# EMORY health

PATIENT CARE, RESEARCH, AND EDUCATION FROM THE WOODRUFF HEALTH SCIENCES CENTER

IS YOUR
BABY
AT RISK OF
DEVELOPING
AUTISM? THE
ANSWER IS
IN THE EYES.



Download our iPad app.

#### **EMORY HEALTH**

Executive VP for Health Affairs S. Wright Caughman

Editor Rhonda Mullen

Art Director Peta Westmaas

Director of Photography Jack Kearse

Graphic Designer Linda Dobson

Production Manager Carol Pinto

Web Specialist Wendy Darling

Advertising Manager David McClurkin

Executive Director, Health Sciences Creative Services Karon Schindler
Associate VP, Health Sciences Communications Vincent Dollard

#### **EDITORIAL ADVISORY BOARD**

Chair Ray Dingledine

Professor and Chair of Pharmacology and Executive Associate Dean for Research, Emory University School of Medicine

#### **EX OFFICIO CHAIR**

Robert Goddard III, Chairman and CEO, Goddard Investment Group

#### **MEMBERSHIP**

Charles Craig, Former President, Georgia Bio

**Laura Hurt**, Director of Nursing Operations, Emory University Hospital Midtown

**Lucky Jain, Blumberg Professor and Executive Vice Chair** of Pediatrics, Emory

Claire Perdue James, Philanthropist

Michael M.E. Johns, Former Executive VP for Health Affairs, Emory

**Jeff Koplan,** Vice President, Global Health, and Director, Global Health Institute. Emory

Sandra Mackey, Executive Director, Marketing Strategy & Support, Emory Healthcare

Kimberly Manning, Assistant Professor of Medicine, Emory

Paul Pendergrass, Independent Communications Consultant, Typing Inc.

Julie Ralston, Director of Communications, Atlanta Regional Commission

Walker Ray, retired pediatrician, member of Campaign Emory School of Medicine Committee

Bill Todd, Executive Director for Health Care Initiatives,
College of Management, Georgia Institute of Technology



Emory Health is published quarterly for Emory neighbors and the community as well as faculty, staff, affiliates, and friends of the Woodruff Health Sciences Center of Emory University.

Produced by the Health Sciences Communications Office, the magazine is made possible by support from the Robert W. Woodruff Health Sciences Center Fund.

Send all correspondence to Emory Health, 1762 Clifton Road, Plaza 1000, Atlanta, GA 30322; call 404-727-8166; or email rhonda.mullen@emory.edu. To see extra multimedia features online, visit emoryhealthmagazine.emory.edu.



Friends have helped us surpass the goals of our seven-year, \$1.6 billion campaign by an impressive margin.

#### FROM THE EXECUTIVE VP

#### A wise investment

EMORY'S WOODRUFF HEALTH SCIENCES CENTER IS TRULY BLESSED TO HAVE FACULTY, STAFF, STUDENTS, SUPPORTERS, AND A COMMUNITY WHO BELIEVE IN OUR MISSION. Together, these friends of our center have helped us surpass the goals of our seven-year, \$1.6 billion fundraising campaign by an impressive margin, and we are grateful to everyone who made the campaign so successful. In the current economic environment, investment from our community of supporters is more important than ever and will help ensure our continued progress in research, education, and patient care.

In this issue of *Emory Health*, you'll read about many of the programs that your support is making possible. For

example, researchers from Emory, the Marcus Autism Center, and Children's Healthcare of Atlanta are making headway in the science of autism, enabling experts to diagnose the disorder much earlier—in fact, as early as 18 months of age. Earlier diagnosis means earlier application of interventions that can improve outcomes for children.

You'll read about a new book by two of our faculty that takes a predictive health approach to empower patients to take control of their own health. The predictive health approach, practiced in the Emory/Georgia Tech Center for Health Discovery and Wellbeing, refocuses energy on maintaining health rather than treating disease.

And you'll read the moving story of how a team of Emory caregivers helped my longtime friend and colleague Rhonda Mullen find the courage to let her beloved mother go.

These and all the other inspirational stories in this issue of *Emory Health* are made possible by the talent, intellect, creativity, curiosity, collaboration, and compassion demonstrated every day by every member of the WHSC community—including our supporters and volunteers. All of us, working together, create these amazing stories of help and hope that make our mission such a wise investment.

Wright Caughman

Please share your feedback at evphafeedback@emory.edu.

Send letters to the editor to rhonda.mullen@emory.edu.

### EMORY | health

#### SPRING 2013







#### **NEW AND NOTEWORTHY**

#### On our radar 2

<sup>2</sup>| Unmasking malaria <sup>2</sup>| Curing brain tumors in man's best friend <sup>3</sup>| The latest news on tPA <sup>3</sup>| Kicking the cocaine habit <sup>4</sup>| Living the mission at Saint Joseph's Hospital <sup>5</sup>| Tracing chemical

signatures 5 Lessons from compassionate bonobos 6 Caregiver extraordinaire 7 Nursing students tackle chronic care

#### **FEATURES**

#### The earlier the better 8

That's the wisdom behind the latest science on how we diagnose and intervene in autism.

#### The game of life 14

The predictive health approach turns the focus from treating disease to nurturing health.

#### The picture(s) of health 18

Campaign Emory has raised \$1.17 billion to contribute to a healthier future for research, education, and patient care in Georgia's largest fundraising effort ever.

#### AND MORE

#### Letting Mom go 24

After her mother's massive stroke, one daughter learned that "sometimes there is no right thing to do, that you do the best you can."

#### CSI Emory 28

A day in the life of Emory forensic pathologist Randy Hanzlick.

Online extras at emoryhealthmagazine.emory.edu. Send letters to the editor to rhonda.mullen@emory.edu.

#### on our radar | New and noteworthy

#### Hide and seek

The parasite that causes malaria is stealthy. When Plasmodium first infects a person via a mosquito bite, it hides in the liver before invading the bloodstream. It changes its outer coat and manipulates the immune system to avoid

arousing the host's defenses.

Many countries around the world are scaling up interventions against malaria, with the goal of eliminating it. That calls for treating everyone who is infected, even people who don't feel sick yet. But here is the challenge: some forms of *Plasmodium* can persist in the liver and emerge to infect the blood

weeks or even years later. The conventional diagnostic testexamining a person's blood sample under a microscope—can miss infections at the stage when parasites are hiding in the liver.

In addition, most drugs against malaria target the later blood-borne stage, not the liver. Parasite resistance to the most effective drugs against malaria, such as artemisinin, is a growing problem, and malaria experts see a need for new drugs that target the liver stage.

A new project based at the Emory Vaccine Center and Yerkes

National Primate Research Center is seeking to address these challenges. The Malaria Host-Pathogen Interaction Center (MaHPIC), funded by up to \$19 million from the National Institute for Allergy and Infectious Diseases, brings together Emory

scientists with partners at the University of Georgia, Georgia Tech, and the CDC. Led by Emory malaria expert, Mary Galinski, left, the project takes a systems biology approach to malaria. Researchers will build an encyclopedia of the disease, studying and cataloging in molecular detail how malaria parasites interact with human and animal hosts. Computational researchers then will design mathematical models to simulate and analyze what's happening during an infection and to find patterns that predict the course of the disease and its severity.

For example, the MaHPIC team will examine how infection produces changes in host and parasite genes, proteins, and metabolites in both non-human primates and infected humans. In addition to tests for dormant parasites, these studies could help doctors identify biomarkers to predict which cases will become the most severe. Knowledge about the early, stealthy stages of Plasmodium infection could direct drug discovery and inform design of a malaria vaccine, Galinski says. -Quinn Eastman

want more?

To learn more about the new collaborations

on malaria, see systemsbiology.emory.edu.

Doggone tumor: After Petey, a 7-year-old pit bull, was diagnosed with a naturally occurring brain tumor, he underwent surgery at the University of Georgia to partially remove the glioma. After surgery he received an experimental drug that was directly infused into the glioma to target any residual tumor cells. After 15 months, Petey no longer has seizures, he is thriving, and his tumor continues to shrink. Approved by the FDA, the experimental drug was developed by Emory neurosurgeon Costas Hadjipanayis in the Winship Cancer Institute Brain Tumor Nanotechnology Laboratory at Emory. Hadjipanayis hopes to apply findings about the safety and feasibility of using the drug for canine gliomas to treating people with brain cancers. Initial funding for the pilot research came from the UGA College of Veterinary Medicine, Winship, the Dana Foundation, and the Boo Radley Foundation. A new grant from the American Kennel Club Canine Health Foundation will fund a clinical trial at UGA in 15 dogs with spontaneously occurring brain gliomas. -Janet Christenbury

Research help from Dr. Dolittle's friends: Rats trained to press

a lever to get an infusion of cocaine pushed the lever less often after being given an experimental drug, nepicastat, according to recent research by Emory scientist Jason Schroeder that was published in *Neuropsychopharmacology*. The ability of nepicastat to stave off relapse-like behavior in animals shows

promise in helping treat cocaine addiction in humans. In fact, the National Institute on Drug Abuse is beginning a clinical trial this spring to test nepicastat in people who are addicted to cocaine. Recent small-scale studies in humans suggest that the drug, which was originally developed for treatment of heart failure, may make cocaine less enjoyable. In the lab of Emory geneticist David Weinshenker, researchers have found that nepicastat makes animals more sensitive to aversive behaviors induced by cocaine, such as repetitive movements. —Quinn Eastman



# Clot buster and brain protector

ver since its introduction in the 1990s, the "clot-busting" drug tPA has been considered a "double-edged sword" for people experiencing a stroke. It can help restore blood flow to the brain, but it also can

increase the likelihood of deadly hemorrhage. In fact, many people experiencing a stroke do not receive tPA because the window for giving the drug is limited to the first few hours after a stroke's onset.

But Emory neurologist

Manuel Yepes may have found a way to open that window.

Even when its clot-dissolving powers are removed, tPA can still protect brain cells in animals from the loss of oxygen and glucose induced by a stroke, Yepes' team reported in the *Journal of Neuroscience* (July 2012).

"We may have been giving the right medication, for the wrong reason," Yepes says. "tPA is more than a clot-busting drug. It functions naturally as a neuroprotectant."

The finding suggests that a modified version of the drug

could provide benefits to patients who have experienced a stroke, without increasing the risk of bleeding.

"This would be a major breakthrough in the care of patients with stroke, if it could be developed," says Emory neurologist Michael Frankel, director of the Marcus Stroke and Neuroscience Center at Grady.

tPA is a protein produced by the body and has several functions. One is to activate the enzyme plasmin, which breaks down clots. But Yepes' team has discovered that the protein has additional functions. For example, in cultured neurons, it appears to protect neurons in the brain, turning on a set of genes that help cells deal with a lack of oxygen and glucose. This result contradicts previous reports that the protein acts as a neurotoxin in the nervous system.

Tweaking tPA so that it is unable to activate plasmin—while keeping intact the rest of its functions—allowed the researchers to preserve its protective effect on neurons in culture. This modified tPA also reduced the size of the damaged area of the brain after simulated stroke in mice, with an effect comparable in strength to regular tPA. The next step is to test the modified version of tPA in a pilot clinical trial.

The possibility that tPA may be working as a neuroprotectant may explain why, in large clinical studies, tPA's benefits sometimes go unobserved until several weeks after treatment, Yepes says. "If it was just a matter of the clot, getting rid of the clot should make the patient better quickly," he says. "It's been difficult to explain why you should have to wait three months to see a benefit." –Quinn Eastman

#### ON OUR RADAR | New and noteworthy



#### New blood

Transfusion of donated blood more than three weeks old results in impaired blood vessel function, according to a new study of hospital patients at Emory. Older blood might be detrimental to patient health due to a deficiency in nitric oxide, a short-lived chemical messenger that relaxes blood vessels. The finding could have implications for blood banks, which now consider six weeks to be the maximum permitted storage time of blood for use in transfusion.

#### The heart and soul of Saint Joseph's

t each new employee orientation session for Saint Joseph's Hospital, after new staff and volunteers have worked through a deluge of paperwork, an 82-year-old nun walks into the room to pose a simple, unexpected, question: "Have you ever thought of yourself as being sacred?"



As director of mission integration, Sister Valentina Sheridan is the caretaker of the values that have been central to Saint Joseph's since its founding in the late 1880s by the Sisters of Mercy. Among those values is the belief that each person, from housekeeper to patient to doctor, is sacred. Describing that belief to new employees and volunteers is one of the favorite parts of her job, she says.

"It seems to me that at any given time I've found the greatest joy in the place that I was," says the woman known as Sister Val. That place has been Saint Joseph's since 1994 when she began as director of pastoral care. She is the hospital's living spirit-bearer: hugging staff, volunteers, and patients and praying with and for them, if they like. While doctors provide a ministry of medicine, hers is one of presence.

"When you stop and recognize somebody, that does something for them," she says. "So I do that with people I see in the elevator, people I see walking down the hall."

"She is comforting them emotionally and spiritually. She is Saint Joseph's Hospital," says Debra Bloom of Emory Healthcare's development office. Bloom helps coordinate Emory Healthcare's Second Century awards, recognizing community leaders who have had the most impact on each of the Emory hospitals. Sister Val was a recipient of the award earlier this year, when the new Saint Joseph's Hospital Award was named the Sister Valentina Sheridan Award in her honor.

"It's humbling—truly humbling," says Sister Val of the award. "But what it keeps throwing back to me is: you have a gift. Use that gift for others."

In 2007, the nun became the hospital's first-ever director of mission integration. "I was 75 at that time and I wanted to slow down a bit," she says, halfway through the latest in a string of 8- to 10-hour days. She does think about retiring—one day. "I can be tired and think, 'Oh, God, please help me today.' All I have to do is walk inside these doors and people are so gracious and loving," she says. "It gives me life." –Dana Goldman

Want more? Sister Valentina Sheridan is one of four recipients of the 2013 Second Century awards, which recognize leaders and catalysts for change at Emory hospitals. Fellow awardees include William Wood (the former Joseph Brown Whitehead Professor and Chair of Surgery for 20 years), Daniel Barker (director of both Emory University Hospital and EUH Midtown—known during his tenure as Crawford Long Hospital—for a combined total of 30 years), and the Emory Johns Creek Hospital Auxiliary (with 150 volunteers who support the hospital through a wide array of activities and serve as its ambassadors to the community). To learn more about Sister Val's work at Saint Joseph's Hospital, visit bit.ly/sisterval.

#### Measuring the metabolome

If we are ever able to design individual or personalized health care, we need to know more than just the sequence of our genes.

Our genome is important, but so are other "omes"—the proteome, for example, and the metabolome.

The metabolome gives us a chemical signature, says Dean Jones, who directs the Emory Clinical Biomarkers Laboratory. "It reflects what we're eating, what the proteins and enzymes are doing, whether the required nutrients are high or low, and the presence of drugs or chemicals from the environment, such as perfumes, pesticides, or flame retardant."

At Emory, researchers in the clinical biomarkers lab use high-definition mass spectrometry to characterize the metabolome in blood or urine samples. With a single 10-minute analysis, they can identify 8,000 to 10,000 chemicals in the sample. They then run each sample six times using two different methods to get a complete picture that is

then stored in a database. Their goal is to build a large reference base that can be mined to see patterns, identify and track natural changes, and then link those patterns and changes to a particular disease.

The Emory lab is collaborating with others across the country and the campus on metabolic studies, including those on transplant and age-related macular degeneration. Its researchers are assisting Emory cardiologist Arshed Quyyumi in creating predictive models for cardiovascular disease by comparing differences in the metabolome of patients who survive five years after treatment in the catheterization lab and that of those who do not. They also are supporting rehab medicine specialist Nancy Kutner in exploring the use of metabolic markers to predict frailty in patients on dialysis and pediatric pulmonologist Ann Fitzpatrick in studying the metabolome to help predict which children will respond to a treatment for asthma. -Rhonda Mullen



**GENOME**: all of our hereditary information, including genes

METABOLOME: the entire set of molecules generated as we absorb and digest food (used to generate energy for cells or respond to threatening invaders)

PROTEOME: the full set of proteins, which are made up of one or more chains of amino acids that supply structure, function, and regulation

Hugs available here: Juvenile bonobos at the Lola ya Bonobo sanctuary in the Democratic Republic of Congo engage in consolation behavior more often than their adult counterparts. The finding—by Emory psychology postdoctoral fellow Zanna Clay and Frans de Waal, C.H. Candler Professor of Psychology at Emory and director of the Living Links Center at the Yerkes Primate Research Center—provides key evolutionary insight into how critical social skills may develop in humans. Starting around age 2, human children usually display consolation behavior.

At the sanctuary, most bonobos arrive as young orphans after their parents are killed for meat or captured for pets. A minority of the bonobos there are second generation and raised by biologic mothers. The researchers found that the great apes who were raised by their own mothers were more likely to comfort others compared with those who had been orphaned. Clay believes that this behavior may indicate that early life stress interferes with the development of consolation behavior. —Lisa Newbern

#### on our radar | New and noteworthy

#### Spotlight on caregiving



On the first day of her internship in social work on Emory's Wesley Woods campus, Ashley Stroud didn't act like a beginning intern. She greeted staff by name, navigated hallways with ease, spoke comfortably with residents, and seemed to feel right at home.

In many ways, she was. While new to the field of social work, Stroud is no stranger to Wesley Woods and Emory. The 25-yearold has logged countless volunteer hours from speaking to nurses at **Emory University Hospital** as a patient family adviser to collaborating with the Wesley Woods Hospital Entity Council. In fact, her work at Emory and elsewhere and her role as a family caregiver led the

Rosalynn Carter Institute for Caregiving to name her Georgia's Family Caregiver of the Year in 2012.

Stroud's volunteer activities helped influence her to pursue a master's degree in social work, and family circumstances also played a part in her decision. At age 20, Stroud assumed legal and medical responsibility for her father, who has struggled with severe mental illness for years, and she began volunteering with the National Alliance on Mental Illness. A few years later, when her grandmother and mother became seriously ill with life-threatening conditions and had to be hospitalized for significant amounts of time, Stroud found herself caring for three family members. She

coordinated finances, medical care, and legal concerns while working to carve out plans for her own life.

"I didn't realize that what I was doing was care coordination," she says now. "But when I discovered that so many people struggle because they don't have the resources to do that, I knew that a career in social work

"I didn't realize that what I was doing was care coordination," she says now. "But when I discovered that so many people struggle because they don't have the resources to do that, I knew that a career in social work was what I wanted."

was what I wanted."

Along with discovering her calling, Stroud also learned some hard lessons of caregiving, including the challenge of isolation. "I really did feel alone," she says. "That's the reason I became so proactive in trying to find resources and organizations and education." She volunteered with the Alzheimer's Association, connected with others through a caregiver network, and became a patient family adviser at Emory. She also participated in a research project at Emory that focuses on caregiving for heart failure patients.

"I don't see many 20-somethings who are responsible for three adults with significant health care needs," says Emory geriatrician Monica Parker, who has provided primary care to Stroud's grandmother for a decade. "Ashley was determined to be responsible for them. She was extremely selfless."

As Stroud prepares for her summer as a National Council on Aging Fellow in Washington, D.C., she hopes to turn the spotlight on caregivers everywhere. "I want family caregivers to have a voice and be visible," she says. "There are resources and support out there." -Dana Goldman

want more?

If, like Stroud, you are the family caregiver of a patient with heart failure and would like to participate in research on caregiving, call the study coordinator at 404-712-8478.



Answering the call for chronic care: At the Nell Hodgson Woodruff School of Nursing, Christine Feeley (right) is a post-doctoral fellow who is concerned with sleep quality, stress, caregiver burden, and quality of life in mothers whose children have bronchopulmonary dysplasia. Brittany Butts (center), in her first year of doctoral studies, is working to reduce inappropriate use of emergency rooms by patients with chronic illness. Nancy McCabe (left), a third-year doctoral student, is looking at self-management of behaviors in adults diagnosed with congenital heart disease as children. All three nursing scholars are among the first at the school to benefit from a \$1.5 million training grant from the NIH to nursing schools across the nation to improve outcomes for patients with chronic illness. According to the CDC, chronic disease causes seven out of every 10 U.S. deaths. Paired with a faculty mentor, Emory nursing scholars will study chronic conditions by surveying markers of disease and examining the cost-effectiveness of interventions. A key goal is to strengthen patient self-management to encourage healthy behaviors and adherence to complex regimens to control disease. -Pam Auchmutey



#### Integration in action

Emory's clinically integrated network (CIN) is a group of physicians and hospitals that coordinate care among members and thereby improve quality outcomes and manage costs more efficiently. The CIN received a major endorsement when Emory Healthcare contracted with Blue Cross Blue Shield of Georgia to provide care to BCBS-covered patients. "This is a major milestone for us," says Patrick Hammond, chief executive director of the CIN. "BCBS is the largest payer in the state, and we are the first organization in Georgia they have partnered with."

# THE EARLIER THE BETTER THAT'S THE WISDOM BEHIND THE NEWEST SCIENCE ON HOW WE DIAGNOSEAND INTERVENE IN AUTISM.

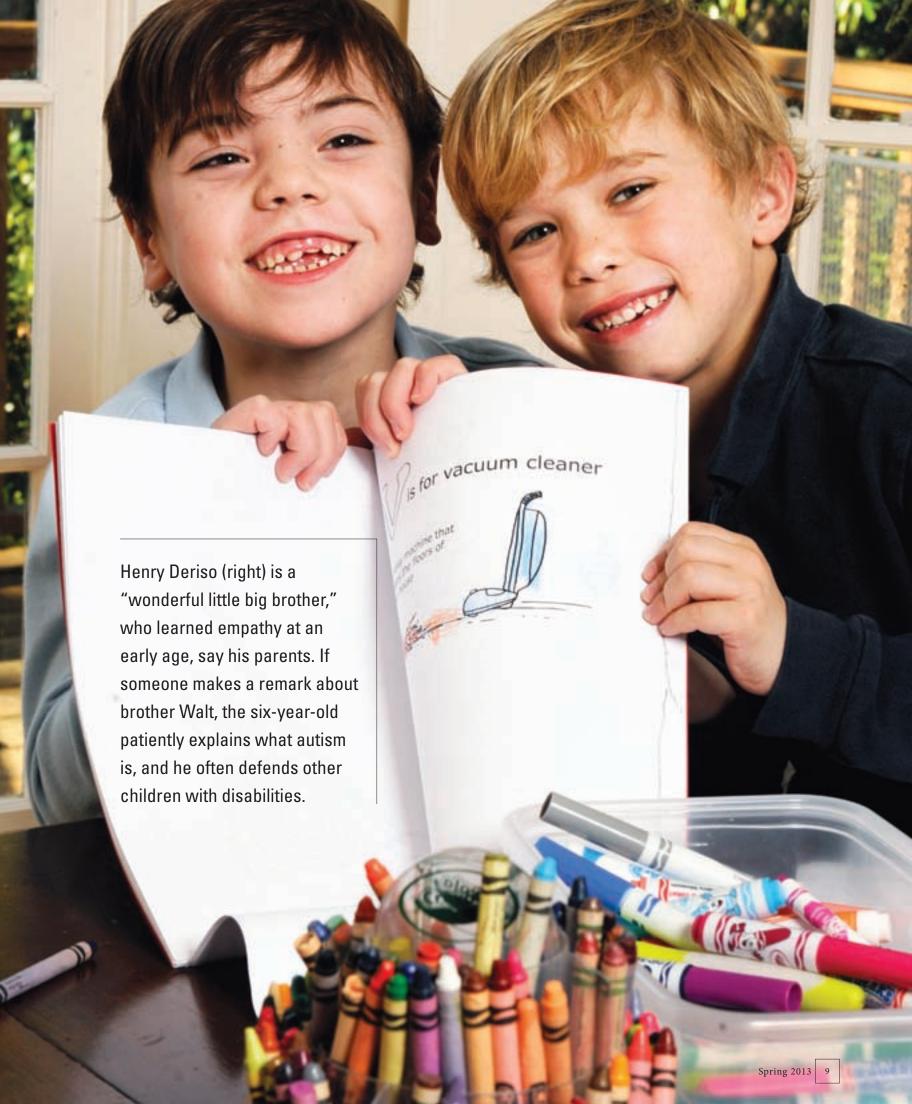
By SYLVIA WROBEL Deriso family photography JACK KEARSE

WHEN FIVE-YEAR-OLD WALT DERISO FINALLY MADE IT TO THE TOP OF THE WAITING LIST AT THE MARCUS AUTISM CENTER, HE SPOKE ONLY THREE WORDS. He wasn't toilet trained. Distraught, often enraged, he threw tantrums. He ran away.

"Anna and I had loved him since he came into our family at five days of age," says his adoptive father, Walter Deriso III, "but we had no relationship with him."

#### THE take-away

The average age of autism at diagnosis is 4.5 years, older for low income and minority families. Emory researchers want to change that timeline, and now they have the science and partners to do it.



WHEN THE THERAPISTS AND STAFF AT MARCUS FIRST ENCOUN-TERED THE YOUNG BOY. THEY **ENCOURAGED HIM TO PUT THE** THINGS THAT INTERESTED OR SCARED HIM ON PAPER. AL-THOUGH SEEMINGLY DISENGAGED. HE DREW HAPPY SCENES FROM A RECENT FAMILY VACATION AT THE BEACH, PERFECTLY SPELLED OUT WORDS FROM A FAVORITE VIDEO. AND PORTRAYED FACES THAT SHOWED DIFFERENT EMOTIONS. THE THERAPISTS USED THE DRAWINGS AS A SPRINGBOARD TO WORK ON WALT'S LACK OF SPEECH AND BEHAVIORAL ISSUES AND TO HELP HIS PARENTS BUILD A RELATIONSHIP BASED ON WHAT THEIR SON WAS CURIOUS ABOUT.

"Our challenge," says his father, "the challenge of all parents of children with autism, was to figure out how to connect with him, to make him care enough to come into our world so we could help him use his gifts."

When intensive applied behavioral therapy did open that world to Walt, it turned out that he had a lot of emotional and intellectual gifts on which to draw. Four years later, the energetic nine-year-old is quick to grin, chatter, tell his parents he loves them, and enthusiastically hug visitors. In fact, the lessons in expressing affection have worked a little too well, and his parents are working to fine-tune the behavior. "He has to learn not to embrace every pizza delivery man!" says his mom, Anna Deriso.

The world fascinates Walt, even if in a very different way from his younger brother Henry. A typical six-year-old, Henry shares his parents' love of sports, closely following the Atlanta Falcons and all the teams at Vanderbilt, the family's alma mater. Little Walt's current passion is vacuum cleaners, on which he is an expert. Last year, to his parent's complete bewilderment, UPS delivered a new vacuum cleaner to their doorstep. Their oldest son,

who only three short years earlier was unable to talk, much less read, explained how he had used his mom's credit card to order the vacuum cleaner on amazon.com. He had selected the one with the highest rating and asked for one-day delivery.

Walt attends school at the Marcus Center five days a week, six hours a day, in addition to private speech therapy, occupational therapy, and special swimming exercises—"more hours than most adults work per week," says his dad. And if Walt works hard, so do his parents. Walt Deriso III is senior vice president at Atlanta Capital Bank, where his father and Walt's granddad, Walter Deriso Jr., an Emory Trustee,

"We have been especially laborious in our scientific vetting," says Warren Jones, "because the autism community has

been offered too

many false hopes."

is chairman. Anna Deriso is a nurse practitioner. Having a child with autism is the third job in the family-requiring hours of therapy and mountains of paperwork. But since Georgia is one of the states that covers little in the way of autism care, neither of Walt's parents has the luxury of not working.

The Derisos

also feel a commitment to help others as they have been helped. Every week, they talk by phone or in person with parents who have a child who may have autism. They are active in the national nonprofit Autism Speaks, and they raise money for scholarships at the Marcus Center, where Walt III serves on the board and where tuition for one-on-one treatment costs more than a year at Harvard.

It's hard, admits Deriso, but "it's worth every minute, seeing the progress that Walt is making."

#### Big changes on a short timeline

Entrepreneur and philanthropist Bernie Marcus created the Marcus Autism Center more than two decades ago after watching an employee struggle to find resources for her newly diagnosed son. Then and there, Marcus decided to hire a developmental pediatrician to help the employee—and allow her to stay in Georgia instead of moving to another state that has insurance coverage for the disorder. Working to mitigate autism and understand how to better diagnose, treat, and prevent it is a slow, expensive process, but as Marcus has said for years, it's a financial as well as moral obligation. It now costs more than \$3.2 million to care for a person with autism over a lifetime.

Ami Klin never planned to leave Yale, where he headed one of the country's most prestigious autism research programs. When Marcus came calling, even talking to him and the prominent members on a search committee felt, he says, like cheating on his wife. "Then pick up the phone and tell her you're coming," Marcus told him.

At Yale, Klin and his team had reached a breakthrough in eye-tracking research that detected signs of autism as early as infancy, which could lead to earlier interventions when the condition is most malleable. They were ready to move the science into broader clinical practice, demonstrating its power and expanding its impact, and, as many in the field believed, changing the autism landscape.

The team saw 300 children a year at Yale. By comparison, clinicians at Marcus, the biggest program in the world by far, see more than 5,500 children a year. The center is involved with thousands more statewide through strong community partnerships. Children's Healthcare of Atlanta, the home organization of Marcus since 2008, embraces research-based care as part of its mission. The Emory School of Medicine, its chief academic partner, has strengths in the genetics and neuroscience of autism, and Emory's pediatrics department has a newly created division of autism and related disabilities.

The Georgia Research Alliance (GRA) and state officials called Klin in New Haven to personally express their commitment in making Georgia a leader in autism research. Marcus and Russ Hardin, president of the Woodruff family of foundations, suggested that Klin





recruit a dream team and build a new research infrastructure. "It was an unprecedented opportunity for myself and my colleagues," recalls the researcher, "but more important, for our true constituents, the children and families impacted by autism."

Klin arrived in Atlanta to assemble his team early in 2011. Many of his colleagues at Yale, 22 who are leaders in their field, followed. That raised the number of clinicians and researchers at Marcus to more than 180.

"Ami Klin has an incredible exuberance about science, spurred by his conviction that we can improve outcomes," says Barbara Stoll—George W. Brumley Jr. Professor and Chair of Pediatrics at Emory and medical director of Children's at Egleston. "Clinically, research-wise, and with one of the best training programs anywhere, the Marcus Center is humming. If I were 25 again, that is where I would want to go work."

Since Klin's arrival, the NIH has created an Autism Research Center of Excellence (ACE)—one of only three in the nation—with an \$8.3 million award shared by the Marcus Autism Center at Children's, Emory's pediatrics department, and Yerkes National Primate Research Center at Emory. Klin added principal investigator and ACE director to his titles as director of the Marcus Center, GRA Eminent Scholar, and Emory professor of pediatrics.

He and a coalition of autism resources in Georgia had done in months what had taken other centers a decade. Governor Nathan Deal announced the "transformational grant" in the Capitol. Efforts for widespread early detection and intervention were poised to take off.

#### Tracking the social brain

Typically developing infants prefer to look at human faces, especially the eyes, and at what scientists refer to as "biological motion." True across the species, this behavior has evolutionary advantages, helping parents bond with helpless offspring and making youngsters aware of predators. The most common signs of autism—the ones that parents usually recognize first—are what attracts their children's attention (preferring objects to playmates) and how it affects their social interactions (seeming uninterested in others' feelings).

These differences appear to be hardwired. Since developing brains can be changed with early enough intervention, early detection becomes "an ethical imperative," says Klin—especially now that a diagnostic tool exists.

The eye-tracking technology in use at the Marcus Center was developed by Warren Jones, then a student at Yale and now an Emory faculty member and research director at Marcus. A dual art and engineering major with a part-time job teaching art to autistic children, Jones became fascinated with how the drawings of otherwise uncommunicative children left a map of how they see the world (as young Walt Deriso's did). Jones built a rudimentary device tracking how the children's eyes moved, then turned to a leading autism expert for advice on how to improve it. He won one of the American Psychology Foundation's highest honors for the instrument and subse-

quent work.

Having a child with autism is the third job in the family, say Anna and Walt Deriso (left), requiring hours of therapy and mountains of paperwork.

Using the noninvasive technology, a child (or infant) watches a video in which mothers interact with babies or toddlers play together. Cameras track microscopic movements of the pupil, hundreds per second, recording what draws the child's attention. Typical two-year-olds, for

example, watch social interactions intently, their eyes moving back and forth as if following a social tennis match. Those with autism focus on a different aspect of the video, such as a door opening and closing.

#### Taking the science to patients

The best clinical experts can diagnose autism at 18 months of age. Five years ago, three-year-olds were the youngest children whom researchers ever had a chance to see. Now, thanks to eye-tracking technology, they can follow children from birth and watch the condition unfold, says Klin.

Celine Saulnier, Emory researcher and clinical director for research at Marcus, says that the studies supported by ACE funding use the eye-tracking technology to identify children in their very first year and then measure the effects of treatment by the time they turn two. A study by scientists at Yerkes uses eye-tracking measurements to quantify social behavior in infant rhesus monkeys in the first months of



Ami Klin oversees a team of more than 180 researchers and clinicians and heads the Autism Research Center for Excellence.



**Celine Saulnier** is able to measure the effectiveness of treatments in children with autism by the time they turn two.



Warren Jones developed an eye-tracking technology now in the pipeline for FDA approval for earlier diagnosis of autism.



Don Mueller has expanded partnerships at Children's and Marcus to reach those who work with children at risk.

life. These studies also include noninvasive brain studies that focus on brain changes resulting from early social experiences.

In a study of social visual engagement in infants, as measured by how they look at people, Jones and Klin are evaluating the social development of 330 babies 13 times over the first two years of life. Clinical evaluations take place between nine and 36 months. Two-thirds of the participants have autistic siblings, making the risk of having autism in these babies shoot to one in five compared with one in 88 in the general population, thereby raising the likelihood of having infants with autism in the study.

A study of social vocal engagement, headed by Emory researcher Gordon Ramsay, director of the Spoken Communication Laboratory at Marcus, builds on studies that begin even earlier. Ramsay records the responses of babies to their mother's voices while still in utero. With funding from ACE, recordings are made every month from birth to age two to test whether social engagement predicts speech and language outcomes.

In all of these studies, children identified as at risk receive additional monitoring and attention, and those who are found to be at risk for autism are then enrolled in a treatment study beginning at the age of 12 months, the earliest of its kind in the country. "We'd rather give a child without autism too much attention than risk not giving a child with autism enough," says Saulnier.

The treatment study focuses on the development of better interventions for younger children. Using a protocol developed by Amy Wetherby, a professor of communication disorders and a speech pathologist at Florida State, Wetherby and Nathan Call, Emory pediatric researcher and director of behavioral treatment clinics at Marcus, are testing the efficacy of community interventions in which providers go into the home and train parents.

The researchers hope to demonstrate in large populations what they already have found in small ones. Seeing thousands of children means that they will be able to work with autism's "orphan" groups, whose smaller numbers of autism diagnosis often exclude them from research. Those groups include girls, African

Americans, and other minorities.

The scientists also are embarking on an FDA clinical trial using the eye-screening technology to identify children with autism. They hope that the technology can become part of healthy baby screenings, giving community doctors a quick and easy tool to use to identify infants at risk and leading families to help to change the course of autism earlier, which could make all the difference.

As Walt Deriso says, "They all feel that dual sense of burden and opportunity, and they all work together to change the lives of children like Walt and the future of autism. There is so much riding on this. The magnitude of the possible change cannot be overstated."

#### want more?



**AUTISM RESOURCES** To see a video of Walt Deriso discussing his family's experiences with autism, visit bit.ly/autismparent.

The Emory Autism Center in psychiatry and behavioral sciences offers diagnosis, family support, and treatment for those with autism and also serves as a vital source of training. psychiatry.emory.edu/PROGRAMS/autism, 404-727-8350.

The Marcus Autism Center, an affiliate of Children's Healthcare of Atlanta, diagnoses and treats children with a wide range of neurologic problems, including autism spectrum disorders. Staff work with parents to find ways to help children cope with their disability, including carefully managed therapy to teach children to circumvent barriers posed by the disability. Marcus.org, 404-785-9400.

To contribute to autism research and programs at Emory, contact Margaret Lesesne, director of development for clinical programs, at margaret.lesesne@emory.edu, 404-778-4632.



# The game of



By RHONDA MULLEN Illustration by LAURA COYLE



the best of it. Thus ends a new book that presents a revolutionary approach to health.

In Predictive health: How we can reinvent medicine to extend our best years, Emory physicians Kenneth Brigham and Michael M.E. Johns argue for an essential shift in how we approach health care. The predictive health approach focuses on prediction instead of diagnosis and health rather than disease.

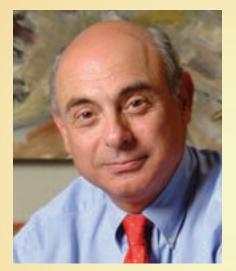
Predictive health, as the authors explain, involves defining what health is and detecting and correcting the earliest unhealthy tendencies long before there is any evidence of disease. It differs from personalized medicine, which is trying to find a drug to fix a problem. Instead it tries to get a step ahead.

"The thinking is a matter of switching your brain a little bit," says Johns. "It doesn't mean that we won't take care of disease when it comes along. But it requires a different way of thinking."

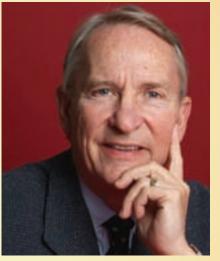
#### тне take-away

Hypertension? Take seven steps back. A healthy diet?

Move 12 steps forward. The predictive health approach turns the focus from treating disease to nurturing health.



"I like to think I am like my mother," says author **Mike Johns**. She is 95, lives in an assisted living facility, and "runs the place." Her continued engagement is good for her health.



"We don't have to be a victim of our genetics," says author **Ken Brigham**. We can make choices that profoundly influence our health from diet and exercise to meditation and resilience.

This different way of thinking could not only extend life (and quality of life) but also save money. Much of the current health care debate in the United States focuses on who should receive coverage, how much it will cost, and who will pay for it. But too few policymakers or medical professionals have recognized the fundamental flaw in this thinking, according to the authors. They argue that disease and its symptoms are late, sometimes

an individual person's health and measuring the consequences of healthy (or unhealthy) living.

#### Writing your own prescription

The predictive health approach is about empowering people to take charge of their own health, as opposed to the current top-down structure of doctors telling them what to do. "We are shifting responsibility back to the patient," Brigham says. "Self-care is the best care, and it is less expensive too. You're never going to be healthy unless you decide to be healthy."

While patients can't change their biology, they can find comfort in knowing that environment and behavior can have major

influences on health. That diet and exercise have strong effects on how our body plays its genomic cards was not much of a surprise to those of us who spend our waking moments thinking about human biology. What did, and still does, surprise us (although it probably shouldn't) is that emotions also affect how genes behave. So what you eat, what you do, and what you feel all matter... Laugh and your genes laugh with you.

The Emory/Georgia Tech Center for Health Discovery and Well Being, which Brigham founded, seeks to empower participants to take

#### Live Long, Live Well, Die Fast-

irreversible, and the consequence of long malfunctioning processes. Almost \$175 million—or one-third of the national Medicare budget—is spent in the final year of a patient's life, and one-third of that total is spent in the patient's last month of life, often on futile and expensive treatments in an intensive care unit.

By intervening early, we could change that scenario, say Brigham and Johns. We could prevent or forestall chronic diseases such as hypertension, cancer, diabetes, and heart disease. And when people stay well longer, they will need less expensive health care.

The system will change because it must. We will not tolerate forever a healthcare system that costs too much and delivers too little. Quality and access are just part of the problem. Continually escalating costs, unchecked, will drive the current system out of business.

The system will also change because it can. We live in a vortex of discovery and invention that is spinning out at a dizzying pace new tools for measuring health. We already have much of the technology for predicting charge of their health. Here, participants undergo a battery of biologic tests (including measures of body fat, bone density, circulatory function, inflammatory status, physical fitness, and brain function). Four processes that play a fundamental role in most diseases—inflammation, immunity, oxidative stress, and regenerative capacity—are charted, and samples of blood are drawn and stored in a biobank. Participants take surveys on lifestyle choices, the environment in which they live and work, and their behavior. They receive a health assessment report that compiles the findings, and they then work with a predictive health partner to develop a personal health action plan.

In general, after six months to a year in the program, participants have lost weight, their blood pressure and blood sugar levels have dropped, and blood lipids and biomarkers of inflammation have improved. Well-being also improves with the perceived decrease in stress, improved quality of life, and less depression.

After his own evaluation, Brigham began to exercise more and pay closer attention to his diet. With a few simple modifications, his risk for heart disease on the standard Framingham risk measure-

ment plunged by 40%. Johns made similar adjustments based on his assessment. He found a personal trainer who is an ex-marine, and he purposely eats "more seafood than moo food," he says. "I feel no obligation to eat everything on my plate like I did when I was a kid growing up in a less than affluent house in Michigan. Now it's about portion control."

But say a person gets the tests and the measurements, understands the consequences of his or her behavior, and follows the predictive health prescription, is success guaranteed? As a society, we might have to do more, write the authors.

To succeed, predictive health must change the game, and not just by replacing the obsession with fighting disease with an emphasis on defining and preserving health. Predictive Health aims to disrupt everything you and the medical community know about health care... A primary need is for a new mindset; measurements are not made to establish a diagnosis but to define the status of a person's health. Predictions based on data are not of risk for a heart attack or Alzheimer's disease, but the odds of staying healthy. And that new mindset requires a new vocabulary. Words and how we use them matter. People are people, not patients. Healthy people encountering the care system should neither perceive themselves as patients nor be perceived that way by care providers. They must be understood as real human beings, with all of the marvelous potential that that implies, and our job as health-care professionals is to help them see that potential and go about realizing it.

#### Live and let die

Now back to that book ending, the inevitability that life is a fatal condition.

In a survey of what is important to people who are dying, more than 70% ranked the same 10 things, all of which are fairly easy to accomplish: be kept clean, name a

#### *-But Not Yet*

decision maker. have a nurse with whom one feels comfortable, know what to expect about one's physical condi-

tion, trust one's physician, have one's financial affairs in order, be free of pain, maintain a sense of humor.

While the growing specialty of palliative care and the hospice movement are making strides toward granting those requests, dying for many Americans does not happen in the

> peaceful and caring confines of a hospice or at home surrounded by loved ones. More than 20% of dying Americans spend their last days in an expensive, high-tech hospital intensive care unit.

The predictive health approach begins in a sense by looking at the end, by acknowledging that everyone will die, by knowing that our lifetimes are brief, by challenging us to make healthy choices and live well. How would we live if we experienced our mortality, realized how short the time is and how sure the final outcome, before being faced with an incapacitating illness? It seems likely that such a realization, internalized, would trigger some rearranging of priorities for most of us. And the reality of an inescapable end to what will be a too-brief life no matter when it ends could be liberating.

Meet Hilda Echt, an affluent 100-year-old Atlantan, who was interviewed for this excerpt from Predictive Health:

"What do you think is the thing old people need the most?" she asked her doctor visitor.

"Medical care" was his stock answer. "Hogwash," she replied. "If you get to be as old as I am, you get medical care. Otherwise you'd have died off a long time ago. It's transportation. Getting places just to do the essentials is a problem, much less going out and among people. I drove until I was past ninety. Without that car, I'm grounded like a naughty teenager."

When the conversation turned to death and dying, Ms. Echt said, "I want to drop dead... but not yet." She died two years later. Maybe she was ready by then.

Socially engaged people do live longer. Information relevant to this point comes from studies of men in Sweden. Socially engaged Swedish men lived significantly longer than their less-engaged peers. That was true even when all other health-related information was taken into account. It was also true whether the men were born in 1913 or 1923. There is something vital about mingling with our kind.

#### want more?





To see a video about Predictive Health and learn life lessons from Ken Brigham and Mike Johns, visit bit. ly/ourbestyears. To hear the authors discuss the book, visit bit.ly/phbookreport.





#### THE take-away

Campaign Emory has raised

**\$1.17 billion for a** healthier

future for Georgia.

In the largest fund-raising effort ever undertaken in Georgia, Campaign Emory has raised more than \$1.69 billion, with \$1.17 billion going to support Emory's Woodruff Health Sciences Center (WHSC). Behind those numbers are the 149,000 alumni, faculty, staff, parents, students, grateful patients, and friends who have contributed to a healthier picture for research, education, and patient care for Georgia and the region.



#### The nursing influence, at home and abroad

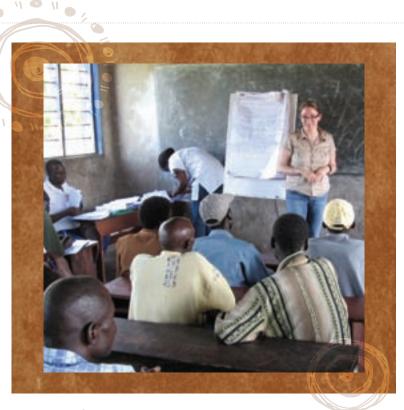
Grants led by nursing researcher Lynn Sibley are improving maternal and newborn survival rates in rural Ethiopia, a key academic focus area of the nursing school. Including gifts of \$8.16 million from the Bill & Melinda Gates Foundation and \$4.5 million from the Canadian International Development Agency, the school generated more than \$27 million in private funding during the campaign.

#### For the tiniest babies (and their moms)

Auxiliaries at Emory University Hospital (EUH) and EUH Midtown gave a combined \$212,000 to support their hospitals, including \$70,000 to expand neonatal intensive care and support maternity center patient and family services at EUH Midtown.



#### CAMPAIGN EMORY | gifts for health sciences



#### Global gifts

Campaign Emory spurred transformative gifts on the world stage, including a commitment of more than \$10 million from the Hubert Foundation. The support enabled the Rollins School of Public Health to name the Hubert Department of Global Health (the first endowed department at Emory), endow two chairs, and increase support for students to pursue global health research.

#### A family's fight against Alzheimer's

Mary Rose Taylor, whose husband Charles "Mack" Taylor died of Alzheimer's disease, has rallied her family and community through fund-raising events and personal contributions of more than \$1 million to support the Emory Alzheimer's Disease Research Center—the only comprehensive Alzheimer's center in Georgia and one of only 32 nationwide supported by the NIH.



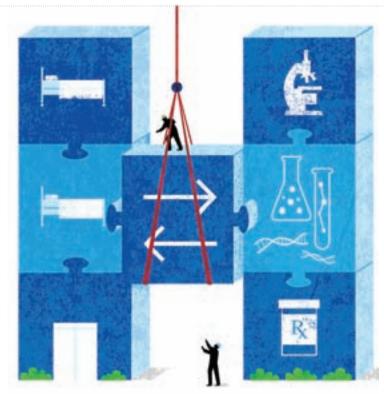
## MORE THAN 85 DONORS CAME TOGETHER TO FUND THE FRAY F. MARSHALL CHAIR OF UROLOGY.



Building contributors include: the O. Wayne Rollins, Joseph B. Whitehead, Robert W. Woodruff, Zeist, Martha and Wilton Looney, Katherine and John Murphy, and Luther and Susie Harrison foundations; the David, Helen, & Marian Woodward Fund, the Georgia Research Alliance; Raymond F. Schinazi; Margaret Hirst Davis; James and Helen Carlos; and an anonymous donor.

#### Room for research

The new Health Sciences Research Building, a collaboration between WHSC and Children's Healthcare of Atlanta, devotes more than half of its 200,000 square feet to pediatric research. It also houses researchers in adult cancer, immunology, and drug discovery and includes a two-story working bridge that connects the building to pediatric outpatient care. The Brumley Bridge is named in memory of Zeist Foundation founder George Brumley Jr., who led Emory's pediatrics department and was medical director at Children's.



#### The tower that Woodruff built

Continued generous support from the Robert W. Woodruff Foundation is helping Emory Healthcare provide an ideal patient-centered experience with construction of a ninestory 210-bed tower for Emory University Hospital. The expansion will include a pedestrian walkway connecting the existing hospital to the new tower and parking facilities.

#### Making primary primary

Philanthropist Margaretta Taylor made a \$5 million gift to support excellence in primary care and medical education through the Margaretta Taylor Clinician Fund in Primary Care. The first Taylor clinician is Emory internist Sally West.



#### Kids count

The Marcus Foundation committed more than \$11 million to Emory's pediatrics department. The gifts created the Marcus Society in Pediatrics. The society is the "intellectual home" for 15 Marcus professors who have expertise in the full gamut of pediatric specialties.



#### Rising to new heights

The Claudia Nance Rollins Building, made possible by a \$50 million commitment from the O. Wayne Rollins Foundation, is named for the mother of longtime Emory benefactor O. Wayne Rollins and his brother John. Ranked sixth among the nation's schools of public health and with more than 1,100 students, the Rollins School of Public Health receives more applications for its masters programs than any school of public health in the country.

#### CAMPAIGN EMORY | gifts for health sciences



#### Supporting a socially responsible career switch

Funded through a \$5 million endowment from the Helene Fuld Health Trust, Fuld fellowships at the Nell Hodgson Woodruff School of Nursing are awarded to students with previous undergraduate degrees in fields other than nursing who want to become nursing leaders focused on issues of social responsibility.



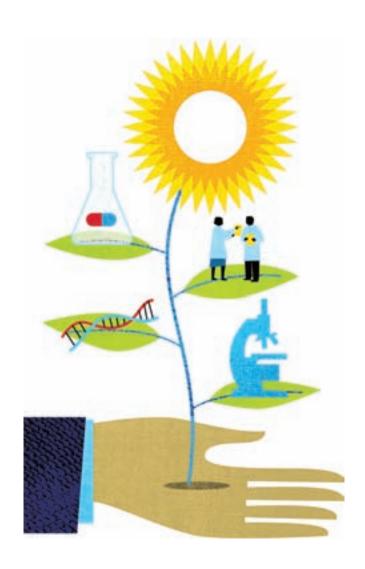
#### Making discoveries make a difference

The family of John Brock, chairman and CEO of Coca-Cola Enterprises, has established the John and Mary Brock Diagnostic and Discovery Fund to help Emory researchers and physicians more quickly bring discoveries from the lab to the clinic.

#### Putting their trust in transplantation

The Carlos and Marguerite
Mason Trust has contributed more
than \$7.7 million to the Emory
Transplant Center and played an
important role in the development
of a new FDA-approved drug that
improves immune tolerance for
patients after kidney transplantation.

#### GENE AND ROSE GANGAROSA FUNDED TWO CHAIRS TO BRING SAFE WATER TO PEOPLE WORLDWIDE.



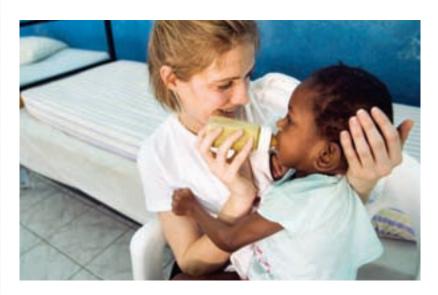
#### **Nurturing hope for cancer cures**

Jim Kennedy, chair of Cox Enterprises, and his wife, Sarah Kennedy, are among many Georgians who want to help find a cure for cancer. The Kennedy Pilot Grant Research Awards help young cancer investigators develop novel ideas. The gift also supports recruitment of researchers and development of the survivorship program at Emory's Winship Cancer Institute.



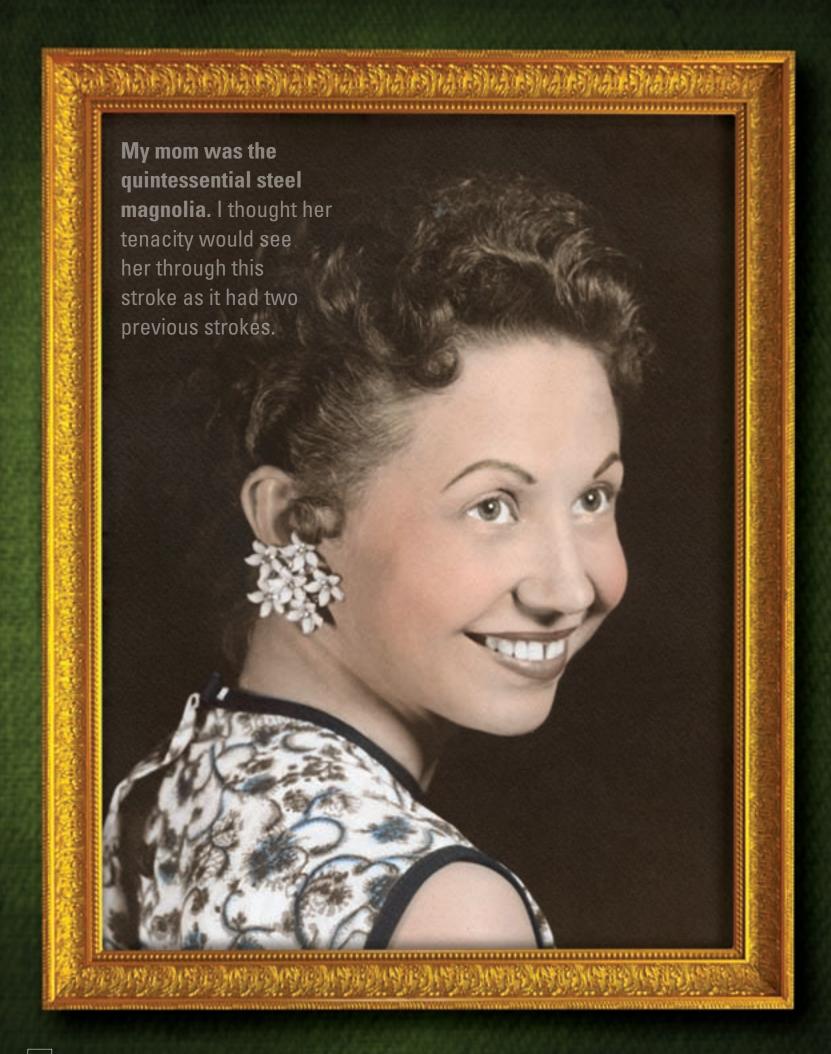
#### Jumping over hurdles in head and neck cancer

Established with a \$2.5 million planned gift, the Lynne and Howard Halpern Chair in Head and Neck Cancer Research honors Fadlo Khuri as deputy director of the Winship Cancer Institute and leader of the head and neck cancer program.



#### Class acts

In 2008, graduates receiving the bachelor of science degree in nursing designated their senior class gift for the Service Learning Trip Scholarship Fund. The fund provides scholarships for nursing students to participate in alternative winter and spring break programs in Jamaica, the Bahamas, and the Dominican Republic, where they provide health care and education.





#### By RHONDA MULLEN

My mom died a few days after Easter a year ago. After a day of labored breathing, she finally was sleeping peacefully when I left for the night. The nurses had drawn a white blanket around her shoulders, her hair was newly washed, and the tubes so often present at the end of life were mostly gone.



I hadn't been home long when the phone rang. It was from one of the many gentle nurses whose names I no longer remember, but I remember what she said. "I am so sorry, but as I walked in to check on your mom, she was taking her last breath."

The finality of death always takes us by surprise. My mom was the quintessential steel magnolia. A Depression-era child who grew up in hardscrabble Northern Mississippi, she worked all her life—on the farm, in a hosiery mill, later still in a shipyard on the coast. I thought her tenacity would see her through this stroke as it had two previous strokes—at least for many more days, even weeks, months.

"What should I do?" I asked the nurse. "Should I come back? Who should I call?" That's the weird thing about moments of crisis. It's hard to make the simplest decisions. All my education and experience had fled. There I was, as I had been since Easter morning, in a state that left me wondering what was the right thing to do.

I was lucky because at Emory, I got answers, help, and support from people who appeared when I needed them most: doctors, nurses, palliative care specialists, students. I learned that sometimes there is no right thing to do, that you do the best you can.

At Emory, Mom was lucky too. All of Emory's hospitals are certified by the Joint Commission as advanced primary stroke centers, which means that they follow best practices in stroke care. In other words, Mom got the best stroke care available.

Outside that Easter Sunday morning, the sky was sunny, a spring nip was in the air, daffodils were blooming. Inside the emergency department at Emory University Hospital (EUH), the neurologist showed me a white area that filled Mom's MRI and showed the massive blockage in her brain. She sat with me and explained what this meant. It would impact areas that controlled speech and movement. The clot-busting drug, tPa, wouldn't work because the window for its effectiveness had passed. Instead of dissolving the clot, the drug now might cause my mother to bleed out. Instead the stroke team proposed to closely follow her over the next 24 hours to see if any of the damage would recede on its own and how much function could be regained.

wait and see The nurses took us in hand in the neurology step-down ICU. They installed Mom in her room, took her vitals, scheduled the next tests. They showed me the essentials—bathrooms, a refrigerator for family use, the cafeteria downstairs. They put their first names on the board in the room as they came and went. When a nurse named Rosa arrived for the night shift, I felt that everything was going to be all right—as much as the circumstances allowed. She talked to Mom, explained what was happening, squeezed her hand. I know enough about hospitals to know that Rosa does this with new patients on every shift, but that night, we felt like we were her first and only concerns.

A medical student came in the early morning to do a stroke assessment. At Emory, students no longer wait until their third year to interact with patients. They work on clinical services beginning in their first weeks of medical school. This young man was close to the age of my oldest daughter, my mother's first grandchild, and



he had never done a stroke assessment before. I could tell that he was nervous, but he had a list of steps, and he went through them.

"How does it look?" I asked when he finished. He was honest: "I'm not sure I did it right." But he walked me through what signs he was measuring, the scores he recorded. Both this young man and I would learn more later in the day.

The resident came next, then the chief resident, then midday, the chief of service. Aaron Anderson was a familiar face. He had evaluated Mom soon after she moved here from her beloved home in Mississippi. To say that she had been less than happy about relocating would be a dramatic understatement. But after a series of falls—broken ankle, wrist, two fractures in her

back—and several smaller strokes, she needed to be near me so that I could see to her basic needs and near a tertiary care hospital to have access to better health care. Anderson won her over not so much for his education, training, and experience but because his wife was—you guessed it—from Mississippi. He reminded her of home.

The news he brought after evaluating the tests and examining Mom was not good. She would not walk or talk again. It would remain difficult for her to swallow. She was left only with the use of her left arm. He asked if I wanted a palliative care consult. Yes, I did.

comfort care The term palliative care may be unfamiliar to some, but I knew about

the specialty after editing an article on palliative care for this magazine. Many people confuse palliative care with hospice because both approaches emphasize the management of symptoms rather than attempting to cure the disease itself. Palliative care sees to the physical, emotional, and spiritual comfort of patients and their families. But unlike patients in hospice, those in palliative care may continue to receive traditional, curative treatment and eventually recover.

"We are called in when it's not so clear what the options are," says nurse practitioner Shella Chawda, who is on Emory's palliative care team at EUH. "We help in understanding the big picture." She does a lot of listening on the job, encouraging patients to talk

about what they expect from quality of life, what they understand about their health and prognosis. The process is guided by the family members, what they need, what they want, and every day Chawda tries to meet the patient and family where they are.

Emory's palliative care team is growing. The service currently includes two physicians, five nurse practitioners, two chaplains, and an RN who cover EUH and EUH Midtown.

The Nell Hodgson Woodruff School of Nursing is taking palliative care at Emory even further with support from a \$1.5 million training research grant from the U.S. Department of Health & Human Services. Led by Carolyn Clevenger in nursing and Tammie Quest, Roxanne Arnold Professor of Palliative Medicine, the grant trains primary care teams to incorporate palliative care practices in general patient care. Over the next three years, training will take place with teams in six units that treat patients with life-threatening illnesses: leukemia, heart failure, hospital medicine (frail elders, those with cystic fibrosis), as well as medical, neurological, and surgical critical care. The teams are customizing the palliative care model for their areas, making modifications in the timeline and steps that work for their patients. As the program unfolds, the researchers will evaluate what is working and what isn't, track improvements in outcomes and quality, and share results so that others can learn from their model.

In talking with Chawda, I shared conversations that Mom and I had had about her wishes for end of life. I told her that I was Mom's power of attorney for health care, that given the prognosis, I didn't want to prolong her life. Even talking to a nurse practitioner as patient, knowledgeable, and concerned as Chawda, it was difficult for me to express those wishes aloud. I didn't want to take my mom's life, but I didn't want her to suffer. Within power of attorney is the word power, and I wanted to use it carefully, wisely.

Chawda explained to me that Mom's caregivers could withhold the heart medication that the medical team had hoped would calm a heart arrhythmia that had contributed to the stroke. But she suggested that they

continue the high blood pressure medicine: withdrawing that might lead to headaches and pain. She asked if I would like to speak to a chaplain, but my own minister and friend was sitting with Mom in her room even as we spoke. She asked if I wanted to consider hospice, given the severity of the situation. Again, yes, I did.

the last goodnight Vista Care Hospice on the fifth floor of EUH is a quiet place with soothing colors, reclining chairs, and a separate lounge where families can read the newspaper, watch television, microwave a meal, check email, or stare out the window at the world going on as if it were a regular day. It sits only three floors above the neurology

**Editor's note**: I wrote this memory

on February 22, what would

have been Mom's 88th birthday.

If she was still here, she would

remind me to thank the

security guard in the Emory

emergency department who

had a kind word for a daughter

who was scared and alone. And

she'd say to give those Emory

doctors, nurses, and staff who

shared their skills and care,

kindness and concern

a big Mississippi hug.

step-down unit, but the beeping monitors and hustle and busy-ness of an active medical floor are gone here.

As I walked through the doors of the hospice the second night after Mom's stroke, a hospice nurse met me with a big hug. All the steel magnolia that I had inherited from my mother flowed out of me and into the open arms of this strong woman. "It's okay, baby," she said. "It's okay. Now it's in God's hands."

Mom and I had come to the last leg of our journey. Other people on the floor had big families, and over the next few days, I could hear them coming and going, crying and laughing, all grappling in their way with the end of a loved ones' life. But our family is small—just me (an only child and adopted at that), my two daughters, a few dear friends, and out of town, a handful of cousins and one uncle in his 90s.

I sat with Mom and talked to her. I asked her if she was going to be happy to see her mom, her sisters, her brother, Daddy, her second husband Bill. I asked her how it would work with two husbands in heaven. If she heard me, she appreciated the irreverent humor. I thanked her for the music and art lessons, the college education, for loving me when I wrecked the car, when I left the marriage.

My pastor brought a simple flower bouquet picked from her garden. My cousin in Kentucky called, and I held the phone up to Mom's ear while she talked. (She had a lot to say.) I started getting together thoughts for the funeral service back in Mississippi: favorite verses of scripture, music. "I come to the garden alone" was the hymn that Mom used to sing every Saturday morning while she cleaned house, but she never got past the end of the first line "while the dew is still on the roses" before she'd rewind the song, over and over, until the vacuuming was done.

> My oldest daughter, Charlotte, stopped by after her art history class at Emory. My best friend of the last 40 years arrived in comfortable shoes and clothes, with a laptop and magazines, prepared to spend the day. True southerners, we ended up sitting in a semicircle by mom's bed and talking. We told stories of Sissy, as Mom was known to all her family. Charlotte practiced her honor's thesis that she had to

present the next morning. She mentioned a boy she had met who she hoped would call.

Wynette Elizabeth "Sissy" Mullen Allen died later that night.

We can't always get our wishes or plan how we'd like to exit this life. Too many of us end up spending more on health care, often futile, in the last month of life than over the rest of our years combined. But Medicare fully covered the cost of Mom's hospice care. More than anything, I am grateful that my mother had a quiet and dignified death with the stories of the ongoing lives of those she loved still ringing in her ears. 🖭

#### THE LAST WORD | Forensic pathology



#### Randy Hanzlick found his calling, thanks to a good teacher.

When he was a young pathology resident at Ohio State, he encountered Nobuhisa Baba, who ran the university hospital's autopsy service and was a forensic pathologist for the coroner. Baba immersed the young resident in the daily life of a forensic pathologist, and Hanzlick has never looked back.

Today Hanzlick serves as an Emory pathology professor and directs the Fulton County Medical Examiner's office. He has written books on investigating death and the role of forensic pathology in criminal cases and helped develop guidelines for his chosen profession. In 2009, the American Academy of Forensic Science presented him with a Distinguished Fellow Award, and he has received both the Lifetime Service Award and the President's Award from the National Association of Medical Examiners.

Although television and film have popularized and romanticized his profession, Hanzlick believes that his calling goes deeper than that, that it can help bring justice to the deceased and give them a final measure of dignity. High-impact cases—those that evoke public interest or are challenging to figure out—seem to surface every few years. Hanzlick has worked, for example, on understanding the death of a young girl with multiple extremity fractures apparently incurred during an attempted exorcism and a dismemberment case in which the perpetrator attempted to get rid of body parts in a kitchen garbage disposal.

But Hanzlick's day-to-day work involves fewer of these attention-grabbing deaths and more of the regular homicides, suicides, and accidental and unexpected natural deaths that cross his door. In Fulton County, the number of homicides has dropped in the past few years, but the pathologist can remember when he would see as many as 300 in a year. In 2012, the county had 126 homicides, an average of one every three days, with many of them involving young adult men. Last year Hanzlick saw as many suicides as he's ever encountered, and he says that number may be as high or higher this year.

Training goes hand in hand with his investigations. Medical students from Emory and Morehouse routinely visit the medical examiner's office for lessons in forensic pathology, and Hanzlick typically trains one forensic pathology fellow a year through a one-year fellowship, jointly sponsored by Emory and the Fulton County Medical Examiner's Office. Emory pathology residents also typically spend at least one month in his office during their anatomical pathology training.

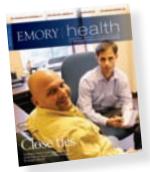
For hospitals and agencies, Hanzlick does on-the-spot training. Personnel from the U.S. Army Criminal Investigation Laboratory stationed at nearby Fort Gillem arrive periodically to familiarize themselves with autopsies, as do military personnel soon to be deployed to the Middle East for body recovery. Trauma surgeons and nurses from Grady Memorial Hospital (where Hanzlick directed the autopsy service for seven years) as well as emergency medical technicians also pass through his doors to receive autopsy training.

Hanzlick passes on the advice of his own mentor to his students: "Leave no stone unturned." –Sally Wolff-King

**In your article, "Interpreting Health,"** it is gratifying to read of the efforts of so many to try to breach the language barrier that often exists for primary Spanish speakers. I would point out, however, that the subtitle of your article, "se hablas espanol,"

is grammatically incorrect. It could be "hablas espanol?" as a question (do you speak Spanish?) or "se habla espanol" (Spanish spoken). While the above is a minor point, I previously have found official hospital signage that was poorly translated into Spanish. Let's continue efforts to remain culturally diverse and competent.

Alvaro Lopez, M.D.



Winter 2013 issue

We like to hear from you. Send us your comments, questions, suggestions and castigations. Address correspondence to Emory Health magazine, 1762 Clifton Road, Plaza 1000, Atlanta, GA 30322; call 404-727-8166; or email rhonda.mullen@emory.edu.



insurance products and are not affiliated with Emory Alliance Credit Union or Alliance Retirement & Investments Services. Products offered are: • Not insured by the NCIA • Not credit union guaranteed • May less value, 9155.05(4.105308



Emory University Woodruff Health Sciences Center 1440 Clifton Road, 1st floor, 150M Atlanta, Georgia 30322

Address Service Requested









As the young son of a country doctor, Linton Bishop helped his father care for patients in the tiny hamlet of Unadilla, Georgia. He followed his namesake to Emory School of Medicine, graduating in 1947 and joining the faculty in 1953. Twenty years later, he helped establish the Carlyle Fraser Heart Center, now a national leader in cardiac diagnosis, care, and research. Bishop and his wife, June Bishop, made the center a beneficiary of their IRA to help ensure its continued success. "We started it, and we want to keep it going," he says.

Learn how you can create a legacy by including Emory in your estate plans. Please call the Office of Gift Planning at 404.727.8875 or visit www.emory.edu/giftplanning.

Plan to extend your reach.

