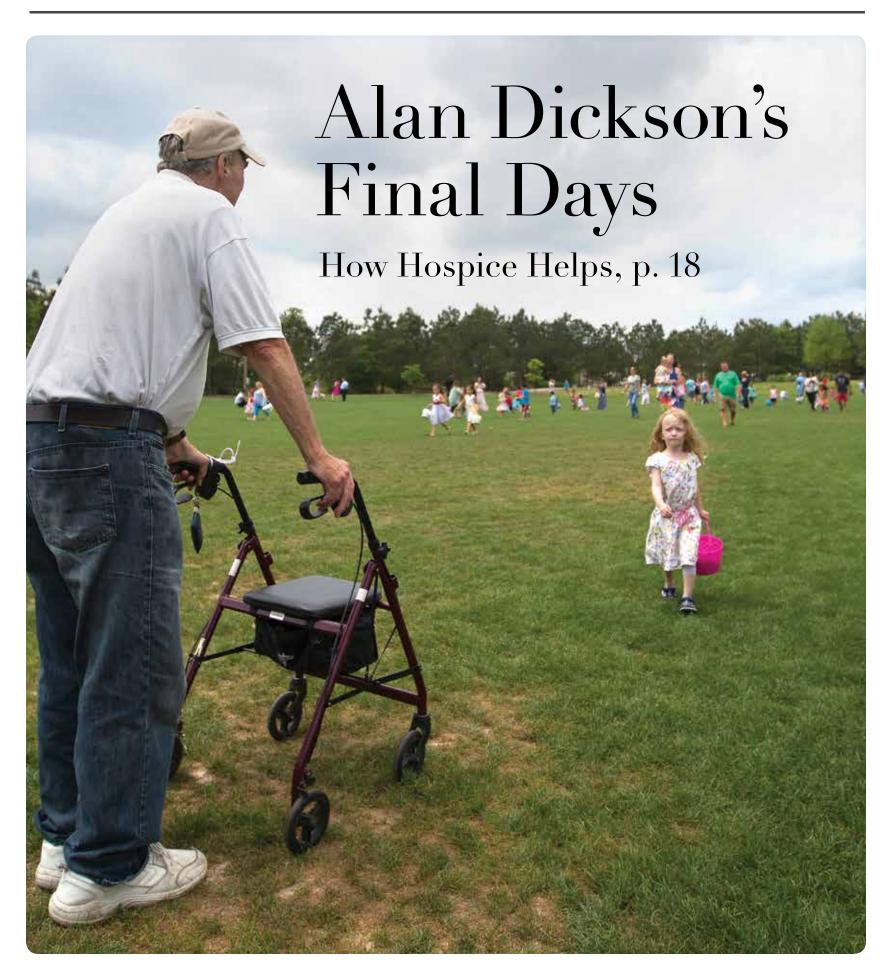
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NEWS OF THE TEXAS MEDICAL CENTER - VOL. 4 / NO. 6 - JULY 2017





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The Vintage Hospital

Conference Room 1-3

Time: 10:00 AM - 1:00 PM

Tuesday, July 25

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Time: 10:00 AM - 1:00 PM

Wednesday, July 26

The Woodlands/Lakeside/ Springwoods Hospital

The Woodlands Hospital
Conference Room 1-4

Time: 10:00 AM - 1:00 PM

Thursday, July 27

Patients Medical Center

Education Conference Room

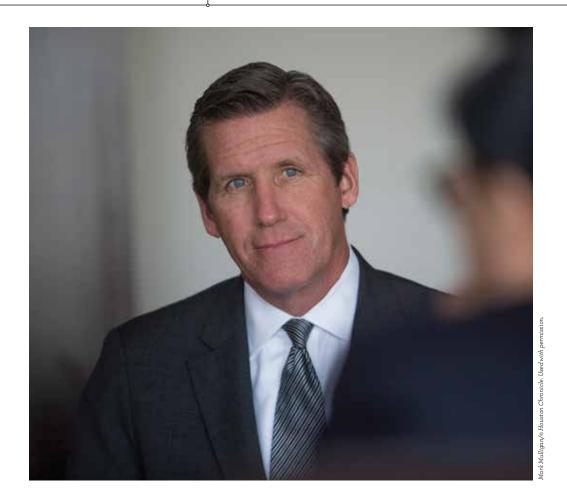
Time: 10:30 AM - 12:30 PM

Friday, July 28

Baylor St. Luke's Medical Center

Fannin Skybridge

Time: 8:30 AM - 11:30 AM



WILLIAM F. McKEON

President and Chief Executive Officer

Texas Medical Center

A number of significant events unfolded in the early 1900s that led to the formation of the largest medical city in the world.

In the 1800s, Galveston served as the center of commerce for Texas and the center for medicine in the region. In 1881, Galveston was chosen as the site for The University of Texas Medical Department, now The University of Texas Medical Branch at Galveston. But in 1900, a hurricane devastated the beautiful island and claimed more than 8,000 lives. Galveston's tragedy led to opportunity in Houston, however, with the development of a deep water shipping channel that extended 52 miles inland to Houston. The Port of Houston is roughly the same size and age as the Panama Canal, a testament to the continued importance of that infrastructure.

Four months after the Galveston hurricane, a well came in at the Spindletop oil field 80 miles east of Houston. That discovery launched the Texas oil boom, which fundamentally reshaped the economy of our city and state.

All of these independent factors led to a population surge in the Houston area. That growth required a strong medical infrastructure to support the ever-expanding community. City leaders formed the Texas Medical Center with a mission to advance research, education and the health of Texas.

Today, the Texas Medical Center is the largest medical city in the world. Our 110,000 employees include some of the very best researchers and clinicians on Earth.

True to our Texan spirit, we are now looking for ways to advance our mission through collaboration. We are uniquely positioned to leverage the resources on our campus to optimize and accelerate discovery and advancement of patient care. This opportunity does not exist anywhere else in the world.

Houston has come a long way since the early 1900s, but its spirit of innovation and entrepreneurship has remained strong for more than a century.

William 7 Myc

TMC PULSE

Vol. 4 No. 6 July 2017

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Running My First Code

A resident's training kicks in

An essay by Benjamin Gold, M.D.

ODE BLUE, 7 SOUTH. CODE BLUE, 7 SOUTH." I'm up and out of my call room bed before fully regaining consciousness from my light sleep. It's 4 a.m. I should feel ready; I've trained with simulations labs, mock codes, and test questions. I passed my CPR and advanced cardiac life support courses. I've done chest compressions as an intern.

But this is different. I'm the resident on call, and if I get there first, I'll be running the code. I've never run one before. I'm terrified. I'm not ready.

Code Blue is essentially a euphemism for being dead. While it technically means "medical emergency," it has come to mean that someone in the hospital has a heart that has stopped beating. The outcome statistics are grim. Even with perfect CPR, inhospital cardiac arrests have a roughly 85 percent mortality. Those patients who somehow survive are often left with irreversible brain damage and lie in comas. Few ever leave the hospital.

Death is greedy.

Still, we have to try. I run down the corridor toward the patient's bed. My sneakers make little squeaks against the linoleum floor, echoing off the walls of the mostly quiet hospital. My mind is a zoo. The flooring makes this place sound like a gymnasium. How many minutes in between epinephrine injections again? I should run more— I'm already out of breath. Think of causes, causes. The 5 Hs, the 4 Ts. What was the room number?

I burst into the room, out of breath. It is pure, primordial chaos. I'm hit with



the sounds first. Bed alarms, blood pressure alarms and heart rate alarms blare insistently, a Greek chorus to the unfolding drama. A string of unanswered questions hangs in the air like a heavy fog. "Can someone page anesthesia?" "Where's the cards fellow?" "Do we need femoral access?" "Where's the EKG?" "Chest X-ray, stat!" "Who spoke to the family?" "Is this guy DNR?" "Who has a hemoglobin?" "Is he on blood thinners?" "What's his history?" I can hardly hear myself think. This must be what it's like in the cockpit of a nosediving plane.

I take stock of the room. One nurse is on the bed performing chest compressions. A second is trying to steady the man's arm to place an IV, but is having a hard time. A third is struggling

66 The patient is staring straight at me. His eyes are glazed and unfocused. He's an older white man with a shaggy beard and sunken temples. His skin is a uniform, a lattice of mottled blue-gray. His head flops every second or so from the force of the compressions. "> >

to hold an oxygen mask to the man's face while squeezing an ambu bag. Pharmacists are rifling through a large red chest of medications. Someone is desperately clicking at a frozen computer in the corner of the room. A gaggle of nurses, aids, and respiratory therapists stands at the door.

The patient is staring straight at me. His eyes are glazed and unfocused. He's an older white man with a shaggy beard and sunken temples. His skin is a uniform, a lattice of mottled bluegray. His head flops every second or so from the force of the compressions. Currently, he's turned to face the door, looking at whoever crosses the threshold.

I take a deep breath. "Is anyone running this code?"

There is only silence. Beautiful, terrifying silence. No one is standing at the foot of the bed, which is where the code leader would normally stand. I'mgoing to have to run it. It's only a second or two, but the moment stretches and stretches. And seconds matter.

The brain is the most adaptable and responsive piece of biological engineering. It responds in real time to the

binary input of billions of neurons to create sight, sound, and sensation. It can accommodate elevation changes, pH changes, temperature changes, volume changes, infectious states, starvation, and fight-or-flight responses. But it has an insatiable demand for oxygen. There is no safe-mode, no low-power state. Four minutes without oxygen destroys 76 years of life.

Here we go.

"I'm Dr. Gold, I'm leading this code. You, keep time. You, continue compressions. Let's hook up the pads. Draw up one milligram of epinephrine ..."

The training kicks in hard. Good hard chest compressions, with epinephrine every two to five minutes. Pulse checks every two minutes. Shock the heart if it's ventricular tachycardia or ventricular fibrillation—a call that will be made by me. I hear a faint crinkling sound with every compression. Ribs breaking. Then a voice: "Two minutes, doctor."

"Pulse check!" The compression stops. Hands immediately reach for the femoral and carotid arteries, straining to feel the reassuring rhythmic pulse of life. All eyes turn to the cardiac monitor. It's hard to interpret while compressions are going, but now it's clear. The heart's electrical system normally conducts each beat with fanatical precision. Now it is in disarray, starved from a lack

It's v-fib. Disorganized, random electrical discharge that is unable to produce heartbeats. "It's v-fib." I say it quietly, almost to myself. No one moves. "V-fib," I say again, louder. Still nothing. Why aren't they moving? Oh, right. They're waiting for me to say something. "Continue compressions. Charge the defibrillator. We're going to shock."

We shock. The patient's body tenses suddenly and violently. It's strange to see him move so much. Strange that our muscles run on electricity. Strange that to save someone you hook them up to an outlet. We're more machine than

we realize. To reset pacemaker: turn it off, turn it on, see if that helps.

We continue CPR. Anesthesiology comes and inserts a tube into his throat so we can breathe for him. But it doesn't matter. We never get another shockable rhythm after the first shock, just a flat line. Asystole.

More compressions. More epinephrine. Other meds, too: amiodarone, calcium, magnesium, bicarbonate. We draw quick-resulting labs. We call cardiology for a bedside echocardiogram to look at the heart. It's not moving at all. After 30 minutes, I ask if anyone has any objections to stopping the code. No one does.

We pronounce him dead.

And just like that, the mayhem ends. The compressions stop. The plastic IV tubes are disconnected and thrown out. The hastily placed endotracheal tube is removed. The alarms are silenced. The defibrillator pads are removed. Pharmacy takes their cart of medications and leaves. The crowd begins to thin.

The patient's nurse begins making the final arrangements before

We shock. The patient's body tenses suddenly and violently. It's strange to see him move so much. Strange that our muscles run on electricity. Strange that to save someone you hook them up to an outlet. We're more machine than we realize.

the family arrives. His jaw, which was slightly gaping, is gently closed. His head is laid straight back, eyes looking up. Bloody linens are replaced with fresh ones. The patient is draped in a new gown.

Despite his recent ordeal, the patient now radiates a sense of calm. The man's stillness is serene, otherworldly. Impossible for a living being to achieve. The few remaining people in the room use hushed voices. The room feels sacred, somehow. I look at the man again. I think of Homer's line from *The Odyssey:* "Upon his eyes gathered the mist of death."

I perform the death exam. I check his eyelids and see no corneal reflex.

Feel no pulse. Hear no breath sounds. It's done. I exit the room.

A few feet from the door, a young black woman in cheery pink scrubs is curled up in a ball on a rolling chair near a desk. Her head is in her hands. Her shoulders jerk intermittently. In printed block letters, her ID badge reads MEDICAL VOLUNTEER.

I ask if she's OK, and she looks up at me. Her eye shadow is starting to streak down around the corners of her eyes. "I was watching him. I—I called for help. He wasn't breathing. I've never seen ... that ... before."

I nod. Words don't come. I stand beside her for a while. After a few minutes, I turn and head back to my call room. Somehow, I feel comforted by her crying. This seems the most appropriate reaction to the last 30 minutes.

I've run a few more codes since this one. It feels, if not routine, certainly easier than the first one. More algorithmic. But I can't shake the feeling that I shouldn't become too comfortable doing this. I want to always remember that volunteer. She didn't know this patient personally; he wasn't family. But she wept all the same.

To me, her tears acknowledged the frailty of it all, the randomness. The callousness of death, the gift that is life. It was inspiring. The day I can't feel the way she does about my patients is the day I need to find a new profession.

Benjamin
Gold,
M.D., is an
internal
medicine
resident
at Baylor
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Another Dimension to Breast Cancer Screenings

A new Texas law mandates coverage for 3D mammograms

By Christine Hall

A new Texas law, which takes effect Sept. 1, will help diagnose breast cancer earlier and more effectively.

The law mandates that all commercial insurance providers in Texas cover certain breast screening procedures, including digital breast tomosynthesis (DBT)—better known as a 3D mammogram—at no additional cost to patients.

Gov. Greg Abbott signed the bill into law on June 15.

The original bill, House Bill 1036, was introduced by Texas Rep. Senfronia Thompson (D-Houston), a breast cancer survivor who was diagnosed in 2004. Her experiences with mammograms, biopsies and radiation inspired the bill. With 3D mammography, she said, physicians can see tumors or lesions as small as two millimeters and women are less likely to need biopsies.

"That could mean less treatment to

get rid of the tumor, or not having to go through days, weeks or months of chemotherapy," Thompson said. "Women also have a head start getting the cancer under control, and the likelihood of going back for a second mammogram is reduced."

This is a big win for women in Texas, where, in recent years, legislative bills supporting women's health issues haven't found huge support. Though HB 1036 sailed through both the House and Senate in less than two months, it wasn't without a fight.

Thompson said she had to act like a "junkyard dog" to get the bill moved out of committee. Fortunately, she had support from colleagues who had lost loved ones to cancer or had fought cancer themselves.

Despite the benefits of DBT, many insurance plans covered only



Texas Rep. Senfronia Thompson

traditional 2D mammograms. The new law updates the legal definition of a mammogram to include DBT.

The denser the breast, the more difficult it is to spot potential cancerous lesions in a mammogram. The difference between the 2D and 3D

mammogram is that the 3D can capture the full thickness of the breast tissue. This is beneficial because patients come in all shapes and sizes, and so do their breasts—big or small; perky or droopy; dense, fibrous or lumpy; or with very little tissue.

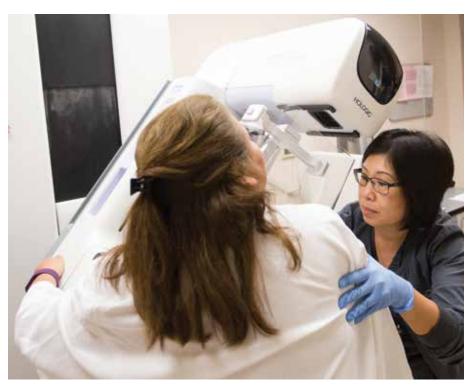
The 3D mammogram takes images in 1-millimeter "slices," so technicians and doctors reading the mammogram can examine each layer of the tissue. For example, if a patient has a group of lesions in close proximity, doctors can examine the images slice-by-slice to see the extent and scope of the lesions.

Moving forward, mammograms will now include both 2D and 3D imaging; 3D mammograms take just a few seconds longer than 2D mammograms.

"A patient likely wouldn't perceive any difference in the length of the screening, but we will tell a difference in the pictures," said Therese Bevers, M.D., medical director of The University of Texas MD Anderson Cancer Center's Cancer Prevention Center.

Of course, any kind of additional imaging is not without risk. A mammogram exposes patients to a low dose of radiation, but Bevers tells patients that those few additional seconds for a 3D mammogram expose them to the same level of radiation they would receive flying in an airplane on a round-trip flight from Houston to Paris.

Overall, the benefits far outweigh the risks, Bevers said. Researchers have found the 3D mammogram reduces the number of false alarms, false negatives and recalls. A recall occurs when a mammogram shows a potential problem area, so the doctor asks the patient to undergo additional imaging.



 ${\it Mammography\ technician\ Neena\ Bui\ gives\ a\ patient\ at\ MD\ Anderson\ a\ 3D\ mammogram.}$



A patient likely wouldn't perceive any difference in the length of the screening, but we will tell a difference in the pictures.

- THERESE BEVERS, M.D.

Medical director of MD Anderson's Cancer Prevention Center

"When we have a question, we have to bring them back," Bevers said. "It could be that what we find is benign, or a false positive, causing more time, cost and anxiety for the patient."

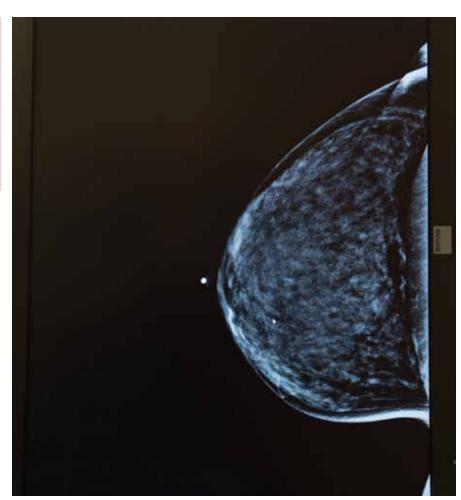
Bevers has also found that better imaging means fewer invasive procedures, including biopsies, in which small samples of tissue are extracted for further examination.

That is good news for people like Thompson, who said the pain associated with a biopsy "scared the daylights" out of her.

Thompson is also adamant about getting annual mammograms, which is how she caught her breast cancer.

"You don't know the magnitude of your problem, and you don't know if the cancer is going to take you out," she said. "I was able to get rid of it, so I always tell women that it doesn't matter how busy you get, don't miss getting a mammogram."

Texas will become the seventh state to have mandates for 3D mammograms in place for insurers. Already, Arkansas, Connecticut, Illinois, Maryland, New York and Pennsylvania have passed similar legislation, while Arizona, Missouri, New Jersey and New Hampshire have similar bills moving through their state legislatures.



A slide from a 3D mammogram shows a layer of tissue inside the breast.



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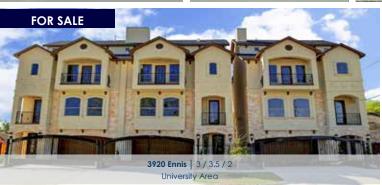






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Bursting the Bubble

Babies born with the same rare genetic disorder as "bubble boy" David Vetter have reason to hope

By Shanley Chien



Sebastian Romero in his crib at Texas Children's Hospital on May 31.

Blanca Romero gave birth to her son, Sebastian, on Feb. 12, 2017, at Houston Methodist Hospital in Katy. At 8 lbs. 9 oz., Sebastian had plump cheeks, big brown eyes and a head full of thick black hair. He was, by all appearances, a perfectly healthy baby boy.

Sebastian was Romero's third child, so she was familiar with the post-delivery drill. She took him to his newborn screening with the pediatrician, but something wasn't quite right with one of his tests. The results showed abnormalities in Sebastian's immune system.

"It was scary to hear your child has something, but you don't know what it is," Romero said.

Romero and her husband, Emil, met with Sarah Nicholas, M.D., an allergy and immunology specialist at Texas Children's Hospital, who explained that their son had a rare genetic disorder called severe combined immunodeficiency (SCID). The condition is more commonly known as "bubble boy disease," named for David Vetter, who suffered from the same illness and was forced to live his short life in a sterile plastic bubble. Born in 1971, Vetter was

also treated at Texas Children's.

Patients with SCID are born missing their T cells, a type of white blood cell that protects the body from foreign invaders by killing viruses and sending instructions to the rest of the immune system. In some SCID cases, patients may be born without their B cells, a white blood cell that produces antibodies, or natural killer (NK) cells, a white blood cell that kills viruses and tumor cells.

Without the body's natural defense system, Sebastian and other babies with SCID are at high risk for severe and recurrent infections, such as pneumonia.

"Even a slight cold could turn deadly, a rash could turn into an infection and turn deadly," Romero said. "Anything could kill him."

But there was hope. With chemotherapy and a bone marrow transplant, Sebastian had a good chance of living in the real world.

Living in a bubble

Although Sebastian didn't need to live in a plastic chamber like Vetter, the environment he required at home created a bubble of social isolation for Romero and her family.

Soon after his diagnosis, Romero's husband and the couple's other two children, Abraham, 7, and Kayla, 5, caught colds.

Romero's instincts kicked in. She began formulating a way to keep Sebastian safe from pathogens and people, including his own family. First, she and her husband disinfected their entire home, buying four air filters to remove dust, pollen, mold and bacteria from the air.

Then, they transformed the master bedroom into living quarters for her and Sebastian. Romero spent her days alone with the baby, venturing outside the room only for brief moments.

"My husband would bring food into the bedroom whenever the kids would leave for school and he would leave for work," Romero said. "He would Lysol the entire house so that I could go ... in the living room or the kitchen to get something to eat, and then I'd go right back into the room."

Romero notified her children's school of Sebastian's condition. The classrooms where Abraham and Kayla spent most of their time were sanitized daily. The school also let Romero know when any students were sent home with fevers, so that she could decide whether or not her children should go to school.

Rather than eating lunch in the cafeteria with the rest of his class, Abraham stayed in the classroom with his teacher and one friend.

When the kids returned home from school, they were required to shower immediately to make sure they didn't carry any outside pollutants or germs into the house.

Even then, the master bedroom was off limits. Although Abraham and Kayla were eager to hold and play with their baby brother, they had to stand far from the door. Romero would hold Sebastian up in the air "like in *Lion King* when they're showing Simba," she said, so they could see him.

"They went from being able to touch and love the baby to not being able to touch him anymore," Romero said. "At first, they didn't understand, so they would cry a lot. ... We had to explain to them that this was life-threatening and he could die."

The kids were isolated from their mother, as well.

"I couldn't hug my kids," Romero said. "I couldn't kiss them because



Emil Romero comforts his son in the hospital.

I have to protect Sebastian as his main caregiver."

Instead, she would give her two oldest children "pretend hugs." She would hug herself and they would hug themselves at the same time, as if they were hugging each other.

"I feel guilty," Romero said.

"Everybody tells me not to because
Sebastian is the one who needs us the
most right now, but I can't help, as a
mother, to feel like I'm failing my
other two children because they also
need me."

Looking for a match

On May 14, Mother's Day, Blanca and Emil Romero packed their suitcases and drove Sebastian from their home in Katy to Texas Children's. They settled into a small room with a metal crib for Sebastian and a sofa that converted into a pull-out mattress. For the next month, this would be their second home.

Currently, the only curative option for patients with SCID is a one-two punch of chemotherapy and a bone marrow transplant using stem cells.

With this treatment, the survival rate at Texas Children's has been shown to be more than 90 percent for patients with SCID if treated within 3 months of age. Left untreated, however, SCID is almost always fatal from infection within a year of age.

"Any time you see your patient go

through a difficult procedure ... you really worry about the risks you're subjecting them to, but SCID is really universally fatal ... without intervention," Nicholas said. "I feel good recommending it to my patients because I know it's a lifesaving therapy."

Stem cells are the "mother cells" of the blood that eventually mature into red blood cells, platelets and white blood cells, explained Caridad Martinez, M.D., Sebastian's bone marrow transplant specialist and associate clinical director of the Pediatric Bone Marrow Transplant Program at Texas Children's Cancer and Hematology Centers. Healthy white blood cells can further divide into various subtypes—including lymphocytes, which are the body's B cells, T cells and NK cells.

"Since the lymphocytes arise from stem cells that are located in the bone marrow, the only curative option for SCID patients is basically to replace that 'sick marrow' producing abnormal lymphocytes with a normal marrow producing functional lymphocytes," Martinez said.

There are three options for patients who need a bone marrow transplant: a sibling donor, an unrelated marrow donor or a cord blood unit.

A sibling donor is the preferred option, but only 25 percent of patients who need a bone marrow transplant will have a matched sibling donor. Patients

66 Even a slight cold could turn deadly, a rash could turn into an infection and turn deadly. Anything could kill him. **99**

BLANCA ROMERO

Mother of Sebastian, who was born with SCID

NEWBORN SCREENING FOR SCID

SCID is a rare condition, originally thought to affect approximately 1 in 100,000 births. But as more states test for SCID in newborn screenings, experts are finding that the statistics are likely closer to 1 in 50,000 or 1 in 60,000 births, said Sarah Nicholas, M.D., allergy and immunology specialist at Texas Children's Hospital.

"We've been missing all these SCID babies," Nicholas said. "These are babies who died early on of infection and people just thought they were unlucky. They got bad pneumonia and they died."

The vast majority of states test for SCID in newborn screenings. Louisiana does not screen for SCID, and six other states—Nevada, Kansas, Indiana, Alabama, North Carolina and Arizona—plan to implement pilot screenings by the end of 2017.

Texas added SCID to the newborn screening panel on Dec. 1, 2012. Since then, Nicholas and her team at Texas Children's have identified more than 35 babies with SCID and successfully treated them with bone marrow transplants.

To learn more about becoming a bone marrow or cord blood donor, visit bethematch.org.

without a matched sibling require either a transplant from an unrelated marrow donor or a cord blood unit—stem-cell-rich blood left in the umbilical cord and placenta after birth that was donated to a public cord blood bank.

But none of these options worked for Sebastian, who is Hispanic.
Minorities—including Hispanics,
African Americans and Asians—are underrepresented in the bone marrow transplant registry, making it difficult for babies of those ethnic backgrounds to find a good donor match.

(continued)

Martinez said it was the first time in her 10 years of transplanting SCID babies that she and her team weren't able to find a matched sibling or cord blood unit for transplant.

Without many options left,
Martinez decided on a different type
of transplant, one that had never been
performed on a SCID patient at Texas
Children's: a haploidentical transplant.
A haploidentical, or half-match, donor
can be a patient's mother, father or
sibling, as long as they haven't been

exposed to certain viruses, including cytomegalovirus (CMV), a common virus that affects 85 percent of adults. Once a person is exposed to CMV, the virus remains dormant inside the body and can be reactivated.

"Those viruses are like common colds, but when they reactivate in the transplant period ... it can be a problem," Martinez said.

Fortunately, Romero tested negative for those viruses, making her an ideal haploidentical donor for Sebastian. Martinez administered a drug called granulocyte colony-stimulating factor to stimulate the production of Romero's stem cells and mobilize them out of the bone marrow to the peripheral blood for extraction. After measuring the amount of cells her body was producing, Martinez and her team discovered that Romero had four to five times the amount of stem cells Sebastian needed for his transplant. Romero called them her "super cells."

The extracted stem cells were then

sent to a lab for graft engineering and T cell depletion, a purification process that separates unmatched T cells to prevent graft-versus-host disease (GVHD).

Finally, on the evening of Thursday, May 25, Martinez and her team walked into Sebastian's hospital room carrying a small blood bag full of purified stem cells. They hooked up the bag to the IV pole next to Sebastian's bed and began administering 78 milliliters of the "super cells."

Romero watched as the pink liquid snaked through the tube into Sebastian's central line. An hour and 10 minutes later, his body received the final drops of lifesaving stem cells.

Homeward bound

But Sebastian wasn't out of the woods yet. He was still experiencing side effects from chemotherapy.

In preparation for the bone marrow transplant, Sebastian underwent 10 days of chemotherapy to suppress any remaining immune response that might reject the donor cells and to clear space in the bone marrow for the new stem cells to grow and expand. Although this is a necessary part of the treatment, it takes a painful toll on the body.

"During the chemo days, he looked fine, but now to see the after effects, I can't do anything and nothing soothes him," Romero said. "I try to hold him and it's horrible. I can't do anything. It sucks. I wish I could just know what he's feeling."

Monday, May 29, was one of their hardest days yet. Emil Romero sat in the pull-out bed, gently holding Sebastian in his arms, while the slack of catheter tubes attached to Sebastian's body trailed around them. Sitting next to her husband, Blanca Romero gazed forlornly at her 3-month-old baby boy and listened to his subdued whimpering.

"He has learned that, if he cries, it hurts him more, so he whimpers more than he cries," she said. "He doesn't babble as much either because it hurts him."

As she caressed Sebastian's head, strands of his hair stuck to her hands, a side effect of chemo. Sebastian inched closer to her and started rubbing her face. Could he sense his mother's pain, or was he just practicing his handeye coordination?

"There are moments when I'm pretty okay and then there are moments when I go into the bathroom and just cry it out," Romero said. "It's tough to



Blanca and Emil Romero at home with Sebastian, Kayla and Abraham.

6 You need to wait until that immune system is mature enough to be functional and able to fight viruses or respond to vaccines. That usually happens about nine months to a year after the transplant is done.

- CARIDAD MARTINEZ, M.D.

Associate clinical director of the Pediatric Bone Marrow Transplant Program at
Texas Children's Cancer and Hematology Centers

see your child going through this stuff ... but he's there fighting and we're fighting along with him."

A new immune system takes time to grow and be normal, Martinez said.

"You need to wait until that immune system is mature enough to be functional and able to fight viruses or respond to vaccines," she added. "That usually happens about nine months to a year after the transplant is done."

On Wednesday, June 14, Sebastian's doctors delivered some surprising news: His T cell count in his bone marrow was steadily increasing above optimal levels. He was going to be released that afternoon, ahead of schedule.

"It was a mix of emotions," Romero said. "You get choked up knowing we're ready to go home, but at the same time, super scared because you've been in this environment where everybody knows they have to protect him."

But it was wonderful to have the family back together again. Sebastian's two older siblings could finally shower their baby brother with affection. They had been waiting patiently and loving Sebastian from a distance, but now, they could hug and kiss him.

"This is the closest they've all been since he was born," Romero said.

Sebastian will continue to stay in isolation at home for at least three months. He was supposed to leave only for clinic visits three times a week to receive blood or platelet transfusions, but because of a fungal infection he contracted, Romero still takes him to the hospital for treatment every day for four to six hours. It's an exhausting routine traveling back and forth from Katy to the hospital, Romero said, but at least they're home.

"We're so thankful that he's been doing so good," she said, her voice a couple octaves higher, as she nuzzled Sebastian's neck and cuddled with him on the sofa in their living room.

Over the past four months, Romero and her family's lives took an unexpected turn because of Sebastian's SCID diagnosis. But Romero, ever the optimist, said she hopes Sebastian's journey will raise more awareness about SCID and inspire others to become bone marrow or cord blood donors.

"I know there's a plan and a purpose. I can see that through sharing our story," she said. "If you could go, be a match and sign up, do it. You can save a life. What's better than that? You can be somebody's hero."



Romero nuzzles Sebastian at home, one week after his release from Texas Children's Hospital.



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Born and raised in Houston's Acres Homes community, SYLVESTER TURNER attended the University of Houston and Harvard Law School, and then returned to his hometown to work as a lawyer. In 1988, he was elected to the Texas House of Representatives, where he served until he was elected mayor. Mayor Turner spoke with Pulse about potholes, the plight of Houston's homeless and growing up without health insurance.

When you encounter people in your travels who are unfamiliar with Houston, what do you tell them? Do you have a go-to sound bite for the city?

A I tell them we are the most diverse city in America more diverse than L.A., New York, San Francisco, Philadelphia, Chicago. I tell them if you want to see where the United States is going to be 15 or 20 years from now, take a look at where Houston is today. I tell them—whether I'm in Mexico, Cuba, South Africa or Bahrain—that this is a city where we don't build walls. We build relationships. And I tell them this is the energy capital of the world and home to the largest medical center in the world.

When you say that Houston, today, is where the U.S. is going to be in 15 or 20 years, what do you mean?

A In this city, there's no single ethnic group that's a dominant majority. Whether you're Hispanic, whether you're African-American, whether you're Anglo or Asian, there is no real majority group. We're a pluralistic society, so we have to pretty much appeal to everyone. We're diverse, but we're seeking to be inclusive. One in four Houstonians is foreign-born. And over the next 15 years, another three million people will be moving into the Houston region, which is the equivalent of placing another Chicago in our midst. We're the fourth-largest city in the country and, in due time, we will be the third. We will pass Chicago.

| Health care in America is poised for change under President Trump. You lost your father to cancer when you were a teenager. What are your thoughts about the current state of health care?

A I'm concerned. You're talking to a person who didn't have health insurance, so I know the impact that it had on my own family. My dad died of cancer when I was 13. My dad didn't have health insurance; he went to the emergency room. I did not even know he had cancer until after he passed. I did know that I saw my

dad falling down at the house. I saw my dad fall down when we were out cutting people's lawns—in addition to painting for Continental Emsco, he did lawns on the weekend-but I thought he was just getting old.

After he died my mom told us that he had been dealing with leukemia. What my dad did was he had a prescription for painkillers. I'd ride with my sister to the Garden Oaks pharmacy on Shepherd. The pharmacist would give us this big bottle of painkillers. That's how my dad kept going. He did not have chemo or anything like that. My dad simply worked until he passed.

So, I've seen the impact of not having health care and how it can shorten your life. And the impact it can have on the entire family. It makes no sense to force people to go to the ER. It's much more expensive, and everybody will pay the tab. It's better to be on the preventive end.

And you can't say the focus needs to be on having access to care, if access is based on affordability. If I can't afford to get to health care, even though it's out there, I don't have access. So I don't like playing games with those type of words.

Q So, what's the answer? Fight to keep Obamacare?

A | We all recognize that with Obamacare there are some fixes that need to occur. But the answer is not to wipe it away. The answer is not to eliminate it and then come up with something where fewer people are going to be covered. We're talking about something that is essential to families. I think the United States is better than the discussion we're having, and I think the United States is better than the course we have taken. My attitude has always been: You don't destroy the good seeking the perfect, otherwise you'll end up

I am an optimist, but I also believe Americans have to participate in this discussion, and we have to be careful we don't just look at our own personal situation. For example, I've got insurance for the rest of my life. Even if I'm no longer mayor, by virtue of

being in the legislature for 20-something years, I've got insurance for the rest of my life. ... So the reality is, I can have Cadillac insurance, but if the people around me are without, and are suffering or going to the ER, and because of this system cost goes up and hospitals close, the winds occurring around me are going to impact me. We have to decide what's best for people in our society. In the end, if people are healthy, if kids are able to go to school and learn because they're not in pain, and if adults are able to go to work and be productive because they are well, we all win. We are all connected, and we fool ourselves if we think we

Q You've been mayor for 18 months. What's been your greatest accomplishment so far, and your greatest challenge?

A When I came into office, I heard a great deal about potholes, potholes. It was taking months and months to fix a pothole. We came in, we streamlined the system early and created an integrated system. The objective was when someone called in about a pothole, Public Works would assess and address the pothole by the next business day. Within a matter of weeks, we had achieved that goal and we maintained that 96 percent of the time in 2016. It's been hugely successful and impactful.

The other end of the equation is that we have a number of people who are homeless in Houston for various reasons. Maybe financial problems, maybe domestic abuse, maybe mental health issues. Even though we've been successful over the years reducing the number of homeless in the city from 8,800 at the highest down to now about 3,600, about 1,100 of that group represent chronic cases of homelessness. You can't miss them. You see the tents. We have communities, neighborhoods that are saying, 'Mayor, you must remove these people. We can't ride our bikes or walk; we don't feel safe.' On the other hand, you also have people saying, 'Mayor, this is our most vulnerable group. They have no place to be. Leave them be.'

(continued)

66 You're talking to a person who didn't have health insurance. so I know the impact that it had on my own family. My dad died of cancer when I was 13. My dad didn't have health insurance; he went to the emergency room. I did not even know he had cancer until after he passed. 🤊 🦻





Previous page and above: Mayor Turner at Houston City Hall.

66 One in four Houstonians is foreign-born. And over the next 15 years, another three million people will be moving into the Houston region, which is the equivalent of placing another Chicago in our midst. We're the fourth-largest city in the country and, in due time, we will be the third. We will pass Chicago. 🤊 🤊

What's the solution? We can all agree that one person living on our streets is one too many. As I said to one person who asked me to move the homeless: 'What would you have me do? Load them up and take them to another neighborhood?' 'No.' 'Put them in jail?' 'No, Mr. Mayor, we're not telling you to do that.'

We know a big problem is housing, and we'll work to house 500 people over the next six months. The federal government cut off funding to certain voucher programs, so that has slowed down permanent supportive housing. And I recognize that even if I go to someone and say, 'I have housing for you,' they might not want to go. So we're looking at establishing low-barrier shelters for people, temporary locations while we work on their individual circumstances to move them to a better place. Another piece of the solution is more funding for substance abuse and detox centers. We're asking people who give to the homeless who are panhandling to redirect their funding—to give to nonprofits and to faith-based operations instead. To give meaningful change, not spare change.

Q You have asked several universities to work together to support an institute for data sciences in Houston. At the same time, the Texas Medical Center is working on TMC3, a translational research campus $where \ major \ medical \ institutions \ will \ work \ together.$ Is there a theme here?

A I think there's an opportunity for this city to create high-paying innovation jobs. All the elements are here. The question is: Are we going to have collaboration? Are we going to get past being territorial and recognize it's in all our mutual interests? You can be territorial and defend your space, but if you're not moving forward, you're moving backward. In the city of Houston, somebody is going to play in that space.

Mayor Sylvester Turner was interviewed by Pulse editor Maggie Galehouse. This interview has been edited for clarity and length.

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Rainbo has been looking forward to painting all morning. Dancing anxiously on his stand, he performs a quick pirouette when Amber Zelmer approaches with his modified paint brushes and palette of colors.

Rainbo, a 26-year-old eclectus parrot who hails from the South Pacific, has been painting artistic masterpieces at the Houston Zoo for nearly two decades.

"Parrots are very smart and they need a lot of interaction," said Zelmer, senior keeper of the children's zoo within the Houston Zoo. "Whether it is painting, interacting with visitors ... or talking to us with the over 30 vocalizations he knows, we use enrichment programs to keep his mind stimulated and keep him active."

Just like hospitals in the Texas Medical Center provide therapy for patients, the zoo offers enrichment programs for animals.

Although caring for sick animals is not the main function of the zoo, enrichment programs are an essential part of daily life. Because the animals are no longer in their natural environments, the zoo uses painting and other activities to help encourage natural responses.

"These activities help to stimulate the same sort of thinking process in the animals as they would have in the wild," Zelmer explained. "Obviously, a wild parrot is not going to be painting—he would be out searching for food, searching for material to build a nest and interacting with other parrots in a social way. When I train with him, that fulfills his need for his social interaction and he gets food for completing a trained behavior."

Biting down on his whittled paintbrush, Rainbo uses water-based, non-toxic paints to make delicate strokes and loops with reds, purples and blues.

"Rainbo is one of the best painters at the zoo," Zelmer said. "He and the other parrots and the elephants are the only animals that can paint with brushes, which makes their work look more human."

When Rainbo and the other animals finish their paintings, the works are sold online and at fundraisers. For zoo visitors who want a more comprehensive experience, a special program allows them to watch the animals

All proceeds from animal paintings go to animal conservation.

"Whenever we sell a painting, we use that money to help animals across the world that might be endangered or sick," Zelmer said. "It not only gives Rainbo a job to keep his mind active, but he is helping other animals, too."





JRATED

By Britni N. Riley

The Intersection of ARTS and MEDICINE

Every Child Can Be a CEO

The TMC Young Inventors Forum featured creative solutions to health care problems

By Christine Hall



hen Mairi, a third-grader, was asked to solve a health care problem as part of a school assignment, she thought of her grandmother.

Mairi's grandmother was diagnosed with amyotrophic lateral sclerosis (ALS), a disease affecting the nerve cells that control voluntary muscle movement. Watching her grandmother struggle to communicate made Mairi want to find a way to make her grandmother's life easier.

So Mairi and three of her third grade classmates at the British International School of Houston—Anaïs, David and Sophie—conceived *Eye Help You*, a computer that helps ALS patients communicate through eye movements.

The device would include eye-tracking technology that sends information to a caregiver. The third-graders even researched similar products and found that those on the market only used letters. They decided their device would need to have full commands using words and pictures.

Mairi and her team pitched their idea to an audience of supporters at the TMC Young Inventors Forum in June. The product was so innovative that judges gave the team the "Degree of Impact" trophy.

We asked the students to come up with a list of problems that have to do with health care and then come up with solutions. Of course, we get an abundance of solutions for broken limbs because that is what they know, but we work with them to think deeper.

- KATE FULLER

Head of Primary at the British International School



Pitch perfect

For the past three years, the British International School of Houston and the Texas Medical Center have partnered on the TMC Young Inventors Forum, a six-week program that teaches 7- and 8-year-old students the fundamentals of innovation and basic health care problems. The students work in teams; each team identifies a problem and devises a solution.

To cap off the program each year, the students visit the TMC Innovation Institute, and each team pitches its health care solutions to parents, teachers and a panel of judges made up of community leaders.

"This is exciting because we started this program

Left: William F. McKeon, CEO and president of the Texas Medical Center, speaks to the young inventors. Right: Mairi, second from right, presents the Eye Help You computer with her team.

not just for fun, but because invention and entrepreneurship are skills that should be learned early on in life," said William McKeon, president and CEO of the Texas Medical Center. "Every child can be a CEO of a company, and every child can have an idea that is a breakthrough."

This year's forum also saw some returning students. Eight teams of fifth-graders—the same students who participated in the inaugural Young Inventors Forum—returned to pitch brand-new ideas and showcase an advanced level of entrepreneurship. The fifth-graders added financial information to their products, including cost, profit margins and pricing.

The judges panel included Julia Andrieni, M.D., vice president of population health and primary care at Houston Methodist Hospital and president and CEO of Houston Methodist Physicians' Alliance for Quality; Karen Bell, consul general of the United Kingdom; Houston City Council members Dwight Boykins and Amanda Edwards; and Bernard Harris, M.D., CEO of Vesalius Ventures.



 $\begin{tabular}{ll} A \textit{ team of young inventors shows off the Sunshine Cast, which helps absorb vitamin D.} \end{tabular}$

The way of the future

The curriculum for the TMC Young Inventors Forum was developed by Katharine Forth, Ph.D., CEO of TMCx alumni company iShoe, which creates products that measure and track balance.

As an entrepreneur, Forth feels that every child should have an education around invention and innovation. When her son was a third-grader at the British International School, she created the program.

Forth plans the curriculum with teachers at the school, including Kate Fuller, head of the primary grades.

"We asked the students to come up with a list of problems that have to do with health care and then come up with solutions," Fuller said. "Of course, we get an abundance of solutions for broken limbs because that is what they know, but we work with them to think deeper."

The goal is for the children to form teams around a passion for a particular problem, rather than simply work with their friends, Forth said. In order to devise a solution, each team researches their problem and talks to people they know who are affected by it. Then, every team writes an executive summary of their findings, explains how their solution can solve the problem, and designs a pitch.

One of the things Forth looks for is that "certain light in their eye," which is how she knows a child has caught the "inventing bug."

"It's awesome," Forth said. "You can see that sparkle. That is the magic of this curriculum." ■



 $\hbox{\it A triboard displays one team's Eco-Mom invention.}$

Every student who participated in the TMC Young Inventors Forum walked away with a medal, a goody bag and a T-shirt, but judges awarded trophies in five categories:

Marketability

Students came up with the *Drive-Me Chair*, a self-driving wheelchair that works off of a smartphone.

Degree of Impact

Eye Help You is a computer that would help ALS patients communicate through eye movements.

Quality of Prototype

The Fluffy Crutch Helper makes crutches softer and more comfortable to use.

Strength of Pitch

Students devised a *Staying Alive T-shirt* that shows the proper hand placement for CPR.

Innovativeness

The *Sunshine Cast* is a cast that helps absorb vitamin D.



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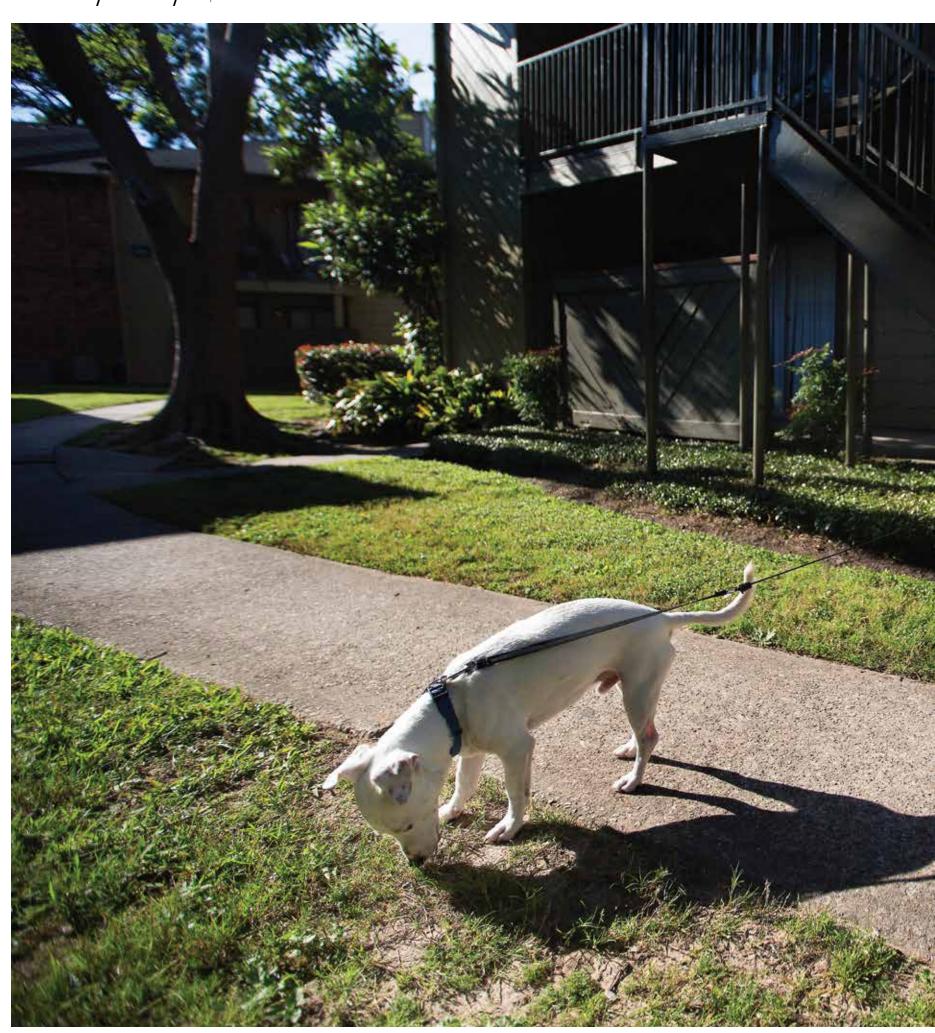




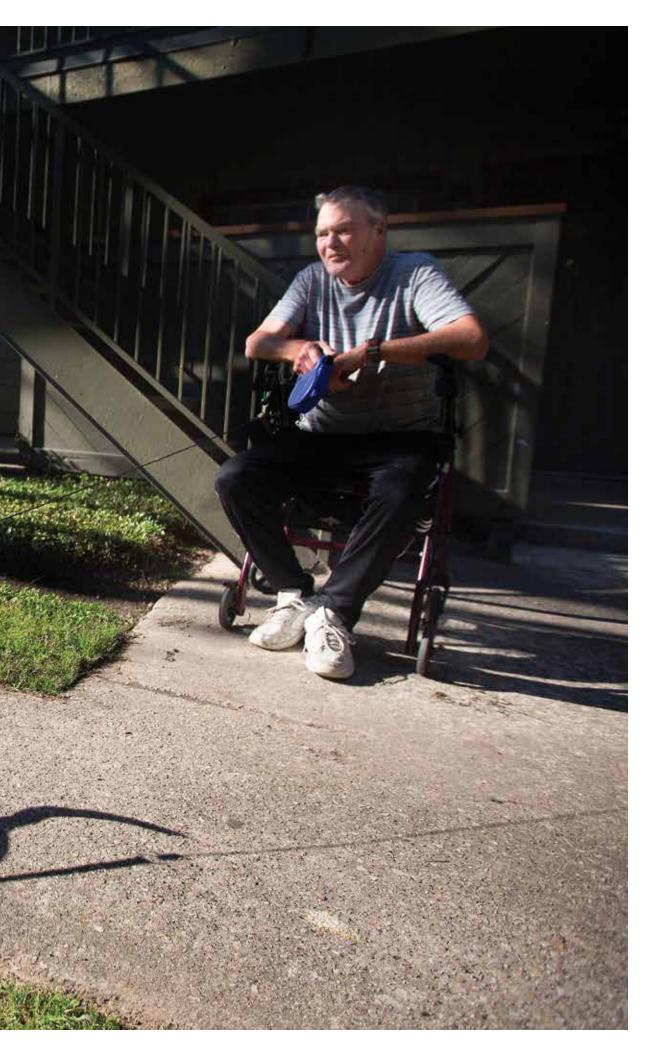
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ALAN DICKSON'S FIN

How Hospice Helps | story by alexandra becker | photography by cody duty



AL DAYS



Terrie Adcock, a social worker with Houston Hospice, settled into her favorite chair with a sigh. Outside her home, the March sky had grown dark, but she was not yet ready to call it a day. She pulled her computer onto her lap and inserted a flash drive filled with photos of a sprightly, 10-year-old Jack Russell terrier named Pal. Dragging her favorite images onto the desktop, she started building a PowerPoint, hoping it would end up in the hands of someone, somewhere, looking for a new companion.

П

Alan Dickson was dying. He was still living in New York when he suffered a series of medical blows—when doctors discovered the steady march of cancer spreading throughout his lungs, when a heart attack paralyzed part of his vocal cords, when he was diagnosed with congestive heart failure and diabetes.

In January 2016, Alan's only living son, Brad, flew to Syracuse and begged his father to move out of his dirty, dilapidated home and relocate closer to family. It was a tough sell. Although he had mellowed over the years, Alan hadn't shed his inclination to push away those closest to him. He liked being alone, liked taking care of himself, and didn't enjoy talking about the hard parts of life. But Brad persisted, and a day after Alan was released from the hospital, father and son boarded an Amtrak bound for Houston.

"I didn't want to push him because I know he's very independent," Brad said. "I didn't want to say, 'You have to move in with me,' because that wasn't my intention. But I needed to get him out of the toxic environment he was in."

Alan moved in with Brad, daughter-in-law Grace, and their 6-year-old son, Matthew. Alan's estranged wife, Carol, was also living in the house to help care for Matthew. Carol and Alan got under each other's skin; they had separated more than 15 years earlier, because living under the same roof proved impossible.

Worse, Alan's constant four-legged companion, Pal, was not welcome in Brad and Grace's home due to a history of biting.

So in November, nine months after relocating to Texas, Alan moved into a small one-bedroom apartment in North Houston, where dishes piled up beside his desk and paperwork lived on a coffee table. Next to the couch he kept an old black and white photo of two children holding hands.

(continued)

Houston Hospice patient Alan Dickson with Pal, his 10-year-old Jack Russell Terrier, in front of his apartment in North Houston.

GUARANTEED QUALITY CALIDAD GARANTIZADA









 $Clockwise from {\it the top:} Alan {\it shops for groceries;} Terrie {\it Adcock,} Alan's {\it social worker at Houston Hospice, goes over legal paperwork with Alan and his son,} Brad; Alan {\it with his grandson, Matthew, at an Easter egg hunt;} Alan {\it looks through old photographs.}$

The tiny girl in the jumper, his sister Gale, may have been the only person he didn't keep at arm's length.

Apartment 1513 was not a home, not really. There were no dents in the walls from rambunctious sons, no stains on the carpet from Super Bowls past, no memories of when his marriage was tender. But it suited Alan just fine. During the day, he would draw open the shades and sit in the sunlight to watch television, mostly shows about wilderness survival and living off the grid. Apartment 1513 was a place for him to crash, to drink beer or the occasional nip of Jim Beam, to spend time alone with Pal.

But Alan's terminal diagnosis soon made it clear that he would have to open his doors to family members, and to hospice. Terrie was assigned to Alan in January, and hospice nurse Karen Hoover soon after. It was important, Alan told them both, that he and Pal be together until the very end.

Ш

Hospice care requires that a patient have approximately six months left to live, although there is no exact science to the timing of death. For nearly 1.65 million Americans each year, death through hospice has become a preferred antidote to the beeping machines and invasive therapeutics of modern medicine. Recent statistics show that nearly 45 percent of all deaths in the United States occur under the care of a hospice program. In 2016, Houston Hospice alone served 2,169 patients.

Once patients enter hospice, they relinquish treatment and concentrate, instead, on pain management, symptom control, and spiritual and emotional comfort.

When Alan still had an appetite, he stocked up on shepherd's pie and butterscotch pudding. But by March, his hunger had already begun to wane. He could feel his energy drifting as he tried to keep up with regular outings, including walking Pal, a Tuesday bridge game and short trips to the supermarket. He often found himself overwhelmed by loneliness, and when members of his hospice care team paid him a visit, he would delay their schedules with stories of his past—growing up on San Diego Bay, working at his father's dime store, a trip to the Philippines decades after he'd been stationed there with the Navy.

Alan loved to sit at his computer and click through photos of his travels with Pal in an old pop-up camper. It had been just the two of them, snaking their way across the country's northern border, staring up at the flecked black skies of national parks.

"How often are you using the morphine?" Karen asked, during a March 20 visit. The hospice nurse put a stethoscope to Alan's chest and listened to his lungs.

"Probably about once a day, at night," Alan answered, his voice gruff and gravelly.

"So that's helping with your breathing?"

At our next visit, we'll have a really hard conversation about what end of life looks like and what your caregiving will have to be. Because you will reach a point where you cannot communicate. You will reach a point where you can't take care of yourself, and we do have to make plans for that, OK?

TERRIE ADCOCK

Houston Hospice social worker

"Yep. It relaxes me. And I was taking the nebulizer and the lorazepam. I found that sometimes adding the morphine helped."

"Perfect," Karen said. "And you can do that anytime during the day, too. It's a good cocktail for the evening; it opens up your airway."

Alan tilted his head back and laughed. "Wheeee!"

There was a note of innocence in his voice, unexpected for someone who used to drink a 12-pack of Milwaukee's Best Light every day, who had lost a grown son to leukemia.

 \mathbf{IV}

Despite a full night's rest—the first in weeks Alan appeared exhausted when Terrie arrived at Brad's house on April 5. She'd set up a brief meeting at Brad's to go over legal documents, but had been cornered by Matthew at the dining room table. He rattled off his encyclopedic knowledge of snakes and sharks. The Megalodon was his favorite shark, if extinct ones counted.

Terrie's big news was that one of her colleagues had found a future home for Pal with a woman named Ann, a retired VA hospice nurse who summered on 20 acres in Washington State.

Alan was pleased.

Brad told Matthew it was time to practice the piano and Carol ushered him into the front room. Terrie flipped through her paperwork, explaining in detail medical power of attorney and durable power of attorney.

"The other thing," Terrie said, looking at Alan, "is that I really want you to have a medical alert system, so that if something happens and you can't get to the phone, you have something around your neck or on your arm that will notify somebody that



Karen Hoover, Alan's hospice nurse, checks his vitals.

you're in trouble."

"I don't know," Alan said quietly. "I'm not too keen on it, but I guess it's probably a good idea."

"Why aren't you keen on it?" Brad asked.

"I don't know." Alan looked down at his hands.

"Is it a cost issue?" Brad asked. "You living alone I think it's a great thing to have."

"Yeah, probably should have it." Alan did not look up.

Terrie interjected. "But what are your concerns?"

"He's cheap. The money," Brad answered. "And it's probably acknowledgment, too."

Terrie nodded. "This is all scary stuff. It's a recognition that you are reaching a point where we at Houston Hospice have to keep a closer eye on you. You just keep getting more tired, and that's all part of it."

"We're there to support you and you won't be alone, you know that," Brad said.

"And I think the backup plan is if he needs to come here..."

Alan interrupted Terrie.

"I'm not too keen on coming here."

The conversation turned contentious. Brad's voice rose above the pings of the piano.

"You can't just push people away. We have to think about it practically."

"So what's the alternative?" Alan asked. He was barely whispering.

Terrie explained that, for the most part, the hospice team was able to manage symptoms in the home, but that caregivers were a critical part of the process. Sometimes, care could be arranged in an assisted living community. If inpatient care was required for severe symptoms, Houston Hospice had beds available.

Matthew skipped into the room. It was time for him to leave for swim lessons.

"Does anyone want a jellybean?"

"Say goodbye," Brad told him, ruffling his hair. "Say it was nice meeting you."

Terrie waved to Matthew as Carol shut the door behind them.

"At our next visit, we'll have a really hard conversation about what end of life looks like and what your caregiving will have to be," Terrie told Alan. "Because you will reach a point where you cannot communicate. You will reach a point where you can't take care of yourself, and we do have to make plans for that, OK?" (continued)

Alan said he was picturing Gale, who was currently under hospice care herself in California. His biggest fear, he said, was that he would end up like his sister: over-drugged, slurry and incoherent.

"I think it's safe to say we really do a very progressive end-of-life medication routine," Terrie said. "Our purpose, our goal for you, is comfort. OK? That doesn't mean you have to be gaga."

"Actually, I just want to die," Alan said, looking at her.

"I know you do. We've talked about that. But you're not suicidal."

"No."

"You're just tired of the fight."



By mid-April, showering had become difficult for Alan, sometimes insurmountably so. The worst part, he said, was putting water on his head and trying to breathe at the same time.

Father Raphael, the chaplain on his hospice care team, paid him a visit. Alan wasn't Catholic, or anything for that matter, but he valued their conversations.

"I believe that we're all connected," Alan said. "We're all a part of everything. Is there a God? Yeah. We are God."

Alan's hands shook as he squirted morphine under his tongue. He was taking a dose once an hour to ease his breathing and the pain knotted throughout his back. There was also methadone, gabapentin for peripheral neuropathy, albuterol for breathing, Senna and Colace for constipation caused by the pain medication, lorazepam for anxiety.

He was sleeping more each day and had all but ceased activity outside his apartment. Occasionally, he managed to take Pal outside, letting him roam as far as the leash would take him.

Alan and Brad talked in earnest. Alan did not want to be a burden in Brad's home. He did not want to live under the same roof as Carol. He did not want his grandson to know he was spending all day in a bedroom, dying. So he was staying in Apartment 1513.

The vast majority of hospice patients—nearly 60 percent—are treated in the place they call "home," which could be a private residence, a nursing home or a residential facility. Alan fit the hospice profile in other ways, too. Close to 85 percent of hospice patients are age 65 or older, and the same percentage receive services through Medicare, which started covering hospice programs in 1982.

Hospice was added as an optional benefit under Medicaid in 1986, but in recent years several states have proposed cutting optional Medicaid benefits, according to the National Hospice and Palliative Care Organization (NHPCO).

Although health care in America is poised for change under the Trump administration, the recent iteration of the American Health Care Act, released by Senate Republicans on June 22, would have a minimal effect on hospice care. Both the Senate and House bills, though, propose deep cuts to Medicaid. Limiting the expansion of Medicaid could reduce the number of Medicaid recipients, said James Faucett, president and CEO of Houston Hospice. The National Association for Home Health and Hospice voiced a similar concern about per-capita caps and the elimination of an important Medicaid option—the Community First Choice benefit—which encourages states to shift spending to cost-effective home care.

Perhaps the biggest threat to hospice care is increasing regulatory demands by the Centers for Medicare & Medicaid Services, said Jon Radulovic, vice president of communications for NHPCO. Increasingly, hospices must allocate already minimal resources to additional administrative efforts.

"Hospices generally have a relatively tight profit margin, so their operational costs are usually just covered," Radulovic explained. "You don't want to have to take dollars away from patient care for regulatory compliance."

VI

A faded pair of black track pants sagged around Alan's thinning waist. It was mid-morning on April 28, a Friday, and Alan was wearing his new medical alert necklace. He was un-showered; his skin sunken, his shoulders wilted with exhaustion.

Pal paced the room, growling at his Kong dog toy and nudging Terrie to play. She picked it up once or twice while she and Alan discussed his will and applications for an in-home caregiver she'd submitted through the VA and the Department of Aging and Disability Services. She said she was hopeful he would be able to stay in his apartment when the time came.

"Soon," Alan said.

"You think it's soon?"

"I think so."

"Are you having more confusion?"

"Yeah, a little bit."

Terrie said his oxygen would help. When it drops too low, she explained, the brain can't function at capacity.

"I've been on oxygen all morning," Alan said quietly. "Maybe I should go use it now."

When he returned to the living area, he said he was ready to call Ann to come pick up Pal.

"It's too much," he said. "I don't want to fight it; I don't want to fight it anymore. My son fought it for six years."

He found his cell phone and started typing on the keypad, then stopped abruptly. "I'm losing it," he said, under his breath. "I'm really losing it."

"Are you OK?" Terrie asked.

"Yeah."

"Do you think you need to get some rest?"

"Getting close to it."

Alan tried typing Ann's number again. "I keep forgetting what I'm doing."

"You're getting sleepy."

"Yeah."

Terrie helped Alan leave a voice mail, then led him into the bedroom where he settled in on his right side, facing the wall. She checked his oxygen and noticed that the machine was bone dry. Without water, nothing had been flowing through the tubes—there was no telling how long he'd been without oxygen. Terrie refilled the machine and hooked up her patient. Alan closed his eyes.

A few hours later, Ann arrived and Alan got up to say goodbye to his best friend. He gave Ann an old sweatshirt with his scent on it and told Pal that she'd be his new mistress now. Alan was stoic. Although he was broken inside, he did not cry.

VII

Brad moved in to Alan's living room with a large air mattress and his Maltese, Casey. By Wednesday, May 10, Alan was sleeping for the better part of the day, always on his right side, always under a red sleeping bag. His body had grown skeletal, his mouth slack-jawed. Each breath was accompanied by a constant gurgling rattle, a final stage of the body shutting down.

Karen taught Brad his father's medication routine and the basics of changing diapers and urine drainage bags. In the absence of a hired caregiver, Brad had stepped in to honor his father's wish to stay put. Through hospice care and family support, Alan would be at peace in his final days.

Over the weekend, he had experienced a surge, a common phase in the dying process during which a person undergoes a wave of clarity, hours or days before death. Terrie described it as a final gift to the family. Brad took advantage by setting up a Clint Eastwood movie marathon and buying ice cream. By the end of the day on Sunday, though, Alan had grown lethargic again.

"I feel like I'm running around like a chicken with my head cut off," Brad told Terrie after returning from a quick trip to Wal-Mart. He unpacked bags of V8 juice, butterscotch pudding and sippy cups like the kind he used to give Matthew.

(continued)

66 I believe that we're all connected. We're all a part of everything. Is there a God? Yeah. We are God. 99

ALAN DICKSON

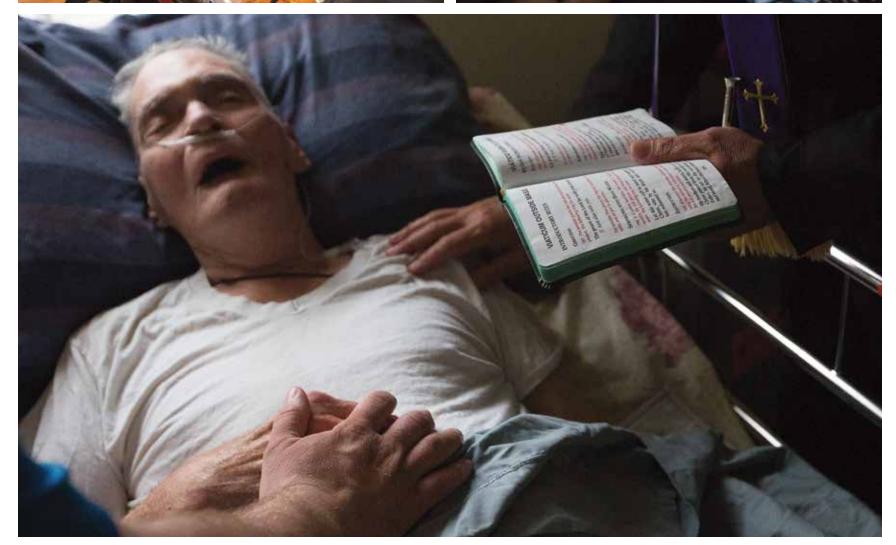
Houston Hospice patient











 $From \ left \ to \ right, top \ to \ bottom: Alan \ at \ home \ in \ his \ kitchen; Alan \ and \ Brad \ watch \ movies \ in Alan's \ bedroom; Alan's \ medication \ sits \ on \ the \ kitchen \ table; \\ Alan's \ daughter-in-law, Grace, gives \ him \ water \ with \ a \ sponge; Father \ Raphael, \ a \ chaplain \ from \ Houston \ Hospice, prays \ over \ Alan.$

"At some point, he will not be able to drink," Terrie said. "You're aware of that?"

Brad nodded.

"When that happens, you use ice chips, just inside his cheek."

"What about IV drips?"

"We don't do that," Terrie said. "Probably one of the hardest parts of hospice is when a patient doesn't want to eat and the family thinks they're starving them. And they're not. At the end of life, that's just a natural progression. When you're sick, you don't eat. And he's very sick."

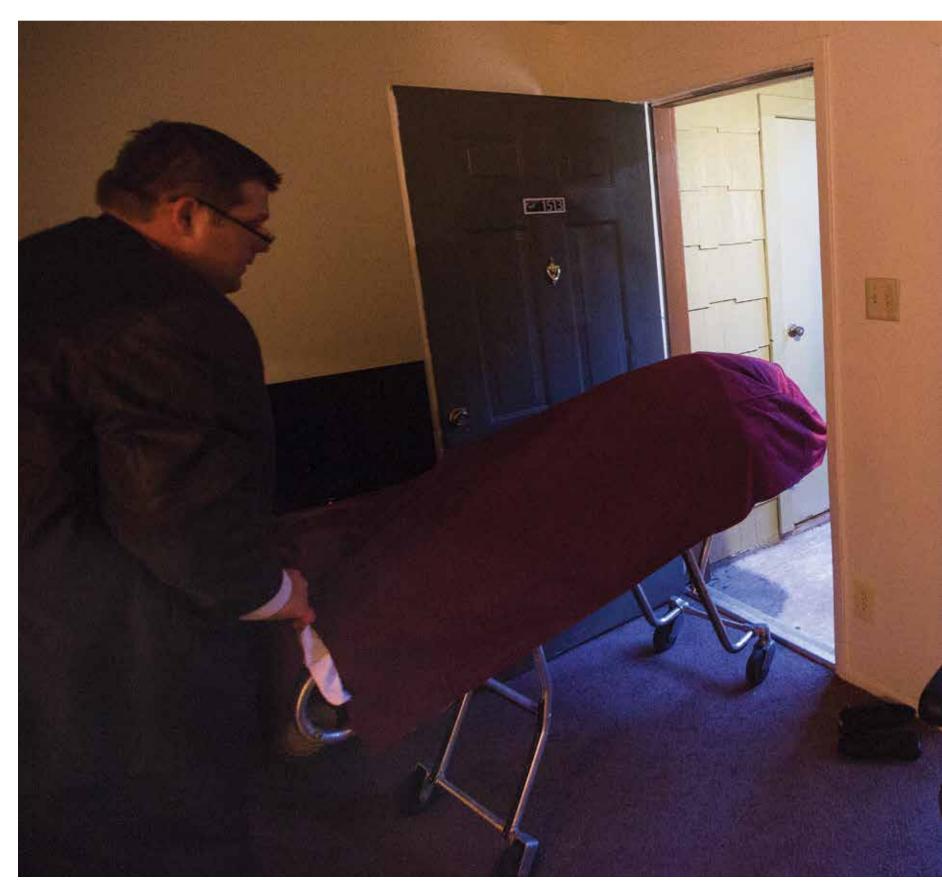
Terrie asked Brad if Karen had talked to him about transitioning. When people begin to detach from life, they often see visions from the past and relive memories and conversations. The visions, Terrie said, start in the corner of the room, up toward the ceiling. By the end, they always move onto the bed. It's a predictable pattern, she assured him, something every hospice worker knows well.

"There's been a lot of talk about Selkirk, which is a place we used to go camping a lot as kids," Brad said. "The other day he was acting like he was fixing a bike and it was the bike reflectors. ... He thinks we're actually there."

VIII

The following morning, Alan tapped on the bed and called for Pal. Moments later, he was petting the air near the crook of his arm.

By mid-afternoon, Father Raphael had arrived at the apartment. Brad led him into the bedroom and showed him a wooden cross he'd found in Alan's pocket. Alan tried to clear his throat.



 $A\, caretaker from \, the \, funeral \, home \, removes \, Alan's \, body \, from \, his \, apartment.$

"We've had a few very long and, to me, very rewarding conversations, just about your life and your journey," Father Raphael said, leaning over Alan's bedside. "We also talked about, in your own faith journey, how open you always tried to be to other people. And that when the moment came, you wouldn't be averse to me praying with you and offering the consolation of the sacraments that I can offer to you. I hope that's still the case, Alan. I thought I just saw you nod, but in any case, I would like to pray with you, Alan. May I pray with you, as we agreed, Alan?"



"Absolutely, Father," Brad said. "Definitely, he's OK with that."

"He did let you know about that?"

"Yes, sir. I know he's OK with that." Brad grasped Alan's hand.

"In the name of the Father, and of the Son, and of the Holy Spirit," Father Raphael began. He spoke in smooth, soft rhythms, reading scripture and offering prayer. He asked Brad to help him with the rite of anointing. Brad placed his right thumb into an oil stock prepared with cassia, aloe and myrrh and traced the sign of the cross on his father's head.

During the prayer, Alan mustered the strength to squeeze Brad's hand.

IX

Karen arrived not long after Father Raphael said goodbye.

"He's making a lot of noises," she said. "Have you felt like he's been anxious because of his breathing? Any distress? Because what I'm seeing looks very peaceful."

"I think he's at tremendous peace," Brad said.
"It makes me feel glad, because he knows that he's here, he's around love."

Karen took Alan's feet in her hands, checking for warmth. They were cracked and stiff and one was very cold. She explained that it was the body's way of fighting for life, that it was doing all it could to shunt blood to the core.

Grace and Matthew insisted on spending the night. After dinner, the three of them piled onto the air mattress and watched a "Tom and Jerry" cartoon. Brad and Grace took turns getting up to check on Alan. Around 1:30 a.m., Brad woke suddenly, drenched in sweat. He slid off the air mattress and quietly opened the door to the bedroom, listening for his father's labored breaths. The silence was deafening.



Brad cleans the apartment moments after the caretaker leaves as a way of coping with his father's death.

"Grace!" he whispered as loudly as he could. He did not want to wake Matthew. He flipped on the light and saw that Alan's dentures had popped out of his mouth.

Both he and Grace checked for a pulse.

Nothing. Unsure, they called Houston Hospice and left a message with the answering service. Then, in a panic, Brad pushed Alan's medical alert button. Soon the tiny apartment swarmed with flashing lights, paramedics and police officers. Carol arrived to take Grace and Matthew home. When the first responders learned that Alan had signed a DNR and was under hospice care, all but one officer left until an on-call nurse from Houston Hospice arrived to declare the time of death.

By dawn, a caretaker from the funeral home would wheel Alan's body out of the apartment and down the uneven sidewalks. While Brad waited, he called his best friend.

"You know what your dad would do right now."

"Get bombed," Brad said, smiling. "You know, I think I could handle that."

He went to the freezer and pulled out Alan's handle of Jim Beam. He drew a few swigs from the bottle, then stood in the kitchen and cried.



 ${\it Brad scatters Alan's ashes in the water off \ Galveston \ Island, per Alan's \ request.}$

A True Story of Pathological Friendliness

An excerpt from a new book by Houston journalist Jennifer Latson

A tiny genetic deletion makes roughly 30,000 Americans indiscriminately loving, trusting and outgoing. The disorder is called Williams syndrome, and it's sometimes labeled the opposite of autism because people who have it tend to be extreme extroverts. Journalist Jennifer Latson spent several years getting to know Eli, a boy with Williams syndrome, and his single mother, Gayle. Like many children with Williams, Eli has relatively well-developed verbal skills, despite an overall IQ around 50, and is obsessed with appliances, specifically the Tennant 5400 floor scrubber. Latson's new book, The Boy Who Loved Too Much, follows Eli into adolescence and outlines Gayle's struggle to protect her vulnerable child while also giving him the freedom to experience the world.



Jennifer Latson has written for The Boston Globe, the Houston Chronicle, and time.com. The Boy Who Loved Too Much is her first book.

ALL THE WAY HOME FROM CAMP, Eli fixated on the idea of becoming a teenager. The thrill of being part of a tribe, surrounded by his Williams peers, had left him aglow, and he was even chattier and more cheerful than usual on the trip back. He seemed to see the social inclusion of his week at camp not as an isolated experience but as a preview of his life to come. He sang improvised songs about his new friends, some of which were ballads devoted exclusively to Susie.

Although Gayle prompted him a few times to sing the song about living in the now, he quickly reverted to his habit of asking endless questions, most of which now centered on the topic of turning thirteen.

"When am I going to be thirteen, Mom?" he asked for the first time just after leaving the campground. She reminded him of his birthday: February 5.

"And then I'm going to be a man?" he asked.

"Well, maybe not immediately," she said. "Give it a little time."

Once again, none of her answers seemed to satisfy his curiosity, either about when he'd be a teenager or about what life would be like once he was. Each answer prompted another question: "I'm going to get taller?" "I can use the Tennant 5400?" "I'm going to go on dates?"

Since Gayle had some of the same questions herself, she was ill-equipped to answer. So the questions kept coming, from Michigan through Ohio, Pennsylvania, and New York. Just across the Connecticut state line, the car came to a stop in a traffic jam on the Merritt Parkway. It seemed to intensify Eli's anxiety, as if the traffic were holding him back from his progress toward adolescence.

"Mom, can I be a teenager? What time?" he asked with renewed urgency.

"You'll be a teenager on February 5 at 5:38 p.m.," Gayle said.

"And then what kind of school am I going to go to?" he asked.

"Oh, you'll still go to the same school," she said. "You won't go to high school until you're fourteen."

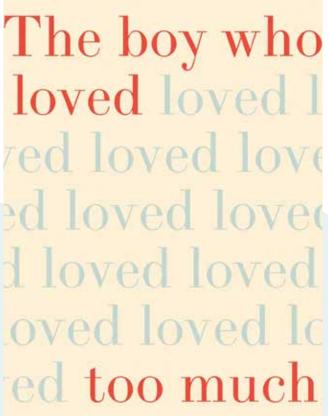
Eli nodded sagely, as if he'd already known this, but was just double-checking. He picked a brown crayon out of his crayon box, gripped it tightly in his fist, and swirled it across a page of his coloring book, obliterating the lines.

"I can't wait to be a teenager," he said.

Gayle looked back at him and smiled, thinking of the rosiness of his vision of adolescence. In his mind it meant boundless joy, visiting friends, scrubbing floors—all the activities he believed he'd been denied by virtue of being twelve and not thirteen.

Her own vision was cloudier. So much of normal adolescence centered on the drive for independence, but she wasn't sure what role, if any, independence would play in Eli's teenage years. It was part of the frustration many teens with Williams endured: the impulse to pull away from their parents coupled with the immaturity and vulnerability that meant their parents couldn't responsibly let them go. They depended on their parents for so much more than the typical teenager did—particularly transportation, since few sixteen-year-olds with Williams, even among the highestfunctioning, could learn to drive a car—and there was a good chance that their dependence would carry over into adulthood. Gayle thought of all the things she still did for Eli: bathe him, get him dressed, help him in the bathroom. He was unlikely to be able to perform these tasks on his own by February. Would she still be helping him with them in five years? Ten, even? When would he be a man, and what kind of man would he be?

Excerpt from The Boy Who Loved Too Much: A True Story of Pathological Friendliness, by Jennifer Latson.Copyright © 2017 by Jennifer Latson. Reprinted by permission of Simon & Schuster, Inc, NY.



A True Story of Pathological Friendliness Jennifer Latson

HOW TMC EMPLOYEES SPEND THEIR SPARE TIME



Tulipfinger is Ryan Ash (bass, trumpet, vocals), Jiyoung Park (vocals), Maho Sasaki (keys), Dillon Baete (drums) and George Denfield (guitar, vocals).

NAME: Tulipfinger

occupation: Neuroscientists

INTEREST: Live karaoke music

Tulip finger is a skin disease that affects people who handle tulip bulbs. But Tulipfinger—one word, not two—is a live karaoke band based in Houston.

When Ryan Ash, George Denfield and Jiyoung Park aren't working in their respective labs at Baylor College of Medicine, the three neuroscientists can be found jamming out in Ash's Rice Village apartment.

"I think everybody needs to express a little bit of themselves in some form," said Park, a graduate student in structural and computational biology and molecular biophysics who sings backup vocals for Tulipfinger. "What we had in common was that we were really curious about neurons and brains."

The band formed in 2011 after Ash, Denfield and Park met as graduate students in Baylor's neuroscience department and discovered their shared love of music. Playing together helped relieve the stress of graduate school and kept them from getting burned out.

Originally, the band was named Spike! Spike! Spike! as an homage to neuroscience.
The brain contains close to 100 billion neurons that constantly fire signals to communicate with each other; every firing signal is known as a spike.

"We were able to make fun songs out of neuroscience," Park said. "I'm not sure how many people we got to really spread that fun to, but I think the neuroscience department enjoyed it."

As Spike!Spike!Spike!, the band often played at Baylor's annual neuroscience conference, performing classic songs with a neuroscience twist. For example, the band's rendition of the 1966 Beach Boys classic "Wouldn't it Be Nice," was titled "Would it Make You Spike."

"Writing and playing music are both very creative enterprises," said Denfield, a neuroscience M.D./Ph.D. student who plays guitar and sings. "Certainly, writing music is creative, but science is very creative, too. Idea generation is important in both of those."

The band is like "Weird Al" Yankovic with a neuroscience flair, "but even nerdier," said Ash, a neuroscience postdoctoral researcher who plays bass and trumpet.

Eventually, the band changed its name to Tulipfinger in 2013 when members decided to focus less on neuroscience-themed songs and more on karaoke. Ash's father, a fellow musician who works in advertising, suggested they combine two random words for a unique-sounding name. They came up with Tulipfinger without knowing that "tulip finger" is a type of dermatitis. (That discovery came years later.) The name stuck.

These days, Tulipfinger is an "activist karaoke band"

with two additional members:
Maho Sasaki, a neurological
music therapist at Sam Houston
University, on keyboard;
and Dillon Baete, a Baylor
neuroscientist-turned-beerscientist at Karbach Brewery,
on drums.

Tulipfinger has close to 100 songs in its set list. When the band plays at a bar, people sign up to sing lead vocals, while the band plays the instrumental music and provides backup vocals.

All of Tulipfinger's songs have been selected in response to political upheaval.

"Recently, there's been some interesting changes in the political climate and the social climate," Ash said. "I grew up listening to the Beatles and stuff, so we got more into protest songs ... and encourage more people to sing those."

Earlier this year, Tulipfinger performed at the March for Science in downtown Houston. The band's song, "M-M-M-March for Science!" was sung to the tune of the Knack's 1979 debut single, "My Sharona."

Combating Human Trafficking

Clinicians can play a key role in Houston's war against sexual exploitation

By Alexandra Becker

A t just 2 years old, Mari became a victim of sexual molestation. The perpetrator, her grandfather, continued to sexually abuse her for years. At 11, she ran away from home and met a man who promised her the world. Then he forced her into prostitution.

For runaways and children of abuse, life can become an unforgiving cycle of commercial sex, trafficking and drug addiction. After a brief arrest, Mari—who asked that her real name be withheld for privacy reasons—worked hard to break free. But after her husband died, she tumbled back into the streets, working truck stops throughout the country and shooting herself numb with drugs to cope. Like many women forced into that world, she was only able to escape through incarceration.

Today, Mari resides at Angela House, a local residential treatment program that helps women transition back into society after leaving the criminal justice system. The nonprofit works closely with Healthcare for the Homeless Houston, an organization that helps women with a history of sexual exploitation regain health and independent living skills through a program called Healthy & Whole. According to Andrea Link, M.D., program manager for Healthy & Whole

66 ... essentially the trafficker tries to depersonalize the victim. Why was this person, this so-called boyfriend's name, tattooed backward on her chest? Because the first thing she would see in the morning when she looked in the mirror was his name.

- REENA ISAAC, M.D.

Medical director of the forensic nursing team at Texas Children's Hospital

and a clinical assistant professor with the Department of Family and Community Medicine at Baylor College of Medicine, a staggering 93 percent of the women at Angela House have a history of sex trafficking or prostitution.

Programs such as these are in high demand in Houston, considered a major hub for all forms of trafficking due to the intercontinental airport, major water port, international border and sprawl across the I-10 corridor. Statistics released by the National Human Trafficking Hotline show that Texas is responsible for the secondhighest number of calls in the country—California is first—and the majority come from Houston.

While in captivity, many of these victims seek medical help.

At war

A study by the Family Violence Protection Fund found that nearly one-third of trafficking survivors had been seen by a health care provider during their time in captivity, for reasons including unwanted pregnancies, STDs, drug-related conditions and other circumstances associated with abuse. Additional studies estimate even higher numbers.

"Emergency departments are often easy places for a lot of these victims to go because they can be anonymous," said Reena Isaac, M.D., medical director of the forensic nursing team at Texas Children's Hospital. Yet as many as half of these individuals were not identified as victims of exploitation during their clinical experience.

"What is needed is not only more resources, but I would also argue training—for the individuals who we know are going to come into contact with trafficking victims," said Lisa Muftic, Ph.D., director of the undergraduate criminal justice and criminology programs at

Sam Houston State University, during a recent forum on human trafficking in Houston. "We know this has been very beneficial and very effective in law enforcement and believe that the same would be true in the health care arena."

Clinicians are in a unique position to break the cycle for victims by connecting them to appropriate care and rehabilitation services. But first, they must recognize the signs associated with trafficking.

Malnutrition, dehydration, drug abuse, skin infections and physical injuries in various stages of healing, including bruises, broken bones, cuts and burns are considered red flags. Victims also often report a high number of sexual partners or may have exposure to HIV and other STDs, fertility issues, genital trauma, multiple unwanted pregnancies, UTIs, and mental health issues, including symptoms of post-traumatic stress disorder (PTSD).



A Vicious Cycle

ften described as a modern-day form of slavery, trafficking is the coercion of human beings for the purpose of forced labor or sexual exploitation. Trafficking does not have to involve the physical movement of a person, and traffickers in the United States prey on U.S. citizens more than international or illegal residents. The average age of a child recruited or forced into prostitution is 11 to 14 years old. An estimated 600 children and adolescents are victims of forced sexual acts every night in the state of Texas.

Common risk factors associated with falling victim to sex trafficking include a history of sexual abuse or substance abuse, disability, mental illness, and unfamiliarity with the local language or surroundings.

"Studies have shown that PTSD rates in women who have been prostituted on the streets are similar to that of combat-exposed Vietnam veterans," Link said. "When we tell the women this, the relief on their faces is incredible. Because they have been at war. I think a lot of people haven't recognized that. But trust me, they've been at war."

Unusual tattoo

Other patterns observed among victims of sex trafficking include scripted answers or inconsistencies in stories about their illness or injury. Their traffickers often accompany them to medical appointments, speaking for them as much as possible.

"Another thing to look out for is simply fear," said Juhi Jain, M.D., pediatric resident at Baylor College of Medicine and a chair of the anti-human trafficking committee within Doctors for Change, a Houston-based organization that advocates for improvements in health care by connecting medical providers to the public health and policy arena. "They're not able to look you in the eye, or they're not able to tell you their story. And if they do, they don't tell you exactly what's happening."

Sometimes, the red flags are staring doctors in the face. Certain tattoos with branding designs and bar code images, for example, serve as physical manifestations of the traffickers' ownership and power over victims.

It was exactly that—an unusual tattoo—that clued Isaac into a patient's story a few years ago. A teenage girl had come in with a fairly minor complaint, but during the examination Isaac noticed the name of the girl's "boyfriend" tattooed backwards in large



Mari, a victim of sex trafficking, now resides at Angela House, a residential treatment program to help women transition back into society after leaving the criminal justice system.

letters across her chest.

"That's a very curious sign," Isaac recalled. "If you understand the psychology of both the trafficker and some of the victims, essentially the trafficker tries to depersonalize the victim. Why was this person, this so-called boyfriend's name, tattooed backwards on her chest? Because the first thing she would see in the morning when she looked in the mirror was his name."

Isaac was able to help rescue this patient from her situation because she knew the signs and, most importantly, asked the right questions. In fact, a study by the Vera Institute of Justice

found that trained health care providers can identify 60 to 80 percent of human trafficking victims by simply asking two questions: Where do you live? What do you do for work?

"Everyone should be able to tell you where they live or what their job is, and if they have a hard time describing that, or if they tell you something that doesn't sound right, then you delve in deeper and things start to come out," Jain explained.

Additional screening questions might be: Is anyone forcing you to do anything you do not want to do? Can you leave your job or situation if you

want? Have you or your family been threatened if you try to leave?

One of the most critical and challenging actions a clinician can take is separating the patient from whomever is accompanying him or her at the time of the visit.

"You want to be able to have a confidential and secure conversation," Isaac said. "Be sure to convey care and concern, keep an open dialogue and show patients respect and patience."

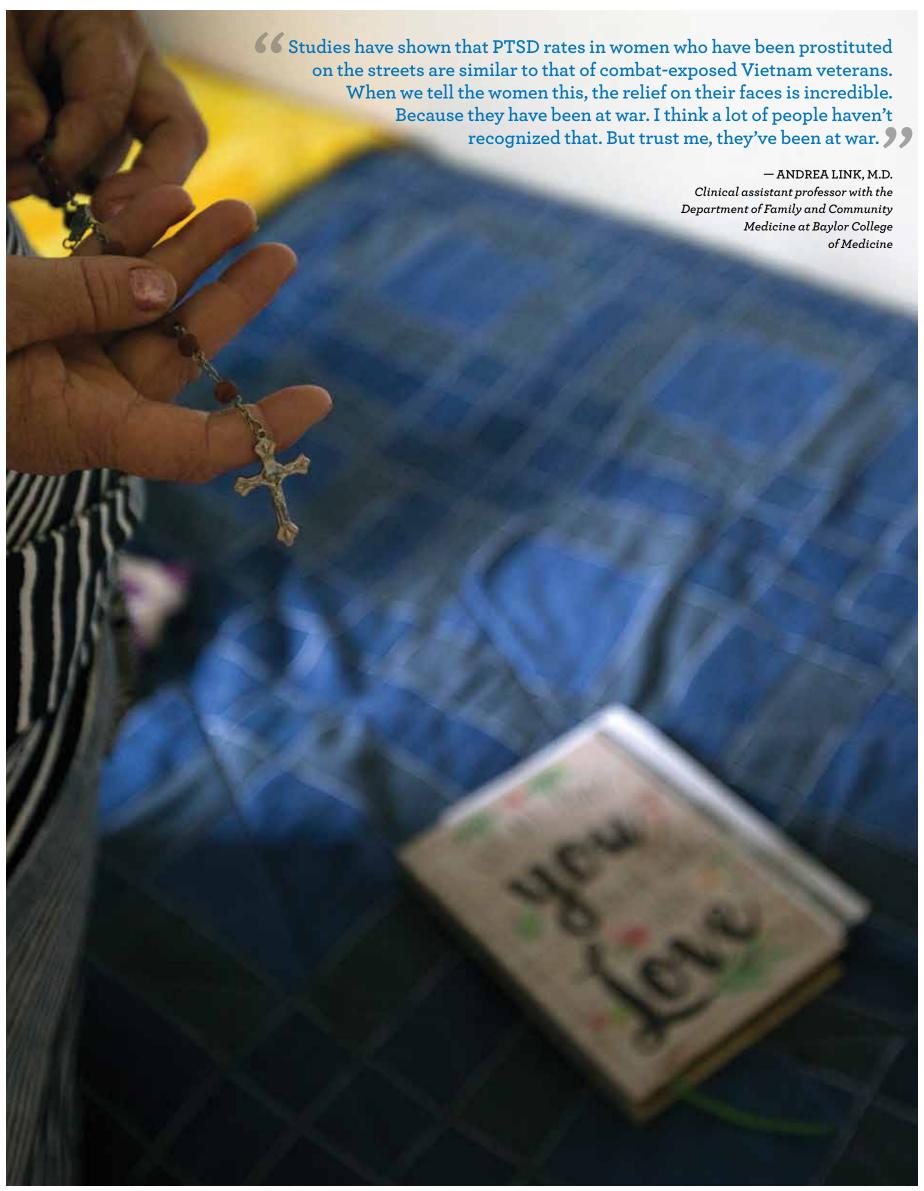
According to Mari, establishing trust with trafficking victims is a critical step in helping them.

(continued)

hours of leaving home.

malls—or, increasingly, via the internet. Advances in technology have granted traffickers more access and increased their methods of exploitation. A recent local Facebook post recounted the story of a young girl who was taped without

place victims in their debt by requiring quotas and demanding long work hours. Through threats, drug or alcohol dependency, isolation and physical abuse, they make victims feel like it is impossible to escape.



COMMON SIGNS of SEX TRAFFICKING: TIPS for the MEDICAL COMMUNITY

- Patient is accompanied by another person who is controlling
- » Patient shares a scripted or inconsistent story
- Patient has visible signs of abuse or physical injuries in various stages of healing
- Patient acts unusually fearful or submissive and avoids eye contact
- Patient is unable to adequately explain where he/she lives or works

- » Patient has branding-type tattoos
- Patient reports an unusually high number of sexual partners and/or unwanted pregnancies
- Patient is not in possession of his/her identification documents, especially if international
- » Patient does not have appropriate clothing
- Clinical signs include malnutrition, dehydration, damage to the reproductive system or genital trauma, urinary tract infections, drug abuse, skin infections, HIV and other STDs
- Mental health issues include depression, acute anxiety, stress and paranoia, selfdestructive behaviors, suicidal ideation, dissociative disorder, eating disorders

Source: doctorsforchange.org

"You have to earn their trust," Mari explained. "Offer little things, just little things to help. Because then they realize that somebody cares about them and doesn't want anything back. It seems like such a little thing to buy them shampoo or give them a sandwich, but it means the world to girls like me that are out there."

A safe place

If trafficking is suspected and the patient is under 18 years of age, individuals are required by Texas law to report it immediately—just like any other case of child abuse or neglect. Reports should be made to law enforcement or the Department of Family and Protective Services (DFPS) at 1-800-252-5400 or at txabusehotline.org. The National Human Trafficking Hotline number is 1-888-373-7888.

If the patient is over 18, clinicians and other individuals are not legally bound to file an official report. Experts suggest that health care providers attempt to separate adult patients from any individuals accompanying them and ask screening questions to assess the situation, but to recognize that some adult victims may not feel comfortable or safe exposing their personal situation to law enforcement at the time of medical treatment. The one exception to this rule: suspected abuse of an elderly or disabled person, which requires reporting in the same manner as minors.

Notably, clinicians may always make anonymous tips without revealing protected patient information to local law enforcement, the DFPS hotline, or the Department of Public Safety, accessible via iWatchTX.org. Clinicians should also refer patients to community resources, even if they are not ready and willing to utilize them at the time of their encounter.

"Even if they don't allow you to report their situation while they're there, it's important to give them a safe place to come and talk if they ever want to get out of that situation," Jain said.

Experts encourage all health care facilities to implement a standard response protocol for suspected human trafficking cases. Ideally, guidelines would include patient assessment and screening tools geared specifically toward trafficking victims, the development of safety protocols, patient separation and reporting procedures, and an easily accessible list of local resources.

Increasing general education and awareness surrounding the issue is also recommended. Doctors for Change has developed a one-hour curriculum approved for Continuing Medical Education credits that is available to local hospitals and health systems. It focuses on identifying potential victims, best practices for helping victims in the health care setting, and available resources in Houston. HEAL Trafficking, a national organization that tackles the issue through a public

health perspective, also released an extensive protocol toolkit for health care settings.

"It's important, especially for us physicians, to be aware of this issue and to have it at the back of our minds when we're seeing patients," Jain said. "If it's there in your mind, you may be able to catch someone who is in that situation and help them. Any small contribution you can do is going to help."

For Mari, incarceration was the way out. But others may be able to escape through the help of a thoughtful clinician—someone who took the time to learn the signs of trafficking and had the courage to ask the right questions.



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A Symbiotic Relationship

UTHealth researchers are working on a new treatment for oral thrush

By Christine Hall

his is a story about a fungus—the cause of some ■ serious infections in hospitalized patients—and a group of microbiologists with McGovern Medical School at The University of Texas Health Science Center at Houston (UTHealth) who want to develop a new antifungal drug.

Two of the most problematic causes of infections are Enterococcus faecalis, a bacterium, and Candida albicans, a fungus, often found together in the gastrointestinal region. These microbes can also cohabitate in the mouth; some studies have found evidence of both in materials extracted from infected root canals.

The presence of these two microbes in the same parts of the body led Michael Lorenz, Ph.D., a professor of microbiology and molecular genetics at UTHealth, and his colleague, Danielle Garsin, Ph.D., associate professor of microbiology and molecular genetics, to wonder how the organisms might affect one another.

When the researchers put the two organisms together, they noticed something interesting.

"We thought the two together would make infections worse," Lorenz said. "What ended up happening was unexpected and fascinating: Enterococcus was actually returning Candida to a benign state."

Doctoral student Carrie Graham deduced that a protein made by the bacterium, EntV, was blocking the fungus' biofilm development. The interaction was



Candida albicans is a fungus, a form of yeast, that can cause oral infections in humans.

inhibiting the Candida's virulence, but not harming it. In fact, it was a completely new type of activity for this protein.

Using this newfound knowledge, the researchers wondered if this EntV protein would be effective against a Candida infection, in this case oral thrusha yeast infection of the mouth and throat that affects millions, particularly babies, seniors and people with weakened immune systems.

In a mouse model, the researchers found that the animals treated with the antimicrobial protein had

fewer symptoms—including a reduction in the creamy, white lesions associated with oral thrush—than those who were not treated with the antimicrobial protein. Their results were reported in the April issue of Proceedings of the National Academy of Sciences of the United States of America.

"These findings demonstrate that EntV has potential as an antifungal agent that targets virulence rather than viability," the researchers wrote in their study.

The next steps are for Garsin's lab to determine how EntV is produced in Enterococcus, and Lorenz's lab to determine how EntV makes Candida less infectious. The researchers are also trying to determine how the protein could be used in a clinical setting.

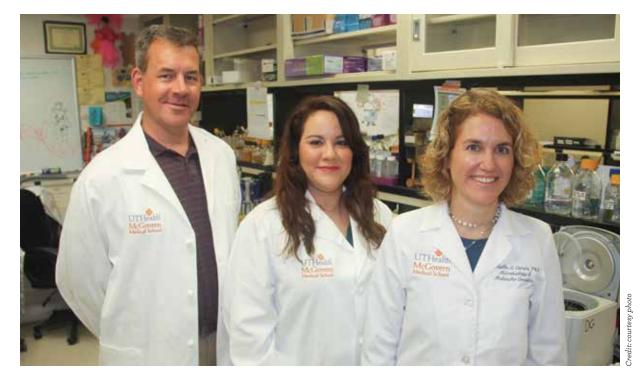
"It's probably many years away," Lorenz said, "in part because the protein needs to be modified to make it a suitable therapeutic."

More testing will determine whether EntV is effective against strains of Candida resistant to traditional antifungals and whether it can be used with them to improve outcomes.

"The long-term goal is to develop a new antifungal drug that takes a different approach to treating oral thrush," Garsin said.

We thought the two together would make infections worse. What ended up happening was unexpected and fascinating: Enterococcus was actually returning Candida to a benign state. 🦻 🦻

- MICHAEL LORENZ, PH.D. Professor of microbiology and molecular genetics at McGovern Medical School at UTHealth



Michael Lorenz, Ph.D., Carrie Graham and Danielle Garsin, Ph.D., researchers at the McGovern Medical School at The University of Texas Health Science Center at Houston.

Relieving the Pressure

NASA technology will help eye patients on Earth and in space

By Christine Hall

he same technology that allows NASA to identify minerals on the surface of Mercury is being adapted to diagnose eye conditions on Earth.

Multispectral imaging (MSI) gathers information across the electromagnetic spectrum. Different surfaces absorb different amounts of light, so MSI captures data in varying wavelengths that can be separated by filters beyond the visible light range. These images provide NASA with information about water, vegetation, soil and the atmosphere on other planets.

Now, local neuro-ophthalmologists Rosa Tang, M.D., and Jade Schiffman, M.D., co-directors at The Optic Nerve Center-a unit of Neuro-Ophthalmology of Texas, in the Eye Wellness Center—are studying the effectiveness of MSI in identifying a number of eye conditions. Their NASA-funded study, led by Baylor College of Medicine's Eric Bershad, M.D., examines eye conditions that astronauts may develop in space.

Tang and Schiffman focused on idiopathic intercranial hypertension (IIH), a condition in which pressure increases in the spaces surrounding the brain and spinal cord. IIH is most common in overweight women of childbearing age, and the increased pressure from IIH can lead to papilledema, a swelling of the optic nerve. Symptoms of papilledema include disturbances in vision, vomiting and headaches.

In some papilledema cases, the retina and choroid—the vascular layer of the eye that contains connective tissue and provides all eye layers with most of their blood supply—may develop folds. The depth of the MSI imaging allows doctors to see the choroid and any potential trouble spots.

Over three months, Tang and Schiffman evaluated about 90 patients using MSI and other imaging devices. MSI reliably imaged the optic nerve swelling and the choroidal folds in these patients, and a preliminary analysis suggests that MSI provided

a unique view of the choroid not seen with other imaging devices. In a healthy eye, the layers within the choroid look like a smooth ocean; if there are folds in the choroid, the layers look like waves.

"Previously, our imaging stayed in the layer of the retina and we could not image deeper into the choroidal layer," Tang said. "Now, we can penetrate into that area more reliably and see the folds."

For decades, medical researchers have found that NASA technology complements their own work. In the 1980s, for example, Houston Methodist heart surgeons Michael E. DeBakey, M.D., and George Noon, M.D., created an implantable heart pump that was inspired, in part, by the way a space shuttle engine operates. More recently, Susan Love, M.D., clinical professor of surgery at the David Geffen School of Medicine at UCLA, was reported to be using technology from NASA's Jet Propulsion Laboratory to study the microbiome of breast ducts, a likely origin for breast cancers.

While Tang and Schiffman are determining the usefulness of MSI in studying eye conditions on Earth, they hope the same technology will be effective in detecting eye conditions in space, specifically microgravity ocular syndrome. This syndrome also results in papilledema, and NASA wants to be able to diagnose it while astronauts are in space.

Though microgravity ocular syndrome causes similar symptoms to IIH, Tang said, it is interesting to researchers that fit astronauts develop it in space, while IIH tends to affect overweight or obese individuals here on Earth.

"If we can learn when exactly the microgravity ocular syndrome develops in the astronauts in space, potentially the cause and prevention may be determined," she said. "Theories about IIH could potentially evolve as a result of future space studies, since IIH is also not well understood."



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[1] Brigadier General Rick Noriega has been appointed CEO of RONALD McDONALD HOUSE HOUSTON.

[2] Great Day Houston invited Shelly Simpson, LCSW, LCDI, from THE MENNINGER CLINIC community integration program and Heather Lambert, LPC, a lead counselor with the BRIDGEUP AT MENNINGER program, to discuss the Netflix series 13 Reasons Why and mental health issues that affect teenagers. From left, Great Day Houston host Deborah Duncan, Simpson, Lambert, Jill Ahrens Tucker, Linda De Sosa and Sahar Paz.*

[3] HULIN WU, PH.D., has been selected as the new chair of the Department of Biostatistics at The University of Texas Health Science Center at Houston School of Public Health.*

[4] Sirj Goswami, Ph.D., founder and CEO of InsightRX, represented one of 21 digital startups that pitched their products as part of the TMC INNOVATION INSTITUTE'S Demo Day.

[5] YOHANNES T. GHEBRE, PH.D., assistant professor at Baylor College of Medicine, was awarded \$1.98 million from the National Institutes of Health for his research involving idiopathic pulmonary fibrosis.*

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[6] RONALD McDONALD HOUSE CHARITIES OF GREATER HOUSTON/GALVESTON and

the McDonald's Owner/Operators Association of Greater Houston awarded 85 high school seniors with scholarships for outstanding community involvement and academic performance.*

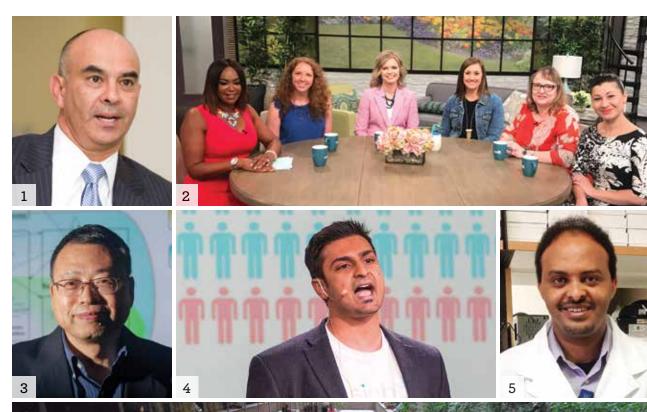
[7] MICHELLE PATRIQUIN, PH.D., has been promoted to director of clinical outcomes at The Menninger Clinic.*

[8] VICTOR E. REYES, PH.D., professor in the Departments of Microbiology & Immunology and Pediatrics at The University of Texas Medical $\,$ Branch at Galveston, was selected as a Piper Professor by the Minnie Stevens Piper Foundation.*

[9] AZIZ SHAIBANI, M.D., director of the Nerve & Muscle Center of Texas and clinical professor of medicine at Baylor, is president elect of Texas Neurological Society and a member of the international outreach committee of the American Neurological Association.*

[10] ALEXANDER BUKREYEV, PH.D.,

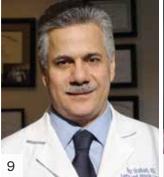
professor at the University of Texas Medical Branch at Galveston, has been named a member of the Vaccines Against Microbial Diseases Study Section, part of the National Institutes of Health, for a four-year term.*













Credit: No. 1: Bill Clark/Roll Call/Getty Images, No. 2: Carbonara Group, Courtesy photo



[11] Cyclists riding to Alaska to raise money for cancer as part of Texas 4000, a nonprofit, spent the day with pediatric oncology patients at THE UNIVERSITY OF TEXAS MD ANDERSON CHILDREN'S CANCER HOSPITAL and presented a \$65,000 check to further cancer research.*

[12] Senior Alfredo Moreno poses inside the new MICHAEL E. DeBAKEY HIGH SCHOOL FOR **HEALTH PROFESSIONS.** The school celebrated the grand opening of its state-of-the-art building at 2545 Pressler Street.

[13] Richard L. Ludwick, Ph.D., has been named the ninth president of THE UNIVERSITY OF ST. THOMAS.*

[14] Lauren Quinn joins the LIFEGIFT executive leadership team as managing director of hospital $development.^{^{\star}}$

[15] Chuck Stokes was appointed interim president and CEO of MEMORIAL HERMANN HEALTH SYSTEM.*

[16] NORA'S HOME, which provides affordable lodging for pre- and post-transplant patients and their families, celebrated the expansion of its facility with a groundbreaking ceremony. The addition will add 16 guest rooms, a communal kitchen, a laundry room and storage space.

[17] The San Diego Zoo's television broadcast channel, San Diego Zoo Kids, has launched in all patient rooms and waiting areas of MD ANDERSON CHILDREN'S CANCER **HOSPITAL.** As part of the launch, the channel shot several segments at the Houston Zoo and patients were also treated to a visit from several animals in the rose garden of the hospital, including a North American porcupine.

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JULY: CORD BLOOD AWARENESS MONTH

July is recognized nationally as Cord Blood Awareness Month to raise attention to the life-saving properties of cord blood. Cord blood—blood from the umbilical cord—contains stem cells. If banked after the umbilical cord is cut, cord blood can cure dozens of diseases, yet more than 90 percent of the stem cells in cord blood are discarded as medical waste today, according to cordbloodawareness.org.

Speak with your doctor or health care provider to learn more about regenerative medicine and the benefits of banking cord blood.

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