already in the marketplace can’t be un-introduced.”

He started meeting a couple of years ago with Dr. Lee Hartwell, Nobel laureate and head of the Hutchinson Center, to talk about economics and early detection. At about the same time, Dr. Hartwell began conversations with Arizona biosciences leaders and Virginia G. Piper Charitable Trust that led to the Partnership for Personalized Medicine.

“We realized that there was a good fit to have an economics argument for personalized medicine as well as a clinical one,” said Ramsey. “But there has been one surprise.

“WE REALIZED THAT THERE WAS A GOOD FIT TO HAVE AN ECONOMICS ARGUMENT FOR PERSONALIZED MEDICINE AS WELL AS A CLINICAL ONE.”

Dr. Scott Ramsey,  
Fred Hutchinson Cancer Research Center

“When we started this, we were actually quite tentative about putting forward the cost-effectiveness and saving-money argument,” he said. “What surprised us is that potential partners like Luxembourg have embraced

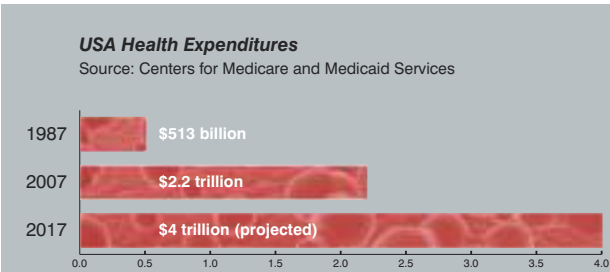
it and see economics and clinical benefit entwined.”

Ramsey’s research focuses mainly on economics evaluations of new medical technologies for cancer, patterns of care and costs of cancer, but he also has a broader interest in health economics and the healthcare system in general. His analysis will integrate economics evaluation into the developmental pipeline for new diagnostic tests.

New tests will better identify patients who are at risk for particular diseases, diagnose diseases earlier and more accurately, and predict who will respond to specific treatments. This analysis will allow doctors to implement appropriate preventive measures and targeted treatments, therefore reducing the costs and suffering associated with more severe disease.

Diagnostics also hold promise for identifying patients who are unlikely to benefit from particular therapies, saving money and keeping patients from treatments that would otherwise be ineffective or carry serious side-effects. \*

## Rising Cost of Healthcare

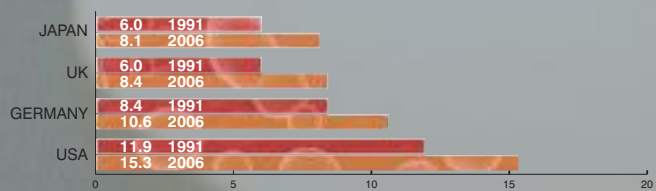




Dr. Scott Ramsey measures cost-effectiveness before diagnostic technologies are developed.

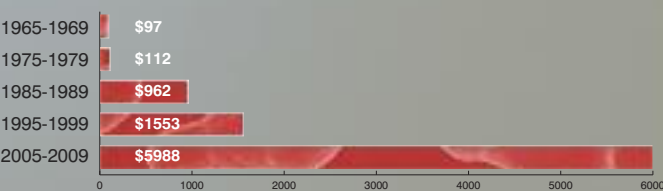
Country Healthcare Expenditure (as % GDP)

Source: Centers for Medicare and Medicaid Services



Median Cost of FDA-Approved Cancer Drugs Price (2007 US dollars)

Source: The New England Journal of Medicine





Dr. Randy Nelson, a proteomics expert, uses specially designed gold plates to discover and validate blood-borne markers of diabetes.



# ASU Research Seeks Early Detection of Adult-onset (Type II) Diabetes

A new team of researchers is taking aim at the sixth leading cause of death in the United States: adult-onset, or type II, diabetes.

Randy Nelson, Ph.D., leads the new research group at the Biodesign Institute at Arizona State University which is advancing the Partnership for Personalized Medicine’s goal to learn how to predict who will develop the disease long before any symptoms appear.

“We have the technologies and tools in place now to construct a detailed molecular signature of diabetes,” said Nelson. “By studying the changes in

“A PROTEIN BIOMARKER IS AN EXTREMELY VALUABLE AND SENSITIVE SIGNATURE OF DISEASE.”

Dr. Randy Nelson, Biodesign at ASU

both the expression and structure of proteins related to diabetes, we can determine their contribution to the disease process.”

Nelson is an expert in proteomics, a scientific discipline that studies changes in protein composition, generally in biofluids such as blood and urine, and how these changes relate to disease.

Proteins, the products of our genes, can reveal the consequences of lifestyle and environmental exposures for disease risk, unlike DNA, which typically reveals hereditary predisposition. Because they change in response to physiological conditions and can be measured from a simple blood test, proteins can be more powerful diagnostic tools than DNA.

The complete entourage of proteins (the proteome) is ultimately responsible for everything—good or bad—related to human health. When a protein is found to have a distinct and consistent relationship to a disease, whether as a protector or enabler, it is called a “biomarker” for that disease.

“A protein biomarker is an extremely valuable and sensitive signature of disease,” said Nelson, who employs sophisticated technology using mass spectrometry. “In a comparison from just a single protein profile, we can detect a slight difference between healthy individuals and those who may be at an early risk for a disease like diabetes.”

Nelson has already identified several new blood-borne markers of type II (adult-onset) diabetes. These biomarkers are now undergoing a stringent validation process to be used for disease diagnosis and management. To prove that the presence of a protein in the blood is a definitive indicator of a disease, researchers must show that the protein profile is consistently present for those with the disease and is rarely present with those who do not have the disease. \*

8.5

Percentage of adult Arizonans diagnosed with diabetes—295,000 people—in 2007  
Source: Centers for Disease Control

19

Times higher incidences of type II diabetes among Arizona Pima Indians than white population.  
Source: American Journal of Epidemiology

58.3

Billions of dollars spent on U.S. hospitalizations for diabetes in 2007.  
Source: American Diabetes Association



Researcher prepares gold plate with minute blood samples for spectrometry analysis.

# TGen Researcher Pioneers Cancer Research and Clinical Care at Scottsdale Healthcare

The paw of a golden-mane lion hangs playfully from the reception desk, striking a disarming pose at TGen Clinical Research Services at Scottsdale Healthcare.

Nearby are other stuffed toys—zebras, a cheetah, a tiger and a four-foot-tall giraffe.

“A lot of patients want to take them home, and sometimes they do,” said Raoul Tibes M.D., Ph.D., one of a rare breed of physician-scientists with one foot at the bench of his laboratory and one foot at the bedside of his patients.

Tibes is riding the wave of the future in medicine. He is a doctor with the academic know-how to stay abreast of the latest scientific research as he expertly guides his cancer patients through the rigors of clinical drug trials.

It isn’t an easy balance, and few cancer specialists are willing to shoulder the burdens of both the lab and the clinic. Most want to specialize as either scientists or doctors. But a few, like Tibes, are both. A board certified internist, hematologist and oncologist, he works as a doctor for the clinic, and also conducts laboratory research for the Translational Genomics Research Institute (TGen) in Phoenix.

His patients have already been through the medical wringer by the time they see him. They must have already exhausted other treatments, including surgery, radiation or conventional chemotherapies. Many have had remissions, only to have their cancers recur.

“We emphasize quality of life,” said Tibes, adding that extending the life of the patients, as well as maximizing their comfort, are paramount concerns. “And we aim to tailor each patient’s new treatment based on the molecular context of the disease.”

Unlike conventional drug therapies, which use a broad spectrum of agents to attack diseases, targeted therapies help avoid toxicities

“WE AIM TO TAILOR EACH PATIENT’S NEW TREATMENT BASED ON THE MOLECULAR CONTEXT OF THE DISEASE.”

Dr. Raoul Tibes,  
TGen Clinical Service  
at Scottsdale Healthcare

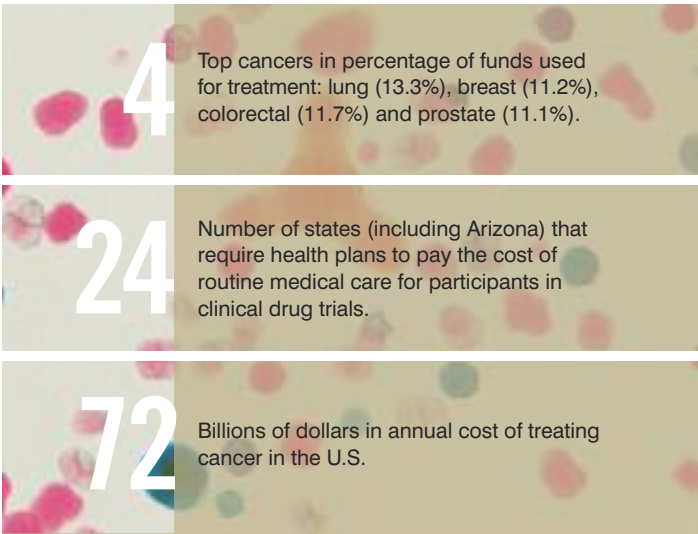
and can result in fewer side effects, while increasing the effectiveness against cancers.

Physicians at the Scottsdale clinic are at the forefront of creating personalized therapies for individual patients based on each cancer’s genomic

profile. Tumors are tested by TGen scientists using state-of-the-art technologies as part of the process of developing specific drug treatments.

Personalized therapy is the new frontier in medicine: Finding a specific drug treatment targeted to the individual needs of each patient, easing their suffering and, hopefully, discovering a cure.

Since opening in 2005, TGen Clinical Research Services at Scottsdale Healthcare has become one of the nation’s most prominent sites for early phase clinical trials. TGen Clinical Research Services has experienced steady growth and had more than 3,000 patient-visits in the last year. \*



Source: National Cancer Institute





*Raoul Tibes, MD, PhD*



Dr. Raoul Tibes is both a clinician and a cancer researcher.



# THE DOCTOR DILEMMA:



# WHEN TO GET READY FOR PERSONALIZED MEDICINE?

**BY LEE GUTKIND**


Dr. Muin Khoury tells this story: A man he knows, 45 years old, took a test advertised by a company offering low cost gene profiles and learned that he had an almost two-fold increased risk of prostate cancer. His doctor did a rectal exam, found something suspicious and ordered a biopsy, which showed he had prostate cancer, said Khoury. The man scheduled a prostatectomy—“utterly convinced that this genome profile saved his life.” Was he right?

Perhaps. But Khoury, director of the National Office of Public Genomics at the Centers for Disease Control and Prevention in Atlanta, points out that men can live long lives with prostate cancer and die from other causes. And removing the prostate creates risk factors, including impotence. So what’s a doctor to do? Order surgery for all patients with gene profiles indicating high risk of prostate cancer? The cost would be astronomical, especially considering, according to Khoury, “the utility of these tests have not been proven.”

## **Need for Genomic Awareness**

But the fact that these tests exist and that they are becoming less expensive and increasingly popular, is a sign that the face of the healthcare system as we know it today will be changing radically, and that healthcare providers need to develop a stronger and more responsive genomic awareness. For a book I have been writing, I have talked with surgeons, oncologists, geneticists, genetic counselors, public officials and media-marketing strategists about what many people are calling the genomic revolution and the impact of “individualized” or “personalized” medicine. Most acknowledge the potential that personalized medicine promises but how to respond now, in the early stages of the revolution, is unclear.

Personalized medicine means utilizing information about a person’s genetic makeup to detect, treat or



EXPERTS ACKNOWLEDGE THE  
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AMAZING SCIENTIFIC PROGRESS HAS BEEN MADE SINCE THE GENOME HAS BEEN MAPPED, ESPECIALLY IN BREAST CANCER—THE POSTER CHILD OF PERSONALIZED MEDICINE—WHERE SPECIFIC CANCER CAUSING GENES HAVE BEEN ISOLATED.

prevent disease. Although it is anchored in doctor-patient interaction, as is traditional medicine, its

meaning is much more wholistic—“wholistic with a W,” according to Dr. Jacqueline

Chadwick, associate dean for clinical affairs at the University of Arizona’s College for Medicine-Phoenix in partnership with Arizona State University. Chadwick means that genomic information will allow providers to look at patients in a more individualized manner, which will not only expand the doctor-patient relationship, but, among other things, also change the way in which pharmaceutical companies test and design drugs and insurance companies authorize coverage.

Chadwick also stresses the vital importance of “biomedical informatics,” which essentially means the use of computers to share information, worldwide, about patients, research and medications to enhance the individualization of treatment. Informatics is a key component at Arizona—a missing link in most medical-educational settings.

It all represents the beginning of a brave new world, approaching but not yet arriving at the tipping point—a reality that shapes what I call “the doctor dilemma:” How to know when to integrate new ideas into patient dialogue and treatments, on the one hand, and how to say to patients, who are waving the printouts that have received from gene profile companies like DeCodeMe and Navigenics, as Dr. Khoury recommends to physicians in an article for the *New England Journal of Medicine*: “Not now. Ask again in a few years.”

The experts I have talked with explain the doctor dilemma in two ways. Amazing scientific progress has been made since the genome has been mapped, especially in breast cancer—the poster child of personalized medicine—where specific cancer causing genes have been isolated, but we are not nearly far enough in our research into most other common diseases to significantly impact on a treatment plan. For example, most doctors will respond to patients whose DNA indicates a high

rate of probability of contracting type II diabetes in exactly the same way they would respond to patients with a family history of the disease: Eat right, lose weight, exercise.

### **Danger in Good News**

Dr. Khoury actually perceives potential danger in getting good news: Patients learning that they have a low possibility of getting diabetes may not care as well for themselves because they feel safe.

But lacking enough data to make an impact in no way means that physicians are up to date on the rapid inroads being made in personalized medicine. “People come to us for meat and potatoes reasons—actionable advice,” says Dr. Jim Evans, editor of *Genetics in Medicine*, published by the American College of Medical Genetics. “We can talk forever about the future benefits of personalized medicine, but let’s face it, a doctor-patient interaction may only last 15 minutes, perhaps less, and there’s a lot to get done.” Family histories, for example, the anchoring element in genetics, can take the better part of an hour. Physicians are not reimbursed by insurance companies for this time. Nor are they paid in an equitably (compared to doing procedures) for genetic counseling.

The problem begins in medical schools, which, early on, offer only a few weeks of genetics (or informatics) education. By the time of their residency, new doctors can employ little of what



Protein based analysis  
of disease can begin  
with something as  
simple as a blood test.





THE CURRICULUM AT UNIVERSITY OF ARIZONA'S COLLEGE FOR MEDICINE-PHOENIX IN PARTNERSHIP WITH ARIZONA STATE UNIVERSITY IS DESIGNED TO INTEGRATE THE ANCHORING ASPECTS OF PERSONALIZED MEDICINE WITHOUT SACRIFICING TRADITIONAL CORE EDUCATIONAL PRINCIPLES.

fewer young doctors are becoming certified in genetics. Fewer geneticists in a medical center diminish the influence geneticists can assert in medical education—and at exactly the wrong time.

This being said, it doesn't mean that doctors in private practice or at major medical centers can remain in limbo or denial for too much longer. Research has a way of sneaking up on society and becoming reality sometimes before the major players are prepared to understand and deal with it. In the 1980s, I wrote a book about heart, liver and lung transplantation—a concept that was always considered nearly impossible. But an immunosuppressive drug was developed and quickly introduced, and in the blink of an eye, patients on the edge of death were suddenly

they learned in a clinical atmosphere. Later in private practice, their introduction to genetics is hardly a memory, exacerbated by lack of reimbursement. Which means, practically speaking,

walking around and returning to the life they left behind before their illness. Healthcare providers, insurance companies and society at large were lost, unable, for years, to catch up and adjust to the to the new replaceable body science.

Inevitably, personalized medicine will precipitate a much more all-encompassing explosion. Those popular gene tests may not tell physicians enough to make a diagnosis and treatment plan at this particular moment, but only a few years ago this very low-cost test was hard to imagine. The tests will become more sophisticated and helpful and less expensive as research is propelled forward—and doctors will be forced to catch up quickly at a cost in time and resources far beyond what might be necessary if they started to get up to speed right now.

### New Steps in Physician Education

There are, in fact, some medical schools and centers attempting to take bold new steps toward introducing personalized medicine. The curriculum at University of Arizona's College for Medicine-Phoenix in partnership with Arizona State University is designed to integrate the anchoring aspects of personalized medicine without sacrificing traditional core educational principles. The importance of family





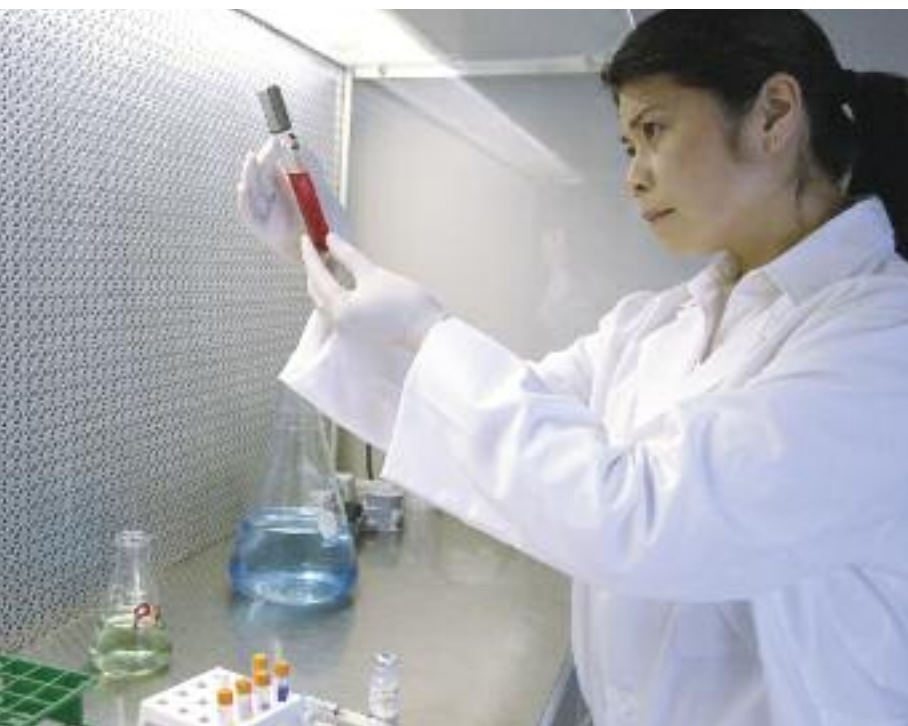
histories, cutting edge genetic research and the utilization of biomedical informatics are key components. (“Wholistic with a W,” as Dr. Chadwick might say.)

Student training also emphasizes patient contact and clinical experience much more rapidly than in more traditional medical school settings. And Arizona has partnered with The Translational Genomics Research Institute (TGen), which allows a student to become comfortable in the laboratory almost from the beginning of the medical school experience. “All of these components are like building a building,” says Dr. Michael Demeure, a surgeon and a researcher for TGen and Scottsdale Healthcare, a clinical partner of TGen and the medical school: “Everyone puts a brick down—and

Geneticists at Harvard are embedding actual genetics residents in treatment teams. Recently, a resident rotating through the Department of Cardiology proved herself so valuable that she was taken into the practice. And at Yale, a genetics fellow, Dr. Steven Murphy, has started his own personalized medicine practice, building a team and seeing patients in a rented Park Avenue office in Manhattan and Greenwich, Connecticut. But these are baby steps—small ripples hardly impacting or noticeable in the ocean of a healthcare system ready for massive change. While it is hard to know exactly when and to what exact extent personalized medicine will become the standard of practice and care, it will surely happen. The dilemma for doctors is not whether to embrace the inevitable—but when.

#### About the Author:

Lee Gutkind, founder and editor of groundbreaking literary magazine *Creative Nonfiction*, is described by *Harper's Magazine* as “the leading figure behind the creative nonfiction movement.” Gutkind is working on a book, projected for 2010, about personalized medicine. He has accepted an academic position in the fall at Arizona State University as distinguished writer in residence at the consortium for Science, Policy & Outcomes and professor at the Hugh Downs School for Human Communication. He also will be affiliated with the Virginia G. Piper Center for Creative Writing at ASU. \*



sooner or later you have a wall—and you keep building.”

Other medical centers are seeing the light of this brave new world—and building their own structures in other ways. I recently visited Dr. Evans at the University of North Carolina at Chapel Hill, where Evans has embedded five masters level genetic counselors in clinical treatment teams—ophthalmology, cancer, cardiology, etc. The counselors consult on all pertinent cases under Evans supervision. This “deployment model” is a way to save physician time and avoid for the moment the issue of equitable physician reimbursement for time and resources.

THE DILEMMA FOR DOCTORS  
IS NOT WHETHER TO EMBRACE  
THE INEVITABLE—BUT WHEN.

## Arts and Culture

**Total grants awarded in this area: \$739,850**

### Actors Theatre of Phoenix

\$100,000/12 months

[www.actors theatrephe.org](http://www.actors theatrephe.org)

To create a permanent cash operating reserve.

### Arizona Opera

\$250,000/12 months

[www.azopera.org](http://www.azopera.org)

To support a challenge grant to increase the permanent cash operating reserve.

### Ballet Arizona

\$200,000/12 months

[www.balletaz.org](http://www.balletaz.org)

To support a challenge grant to increase the permanent cash operating reserve.

### Childsplay, Inc.

\$19,850/12 months

[www.childsplayaz.org](http://www.childsplayaz.org)

To support expenses related to the development of a strategic plan.

### Mesa Arts Center Foundation

\$20,000/12 months

[www.mesaartscenter.com](http://www.mesaartscenter.com)

To support upgrading Mesa Arts Center's website.

### Phoenix Art Museum

\$150,000/24 months

[www.phxart.org](http://www.phxart.org)

To launch and sustain a Valleywide Culture Pass program designed to develop new audiences by distributing free passes to a number of arts institutions at public libraries.



## Children

**Total grants awarded in this area: \$1,437,925**

### A Stepping Stone Foundation

\$19,425/12 months

[www.astepplingstone.org](http://www.astepplingstone.org)

To provide start-up supplies for a new preschool program in the Fowler District and support existing programs.

### Association of Arizona Food Banks

\$25,000/12 months

[www.azfoodbanks.org](http://www.azfoodbanks.org)

To provide general support.

### Crisis Nursery, Inc.

\$600,000.00/36 months

[www.crisisnurseryphx.org](http://www.crisisnurseryphx.org)

To support shelter services and a new day-respite program for children whose families are in crisis.

### First Things First

\$3,500/3 months

[www.azecdh.gov](http://www.azecdh.gov)

To support printing costs for Spanish promotional materials for implementation of Quality First.

### Pediatric Foundation of Arizona, Inc.

\$20,000/12 months

[www.azaap.org](http://www.azaap.org)

To develop a website that will improve the abilities of healthcare providers to provide comprehensive, developmentally appropriate healthcare and health information and resources to adolescents, families and the community.

### St. Mary's Food Bank Alliance

\$750,000/48 months

[www.firstfoodbank.org](http://www.firstfoodbank.org)

To support a capital campaign to expand food services including the Kids Café program.

#### The University of Arizona Foundation

\$20,000/12 months

[www.al.arizona.edu/foundation](http://www.al.arizona.edu/foundation)

To support the expansion into Maricopa County of the Understanding Youth Development program, a 36-hour certificate program for youth development professionals.



#### Education

**Total grants awarded in this area: \$1,221,700**

##### Back-to-School Grants

\$501,700/12 months

To provide back-to-school clothing for children in need at approximately 260 schools.

##### Be A Leader Foundation

\$20,000/12 months

[www.bealeaderfoundation.org](http://www.bealeaderfoundation.org)

To improve technology for underserved students through e-mentoring.

##### Expect More Arizona

(Arizona Community Foundation as fiscal agent)

\$200,000/24 months

602.381.1400

To support a public campaign to champion education in Arizona.

##### International Rescue Committee

\$100,000/12 months

[www.theirc.org/where/united\\_states/phoenix\\_az](http://www.theirc.org/where/united_states/phoenix_az)

To support a new interpreter project that will benefit young refugee children and their families.

##### Science Foundation Arizona

\$400,000/24 months

[www.sfaz.org](http://www.sfaz.org)

To provide operational support including personnel and program costs.

#### Older Adults

**Total grants awarded in this area: \$37,500**

##### City of Phoenix Human Services Department

\$9,500/12 months

<http://phoenix.gov/humanservices/index.html>

To support a planning grant for an independent study of the Senior Services Division's current meal operations to identify areas for improvement and cost savings.

##### Solecito Services, Inc.

\$8,000/24 months

623.876.5331

To purchase and maintain home health equipment and upgrade computers.

##### The Tremble Clefs Arizona Chapter,

National Parkinson's Foundation

\$20,000/24 months

480.838.4658

To support expansion into the West Valley of the choral music program that helps Parkinson's patients strengthen their voices.

#### Other

**Total grants awarded in this area: \$122,500**

##### Media In The Public Interest, Inc.

\$10,000/12 months

[www.mediainthepublicinterest.org](http://www.mediainthepublicinterest.org)

To support the launch of a radio and online news service in Arizona through Public News Service to cover arts and culture, older adults, philanthropy and nonprofit emergency services.

##### Rio Salado Foundation

\$100,000/12 months

[www.supportriosalado.org](http://www.supportriosalado.org)

To support reconstruction of the O'Connor House at its new Papago Park site.

##### The Collaboration for a New Century, Inc.

\$12,500/12 months

[www.thecollab.org](http://www.thecollab.org)

To support the AZ LeaderForce Initiative and develop a network of community leaders and human service partners.





### Piper Fellows

**Total grants awarded in this area: \$160,000**

Chicanos Por La Causa, Inc.  
 \$40,000/12 months  
[www.cplc.org](http://www.cplc.org)  
 To support Edmundo Hidalgo’s sabbatical as a Piper Fellow and related staff and board development.

Foundation for Blind Children  
 \$40,000/12 months  
[www.seeitourway.org](http://www.seeitourway.org)  
 To support Mark Nelson’s sabbatical as a Piper Fellow and related staff and board development.

Great Hearts Academies  
 \$40,000/12 months  
[www.greatheartnaz.org](http://www.greatheartnaz.org)  
 To support Daniel Scoggin’s sabbatical as a Piper Fellow and related staff and board development.

Mountain Park Health Center Foundation  
 \$40,000/12 months  
[www.mphc-azfoundation.org](http://www.mphc-azfoundation.org)  
 To support Dr. John Swagert’s sabbatical as a Piper Fellow and related staff and board development.

### Religious Organizations

**Total grants awarded in this area: \$20,000**

Valley of the Sun Jewish Community Center, Inc.  
 \$20,000/12 months  
[www.vosjcc.org](http://www.vosjcc.org)  
 To provide partial funding for a community performing arts venue serving Northeast Scottsdale.

### Community Relief Grants

**Total grants awarded in this area: \$1,000,000**

A New Leaf  
 \$20,000/12 months  
[www.prehab.org](http://www.prehab.org)  
 To support the La Mesita family shelter.

A New Leaf  
 \$20,000/12 months  
[www.prehab.org](http://www.prehab.org)  
 To support the East Valley Men’s Center.

André House of Arizona, Inc.  
 \$10,000/12 months  
[www.andrehouse.org](http://www.andrehouse.org)  
 To support meal services.

Association of Arizona Food Banks  
 \$30,000/12 months  
[www.azfoodbanks.org](http://www.azfoodbanks.org)  
 To support food purchases for food banks and pantries.

Association of Arizona Food Banks  
 \$30,000/12 months  
[www.azfoodbanks.org](http://www.azfoodbanks.org)  
 To support bulk food purchase and distribution for emergency food boxes.

Central Arizona Shelter Services  
 \$25,000/12 months  
[www.cass-az.org](http://www.cass-az.org)  
 To provide general support.

Central Arizona Shelter Services  
 \$25,000/12 months  
[www.cass-az.org](http://www.cass-az.org)  
 To support the Vista Colina shelter.

Clinica Adelante, Inc.  
 \$20,000/12 months  
[www.clinicaadelante.com](http://www.clinicaadelante.com)  
 To support the Rural Health Team Mobile Medical Clinic.

Community Information & Referral  
 \$20,000/12 months  
[www.cir.org](http://www.cir.org)  
 To support telephone system enhancements.

HomeBase Youth Services  
 \$20,000/12 months  
[www.hbys.org](http://www.hbys.org)  
 To support emergency housing services.



**Human Services Campus, LLC**  
 \$50,000/12 months  
[www.maricopa.gov/hscampus](http://www.maricopa.gov/hscampus)  
 To provide general support.

**Lodestar Day Resource Center**  
 \$25,000/12 months  
 602.393.9930  
 To provide general support for homeless services.

**Maggie's Place**  
 \$20,000/12 months  
[www.maggiesplace.org](http://www.maggiesplace.org)  
 To support emergency housing services.

**Mission of Mercy**  
 \$20,000/12 months  
[www.amissionofmercy.org](http://www.amissionofmercy.org)  
 To support the mobile health clinic.

**PAFCO Education Fund**  
 \$10,000/12 months  
[www.pafcoeducation.org](http://www.pafcoeducation.org)  
 To support access to information on critical human service issues.

**Paz de Cristo Community Center**  
 \$10,000/12 months  
[www.pazdecristo.org](http://www.pazdecristo.org)  
 To support meal services.

**Phoenix Children's Hospital Foundation**  
 \$20,000/12 months  
[www.phoenixchildrens.com](http://www.phoenixchildrens.com)  
 To support the Crews'n Healthmobile.

**Phoenix Rescue Mission**  
 \$20,000/12 months  
[www.phoenixrescuemission.org](http://www.phoenixrescuemission.org)  
 To support the men's shelter.

**Society of St. Vincent de Paul**  
 \$100,000/12 months  
[www.stvincentdepaul.net](http://www.stvincentdepaul.net)  
 To provide general support.

**St. Joseph the Worker**  
 \$25,000/12 months  
[www.sjwjobs.org](http://www.sjwjobs.org)  
 To provide general support.

**St. Joseph's Foundation**  
 \$20,000/12 months  
[www.stjosephs-phx.org](http://www.stjosephs-phx.org)  
 To support the Maternity Outreach Mobile Clinic.

**The Salvation Army**  
 \$20,000/12 months  
[www.tsasu.org](http://www.tsasu.org)  
 To support the Kaiser Family Center.

**Tumbleweed Center for Youth Development**  
 \$20,000/12 months  
[www.tumbleweed.org](http://www.tumbleweed.org)  
 To support emergency housing services.

**UMOM New Day Centers**  
 \$75,000/12 months  
[www.umom.org](http://www.umom.org)  
 To support emergency housing services.

**Valley of the Sun United Way**  
 \$325,000/12 months  
[www.vsuw.org](http://www.vsuw.org)  
 To support the collaborative efforts of funders in Maricopa County to match community donations through ChooseToHelp.org.

**YWCA of Maricopa County**  
 \$20,000/12 months  
[www.ywca.org/maricopacounty](http://www.ywca.org/maricopacounty)  
 To support the home delivered meal program for low-income older adults.

**Total of all Published Grants    \$4,739,475**

## Funder Collaborative—ChooseToHelp.org: Arizonans invited to match donations for multi-million dollar community relief fund

Ten Arizona foundations and funding organizations, including Virginia G. Piper Charitable Trust, pooled their resources to match donations for basic human needs in Arizona.

Grants are going to nonprofit agencies that provide critical human services to a growing population of Arizonans in distress due to the economic crisis.

The funding partners offered a \$1.3 million community relief matching fund via a statewide marketing campaign that has aimed to shed light on the changing face of poverty. Donations are being matched dollar for dollar, creating a multi-million dollar pool to provide grants to qualifying nonprofits.

### Giving Online

Donors give online at [www.choosetohelp.org](http://www.choosetohelp.org), with gifts matched through April. Links direct those who need assistance for themselves or their families to other sites for help. Contributions may focus in Maricopa County or in a particular region of the state at the donor's choosing.

Nonprofit organizations have been invited to apply for grants to fund the following emergency services:

- **Emergency Assistance:** assistance for payment of rent/mortgage and utilities, resource centers for the homeless.
- **Food Services:** food banks, congregate meals for homeless and domestic violence victims, food for youth programs, home meal delivery for older adults.
- **Shelter Services:** emergency shelter, domestic violence shelters, transitional housing.

- **Health Services:** medical assistance for the uninsured and underinsured.

The effort is one phase of an overall statewide campaign designed to bring awareness to the need for not only financial donations but also contributions of time and food, as well, under the theme, "The Changing Face of Poverty." Arizona Community Action Association, a statewide nonprofit agency representing Community Action Programs (CAPs) in every county, is organizing the statewide campaign. CAPs provide resources and services to the working poor and those in severe financial distress.

### Funding Partners

The project is a funders' collaborative of the Arizona Grantmakers Forum. Contributing partners include Arizona Community Foundation, Arizona Republic Charities, The Bidstrup Foundation, JPMorgan Chase, Lodestar Foundation, Nina Mason Pulliam Charitable Trust, Valley of the Sun United Way and Wells Fargo, in addition to Piper Trust. Lodestar is covering overhead costs, allowing 100 percent of donor gifts to be awarded. \*





Central Arizona Shelter Services provides beds for homeless men.



Beatitudes Center D.O.A.R. delivers food boxes to older adults.



Maricopa County Health Care for the Homeless at the Human Services Campus

## Nonprofit Leaders Take Sabbaticals: Notes from the Field

### Piper Fellows Program

Four exemplary nonprofit leaders—Edmundo Hidalgo, Chicanos Por La Causa; Mark Nelson, Foundation for Blind Children; Daniel Scoggin, Ph.D., Great Hearts Academies; and John Swagert, M.D., Mountain Park Health Center—are completing self-designed sabbaticals for professional development and renewal during 2009.

These Piper Fellowships provide up to \$30,000 for education and travel expenses. The fellow organizations provide a minimum of one month to a maximum of two months work-release time. Sabbatical experiences have ranged from seminars at leading universities to visits to nationwide best-practice sites to leadership development programs and personal coaching.

Since 2001, the Piper Fellows program has funded 32 nonprofit executive sabbaticals.



**Piper Fellow Edmundo Hidalgo**  
Chicanos Por La Causa

One of Chicanos Por La Causa's strengths has always been supporting mission-driven work and pursuing financial sustainability through entrepreneurial activities. Now that social entrepreneurship has gained currency, Edmundo Hidalgo who became the new CEO a little over a year ago decided to learn how new models and thinking might shape the organization's future programs.

His Piper Fellowship combines visiting best-practice sites around the country with professional education and development at the Stanford Graduate School of Business Executive Program in Leadership and Performance at the Peak in Colorado.

A number of conversations shaped Hidalgo's sabbatical. Dr. Jane Delgado, head of the National Latino Health Alliance and trustee of the Kresge Foundation, challenged him to see if Chicanos Por La Causa itself was a model as he assessed other social entrepreneur programs.

"It is possible that there is some DNA in those organizations to be entrepreneurial for themselves and their clients," said Hidalgo. "I'm not sure it's a total cultural shift for us, and I will be glad to bring my learning back to our community."



**Piper Fellow Mark Nelson**  
Foundation for Blind Children

Mark Nelson has worked in blind services for 19 years. He brings a strong background in assistive technology and management to his current position as COO of the Foundation for Blind Children, a 56-year-old organization that provides education and rehabilitation programs for the blind.

Changes in executive leadership have led to new organizational challenges, and he is using the Piper Fellowship to strengthen his leadership skills during the transition.

The main piece of his program doesn't start until late spring when he leaves for sabbatical. Nelson will attend three programs: Performance Measurement for Effective Management of Nonprofit Organizations at the Kennedy School of



Government at Harvard University; an Executive Program in Strategic Perspectives in Nonprofit Management at Harvard Business School; and the Stanford Graduate School of Business Executive Program in Leadership.

But just because he hasn't begun his sabbatical doesn't mean that Nelson hasn't already been a full participating fellow. "I've been part of a learning circle and the monthly meetings of fellows where we discuss issues common to nonprofit leaders and hear solutions, strategies and philosophies. Great stuff!"



**Piper Fellow Daniel Scoggin, Ph.D.**  
Great Hearts Academies

In 2005, Daniel Scoggin became the first CEO of Great Hearts Academies, a charter school management company with six schools in Greater Phoenix. With the advent of a new Telos Preparatory Academy in South Central Phoenix next year that will serve primarily minority, first-generation college bound students, Scoggin wanted to expand his expertise in delivering quality education to underserved populations.

He won a Piper Fellowship to do site visits at top-performing urban schools across the nation and bring best practices back to Arizona. So far, he has travelled to Texas to visit KIPP School and Yes College Prep in Houston and Uplift Academies in Dallas. In Newark, N.J., he spent time at Northstar Academy, where inner-city students catch up a couple of grades each school year.

Scoggin says all the schools are excellent models with shared principles of hard work and accountability for students. A common practice is beginning each school day with a student assembly to create anew a culture of expectation.

To round out his sabbatical, he will attend the Stanford Business School Executive Program for Leaders of Small and Growing Companies.



**Piper Fellow John Swagert, M.D.**  
Mountain Park Health Center

John Swagert who leads an organization that works to make healthcare affordable for patients just got back from two weeks at the Stanford Business School Executive Program for Nonprofit Leaders.

The course offered nationally recognized Stanford professors, and the opportunity to learn with 55 diverse colleague nonprofit leaders from around the world. It was a crash MBA course, or "MBA lite," as he says.

Swagert had delivered 3,405 babies in his career before deciding in 2006 to leave the clinical side of medicine to become the CEO of Mountain Park Health Center. In that role, he sought ways to develop an organization capable of adapting to the changing healthcare and economic environments. The idea of a Piper Fellowship became appealing.

"The training at Stanford has filled in gaps—things that I haven't had a chance to study in my career," he said. The biggest take-away for him is learning the framework for strategic planning that he knows will affect his organization going forward.

To complete his sabbatical, Swagert will also spend time in the summer at a Minneapolis advertising agency to learn about marketing development and branding opportunities for his organization. \*



# More About Piper Fellowships

**Yearly Fellowships.** The program offers a maximum of five awards up to \$30,000 each to support the professional development of outstanding senior executives of 501(c)(3) nonprofit organizations serving Maricopa County. Awards go to an organization in recognition of an executive who has demonstrated both leadership and potential for a significant role in the organization’s future.

**Staff Development.** Recognizing the need to stimulate learning and exploration among the rest of the staff and board, the Trust provides \$10,000 to each organization for professional staff and board development.

**Organizational Award.** Piper Fellows also are eligible to apply for up to \$50,000 for a Piper Organizational Enhancement Award to support a project to address one of the major opportunities or challenges facing the organization. Fellows may apply for a one-year grant award at any time during their fellowship year and up to six months following the completion of their fellowships. Fellows must indicate how their fellowship connects to the request for organizational funding.

**Retreat.** Each new class of Piper Fellows has a one-day retreat early in the fellowship year. This retreat establishes relationships and further strengthens networking within the new class.

**Fellow Meetings.** To expand and enrich the fellowship experience, there are ongoing informal monthly breakfast meetings for all current and past fellows. These meetings draw on the expertise of community leaders and visiting thought leaders. There is always time at the monthly meetings for dialogue around common topics of interest.

**Learning Circles.** Piper Fellows also can participate in monthly facilitated learning circles where they can share both personal and professional issues common to nonprofit leaders. These circles focus on the concept of building community among nonprofit leaders.

**Selection.** Each year, an independent committee of distinguished Valley leaders knowledgeable about the importance of the nonprofit sector and its contributions to the region conducts the selection process. The selection committee operates independently and makes its recommendations directly to the Piper Trust Board of Trustees for its consideration.



**Chris Tompkins**  
Coordinator,  
Piper Fellows Program

*From the beginning, Piper Fellows decided they didn't want to limit their experience to a single year: they wanted to continue the ongoing support and shared experiences. The enhancement and enrichment of the fellowship program reflects the tremendous continuing engagement of past and current fellows. The learning circles, for example, really started with a weeklong Peter Senge workshop that Piper Trust funded for senior executives of a dozen nonprofits. Tamara Woodbury, CEO of Arizona – Cactus-Pine Council Girl Scouts, and I went through the program along with several other Piper Fellows. Afterwards, we talked about continuing the experience through a learning circle. That model of nonprofit leaders sharing with each other monthly was the basis for expanding leadership circles to all fellows.*

KEY PIPER FELLOWSHIP DATES	
June 11	Piper Fellows Community meeting
September 15	Postmark deadlines for completed applications
October-November	Finalist interviews at Piper Trust Offices
Early December	Announcement of Piper Fellow awards
For more information about eligibility and the application process, go to <a href="http://www.pipertrust.org">www.pipertrust.org</a> , or call 480.948.5853.	

**VIRGINIA G. PIPER  
CHARITABLE TRUST**

Virginia G. Piper Charitable Trust is a private, independent foundation committed to honoring Virginia Galvin Piper’s legacy of supporting organizations whose work enhances the lives of people in Maricopa County, Arizona. Following the philanthropic example of her first husband, Paul V. Galvin, the founder of Motorola, Mrs. Piper wrote, “For me, managing the stewardship of charitable giving is a moment to moment dignified responsibility of a truly high calling in human affairs and human relations.”

Moving from Chicago with her second husband, Kenneth M. Piper, Mrs. Piper lived in Paradise Valley, Arizona, for the last three decades of her life and quietly but steadily worked to strengthen Phoenix-area nonprofits. Following her death in



1999, the Trust received approximately \$600 million, becoming the largest foundation in Arizona. In its grantmaking, the Trust has continued Mrs. Piper’s interest in supporting healthcare and medical research, children, older adults, arts and culture, education and religious organizations.

Today, trustees and staff strive to preserve Mrs. Piper’s spirit of “high calling” and stewardship in all their work. Piper Trust has invested more than \$245 million in nonprofits and programs. Trust grants have benefited nearly 850 nonprofit organizations. With its focus on one geographic region, Piper Trust works to be more than a grantmaker by convening groups to address community issues, bringing national thought leaders to meet with nonprofit executives and fostering collaboration in the philanthropic sector. \*



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