Social Media & Medicine

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This month’s issue of Pulse considers the myriad ways social media is changing the world of medicine.

We’ve known for some time that people with a community—people who have meaningful human interactions—will do better in terms of health. They live longer. They’re happier, whatever “happier” means. Actually, if you really dig deep, you’ll find that happiness is often service to others. And so many of the anecdotes in the “Social Media & Medicine” story bear this out. One woman who has struggled with miscarriages shares personal stories on her blog. This act of sharing is therapeutic for her and affirming to her readers who are also mourning babies.

Finding public and private forums to share detailed medical information has become increasingly important to a public that wants better, faster answers about doctors and possible treatments. This is particularly true of rare or orphan diseases. Nobody’s making drugs for them because it’s not profitable. Nobody’s creating medical devices for them because it’s not profitable. Patients are caught in this conundrum, so they all band together on social media. They basically run a service that steers patients away from hacks and toward doctors and researchers who offer compassionate care and results.

Health providers are profoundly limited in the medical information they can share, but regular people aren’t. Right now, you have to ask permission to get your health data from the hospital, but eventually people will control their own data from a device. Think about it. You know all about your car, but you don’t know all about your own body. When you control and manage your own health data, you’ll probably be healthier. You’ll say, “Wow, that’s my BMI? That’s my blood pressure? That’s my cholesterol? I need to do something to get healthier.”

As medicine becomes more collaborative, social media platforms and smartphone apps are, quite literally, placing our health in our own hands. Just like the human body, social media is a fascinating, ever-changing world of networks and connectivity.
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ON THE COVER
Original illustration by Melinda Beck.
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Selective Predators

*Natural Killer T Cells Take Aim at Solid Tumors*

**By Shanley Chien**

While surgery, radiation therapy and chemotherapy are still considered mainstays in cancer treatment, many oncologists and researchers are looking to immunotherapy as a way to treat cancer patients.

Baylor College of Medicine has announced a major collaboration with biotech company Cell Medica, to develop advanced technology for genetically engineered immune cells designed to treat solid tumors.

“This is really quite an important scientific endeavor because we’re working with leading-edge technology,” said Gregg Sando, chief executive officer of the London-based Cell Medica, which has its U.S. headquarters in the Texas Medical Center. “There are current generation products that we could start using now, but the focus is to take this technology to another level and make it work much more effectively against solid tumors.”

The partnership aims to accelerate the pre-clinical research of Leonid Metelitsa, M.D., Ph.D., professor of pediatrics – oncology at Baylor College of Medicine. His research team is part of the Texas Children’s Cancer Center and the Center for Cell and Gene Therapy at Baylor and Texas Children’s Hospital. Metelitsa investigated chimeric antigen receptor (CAR)-modified natural killer T cells (NKT) as a safe and effective platform for cancer treatment.

In exchange for Cell Medica’s expertise in cell therapy manufacturing and commercialization, Baylor provided the company with exclusive rights to the proprietary NKT cell platform, five product candidates and the option to license additional future products.

Clinical trials should begin within the next two years.

“This is an exciting development in the field of cancer immunotherapy,” Metelitsa said. “The joint program with Cell Medica provides a unique opportunity for me to see a real translation of my pre-clinical research into clinical practice.”

The partnership heralds a significant adjustment in the therapy industry shapes up in the years ahead,” Sando said. “We’ve got the advantage of two really good players working together, we were delighted to have the possibility of working with Baylor College of Medicine in a new collaboration.”

Baylor’s team, led by Andrew Wooten and Michael Dilling, Ph.D., helped structure the partnership. Under the direction of a joint steering committee, Baylor will oversee the first clinical trials. Meanwhile, Cell Medica will develop a manufacturing strategy and, after the first trials are complete, assume responsibility for taking the therapy to market.

While the Baylor and Cell Medica collaboration marks a pivotal point in the future of Metelitsa’s work, the partnership heralds a significant adjustment in the quest for a cancer cure.

“Since then, we’ve been able to accomplish a huge amount together,” Sando said. “We’ve got the advantage of two really good players working together, and we’re delighted to have the possibility of working with Baylor College of Medicine in a new collaboration.”

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“We are at the beginning of a paradigm shift in the way we treat cancer, and Houston’s certainly going to have an important role to play in how this immunotherapy industry shapes up in the years ahead,” Sando said.
Anatomy of a Workday
Sixteen hours with a first-year resident

By Alexandra Becker

We’re very lucky to get to do what we do, and sometimes we forget that when we work really long hours. We get to help people and be an important part of their lives.

— BRENNAN ROPER, M.D.
First-year Orthopedic Surgery Resident at McGovern Medical School

Just shy of 5:30 a.m. on a recent Wednesday, Brennan Roper, M.D., arrives at Memorial Hermann-Texas Medical Center. The first-year resident in the department of Orthopedic Surgery at McGovern Medical School at UTHealth lives less than five minutes from the hospital. He set his alarm for 4 a.m. so he would have time to shower, review anatomy books, and make his daily breakfast: an egg and turkey sandwich on a toasted English muffin.

On this particular day, he will not touch food for another 12 hours.

By 5:40 a.m. Roper is bedside, speaking with a patient from his previous day’s rounds. Twenty minutes later, the team convenes for their morning meeting. Residents, nurses and physician assistants are always joined by the on-call attending physicians to review the day’s case list and to discuss diagnoses, doses and expected outcomes.

The human body contains a mighty 206 bones, but there are infinitely more ways to break them. Roper ticks off a list of likely sources: monkey bars, excited dogs, contact sports, slippery tile, upturned rugs, rollerblades, ATVs, cars, baseball bats, and guns. People fall, trip and crash. And the orthopedic trauma team at the nation’s busiest Level I trauma center puts them back together.

A Bloody, Mangled Hand
At 7 a.m. Roper hurries to McGovern Medical School to attend a lecture led by Kyle Woerner, M.D., an assistant professor in the department of orthopedic surgery. Woerner, who specializes in the upper extremities, begins his PowerPoint with a close-up photo of a bloody, mangled hand.

“Can anyone tell if the flexor tendons were cut here?” he asks.

“Definitely,” a student calls out.

Woerner smiles. “Look carefully,” he says. “Do you see the cascade? All the fingers are still slightly flexed.”

What follows is an animated overview of surface anatomy (bones, tendons, nerves), common pain points (distal radius metaphysis, anatomical snuffbox, hamate hook, dorsal
triquetrum), and range of motion diagnostics (pronation/supination, wrist flexion/extension, radial/ulnar deviation, digital motion, the forming of a full fist).

“Be curious little kids,” Woerner says to the class. “You don’t want to miss anything.”

After the lecture, Roper joins members of his team in the operating room to clean infected hardware in a leg. By 9:15 a.m. he’s in the emergency center at the Memorial Hermann Red Duke Trauma Institute rounding on a list of new patients. His typical questions: “Do you smoke? Are you feeling sick? Are you having any problems with your heart? Fevers? Chills?” He often tells his patients: “You’ve been through a lot. We are going to take great care of you.” To babies, he tries to speak softly, soothingly: “Hi, sweetheart. I’m sorry, sweetheart.”

Bone Phone
As a first-year resident and intern, Roper gets some of the most monotonous jobs. Glued to his hip is the so-called “bone phone,” dialed for all ortho-related requests. His days are constantly interrupted by its ring and he often adds names of patients to a list he keeps in the back pocket of his scrubs. The most common ask is for surgery consent—a tedious task but an important one.

At lunchtime, Roper choose to skip the cafeteria to input patient notes into the medical records system. He knows the inside of Memorial Hermann as well as he knows the intricate anatomy of a hand. Even though his residency has just started, the campus is familiar; he studied here as part of his curriculum at McGovern Medical School, his top choice after attending The University of Texas at Austin for undergrad.

Roper always enjoyed playing sports and appreciated the intricacies of the human body, but he didn’t always plan on being a doctor. After some trying family medical experiences and surgeries of his own, however, he set his sights on becoming a physician and never looked back. At times he questioned whether he had what it took to really make it to medical school and beyond, but with constant encouragement from professors, he kept pushing.

“I’ve had a lot of great mentors and influences in my life all along the way that have helped guide me and get me to this point,” Roper said. “I wouldn’t be here without them.”

Being Thankful
At 5 p.m., followed by a medical student who has been assigned to shadow him, Roper walks back to the classroom to attend the weekly fracture conference, where residents and faculty eat pizza, present X-rays and ask questions. It lasts until his 7 p.m. team meeting.

Everything is a learning opportunity, a charge to be better.

There is a strict rule that says residents may work no more than 80 hours a week. Even that might seem excessive, but for new doctors, excited about their first jobs, the cap can be frustrating. Roper is 26. When asked about exhaustion and burnout, he says he tries to focus on being thankful instead.

“We’re very lucky to get to do what we do, and sometimes we forget that when we work really long hours,” he explains. “We get to help people and be an important part of their lives. Not everybody gets an opportunity like that.”

After the evening meeting, Roper heads back to the ER to complete a few more patient consults and write a few more patient notes. After a 16-hour workday, his final stop is home, where an anatomy book waits, open, on the kitchen counter.
'Balanced Rock,' Big Bend National Park, Texas. Credit: Copyright © Mark Burns – All Rights Reserved
PHOTOGRAPHER MARK BURNS crisscrossed the United States for four-and-a-half years to capture images of all 59 national parks. The native Houstonian planned ahead, paying close attention to the weather, the tides, and the position of the sun and the moon. During a walk through his exhibit at the Houston Museum of Natural Science with Pulse reporter Britni N. Riley, Burns reflected on his journey.

**What inspired you to do this project?**

A | 2016 marks the centennial anniversary of the National Park Service. It’s a special time to reflect back on the 100 years we have had, but it is also a time to look forward to the next 100 years and what the plan is going to be to continue to protect the parks and keep them special and sacred.

**How did you prepare for your trips?**

A | Weather was a huge part of my project so I would print out sheets of paper with sunrise and sunset times, moonrise and moonset times. I would keep a book with me to know where the sun and moon would be at all times. I also included tide tables when I was at parks near water. I also made and canceled a lot of hotel reservations, depending on weather patterns that I was following.

**How did you get to all of the parks?**

A | I drove 160,000 miles in my Toyota FJ Cruiser to every national park in the lower 48 and flew out of Alaska and Hawaii to get to the rest of the parks.

**How did this project affect you physically?**

A | I am 57 now, but when you are 55 and you’re at 13,000 feet elevation with 50 lb. packs on your back, it is kind of tough to walk and hike. Carrying around my camera equipment gave me a bit of a handicap and I realized I had to slow down. I told people I was a turtle; I would go low and slow.

**Did you have specific shots in mind when you went to each park, or did you let the parks dictate the images?**

A | It was all about captured moments for me, which meant a lot of waiting. It wasn’t just running around taking pictures of everything, it was spending a few days looking for a composition that I really liked and then just waiting for the composition or the atmosphere or the time of day that I liked. That being said, not all of the shots worked out. I went back to some of the parks three or four times trying to get clouds or atmosphere or fog.

**What was the most unusual park you visited?**

A | One of the most different parks I visited was in American Samoa, way out in the Pacific Islands. One of the mammals they protect is the fruit bat. They fly all over the park and they are huge—like Chihuahuas but with bat wings.

**Where was the most remote location you visited?**

A | Wrangell—St. Elias in Alaska, which is the largest park in the national park system. It is about as big as the state of Maryland. This was one of the few that was done from an airplane. We had the doors off of the little bush plane. If you landed or you walked or you hiked, you wouldn’t be able to capture the scale. I wanted to do it from the air to show the miles and miles of glacier.

I drove 160,000 miles in my Toyota FJ Cruiser to every national park in the lower 48 and flew out of Alaska and Hawaii to get to the rest of the parks.
**Q**: What did you learn from this project?

**A**: It was a life-changing experience. I always had an appreciation for the outdoors and nature, but now I have just a really deep connection and appreciation for the earth and all of the cycles. I didn’t believe in global warming before I started this project, but there is definitely a warming cycle happening and I think seeing how many glaciers have melted in the past 100 years is a reminder that we all need to be more aware of our responsibility to protect this land.

**Q**: What do you hope visitors will take away from your exhibit?

**A**: Nature is a great soother and healer and, in a lot of ways, it is a total contrast from the normal busy world of iPhones and schedules and appointments.

When you are able to go into a park and spend a few days in nature with that sort of solitude, it is just a great therapeutic experience. I want to increase awareness of what the parks offer and I want people to be aware of the value of protecting natural lands.

**Q**: How does it feel to have your work on display in a major Houston museum?

**A**: It’s almost surreal because when I was growing up here in Houston, we would come on field trips to the Houston Museum of Natural Science. And now, today, I see kids from all over being bussed into the museum and they are coming to see my photographs! So it is a huge honor.

**Q**: What is your next project?

**A**: My next project will start this fall in the Grand Canyon, which celebrates its 100th anniversary as a national park in 2019. I will do both black and white and color, and I’ll be using different sizes of cameras to get an in-depth look at all angles of the canyon.
When Christina Harper’s daughter was an infant, surgeons cut a hole through the front of her neck and into her windpipe. By inserting a breathing tube in the tiny opening, they gave her lungs quick, easy access to air. Hours later, Harper joined the Facebook group “Moms of Trach Babies.”

“That resource was a godsend for me,” said Harper, who lives in Orange County, Calif. “The group had all different mothers from all different stages of life—new trach moms, older trach moms, kids who have had their trach tubes since birth and are now in their teens. Without them, I would have had no clue what to do, how to do it or what meant what.”

Her daughter Harlow lived with the tracheostomy tube for about two years, at which point Harper began asking when it could be removed. It was limiting Harlow’s development, impeding her ability to eat and speak, and no longer seemed medically necessary. When the doctor said it was too soon, Harper reached out to multiple specialists in Southern California, all of whom told her the same thing: not until the age of five.

“That was disheartening, but I’m persistent and I’m her advocate,” Harper said. “I went back to my trach moms group and a lot of them were having success doing a procedure called LTR. They were having this done as early as 18 months old, and here we are, two years old and beyond, and people are still telling us ‘no.’”

With laryngotracheal reconstruction, or LTR, grafts are taken from either the ribs or thyroid cartilage of the larynx and placed on the walls of the airways, ultimately allowing for removal of the tracheostomy tube and restoration of airflow in the windpipe. Through Facebook conversations and Google searches, Harper found Dr. Deepak Mehta, otolaryngologist at Texas Children’s Hospital and associate professor of otolaryngology at Baylor College of Medicine. After one visit to Houston, Harlow—who Mehta described as “the perfect candidate”—was scheduled for surgery.

“I seriously owe it all to this group of women,” Harper said. “Social media has saved me from having a nervous breakdown because I have someone to speak to that truly understands what I’m going through.”

Today, Harper is paying it forward, regularly monitoring her Facebook group for moms like her and for the opportunity to share Dr. Mehta’s information. As for Harlow, her tiny voice can be heard filling up rooms and cars and grocery store aisles. She loves to sing.
Only Connect

Now more than ever, the human race is intertwined. We communicate on Facebook, blogs, Instagram, Twitter. We sit late in front of computers, stare at our smartphones, download social media apps. Our exchanges are instantaneous, global, ubiquitous.

According to a recent study by Pew Research Center, nearly two-thirds of American adults use social networking sites. This is powerful, because in a world where mass shootings occur almost weekly and everything from our morning lattes to our fathers’ strokes are made public via Instagram and Facebook, we are finding less solitude and more solidarity. We have created new communities and, through them, found support. Nowhere is this more meaningful than in the vast world of medicine.

Sharing information can be therapeutic for individuals faced with traumatic experiences, challenging diagnoses, or controversial treatments. Popular health-related websites now considered mainstays, including CaringBridge, grew out of a need to share one patient’s sensitive health information with a close circle of family and friends. And for a patient with a rare genetic condition—so rare that it has only just been named and doctors are still in the process of gathering and crunching data—finding others with the same diagnosis will help close the distance between effective treatments and, hopefully, a cure.

According to Pew, seven in 10 adult internet users say they have searched online for information about a range of health issues, including specific diseases and treatments. But that’s just the tip of the iceberg. Patients turn to social media to seek out specialists, swap personal medical information, and, when necessary, grieve.

About a Blog

Nothing in me wants to write this post.

So begins a blog entry from Oct. 16, 2015. Written by Casey Wiegand, it details the heartbreak behind three miscarriages.

“I honestly have dreaded typing these words. Dreaded in a way facing the feelings, dreaded the judgments that will be out there from people who don’t know all the details. But I feel a constant soft nudge to be the voice for those in my shoes... So here I am raw and stumbling out to share more of my story... humbled again and putting out my life and my hurt for those of you who understand. Those of you who scroll through your feeds every day and rejoice at the new lives growing in all the beautiful bellies but weeping for the lives that keep getting lost in your own.

Wiegand, who initially set up her popular site, CaseyLeigh, to update family while her son was in the NICU, quickly realized the value of connecting to other families with similar struggles.

“I stumbled upon this whole community of bloggers and I thought, ‘I want to build something like that for my family,’” she said. “Originally I thought it was such a sweet way to capture our life and be intentional about it. Then when my second child was about 10 months old, we got pregnant and we lost that baby. I had already been using this space to talk about our life, so it was really natural for me to process that grief here.”

Wiegand’s posts are full of unedited emotion; they are honest and sometimes heartbreaking to read. On Instagram she has more than 106,000 followers, and her carefully curated posts complement her blog and direct traffic to her site. She’s shared her emotional, spiritual and medical journey through three miscarriages. Happily, she’s also shared the joy of two additional births. Her youngest daughter was born in August.

“It has been amazing how many women connected with my story,” Wiegand said. “It made me feel so much less alone because as I was hurting and processing, I was suddenly connecting with people all over the world who had walked through that and who had felt similar.”

After her miscarriages, Wiegand set out to uncover a cause. Through blood tests and genetic evaluations, she was diagnosed with methylenetetrahydrofolate reductase (MTHFR) deficiency, a mutation associated with elevated levels of homocysteine and lower levels of folate in the body. She has written about it on her blog—from her diagnosis to treatments to the name of her doctor. That’s an important point, because not everyone in the medical community agrees that mutations in the MTHFR gene are associated with recurrent miscarriages, so not everyone tests for it. Wiegand’s public disclosure of her own medical journey places her in the role of advocate, empowering other women struggling with loss to seek out testing, ask specific questions, and demand answers.

“Being able to connect with your friends and family no matter where they are, whether they’re across the street or around the world, is healing.”

— SONA MEHRING
Founder and Chief Ambassador of CaringBridge
Sona Mehring, founder and chief ambassador of CaringBridge, walks with Amy Townsend, a CaringBridge user who set up her site in 2014 after she was diagnosed with breast cancer. “Writing posts after my appointments always helped me process everything,” Townsend said. “It would allow me to get all of the details down and really think through what was happening in my life before I shared it with everybody. It was amazing to me, but nearly every one of my posts started as an update and ended as a prayer.”

The Mitchell and Hanners families, who connected via Lace Mitchell’s Facebook group for individuals affected by Schaaf-Yang Syndrome, enjoy a day together at The Houston Zoo.
“It honestly makes me feel better thinking, ‘OK, we went through all that heartache, but maybe we can help someone else,’” Wiegand said. “It gives you a peace in your heart.”

Building Bridges
On June 7, 1997, nearly seven years before the launch of Facebook, Sona Mehring set up a social media platform, although she didn’t know it at the time. She had been asked by two close friends to share health updates about their daughter Brighid, born prematurely that day. After two emotional phone calls that lasted 45 minutes each, an exhausted Mehring decided there had to be a better way, and so CaringBridge.org came to life.

“It certainly eased the burden of telling people what was going on,” Mehring explained, “but the wow factor was the ability to bring together that community when everyone needed it most.”

Today, more than half a million sites have been created on CaringBridge. Advertised exclusively through word of mouth, the non-profit’s free, user-friendly appeal lies in its capacity to rally support for a loved one while sharing important, often difficult, health news. Users create a site and share their unique link with friends and family; they set their account to be as private or as public as they feel comfortable and update with news and photos as often as they wish. In turn, people visit the page for new information, posting well-wishes and words of encouragement. Each page is a virtual living room, a place to go for comfort and kinship.

“Being able to connect with your friends and family no matter where they are, whether they’re across the street or around the world, is healing,” Mehring said.

That’s not just a hunch. Numerous studies have shown that social ties enrich lives and play crucial roles in health and longevity. A 2010 study published in the journal Plos Medicine found that a lack of connections can be so detrimental to health that individuals with strong social relationships had a nearly 50 percent increased likelihood of survival compared to those without.

Mehring recounted a story about a woman who called to tell her that CaringBridge helped save her husband’s life after he’d been diagnosed with cancer.

“He had basically given up and was in a cycle of despair,” Mehring recalled. “One day, his wife sat him down in front of the computer and he spent the next three hours reading the CaringBridge site she created for him. He read not only what she had written, but what other people had written. From that moment, his despair turned to hope and his whole attitude and story turned around.”

Six years later, Mehring was attending a conference when a couple came up and introduced themselves.

“There he was,” she said.

13 Years
When Michael Mitchell was born, his mother knew immediately that something was wrong. Just three years earlier, her firstborn, a daughter, died from a mysterious condition characterized by low muscle tone and contracted fingers—symptoms undeniably present in her son. Physicians ran test after test, but all came back inconclusive. The ambiguity was wrenching. Without a diagnosis, there was no hope for treatment. Without an explanation, nobody could tell the Mitchells what the future might hold. Was this a progressive disease? What sort of therapy might be most beneficial to Michael? What was his projected lifespan?

“When Michael was younger, we were told that he would not walk, he would not crawl, he would not sit up, he would not, would not, would not,” his mother, Lace Mitchell, recalled.

And yet, walk Michael did. Without anyone to turn to, Lace and her husband forged their own way, enrolling Michael in various forms of therapy, supporting him and pushing him to try his best, all the while not knowing what his condition was or what they could expect.

This went on for 13 years.

What finally cracked Michael’s case was the development of two genetic tests, considered game-changers in the field: chromosomal microarray analysis (CMA) and whole exome sequencing. Before these tests, only 10 percent of rare genetic conditions were diagnosed. After, that number climbed to nearly 50 percent.

Geneticist Christian Schaaf, M.D., Ph.D., who works as an investigator at the Jan and Dan Duncan Neurological Research Institute at Texas Children’s Hospital and as an assistant professor in the Department of Molecular and Human Genetics at Baylor, explained the value of the tests through analogy: If you think of the genome as a library, then the CMA provides you with an inventory of the library; it looks at the number of shelves (read: chromosomes), and counts the number of books on the shelves to ensure there are no missing or extra copies. The exome sequencing test takes it a step further and actually opens the books to check for misspellings (or mutations) in the expressed genes in the genome.

In Michael Mitchell’s case, the tests revealed a mutation on the MAGEL2 gene. But here’s the rub: until another patient was identified with the same genetic mutation and the same observable characteristics, it was all hypothesis, and MAGEL2 was just considered a “candidate gene,” a potential cause for Michael’s condition.

“Nobody has a perfect genetic code; we all have thousands of misspellings or mutations,” Schaaf explained. “So the challenge is not so much in generating the data, but in the interpretation.”

The key for these rare genetic conditions is finding another patient with not only the same mutation but similar physical symptoms as well, thus verifying suspicions that it is that exact mutation on that exact gene that is causing those exact symptoms. Interestingly, many individuals turn to social media to find a match when a diagnosis cannot be made after testing. Armed with a handful of “candidate genes,” they take matters into their own hands, posting their genetic results and details of the condition in

“ ‘When Michael was younger, we were told that he would not walk, he would not crawl, he would not sit up, he would not, would not, would not.’”

— LACE MITCHELL
Michael’s mother
hopes that someone, somewhere, might recognize it.

Michael Mitchell was lucky. He was referred to Schaaf by a colleague just as Schaaf had linked four other individuals with the MAGEL2 mutation, each of them exhibiting the same physical characteristics. Shortly thereafter, Michael became the fifth person in the world to be diagnosed with Schaaf-Yang Syndrome.

Finding Your Tribe
The importance of a diagnosis cannot be overstated. Families dealing with rare genetic disorders are plagued by frustration, uncertainty, guilt and isolation. By obtaining a name, they gain an answer, and that simple distinction is empowering. However, because many of these conditions are so rare and, in some cases, brand new, physicians are often unable to offer anything comforting or concrete to families seeking information. So families go in search themselves.

“I think there’s a paradigm shift in medicine and science in general,” Schaaf said. “The paternalistic approach has really come to an end. It’s not just us as physicians telling people what to do. It’s more of a team effort now.”

When Lace Mitchell scrolled the internet looking for a support group for moms of kids with Schaaf-Yang Syndrome, nothing came up. So she decided to create one.

“God put it in my heart and I started the page without a lot of information, just with the idea that this was for families to connect,” she said.

It has morphed into a main page, intended primarily for

“I hear it over and over again, how places like Facebook are a lifeline because it is a way to connect with other families.”

— CHRISTIAN SCHAAF, M.D., PH.D.
Investigator at the Jan and Dan Duncan Neurological Research Institute at Texas Children’s Hospital

general information about Schaaf-Yang and current clinical studies, but it is supplemented by a private Facebook group where parents communicate more openly. Like Harper’s “Moms of Trach Babies” group, these parents use the private page to post personal photos, share the nitty gritty details of their experiences, and seek advice. Today, there are close to 60 members. For a rare and newly identified genetic disorder, that is considered robust. In fact, for many of the members, it was finding the Facebook group that helped them make a diagnosis in the first place.

Lace Mitchell is active on the page, updating it frequently and openly sharing her son’s experiences with the community. It is the exact kind of support she had yearned for all those years.

Michael has exceeded all expectations, and it’s inspiring to the families in the Facebook group to hear his story: how he loves

Christian Schaaf, M.D., Ph.D., investigator at the Jan and Dan Duncan Neurological Research Institute at Texas Children’s Hospital and assistant professor in the Department of Molecular and Human Genetics at Baylor College of Medicine, in his lab.
to ride horses and is proficient in sign language, how he can be smart and funny at the same time. He is a whiz at Houston landmarks—even zooming down I-45 in a car, he can tell you exactly where he is and, most importantly, where the Target is located.

“I hear it over and over again, how places like Facebook are a lifeline because it is a way to connect with other families,” Schaff said. “One of the families I work with calls it her tribe. She mentioned that the other day, she was at the store and someone made a comment about her children, like, ‘What did she do? She probably drank or did drugs during pregnancy to cause this.’ She said, ‘I’ve had these situations a few times over the years and this time, for the first time, I could laugh about it because now I have an answer and I know for myself what caused it, and that it wasn’t me. And I have my tribe.’”

**Going Viral**

Many health care institutions are embracing social media to help their research and patient care. Digital platforms such as MyGene2, for example, encourage individuals to input their genetic information into an online database with hopes of building a large, searchable information system.

“I think, increasingly, we’re recognizing that one of the big obstacles to gene discovery has been sharing data,” said Michael Bamshad, M.D., pediatrician and human geneticist at the University of Washington and co-founder, along with Jessica Chong, Ph.D., of MyGene2.

While clinicians and researchers can create public profiles as well, they are bound by ethics (specifically, the International Review Board’s common rule) and by HIPAA regulations, which are designed to protect the security and privacy of health information. So they can’t share nearly as much information as a patient’s family can. A family can post detailed health information, including all of their candidate genes, genetic test results and genetic data. They can share as much as they want, and the more they share, the more likely it is that matches will be made.

To moms who are ready to advocate for their children, to parents who are determined to find answers, to anyone struggling with new diagnoses, grief or loss, the sharing of knowledge and of personal health stories can be invaluable.

It can also be lucrative.

Two years ago, the Ice Bucket Challenge went viral on social media. Participants posted photos and videos of buckets of ice being dumped on their heads—all to encourage donations for research related to amyotrophic lateral sclerosis, or ALS, an incurable neurodegenerative disease that affects nerve cells in the brain and the spinal cord. Recently, the ALS Association announced that funding from the challenge—which amassed millions—directly aided in the discovery of a newly identified gene, NEK1, now considered one of the most common genes responsible for ALS. This breakthrough will help researchers develop therapies for the devastating disease.

And just this past May, Humans of New York, a blog-turned-social-media-force with more than 20 million followers, published a series of short narratives highlighting patients, families, caregivers and clinicians at New York’s Memorial Sloan Kettering Cancer Center. The stories were part of a fundraising campaign.

In the introductory Instagram post on May 5, Humans of New York creator Brandon Stanton wrote: “Obviously, these are not going to be easy stories to read. These are war stories. The treatment of cancer can be nearly as violent as the condition itself, and even the doctors will frame their efforts in terms of warfare. But the fight against pediatric cancer is uniquely tragic because the battlefield is the body of a child. ... So yes, these are war stories. But this is also the story of humanity’s bold response to the greatest injustice of nature. And as we learn these stories, we’ll be raising money to play our own small part in the war.”

The initial goal was to raise $1 million for the Center. By May 20, the last day of fundraising, Stanton announced that 90,000 readers had donated nearly $3.4 million. He gushed: “You are the most caring community of people on the internet.”
A Fresh Start

HE/AL, a program at The University of Texas Health Science Center at Houston School of Public Health, helps expectant mothers eat, cook and live healthy

By Britni N. Riley

It was not as easy as she had hoped. “I was really nervous about cooking healthier food,” she said. “Living in Houston, it is a lot easier to stop at a taco stand or pick up a burger for dinner.”

At a routine check-up with her doctors, Darby learned about HE/AL. Healthy Eating, Active Living is a community health initiative started by Shreela Sharma, Ph.D., of The University of Texas Health Science Center at Houston School of Public Health, in collaboration with Phil Nader, M.D., a pediatrician in San Diego, Calif. For three years, Sharma and Nader have been working to create a clinic and community dedicated to solving health-related issues facing the local low-income population, including obesity and diabetes. In addition to learning about nutrition and exercise, participants take home fresh food from the Houston Food Bank after each meeting.

“Community health workers are sort of the bridge between the healthcare industry and the families because they speak the language of the families and they are trained in health education.”

— SHREELA SHARMA, PH.D.

Director of HE/AL at The University of Texas Health Science Center at Houston School of Public Health

Spring was a bittersweet season for April Fuentes and her husband. When they found out they were expecting their second child—a girl, in November—they rejoiced. But in May, the couple learned that Fuentes’ father had stage four colon cancer, a diagnosis that would change more than one life. “After my father was diagnosed, my parents watched Forks Over Knives and they told me to watch it,” Fuentes said. “It’s really eye-opening because it shows people who have diabetes and high blood pressure, and these people start only eating plant-based foods and their problems start going away. They don’t need to take diabetes medicine anymore.”

After watching the film, which explores the idea that many degenerative diseases can be controlled by rejecting processed and animal-based foods, Fuentes and her family decided to get healthy together.

Top: Expectant mothers and their families meet at The University of Texas Health Science Center at Houston School of Public Health to discuss healthy options for eating and exercise. Bottom: HE/AL nutritionists prepared a butternut squash macaroni and cheese with turkey bacon, and a salad for the weekly meeting.

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“Community health workers are sort of the bridge between the health care industry and the families, because they speak the language of the families and they are trained in health education,” Sharma explained. “The program creates a feedback loop back to the clinic and provider about what is going on with the patient when they attend this program.”

The six-week program Fuentes attends is geared toward expectant mothers in their first and second trimesters, but also encourages partners, friends and
I was really nervous about cooking healthier food. Living in Houston, it is a lot easier to stop at a taco stand or pick up a burger for dinner.

— APRIL FUENTES
HE/AL Participant

family of the mothers-to-be to participate. HE/AL also offers a program for new mothers and their infants that focuses on healthy goals and activities that can be incorporated into daily routines.

Weekly meetings last 90 minutes.

“When we first started HE/AL, I set two goals for myself,” Fuentes said. “One was to eat three servings of fruits and vegetables every day, and the other was to make healthier choices for myself. So instead of the fried chicken, it’s the salad or the chicken breast.”

During the weekly meeting, participants have a chance to share their stories and struggles, watch a cooking demonstration with fresh ingredients chosen by HE/AL dietitians, and exercise. Participants learn about the kinds of exercise that are safe during pregnancy and beneficial after babies are born, including yoga, aerobics, and exercises with resistance bands. All participants are encouraged to try the movements and techniques at home.

Esco Zepeda, HE/AL community health worker, helps HE/AL participants with day-to-day questions—including fielding 10 p.m. phone calls about how to make whole-wheat tortillas—and also serves as the fitness instructor. During a recent class, Zepeda moved through different aerobic poses and made sure everyone understood the benefits of the movements and how to have fun doing them.

“This is not a class, this is more of a facilitated conversation,” Zepeda explained. “We believe that a community will make a change when the information is coming from them, not when it is coming from someone they don’t know in the health industry. Little by little, we are just delivering information—like, try this new recipe, this new fruit, or this new vegetable.”

Each week the HE/AL program directors plan a healthy menu for the women, based on what is available at the Houston Food Bank.

“The first dish we had while I was in the class was the pink spaghetti,” Fuentes said. “Instead of using noodles, they used beets. I rarely eat beets and I loved it. They used beets and diced tomatoes instead of a thick sauce so it was all fresh and really good.”

After each meeting, the women are given 10-15 pounds of food from the food bank, based on what was prepared in class. This has made a huge impact on grocery shopping for Fuentes.

“I usually do my grocery shopping once a month because that is when I get paid, and then I don’t have to make tons of trips back,” she said. “Because of HE/AL, I really haven’t had to buy a lot of fruits and vegetables, because we get them every week.”

On a recent shopping trip to the Fiesta Mart in downtown Houston, Fuentes examined the fresh produce in the store before selecting her items.

“I love making salads, but I don’t buy iceberg lettuce anymore,” she said, pushing her cart slowly down the produce aisle. “I use spinach, because the iceberg lettuce doesn’t have a lot of nutrients. I also put tomatoes, cucumber, bell pepper and a little bit of shredded cheese for protein.”

The changes that Fuentes and her family have made in the last few months have not only improved her health during pregnancy, but they have also improved her father’s quality of life after his cancer diagnosis. He is currently finishing chemotherapy treatments in Austin and his doctors have said that the changes in his diet have helped his overall health.

“After the class ends, I know I will continue to eat healthy, but it’s sad the class has to end because I know there is so much more they can teach us,” Fuentes said. “The women are positive, successful. They care about us and our babies and they want to help make us do better.”
Dr. Sharma’s Healthy Six-Pack

Shreela Sharma, Ph.D., directs the Healthy Eating, Active Living program at The University of Texas Health Science Center at Houston School of Public Health. A trained dietitian and physical therapist, Dr. Sharma offers six healthy meal and snack options for busy parents and kids.
1. **Fruit smoothies**
   Place a variety of frozen fruit (pineapple, strawberries, mixed berries, frozen banana) in a blender with water and a tablespoon of lemon juice. Blend. Add plain or flavored yogurt if you like and blend again. Portion into to-go coffee mugs and garnish with a straw.

2. **Trail mix**
   Combine regular Cheerios with a variety of nuts such as almonds, walnuts, peanuts and cashews. Toast this mix lightly together. Add raisins. Drop into snack-size baggies to take to school or work.

3. **Fruit with nut spread**
   Slice an apple and serve with peanut butter or almond butter.

4. **Warm breakfast tacos**
   Heat up some corn tortillas or whole wheat tortillas on a skillet. Add cheese, sliced avocados and tomatoes, salt and pepper. Roll up to eat.

5. **Peanut butter and banana sandwich**
   Toast a slice of whole wheat bread. Spread with peanut butter and place sliced bananas on top. Finish with a drizzle of honey for an open-faced sandwich.

6. **Hard-boiled eggs**
   Boil and shell eggs over the weekend and store in the refrigerator for an easy grab-and-go protein. Or, add the eggs to sandwiches.
Seven Years a Survivor
James Ragan was diagnosed with terminal cancer as a young teen. Until 20, a documentary, captures the life of this determined Texan who raised millions for pediatric cancer research.

By Britni N. Riley

Until 20 Screening

When
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Where
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Free; donations welcome
All donations go to the Triumph Over Kid Cancer Foundation.

Panel Discussion
Moderator
Robert C. Robbins, M.D.
President and CEO of the Texas Medical Center

Opening Remarks
Ronald A. DePinho, M.D.
President and CEO of The University of Texas MD Anderson Cancer Center

Panelists
Winston Huh, M.D.
Pediatric Hematology and Oncology at The University of Texas MD Anderson Cancer Center

Valerae O. Lewis, M.D.
Orthopedic Oncology at The University of Texas MD Anderson Cancer Center

Geraldine Moriba
Director and Producer of Until 20

Please register at Eventbrite if you plan to attend:
tmcscreeningofuntil20.eventbrite.com
While playing in a tennis tournament in Italy when he was 13, James Ragan noticed swelling in his left knee. At the end of the match, the Corpus Christi native was taken to a local hospital.

The diagnosis was devastating.

In Italy, Ragan learned he had a rare bone cancer called osteosarcoma, a diagnosis verified by doctors at The University of Texas MD Anderson Cancer Center upon his return to the United States. This news marked the beginning of a journey that changed not only Ragan and his family, but the lives of many others.

Ragan died at age 20 in 2014. He was a junior at Rice University.

“I met James when he was first admitted to MD Anderson,” said Valarae O. Lewis, M.D., an orthopedic surgeon and oncologist. “He was an incredible tennis player, but when we took out his bone and reconstructed it with a metal prosthesis, he could no longer play high-impact sports.”

Following Ragan’s initial surgery, he completed a round of chemotherapy and was cleared of cancer. In remission, he rechanneled his passion for tennis into learning more about golf. But his cancer-free days were short-lived. Within four months, the cancer had returned and spread to his lungs.

“Osteosarcoma is like one of those flowers that you blow and the seeds go everywhere,” said MD Anderson nurse Anna Foy in a documentary about Ragan’s life, titled Until 20. “There are tiny, tiny particles of this cancer in your blood, and once it spreads it is just like a wildfire.”

Ragan returned to MD Anderson to continue treatment and begin his fight to end pediatric cancer.

“It was just his nature to fix a problem when he saw one,” Lewis said. “He was very proactive in that sense. He saw what he and his family had to go through and he did not want anyone else to have to do that.”

For his 16th birthday, Ragan threw a toga party to kick off the Triumph Over Kid Cancer Foundation, which he started with his sister, Mecklin, to fund research for osteosarcoma treatments. The foundation partners with MD Anderson Children’s Cancer Hospital and the Driscoll Children’s Hospital in Corpus Christi, Texas.

Over the seven years Ragan battled cancer, he underwent six surgeries and numerous rounds of chemotherapy and radiation to attack the tumors that had metastasized to his lungs. In spite of his illness, Ragan graduated second in his high school class and went on to play Division I golf for Rice University.

While in treatment at MD Anderson, Ragan became an ambassador for the hospital and worked with government officials to raise awareness of the lack of funding for pediatric cancer research. He became close to many other patients and helped them in any way he could.

“There was another sarcoma patient I was treating whose cancer had metastasized all over his body, and he was not able to go to his high school graduation,” Lewis said. “James saw this, and he and his mother got in touch with the superintendent of schools and we were able to have a graduation for the patient at MD Anderson. It meant so much to this child. To this day, I remember that boy’s face when he received his diploma in his cap and gown. That was because of James.”

Fellow sarcoma patient Geraldine Moriba heard about Ragan while she was receiving treatment at MD Anderson. The Emmy Award-winning CNN journalist and filmmaker enlisted the help of filmmaker and friend, Jamila Paksima, to document Ragan’s story.

“When I met James, he knew that he only had about a year to live,” said Paksima, who co-directed Until 20 with Moriba. “Because of this, our conversations were very delicate, but I was so inspired by his optimism and his mission to raise awareness of childhood cancer.”

Paksima and her film crew followed Ragan, his family, friends, doctors, and entire care team, all the while highlighting the lack of research and federal funding for pediatric cancer.

“James wanted to do this documentary because he wanted pediatric cancer to end with him, and I really wanted that for him,” Paksima said. “I thought he was invincible—even though they said he only had one year. We all kept saying something was going to happen, he’s too good to be taken by this disease.”

— JAMILA PAKSIMA
Co-director/Producer of Until 20

James Ragan, the subject of Until 20. Credit: Courtesy Photo

THE TRIUMPH OVER KID CANCER FOUNDATION

has funneled more than $3 million to pediatric cancer research through a partnership with MD Anderson and the Children’s Sarcoma Project.
GINA LUNA, managing director for JPMorgan Chase in the Houston region and immediate past chair of the Greater Houston Partnership, spoke with William F. McKeon, executive vice president and chief strategy and operating officer of the Texas Medical Center, about leadership styles, work-life balance, and the benefits of living and working in Houston.

Q | Take us back to the very beginning. Where were you born and raised?
A | I was born in Hereford, Texas. Let me start by saying it’s a very glamorous place, in the Texas panhandle, near Amarillo. There’s maybe 15,000 people on a really good day, and it’s named after the Hereford white-faced cow. It’s feedlots, the beef capital of the world. My mom’s family business was farming and ranching, so my grandparents had lots of farm and ranch land. My dad was a banker, so we lived in the “city.” I did spend time on the farm and in the country. We knew almost everybody in the town. What’s so fun is I often meet people who know somebody from Hereford, because if you say, ‘Hereford,’ of course they remember and say, ‘Oh, you must know so-and-so,’ and invariably I do know the name. I have a brother, two years older than me, and a sister who’s four years younger.

Q | Did either of your siblings also follow in your father’s footsteps and pursue a career in banking?
A | My sister worked for Chase, in the investment bank, as an analyst after undergrad, and then when it was time for her to go back to graduate school, instead of going to business school she went to culinary school. She and my brother are actually both trained chefs. Neither is a professional in that field now, but it’s a little intimidating if you’re in the kitchen together. My mom is basically Martha Stewart and the two of them are trained chefs and I’m not, but I can follow a recipe.

Q | Tell me about your parents.
A | My father was in local banking at Hereford State Bank, what we would call consumer and small business banking—the friendliest man in town who knows everybody. It was perfect for him and he did it until he retired. Now his favorite thing to do is go to Hereford State Bank on Fridays and serve popcorn to the customers that come in the lobby. I always say he’s the public relations arm of the bank. My mom is an amazing role model for me. She is among the smartest people I know, and she is definitely the most resourceful. There is nothing she can’t do. My parents raised us to have a strong work ethic and to be responsible and resilient.

Q | When did you leave Hereford? Was it university that took you out of your hometown?
A | I went to Texas A&M because I loved the Aggie traditions and values and I thought I would get a good education. During my junior year at A&M, I was in business school and I thought I wanted to do an internship in banking and finance, so I went to a...
professor and said, “Where do you think would be a good internship?” He said, “There’s one internship for an Aggie at Texas Commerce Bank in Houston, and you need to get that internship because that’s the best one and you’ll get the best experience.” I did, and I came here as a summer intern between my junior and senior year. I had a great experience. I loved the work, I loved the people. My now-husband was a few years ahead of me; he was working at the bank already, and he was the person they assigned to be my mentor for the summer. I met him on my second day of work.

I ended up getting an offer at the end of the summer to be an analyst after I graduated, which I didn’t accept because I thought, ‘Who would accept the first job they’ve ever been offered?’ It didn’t seem like the right thing to do. I said, “Thank you very much but I would like to think about it.” I went back to school and interviewed with everybody and got lots of job offers and then thought, gosh, I think I really liked what I had. I ultimately accepted the offer, so this is literally the only place I’ve ever worked.

**Q | What’s the best part of banking?**

A | To me, the fun part is doing the things that are not what people expect. In this company of 235,000 smart people all over the world, we have somebody who knows a lot about almost everything. When I’m able to find the right person or some valuable information and make connections that help people, that’s exciting. We do this inside the firm, but it’s also really fun to do that in the community because we’re in a position to know a lot of people and know about their businesses.

**Q | How would a colleague describe your style?**

A | They would say I have a lot of energy. I’m very collaborative. I don’t take no for an answer very easily. I always think there’s a way to get something done. I often see people referring to optimism as a trade-off, as if you cannot be both an optimist and a pragmatist. I don’t buy that at all. It ties very much into my belief that there’s always a way. Short of being in two places at once, which is what I always want most, I really believe I can almost always find a way to make something work. It also comes from being very grateful for the big things and the small things every day, and having the perspective that things happen for a reason.

**Q | Has your leadership style remained constant or has it evolved over the years?**

A | I do think you learn from people all along the way. People who you work for, people who you work with. I think my style is consistent, but I hope people would say I’ve refined and learned skills. I do think you have to, at some point, make a conscious decision to step up and lead in a certain way. I would say five years ago my leadership was much more around doing my job well, if you will, and then the last five years I’ve had more opportunity to lead more broadly and through community impact, like with the Greater Houston Partnership. In our company, there’s a strong culture and so you learn to be successful within that culture. Then when you lead more broadly, you realize, “You know what? Not everybody grew up in the JPMorgan Chase culture.” The way we all hold each other accountable and the standards that we have don’t necessarily apply to everybody else. You learn a different way of driving at the same pace. I think we move fast in this organization. Patience is probably not my strongest attribute. People at the Partnership would say, ‘Gina, Rome was not built in a day,’ and I’d say, ‘If it could be, we should go ahead and do that.’ It’s always a matter of prioritizing, right?

With that said, there have been several points in my career where I’ve had to rely on borrowed confidence, where I have been asked to take on a responsibility, a role, whatever, that quite honestly, in my heart of hearts, I was thinking, ‘I wonder if anybody knows that I don’t have a clue how to do this.’ But then there is someone who thinks I can do it, so I think I must be able to do it. You fake it until you make it.

**Q | What is your perspective of the Texas Medical Center?**

A | I think the medical center is an absolute jewel. It is one of the most valuable assets we have. Of course, I mean that from an economic impact perspective, but to me it’s on a very personal level, too. When someone from outside Houston just gets a cancer diagnosis and they’re calling me saying, “I have to go to MD Anderson and I don’t know how,” because it’s Houston, I say, “I’ll be thrilled to help you.”

In the bigger picture, when I sit and listen to the plans for TMC3 [an ambitious new innovation campus still in the planning stages], and TMCx [an accelerator program, launched in 2015, that offers startup companies shared workspace and guidance from health care leaders], I get so excited because I think about what that will mean for Houston in terms of our next generation. The things that will come out of that, that will change people’s lives, save people’s lives, improve people’s lives—we can’t even imagine what that’ll be. It’s exciting to me. It’s so big, it’s so impactful, it’s so innovative, that we will attract the best talent in the world to be a part of it.

**Q | How do you balance your personal life with the work demands that come with leadership?**

A | I follow this rule when I’m trying to determine where I should be, particularly when it’s work or community-related versus family, because those things overlap all the time. My rule is to think about who’s going to miss me. If I’m not at a cocktail reception, is anybody even going to go, “Gina Luna is not here.” Probably not. If I miss an important ball game or school event, though, my child’s going to know I wasn’t there. That’s a good barometer for me. Then I also do the five-year rule—in five years if I look back, am I going to be really regretful that I missed this or I missed that? That’s how I make decisions.

On the other hand, I’ve never wanted my kids to have the notion that the world revolves around them. I like them to see that their parents have responsibilities, and we do lots of things in the world, not just doting on them. That’s reality.

**Q | What advice have you received from mentors?**

A | I have as many mentors for personal life as I do for professional life. When my boys were very little, one of my mentors said, “One of the things I did with my kids was just sit them down and tell them very overtly, you are the most important thing in the world to me, so if you ever need me, I will drop everything else and be there for you.” I thought actually saying it seemed like a good idea. My older son was like, “I know, Mom.” A few years later it was time for the third-grade musical and I had to be in Chicago. It was a meeting I couldn’t change and I couldn’t miss. I was really feeling bad about it. We had a talk about it and he just looked at me and goes, “Mom, this is not one of those things. It’s not that big a deal.” So there will always be challenges and choices, but I think that honesty and just being open really helps.

(Continued)
Q | What advice do you have for young executives who aspire to be leaders and still have a great home life and raise a family?
A | I always say that early in your career, you need to be really good at what you do. Don’t spend so much time thinking about your ascent to CEO-hood. You miss the table stakes along the way, which is being capable and credible and reliable. I think the key is to be the person that people can call on to do what needs to be done. If there’s a problem, call me. If there’s an opportunity, call me. You deliver on that. I’ve taken on some pretty unattractive assignments because I could see that it needed to be done, and I thought, “I can do that.” Looking back, some of those things were the opportunities that got me exposure and credibility that it would have taken ten extra years to get if I would have said no thank you. Don’t think small, think big about what’s possible, because what’s possible is amazing. TMC3 is an example of that. Why would we ever assume we couldn’t do that? Of course we can.

Then you have to have sponsors, people who help you along the way. I don’t know of people who have a great, successful career who do it on their own. The relationships you develop are critical to moving you along that path. I also think that’s what makes it fun. When I reflect back on my career, someday, I think it will be the relationships and what people did to help me and what I did to help other people that will be the most meaningful.

Q | I remember someone once told me that you should never worry about your first job, but rather focus on your first boss, as you want to find someone who is confident enough in themselves to be your advocate.
A | I couldn’t agree with you more. I think the best leaders are the ones who are always looking to make somebody else look good. The person who works for me, I want to make them look good. The person I work for, I want to make them look good.

Q | Tell me your thoughts about Houston.
A | I love Houston. I really do love this city. I think this is a city of people who help each other. People are accessible, and they’re open; they’re non-judgmental and they’re accepting and they’re more than willing to help or to have a conversation. I love the diversity of our city. I think that is a huge strength for us. Houston, to me, is optimistic. We are a can-do city. Whatever the problem we’re facing, whether it’s municipal finance, or it’s flooding, or it’s the workforce gap, I have confidence we’ll figure it out. We always do.

“ I think the best leaders are the ones who are always looking to make somebody else look good. The person who works for me, I want to make them look good. The person I work for, I want to make them look good.”

— GINA LUNA
Managing Director for JPMorgan Chase in the Houston Region

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The Poor Among Us

In his new book, Dr. Peter J. Hotez argues that most of the world’s neglected tropical diseases can be found in pockets of poverty amid the world’s wealthiest economies

By Maggie Galehouse

Dr. Peter J. Hotez became the voice of the Zika virus some 18 months ago, in part because of his prescience.

“I was one of the first to predict, in 2014, that Zika was coming to the western hemisphere,” said Hotez, M.D., Ph.D., and dean of the National School of Tropical Medicine at Baylor College of Medicine. “Then, at the end of 2015, I wrote that Zika was headed to Florida, to the Gulf Coast.”

His New York Times op-ed piece in April 2016, titled “Zika is coming,” drew national attention, as did his interview with National Public Radio in early August.

“I have been pretty much predicting Zika is going to do,” said Hotez, 58. “I’ve been ahead of the curve every step of the way.”

But the Zika virus, which can lead to microcephaly in babies, is only one of his specialties.

Hotez, a professor of pediatrics, molecular virology and microbiology at Baylor and president of the Sabin Vaccine Institute, has been studying neglected tropical diseases for several years. Zika is just one of many threats he describes in Blue Marble Health, his new book that outlines a new global health paradigm.

The traditional understanding of global health, which compares unique diseases in less developed countries with more developed countries, is outdated, Hotez says. Today, he argues, most of the world’s neglected diseases can be found in vast pockets of poverty inside the world’s wealthiest economies.

And these poor enclaves are close to home, close to the Texas Medical Center.

Hotez moved to Houston in 2011 to launch the National School of Tropical Medicine. He had been exposed to poverty when he lived in Washington, D.C. and during his travels abroad, but after driving around some of Houston’s Fifth Ward neighborhoods, he had a revelation.

“The poverty I saw was a real eye opener for me,” Hotez said. “It had a huge impact on my research. I was driving through these places and saying ‘You know, this reminds me of Tegucigalpa. This reminds me of Guatemala City. This reminds me of Recife in northeastern Brazil.'”

He and his team found neglected tropical diseases amid poor populations in Texas and elsewhere, among them parasitic infections including Chagas disease, cysticercosis and trichomoniasis.

In Blue Marble Health, Hotez says neglected diseases need help from the leaders of the G20 countries—the 20 major economies, including the U.S. and the European Union—who meet to discuss key issues in the global economy.

“Leaders of the G20 countries need to redouble their commitment to their own neglected population, which in the U.S. includes 12 million Americans who live with neglected tropical diseases,” Hotez said.

Hotez calls for new vaccines, new drugs, and new diagnostics for Zika and other diseases. He hopes his book will reach everyone from university undergraduates to political leaders.

“I want this to become a book that can actually influence public policy,” he said.

Hotez’s involvement with the Clinton Global Initiative, which enlists global leaders to find solutions to world problems, led to friendships with politicians and celebrities.

The foreword to Blue Marble Health was written by Cher, the singer, actress and activist.

“Yes, I know Cher,” Hotez said. “I got connected with her a few years ago because she got interested in the whole problem of neglected tropical diseases, and I spent a day at her wonderful Malibu mansion tutoring her. She’s very committed. Very opinionated about her political causes. Very much a dyed-in-the-wool Democrat. She started a school in Africa and very much wants to do good in the world.”

Connecting with the public is another one of Hotez’s specialties.

“I’m an interesting scientist in that I have an M.D., a Ph.D., I keep up with the grants and the papers, but I also have another side of me which is public engagement,” he explained. “And that’s a little unusual. I write a lot for the public. I enjoy interacting with a general audience, either speaking to them or going on radio or TV. This is one of the problems with training young scientists today. We discourage them from doing public engagement. It’s seen either as a waste of time or, even worse, it’s seen as a form of grandstanding or self-promotion.”

Research!America, a policy organization, published a survey in 2013 that found that 70 percent of Americans cannot name a living scientist, Hotez said. Another survey by the same organization found that 59 percent of Americans could not name any institutions where medical and health research were conducted; even more galling, none of the top institutions named by the other 41 percent were part of the Texas Medical Center.

“And I say that’s our fault,” Hotez said. “You have to get out there. You have to shape a brand.”
Suite Life

Hospital suites across the Texas Medical Center offer patients a hotel-like experience

By Christine Hall

A great view, a gourmet meal and a comfortable place to lounge are amenities all of us expect at upscale hotels. But these luxuries are available at hospitals across the Texas Medical Center, as well.

For patients who want to make their stay a little more comfortable and are willing to spend over and above what insurance will cover, hospitals including Houston Methodist, Texas Children’s, Memorial Hermann-Texas Medical Center, and CHI St. Luke’s Health–Baylor St. Luke’s Medical Center offer suites for one night or extended stays.

Courtney and Chris Shields heard about the Signature Suites at Memorial Hermann-TMC from their obstetrician. Courtney enjoyed the experience so much with her first child that when she was ready to deliver her second, she chose to stay in a suite again.

“It’s so nice, and has room for our family and friends to visit,” Shields said. “It feels cozy like a hotel room, but you are still in the hospital.”

The 11 suites at Memorial Hermann-TMC run an additional $250 a night. Benefits include a one-nurse-to-three-patient ratio, a tea station that serves continental breakfast, and afternoon hors d’oeuvres. One of the suites features a larger bed for athletes.

Many of the hospitals treat high-profile patients—celebrities, politicians and athletes—as well as patients from countries with strained governments. Most take special precautions that include elevated security systems.

Former president George H. W. Bush favors Fondren 12, the tony 12th floor of Methodist Hospital where he has stayed for bouts of pneumonia and flu, according to media reports. But as the Shields’ know, the suites aren’t just for the rich, famous or powerful. Patients from all walks of life who come from all over the world try to secure these special rooms, sometimes months in advance.

“Our large and medium suites are the most popular, and we are full most of the time,” said Alice Baker, guest relations manager for Houston Methodist, which has offered suites for nearly four decades.

Fondren 12, which has 27 rooms, was named for Sue Fondren Trammell. It opened in 1979, after the hospital began attracting presidents, kings and other dignitaries from around the world, many of whom came for care by famed cardiologist Michael DeBakey.

The out-of-pocket cost for a night in one of these suites ranges from $300 to $1,345.
Rooms With a View
Patients get luxury treatment in the four suites at Texas Children’s Pavilion for Women, which opened in 2012. They are first-come-first-served, and Gina Marrinucci, manager of retail and concierge services, says they turn over quickly. The suites include a separate space with room for visiting family and friends. A stay here costs $750 for up to three nights.

“We believe in family-centered care, where mom and baby are kept together to the extent possible,” Marrinucci said. “There is also space for dad to hang out or do business while mom has some quiet time.”

The spacious living area and view of the medical center from one of the nine suites at Baylor St. Luke’s Medical Center could almost be considered visual therapy for patients. These suites, known as 23 Terrace, cost an additional $950 a night. Suites have been available at the hospital for close to 30 years, but moved to the 23rd floor about 10 years ago.

It’s been widely reported that late Houston Mayor Bob Lanier liked to stay in these suites when he was treated for heart disease. The 6’4” former cowboy slept in an extra-long bed.

The Royal Treatment
All of the hospitals top off the suite experience with special features, including afternoon tea service complete with cookies, cake, beverages and other goodies. Deluxe bedding, toiletry kits, newspapers and pretty much any food patients desire are also available.

Houston Methodist’s Michael McMurtry, a Culinary Institute of America-trained chef, learned to cook a lot of different delicacies in order to cater to the international patients at Fondren 12. He has also prepared food for wedding receptions, christenings and holiday parties in the hospital.

“Patients upgraded to suites definitely feel like they are staying in a hotel, but in a hospital setting.”

— ALEZA ESPINOSA
Manager of Patient Care, RN, Baylor St. Luke’s Medical Center
The staff at Baylor St. Luke’s Medical Center recently threw a birthday party for a patient, said Aleza Espinosa, RN and manager of patient care at 23 Terrace. It’s an example of the lengths staff will go to make sure patients are happy.

At Texas Children’s, new parents receive special touches including a gourmet celebration meal, a fully stocked refrigerator, and a swaddle receiving blanket. Massages and bedside spa services are available for an additional fee.

Each hospital can also bring in outside vendors to pamper patients with haircuts, massages, manicures and pedicures.

The hospitals work to make sure all patients feel welcome. During a recent afternoon tea at Houston Methodist, a woman in a burqa could only communicate through a translation app on her phone to convey which food her family member wanted. The two men working the food cart took it in stride.

While some patients may be recuperating from elective procedures, close to 40 percent of the patients at Houston Methodist suites come from the emergency room, Baker said. The rest come from different departments, including neurology, oncology, cardiology, urology, and plastic surgery.

The nursing staffs across the different hospitals take pride in being able to cater to vastly different patients with varying needs.

“Patients upgraded to suites definitely feel like they are staying in a hotel, but in a hospital setting,” Espinosa said.

### TMC HOSPITAL SUITES AT A GLANCE

<table>
<thead>
<tr>
<th>CHI St. Luke’s Health-Baylor St. Luke’s Medical Center</th>
<th>Houston Methodist Hospital</th>
<th>Memorial Hermann-Texas Medical Center</th>
<th>Texas Children’s Pavilion for Women</th>
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<tr>
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<td>23 Terrace</td>
<td>NAME</td>
<td>Fondren 12</td>
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<tr>
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<td>NO. OF ROOMS</td>
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<td>$1,345 for large, $645 for medium, $300 for small per night</td>
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Pomona is the first LiveSmart master-planned community in the Houston area by Hillwood Communities, a Perot company. Featuring a relaxed, coastal atmosphere, this 1,000-acre community in the heart of the rapidly growing Highway 288 corridor makes it easy to live a happier, healthier lifestyle with a resort-style amenity center, miles of walking trails, sports fields, Fish Camp, Exploration Zone Park and an on-site Alvin ISD elementary school. And with 300 acres left untouched or as dedicated green space, Pomona is setting the standard for what it means to LiveSmart.

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The intersection of ARTS and MEDICINE

By Britni N. Riley

He calls it “doodling” and says that any reference to medicine in his art is utterly unintentional.

But walking into Archway Gallery in Montrose to view Michael Mistric’s work, it’s easy to see how more than three decades of nursing have influenced his aesthetic.

Many of the images recall shapes you might see in a petri dish under a microscope. The colors are striking, often neon, reminiscent of pop music posters from the 1980s—with a zany, biological twist.

Mistric began his career as a combat medic for the National Guard in the 1970s. When he finished his training, he decided to continue his career in medicine, eventually working as a nurse practitioner at the Michael E. DeBakey Veterans Affairs Medical Center Houston. Today, he teaches at the Texas Woman’s University Institute of Health Sciences-Houston and The University of Texas Medical Branch at Galveston.

Mistric’s self-proclaimed “doodling” started as a hobby to get through long conferences in the early 1990s. He applies bold colors to canvases, boxes and plates, and then takes a black oil pen to outline shapes.

He does not have a plan for his pieces when he starts them. Using free-hand techniques, he lets the shapes, images and colors come to him organically.

“T”

Michael Mistric, in front of one of his paintings at Archway Gallery, 2305 Dunlavy; 713-522-2409 or archwaygallery.com.
Health in Your Hands
Tech innovations for the 50+ crowd

By Christine Hall

People past the half century mark are not as technologically challenged as younger generations might assume. A recent AARP study found that many individuals 50 and older use smartphones and tablets. As a result, people in that demographic are interested in improving their health using digital health technologies.

The AARP study, “2016 Health Innovation Frontiers,” estimates that of the $102 billion in market revenue over the next four years, $34 billion will be in new revenue opportunities from health and wellness technology across nine separate markets, including medication management, care coordination, cognitive health and social wellbeing.

“While people aged 50 to 75 are buying standalone technology like Fitbits and activity trackers, the big takeaway is that entrepreneurs are selling peace of mind to baby boomers when they should be focusing on the boomers’ parents and what is important to them,” said Jody Holtzman, AARP’s senior vice president for market innovation.

But while most players in the marketplace are focused on selling a product, family members want to give their older loved ones some peace of mind.

“We will spend whatever to protect our parents, and that said, you have to get the OK from my mother to put the product in her house,” Holtzman added. “The conversation is not about my peace of mind because she will tell me to ‘Stick it.’ A conversation with my mother will be about the things that are important to her—like freedom, control, independence and staying connected to family, neighbors, friends and the community.”

A big surge in telemedicine could also benefit the 50+ crowd, said Jason Burnett, Ph.D., who co-directs The Texas Elder Abuse & Mistreatment Institute.

“A lot of information that is not available during clinic visits ... will become available by being able to assess the patient in their home environment,” said Burnett, assistant professor of geriatric and palliative medicine at McGovern Medical School at The University of Texas Health Science Center at Houston. “In a sense, it will be comparable to a house call. Couple this approach with mobile health applications or in-home health monitoring technology and you have a virtual home clinic of sorts.”

Here are four health tech innovations tailored to individuals 50 and older:

**intelliAIDE**
This mobile health platform helps doctors, patients and caregivers communicate in real time. Caregivers can alert providers instantly about care issues—including the timing of meals and medicine—and create a “village” of family support to share duties and information. Clinicians and researchers can view a patient’s status and monitor the health of patients they’ve referred to specialists.

**Jitterbug smartphone**
This simple smartphone from GreatCall offers large letters, easy navigation, and built-in health and safety apps.

**Caremerge**
To simplify communication between health care providers, caretakers and patients, companies like Caremerge will manage activities, connect family and coordinate care. Caremerge offers an easy-to-use mobile and web-optimized software that is HIPAA compliant.

**Posit Science**
This company has created brain training software, including brain fitness games that help with word retrieval, memory and mental improvement. In a study of older adults, the company found that brain exercise cut the long-term risk of dementia nearly in half.
Heavy Lifting
Memorial Hermann Life Flight celebrates four decades in the air

By Britni N. Riley

Forty years ago, Houston’s first air ambulance lifted off from the rooftop of Hermann Hospital.

James “Red” Duke Jr., M.D., the late, legendary founder of the Memorial Hermann Life Flight program, knew from his military training that nothing was more precious than time when caring for patients in a trauma setting.

“When you look at Houston and Harris County geographically, the way it has grown and the way it was built to begin with, it is 50 miles wide one way and very spread out,” said Tom Flanagan, vice president and chief operating officer of Memorial Hermann-Texas Medical Center. “When you look at trying to get patients care in a timely manner when it comes to cardiac, stroke victims and trauma patients, time is of the essence.”

Life Flight began in 1976 with one aircraft. On each trip, a nurse, a resident and a pilot were sent out to receive and stabilize a patient, and then bring the patient back to the Texas Medical Center for treatment. In the beginning, Duke and his staff anticipated the helicopter would be used 10 or 15 times each month. In the very first month, the air ambulance received 50 requests for its services.

Flanagan worked as a flight nurse with Life Flight for 23 years before assuming the role of chief flight nurse and program director.

“I got to watch the growth of the program and see the difference the technology has made,” he said. “We have increased the speed at which we can travel and that has improved the outcomes for our patients.”

The helicopters are now equipped with devices that allow Life Flight staff to perform ultrasounds. Staff also have the ability to administer blood. But perhaps the biggest change since the early days: aircraft can accommodate two patients at a time.

“The ability to double-load and bring two patients at one time back to the hospital makes a huge difference,” said Joseph Love, M.D., medical director of Life Flight and assistant professor of surgery at McGovern Medical School at UTHealth. “Having more space in the helicopters also allows us to do some of the more advanced trips—for example a patient on a balloon pump or an ECMO machine [which pumps and oxygenates a patient’s blood, giving the heart and lungs a rest]. We tend to focus a lot on the trauma side of what Life Flight can do, but the enormity of what we do and the scope of what we practice is very broad. We can take very complex patients and bring them to the medical center.”

Today, Life Flight retrieves critically ill and injured patients from a 150-mile radius that includes Houston, Harris County, southeast Texas and parts of western Louisiana. The fleet now consists of six aircraft, 21 pilots, 20 flight nurses, 18 paramedics and dispatchers, and eight mechanics. The program runs 24 hours a day, 365 days a year. In all, Life Flight has flown close to 150,000 missions.

This year marks the 40th anniversary of the program and the first year without Duke, who passed away in August 2015.

To celebrate the anniversary, Memorial Hermann-TMC launched a campaign of gratitude to say thank you to the community. The hospital also unveiled commemorative patches and logo decals for the pilots and aircraft in August.

“Red was a good friend and mentor of mine,” Love said. “Here we are one year later and we’re still doing fine.”

James “Red” Duke Jr., M.D., founder of Memorial Hermann Life Flight program.
Credit: Photo provided by Memorial Hermann-TMC
During surgery, many patients are outfitted with a urinary catheter, which drains urine into a bag outside the body. Due to the risk of contamination and the length of time a catheter remains in place, urinary tract infections (UTI) are the fourth most common infection in surgical patients, says Thomas Aloia, M.D., director of quality and outcomes for the surgery division at The University of Texas MD Anderson Cancer Center.

To improve those odds, Aloia helped organize a team of nurses, nurse practitioners, surgeons, anesthesiologists, physician assistants and others. Working with the American College of Surgeons and National Surgical Quality Improvement Program, the team collected data from 1,000 patients to analyze the rate of complications. According to the data, UTIs occurred in 2.8 percent of the patients.

To understand how the hospital environment could be improved to reduce the number of infections, Aloia’s team developed the S.T.O.P. program. An innovative way to assess the handling of catheters, S.T.O.P. articulates best practices via four succinct, memorable guidelines. Using these guidelines, the team identified specific areas that needed improvement. Subsequently, urinary tract infection rates in surgery patients dropped to 0.5 percent.

“We then noted that the urinary tract infection rate went down across the entire hospital,” Aloia said. “As we presented last month at the American College of Surgeons quality meeting, these best practices diffused out to the rest of the hospital via the nursing staff, and the whole hospital got better. It’s a great secondary outcome.”

**S.T.O.P. PROGRAM**

**S** **Sterile placement** | Insert the catheter cleanly and properly.

**T** **Timely removal** | Remove the catheter within two days or as soon as the patient is able to make it to the bathroom independently.

**O** **Optimal position of the urine bag** | Use hooks at a lower height on the IV pole and beds to attach the urine bag. Especially during patient transport, there is a chance for reflux back to the bladder if the urine bag is placed above the bladder.

**P** **Proper sampling** | Obtain clean, uncontaminated urine samples to validate the diagnosis of a urinary tract infection.
AMY ARRINGTON, M.D., PH.D., medical director of Texas Children’s Special Isolation Unit at Texas Children’s Hospital, was recently named one of Healthcare Design magazine’s 4th Annual HCD 10, an elite group of design and architect professionals who represent the most influential health care work of the previous year. Arrington was recognized under the clinician category for her work in the development and design of Texas Children’s Special Isolation Unit, which opened November 2015 and is the only one of its kind in Texas and the southwest region.

DAVID BASKIN, M.D., vice chair of the department of neurosurgery and director of the Kenneth R. Peak Brain and Pituitary Tumor Treatment Center at Houston Methodist Hospital, has been recognized by his patients as one of America’s Most Compassionate Doctors by Vitals, a company that works to provide tools to engage patients in their health care. This is the fifth year in a row Baskin has received this honor.

WAYNE J. FRANKLIN, M.D., director of the Adult Congenital Heart Disease Program at Texas Children’s Hospital, has been accepted into the second class of The Aspen Institute’s Health Innovators Fellowship. Franklin is among 21 health care leaders who will participate in the two-year fellowship designed to strengthen innovation across the U.S. health care ecosystem and create new approaches that will improve the well-being of Americans.

JAMES LANGABEER II, PH.D., professor at the School of Biomedical Informatics at The University of Texas Health Science Center at Houston, has been asked to chair the national committee that will implement Guideline Advantage, a comprehensive quality improvement tool for analyzing digitized electronic health records. The tool, developed by the American Heart Association in conjunction with the American Diabetes Association and the American Cancer Society, emphasizes chronic diseases, including cardiology, neurology, endocrinology and oncology.

ANTONIOS MIKOS, PH.D., the Louis Calder Professor of Bioengineering and Chemical and Biomolecular Engineering and director of the J.W. Cox Laboratory for Biomedical Engineering and of the Center for Excellence in Tissue Engineering at Rice University, has been elected to the Academy of Athens—Greece’s national academy and highest research establishment—as a corresponding member in the Section of the Sciences.

EMILY SEDGWICK, M.D., associate professor of radiology in the section of breast imaging at Baylor College of Medicine, has been named the 2016 recipient of the Ben and Margaret Love Foundation Bobby Alford Award for Academic Clinical Professionalism, an honor given annually to a Baylor physician who best exemplifies professionalism in the practice of medicine. Throughout her career, Sedgwick has been dedicated to improving health care and making the breast cancer treatment process more streamlined and less intimidating for patients.

MARGARET SPITZ, M.P.H., professor in the NCI-designated Dan L. Duncan Comprehensive Cancer Center at Baylor College of Medicine, has been appointed by President Barack Obama to the National Cancer Advisory Board. An expert in molecular epidemiology, Spitz has a long-standing interest in genetic susceptibility to lung cancer. The primary task of the 18-member advisory board is to advise the Secretary of Health and Human Services and the director of the National Cancer Institute on a range of issues affecting the nation’s cancer program and NCI operations.

GREGORY WILLIAMS, PH.D., a member of the senior administration team in the department of OB/GYN at Baylor College of Medicine, will release his first book, Shattered in the Darkness, in December 2016. The book, which will be published by Thomas Nelson Publishing Company, encourages discussion, education and awareness of child abuse.
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- Anthony Haas
  “Danish Healthcare Design Competitions: Diving into the Difference Between Danish and American Project Team Selection”

- Laurie Waggener
  “Psychology in the Workplace: A Foundation for the Importance of Patient Experience”

- Laurie Waggener

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