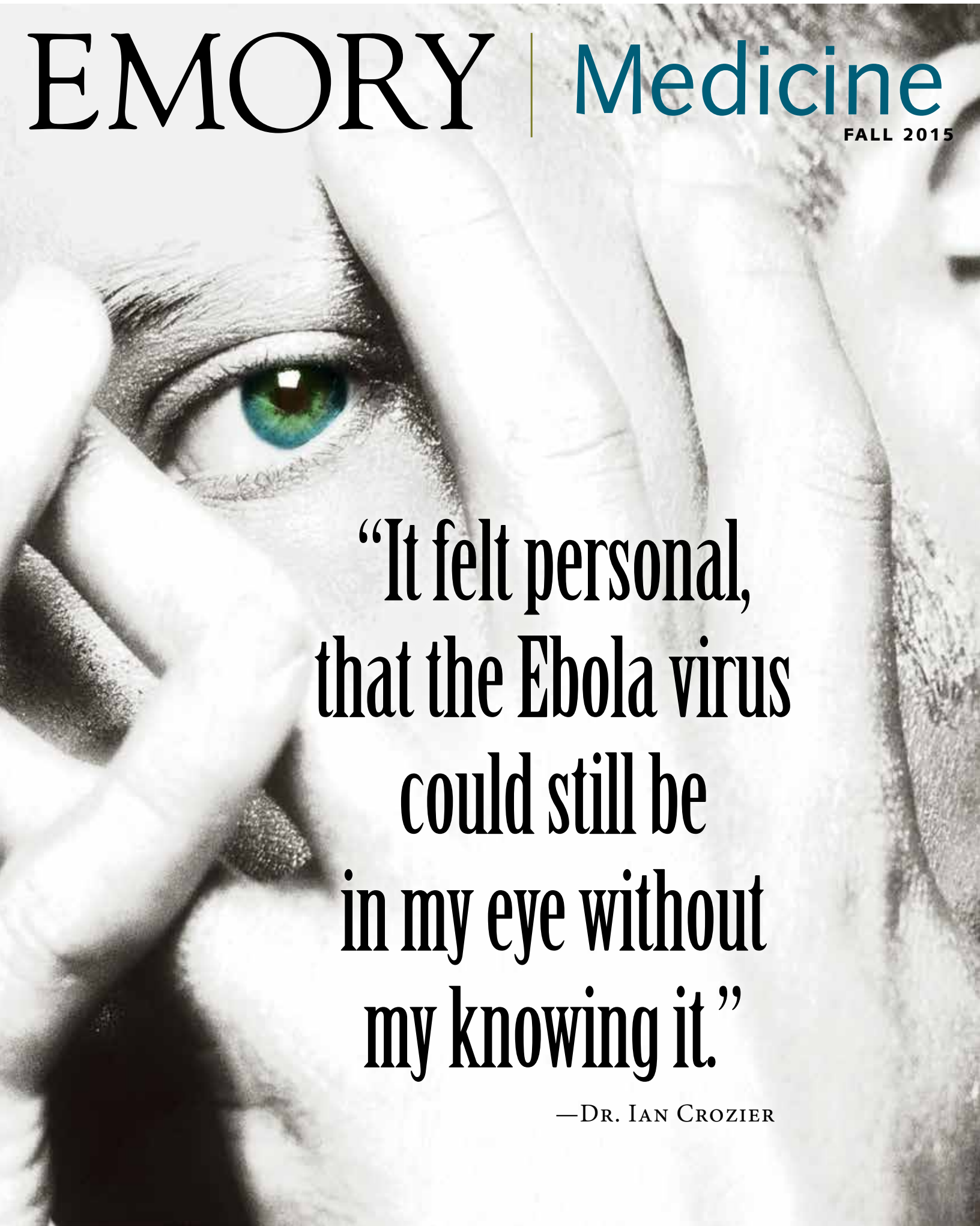
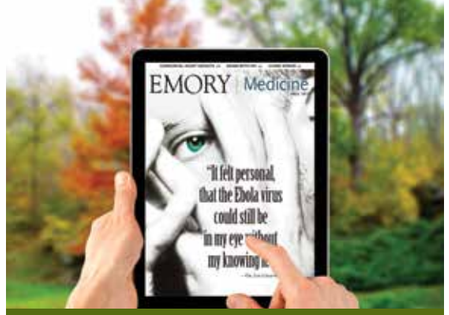
EMORY | Medicine
FALL 2015



"It felt personal, that the Ebola virus could still be in my eye without my knowing it."

—Dr. Ian Crozier



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Emory Medicine

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Continuity of Care

In past generations, when babies were born with hearts that didn't form properly—with leaky or narrow valves, holes in the wall between the chambers, or muscle abnormalities—parents were not offered much hope.

Christian Larsen
Dean, Emory School of Medicine
President, Emory Healthcare Physicians Group

Even if the child survived, it was expected that they would have an abbreviated, curtailed life.

Today, for the first time, there are more adults than children living with congenital heart defects (CHDs). They are going to college, having children themselves, and becoming scientists and researchers and musicians and teachers (see p. 18).

That's why medical homes like Emory's Adult Congenital Heart Center—the only one in the state and one of the largest in the country—are important. They provide a continuity of care vital for patients with lifelong conditions like CHD.

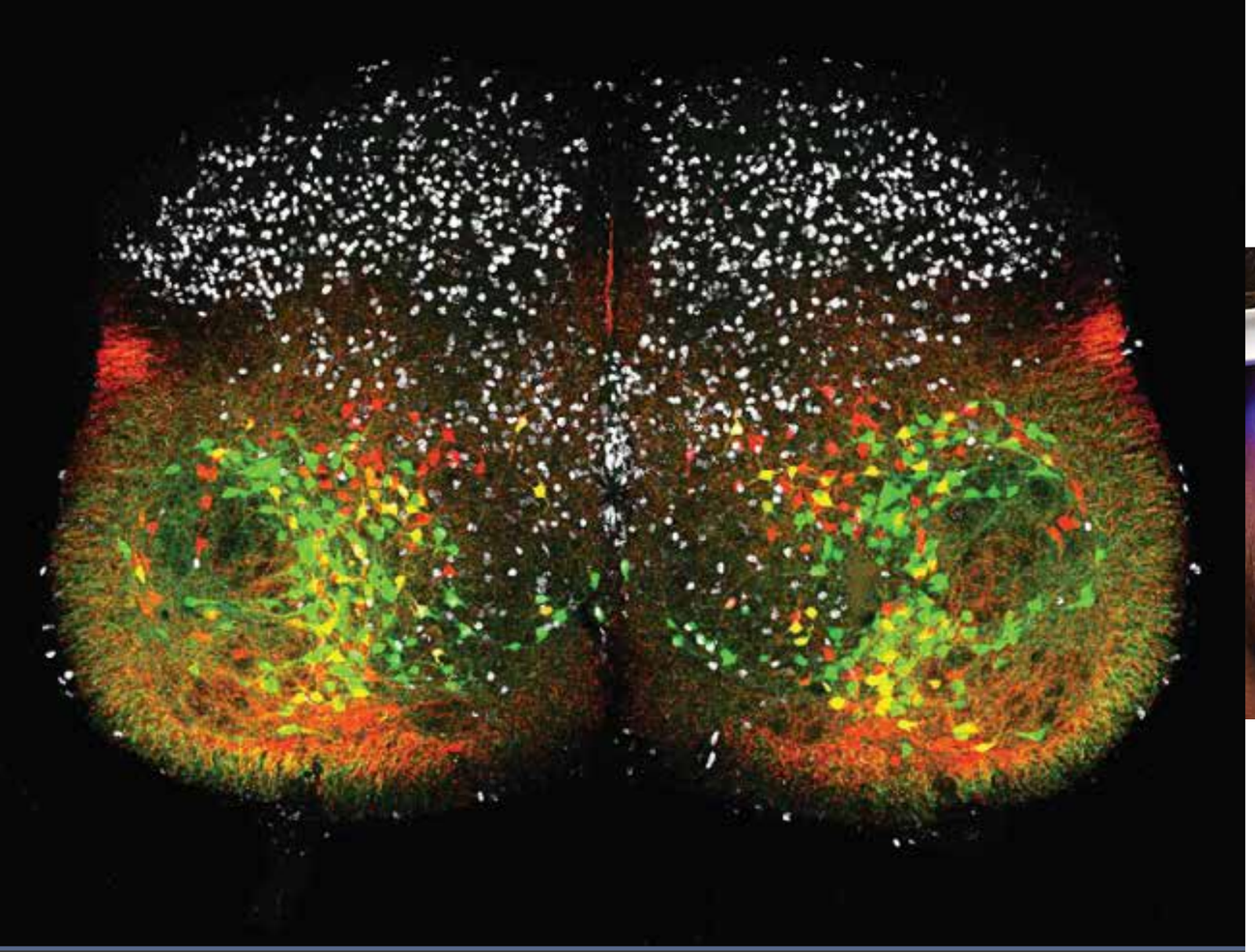
Emory's center follows more than 3,000 CHD patients, with about 2,000 patient visits and 100 heart surgeries yearly. Multidisciplinary teams include adult and pediatric cardiologists, congenital cardiac surgeons, electrophysiologists, interventional cardiologists, nurse practitioners, nurses, social workers, and echocardiographers. The center also provides genetic counseling and partners with our ob/gyn staff to provide high-risk pregnancy counseling and management.

"As these children grow into adults, they need ongoing specialty cardiac care," says center director and cardiologist Wendy Book. "Yet this high-risk group often experiences lapses in care because of the perception that they are 'fixed' or because they aren't experiencing symptoms. CHDs are so closely associated with infancy and childhood that people often think the conditions just don't affect adults."

We are also helping to provide continuous care and support for adults with another disease once thought to be a death sentence—HIV. Now, people who are HIV-positive are routinely living long enough to become senior citizens, grandparents, and retirees (see p. 25).

At the Ponce de Leon Center, part of the Grady Health System, Emory doctors and researchers, under the direction of Wendy Armstrong, serve more than 5,200 people in the greater Atlanta area with HIV/AIDS. Many of the center's patients volunteer to participate in research because they want to give back, Armstrong says. Patients have told her: "I was planning my death. I never expected to be able to plan my life." A growing number of these patients are older than 50. The Atlanta VA Medical Center is also experiencing this "graying of an epidemic"—of its 1,600 HIV-positive patients, the median age is 52.

The medical and research communities have done a great job of keeping patients with these conditions alive. Now we need to keep them active and healthy so they can make the most of their additional hard-won years.



It's not what you think...

This cross section of a five-day-old mouse's spinal cord highlights developing inhibitory neurons, which control movement, in red and green. Vibrant microscopic images such as this, which won the Best Image contest at the Emory Postdoctoral Research Symposium, help researchers find out more about metabolic processes and molecular interactions, advancing knowledge that can save lives.

(Emory postdoctoral fellow JoAnna Anderson with Andre Rivard, Francisco Alvarez's lab.)

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EMORY | Medicine

FALL 2015

NEW AND NOTEWORTHY

FEATURES

AND MORE

"I sit here, alive first of all, and looking through two eyes, which is absolutely remarkable for me personally, but there are 10,000 to 15,000 Ebola survivors in West Africa who are grappling with these types of ailments as well." 12

Visit us online at **emorymedicinemagazine.emory.edu** for bonus content. Send letters to the editor to **mary.loftus@emory.edu.**

I am a quadrilateral amputee. In 2008, I contracted a Group A strep infection of the blood that caused toxic shock syndrome and necessitated the amputation of my hands below the elbow and my feet below the knee. Becoming independent has been my goal, just as Aimee Copeland expressed in *Emory Medicine* magazine (Spring 2015). I first learned to feed myself with body-powered prosthetics. I flipped many a forkful of food on the floor, but with practice I have learned to eat at restaurants. I have learned to walk unaided and try to get in my 10,000 steps each day (I'm a bit obsessed by the Fitbit). I love Aimee's idea of planning an outdoor area accessible to all. My husband and I have visited several national parks and have found them surprisingly accessible. Like Aimee and her physical therapist, I also love my "torturer," my personal trainer. I protest but I know it's good for me.

Cheryl Douglass
Chevy Chase, Md.

Find the Spring 2015 issue online
emorymedicinemagazine.emory.edu

My husband, Donald Page, is a 1983 graduate of the School of Medicine and also did six years of post-grad training through Emory, which is why we receive your great publication: *Emory Medicine*. The article in your Spring 2015 issue about Aimee Copeland moved me. Aimee's life taught me so much about stepping up and choosing to be brave.

Joan Walker Page
Marietta, Ga.

My husband, George Wallace, had to get two polyps removed after a colonoscopy, and they later proved to be cancerous. Dr. Patrick Sullivan did TAMIS (transanal minimally invasive surgery) on him. We both feel it saved his life. We spent one night at Emory Midtown, and the nursing staff and everyone else was just wonderful. The experience was with a culture I had not been exposed to in other hospitals with other doctors. I felt like Dr. Sullivan was treating us like he would treat someone in his own family. My husband is an artist and gave him one of his paintings in return. More people should be aware of this fairly new procedure, and that it can save a lot of pain and recovery time.

Sandy Wallace
Conyers, Ga.

My wife was recently receiving four weeks of intense physical therapy for Parkinson's at the Emory Rehab Hospital under the direction of Dr. Stewart Factor. I picked up a copy of *Emory Medicine* and, as a former health care administrator, I found the articles very intellectually stimulating. Our son is enrolled in the Emory School of Nursing and is completing his MSN in the Family Practice NP Program. Emory has been a wonderful experience for my wife, our son, and myself (I experienced a top-notch neurological workup there several years ago.)

Bernie Gaydos
Roswell, Ga.

We like to hear from you. Send us your comments, questions, suggestions, and castigations. *Address correspondence to* **Emory Medicine** *magazine, 1762 Clifton Road, Suite 1000, Atlanta, GA 30322; call 404-727-0161; or email* ***mary.loftus@emory.edu****.*

People are talking...

"There is no science fiction anymore. Everything I read about as a kid, we're either doing it or we're trying to do it. ... Synthetic biology, for instance, actually genetically engineers animals who create our drugs in their blood or milk."

-Paul Root Wolpe,
BEINGS Summit,
May 17-19.
http://bit.ly/beingswolpe

"Our finding of similarity in clinical progression between human patients and Huntington's disease monkeys suggests monkeys could become a preclinical, large animal model for the development of new treatments...Right now, we can address the symptoms but we want to do more."

-Anthony Chan
http://bit.ly/huntingtonsmonkeys

MyLife: Adults with autism practice life skills on campus

DAMON MEHARG

Working out at the gym, swimming, riding the shuttles, sharing a meal...all are part of myLife, an Emory Autism Center pilot program that uses the Emory campus as a behavioral training ground for adults with autism. Participants are paired with peer volunteers, many of whom are Emory students.

"They need guidance, patience, and repetition," says Catherine Rice, director of the center, "in terms of helping to practice life skills."

These skills, selected to foster independence, include interacting with others, communicating needs, participating in community events, exercising, and getting around on public transportation. There is even an apartment on campus where they can practice cooking healthy foods, cleaning, doing laundry, or just hanging out with friends. Activities like woodworking and gardening are included to introduce hobbies or potential job skills.

Doing activities together allows counselors and peer volunteers to give feedback. For example, if a participant sits right next to a stranger on the shuttle, even when there are several other seats available, they can be reminded about personal space and that this sometimes makes the other person feel uncomfortable.

"You want real life to happen," says Toni Thomas, program manager for adult services at the Emory Autism Center. "You don't get that in a clinic room." ■

Sleep 101

Want to improve your sleep? David Rye, of Emory's sleep medicine program, says it's all about the basics. For good sleep hygiene you should:

- **Keep a regular schedule**
- **Go to bed near the same time every night**
- **Wake up early**
- **Get exposure to the sun**
- **Don't take your cell phone or laptop to bed**
- **Try not to take long naps**

Back to School

Remember school nurses? While the workload for school-based clinics has skyrocketed, fewer than half of public schools in the country now have a nurse on staff, according to the National Association of School Nurses. Emory Pediatric Urban Health Program's school-based clinics are designed to help close those gaps in Georgia. They offer regular checkups and dental care along with more urgent-care services. Many offer mental health counselors.

"Our primary goal has always been to increase access to health care in many of our underserved areas," says Veda Johnson, assistant professor of pediatrics, who oversees the program's Georgia expansion efforts. "Nurses are at the core of these programs. They are the ones who know the children and develop trust." ■

Emory to lead National Ebola Training and Education Center

Nurses Crystal Johnson and Jason Slabach practice donning and doffing personal protective equipment in Emory University Hopsital's Serious Communicable Diseases Unit.

Because of its experience in helping four patients recover from Ebola, Emory was named by the U.S. Department of Health & Human Services to be lead coordinating center of the National Ebola Training and Education Center.

Emory will collaborate with the University of Nebraska Medical Center, the New York City Health and Hospitals Corporation (Bellevue Hospital), the HHS's Assistant Secretary for Preparedness and Response, and the Centers for Disease Control and Prevention (CDC).

The center will support training of health care providers and facilities on strategies to manage Ebola virus and other emerging infectious diseases and will receive $12 million over the next five years.

"Based on the knowledge we have gained from caring for patients with Ebola virus disease, we will develop and teach best practices to other health care workers who could be faced with caring for similar patients in the future," says Bruce Ribner, medical director of Emory University Hospital's Serious Communicable Diseases Unit. Ribner will be principal investigator of the center.

Since December 2014, Emory, the University of Nebraska, and the CDC have trained more than 460 health care workers from 87 health care systems on all aspects of Ebola infection control and patient care. Emory is part of a national network of 55 Ebola treatment centers. ■

Stand up!

Sitting can be hazardous to your health. That's right, what you are probably doing now, even as you read this article, may be increasing your risk for developing diseases like cancer.

Between working at a desk, watching TV, and driving, the average American spends more than eight hours a day sitting.

Alpa Patel, who has an MPH from Emory and is the strategic director of the Cancer Prevention Study (CPS)-3 for the American Cancer Society, has focused her research on the role of physical activity in cancer prevention and obesity as a risk factor for cancer.

Studies have found that people who sit a lot, particularly women, tend to die earlier. Women who sat for more than six hours a day were 37 percent more likely to die during the 13 years of the study than those who sat for less than three hours a day. Men who sat more than six hours a day were 18 percent more likely to die than those who sat less than three hours. Researchers estimate that two years of life can be gained by reducing sitting to less than three hours a day.

Surprisingly, this level of risk applied even to people who regularly went to the gym but sat at desk jobs the rest of the day—a group Patel calls "active couch potatoes." *—Martha McKenzie*

High-tech heart help

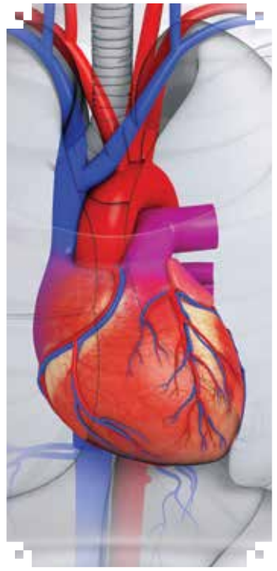
Two lifesaving devices have made it through clinical trials and are on their way into more patients' hearts.

The CardioMEMS HF System is the first FDA-approved heart failure monitoring device shown to reduce hospital admissions.

The device, invented at Georgia Tech using jet-engine technology, is delivered to the heart with a catheter and implanted in the pulmonary artery, where its paper-clip-sized sensor measures interior pressure. An increase in this pressure can indicate worsening heart failure.

Once implanted, the wireless sensor sends regular pressure readings to an external electronic system. "We're able to detect changes from a distance and, if needed, adjust a patient's medication regimen to stabilize pulmonary artery pressures," says Emory cardiologist Rob Cole. Cole and colleagues recently implanted metro Atlanta's first FDA-approved CardioMEMS device, although Emory Healthcare has been offering the device for years as part of a clinical trial. The sensor is designed to last a lifetime and does not require batteries.

Also, patients with non-valvular atrial fibrillation (AFib) now have an alternative to long-term warfarin medication with the Watchman Left Atrial Appendage Closure Implant.



During a minimally invasive procedure, the implant is delivered to the heart via a catheter, closing off the left atrial appendage (LAA). The LAA is a thin, sack-like appendage attached to the heart and is thought to be the source of the majority of stroke-causing blood clots in people with non-valvular AFib.

Cardiologist David DeLurgio, director of electrophysiology at Emory Saint Joseph's Hospital, and an Emory team have been implanting the device for the past seven years in clinical trials, testing the new technology. He recently implanted the region's first FDA-approved device in the Southeast. ■

And the heart scan shows...

A simple heart scan can predict early death. The coronary artery calcification (CAC) scan, an X-ray test that looks for specks of calcium in the walls of coronary arteries, is helping physicians identify patients at risk. These specks, or calcifications, are an early indicator of coronary heart disease. Led by cardiologist Leslee Shaw, researchers from Emory's School of Medicine collected CAC scores and risk factor data from more than 9,700 volunteers between 1996 and 1999. All participants were scanned as part of a community-outreach screening program at an outpatient clinic in Nashville. None showed symptoms of coronary artery disease at the time.

Dr. Leslee Shaw

The findings, published in the July 7 online issue of *Annals of Internal Medicine*, showed that CAC scores accurately predicted premature death from all causes up to 15 years in advance, in patients without any symptoms. "This gives us a better understanding of the importance of coronary calcium scans," Shaw says. "Patients with high calcium scores might be advised by their physicians to adopt healthier lifestyles, which could lead to better outcomes and help lengthen their lives." ■

You have the power

Preventable risk factors, such as obesity and smoking, continue to account for half of all heart disease deaths, found Emory researchers. A team led by Shivani Patel, a researcher in the Hubert Department of Global Health at Rollins School of Public Health, studied data from the Behavioral Risk Factor Surveillance System national surveys from 2009 to 2010. The goal: to find out how much national cardiovascular mortality might decrease if all states reduced risk factor levels to target levels. The top five preventable risk factors for heart disease are elevated cholesterol, diabetes, hypertension, obesity, and smoking. The fraction of cardiovascular deaths that could have been prevented were reported under two scenarios: completely eliminating risk factors, and the more realistic goal of reducing risk factors to rival the best in the US. The findings, published in the June 30 issue of *Annals of Internal Medicine,* suggest that about half of deaths could be prevented if the modifiable risk factors were completely eliminated. About 10 percent of cardiovascular deaths could be prevented if all states were to achieve risk factor levels observed in the best-performing states. "All states could benefit from more aggressive policies and programs to help reduce risk of death from heart disease," Patel says ■

Secondary comforts

You might think it would be the amenities—like a comfortable reclining chair to sleep in or a washer and dryer to use—that would be most appreciated by family members of a patient in an intensive care unit.

Actually, the most important needs identified by such families were those that revolved around patient information.

Emory University Hospital's 2D Neuroscience ICU Research Team

In a recent survey of 45 family members of patients by Emory University Hospital's Neuro-ICU, the top-rated needs included unrestricted visitation, talking with a doctor each day, being assured that the best care is being provided to the patient, and being given hope and encouragement.

Emory's Neuro-ICU allows continuous family member visitation in the patient's room. Having the family present is beneficial for the patient, the family themselves, and the health care providers, says unit research committee chair Mini Jacob. Unrestricted family access allows the family members to see changes in the patient's health status, to be present for bedside shift reports, and to join in open communication regarding the patient's health goals with staff.

In addition to Emory's unrestricted visitation policy, the unit also provides amenities like a washer and dryer, sleep rooms for families staying overnight, family counselors, and mentors who are family members of former ICU patients. "Everyone has been great to us. They answer all questions and provide information needed," said one family.

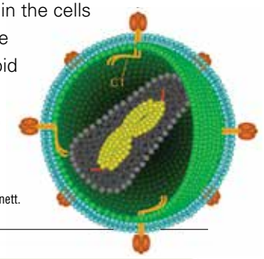
The study found that although families loved the amenities and services, their main concerns were being kept up to date and well informed about the care provided to their family member, and the ability to stay with the patient, says Carmen Frobos, the unit's family coordinator. *—Aspen Ono 18C*

Easing Phantom Limb Pain

Amputees sometimes experience shooting pains or burning sensations in limbs that are no longer there. These sensations seem to originate in the spinal cord and brain, perhaps because neural pathways are receiving mixed signals that something is not right. A clinical trial by Emory Saint Joseph's Hospital interventional radiologist J. David Prologo is studying a minimally invasive treatment, cryoablation therapy, to see if it helps relieve symptoms. Prologo is using CT imaging guidance to position a probe near the nerve responsible for the residual phantom pain. Once the probe is placed, the temperature is dropped for 25 minutes to create an ablation zone, and the signals the nerve was previously carrying are shut down. The outpatient procedure takes about one hour, and some patients have reported significantly decreased pain and improved function. Norma Jean Robinson was one of the first patients to complete the cryoablation therapy at Emory Saint Joseph's. "On a scale of one to 10, my [phantom] pain had reached the highest level—a 10," says Robinson, whose leg had been amputated six months before. "This procedure dramatically changed the quality of my life." ■

Why HIV's cloak has a long tail

Emory virologists have uncovered a critical detail explaining how HIV assembles its infectious yet stealthy clothing. For HIV to spread from cell to cell, the viral envelope protein needs to become incorporated into viral particles as they emerge from an infected cell. Researchers led by Paul Spearman, Nahmias-Schinazi Professor and vice chair of research in Emory Pediatrics, found that a small section of the envelope protein, located on its cytoplasmic "tail," is necessary for it to be sorted into viral particles. "Many viral envelope proteins have very short tails," Spearman says. "Why HIV envelope has such a long tail has been a mystery. Now we are beginning to understand that HIV uses specific host cell factors to deliver its envelope protein onto the viral particle. Not only can this help us design better vaccines, it provides a new target for drugs to inhibit HIV." The tail is required for HIV to infect and replicate in the cells it prefers: macrophages and T cells. The long tail is also thought to help HIV avoid the immune system, says Eric Hunter, co-director of Emory's Center for AIDS Research. ■



CT = cytoplasmic tail
Figure modified from image of HIV virion created by Atuhani Burnett.

Extraordinary Ebola care

Emory University Hospital's Serious Communicable Diseases Unit team received the National Patient Safety Foundation's DAISY (Diseases Attacking the Immune System) Award for Extraordinary Nurses. Members of "Team Ebola" were selected for their care and successful treatment of four critically ill Ebola patients at Emory last summer and fall. ■

The DAISY FOUNDATION
IN MEMORY OF J. PATRICK BARNES

Research dollars Researchers in Emory's Woodruff Health Sciences Center received nearly $483 million in funding last year, 93 percent of the university total, with nearly $325 million in federal funding, including more than $288 million from the NIH. ■

You be the doctor

The Case of the Waxing Moon Face

After a peripatetic electronic journey, a photo of a middle-aged schoolteacher found its way to the cell phone of Clyde Partin, director of Emory's Special Diagnostic Services clinic.

"Face is swollen" was the only information that accompanied the picture.

The woman's head was tilted back, reminiscent of a Vesalius drawing, Partin says, and her neck was erythematous—abnormally red, perhaps from inflammation or infection.

Her facial features appeared normal, but she had a tired appearance. Partin agreed to examine her in the Special Diagnostic clinic.

In his office, he encountered a seemingly exhausted 45-year-old woman, slightly overweight.

She showed him a photo of herself taken at a party. She was wearing a college football jersey, her face thin and youthful, exceedingly healthy in appearance.

"I wondered why she was showing me a photo of her college days but she reassured me the photo was taken only five months prior," he says. "The contrast between her then and now was striking and disconcerting. The bloated face was now fully obvious to me."

She told him that she was, indeed, exhausted and had gained twenty pounds. "My legs feel so heavy, I can hardly get up steps," she said. "And my sideburns are growing."

Her past medical history included migraine headaches, which were worsening, and neck and back pain.

The rest of her exam was mostly unrevealing. No purple striae—stretch marks that could be caused by rapid weight gain or certain diseases. No buffalo hump, which could indicate certain conditions. Some terminal facial hairs were noted.

Neck and facial erythema in a butterfly pattern was observed but multiple ANA (antinuclear antibody) lab test results were negative, suggesting lupus was not the culprit. Electrolytes demonstrated a subtle metabolic alkalosis.

"How are your neck and back doing?" Partin asked.

"Better after the shots," she replied.

"What kind of shots?"

"I'm not sure."

"Epidural steroid shots?"

"Yes, I think so."

She recalled perhaps 10 such shots in the past 13 months. And that, careful reader, was the culprit.

Her plethoric, if not fully developed, moon face was due to excessive exogenous steroids. Further lab testing revealed the presence of synthetic corticosteroids, even though it had been months since her last steroid shot, and suppressed adrenal glands causing a low endogenous cortisol level.

She had received so much steroid her proximal leg muscles were weak from steroid myopathy, explaining her trouble with steps.

Her symptoms could be attributed to the steroids, which had produced Cushing's syndrome. The cure? Mostly time, letting her adrenal glands recover, and a touch of hydrocortisone when needed. ■

Dr. Steven Yeh checks Ian Crozier's left eye at a follow-up appointment in June. Crozier developed severe vision loss months after he recovered from a near-fatal Ebola infection. During testing, live Ebola virus was found inside Crozier's eye

Hiding in Plain Sight

A lot remains unknown about Dr. Ian Crozier's left eye. Does it still harbor the Ebola virus? Is that what made his iris turn from blue to green? Was Crozier an outlier, or do many Ebola survivors have remaining live virus in their eyes? All that is known, definitively, is that after very nearly taking his life, Ebola then tried to steal his sight.

Dr. Ian Crozier survived Ebola but months later, while being treated at Emory Eye Center for vision problems, the virus was found inside his eye. During this time his iris changed from blue to green.

When his vision started to deteriorate, it was a devastating blow to Ian Crozier, a 44-year-old doctor infected with the Ebola virus while treating patients in Sierra Leone at the height of the epidemic in the summer of 2014.

After being diagnosed in early September, Crozier was flown back to the United States and spent "40 days and 40 nights" in Emory University Hospital's Serious Communicable Diseases Unit. He remembers little of the first weeks of his stay, beyond his few steps from the ambulance to the unit in full protective gear.

He was by far the sickest Ebola patient Emory doctors had cared for. After experiencing multiorgan failure, he had been placed on a ventilator for several weeks to help him breathe and underwent kidney dialysis to clear toxins from his body.

"The general dogma at the time was that if Ebola patients needed dialysis or a vent, they would invariably die," says Bruce Ribner, medical director of the unit. "This changed the algorithm for how aggressive we could be."

Slowly, Crozier had come back to himself. He was found to be virus free and was discharged on Oct. 19. He traveled to his family's home in Phoenix to recuperate from fatigue and deconditioning, like an astronaut returning from a long journey. But the virus had another surprise in store. In December, Ebola was found hiding inside his eye, an alien stowaway that wasn't quite willing to give up its host just yet. "It felt personal, that the Ebola virus could still be in my eye without my knowing it," he says.

Crozier's own story began in what is now Zimbabwe, where he was born and spent his childhood years. A place nourished by the Zambezi River, it was home to hippos and rhinos and boyhood adventures, but also to years of a protracted war leading to the country's independence in 1980. His family moved to the U.S. when Ian was 10, and he went on to graduate from medical school at Vanderbilt, later training in internal medicine and infectious diseases.

Feeling drawn back to Africa, Crozier was

By Mary Loftus

Courtesy of WHO

Dr. Ian Crozier with a group of Ebola survivors and a nurse at the Kenema Government Hospital in Sierra Leone. Ebola survivors are reporting a variety of ailments after recovery, including fatigue, headaches, joint pain, memory loss, and eye diseases.

living in Uganda, caring for HIV patients and training physicians, when the Ebola outbreak occurred. He volunteered with the World Health Organization (WHO) to go to West Africa, where he was assigned to the Ebola Treatment Unit in Kenema, Sierra Leone. One of the unit's main doctors had just died of the virus, and Crozier joined a staff already long overwhelmed by unexpected volumes of patients as the virus spread throughout the country.

Ebola is not a tidy disease—blood, vomit, and diarrhea are ever-present and tending to the ill in full protective gear is hot, exhausting work. In the middle of so much death and suffering, Crozier noted a remarkable fortitude in local health care workers and in patients and families. "Childless parents took care of parentless children," he told *The New York Times*.

Local and foreign health care workers alike were being infected at an alarming rate. "Ebola kills thrice: first the patient, then the patient's closest caretakers (family), then the doctors and nurses," Crozier says. "It leads to multiplied devastation."

He sent home a young nurse from England who was infected—William Pooley—on a medical evacuation flight, and wryly joked with the flight crew later that he didn't want to see them again.

In early September, Crozier developed a fever and headache, and drew his own blood for a diagnostic test. It was positive for Ebola. On Sept. 9, he was flown to Emory University Hospital, where he was admitted to the Serious Communicable Diseases Unit. "I would have been dead in a week had I not been evacuated, and for that I'm incredibly grateful," says Crozier. "I have to hold that gratitude in tension with the present awareness that many of my patients, some of my colleagues, and a few of my friends were not afforded the same opportunity and died in Kenema."

Crozier was Emory's third Ebola patient, taking over the room recently vacated by Dr. Kent Brantly, who had acquired the virus while caring for patients in Liberia. Crozier's family kept his identity confidential, so he was known only as "Patient 3" outside the unit.

Since no "cure" exists for Ebola, the infectious disease team concentrated on providing supportive care, trying to keep Crozier alive long enough for his own body to battle back the disease.

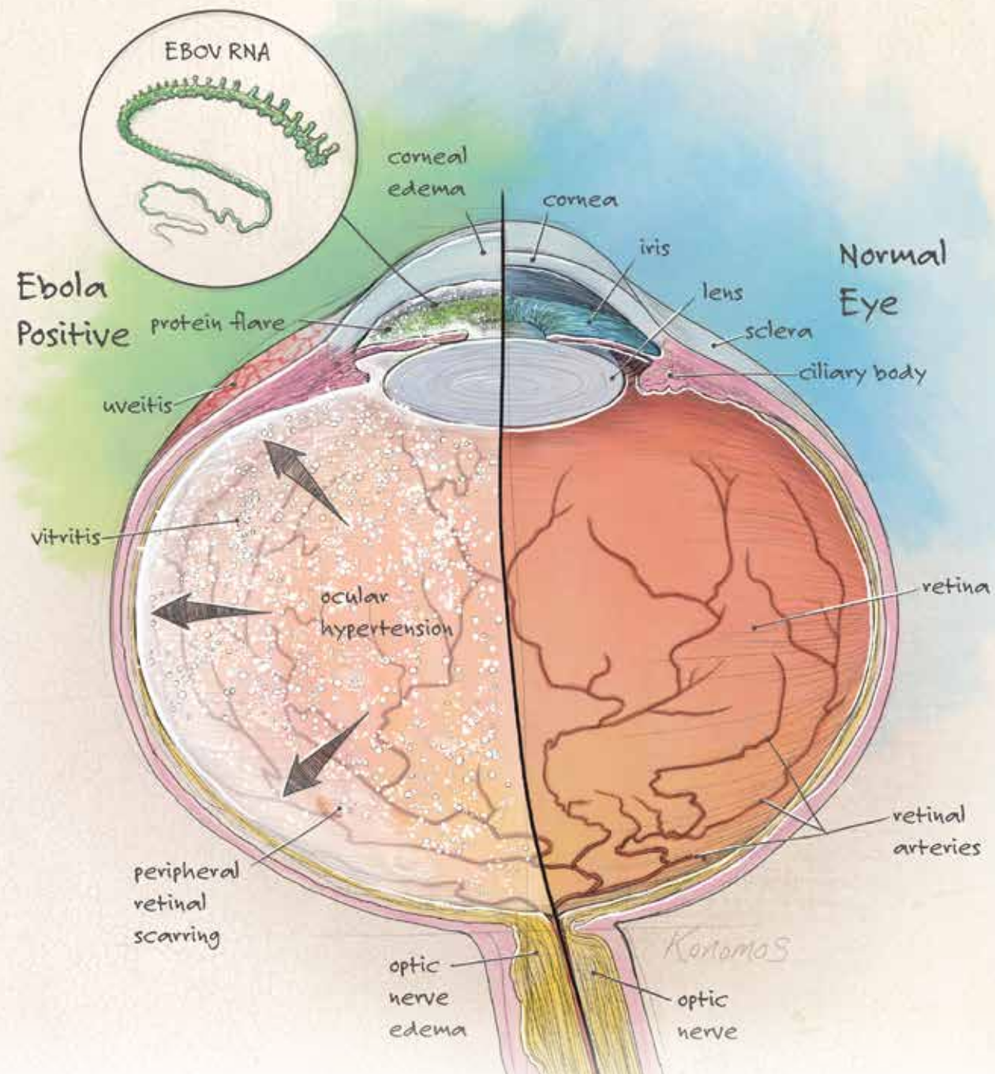
The only therapeutic weapons available were plasma from Ebola survivors' blood and experimental antivirals—but no clinical trials had been done on what actually worked, how much to give, or what combination of the two would be most effective.

English nurse Pooley, whom Crozier had seen off, flew to Atlanta to donate his blood so that his "survivor plasma" could be given to Crozier. (The plasma of Ebola survivors is now being banked at Emory.)

As Emory doctors and nurses were discovering, "best practices" for the clinical care of Ebola patients were often a guessing game. Crozier was an ideal teaching case, though, precisely because he was so ill. When he arrived at Emory, his blood had 100 times the viral load of any previous patient. "I want to make sure that what was learned at my bedside, and at the bedside of the other survivors at Emory, is translated and applied to a West African setting," he says.

After his recovery and discharge, he be-

"Among survivors of Ebola virus disease, late complications that include ocular disease can develop during convalescence, such as this case of acute uveitis. Also, viable Ebola virus was detected in the aqueous humor obtained from the inflamed eye 14 weeks after the onset of the initial symptoms of Ebola virus disease, and 9 weeks after its clearance." NEJM, May 7, 2015.



Medical Illustration By Michael Konomos
Emory Visual Medical Education Team

gan hearing that fellow survivors in Kenema were struggling with post-Ebola ailments. Several common symptoms kept popping up: profound and disabling fatigue, severe joint and muscle pain, headaches, short-term memory loss and other neurocognitive problems, and vision problems.

Crozier was surprised to hear that 30 to 40 percent of survivors were having eye problems. "That made me pay attention to a very mild burning I was having in both eyes, and a bit of light sensitivity and difficulty seeing things when I was reading or looking at my phone," he says. Since he was returning to Emory regularly for follow-up care, he mentioned this to his doctor, infectious disease specialist Jay Varkey, who referred him to ophthalmologist Steven Yeh at the Emory Eye Center.

In November, Yeh examined Crozier's eye and saw nothing out of the ordinary at first. But a look through dilated pupils to the back of the eye showed slight, strange scars in the periphery. "Somebody in their 40s shouldn't have these scars," says Yeh, "so we performed a fluorescein angiogram—a dye test that allows us to look at the physiology of the blood vessels and the optic nerve—and he did have some unusual abnormalities."

Beth Fankhauser

Dr. Ian Crozier (far right) performs an intake interview with an Ebola survivor in April in Monrovia, Liberia. Up to 40 percent of survivors are reporting some type of ocular problem, from eye irritation to vision loss.

Then, in December, Crozier developed severe left eye pain, a left-sided headache, and nausea. He was walking back to his Atlanta hotel room one night when he noticed halos around the streetlights. He contacted Yeh who, with ophthalmology resident Jessica Shantha, met him at 11 p.m. at the clinic. They found that the pressure in his eye, which normally should be between 10 to 20 millimeters of mercury, was very high—44 mmHg. Yeh noticed inflammation in the anterior portion of the eye, signifying uveitis, which can cause blindness if left untreated. Over the next few days, the inflammation got worse, as did Crozier's vision. They began to believe that the aggressive uveitis was associated with Ebola. "Ebola and uveitis do have this very loose association," says Yeh. "Uveitus was observed in survivors of the 1990s outbreak in the Democratic Republic of the Congo."

Using a hair-thin needle, Yeh took a sample of fluid (aqueous humor) from the anterior chamber of Crozier's eye.

Survivors are cautioned that the virus might still lurk in a few isolated, immune-protected parts of their body, such as the testes (and so are urged to use protection when having sex). But no one expected to find live, viable virus in Crozier's eye months after his blood had cleared. Just before the procedure, Crozier turned to the small group in the room and said, "This is not going to be Ebola, but just in case it is remember what it feels like to be right in the middle of a paradigm shift."

A few hours later, the rapid molecular test came back positive. At first, everyone was in shock. The eye care team consulted with the infectious disease team, then thoroughly decontaminated the exam room and informed others at the eye center.

The next day, a more comprehensive test showed that Crozier's eye fluid "wasn't just positive for Ebola but was positive at levels that were even higher than they had been in my blood," says Crozier. "And the levels in my blood had been orders of magnitude higher than any other of the U.S. survivors, at least to that point."

In fact, Crozier's left eye was teeming with Ebola—and not just pieces of dead virus or antigen, but viable, active, replicating virus. "After everything that I'd been through, it was still there," he says.

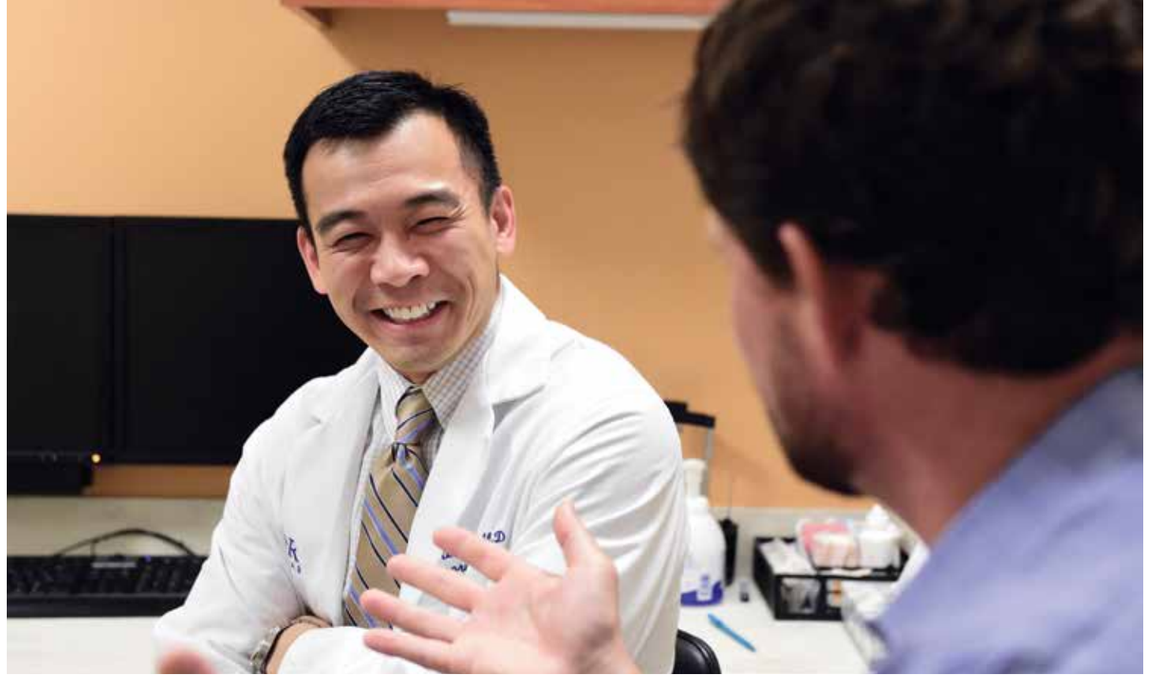
The team quickly swabbed and tested the surface of Crozier's eye and his tears, but no virus was present. This meant that he was not a risk for casual transmission or transmission to his family, since the virus was active only deep within his eye.

Yeh, who had been wearing gloves, a gown, and a mask when he did the sampling, nevertheless voluntarily isolated himself at home, sleeping in the guest room and separating himself from his wife and infant son for the incubation period of 21 days.

Meanwhile, Crozier's sight was deteriorating at an alarming rate. Worse yet, the usual treatment for uveitis—steroids—has the potential to make a viral infection like Ebola explode. The team decided it had to treat the eye to save it, however, and progressed from topical cortical steroids to oral steroids as the severity of inflammation worsened.

By the end of the year, Crozier could only sense hand motions with his left eye and was wearing a patch over it much of the time. Then the pressure in his eye normalized—and continued dropping until it was nearly undetectable, which was also very worrisome. "Your eye should feel like a hard-boiled egg to the touch. That's normal pressure," Crozier says. "Mine began to soften, and we noticed it was losing some of its architecture."

Crozier was admitted on Christmas Eve to the very bed in the isolation unit that he had left in October. His brother stayed with him, trying to bring some holiday cheer, but there wasn't much to be had. The vision in his eye had decreased from a baseline of 20/15 (better than perfect) to what was considered legally blind over a span of just a few weeks. "It was a very dark December," Crozier says. "I was convinced I had lost the sight in the eye permanently."



Ophthalmologist Steven Yeh shares a light moment with Ian Crozier during a follow-up exam at the Emory Eye Center. Yeh helped restore Crozier's vision after he developed uveitis and dangerous ocular pressure levels during his recuperation from Ebola virus.

During this period, he awoke one morning, looked in the mirror, and realized his left eye had changed from blue to green. (Infrequently, viruses can cause this.) "This felt like an increasingly personal attack, as the virus stole both my sight and my eye color," he says.

After taking a course of an experimental antiviral drug, Crozier realized that if he moved his eye up and down he could create a kind of portal—a "wormhole," he started calling it—through which he could see. It was a good sign, the beginning of regaining his vision.

"Ian's case was, I would say, easily the most complex and challenging one I've ever had," Yeh says. "What exactly worked, I think we're still sorting out."

Crozier was eager to take on the roles of clinician, researcher, and healer again. "I sit here, alive first of all, and looking through two eyes, which is absolutely remarkable for me personally," he says. "But there are 10,000 to 15,000 Ebola survivors in West Africa who are grappling with these ailments as well."

Drs. Yeh, Shantha, and Varkey, who had bonded with each other and Crozier as his case progressed, also were curious to see if the care Crozier received could be translated for use in Africa, to prevent other Ebola survivors from going blind.

"It could be that I'm an outlier of sorts and, because my acute illness was so severe it probably should have killed me, I may have some odd manifestations of the virus," Crozier says.

To learn more, a team led by Yeh, including Shantha, Crozier, and oculoplastic surgeon Brent Hayek, went to West Africa in early April. They took donated eye exam equipment—slit lamps and indirect opthalmoscopes and vision test cards—and flew to Liberia for a week, setting up in an outpatient clinic at ELWA Hospital in Monrovia.

They saw about 100 survivors. Some had uveitis, others had cataracts, dry eyes, or glaucoma. (They didn't test for Ebola, due to exposure risk.)

The doctors taught the local staff how to check ocular vitals and detect uveitis, which needs to be treated quickly and aggressively, says Yeh.

The hope is to develop protocols for the diagnosis and treatment of Ebola survivors with vision problems. "Visiting Liberia, it touches you," says Shantha. "It motivates you to do more."

Varkey, Shantha, Yeh, Crozier, and other colleagues coauthored a report about Crozier's eye condition that ran in the May 7 online issue of the *New England Journal of Medicine*, "Persistence of Ebola Virus in Ocular Fluid during Convalescence."

It concludes: "This case highlights an important complication of Ebola Virus Disease with major implications for both individual and public health that are immediately relevant to the ongoing West African outbreak."

The team was especially moved by a survivor who, after losing her husband, father, and two children to Ebola, was now losing her vision in both eyes. "How much," asked Crozier, "does this virus take from us?" ■

For the first time, more adults than children have congenital heart defects. They're leading full, active lives. This doesn't mean they're cured.

BALANCING *ACTS*

By Dana Goldman

Steven Mets is used to blending in—and being misunderstood. After all, he seems like a typical 21-year-old college student, into gaming and the outdoors. "I've had doctors look at me like, 'Why are you here? You're fine,' " says Mets, a student at Clemson University.

But in his case, appearances are deceiving.

Look more closely and there are clues that Mets is, in many ways, exceptional. Take the scars on his body, remnants of a series of heart surgeries that started when he was just four days old (and that he expects will someday include a heart transplant.) Or his panoply of pills, the type of medications usually prescribed to much older adults. You might see his roommates lifting heavy objects for him, or, until recently, slowing down when walking up hills to make sure he could keep up.

Steven Mets was born with a rare congenital heart defect called Shone's complex and has a pacemaker, a bovine valve, and a mechanical valve.

Mets was born with a rare congenital heart disease called Shone's complex, involving multiple cardiac defects. He has a pacemaker, a bovine valve, and a mechanical valve that all help keep his heart going.

He is one of a growing number of adults now living with congenital heart defects (CHDs) that, a few decades ago, would have been a sure death sentence. "Someone who was born in the 1950s with a heart defect—just about any heart defect that wouldn't spontaneously resolve—their chances to survive to adulthood were poor," says Wendy Book, Mets's cardiologist and director of Emory's Adult Congenital Heart Center.

Patients with a hole in their heart or a missing chamber would rarely age out of a pediatric practice and grow up to need adult health services. But in the past few decades, a series of medical advances began extending these children's lives, sometimes just for a few years—and then a few more.

Treatment is advancing so rapidly that even a five-year fix will often buy the patient enough time that a new treatment is available when the last one stops working. "That can make a huge difference in giving them a chance at the life they want so badly," Book says.

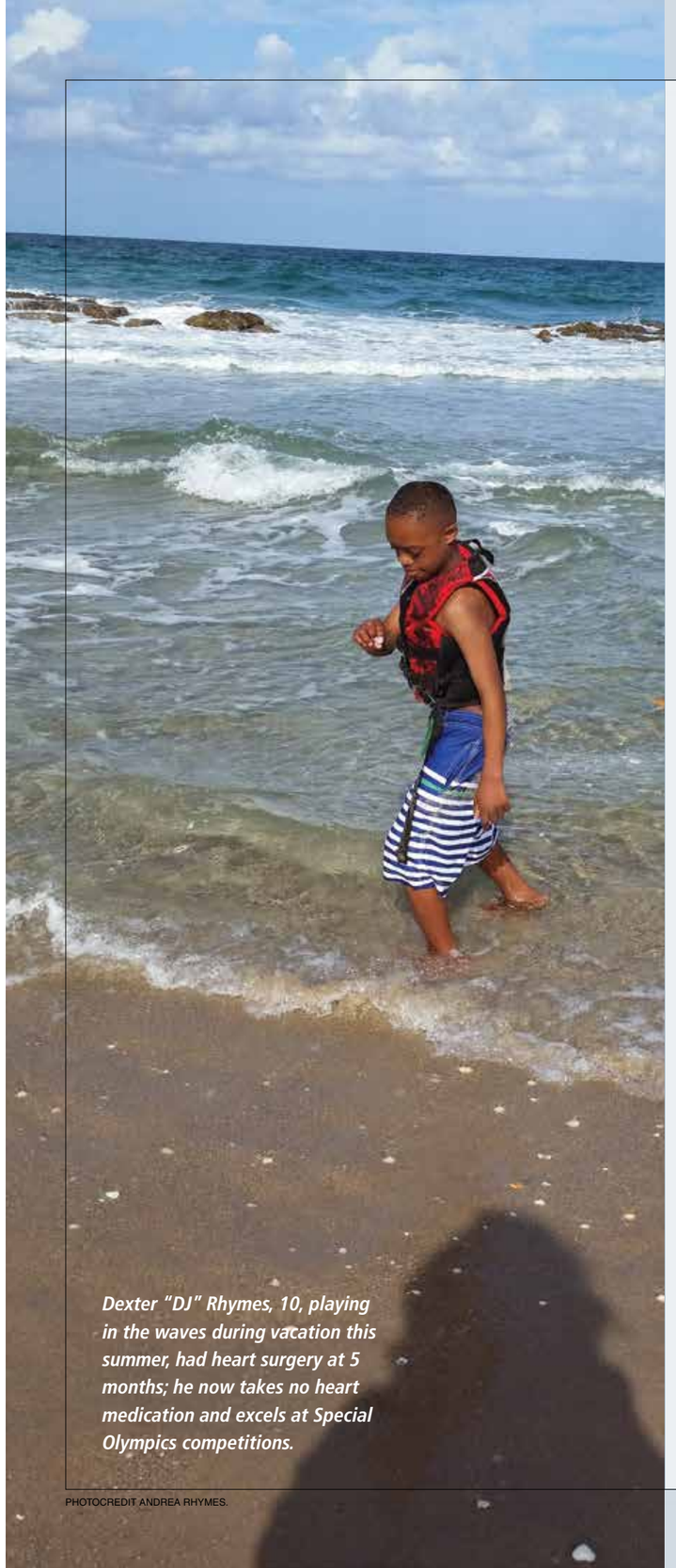
When the first wave of children with CHD grew too old for pediatric cardiology services, they sometimes found themselves out of competent medical hands. "Nobody was prepared to take care of them when they grew up," says Book, a professor of medicine at Emory.

Cardiologists specializing in adults are trained to help patients with blocked arteries and cardiovascular disease. As Mets discovered, most had rarely if ever seen a patient with unusual circulation, valve problems, or only one pumping chamber of the heart, and the complications caused by these structural issues. If adult patients with heart defects required surgery, they often ended up back at a pediatric hospital with a pediatric cardiac surgeon.

The amount of care these patients require is both time-consuming and expensive. "But when you're talking about people with 50 years ahead of them, how can you not put forward the resources to help?" asks Book.

Attention is being paid: Congress passed the Congenital Heart Futures Act in 2010, a law that provides funding for Centers for Disease Control and Prevention (CDC) tracking across a patient's lifespan. And adult congenital heart disease

Asha Krishnaswamy, an IT specialist at the CDC, was born with a cluster of congenital heart defects collectively called tetralogy of Fallot and wasn't expected to live past her teens.



Dexter "DJ" Rhymes, 10, playing in the waves during vacation this summer, had heart surgery at 5 months; he now takes no heart medication and excels at Special Olympics competitions.

PHOTOCREDIT ANDREA RHYMES.

Down Syndrome and Congenital Heart Defects

The risk of congenital heart defects is greatly increased in babies with Down syndrome. About half of children with the genetic disorder have a heart defect, with atrioventricular septal defect (AVSD) being the most common.

Although sometimes it is possible to detect heart defects before birth through fetal ultrasound, the effects of an AVSD usually become apparent in the first few weeks of life. Often the clearest sign is difficulty feeding, says pediatric cardiologist Ken Dooley, associate professor of pediatrics: "The baby will feed one ounce and then go to sleep exhausted."

With AVSD, the central region of the heart separating the atria from the ventricles fails to form properly. Such defects can increase the workload on the heart, and a "complete" defect leads to heart failure: fluid buildup in the lungs and difficulty breathing, requiring surgery in the first year of life.

Before surgery, the goal is usually to have the child reach a weight of 11 pounds, Dooley says, at which point the risk of complications and poor outcomes are reduced. In the meantime, medications similar to those taken by adults with heart failure can help. Not all AVSDs are complete; some are milder and become apparent in the teenage years.

Emory researchers are taking part in a national study investigating the genetics of heart defects in the context of Down syndrome. Geneticists Stephanie Sherman, Michael Zwick, Lora Bean, and Tracie Rosser have been working with Dooley and colleagues across the country. "Studying congenital heart defects in the at-risk Down syndrome population can make it possible to reveal genes that impact the risk of heart defects in all children, including those with a typical number of chromosomes," Zwick says.

Folic acid taken during pregnancy can reduce the risk of some types of heart defects with Down syndrome, the researchers have found. Variations in genes connected with folic acid biology appear to play a role.

More recently, the team has found that infants with heart defects and Down syndrome are more likely to have rare, large genetic deletions. Those deletions tend to involve genes that affect cilia, cellular structures that are important for signaling and patterning in embryonic development. These findings, along with other recent studies, suggest that congenital heart defects can come from several genes and environmental factors, in addition to the substantial risk from extra chromosome 21. "Our partnership with families who have a child with Down syndrome and our investment in a comprehensive clinical database and biorepository will continue to provide resources to study Down-syndrome associated conditions," Sherman says.

Pediatric cardiologist Martha Clabby (left, with patient), director of the Sibley Complex Congenital Heart Disease program, cares for children with congenital heart defects, many of whom will transition to Emory's Adult Congenital Heart Center, directed by cardiologist Wendy Book (right, with patient).

has become a new subspecialty in internal medicine, with the first board exams scheduled for 2015 by the American Board of Internal Medicine.

Emory's Adult Congenital Heart Center, designed at the turn of the millennium to serve the growing number of patients older than 18, is one of a handful of such emerging centers around the country and the only one in Georgia.

"The challenges are infinite," says Book. "These patients are often in the first wave for surgical procedures. We work without knowledge of long-term outcomes. The defects are all very rare and very different. Everything about them is unique and we are often faced with doing procedures that have never been done before because a patient's situation calls for it."

Mets knows how tough it can be. He prioritizes his medical care even when it means driving the 120 miles to Emory during a busy week at college. Even so, there are continual dangers. Two years ago, he came down with pneumonia. "My heart wasn't strong enough to handle it," he says. "My condition kept getting worse." His liver and kidneys began to fail. Book had planned to replace his failing aortic valve with a bovine valve after his recovery, but decided Mets's only chance was to go ahead and replace the valve immediately.

Conducting open heart surgery on a patient with cardiac defects and pneumonia is anything but easy. It took three attempts to replace Mets's aortic valve. During the last attempt, he went into cardiac arrest twice. At one point, his heart stopped pumping enough blood to keep his organs going. The surgery was so fraught that doctors decided to keep him unconscious and on life support for a few weeks after the procedure in hopes that this would take pressure off his heart and allow it to heal. "Against all odds, I eventually woke up," Mets says.

Months of physical rehabilitation followed before he was strong enough to return to college. "I've had more close calls than I would like," he says.

Since recovering from his last aortic valve replacement, he can walk up hills without stopping for the first time in many years. "I now have better heart function than I've ever had," says Mets, who is majoring in computer science and conducting research on virtual reality. "I have a lot of hope that I'll wind up with a long and full life."

Which is exactly what Asha Krishnaswamy, an IT specialist at the Centers for Disease Control and Prevention (CDC), is doing—flourishing as a wife, mother, and professional, against all odds.

She was born with the congenital heart defects collectively called tetralogy of Fallot and wasn't expected to live past her teens. "Most kids today have correction surgery within the first six months of life," she says. "But nearly 40 years ago, they didn't have that surgery."

Instead, Krishnaswamy's early life in India was confined by clear warnings from her parents and doctors about what was and was not safe for her to do. "I had a lot of dos and don'ts," she remembers. "One of them was not to ride a bike. I've never been on a bike." Embarrassed by her scars, she avoided swimming into her late 20s.

Now at 55, she has received care for her condition across three continents (India, England, and the U.S.) and is a survivor of four heart surgeries. Krishnaswamy has been coming to Emory for treatment since 2005 and no longer worries about what others might think when they see her scars. "I show them as a badge or an emblem," she says, laughing. "It's like beating nature."

She is paying her good fortune forward, working at the CDC's Center for Birth Defects and partnering with Book on a longitudinal study of patients with cardiac defects. "We're looking at the population from a public health perspective," says Book.

Adds Krishnaswamy, "We don't know how many such individuals there are—the prevalence, the incidence, the racial profile. I'm trying to develop an algorithm to identify congenital heart disease."

After identifying patients, the next step is to follow them to see how different procedures impact their lifespan and quality of life.

Proactive, consistent care from the very beginning is critical for children with CHD, says Martha Clabby, pediatric cardiologist and director of the Sibley Complex Congenital Heart Disease program, a decade-long collaboration between Emory and Children's Healthcare of Atlanta.

Clabby and her team care for infants who often require surgery immediately after birth. "Some of these babies are diagnosed prenatally," she says. "Parents might not even be able to hold the baby before they get airlifted here to start treatment."

The program began after Clabby's team noticed that despite good surgical outcomes, babies born with CHD still experienced a higher than normal incidence of sudden death once they left the hospital.

"One of the really important things when you have an at-risk patient population is for them to know they're at risk," says Clabby, an assistant professor of pediatrics who also directs the cardiac step-down unit at Children's Healthcare. "So our program involves an intensive parent education process that takes a multidisciplinary approach."

Teams include physicians, nurses, social workers, physical therapists, outpatient nurses, and special nurse educators who provide extensive one-on-one teaching about what is wrong with the babies and what parents need to do if they see something amiss.

Part of this instruction is emphasizing to parents, and later, the patients themselves, a difficult fact about CHDs: there is no perfect fix.

Doctors can work around defects, but rarely can the complications be fully mitigated, says Clabby. "If someone is born with half a heart, we can crudely mimic what the normal blood flow is, but not restore normal physiology," she says. "You can't create chambers of the heart that aren't there— at least not yet. But we use what we can to make things as normal as possible."

Clabby and her team have established procedures that are being picked up by other specialty centers around the country through their participation in the Joint Council of Congenital Heart Disease. Since 2004, these steps have dramatically decreased the rate of sudden deaths among young patients at Sibley. They include placing alerts on the patients' electronic healthcare records, making sure CHD patients are seen immediately if their families call, and educating families about the need for proactive care and vigilance.

Simple tactics are often the most effective. "Congenital heart disease patients literally have a blue sticker on their hospital room door that says they're high risk so that anyone walking by, whether it be a cardiologist or a social worker, should respond in even more of an acute way than we already do with our other patients," says Clabby.

And while she is realistic about the challenges her patients face—many will need three open heart surgeries before the age of four—Clabby says the work offers long-term rewards. "It's not enough to get a child to survive, right?" she asks. "That's great as a first step, but really what we want is to provide functional and happy lives for these kids. Getting them through the first years is just the beginning. To see them outside the hospital doing well—playing soccer or taking prom pictures—that's extremely gratifying."

Such success brings its own problems, however. "Many of our young adult patients have the perception that if they feel fine they don't need care," says Book. "They're busy—going to college, getting married, starting a career. Then, later, they come in during a crisis with an acute problem or when they're pregnant."

Up to 40 percent of patients with cardiac defects nationally fail to make the transition from pediatric to adult care.

That's where Fred "Rusty" Rodriguez III comes in, the rare cardiologist trained to work with both children and adults. His rounds regularly take him to hospitals including Egleston, Scottish Rite, Northside, and Emory.

On a recent Saturday morning, the Emory professor of pediatrics and internal medicine found himself in a back room at the arcade game center Dave & Buster's, talking about everything from sex to alcohol to life expectancy with a group of teens with congenital heart defects and their parents.

"How important is it to take my medications?" asks one.

"Can I get pregnant?" asks another.

All are curious to hear Rodriguez's answers about their own concerns.

These young adults might not stand out in a crowd. But all of them have a heart defect that requires regular monitoring and care.

"Some were born with holes in their heart," says Rodriguez. "Some with one functional pumping chamber rather than two. Some have problems with valves in their heart—either they're too narrow or too leaky. Some have large blood vessels coming off their heart in the wrong orientation."

Rodriguez and his team know that the more teens grasp about the seriousness

At 62, Teresa Harper—music teacher and roller coaster enthusiast— may be one of the oldest women alive with her congenital heart defect, in which the main blood vessel leaving the heart failed to divide.

of their condition, the greater responsibility they will take for their health, no matter how good they're feeling. "We want to encourage our teenagers to follow up with us their entire lives," he says.

Knowing what's wrong, what to do, what to look for, and what to anticipate is critical, says Clabby. "We have to balance giving families hope with being realistic about the dangers and need for chronicity of care."

An eventuality for some patients with congenital heart defects is a heart transplant. In a recent paper in the April 25 issue of *Annals of Thoracic Surgery*, Emory doctors David Vega, Wendy Book, and Brian Kogon, reported that of 12 adult patients who had a heart transplant because of a CHD at Emory Hospital between 2005 and 2013, all survived.

Such transplants are "challenging, fraught with adverse events, and require meticulous care and teamwork for success," the authors wrote. They attributed the high success rate to the transplants being performed by a surgeon specializing in congenital heart disease at an adult hospital, and to the postoperative care provided by both the congenital and the adult transplant teams.

"The strong relationship between Emory and Children's Healthcare enables us to collaborate and achieve outstanding results for our patients," says Kogon, chief of cardiothoracic surgery at Children's and associate professor of surgery at Emory's School of Medicine.

Teresa Harper, 62, may be one of the oldest women alive with her condition. At age 3, she was diagnosed with the rare congenital defect known as truncus arteriosus. The main blood vessel leaving her heart, the "truncus," failed to divide into the aorta and the pulmonary artery. She wasn't supposed to live past her teens but made it to her 40s before her heart and lungs began to fail. Doctors put her on the transplant list, and she resigned herself to life in a wheelchair. "I was in pretty bad shape," she says. "I couldn't even walk across a room without sitting down to rest."

She ended up at Emory's Adult Congenital Heart Center, and Book and her team saw something other doctors hadn't. "We noticed she had a loud continuous murmur, the type that suggested a 'kink' in one of the arteries to her lungs," says Book.

They decided to try an angioplasty to improve blood flow—something not done for patients like Harper even a decade ago. It increased her oxygen levels, improved her symptoms, and allowed her to be removed from the transplant list. A second angioplasty was also successful.

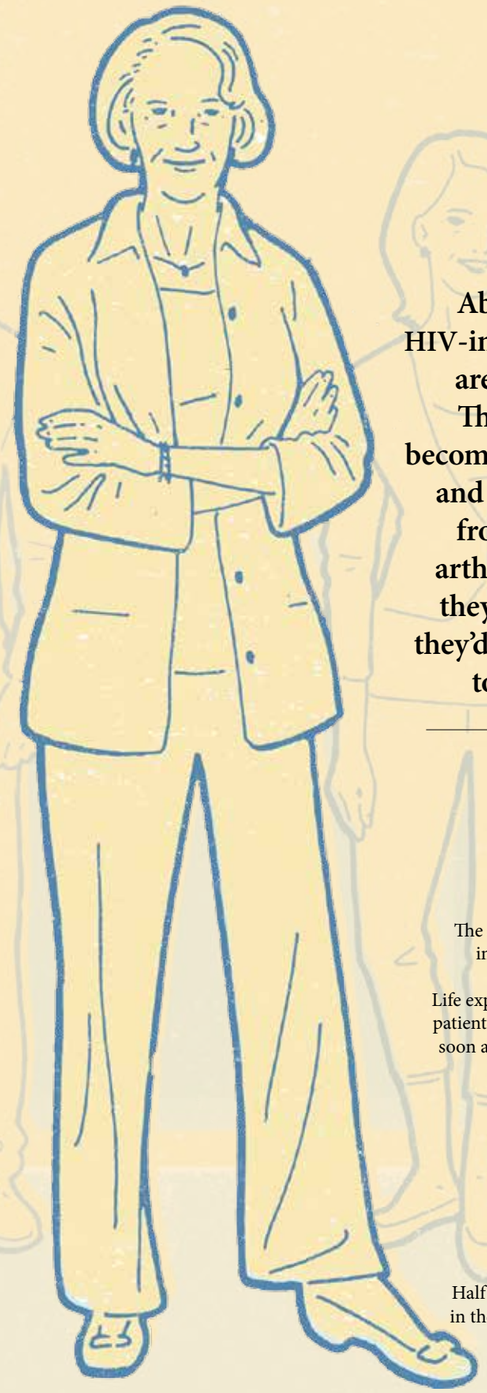
"Working with patients like Teresa is an honor and privilege," says Book. "From a medical perspective, they challenge us to come up with novel ways to improve a malfunctioning circulatory system and make it work better. From a personal perspective, these patients inspire us and teach us how to live fully."

Harper is now well enough to feed her chickens, teach piano, and work at her church.

And while she still can't walk long distances, she is able to indulge one of her biggest thrills. "I love to go to Six Flags, because I can ride those rides," she says. "I'll ride anything—the higher the better." ■

AGING WITH HIV

By Marlene Goldman



About half of all HIV-infected Americans are 50 and older. They're retiring, becoming grandparents, and facing ailments from diabetes to arthritis—all things they never thought they'd live long enough to experience.

4.2

Globally, 4.2 million people older than 50 have HIV.

30 to 50

The National Institute on Aging says that a person who today begins highly active anti-retroviral therapy could live another 30 to 50 years.

12

Older patients frequently develop AIDS sooner (within 12 months) than their younger counterparts after they are infected.

78

The average life expectancy in the U.S. is 78 years.

Life expectancy for HIV-infected patients receiving treatment may soon approach normal in high-income countries.

50

Half of HIV-positive people in the U.S. are older than 50.

MARIANNE SWANSON: NURSE, PATIENT ADVOCATE, GRANDMOTHER

Marianne Swanson remembers well when the diagnosis of HIV was a death sentence. The virus killed most of her young family.

It was 1987, and the wife and mother of two sons was beside herself as her youngest, two-year-old Joshua Paul, grew sicker and sicker. He developed a host of scary and confusing symptoms, including swollen lymph nodes that turned out to be cancerous. Two weeks before he died, he was tested for HIV.

"No kids were being tested for HIV then, but because of my husband's past and his risk factors, we asked for the test," says Swanson, a nurse, who was pregnant with her third child at the time. (Her husband had told her that he had struggled with his sexuality in the past and had had an affair with a man.)

"Joshua Paul died in July, and in August I got a call from the doctor that he had tested HIV positive and that the whole family needed to be checked," she says.

Those tests brought more devastating news: Swanson and her husband both had HIV. Only three-year-old Jonathan was spared.

Their third child, a girl they named Annalisa, was born with full-blown AIDS, a medically fragile child who spent half of her short life in the hospital. She was 17 months old when she died.

"We tried everything to save her, even enrolled her in a National Institutes of Health study, but she lost her battle with HIV in May 1989, when there was really no therapy for anyone, let alone children," Swanson says.

HIV combination antiretroviral therapy was introduced in the summer of 1996— too late for Swanson's husband, who died two days before the Olympics opening ceremony in Atlanta.

"I never blamed him, to be honest, because I saw the way he suffered. He saw the two kids die. He did not need the burden of a wife blaming him. He didn't need me to say it," she told CNN, in a previous article about her experiences.

Swanson, whose life was saved due to the new therapeutic drugs and who now works with HIV patients at Atlanta's Ponce de Leon Center, decided to speak publicly about her experiences to battle the stigma that can still accompany the disease.

"It's quite sad but a miraculous kind of story because I survived through all that and I'm living a totally different life now," she says. "I have suffered my losses, but I not only survived, I thrived in the setting of HIV."

It is strange and wondrous to her, even now, to be thinking about aging. "A lot of people who have survived as long as I have remember the time when we were literally dying or waiting to die, and we are now living and aging just like everyone else. Getting older is a good problem to have—I'm overjoyed to be aging," she says.

When her surviving son graduated from high school and enrolled in Georgia Tech, Swanson took a job with the Grady Hospital Infectious Disease

Jeff Lennox, HIV/AIDS researcher

THE PONCE CENTER: HIV AND DISEASES OF AGING

Until about five years ago, much of HIV/AIDS research focused on treatment. Now, patients have access to a combination of easily tolerated, convenient medications that promise to keep viral loads suppressed for decades.

So the research focus has radically shifted to looking at chronic conditions or diseases that often accompany long-term HIV.

Grady Health System's Ponce de Leon Center, one of the largest and busiest HIV centers in the country, provides care and support services to 5,000 men, women, and children living with HIV/AIDS. These patients are living well beyond what was once only dreamed of, but that has presented its own complications, including early onset of illnesses associated with aging.

"We see patients with heart disease, strokes, thinning of bones, hip fractures, and cancers at a younger age than they would otherwise expect," says HIV researcher Jeff Lennox, professor of medicine at Emory, and associate chair for Grady affairs.

This might be due to inflammation, antiretroviral therapy itself, or classic behavioral risk factors like smoking, he says. One study showed that HIV patients on antiretroviral therapy who smoked lived an average of 12 years less than those who didn't smoke. "In the past, there really wasn't a strong motivator for patients with HIV to quit," he says. "But now that people are living longer with HIV they are suddenly having to come to grips with stopping smoking."

HIV-positive populations also tend to have higher rates of heart disease, which is probably due to a combination of smoking, the virus itself, and HIV medications that can elevate lipid levels.

Certain types of cancers—rectal, lymphoma, and liver cancer in patients infected with hepatitis B and C—also occur at a higher rate in HIV patients.

Researchers have also noted an increasing prevalence of cognitive impairment in HIV-positive adults. Some evidence indicates that virus replication in the brain is not as easily controlled as in the rest of the body, perhaps because medications cannot easily penetrate the brain.

For patients with long-term HIV, doctors must tease out these multiple variables. "It's a very complex area, when a patient starts to notice problems," Lennox says. "Are these problems due to aging, HIV, medications, or something else?" ■

Marianne Swanson lost her first husband and two of her children to AIDS, but survived because of antiretroviral therapy. "Getting older is a good problem to have," says Swanson, who is remarried to Darrell (above) and is now a grandmother.

Program, at the women's clinic, then transfered to the main clinic. She first visited Grady Health System's Ponce Center as a patient. Now a senior staff nurse, Swanson has spent more than a decade talking to HIV-positive men and women about how to live with the disease.

Sometimes she bridges the gap between herself, a 58-year-old Italian woman, and her younger patients, many of them African American men, by sharing her own experience.

"HIV is the great equalizer, no matter your age or background," says Swanson.

"I don't think my older patients struggle as much with HIV as my young men do. HIV is too big for them. They don't have the skill set to navigate the public health system. I have patients who weren't even born when I contracted HIV."

When a patient's HIV status is compounded by homelessness, substance abuse, or other difficulties, Swanson is called upon to be their champion and cheerleader, lobbying for them, encouraging them, and cajoling them to return for check-ups and stay on their meds.

Some need to be reminded that it can be a fatal illness.

"They were born in a day and age of HIV treatment; they don't know the death stories," she says.

Swanson has remarried and between her and her husband, Darrell, they have six children and seven grandchildren. Surviving long enough to be a grandmother was an unexpected joy.

Sometimes, she feels that she is aging better than many of her HIV-negative counterparts because of the diligence required.

"I have a life-threatening illness so I have to pay attention to my health," she says. "I see my doctor three or four times a year, I get my blood pressure and mammogram done. I get my blood work, I know what my cholesterol is."

She takes four pills a day for her HIV (fewer than in the past, with fewer side effects), a drug to control her cholesterol, a baby aspirin, multivitamins, calcium, and vitamin D for her bones.

"A lot of us who have survived for 25 or more years, we don't take this for granted," she says. "We understand the gift we have been given, because a lot of our loved ones, partners, and friends did not survive to see it." ■

RICHARD RHODES: AIDS ACTIVIST, NAVY VETERAN, AARP MEMBER

Richard Rhodes's birthday present to himself the year he turned 65 was an HIV test at AID Atlanta. He'd been getting the test every year on his birthday since the organization was founded some 15 years earlier. This time, he was HIV positive.

At first he shared the news with just a few friends and those who needed to know, but in recent years, the 77-year-old Atlantan has been publicly sharing his experiences with HIV and promoting the need for everyone to be tested.

"It doesn't make any difference how old you are," he says. "All people should practice safe sex and everybody should have an HIV test at least once a year, whether they are at risk or not, because you never know. You can't judge a person by how they look."

Educating others about HIV is consistent with Rhodes's long history of championing social and political causes.

After moving to Atlanta in 1972, he became the first openly gay candidate to run for the Georgia House in 1988, the first openly gay delegate to the Democratic National Convention from Georgia the same year, and the first to serve as chair of the DeKalb Democratic Party.

A founding member of SAGE (Services and Advocacy for GLBT Elders) in Atlanta and the Atlanta Prime Timers, a social group for age 40 and older gay and bisexual men, he received a Lifetime Achievement Award from the Atlanta Gay and Lesbian Chamber of Commerce.

Today, as an AARP (American Association of Retired Persons) volunteer, Rhodes also frequently speaks to groups about the advantages of membership in that organization, such as political leverage.

Rhodes feels fortunate to have been diagnosed with HIV later in life when medications were better, unlike many people he knew who were hit by the first wave of HIV/AIDS.

"Sometimes they died within a week of being diagnosed," he says. "There was only one drug, AZT, and it was pretty toxic. There were times when I was going to at least two funerals a week."

In the beginning of the epidemic, he kept a list of people he knew personally who had died of HIV. "But when it reached 100," he says, "I just shredded the list and said I'm not going to worry about this anymore."

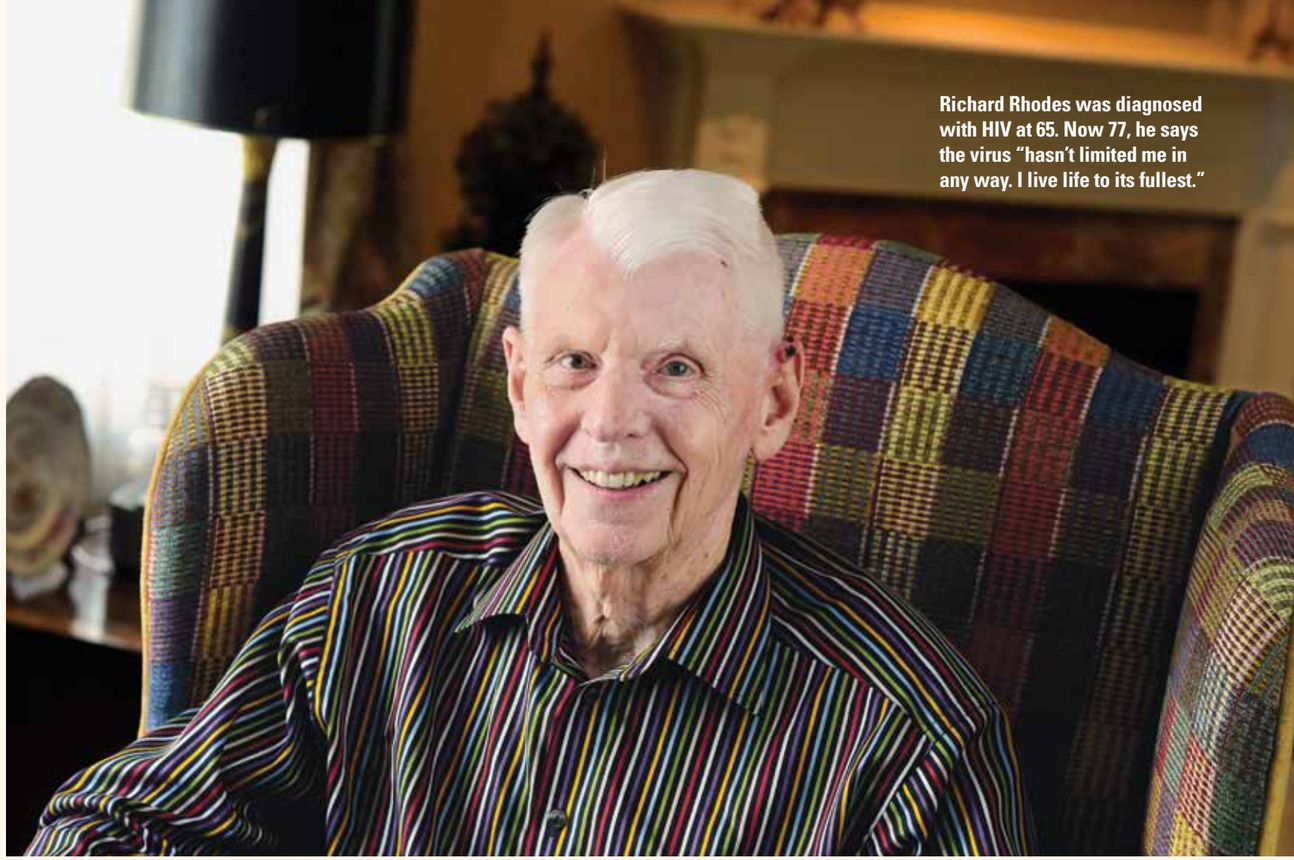
Now, he says, HIV is "pretty much like any other disease—if you take good care of yourself and take your medications, it's controllable."

In recent years, though, Rhodes has dealt with other serious health issues: stage 3 kidney disease, diabetes, and a triple bypass. "So I don't even worry about AIDS," he says.

The veteran, who served in the U.S. Navy in the late 1950s aboard the USS Lexington stationed out of San Diego, makes regular visits to the Atlanta VA Medical Center for treatment.

He's one of a growing number of older veterans who receive treatment for HIV there.

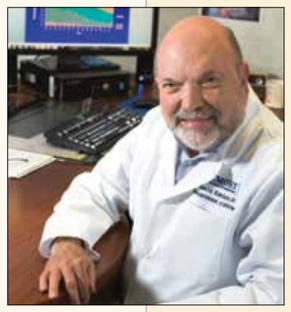
"I see a kidney specialist, someone for diabetes, a heart specialist, an infectious disease specialist, and a dermatologist—they keep me running well," he says. "I spend a third of my income on medications and doctors, but that's the life I live and I'm very happy to be alive. "



Richard Rhodes was diagnosed with HIV at 65. Now 77, he says the virus "hasn't limited me in any way. I live life to its fullest."

Rhodes's parents lived into their 90s and his infectious disease physician tells him he has a good chance of reaching that milestone as well. Good genes and treatment aside, Rhodes attributes his longevity to attitude.

"HIV hasn't limited me in any way," he says. "I wake up every day and take my diabetes medication and other meds, but I don't even think about having HIV, maybe because I don't have any bad symptoms. In spite of all the things that are wrong with me, I live life to its fullest." ■



David Rimland, VA infectious disease chief

THE ATLANTA VA MEDICAL CENTER: HIV AND AGING VETERANS

The Atlanta Veterans Affairs Medical Center (VAMC), which serves 1,600 HIV-positive patients, has the largest HIV patient population of any VAMC in the country, and the median age of these patients is 52.

Guidelines in place since 2009 require testing everyone serving in the military for HIV. Also, the military has not accepted HIV-positive recruits since 1985, when testing became available. "So between these two things, we have this older age group who is being found positive," says David Rimland, chief of infectious diseases at the Atlanta VAMC and Emory professor of medicine. "We're also diagnosing more people in their 60s and 70s. Older people are having sex but may not know that they are HIV-infected or that their partner is infected."

The VA has been proactive about getting HIV-positive patients into care and on medication, following up to make sure they have no detectable virus, and providing counseling. In turn, mortality rates decreased from 25.9 per 100 veterans in 1994 to 1.2 per 100 veterans in 2012. "We've done a great job of keeping people alive," Rimland says. "This older population is doing very well from an HIV standpoint."

But now, they are dealing with other diseases as well as the challenges of retirement and old age. "Can you imagine if you were diagnosed 20 years ago when you were 40? We didn't have much to offer back then, in terms of treatment, so you thought you would be dead in five years," he says. "Then suddenly you're doing great, you're getting older, and you hadn't planned on that at all." ■

windows OF OPPORTUNITY

If you've been touched by a story or stories in this issue of *Emory Medicine*, these windows can open up ways for you to turn your inspiration into action. Here you'll see how you can invest in the people, places, and programs you're reading about. Gifts to Emory produce powerful, lasting returns: they help create knowledge, advance research, strengthen communities, improve health, and much more.

Find your window.

go giving opportunity

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ASSESSING POST-EBOLA THREATS TO VISION

Very little data is available for Ebola survivors who suffer from persistent eye problems caused by the virus, and Emory Eye Center researchers have made significant contributions to understanding this progression. Quiet Eye West Africa represents their efforts to educate, treat, and support health care providers in this area. As they work to set a standard of care, donors to Global Ophthalmology Emory have an opportunity to support a new area of research and patient care.

Contact director of development Kate Myers at 404.778.4121 or kate.myers@emory.edu.

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SURVIVING A FAULTY HEART

Dr. Wendy Book and the Emory Adult Congenital Heart Center of Georgia are determining the links between genetic abnormalities and congenital heart defects. Because of such leaps in knowledge, therapies, and technologies, people born with faulty hearts are experiencing longer, fuller lives.

To support this effort and Emory's cardiac care programs, contact senior director of development Steven Wagner at 404.727.9110 or steven.wagner@emory.edu.

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ENSURING THE BEST REST

The Emory Sleep Center has attracted national attention for its research to advance the understanding of sleep disorders and develop new tools for diagnosis and treatment. A focus area is hypersomnia (excessive daytime sleepiness). Stay tuned for an update on Emory's new suite of sleep labs and the 2015 Hypersomnia Conference held at Emory in July in the next issue of *Emory Medicine*.

Director of development Courtney Harris can provide more information; reach her at 404.727.5282 or courtney.harris@emory.edu.

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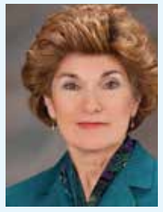
EXTENDING HIV PATIENTS' LIVES

Emory infectious disease researchers are at the forefront of understanding HIV among the aging. Dr. Albert M. Anderson, a clinician at the Grady Ponce de Leon Center, is studying cognitive decline in HIV patients. Dr. Igho Ofotokun, who has been recognized nationally for outstanding contributions to HIV research, is studying bone loss among HIV-infected patients.

To donate to the Emory Center for AIDS Research Clinical Research Core, contact Jonathan Russell, director of development, at 404.727.9567 or jrusse5@emory.edu.

GIFTS OF NOTE

To celebrate his professional achievements and his remarkable legacy in medical education, several alumni and former colleagues have established an endowed scholarship honoring Dr. Jonas A. (Jack) Shulman. He served Emory School of Medicine for 45 years in teaching and leadership roles including director of the Division of Infectious Diseases and executive associate dean of medical education and student affairs. The Dr. Jonas A. (Jack) Shulman Medical Scholarship will support deserving students with strong financial need and will continue Emory's ability to train outstanding and compassionate physicians.



Several generations of Debra Owens' family have suffered from normal-tension glaucoma, a form of the disease that is particularly insidious because the pressure inside the eye registers as normal and the diagnosis can be missed. The Owens Discovery Fund will support the Emory Eye Center's research team, one of few in the world that can define complex genetics associated with glaucoma. "My hope is that my family's gift will help place the Emory Eye Center—with top clinicians like Dr. Anastasios Costarides and the research possibilities offered by Dr. Eldon Geisert—at the forefront in developing innovative new treatments for this stealthy, persistent disease that affects millions of people," she says.

When Emily Shapiro, a 49-year-old mother of four from Marietta, Ga., sought medical care for a facial cyst, a scan discovered an unrelated, urgent problem: an unruptured brain aneurysm. Her family was so impressed by the skill of Emory neurosurgeon Dr. Daniel Barrow that they made a donation to the Department of Neurosurgery, which he chairs. "We were blown away by the care that my wife had at Emory," said Louis Shapiro. "From walking in the door, to the nurses and surgical staff, it was incredible."

Because of the wide range of symptoms, Parkinson's disease patients often need to see a variety of specialists. The Dan and Merrie Boone Foundation has made a $3 million commitment to expand Emory's multidisciplinary Parkinson's clinic to serve more patients and help shape the national model for Parkinson's care. In recognition of this generous endowment from Dan Boone and his late wife, Merrie, the clinic will be named the Merrie Boone Comprehensive Care Clinic for Parkinson's Disease. "Integrated assessment can reveal opportunities to improve treatment plans for individual patients," Boone says. Clinic patients see nine different specialists over the course of two days, and a nurse practitioner manages the program and follows up with patients.

From the Woodruff Health Sciences Center

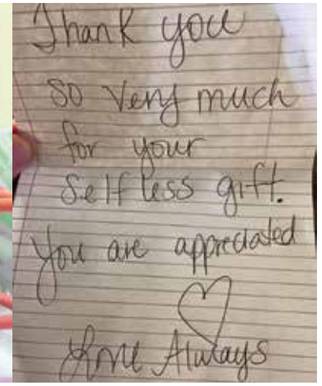
Changing lives

Wright Caughman
Executive Vice President for Health Affairs

When Emory became the nation's leading authority on the treatment of Ebola virus disease last summer, Dr. Ian Crozier was our most challenging—and ultimately rewarding—patient. Dr. Crozier arrived at Emory carrying 100 times the viral load of any other patient we had treated. After 40 days of critical care in our isolation unit, during which he suffered multi-organ failure, was placed on a ventilator, and required dialysis, he rallied and was declared free of Ebola.

Crozier later began to experience serious problems in his left eye—decreased vision and increasing pain, problems we now know affect some 30 to 40 percent of Ebola survivors. Unfortunately, that's the way of many life-threatening illnesses and a hallmark of the extraordinarily complex cases Emory specializes in treating. Occasionally, long after some diseases appear to be cured, new problems appear that require additional specialized services, such as those provided by Emory Eye Center. That's the strength of a comprehensive academic medical center. When Dr. Crozier first came to Emory, he had the benefit not only of some of the best physicians, nurses, researchers, and staff in the country, who managed his acute Ebola infection, but when his eye problems occurred we were able to address that potentially devastating ailment as well. That's true for all of our patients. At Emory, they will find the best health care available across specialties and providers.

Congratulations to Dr. Steven Yeh and to everyone at the Emory Eye Center on the speed, compassion, and ingenuity with which they identified and treated a potentially disabling vision problem. Consequently, we learned more about post-Ebola ailments and how to diagnose and manage them, and are sharing that knowledge with the world. Our deepest thanks to Dr. Crozier, whose brush with Ebola and its aftereffects has made him all the more determined to understand and combat the virus.



The First Link

This summer I took a few weeks off from medical reporting at Atlanta FOX 5 to do something I've felt led to do. On Tuesday, June 9, at Emory University Hospital, I became a kidney donor. I was inspired by a story I reported about Chamblee Assistant Police Chief Mike Beller, a father of five who donated his kidney at Emory in 2013. Mike says he never regretted his decision and that when he thinks about the donation, it still makes him happy.

I had been thinking about this for a while, during 15 years of reporting about health and meeting people waiting for organs who were trying so hard to find donors. I became very aware of the need.

I chose to become an "altruistic" kidney donor—meaning that my kidney would be given to a stranger and start a chain of donations—so that I could help not just one person, but several. These transplant chains, created by the National Kidney Registry, are pretty new and solve a major obstacle in transplantation. About 30 to 40 percent of kidney failure patients who have a willing kidney donor aren't biologically compatible.

The registry takes all those non-matching pairs and adds them to a database of waiting recipients and willing donors from all over the country. It uses an algorithm to find matches and build a chain. Each donor volunteers to give a kidney to a stranger so that someone they care about will receive one—the ultimate "pay it forward." For patients, this can cut the waiting time from years to months. In my case, as the beginning donor, I was found to be a strong match for a man in LA.

On the eve of the surgery, I was anxious. But at 4:30 a.m. on surgery day, total peace. No anxiety. I just felt ready. Someone even slipped a "thank you" note under my door.

Beth Galvin is the medical reporter for Atlanta's Fox 5 news.

The chain I like to think of as "mine" began in Atlanta, where my left kidney was removed laparoscopically in an hour-and-a-half-long operation. It flew on a noon Delta flight to LAX. That afternoon, my kidney was sewn into my recipient at UCLA Medical Center. His donor gave a kidney to another stranger, and so on. Back and forth it went, the giving and receiving. In all, there were 12 people in "my" chain. Six donors gave to six recipients. These chains rely on people keeping their promises. If someone backs out or changes his mind, the chain is broken.

Going into this, I listened to all the risks carefully. There were many: I could get an infection, I could bleed. The kidney could be damaged in transport. Something could happen during the recipient's surgery. I was offered the chance to back out over and over and was assured my recipient would never be told what happened. I considered all the risks and proceeded because I trusted my team, led by Dr. Nicole Turgeon.

I'm proud of my UCLA kidney, and I've got a lot of love and respect for my hardworking remaining kidney. I'm doing everything in my power to take care of it: losing a little weight, watching my blood pressure, and avoiding certain medications I used to take like candy. As for any remaining doubts?

The night of my surgery, Dr. Turgeon told me a little about my recipient: He is a father of two young children, a volunteer coach, and works full time. He'd spent two years on dialysis. Waiting. Then Dr. T read a text from him: He says you're giving him his life back. I cried. I've cried a lot on this journey, but this time, I cried because I knew I'd done the right thing. ■

To learn more about Beth's experience go to **bit.ly/galvinkidney**

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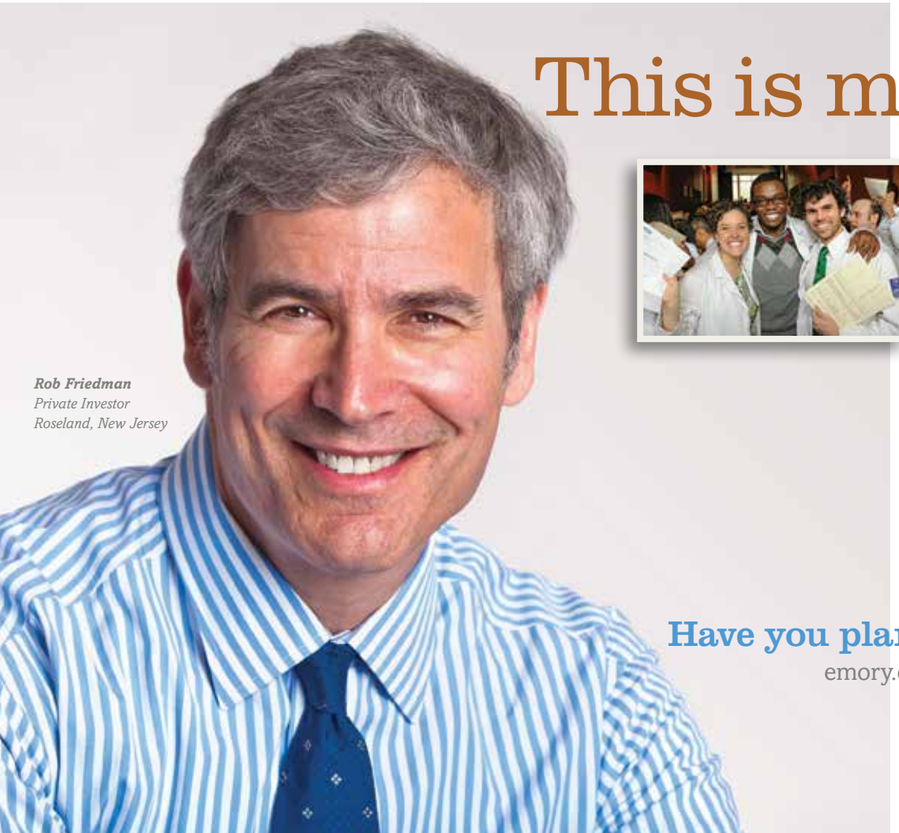

Rob Friedman
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"MY INTEREST in Emory School of Medicine was spurred by a deep debt of gratitude; my late father underwent highly successful triple bypass surgery at Emory in 1983. I toured the medical school's facilities in 2014 and observed that innovation, continuous improvement, and humility were deeply embedded in Emory's DNA. I decided to set up a scholarship fund for current medical students and revise my estate plans to include sustainable scholarship funding."

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