10 Go Where the Pros Go

If an Atlanta Hawks player gets injured at practice, he can walk right across the hall to the Emory Sports Medicine Complex, adjacent to the team’s front office and practice facility. And it’s not just for elite athletes—staffed by Emory sports medicine specialists, the medical and rehabilitation complex is open to the public. Take a look inside.

Coping with Chronic Pain 22

Pain can be helpful and necessary—an alarm system warning us when something is awry. But what happens when pain is severe, disabling, or unending?

An Extraordinary Clinic 32

For too long, sex chromosome disorders remained unrecognized and undiagnosed. Now, children who have x and y variations and their families have a place to turn for help.

“It’s important to treat pain responsibly, and we’re increasingly using more kinds of natural medications.” 22
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Why the “public health capital of the world” has such high rates of HIV/AIDS, and how researchers are trying to turn the tide.

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ALS patient Steve Dezember talks about his diagnosis, hope and Hope (his wife), wheelchair art, and what really matters.

Policy Wise 48
Stress stemming from racism takes a toll on black mothers’ health, writes Akilah Wise, Rollins School of Public Health fellow.
The Dream Teams

It’s official: Emory Healthcare is now the Atlanta Dream (pictured, right) and the Atlanta Falcons team health care provider, a role Emory already serves for the Atlanta Hawks and the Atlanta Braves.

This gives the teams access to Emory’s sports medicine, orthopaedics, and spine center physicians, a team doctor, and sports science research and performance measurement at the new Emory Sports Medicine Complex.

“We are honored to be chosen to care for these elite athletes and look forward to helping them stay healthy and maximize their playing careers,” says Scott Boden, director of Emory Orthopaedics and Spine Center and vice president for business innovation for Emory Healthcare.

PHOTO BY SCOTT CUNNINGHAM
I'm happy to announce that we recently expanded our partnership with the Atlanta Dream and the Atlanta Falcons, making Emory Healthcare the teams’ official health care provider, as we are for the Atlanta Hawks and the Atlanta Braves.

Indeed, it was exciting to be at the November opening of the first-of-its-kind, shared Emory Sports Medicine Complex and Hawks training facility (above, with Tony Ressler, principal owner of the Atlanta Hawks). We have become the health destination for everyone from pro athletes optimizing their game to weekend warriors recovering from strains and sprains. (See p. 10 for an inside look at the sports medicine complex.)

More broadly, for people in chronic or acute pain, the Emory Pain Center at Emory University Hospital Midtown and our pain medicine specialists can help (p. 22). With options beyond just pain medications, the interdisciplinary team works to create personalized plans to get people back to their active lives.

As always, with every issue of the Digest, we aim to inform, inspire, and make you say, “I didn’t know that.” Send us an email to let us know how we’re doing, and be well.

Jon Lewin
evphafeedback@emory.edu
We all want to feel good in our own skin. After all, isn’t that what health is about? We want to feel connected to those we love most. We want to have the emotional resilience needed to cope with life’s challenges and to have a positive attitude that helps us feel grateful and enjoy living. We believe that when the body gets into motion, it unlocks parts of the mind and spirit that are reservoirs of energy and goodness.

Chances are you’re not eating as well or being as active as you’d like to be—hardly anyone is. Every day, each of us can take control over our exercise, eating, and attitude by having specific cognitive strategies.

We encourage you to start out by journaling.

Your journal will inspire you and will be a pivotal part of your success in reaching your health goals. Improving your health depends on becoming an expert on your own mind, body, and spirit. The key is being rigid about organization, note taking, record keeping, and making time for personal reflection. Women who are successful in achieving their health goals have cultivated the habit of recording four variables each day: sleep, exercise, food, and health numbers (weight, blood pressure, etc.)

Keeping a health journal harnesses your focus, attention, motivation, and insight and is essential for gaining knowledge about yourself.

The act of gathering data and recording it activates your problem-solving brain, giving you control over your daily activities and food choices. This puts you in command of each area of your health, every day. Journaling prompts you to record daily and reflect weekly.

The health journal also is designed to help you navigate meaningful conversations with your doctor. And it will provide you with a starting point, so you will have a better understanding of your progress when you look back over the weeks and months.
Faith Healing

Does attending religious services make you healthier? It appears so.

Epidemiologist Ellen Idler, a professor at Emory’s Rollins School of Public Health, found that regular weekly attendance of any religion’s services leads to increased longevity in middle-aged people and seniors.

Even those who attend services less frequently had a greater protection against mortality than those who didn’t attend at all. There were no differences by religious affiliation. Idler and colleagues say it could be because religious people tend to have healthier habits, such as being less likely to smoke or drink alcohol and more likely to exercise and get health screenings.

People who attend religious services also experience social benefits linked to health, such as being part of a socially supportive community and volunteering to help others.

Germs on a Plane

GRAB A WINDOW SEAT AND STAY PUT

Are you a fan of the window seat? Good choice.

Sitting in a window seat—and staying seated for the duration of the flight—may be your best bet for not getting sick from fellow passengers, found Emory and Georgia Tech researchers in a study published in the March 19 issue of the Proceedings of the National Academy of Sciences. Sick passengers will most likely not transmit droplet-spread infections to passengers seated farther than two seats beside them, and one row in front or in back. Vicki Hertzberg, an Emory nursing professor, and Howard Weiss, a Georgia Tech mathematics professor, assessed rates and routes of possible germ transmission during flights. Team members monitored specific areas of the passenger cabin during five round trips from the East to West Coast, recording movements of passengers and crew. They collected air samples and surface samples from areas most likely to harbor microbes. The study, funded in partnership with Boeing, used the data to create thousands of simulated flight scenarios. “Respiratory diseases are often spread through close contact,” says Hertzberg. “We now know a lot about how passengers move around on flights.” Around 40 percent of passengers never leave their seats, another 40 percent get up once during the flight, and 20 percent get up two or more times. Also, people closer to the aisle moved around more: About 80 percent of those in aisle seats got up during the flight, 60 percent in middle seats, and 40 percent in window seats. Passengers who leave their seats are up for an average of five minutes. Another way germs are spread, researchers found, was through exposure to viruses that remain on surfaces such as tray tables, seat belts, and handles: Fliers “can eliminate this risk of indirect transmission through hand hygiene and keeping their hands away from their nose and eyes.”
Maternal Vaccines

When a woman is expecting, she has a lot of to-dos—take prenatal vitamins, avoid alcohol and hot tubs, eat well. Researchers at Rollins School of Public Health want to add another—get vaccinated.

Specifically, pregnant women are encouraged to get vaccines for influenza and Tdap, which includes tetanus, diphtheria and pertussis (whooping cough), with pertussis being the main concern. That’s because children’s immune systems are not mature enough to mount an immune response until they are at least six months old.

By that age, some babies will be lost to a disease that is preventable. During the past five years, an average of 12 babies ages five months and younger died each year of influenza, according to the CDC. During the same period, an average of nine children under one year died of pertussis each year.

Saad Omer, the Foege Chair in Global Health at Emory, found that vaccines given to the mother during pregnancy protect infants during this vulnerable time. Also, infants born to women vaccinated during pregnancy were less likely to be premature.

The immunizations are safe for mother and child since neither are live vaccines. They cannot cause even a mild case of the disease, contrary to popular myth. Yet, despite the safety of vaccines and the risks associated with foregoing them, less than half of pregnant women in the U.S. get a flu or Tdap vaccine during pregnancy.

“Not vaccinating against the flu or pertussis during pregnancy is not a benign decision,” says Omer. “You can increase the risk to your baby and, in the case of flu, to yourself.”

To Whom Much is Given...

The Robert W. Woodruff Foundation has pledged $400 million—the largest gift ever received by Emory—to find cures, develop patient care models, and improve lives while enhancing the health of people in need.

The gift will be used to fund a Winship Cancer Institute Tower in Midtown and a Health Sciences Research Building on the main Emory campus. “This will allow us to accelerate the scientific discoveries needed for breakthroughs in patient care and to extend our reach in reducing the burden of disease for patients and their families,” says Jonathan Lewin, executive director of the Woodruff Health Sciences Center and CEO of Emory Healthcare. The Winship Cancer Institute Tower in Midtown will provide urgently needed infusion facilities, operating rooms, clinical exam rooms, and spaces for rehabilitation, imaging technology, and research. The Health Sciences Research Building will house faculty and staff charged with developing a pipeline of cures, interventions, and methods of preventing disease.
Living in the In-Between

I am holding my husband’s hand, but I can’t form words. In truth, there is nothing to say. It occurs to me it’s been a full day since we’ve spoken to each other. It’s a blistering hot day, and I take note of the heat the same way I might notice a buzzing fly; it is around me but I cannot feel it.

My phone rings: “The doctors are here with the results.” I don’t say anything, just spring from the bench and sprint for the hospital door. I’m grateful for the mostly empty hallways as we run, my husband shouting the way behind me—“Right!” then “Left!” I begin to cry, my chest burning and arms pumping, because I don’t know what I’m sprinting toward. Whatever it is, I must get to it.

The night before, our 10-year-old daughter, Iris, had been admitted to Children’s Healthcare of Atlanta with pneumonia. Just when she appeared to be getting better, a limp had begun. I’m the idiot parent who had recently bought a backyard trampoline, so I told myself that could be it, but even as I thought it, I knew it was a lie. “It’s bad news,” the kindly ER doctor told us hours into the night. I will be old and gray and remember, “It’s bad news.”

A bone infection, they said. Bacteria from the pneumonia had likely gotten into her bloodstream and traveled to her knee. They would start strong antibiotics right away because bone infections are stubborn things, tough to treat. We were scared, but experienced a new level of fear the next morning when doctors swarmed our room announcing antibiotics were being stopped because they believed it to be a tumor.

As a television reporter, I had told stories of children with osteosarcoma. That, combined with some Googling, confirmed that tumors in little children’s bones are almost never good. Off Iris went to the MRI tube, weeping tears of fear. A child-life specialist walked her through it, and I sat next to my ailing daughter, wishing there were a mom-life specialist for me.

It was after that late afternoon sprint that the Emory doctors would tell us we were back to a bone infection. Just a bone infection. In the two weeks that followed, our little girl would have surgery to remove infected bone from her tibia. The drugs to fight the infection were so strong they would consistently blow out her tiny veins, necessitating daily new IV’s. The care we received was extraordinary but still hideous, because watching your child suffer is the definition of hell.

Another team of doctors believe her bone infection was instead a rare inflammatory disease that affects one in a million—a disease that is difficult to diagnose and precisely mimics bone infections. As of this writing, we still don’t know.

It hurts my heart that people whose children have been diagnosed with cancer will read this—how we dodged that bullet, while their fear was instead confirmed. I know how it happens, that in a horrifying instant the bottom falls out of your life.

I will never forget the hours we lived in the in-between. I was breathing but I couldn’t get air. I was walking yet my legs were a thousand pounds of solid lead. I heard myself participating in discus-
sessions, yet I couldn’t think. The chatter of my constantly unspooling inner-narrative vanished. The silence was terrifying. Even prayer fled me. At the moment I needed it most, I could not pray. Prayers were replaced by grunts of “please” and “help.”

The sight of my daughter was exquisitely unbearable. The sprinkle of freckles across the bridge of her nose. Her wide hazel eyes looking to me for reassurance. Her weak hand with its brightly painted fingernails intertwined in mine. The utter innocence of her sweet little soul that had done exactly nothing to deserve this.

Almost a month after surgery, Iris is running and playing and slowly regaining weight. Friends remark that I must have cried a lot, but I don’t think I shed a single tear aside from that sprint through the hospital. All those pent-up tears came after Iris got out of the hospital, when my husband and I went to a U2 concert. I sobbed so fitfully, I’m fairly certain the woman next to me thought I was not of sound mind. I flashed back to 17-year-old me at a U2 concert 30 years earlier. Young me wasn’t so sure she could do the “family thing.” Only much later would I realize the sound of your husband and children laughing in the next room is the holiest sound on the planet.—By Jaye Watson
GET BACK TO IT

Photos by Jack Kearse

At the new Emory Sports Medicine Complex and Atlanta Hawks training facility in Executive Park, a team of sports medicine specialists treats everyone from pros looking to get back in the game to hobbling trail hikers to league players with tennis elbow.
LEFT: Morehouse student Dovuntai Rouse (left) waits with Martravious Little, a college basketball player.

LOWER LEFT: NBA basketball player Jordan McRae works with a Peak Performance Project (P3) trainer.

LOWER RIGHT: Sports medicine physician Kenneth Mauntner reviews patient X-rays.
TOP LEFT: Rouse looks out onto the Emory Healthcare Courts, where the Atlanta Hawks practice.

TOP RIGHT: Lena Weiss, who had ACL surgery a month ago for a soccer injury, works with physical therapist Emily Bolthouse.


BOTTOM MIDDLE: Atlanta Rollergirl Penelope Kelley-Harrell (aka Master Blazer) heads to a follow-up visit for her fractured collarbone.

BOTTOM RIGHT: Atlanta Hawks guard Kent Bazemore in a post-practice interview.
Word Play “The water is wet.” “The towel feels warm!”

Feeding young children a constant diet of new words is critical to their development, says Jennifer Stapel-Wax, associate professor of pediatrics at Emory and director of Infant and Toddler Clinical Research Operations at the Marcus Autism Center. “There’s this dance that a baby and caregiver get into that is all about social communications and the use of language.” To ensure that every child is “fed” the language they need to thrive, Georgia’s Talk With Me Baby (TWMB) partnership was formed between Marcus Autism Center, Emory’s schools of medicine and nursing, and other community organizations. “Talking with your baby is essential because 85 percent of all brain neurons are developed by age three,” says Ashley Darcy Mahoney, assistant professor of nursing at Emory. TWMB has a website, curriculum, training materials, and now a mobile app. The app has information about brain development, tracks milestones, and prompts parents with phrases to use during everyday activities, from visits to the park to bath time. For more, www.talkwithmebaby.org.

Finding Protection By now, many who are at risk of HIV have heard of PrEP (pre-exposure prophylaxis), a daily pill that helps protect against infection, available since 2012. What they may not know is where to get it or how to navigate the insurance paperwork to pay for it. To help, Rollins School of Public Health researchers developed the PrEP Locator app, which gives users easy access to the first online national database of PrEP providers. When a user logs on, a map pops up with nearby providers. The database is also searchable by zip code. “PrEP has the potential to substantially reduce the number of new HIV infections in the U.S., but only if people know how and where to get it,” says Aaron Siegler, a research assistant professor in Rollins who developed the app. The app also identifies providers with PrEP navigators, who can help clients with logistics. “We’ll keep working to find ways to get it to everyone who needs it,” says Siegler. For more: preplocator.org.

Healthy Smiles Students at Hollis Innovation Academy in northwest Atlanta now have easy access to dental care through a program created by Emory and Grady clinicians. All students have to do is visit the dental exam room that opened in the school’s health clinic as part of OH I CAN (Oral Health in Communities and Neighborhoods), which provides affordable dental care to low-income families. Quite often, when patients are referred to a dentist, they never make the trip because of cost, work conflicts, and lack of transportation. A new OH I CAN app helps providers by capturing patients’ dental histories. Developed at the Nell Hodgson Woodruff School of Nursing, the app has versions tailored for children and adults. Users create a confidential oral health profile that is saved to a data registry. Providers can use the data to assess patients’ needs and provide care. A website is also in the works.

Long term, the team plans to introduce their model to urban and rural communities across Georgia.
A sexual assault forensic exam, sometimes called a “rape kit,” preserves DNA as well as other physical evidence. It may include a full body examination, including internal examinations of body orifices.

To be viable, DNA evidence needs to be collected within 72 hours, but survivors may decide to report a sexual assault immediately or at a later time.

Rape kits increase the likelihood of prosecution and also provide medical care for injuries, sexually transmitted diseases, and emergency contraception.

What are the reasons we would not perform the forensic exam?

The primary reason not to conduct the exam is the value of autonomy (right to self-determination), which means patients must consent to receiving medical care.

The need for consent can be waived in urgent, life-threatening situations, but a forensic exam is not medically necessary or life-saving.

Another consideration is that just 31 of every 100 sexual assaults are reported to police, per Bureau of Justice statistics. Of those that are reported, most will not result in an arrest.

If, like the majority of survivors, this patient chooses not to report her assault, performing the exam might be a second non-consensual invasion of her body, as well as an unnecessary collection of evidence. This runs counter to the dictate “do no harm.”

What are the reasons we would perform a forensic exam?

Doing so might provide the patient the option of pursuing legal action later.

The patient is currently unconscious and thus, unable to make an immediate decision about reporting the assault to law enforcement.

Would it be fair for her temporary loss of capacity to permanently eliminate this option? Performing the exam would in this situation seem to be in line with our ethical value of justice (each patient being offered commensurate care).

Ultimately, the ethics committee and the medical team decided to delay the forensic exam to allow as much time as possible to find a relative or surrogate who could advocate for the patient’s wishes.

If a surrogate could not be found or legally appointed within the 72-hour window, they agreed that a forensic exam should be performed before this critical time period ends.

This allows the patient the ability to make a decision about legal action if or when she is ready.

Michael Arenson has a master’s in bioethics from Emory and is a current medical student. “You Be the Ethicist” is based on real Emory cases, with some details changed to protect patient identity.
Now that spring is here, the worst influenza season in nearly a decade is winding down. So you don’t need another flu shot until next fall or winter—correct? It depends. If you’re traveling outside the United States for pleasure or business, it’s important to remember that it’s always flu season somewhere.

In the Northern Hemisphere, flu season lasts from November through April. In the Southern Hemisphere, it’s the opposite: May through October. In the equatorial regions of the Caribbean, Africa, and Asia, the flu circulates year-round.

“People don’t think of a flu shot as a travel vaccine,” says Phyllis Kozarsky, an infectious disease specialist at the Emory TravelWell Clinic. “But influenza is the most common vaccine-preventable illness. It’s a good idea to get vaccinated, even when traveling off season.”

Kozarsky also advises travelers to make sure they are up to date on vaccinations most people get during childhood: MMR (measles, mumps, and rubella, known as the German measles), varicella (chickenpox), and hepatitis A and B (which cause serious liver inflammation). Some adults may lack protection, depending on whether a particular vaccine was available when they were children.

“We forget that measles is incredibly common worldwide,” says Kozarsky. “There have been major outbreaks in Europe, where the vaccine is not mandatory. We see returning travelers come back with measles, which can kill people. The same goes for chickenpox, which may be more serious in adults.”

Several years ago, Kozarsky treated a man from Africa who was quite ill. His symptoms included swelling on one side of his neck. Turns out he had the mumps, which physicians now rarely see in the U.S. because of the MMR vaccine. “These diseases still occur in travelers,” she says. “We see these kinds of illnesses with greater frequency than exotic diseases.”

At TravelWell, vaccinations for exotic diseases such as yellow fever, typhoid fever, Japanese encephalitis, rabies, and cholera (now reserved for relief workers in disaster areas) are given to travelers based on their needs. Factors include destination, time of year, activity, and access to safe water and food.—Pam Auchmutey

**Traveling? Get Vaccinated**

**Vaccinate Early**

It’s best to make an appointment four to six weeks before you travel outside the U.S., as some vaccines have a dosage schedule, requiring more than one shot. Other vaccines you can get all at once.

To learn more, call the Emory TravelWell Clinic at Emory University Hospital Midtown at 404-686-5885.
“CAREGIVING HAS BEEN CENTRAL TO MY LIFE and I wanted to make a planned gift to enhance the quality of life for those who deal with brain disease and disability. When my family members and friends have had strokes and brain tumors, all were treated at Emory. Having the backup of the whole Emory medical community has meant the world to me as a caregiver, and my experiences brought out empathy and appreciation that inspired my planned gift.”

Margaret Hylton Jones 69C
Political consultant and publicist
Founder, Margaret Jones & Associates
Decatur, Georgia

Her estate gift will provide unrestricted funds for research, teaching and patient care by Emory experts in neurosurgery, psychiatry and related brain health areas. These resources became important to her shortly after she arrived on campus in the mid-1960s.
4Q Nursing in Action

Mary Gullatte began her career on a leukemia unit at Emory. Four decades later, she directs nursing innovation and research for Emory Healthcare and is editor of the recently published book *21st Century Nursing Leadership*. We posed four questions:

1. **What did working as an oncology nurse teach you?** It gave me a holistic view of nursing, which is about the mind, body, and spirit. When someone has cancer, they need people who know how to manage their disease and help them on their journey, physically and emotionally.

2. **What makes a nursing leader?** Every nurse is a leader. It’s not about job titles. It’s not about where you work but what you do, whether caring for patients in a clinic or leading a hospital system. You want to make people feel that you value them and what they bring to the table. You must be able to hear and embrace their ideas while pulling everyone together as a team to reach a common goal.

3. **How has nursing changed?** We have a multi-generational, high-tech workforce and a patient population that is diverse in terms of age, language, and culture. Connecting with these patients is important. We’re here to teach them how to care for themselves and manage their disease. We’re so high tech that we sometimes forget about the high-touch piece—that the patient is still a human being.

4. **Where is nursing headed?** Health care advocacy is our next frontier. Nurses can be strong, active leaders in different environments. You can be a voice in the legislature to craft a health care bill. You can be governor. You can be a school principal. Think about the difference you could make in a school system as a principal with a nursing background.

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Join today and discover the benefits of being a member.

Visit emoryacu.com to learn more.
Paging Dr. Robot

Robotic surgery is increasingly allowing doctors to do complex procedures with more precision, smaller incisions, less blood loss and pain, and quicker recovery times. And it’s growing in popularity—about 4,000 surgical robots are currently in use, a four-fold increase over the past decade.

How it works: Surgeons perform their usual movements on a console while watching the magnified surgical site on a 3D monitor. Their actions are translated into steadier and more accurate movements by a computer, and are carried out by a multi-armed robot positioned above the patient, which controls all of the surgical instruments.

Douglas Murphy, chief of cardiothoracic surgery at Emory Saint Joseph’s Hospital (right), and Michael Halkos, chief of the division of cardiothoracic surgery at Emory School of Medicine, recently hosted an Intracardiac Robotics Conference for surgical teams from Australia, England, Canada, and cities around the U.S.

The conference was sponsored by the International College of Robotic Surgery and the Emory School of Medicine, and gave teams the opportunity to learn specifics about establishing an intracardiac robotics program, hands-on laboratory work, and discussions with surgeons sharing the best techniques in robotics. “What the patient sees is a fast recovery—out of the hospital in three days, playing golf in three weeks, and cosmetically the scar is minimal—but that’s not the reason we do it,” says Murphy. “The reason we do it is because we can do the operations better.”

Murphy is a pioneer in robotic surgery, performing Georgia’s first robotic heart surgery at Emory Saint Joseph’s in 2002. Last year, he achieved a world record after completing his 2,000th robotically assisted mitral valve surgery.

In addition to repairing mitral and tricuspid valves, surgeons can also remove tumors and repair holes in the heart during robotic surgery.

Paul Modi, a surgeon from Liverpool Heart and Chest Hospital who has trained extensively with Murphy, recently performed the U.K.’s first cardiac robotic heart procedure with his assistance after the conference.

Emory’s Winship Cancer Institute has expanded surgical options for pancreatic cancer patients with the addition of robotic surgery. “Pancreatic cancer is very aggressive. If there are five people diagnosed, only one of the five is a candidate for surgery,” says David Kooby, professor at Emory School of Medicine and director of surgical oncology for Winship at Emory Saint Joseph’s and Emory Johns Creek hospitals.

Until recently, pancreatic cancer patients who were candidates for surgery had two options: traditional open abdominal surgery or minimally invasive laparoscopic surgery.

“Robotic surgery is a newer surgical option,” says Kooby. “The technical aspects of this surgery are pretty similar to open abdominal surgery, but without making a big incision.”—Mary Beth Spence
Fantastic Voyage

Rods and rings are mysterious subcellular structures identified just a few years ago by scientists studying how cells respond to antiviral drugs, such as those used against hepatitis C.

Image by Cara Schiavon, a graduate student in Rick Kahn’s lab in the Department of Biochemistry, Emory School of Medicine.
COLOR CODED
These are mouse embryonic fibroblasts stained for microtubules (turquoise), nuclei (orange), and rods and rings (light green).

DISCOVERY
The rods and rings appear to contain enzymes that cells use for synthesizing DNA building blocks. Patients treated with some antiviral drugs develop antibodies against these enzymes.

IMAGING
This image is a “z-stack projection” acquired using the Olympus FV1000 microscope in Emory’s Integrated Cellular Imaging Core.
Pain can be helpful and necessary—a physiological alarm system warning us when we have been injured, have touched something sharp or hot, or have an infection that needs attention. **But what happens when it doesn’t end?**
Chronic pain can be caused by inflammation, injury, infections, surgery, cancer. But there are times when zeroing in on exactly where the pain is coming from—and what can best be done to relieve it—isn’t obvious or easy.

Patients may find themselves with prescribed medications that leave them feeling dazed or nauseous, unable to drive or work, and with the potential for addiction or abuse. “Our focus is treating pain and function, but in the healthiest way possible so we can get patients back to where they enjoy their life again,” says Anne McKenzie-Brown, director of Emory’s division of pain management and director of the Emory Pain Center at Emory University Hospital Midtown.

Back pain is the most common type reported and it’s the leading cause of disability for people under the age of 45, according to the American Academy of Pain Medicine.

“These patients fall into a couple of categories,” McKenzie-Brown says. “Some may have degeneration of the spine. We also see, in the older population, disc or spinal stenosis, which is a narrowing of the spine. And a lot of patients have lumbar spondylosis—back pain caused by arthritis of the facet joints, or following some kind of injury that doesn’t get better after many months. We also see a lot of patients with back pain that didn’t quite get better after back surgery.”

Other common types of pain include severe discomfort in the middle of the spine that may radiate to the hip from the sacroiliac joint, and radicular pain—back pain that shoots down the leg—known as sciatica.

While neurologists tend to treat vascular and migraine headaches, Emory Pain Center physicians typically treat headache patients whose pain originates from the back of the head and the neck.
due to occipital neuralgia (nerve pain). Headaches can also arise after accidents from trauma to upper cervical facets—small flexible joints containing nerves that exit the spinal cord on their way to other parts of the body. “People will say they have headaches coming from their necks, and they actually do,” McKenzie-Brown says. “We see headaches combined with neck pain that may radiate to the arm and shoulder too.”

Peripheral neuropathy—nerve damage that can cause weakness, numbness, and pain—can be the result of long-standing diabetes and is becoming more common with the epidemic of type 2 diabetes in the U.S. “There can also be medication-induced neuropathy, especially in people who had cancer treated and are in remission, but are left with some nerve damage,” McKenzie-Brown says.

The Opioid Factor
Once a patient comes to the pain center, the physicians may order tests such as EMGs (a test that records the electrical activity of muscles), MRIs, and others, depending on what is appropriate to make a diagnosis. A personal plan of action is then determined with input from the patient. This may include, but is not limited to, pain medication.

Since opioid addiction and abuse have been declared a national emergency, their use and prescriptions are under increased scrutiny. “Opioids present a double-edged sword,” says Emory pain specialist Boris Spektor, pain fellowship program director and assistant professor of anesthesiology. “They are extremely effective in the short term for acute pain that subsequently resolves, although potential side effects include nausea, sedation, and constipation.” Physicians must ensure that opioids are being taken as directed, are improving function, and are allowing patients to reach their goals, he says. Unfortunately, chronic exposure to opioids often leads to development of tolerance and an increase in dose, with a corresponding increase in risk of side effects. “This can create a downward spiral,” says Spektor. For chronic pain patients who have not been helped by other treatments and are on stable amounts of opioids, it may be necessary to continue this therapy. “But it’s important for them to understand the potential downstream effects,” he says, “which include hormonal changes, immunosuppression, increased risk for fractures, and risk of addiction.”

The majority of pain medications used at the center are non-opioid. “And most of the patients we have on opioids we are weaning to the lowest possible dose,” says McKenzie-Brown, who recently served on a national committee of 18 health experts who produced a report on opioid overuse for the National
TARGETING THE SOURCE
For years, Margaret Freeman went to her information technology job in pain, trying to tough out the aches in her neck, back, and shoulders. At first she thought it must be yard work or exercise class, but then realized she hurt even when she hadn’t engaged in any activity. “I tried to convince myself it was stress and the pain would go away,” she says. “But it never did.”

Freeman, 51, tried over-the-counter pain relievers, hot and cold packs, and chiropractic treatments. Nothing gave much relief. “I would wake up all the time at night with pain,” she says. She made excuses when friends invited her out. She even missed a large family gathering honoring her mom on Mother’s Day. Instead, she was flat on her back at home—alone, sad, and in pain. She finally confided in a co-worker, who told her she needed to see a pain specialist. But she hesitated. “I figured I’d be handed a prescription for some heavy-duty pain reliever I wouldn’t want to take anyway.”

In fact, just the opposite happened. Anne McKenzie-Brown, director of the Emory Pain Center, listened carefully to her symptoms: “She knew the right questions to ask, the right places to touch.” The diagnosis was cervical spondylosis, an arthritic condition from wear and tear affecting the spinal discs in her neck, and lumbar myofascial pain, triggered by sensitive points in her muscles.

Physical therapy helped, but she didn’t have complete relief until after two minimally invasive procedures. “I used radiofrequency denervation and ablated the nerves in specific facet joints,” McKenzie-Brown says, “as well as lumbar trigger point injections with local anesthetic.”

Freeman checks in at the center if she has symptoms: “She knew the right questions to ask, the right places to touch.” The diagnosis was cervical spondylosis, an arthritic condition from wear and tear affecting the spinal discs in her neck, and lumbar myofascial pain, triggered by sensitive points in her muscles.

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tional pain specialists, and they get together frequently to discuss different kinds of pain and treatment options. The following are some of the most common minimally invasive options:

- **Radiofrequency denervation.** Also known as radiofrequency ablation, this procedure relieves facet joint pain and pain caused by trauma to the back, such as from a car accident. First, nerves thought to be causing the pain (usually in the neck and lower back) are injected with a tiny amount of numbing anesthetic. If the pain is relieved for hours to days, the patient is considered a good candidate for radiofrequency ablation, which involves zapping the troublesome nerves with pinpointed heat, causing a tiny lesion that “kills” the nerve. In some patients, the nerves regenerate and pain returns in six months to a year. For others, relief can last for years or never return.

- **Spinal cord stimulation.** A small electrode implanted in the epidural space allows electrical impulses to be sent to the spine, via a control device. The stimulation changes pain signals to a more pleasant feeling, or may block pain entirely. The stimulator is primarily used for neuropathic pain and for a condition known as “failed back surgery syndrome,” which can occur when people have scar tissue or persistent pain in their back and legs after surgery.

- **Trigger point injections.** This outpatient procedure is used to relieve musculoskeletal and myofascial pain caused by trigger points—small knots in muscles. Depending on the type of pain and the area to be treated, doctors insert a small needle into the patient’s trigger points. The injections, which contain a local anesthetic (such as lidocaine), saline, or steroids, may be repeated as needed. Trigger point injections break the cycle of pain by relaxing the muscle and are most effective when combined with PT.

- **Nerve blocks.** In this technique, numbing medication is injected in a group of nerves to block pain to a specific body part. For example, sympathetic nerve blocks treat pain that may persist after an injury or surgery, occipital nerve blocks can help headaches originating from the neck, and epidural nerve blocks are used to relieve spinal stenosis pain and herniated disc pain. When the appropriate area is numbed, the extremity gets warmer because the area receives more blood flow, which relieves pain and allows patients to do more PT.

### Surgical Option

While treatments and therapies can help, there are times when surgery is necessary. Emory surgeons and pain center physicians have a close, collaborative relationship. “I look at MRIs and talk with the surgeons and discuss why they are using one approach...”
Brenda Jones, 65, loves to be active, going out with friends, making art, and gardening. These simple pleasures, though, were sometimes too painful to pursue.

When Jones was 17, she had several surgeries for scoliosis, involving nearly her entire spine and resulting in postoperative pain. She has had spinal degenerative disease above and below her surgery sites, chronic nerve pain, rheumatoid and psoriatic arthritis (which causes her immune system to attack her joints), and chronic nerve pain from carpal tunnel syndrome. She’s also had multiple joint replacement surgeries, including her hip and, most recently, her shoulder.

In 1992, she could no longer work. “I’ve been in so much pain I felt delirious at times,” she says. “I could hardly do anything. It was difficult to even think clearly.”

She sought treatment from Emory pain specialist Boris Spektor, who devised a personalized treatment plan. “Brenda was open-minded to combining several treatments to achieve relief,” he says.

First, she discontinued chronic opioid therapy, switching to non-opioid nerve pain medications, topical complementary medications, physical therapy (including competitive table tennis), and injection therapy.

Spektor also performed radiofrequency ablation of the medial branch nerves in her neck and lower back. “This essentially silenced the nerves that were transmitting pain signals from the facet joints,” he says. “She experiences about a year of substantial pain relief from each procedure.”

Jones understands she will never be truly cured. “I’ll need ongoing care and treatment,” she says. “But for six years so far, Dr. Spektor has helped me get back on my feet, literally, and do some of the things I enjoy.”

**ACTION PLAN**

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**Treating Cancer Pain**

Malignancies, especially when advanced, can bring pain in and of themselves. “Pancreatic cancer and metastatic lung, metastatic breast and, in general, any cancer that has spread is more likely to cause pain,” says Vinita Singh, director of cancer pain treatment at the Emory Pain Center and chief quality officer for Emory’s pain division.

The Emory Pain Center has an acute pain service to help patients hospitalized with intense cancer-caused pain. For instance, doctors may perform a celiac plexus block—an injection that blocks nerves transmitting pain signals from the abdomen—to help pancreatic cancer patients decrease their hospital stay and go home with their pain relieved.

When Singh first started in pain medicine, oncologists did not frequently refer patients to her who compared with another,” says McKenzie-Brown. “Sometimes, we send patients for surgical evaluation and the surgeon says, yes, we can perform surgery, but let’s wait six months and try more non-surgical approaches—especially if patients are high risk due to additional health problems.”

On the other hand, if a patient complaining of back pain is experiencing neurologic changes, such as weakness or a sudden lack of coordination with their hands, or difficulty controlling their bladder or bowel, the clinic immediately contacts a surgeon and sends images. “Usually, they will see our patients relatively quickly,” McKenzie-Brown says.

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were just starting treatment. But that’s changed with increased awareness of the clinic and the importance of early pain management. The number of people coming to the Emory Pain Center with cancer-related pain is steadily rising.

In all, about 40 percent of the patients Singh treats have cancer or are cancer survivors still plagued by pain and discomfort. “Cancer doctors are realizing it’s helpful for us to address any cancer-caused pain early on so I can do a multi-modality treatment, instead of waiting until patients are on an opioid mountain that’s difficult to get off of,” she says.

Cancer patients not only have a challenging diagnosis to deal with, they often have so many medical appointments they may forget to come to a pain treatment appointment or are too exhausted to follow through. “That’s one of the biggest challenges,” Singh says. “But when they do come and get treated, cancer patients appreciate the fact that it ultimately makes them feel better. This is an opportunity for them to talk about their pain and their quality of life, and for us to figure out a way to help.”

**Post-treatment Pain**
Chemotherapy, radiation, and surgery can all cause lingering pain.

Post-mastectomy pain, pain after thoracotomy (surgery involving the chest wall), and chemo-induced peripheral neuropathy are some of the pain problems Singh sees that are not caused by cancer but by its treatments.

“Neuropathy can be especially worrisome because it may cause a loss of sensation to feet or hands and lead to falls and an inability to drive,” she says. Fortunately, chemo-caused neuropathy often gets better in a year or so, but not always.

Singh uses non-addictive medications, primarily gabapentin (a drug that treats nerve pain) and topical lidocaine creams to treat patients. If that doesn’t succeed, other options—including radiofrequency ablation—are considered. Singh also frequently recommends physical therapy and complementary therapies, including yoga, tai chi, and acupuncture.

“I try to think outside the box, using all the principles of anatomy and anesthesia, seeing how we can get pain relief while minimizing the risk and side effects of opioids,” she says.

Singh, who sees acute pain patients at Emory University Hospital and Emory Hospital Midtown, has established monthly, multi-disciplinary pain board meetings that bring together Emory physicians and specialists in oncology, psychiatry, interventional radiology, and other relevant disciplines to discuss complex cases.
THE TOUGHEST BATTLE

In June 2007, while serving in the Army in Iraq, David Kendrick’s unit received intel that there was going to be an attack on a nearby college. “I had just finished checking a backyard and was walking back to my Humvee when I heard the crack of a rifle,” he says. “I fell to the ground and blacked out from the pain.”

Thanks to quick and courageous action by fellow soldiers, he survived. But his femur had been shattered in three places and his femoral artery was severed. He was in and out of the hospital for 14 surgeries.

During one of his many medical visits, he wondered out loud why he was always trying to get back into the hospital. “Because you’re addicted to opioids,” a doctor answered.

Yet the prescriptions didn’t stop. Kendrick wasn’t ready to believe the drugs he was taking—Vicodin and morphine—were a problem. After all, he had severe injuries and was in pain, and the drugs helped.

Once he was out of the hospital, he was placed in a Warrior Transition Unit in Colorado Springs for soldiers who needed at least six months of rehabilitation. “We all had some kind of opioids, and we passed them around like candy,” he says. After a friend and fellow vet died from drug use, however, Kendrick decided to get clean and sober, which he has been for seven years now.

He moved to Atlanta five years ago and sees Emory doctors and specialists at the Atlanta VA Medical Center.

Although often still in pain, Kendrick says he doesn’t need or want heavy-duty medication. “I’ve sat in on some physical therapy orientation sessions at Emory because I want to encourage others,” he says. “There is pain, but you will get through it.”

Kendrick earned a degree in business and is now a professional public speaker. After word got around that he had found a way out of opioid addiction, a few friends from the unit reached out. “I’m trying to be a mentor to them,” he says. “I tell them to focus on what’s really important in life.”
Nearly two million Americans are addicted to prescription opioids and an additional 600,000 to heroin. Drug overdose deaths have surpassed deaths from both car accidents and guns.

The following are highlights from a recent discussion at Emory with leaders from public health, law enforcement, and medicine on combating the epidemic.

“The epidemic is driven by the over-prescription of opioid pain relievers.” — Christina Mikosa, medical officer, CDC Division of Unintentional Injury Prevention.

“A patient may be an addict and present with other conditions. They are treated for the other conditions but not the addiction.” — Carlos del Rio, chair, Department of Global Health at Rollins School of Public Health.

“This is an epidemic fomented by profit.” — Jack Killorin, director, Atlanta-Carolinas High Intensity Drug-Trafficking Area.

“Today 1 in 11 organ donors died from an opioid overdose.” — Carlos del Rio
“There have been three waves of the epidemic: First was prescription opioids, especially Oxycontin. The second wave was heroin—at one-tenth the cost of prescription opioids and coming from Mexico. The third wave was fentanyl, which has low production costs and originates in China.” — Christina Mikosa

“Fentanyl has become the addictive booster of choice. You find it in marijuana, in cocaine, in methamphetamine.” — Jack Killorin

“You can make a very nice living refilling your opioid prescription and selling it on the street.” — Carlos del Rio

“Transnational gangsters now make billions a year feeding our national hunger for painkillers.” — Jack Killorin

“Opioid addiction is killing almost 100 people every single day, and that’s just in the United States.” — Carlos del Rio
Families have a place to turn for help with sex chromosome disorders

Extraordinary Care

by Pam Auchmutey

Families have a place to turn for help with sex chromosome disorders.
EMMA ST. GERMAIN, A DARK-EYED, DARK-HAIRED EIGHT-YEAR-OLD, LOVES PLAYING WITH DOLLS AND LEGOS.

Shy at first, Emma warms up quickly when Sharron Close, the pediatric nurse practitioner at the eXtraordinarY Clinic at Emory, notices the doll she’s holding.

“Tell me about her,” Close says to Emma, who has come for a follow-up on her condition, a sex chromosome disorder called trisomy X. Within minutes, Emma and Close are looking at doll outfits on a smartphone.

During the visit, Emma’s mother talks with Amy Talboy, the clinic’s medical director, about her daughter’s progress at school. “Emma loves school and her teachers,” says Tori St. Germain. “But she struggles with reading and math. Socialization is hard for her. Emotions are hard for her. The older she gets, it’s important to keep her on a schedule.”

Talboy, a developmental pediatrician, understands what the St. Germain family is going through. “I think we can come up with a plan to

“Families have been falling through the cracks for decades,” says Sharron Close. “Our clinic meets a tremendous need.”
help Emma more at school,” the physician says.

Talboy’s assessment is welcome news for Tori, who has pushed Emma’s teachers to provide her with more individualized instruction.

Until recently, families like the St. Germains had few places to turn for guidance and help. The eXtraordinarY Clinic at Emory, established by Talboy and Close in 2016, is the first in the Southeast and one of a few in the nation that provide information, medical interventions, and access to research for sex chromosome disorders, also known as X and Y variations.

These variations are not inherited and occur randomly when girls (XX) and boys (XY) are born with more or fewer than the expected number of sex chromosomes. Some people born with trisomy X (occurring in one out of 1,000 female births) and XXY or Klinefelter syndrome (occurring in one out of 500 male births), are free of or only mildly affected by symptoms, while others struggle with lifelong medical, developmental, and behavioral challenges. X and Y variations are not rare but often go undiagnosed, leaving children, adults, and families to struggle on their own without knowing why.

“Families have been falling through the cracks for decades,” says Close. “Our clinic meets a tremendous need.”

Close and Talboy currently see patients, mostly from the Southeast, who have been diagnosed via chromosome analysis. The clinic evaluates their needs and connects children and parents with early intervention programs, speech and language therapies, and occupational and physical therapies as needed.

As their patients grow older, clinicians can address problems related to sexual development during puberty.

The clinic also counsels expectant parents about possible risk of X and Y variations detected through prenatal screening.

A genetic counselor, nurse navigator, neuropsychologist, pediatric endocrinologist, and adult urologist staff the clinic, in addition to Close and Talboy. The clinic sees patients once a month and has a waiting list. Its co-directors are considering adding a second clinic day.

“We are growing a step at a time,” says Talboy, an assistant professor in Emory’s departments of human genetics and pediatrics. “We want to be available to anyone who would like to see us. We will follow every child over time to make sure their needs are addressed, their therapy is adequate, and they are progressing as hoped. We can also educate families about research opportunities available to them.”

With the help of the eXtraordinarY Clinic, Emma has successfully completed physical therapy, occupational therapy, and vision therapy. Learning remains a challenge, as do the seizures and migraines she has experienced since age four.

Humans are typically born with 46 chromosomes in 23 pairs. The X and Y chromosomes determine a person’s sex. Most women are 46XX and most men are 46XY. In a few births per thousand, some infants are born with a single sex chromosome (45X or 45Y) and some with three or more sex chromosomes (47XXX, 47XYY or 47XXY, etc.) Additionally, some males are born 46XX due to the translocation of a tiny section of the sex-determining region of the Y chromosome, and some females are born 46XY due to mutations in the Y chromosome.

source: World Health Organization
Clinicians believe she may outgrow the seizures. The cause of her migraines remains unknown for now.

“If you put 15 girls with trisomy X in the same room, each one would present with different problems,” says Close, an assistant professor at the Nell Hodgson Woodruff School of Nursing. “We’re here to support families and figure out a targeted therapy for each child.”

In years past, families affected by X and Y variations had few treatment and research options. To close the gap, Close organized conferences in 2015 and 2016 to engage patients, families, doctors, and researchers in developing ways to help children and parents manage X and Y symptoms and cope with the issues they face.

Georgia Governor Nathan Deal signed a proclamation declaring May as X & Y Chromosome Variation Awareness Month, marking a milestone in a grassroots campaign led by Close, Talboy, and Dorothy Boothe, whose teenaged son has XXY syndrome.

Boothe is a parent leader with the Southeastern Regional X and Y Support Group, which draws patients and families from Georgia and five surrounding states. The group meets bimonthly, often at Emory. “The first time we met, we had five or six times more people than we expected,” says Talboy. “Everybody feels they are on their own, and when they come together, it’s just remarkable.”

When Tori St. Germain brought her daughter Emma to the eXtraordinarY Clinic, she found solace in being at a place that understands her family’s needs. Her younger daughter, four-year-old Megan, has a different disorder—chromosome 6, a rare type of genetic disorder that can cause speech and developmental delays and chronic health conditions.

A devoted mom, Tori has learned everything she can about her daughters’ conditions to help them grow up normally. Each day has its joys and challenges. “It’s a lot to deal with,” she says. “The eXtraordinarY Clinic is there to listen and to help.”

To support clinical care and research for patients with sex chromosome variations, contact Amy Dorrill, senior director of development, at 404.727.6264 or amy.dorrill@emory.edu.

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Hiding in Plain Sight
Sex chromosome disorders occur in one of every 400 live births, but too often remain undiagnosed until much later—if at all. To increase awareness, Emory nursing researcher Sharon Close (left) is collaborating on a documentary with filmmaker Dianne Steinkraus, whose sister, Carole, was diagnosed with trisomy X at 53. The diagnosis finally explained Carole’s lifelong struggles with anxiety, insecurity, and difficulty connecting with friends and family (as well as her reaching the height of six feet by age 12). Now in her early 60s and in assisted living in Minnesota, Carole inspired the documentary, which will feature experts and projects from around the country, including the eXtraordinarY Clinic at Emory. “There probably are many other women like Carole,” says Close. “The truth is, they most likely have escaped being diagnosed during their lifetime. Advances in genetic testing now make diagnosis possible.”
AIDS in Atlanta

Why does the ‘Public Health Capital of the World’ have such high HIV rates—and what is being done to combat it?

by Martha McKenzie
The young man had been getting treatment for AIDS at the Ponce de Leon Center in downtown Atlanta for some time, but suddenly he stopped showing up. His doctors weren’t sure why. Maybe he was depressed. Or ill with a related infection. Or he just couldn’t get a ride.

He finally did find his way back to the center, but by that time his AIDS had progressed. He died a few days later.

In metro Atlanta there are thousands of men just like him—young, black, gay, and HIV positive. And an alarming number are progressing to AIDS and dying of a disease that has, for decades now, been treatable.

The city that is home to the Centers for Disease Control and Prevention, one of the largest clinics for HIV/AIDS patient care in the country, and top-funded HIV research programs, is also an epicenter of the HIV epidemic in the U.S.

Some zip codes in the Atlanta area have rates of HIV/AIDS that are six- to eight-times higher than the national average. And by the time patients in Atlanta are diagnosed as HIV positive, about a quarter have AIDS, which means they have likely been living with the virus for eight to 10 years.

“Downtown Atlanta has a generalized HIV epidemic that mirrors what we see in some African cities,” says Carlos del Rio, Hubert Professor at Rollins School of Public Health and co-director of the Emory Center for AIDS Research (CFAR).

The reasons have more to do with poverty, lack of insurance, and stigma than with sexual practices. The high rates of HIV/AIDS are mostly confined to a specific group—young, black men who have sex with men. In fact, AIDS is the leading cause of death for black men in Georgia between the ages of 35 and 44.

These men don’t have more partners or indulge in riskier sexual behaviors than their white counterparts, according to studies at Emory’s Rollins School of Public Health. But they are more disadvantaged. They often lack insurance. They may not have transportation, so getting to a clinic can be a challenge.

And due to the stigma associated with their sexual orientation, many don’t have a support system of family and friends.

The result is that advances in drug treatments and care that have transformed HIV into a manageable disease are not being equitably realized by the same men who make up 60% of all new cases of HIV in the U.S., according to the CDC.

Carlos del Rio, chair of the Rollins Hubert Department of Global Health, is co-director of the Emory Center for AIDS Research.
chronic disease for many have been out of reach for this group.

“A lot of headlines talk about the end of AIDS, but there is a lot of slip between the cup and the lip when you have a population as vulnerable as ours is,” says Wendy Armstrong, an Emory professor of medicine and director of the Ponce de Leon Center, which is part of the Grady Health System and is staffed by Emory doctors. “These are people who are more worried about where they going to sleep or where they’re going to get their next meal than about getting their next HIV treatment.”

Curbing the HIV epidemic in this disenfranchised population will require more than developing better treatments and drugs.

“This is not something that is going to be solved by biomedical researchers,” says del Rio, chair of global health at Rollins. “We need everyone working together to address all the things that keep people from getting the diagnosis and treatment they need—lack of insurance, barriers to care, stigma, and poverty. Emory and our partners are making real progress in Atlanta, but we still have a long way to go.”

OVERCOMING STIGMA

Getting high-risk men to go in for testing has long been a high hurdle. Some just don’t realize HIV is still such a threat. Others may be in denial. And many do not want to be linked to homosexuality, IV drug use, or an HIV diagnosis.

“There is tremendous stigma in many black communities around being gay or bisexual or having HIV,” says Patrick Sullivan, the Charles Howard Candler Professor of Epidemiology at Rollins and director of the school’s Programs, Research, and Innovation in Sexual Minority Health (PRISM). “Some of this is wrapped up...
in religion and in concepts of masculinity. We did a study about perceptions of stigma around being gay, and white men reported feeling less stigma associated with their sexuality than black men."

One of Armstrong’s patients had moved out of his mother’s house to keep her from finding out about his HIV status. “He’s been staying in transient housing, dealing with bedbugs and fleas. He said if he were to tell his mom of his diagnosis, he’s afraid it would kill her,” she says.

To overcome obstacles to getting tested, Emory and its partners have been working to make HIV testing routine and free in a variety of sites. Grady Memorial Hospital began “opt-out” HIV testing in its emergency room—you check a box if you don’t want to be tested. This testing often results in one to two new diagnoses a day and has since been expanded to 13 sites, including primary care and neighborhood clinics.

“I’m really passionate about screening patients for HIV,” says Emory emergency medicine physician Bijal Shah. “In 2006, the CDC actually recommended that all patients in acute care settings ages 13 to 64 be tested for HIV, regardless of their chief complaint or risk profile. I had the opportunity to make routine HIV testing part of what we do every day at Grady. I’m proud to say we’ve tested more than 80,000 patients and made more than 500 new HIV diagnoses.”

Rollins physician-researcher Anne Spaulding believes that jails are another place where voluntary screenings could have a large impact. Inmates in Atlanta’s Fulton County Jail are predominantly young (median age 33), male (71 percent), and black (87 percent)—a close match to the high-risk HIV population. Spaulding piloted the use of a voluntary, rapid HIV testing regimen as part of the medical intake process at the jail.

Inmates who tested positive were quickly started on treatment—even before they even left jail. “This was not about detecting HIV/AIDS cases newly acquired within jails,” says Spaulding. “This was about making sure previously infected people didn’t leave jails unaware that they were positive and inadvertently spread the infection.”

Fulton County has since suspended the rapid HIV testing program, even though it was successful. The move disappointed many and underscores the belief that Atlanta could do more to expand routine HIV testing.

“We could take a page from other cities’ playbooks,” says Sullivan. “In D.C., you can get an HIV test at the Department of Motor Vehicles. In London, there are self-service kiosks for testing. New York, San Francisco, and Boston are all more aggressive in their fight against AIDS than Atlanta has been.”

**STREAMLINING THE PROCESS**

Testing is just the first step. Patients then have to get into treatment, a process that can be slow and challenging even for those fortunate enough to have insurance. Those without insurance rely on the Ryan White HIV/AIDS Program to cover their medical care and support services.

Enrolling requires assembling a daunting set of documents—a task that can prove virtually impossible for a person without transportation or a permanent address.

A couple of years ago, Fulton County created a task force to curb AIDS, which included Emory clinicians as well as
other local health care providers, people living with AIDS, community advocates, and others. The group set an ambitious goal of getting newly diagnosed patients into treatment within 72 hours.

Toward that end, the local Ryan White program relaxed the time frame required to submit documentation for eligibility.

Then the physician leadership at the Ponce Center led an effort to restructure the admission system and reworked doctors’ schedules. The streamlined process worked so well that the facility was quickly overwhelmed.

“We got more new patients in six weeks than we normally get in a year,” says Armstrong. “We can treat our way out of this epidemic if we can get people into care.”

KEEPING THEM WELL
Making sure that patients keep taking their medications can be a job in itself, according to Atlanta physician Melanie Thompson, an Emory School of Medicine alumna and chair of the HIV Medicine Association.

She tells of one of her patients who worked a manual labor job with no health benefits, slept on friends’ couches, and relied on others to bring him to appointments.

Thompson and her staff worked out a system to keep close track of his medicine refills, calling to remind him when his medicine was going to run out and when he was scheduled for appointments.

“To keep this man in care, we have to do an awful lot of hand-holding,” says Thompson.

“And that is just the reality. In some sense, the easy job has been done. People who have insurance and more stable lives are doing really well. But it’s going to take a lot more energy and resources to help those who have more complex lives.”

“We are reaching teens who are not yet sexually active to try to get them to adopt good habits,” says Patrick Sullivan, Rollins professor of epidemiology.

Ponce Center
The Ponce de Leon Center in downtown Atlanta, part of the Grady Health System and staffed by Emory doctors and researchers, provides medical, dental, and support services to about 6,200 people living with HIV/AIDS. To qualify for care, adult patients must have a previous AIDS diagnosis and/or a Nadir CD4 count below 200. Pediatric and adolescent patients have no such restrictions. For more, go to www.grady-health.org/specialty/ponce-de-leon-center/ or call 404-616-2440.
AVOIDING INFECTION

HIV-negative men can avoid infection, even when they couple with positive partners, thanks to an extremely effective pre-exposure prophylaxis (PrEP) marketed under the brand name Truvada, which contains the Emory-developed drug Emtriva. The problem for some is finding where to get it.

Rollins researchers developed the PrEP Locator, the first searchable national database of clinics that prescribe PrEP.

For Rick Perera, an Atlanta man who has been on PrEP for several years, the locator’s ability to identify which providers have PrEP navigators—people who can help clients through the labyrinth of requirements and forms—is especially valuable.

“It is a lot to take on,” says Perera. “In addition to the medication itself, you have quarterly office visits and testing. Insurance might pay for some or all of it. Financial assistance is available. But wading through all the paperwork that is required can be very hard. Being able to find a PrEP navigator is a tremendous service.”

The PrEP Locator has been useful in highlighting where providers are not available, as well.

“We discovered there is just one PrEP provider south of I-20, even though that is where most of the risk and the HIV cases are,” says Sullivan. “Until you know where the services are being provided, you can’t know where the gaps are.”

The Rollins PRISM program has developed a variety of tools and apps aimed at preventing infection and initiating treatment. One app being tested is aimed at 13- to 18-year-olds. “We are reaching teens who are not yet sexually active to try to get them to adopt good habits,” says Sullivan. “This type of technology can reach young people where they are—which is on their phones.”

REACHING OUT

The strongest concentrations of HIV/AIDS cases in Georgia are found in Fulton, DeKalb, and Clayton counties. Metro Atlanta has the fourth-highest HIV rate of major U.S. cities.

Finding and helping the people these statistics represent can be daunting. “There is still a lot of work that needs to be done here, but we are finally lining up everyone to work together,” says del Rio.

A case in point: researchers at Rollins, the University of Houston, and the Southern AIDS Coalition are establishing a center for a new 10-year, $100 million initiative by Gilead Sciences, through which they will map service providers and areas of need across the South.

“A lot of smaller organizations have strong connections in the community, but they may not have the resources to compete for grants or access to the latest training and technology,” says Neena Smith-Bankhead, a Rollins program director. “We want to work with them to build their capacity to better serve and care for those with HIV in their own communities.”

Rollins epidemiologist Patrick Sullivan (left) and Rob Stephenson of University of Michigan collaborate on a study of HIV prevention in male couples in Atlanta.
Sara’s Journey

A baby in need of complicated surgery. A medical student volunteering in Haiti. A chance for a better life.

by Mary Loftus

DOZENS OF PEOPLE A DAY STREAMED INTO THE HOSPITAL TO SEE THE MEDICAL VOLUNTEERS, HAVING HEARD ABOUT THE CLINIC ON THE RADIO OR BY WORD OF MOUTH. Some traveled two and three hours to get there, over dirt roads and on crowded buses. They came from rural villages and the capital city of Port-au-Prince, carrying sick babies or supporting elderly relatives.

Haiti, already one of the poorest countries in the world, had been further devastated by the 2010 earthquake. Most of its 10.5 million residents live on less than $2.50 per day, and medical resources and staff are scarce. The quake demolished 50 health centers and the ministry of health.

The Emory Haiti Alliance (formerly Emory Medishare) has organized a surgical trip to the island each summer for more than a decade—with volunteer surgeons, anesthesiologists, medical students and residents, and nurses providing free care at Hospital St. Therese in the Central Plateau, the most medically underserved area of Haiti.

The month-long trips combine student education with care, and the medical teams perform multiple surgeries each day, seeing more than 100 patients in all. Medical students assist surgical residents and faculty, who bring their own supplies and face challenging conditions: minimal running water, ORs that function on a diesel generator, intermittent power outages, operating by headlamps.

In 2016, medical student Justine Broecker was in Haiti volunteering with her father, Bruce, a pediatric urologist and Emory adjunct faculty member. “With two parents who are physicians, I had been exposed to medicine my whole life,” she says.

One of the local Haitian doctors, Rony Destine, a program manager with Project Medishare, had hopes that surgeons at the clinic could help an infant he had encountered in Port-au-Prince with a rare birth defect. The child, Sara, and her mother, Michel-Ange, had traveled to the clinic. “I was with my dad when he was examining Sara, who was just three months old,” says Broecker. “My

Sara with Emory medical student Justine Broecker, who arranged her trip to Atlanta for treatment.
dad recognized the disorder—bladder extrophy.” Sara’s bladder was on the outside of her abdomen, and she didn’t have normal closure of her abdomen and pelvis. The disorder requires a complex repair involving both urologic and orthopedic surgery. Typically, in the U.S., bladder extrophy is recognized in utero or directly after birth and repaired within a few days or weeks. But the clinic’s team lacked a pediatric orthopedic surgeon and proper equipment. “It was beyond what we could do at that hospital,” says Broecker.

Delaying the repair can be hazardous to an infant’s health, with risks of inflammation and infection, and the longer it takes, the more difficult closure becomes. “It was pretty disheartening,” Broecker says. “We couldn’t make any promises. But it was difficult to give Sara this diagnosis and then tell her mom we couldn’t do anything to fix it.” Upon her return to Emory, she started making calls and mobilizing support to bring Sara and Michel-Ange to Atlanta for the repair. “The surgeons had volunteered their time, but we didn’t have a way to pay for visas and travel, or a place for Sara and her mother to stay,” Broecker says.

Willy Blain, an anesthesia technologist and a member of the Emory Haiti Alliance team of Haitian origin, helped to translate for patients, and stayed in contact with Sara’s family. But when Hurricane Matthew hit Haiti as a Category 4 storm in October 2016, the country was again pitched into chaos. “We lost contact with Sara’s mom after the hurricane,” Broecker says. Their old phone number didn’t work and no one had an address for them.

Broecker had gotten in touch with the charity Childspring International, which was offering to pay for travel, help with logistics, and arrange for a host family in Atlanta. Best of all, Childspring representatives in Haiti managed to locate Sara and her mother and reinstate contact after the storm.

Broecker and the host family met Sara and Michel-Ange at the airport on February 11, 2017. Sara was initially scheduled to have surgery right away but wasn’t well enough. She had a cold and was malnourished and anemic. “The decision was made to delay the surgery and let her gain more strength,” Broecker says. “I was pretty happy to see her. It was all a little surreal. When we first encountered them in Haiti, I didn’t think any of this would be possible. I was grateful to see everyone’s hard work pay off, but getting her here was just the first step.”

At Childspring International’s annual gala at the Ritz Carlton Downtown in Atlanta the following month, 11-month-old Sara and her mother, Michel-Ange, were special guests. Childspring holds the event to raise funds for surgery for children from all over the world.

Sara, a bundle of energy, spent much of the night in the foyer crawling around on the carpet in her leggings and white party dress. Michel-Ange, who spoke through a volunteer interpreter from Atlanta’s Haitian community, said Sara’s father had died when the baby was 2 months old; her three older children were staying with relatives in Haiti. “Sara is my heart,” Michel-Ange said. “I asked God not to let me lose her. She was meant to be here.”

Physicians Brad and Laura Lord were their local host family. Laura Lord, a neonatologist, was at the gala, where Sara bounced happily from person to person all evening. “I thank them for opening their home and heart to us,” said Michel-Ange.

Sara went into surgery on April 21, 2017, at nearly a year old. Broecker was invited to scrub in, with pediatric orthopedic surgeon Robert Bruce.
and pediatric urologic surgeon Edwin Smith. “It was a great opportunity, since it’s such a rare disease,” she says.

“Justine had sent images to us and given us a bit of the history and Sara’s medical condition,” Smith says. “She was the bedside identifier of the problem and started the ball rolling.”

Bladder extrophy occurs in about three of every 100,000 births. Smith’s group sees three to four cases a year, since they have expertise in dealing with the disorder. “It used to be that we would rush to close the infant’s bladder during the first three days, to take advantage of the effect of maternal estrogen and the malleability of the pelvis,” he says. “But then we discovered there is some flexibility.”

The congenital birth defect, while not fatal if unfixed, does carry a social stigma—and the surgery is the first step toward continence. “If you look back in medical archives, patients can live for many decades with bladder extrophy, but it makes you more prone to bladder cancer at a younger age,” Smith says. “And other conditions attend it, such as uterine or rectal prolapse. Other pelvic structures are unsupported because pelvic muscles are not in the right position.”

Sara, in fact, did have rectal prolapse. Bruce started off the procedure with an osteotomy, a controlled break in the iliac bones—the upper crest or “wings” of the pelvic girdle. The pelvis was opened and the pubic bones separated. “This hinges the bones, allowing the pelvic bones to meet in front of the bladder, and puts the muscles in a better position to support the bladder,” Smith says.

The careful dissection of the bladder neck area is critical, Smith says, as is the closure of the bladder neck and urethra, and sinking them down behind the pubic bone and within the pelvic muscles. When a bladder forms on the outside, it may be deficient in a variety of ways—smaller, less elastic, or not of normal innervation—which can make the outcome less desirable. “We try to do as limited a dissection as possible, yet securely close the bladder, pelvis, and abdomen,” Smith says. “You don’t want to lose nerve or blood supply to the organ. That’s part of the art of doing this.”

The operation went smoothly, he says: “It was a coordinated effort with urology, orthopedics, anesthesia, and pediatrics—a multidisciplinary team makes a good result much more likely.” The doctors put Sara in a suit of pants made of casting material, a critical step to stabilize the pelvis while adding to the security of the surgical closure. The team has about 60 bladder extrophy patients they follow long-term.

“I’ve personally seen how well these kids can do. We’ve cared for infants that grew up to become a high school cheerleader and an All Star second baseman,” Smith says. “They can have very normal lives.” Some patients’ bladders function normally after the initial operation, while others need additional surgeries.

Broecker, now a surgical resident at Emory, was busy with medical school graduation right after the surgery, but had the chance to visit a few more times with Sara and her mother before they left Atlanta. Sara was out of her cast and doing well. “Sara’s situation made an impression on me from our first meeting in Haiti,” Broecker says. “I realized her mother’s determination to do anything and everything to help Sara get the operation. That inspired me to do everything I could to help her as well.”
It’s nice to participate in the world still. I love seeing people’s interpretations of the paintings, and it brings me great joy.—Steve Dezember

In late summer 2011, at 28 years old, Steve Dezember was diagnosed with amyotrophic lateral sclerosis (ALS), an especially cruel neurodegenerative disease that steals a person’s mobility, voice, and, ultimately, their ability to swallow and breathe. Dezember and Hope Cross married shortly after he was diagnosed. “Watching Steve fight so hard for his life is worth every ounce of stress and work that goes into it,” Cross says. “The look of joy when he sees a painting he’s made, the smile he gives to every person who interacts with him, the way his eyes light up when he’s watching football. He has taught me that every single thing is a gift, and the power of your mind can get you through anything.”

Dezember painstakingly typed the following with a Tobii eye gaze communication device and created the artwork with his electric wheelchair.

First symptoms
I was a longtime hockey player who naturally picked up golf. One day I noticed I couldn’t play with the same ease, and found my hand getting weaker. The doctor believed it was a side effect from a previous hockey injury. Then I began to trip and my foot felt heavy (a symptom called “foot drop”). It wasn’t long before my falling was fairly regular, and I became more aggressive about finding the right doctor.

I was being seen at the Emory ALS Center (after my diagnosis) but the distance made the trips too difficult so we developed a relationship with Emory Johns Creek Hospital, as it’s less than 10 minutes from our house. It’s our home hospital now. The very first visit where it was more than just a trip to the ER for a catheter or some antibiotics was an intense trip. I actually coded twice, with one of those being a code blue. I had to have an emergency tracheotomy, which wasn’t expected—I wasn’t prepared to lose my voice. Not only did the staff save my life, they also helped us learn how to communicate with boards. They were patient with my wife and helped her through her anxiety of learning how to suction and do trach care.

Above and beyond
I’ve spent many weeks in and out of the hospital for infections, comas, gallbladder removal, and other complications. The medical team helped me when I had gastroparesis and couldn’t tolerate food by getting me on IV nutrition and changing the formula as needed. They have never given up on me, even when I was 67 pounds and couldn’t tolerate water in my feeding tube or when I was in a coma because of malabsorption problems and overdosing on my pain medication. Dr. Titu Das, an infectious disease physician, follows us at home for my infections to try to keep us out of the hospital and away from any germs or flu. Wound care nurse Janelle Dees has become a friend of Hope’s and will help her at home when she’s in a panic.

I was in a clinical trial a few months after I was diagnosed but did not see any improvements. Hope would do things like stretching and massaging my muscles to help me keep moving. I did breathing exercises to try to keep my lungs healthy before the ventilator.
I’ve tried all the supplements around, with little improvement. After I was colonized with infections and diagnosed with anemia, my wife began to study herbal medicine and has helped with my blood counts, which gives me the energy to keep fighting the complications.

**Love as art**

Hope and I were making a painting with artist Jeremy Brown. Hope was holding me up, since I was unable to stand or walk at this point. He dumped paint on us embracing, and wrapped the canvas around us to capture the love.

We got paint on my wheelchair, and Jeremy and Hope encouraged me to make a painting to clean the wheels. Jeremy stretched the painting and we hung it in our living room. Visitors began asking if they could buy one, and it really gave me purpose and motivation to get out of bed, which is just so very hard to do.

**Advice to new ALS patients**

Record your voice and make videos for your family. Eat your favorite meals and travel to places you’ve always wanted to go. Handle the important stuff, even though it’s sad to face—like getting your spouse’s/caregiver’s name on everything. Set up power of attorney and have all the documentation done right away. I waited because I didn’t want to accept my diagnosis, which made it more complicated when I couldn’t speak or sign for myself. It can be easy to focus on what you are losing—your ability to walk, eat, breathe, speak, etc.

So hold on to what you have left and try to find solace in it. Make plans with your family, and have the difficult conversations early. Thankfully Hope and I did speak about these things, so when I coded and needed emergency surgery to survive, she knew it was my wish and told them to operate.

Build your community and embrace those who want to help. Finally, share your story: As ALS patients, we have a unique opportunity to help others learn to live life a little more fully and with more gratitude. EHD

To support Emory’s ALS research, patient care, and the Emory ALS Center under the direction of Dr. Jonathan Glass, contact Camille Sears, director of development, at 404.727.9346 or camille.sears@emory.edu.
Fight For Black Mothers’ Health

It is one of the most grave public health statistics in the country: Black mothers die at three to four times the rate of white mothers, one of the widest of all racial disparities in women’s health.

Chronic stress is seen as the primary factor in racial disparities in maternal death. It also can lead to poor sleep quality, heart disease, and accelerated biological aging.

Such factors as poverty, polluted neighborhoods, discrimination, abuse, and exploitation undermine the health of black women and members of other marginalized communities.

Despite its wealth, the U.S. has a weak and fragmented social safety net, including a health care system that continues to fail those most at risk.

Access to health care is largely determined by employment status in the U.S., and high-quality programs that protect poor and vulnerable people are few and far between.

Organizations such as the Black Mamas Matter Alliance are advocating for real change. The alliance is a committee led by black women with a mission to “advocate, drive research, build power, and shift culture for black maternal health, rights, and justice.”

Tiffany Hailstorks, assistant professor of gynecology and obstetrics at Emory, says, “As a provider, it is important to recognize the direct impact of lived experiences on one’s health, as well as to understand how these further influence health behavior and compliance with recommended treatments.”

A recent New York Times Magazine article about the disparity points out that high blood pressure and cardiovascular disease are two of the leading causes of maternal death, and hypertensive disorders in pregnancy, including pre-eclampsia, have been on the rise over the past two decades. A Department of Health and Human Services report last year found that pre-eclampsia and eclampsia seizures are 60 percent more common in African-American women than in white women, and also more severe. “Recognizing the stark difference in health outcomes for women of color is only the first step in the fight to combat racial disparities,” says Hailstorks.

Quality prenatal care and attentive medical caretakers are clearly the first line of defense in detecting and monitoring conditions that place black expectant mothers particularly at risk.

Strengthening the systems that support better general health can mitigate the stressors of pregnancy and childbirth. And providing additional support to pregnant women, new mothers, and their families, such as home visit programs, can improve care management for at-risk women.

More than 80 percent of black mothers are considered breadwinners in their households, meaning black mothers are usually working mothers as well as caregivers to others in their families and communities.

When we, as a society, fight to protect black women’s health, we are supporting their own strength and resiliency. And we are paying it forward to the next generation, who deserve a solid start.

By Akilah Wise, a post-doctoral fellow at Rollins School of Public Health.
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“It really gave me purpose and motivation to get out of bed, which is just so very hard to do.” — Emory ALS patient Steve Dezember, who uses his wheelchair to create art.
Emory Healthcare in Georgia

Emory Healthcare is the most comprehensive health system in the state, with locations all over Georgia, including seven hospitals, outpatient locations in 24 counties, and 23 regional affiliate hospitals in 21 counties. Winship Cancer Network has three locations.
The Clifton Corridor ... and Beyond

1. Emory University Hospital
2. Emory Clinic (multiple buildings)
3. Winship Cancer Institute
4. Emory Rehabilitation Hospital
5. Yerkes National Primate Research Center
6. Emory School of Medicine (education and research buildings)
7. Woodruff Health Sciences Center Administration Building
8. Rollins School of Public Health
9. Nell Hodgson Woodruff School of Nursing
10. Emory University Hospital Midtown
11. Executive Park (Emory Healthcare clinics in brain health, orthopaedics, and sports medicine)