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

—Dr. Ian Crozier
A simple saliva test can help you plan for a healthy family.

Based out of Emory University, the JScreen program offers affordable, at-home genetic testing 24/7 across the U.S.

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.

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. CHD is 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.)
**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 their drugs in their blood or milk.*


**MyLife: Adults with autism practice life skills on campus**

*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 woodwoking 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.”
ON OUR RADAR | New and noteworthy

Emory to lead National Ebola Training and Education Center

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 NIH’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 66 Ebola treatment centers.

Critical Training for Critical Issues.

Highlights of Emory’s Master of Arts in Bioethics program:

- Ethics faculty scholars across clinical, research, and policy arenas, including neuroethics and biotechnology, religion and bioethics, and public health ethics
- Part-time study is available
- Innovative Practicum sites: CDC, NASA, etc.
- Two track options: Thesis or Exam

The Master of Arts in Bioethics program at Emory University’s Center for Ethics provides rigorous, advanced, and interdisciplinary training for professionals and students interested in social and ethical challenges in health care and the life sciences. Students in the program are connected with a dynamic network of experts, scholars, and resources in order to prepare themselves to constructively address ethical issues in bioethics.

Current MA-Bioethics student and Emory anesthesiologist, Dr. Jose Zvail, says, “My experience as an MA student with the Ethics Center at Emory has been extremely positive. The Center is very supportive and the experience thus far has left me feeling intellectually exhilarated. I have had opportunities to lend my voice to important ethical issues as the MAB has given me the confidence and credibility to join these debates. I would strongly recommend the program to practicing physicians.”

To learn more, visit our website at ethics.emory.edu/mabioethics and join the conversation.

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

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

Emory Alliance Credit Union offers free pre-approvals online 24/7 on first mortgages. Come into a branch today or visit us online at emoryacu.com.
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 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 cardiology professor Rob Cole. Cole and colleagues recently implanted the device in 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 DeLarios, 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 spots of calcium in the walls of coronary arteries, is helping physicians identify patients at risk. These spots, 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.

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 16 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 all 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.

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 One HHC
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, cryoaulation 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 cryoaulation 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-Schniz 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.

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.
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.

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 multi-organ 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
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.”

Crozner 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.

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-
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. “Someone 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.”

Then, in December, Crozier developed some odd manifestations of the virus: eye irritation to vision loss.

Antiviral drug, Crozier realized that if 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 decreased from 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.”

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 though 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 had 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.”

Dr. Ian Crozier (far right) performs an 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.

**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.**

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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?”

**But there aren’t much to be had. The vision in his eye decreased from 20/15 (better than perfect) to what was considered legally blind over a span of just a few weeks. **
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.
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 specialists across a patient’s lifespan. And adult congenital heart disease

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unique and we are often faced all very rare and very differ-
surgical procedures. We work says Book. “These patients
only one in Georgia.
ful of such emerging centers
the growing number of patients
Heart Center, designed at the
Internal Medicine.
2015 by the American Board of
in internal medicine, with the
has become a new subspecialty
Emory’s Adult Congenital
Pediatric cardiologist Martha Clabby (left, with patient), director of the Sibley Complex Congenital Heart
attempt, he went into cardiac
aortic valve. During the last
was to go ahead and replace the
bovine valve after his recovery,
his failing aortic valve with a
Book had planned to replace
liver and kidneys began to fail.
“Again against all
She was born with the con-
who often require surgery immediately after
birth. “Some of these babies are diagnosed
prenatally,” she says. “Parents might not
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 care and out-
comes, babies born with CHD still experi-
enced a higher than normal incidence of
sudden death once they left the hospital.
“One of the really important things
where parents need to be
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 ap-
proach.”
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 some-
thing off.
Part of this instruction is emphasizing
to parents, and later, the patients them-
selves, a difficult fact about CHDs: there is
no perfect fix.
Doctors can work around defects, but rarely
can the complications be fully miti-
gated, says Clabby. “If someone is born with half a heart, we can crudely mimic what
the normal blood flow is, but not restore nor-
mal 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 plac-
ing alerts on the patients’ electronic health-
care records, making sure CHD patients are
seen immediately if their families call, and
educating families about the need for proac-
tive care and vigilance.
Simple tactics are often the most ef-
cfective. “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 cardio-
lgist 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 chal-
 lenges her patients face—many will need
prolonged hospital stays—she says “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—all 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
kids with congenital heart defects and their
parents.
“How important is it to take my medica-
tions?” 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
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 orienta-
tion.”
Rodriguez and his team know that the
more teens grapple with the seriousness
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
turning of the millennium to serve
the growing number of patients
older than 18, is one of a hand-
ful 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 differ-
ent. 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 medi-
cal 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 con-
dition 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
heart defects and pneumonia is
anything but easy. It took him
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 proce-
dure 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 rehabili-
tation 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 stop-
ping 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 conduct-
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 special-
ist 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 con-
genital heart defects collectively
called tetralogy of Fallot and
wasn’t expected to live past her
teens. “Most kids today have
cardiovascular 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
donts,” 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 lon-
gitudinal study of patients with cardiac de-
fects. “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 iden-
tify 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
director of the Sibley Complex Congenital
Heart Disease program.
As an example, she cites the case of
Noel, a child with congenital heart disease
that lead to early death.
“Most kids today have
cardiovascular surgery within the
first six months of life,” she says.
“But nearly 40 years ago, they
didn’t have that surgery.”

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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

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 post-operative 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 congenital heart defect, in which the main blood vessel leaving the heart failed to divide. Such 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.

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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!”

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.
MARIANNE SWANSON: NURSE, PATIENT ADVOCATE, GRANDMOTHER

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 devasting 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 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 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 Hospital Infectious Disease Medicine.

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?”

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.

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.
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 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.”

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.”

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.”

Richard Rhodes was diagnosed with HIV at 65. Now 72, he says the virus “hasn’t limited me in any way. I live life to its fullest.”
Investing in discovery

Vision
Investing in discovery
Today’s Emory scientists are developing innovative new treatments for this stealthy, persistent disease that affects millions of people,” she says. “Research is critical to helping us understand the disease and finding ways to treat and prevent it.”

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 day-time 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.

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.

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 404.727.3810 or steven.wagner@emory.edu.

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. Igbo Ofofoku, 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 404.727.3967 or jonruss@emory.edu.

Giving Opportunity
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 Katie Myers at 404.776.4121 or klaus.myers@emory.edu.

GIFTS OF NOTE

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.

PAGE 18
S U R V I V I N G A F A U L T Y H E A R T

PAGE 25
E N S U R I N G T H E B E S T R E S T

PAGE 2
A S S E S S I N G P O S T - E B O L A T H R E A T S T O V I S I O N

PAGE 5
E N S U R I N G T H E B E S T R E S T

PAGE 12
E N S U R I N G T H E B E S T R E S T
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.

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
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.

This is my legacy.

Have you planned your legacy?

emory.edu/giftplanning 404.727.8875