

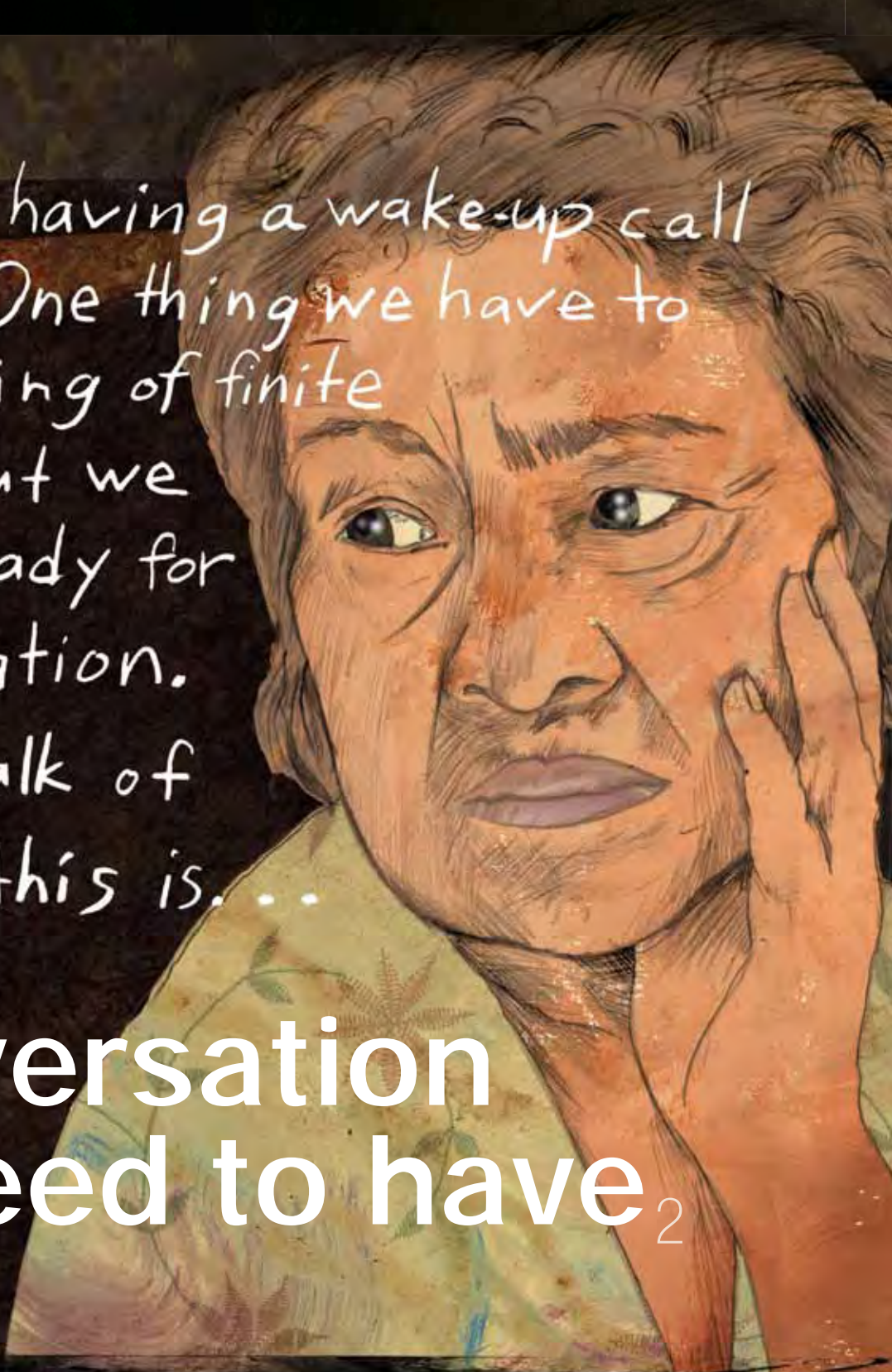
EMORY | health

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

William Bornstein:

Our country is having a wake-up call for health care. One thing we have to face is the meaning of finite resources. But we have not been ready for that conversation. It leads to talk of rationing. Still, this is...

**A conversation
we need to have**₂



FROM THE EXECUTIVE VP



Reforming our health care system

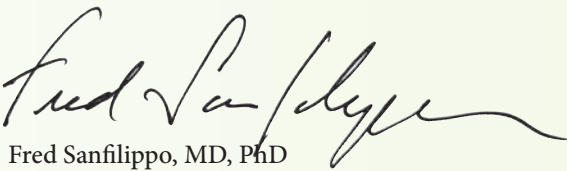
Try to imagine all of the goods and services currently consumed each year in the United States. The magnitude is almost incomprehensible, and yet, left unchecked, that's just how much one study predicts the U.S. health care system will cost within the next 40 years. Already we spend more than \$2 trillion a year—far more than any other country in the world—on a system that provides consistently poorer outcomes and lower satisfaction, by most measures, than dozens of other countries.

In this issue of *Emory Health*, you'll learn about some of the many ways in which Emory's Woodruff Health Sciences Center (WHSC) is engaged in transforming the health care delivery system. WHSC leaders are at the forefront of local, regional, and national reform efforts. Whether drafting potential reform policies, convening the best health care minds to develop solutions, or implementing improvements within our own health system, WHSC faculty and staff are committed to leading the much-needed overhaul of the nation's current health care system, which many agree "is neither healthy, caring, nor a system."

Perhaps one of the most important ways we're leading change is by collaborating with other individuals and institutions through the Blue Ridge Academic Health Group. Founded in 1993 and hosted by WHSC since 2002, the Blue Ridge Group is a coalition of leaders of academic health centers and health policy and practice experts from across the country. The group meets annually to address a groundbreaking topic related to health care and to create a report based on its research and recommendations. The report is made available to thought leaders, policymakers, and other interested individuals and institutions.

To date, the group has issued 13 reports on topics such as quality and safety, informatics, conflict of interest, medical education reform, and most recently, a policy proposal for a U.S. health board (whsc.emory.edu/blueridge/reports.cfm). When the group convened this summer, topics of discussion included health care value and social determinants of health.

As you read the articles in this issue, you'll learn more about the Blue Ridge Group and many other ways that WHSC is leading the national health care reform debate and transforming health and healing ... together.


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Please share your feedback at evphafeedback@emory.edu.

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

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What do you think? *Emory Health* welcomes your comments—pro or con—about topics and issues covered in this magazine. Please send comments, letters to the editor, address changes, and other correspondence to **Emory Health**, 1440 Clifton Road, 150M, Atlanta, GA 30322; email to rhonda.mullen@emory.edu; or call 404-727-8166.



Want a free lunch?

Just take our short survey for *Emory Health*, and you'll be entered in a drawing for a lunch for two at Caffè Antico in the Carlos Museum on the Emory quadrangle. We'll get your valuable opinion, and you'll get a chance to choose from seasonal salads, sandwiches, and entrees at Emory's most artsy café. Drawing to be held August 17. To get started, visit: whsc.emory.edu/r_survey.html



ART KELLERMANN: A single payer system for health care is not going to fly in the United States. That's too radical an idea for us. We need something in the middle that combines public and private payers. Free enterprise will kill way too many people. We have to have a hybrid.

KIMBERLY RASK: Health care is not just a money issue. In the United States, we think if you spend more, you get more. Not really. When we compare ourselves to other countries—Germany and the Netherlands, for example—we spend more, and we may get more technology, but we don't get better outcomes. The United States has the worst infant mortality rate of all the developed nations.

MICHAEL JOHNS AND KEN BRIGHAM: Appropriate management of chronic diseases decreases complications and hospitalizations, improves health, and enhances quality of life. But hospitalizations are what get paid for. The system rewards disease care, not health care.



WORDS OF WISDOM

By Rhonda Mullen • Illustrations by Karen Blessen

It's broken, and it needs fixing. That much everyone can agree on when it comes to health care in the United States. Much of the conversation about reform centers on cost, but access and quality of care are key factors too.

Any serious discussion has to start with where we are now, and it's not good. The United States is spending \$2 trillion a year (almost \$8,000 per person). We spend more than any of the other top 20 developed nations, but our health outcomes scrape the bottom of the barrel compared with theirs. Medicare and Medicaid account for 23% of federal spending, almost 6% of GDP, but Americans receive only half the screening and preventive care recommended for each age group.

The challenges range from lack of universal coverage to unequal access to care. The U.S. system has fragmented and uncoordinated care with wide regional variations. Its payment incentives fail to reward for good outcomes. Vested interest groups vie for their share of the trillion-dollar health care pie.

In the midst of national debates on how to approach the challenges, Emory experts are adding their voices, testifying before Congress, drafting reform policies, and hosting meetings of the best minds to discuss reform. How would they fix the dysfunctional system?

MODERNIZING MEDICARE

Adam Atherly would start with Medicare. “Medicare is a time capsule of health insurance in the 1960s,” he says. “Part B is almost straight from the Federal Employee Health Plan of 1965.” That plan is built on a fee-for-service model with high cost-sharing through co-pays and deductibles, and it includes no stop loss or limits. Until recently, it included no prescription drug coverage.

Atherly, a health policy expert at Emory’s Rollins School of Public Health (RSPH), believes “it makes sense to do a good job of running the programs we have already.” Specifically he’d simplify the federal program, eliminating Parts A and B to make Medicare more user-friendly.

Atherly’s research focuses on Medicare Advantage plans, supplemental policies that offer low co-pays for office visits, drug formularies, and low deductibles for hospital stays. Although these plans are politically controversial, they are not going away, he says.

Another tack, he suggests, is to give CMS (the agency that administers Medicare, Medicaid, and the Children’s Health Insurance Program) more teeth. “Currently, it doesn’t have enough money or power,” he says. For one thing, doctors who lose their medical licenses due to fraud can simply move across state lines and set up a new practice, and CMS has to accept them as providers. For another, Medicare pays 50% to 100% more than private insurers for durable

medical equipment. “Medicare is too easy to exploit,” he says.

MEDICAID PROMISES

Some experts believe Medicaid has done a better job than Medicare. Research in *Health Affairs* reported that Medicaid was better run, more successful in making incremental changes (such as introducing prescription coverage without fanfare in the 1970s), and offered a more proactive benefit package, including services such as dental care.

“Given the constraints and burdens on Medicaid, it has done pretty darn well. I’d give it a solid B,” says Kathleen Adams, a health economist at the RSPH who has headed several large projects on Medicaid populations and policies at the national level.

“The states are laboratories for health care reform, and they bubble up ideas to the federal level,” says Adams. The \$87 billion in stimulus funds for Medicaid is an opportunity for states to maintain their efforts and for some of the successful state programs to perhaps be replicated elsewhere, she says. Vermont, for example, is allowing for more patient-oriented choices as well as developing a pay-for-performance system. By requiring mandatory health insurance, Massachusetts has come close to insuring 100% of its citizens. PeachCare in Georgia has expanded insurance access to more than 200,000 children.

Unfortunately, these separate efforts lead to fragmentation, says Adams. “We really have 50 Medicaid programs, not one.”

In addition, categories that determine who is eligible for Medicaid are seriously flawed. Currently, Medicaid will cover a parent with dependent children, the elderly and disabled, and pregnant women and children at varying federal poverty levels. “This leads to people being in and then out of the health care system if their income or category changes,” Adams says. “For example, we cover a woman once she’s pregnant, but we won’t give her any prenatal counseling or health care before or after she’s pregnant.”

A new Medicaid vehicle addresses this flaw and also allows states to use family planning waivers. Georgia, however, is not one of the states using the waiver—despite the fact that the state’s Medicaid program pays for an estimated 50% of births here. “It’s so sensible. Why not do it?” asks Adams. “With family planning, we could potentially reduce unintended pregnancies and have better birth outcomes.”

Adams would like to see reform efforts eliminate Medicaid’s categories and handle coverage for the uninsured with a mix of public and private funds and programs. More than anything, she’d like to see a uniform system across all states.

She also supports expansion of model programs, such as the Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA) for underserved women. BCCPTA has drawn more women into Medicaid earlier, potentially saving lives by detecting disease earlier and thereby saving money as well. “It is having a wow effect,” Adams says.

She advocates rewarding programs that work, such as the SCHIP (State Children’s Health Insurance Program) for low-income children who are ineligible for Medicaid but who are near-poor and cannot afford private insurance. Re-authorization of this program early this year shows how federal and state governments can work through Medicaid to expand coverage while allowing states flexibility in how to achieve this goal.

UNIVERSAL CONSEQUENCES

Art Kellermann knows the statistics on the uninsured inside and out. Emory’s health policy dean and emergency medicine professor co-chaired the Institute of Medicine’s Committee on the Consequences of Uninsurance. At a recent lecture, Kellermann noted that at least 60 million Americans lack health insurance or live with an uninsured person. And the problem is rapidly worsening as millions of Americans lose their jobs and employment-based health coverage.

Why do the number of uninsured people matter? Typically, uninsured adults receive less timely and preventive care, fewer screening procedures, and inconsistent care for chronic diseases, Kellermann says. Because they are frequently denied care in other settings, they often seek treatment in emergency rooms, which charge substantially more for care than a typical office visit.

“Because we don’t cover everyone, uninsurance has consequences for everyone,” Kellermann says. “Communities struggle to recruit and retain doctors. Specialists are reluctant to take ER and trauma call because of payment issues, and hospitals are less likely to offer vital but unprofitable services.”

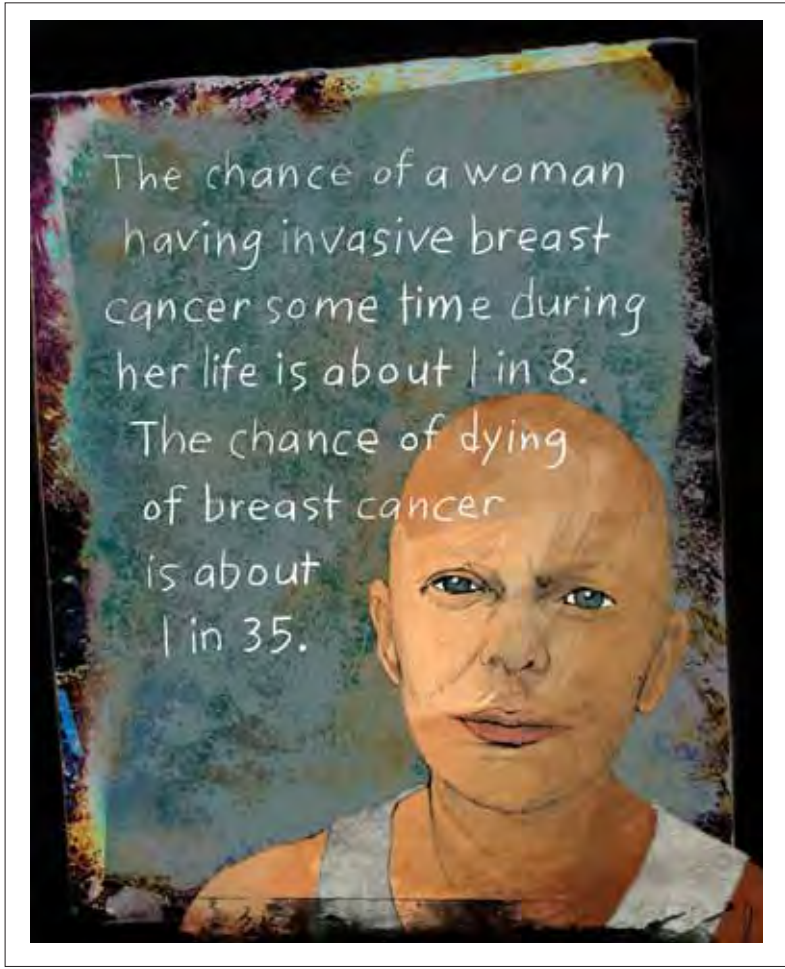
People who lack coverage are not all alike. They range from 20-somethings, who tend to be healthy but have entry-level jobs that don’t offer coverage, to workers in their 30s and 40s, who make too much to qualify for Medicaid but not enough to afford insurance for their families. Then there are those who are older and millions with a chronic illness that effectively renders them “uninsurable.”

No matter the bracket, the conclusion of Kellermann’s committee was definitive. The President, Congress, and leaders in the public and private sector urgently need to figure out

how to achieve health insurance coverage for everyone. To make the coverage sustainable, the cost of health care must be stabilized.

PRIMARY CARE PULPIT

When Emory primary care physician Kimberly Rask looks at a patient, she sees a human being, not a disease: “The person may have no health issues, or one disease, or 12. But our literature tends to focus on one disease at a time rather than the whole person.”



As director of the Emory Center on Health Outcomes and Quality at the RSPH, Rask wants to go beyond the debate on cost. “In the long run, achieving cost savings depends on how we organize our health care,” she says. “We need programs that provide the right care at the right time for the right condition.”

For Rask, that means evidence-based care. Far too often, care is based on ability to

pay rather than evidence indicating that it is beneficial. Take MRIs, for example, she says. “An MRI won’t necessarily help a patient get better, but it is helpful if it helps inform and improve a treatment plan such as ruling out cancer or stroke. Often, for some conditions, such as an injured knee ligament, watchful waiting may be just as helpful and far less costly. However, trying to talk family members out of unnecessary treatment or even antibiotics can be challenging.”

Evidence-based care is a key ingredient to the concept of a “medical home.” The medical home (not a physical place) is an approach in which health care is continuous, coordinated, and comprehensive, with a partnership between patients and providers. Other ingredients include 24/7 access to care, team-based care with prominent roles for nurses, coordination across sites of care, predictive analytics to identify high-risk patients, and performance reporting.

But a medical home cannot become a reality until the United States addresses the current shortage of primary care physicians, Rask says, quoting statistics that fewer than 2% of medical school graduates are going into the field. Why the low number? “Internists are expected to see a patient every 15 minutes,” she says. “The way the system is set up, the internist is a paper manager, leading

many to leave primary care and set up boutique practices, where they can spend more time with patients. The concept of the medical home could bring joy back into the field.”

CONTROLLING CHRONIC CONDITIONS

In West Virginia, Emory’s Ken Thorpe is helping chart an overhaul of the state’s health care system. What the Woodruff Professor in

KENNETH THORPE: Two recent studies have shown that seniors aged 65 to 70 who are normal weight, with no chronic diseases, spend 15% to 40% less over their lifetime than do obese adults with chronic diseases. If we applied those potential savings to Medicare for just this year, that would represent between \$66 billion and \$177 billion.

health policy has found is that three-fourths of that state's health care spending is linked to chronic disease. If the state took on management of just obesity and chronic illness, Thorpe estimates it could save roughly \$2.7 billion by 2018.

The national picture mirrors those numbers. By Thorpe's calculations, if Medicare focused on managing obesity and chronic diseases, the program could save between \$66 billion and \$177 billion in just one year. Testifying before Congress, Thorpe, chair of the department of health policy and management at the RSPH, reported that 75% of national health spending is for chronic conditions such as diabetes and hypertension. Rising rates of obesity, which have doubled for adults and tripled for children since 1980, account for 20% to 25% of the overall rise in spending. And right now, less than 1% of national health spending is directed to avoiding health problems rather than fixing them.

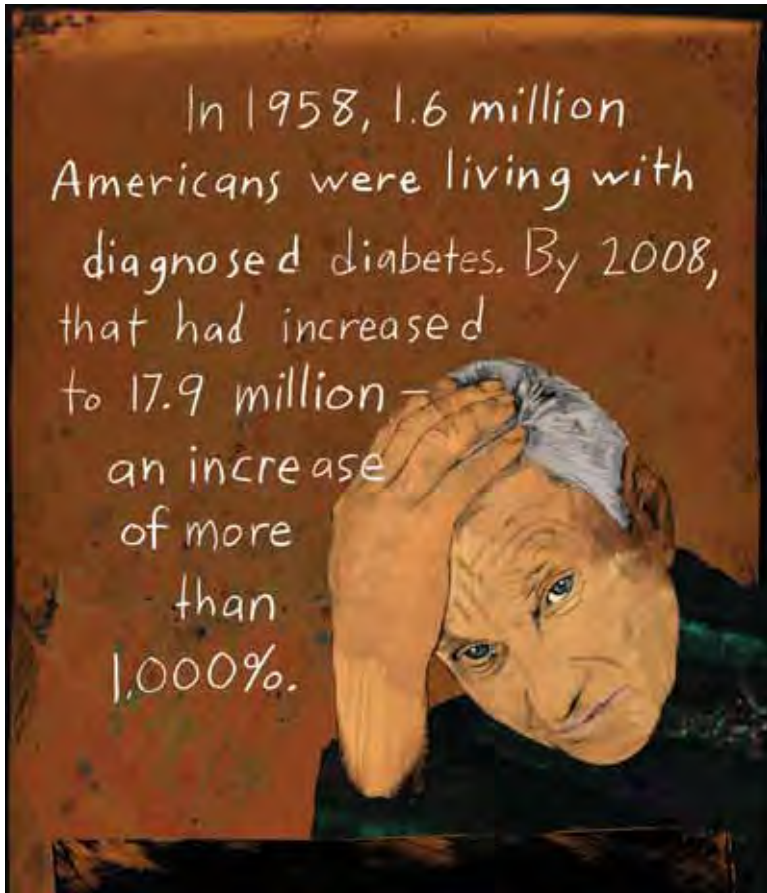
Thorpe argues that even modest investments in prevention can yield surprising savings in public and private sectors alike. For example, work site health promotion programs have helped U.S. companies reduce both medical costs and absenteeism. A health management program at Citibank showed an ROI of \$4.70 for every \$1 in cost. A similar program at Johnson & Johnson reduced health risks such as high cholesterol, cigarette smoking, and high blood pressure, saving the company \$8.8 million annually.

ARGUING FOR BASICS

Years ago, when William Bornstein was a medical resident, he tried to impress his teachers by pursuing unusual diagnoses. "I'd come up with all the weird tests to order for

a rare condition, and I got positive reinforcement for that," he says. "What would have been more impressive but less dramatic would have been to recommend something basic, like suggesting everyone get a flu shot."

Bornstein's story illustrates both a strength and weakness in America's health care system. A focus on innovation and discovery has contributed real breakthroughs, like cimetidine (Tagamet) for reduction of stomach acid and sequencing of the human genome. Along the way, however, argues



Bornstein, we have lost sight of important fundamentals.

"We have focused on the rocket science instead and have left out the basic blocking and tackling, and now we need to rebalance," says Bornstein, who is chief quality officer for Emory Healthcare. "If we just gave regular immunizations, we'd have had more impact on saving lives than we've had with some

groundbreaking discoveries. The epiphany is that we need to excel at both—the brilliant and the routine. As an academic medical center, we also need to lead the way in discovering and teaching new ways to deliver care more reliably and effectively."

THE IT OF HEALTH

"I can put my ATM card in any bank machine in the world and withdraw cash, but I can't go across town and access my health care record," says Art Kellermann. He's onto something that President Obama has identified as one of the crucial tools to lower health costs: health information technology. The United States will invest \$10 billion each year for the next five years to move the country to adopt standards-based electronic health information systems.

The Blue Ridge Academic Health Group—comprising health care experts from universities and organizations such as the Burroughs Wellcome Fund, Association of American Medical Colleges, Emory, and others—took on informatics at its annual meeting in 2008. Useful technologies they identified included electronic health records, computer-assisted clinical decision supports, and genomic data warehouses that "promise efficiency, automation, effectiveness, transparency, decision-support, personalization, portability, and consumer empowerment." Their conclusion: these technologies can improve quality and safety, and health centers need to embrace and learn to use them.

At Emory, leaders are taking the promise of health IT seriously. The Emory electronic medical record has been used throughout Emory Healthcare for almost five years. Patients can create their own personal

KATHLEEN ADAMS: State Medicaid programs are our labs for health care reform. They bubble up ideas to the federal level. Unfortunately, that is adding to the fragmentation in health care. What we really have is not one but 50 Medicaid programs. I ask my class: 'Is that good?' By and large, within each state, I think Medicaid does a tremendous job, but is it right that the programs are so unequal?

electronic health record on Emory Healthcare's website. A Center for Comprehensive Informatics was created recently to empower more precise and scientifically informed decision-making in patient care. And Emory and Georgia Tech are launching a new joint department of

Biomedical Informatics to train new leaders in this expanding discipline.

A MANDATE FOR REFORM

Every 15 years or so, health care reform catapults to the top of the U.S. political agenda. The past three presidents all took steps to

enact significant reforms, but these efforts fell short. "Because of the economy, the likelihood that some reforms will come to fruition is higher than it has ever been," says Thorpe, who served as deputy assistant secretary for health policy under President Clinton.

Kim Rask sees glimmers of hope at the grass roots level, where she is interacting with communities and studying plans put forth in places like Findley, Ohio. There, private employers and health insurance companies are banding together to standardize health care benefits for patients with chronic diseases (for example, requiring no co-pays for diabetic supplies). In addition, they are encouraging use of primary care physicians as coordinators of care.

Kellermann believes the public mandate from the 2008 election will help carry reforms through. "Voters want something done. The No. 1 priority was to make health care affordable, and the No. 2 was to expand coverage to the uninsured. Eight out of 10 voters called for a major overhaul and fundamental reform. We know we can do better than this." ■

JUST THE FACTS

- One in five adults under age 65 and nearly one in 10 children are uninsured.
- Tobacco use causes 440,000 deaths in the United States each year. Deaths associated with smoking account for more deaths than AIDS, alcohol use, cocaine use, heroin use, homicides, suicides, motor vehicle crashes, and fires combined.
- Mental health disorders are the leading cause of disability in the United States for ages 15 to 44.
- More than 2.3 million women in the United States have survived breast cancer or are living with breast cancer today.
- Two recent studies have demonstrated that seniors aged 65 to 70 who are normal weight, with no chronic diseases, spend 15% to 40% less over their lifetime than do obese adults with chronic diseases.
- One-quarter of Americans have two or more chronic diseases.

WEB CONNECTION To see a video of Art Kellermann's recent address to President Obama on health care reform, visit whsc.emory.edu/r_kellermann.html. To hear Kellermann's July interview on NPR, visit whsc.emory.edu/r_kellermann_npr.html.

SUGGESTED READING: *Blue Ridge Academic Health Group, Fall 2008 policy proposal: A United States Health Board*, whsc.emory.edu/blueridge/reports.cfm.

"Transforming Health Care through Prospective Medicine: The First Step," by Michael Johns and Kenneth Brigham, Academic Medicine, August 2008, whsc.emory.edu/r_academic_medicine.html.

TO TEACH

The president of the Association of American Medical Colleges weighs in on health care reform.

By Darrell Kirch

As you read this article, a vigorous debate is being waged on Capitol Hill and across the nation about health care reform. In many ways, this debate affirms what a number of leaders in academic medicine have stated and what forums like the Blue Ridge Academic Health Group already have shown—that the keystone of any reform effort is improved integration among providers. In other words, for reform to be successful, we must do a better job of aligning incentives and improving synergies among the various components of our health care system, including insurance coverage, delivery systems, financing, and information technology.

Accomplishing lasting reform requires a unique kind of leadership, one that is highly credible and includes a breadth and depth of clinical expertise; a track record of serving all population segments; an approach that is national in scope, but focused

on patients and communities; and the infrastructure to collect and analyze data on new care models. Sustaining this transformation will require the ability to train new leaders to be change agents and mentors to future generations. These five factors—Training, Expertise, Access, Central focus on patients and com-

munities, and Health services research capacity (TEACH)—make academic medicine uniquely qualified to lead our nation in health care reform.

Training: As the training ground for health professionals at all levels, medical schools and teaching hospitals are preparing new doctors and other health care providers for a patient population that is growing, aging, and becoming increasingly diverse; care delivery that is more patient-centered; and work environments that are increasingly inter-professional and team oriented. By exposing professionals at an early stage of training to large-scale innovation and dynamic delivery environments, academic medicine is fostering change agents who will, in turn, mentor future generations.

Expertise: With clinical expertise that is as comprehensive as it is deep,

academic medical centers (AMCs) are able to provide the entire spectrum of health care services from preventive to specialized care. Additionally, as part of larger university systems, AMCs can draw on the knowledge of numerous disciplines (as shown by this month's cover story featuring interviews with Emory experts in primary care, quality, public health, and economics).

Access: This expertise is enriched by a track record of caring for patients from all population segments. (Notably, major teach-

ing hospitals, which comprise only 6% of hospitals nationwide, provide nearly half the nation's hospital charity care.) Many AMCs are large systems that already encompass the components needed to test new models of integrating care (for example, hospitals, physician practices, post-acute care) and possess longstanding relationships with local partners.

Central focus on patients and communities: From a structural standpoint, AMCs reach all parts of the nation, but their focus is on patients and communities. The ability to effectively communicate with patients and their families is a fundamental competency reinforced throughout the continuum of medical education. On a broader scale, AMCs as institutions apply this deep concern for patient health and well-being through a variety of community service and outreach activities.

Health services research capacity: As research institutions, AMCs have the built-in infrastructure to collect and analyze data related to new care delivery models.

Some may ask, "If academic medicine is so well suited to lead the way, why haven't we seen a more visible demonstration of integrated care?"

First, the level of health care innovation now taking place at AMCs is dynamic, with much of the activity occurring under the radar. With so much activity taking place simultaneously, the rate of innovation outpaces the ability to document or publicize the degree of transformation now under way.

Second, to the extent that some institutions already have emerged in the public spotlight, it is due largely to their unique position geographically and demographically (for example, ability to leverage existing health care spending for large populations in defined geographic areas). This enables them to support sys-

tems that better align benefits, delivery, and information, and to test innovative business models (for example, the medical home and accountable care organizations).

The issue, therefore, is not whether our leadership goes unnoticed, but how can we fully leverage "the five factors" to improve the health of our nation?

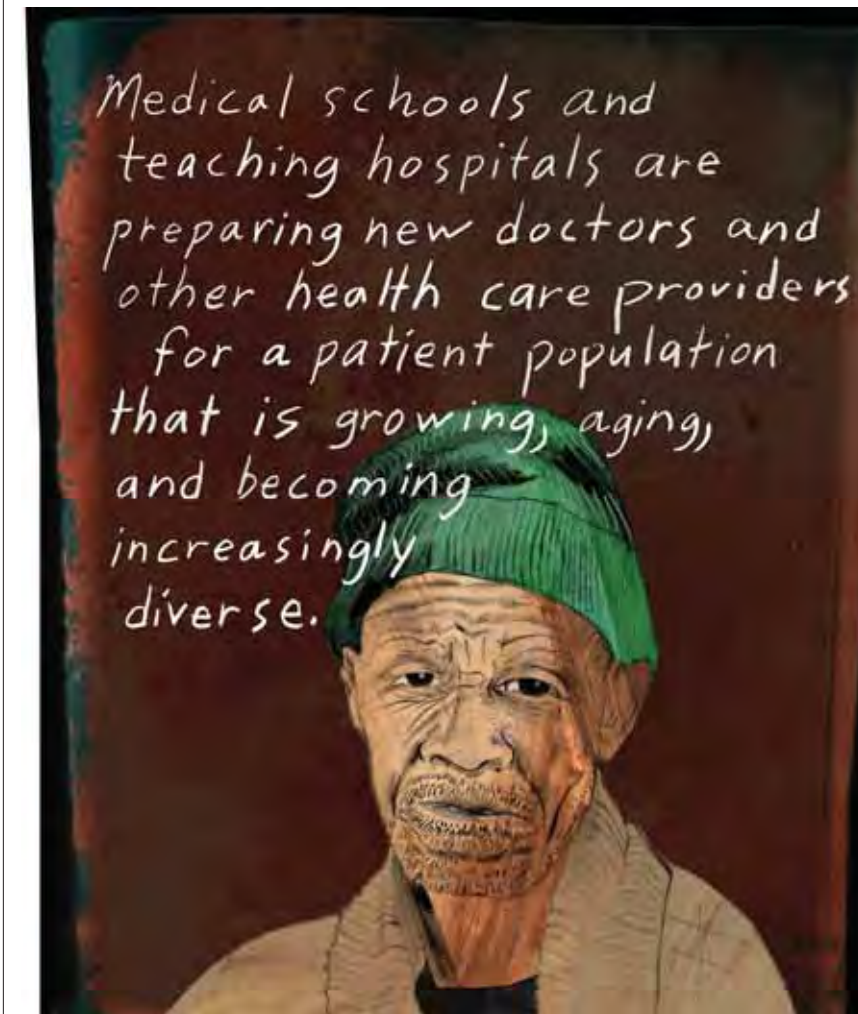
As we move forward, a critical step will be addressing the barriers posed by a financing and delivery system that prevents

other components from functioning effectively and efficiently. Achieving the level of integration necessary for true reform requires changing both financing and delivery systems in tandem. This will necessitate an unprecedented public-private partnership that we hope will be embodied in any health care reform legislation. Given the scale of the challenge, it makes sense that there should be pilots before any option is widely implemented, and such demonstrations will benefit from having an AMC at their core.

We are hopeful that the current debate and proposed reforms lead to comprehensive change that results in true health care transformation. At the same

time, we, as a community, must realize our potential to help bring about this transformational change. No one is better qualified than academic medicine to lead the nation in health care innovation and we should not hesitate to embrace this opportunity. ■

Darrell Kirch is president and CEO of the Association of American Medical Colleges, which represents the nation's medical schools, teaching hospitals, and academic societies. A member of the Institute of Medicine, Kirch is a distinguished physician, educator, and medical researcher based in Washington, DC.



With 62 surgeries behind him, Joey Finley has fought back against a rare disease that tried to silence his voice.

How Joey Finley found his new voice.

The cheerful chatter of children at recess fills the playground at Kennesaw Charter School, where Joey Finley, 8 years old and freckle-faced, sits atop a large yellow tube—King of the Slide. Then he’s caught up in a game of tag, a blur of boundless energy in a short-sleeved white shirt and khaki pants.



“I never thought I’d be so happy to see my child be completely average,” says his mom, Melanie Finley-Ellis, a volunteer at the charter school, as she watches her son play.

Not so long ago, Joey would have been sitting on the sidelines. When he did talk, which wasn’t very often at school, his voice came out as a hoarse croak. “His textured, Janis Joplin voice,” his mom calls it.

Video from that time shows a shocking disconnect—a fresh-faced boy in a chair at the Emory Voice Center speaking with the hoarse, gravelly voice of an elderly man.

“I was pretty used to it,” Joey says now. “But it was hard to talk. It was hard to say certain letters.”

The path from there to here—or as Joey calls it, from OV (old voice) to NV (new voice)—wasn’t easy for his family, his doctors, or Joey himself.

Joey’s first hospitalization came when he was 2 months old. When he wasn’t eating, he was switched to soy formula. As a toddler, he continued having sporadic difficulties with speaking, swallowing, and breathing. Doctors thought it was asthma, or perhaps a vascular condition.

“When he was 4, he started complaining that it hurt to talk,” his mom says. “You could see the muscles in his neck tensing and showing strain when he tried to speak.”

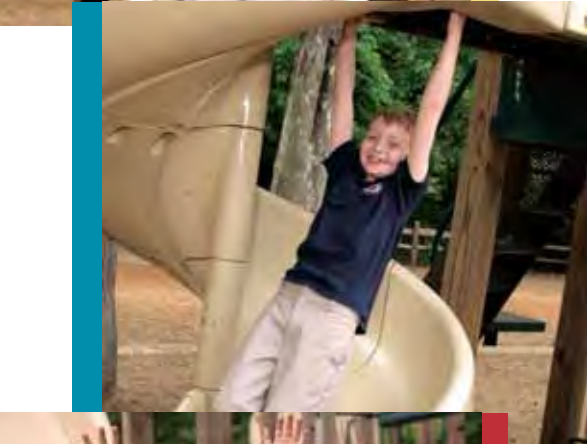
After years of visits to a few different pediatricians and ear, nose, and throat specialists, Finley-Ellis was desperate to find out what was wrong. Joey had had an MRI and CT scan, but the results came back normal.

Then came the turning point.

On a trip home from one of his hospital visits, she realized that her son in his car seat was choking on the crackers and juice he had gotten in the emergency room.

“I pulled the car over and called 911, then

By **Mary Loftus** • Photography by **Jack Kearsse**



“Joey’s whole personality changed when he got his voice. He started singing in music class, playing with friends, doing gymnastics.”
—Edie Hapner, Emory Voice Center

was doing mouth sweeping trying to get him to breathe when the paramedics showed up,” she says. “They wanted to take him back to the ER.”

But she insisted that they take Joey elsewhere—anywhere else—and decided that she wasn’t going to leave until the next doctor figured out what was wrong. “I was at the end of my wits,” she says. “I wanted someone to tell me how to help my child.”

THE DIAGNOSIS

Joey ended up at Children’s Healthcare of Atlanta at Egleston and, ultimately, Emory otolaryngologist Steven Sobol examined him.

“When children come in with a hoarse voice and problems with breathing, that’s a light bulb,” he says. “It’s papillomavirus unless proven otherwise. And my role is to protect the airway and get the child breathing.”

Recurrent respiratory papillomatosis (RRP), a rare disease in which small growths form in the upper airway including the vocal cords, is caused by human papillomavirus (HPV), which infects the skin and mucus membranes and often lives in the cervix.

While most women with HPV have children without complications, some will pass the virus on to their babies during birth. About 2,000 children get RRP every year.

For children like Joey who do develop the disease, it can be life threatening: the wart-like growths caused by a flare-up of the virus can block airways.

And while laser surgery can remove the papillomas, they often grow back while the disease is active. Joey has had 62 procedures, 16 of which were surgeries performed by Sobol. “This disease tends to show itself in the first few years of life, and the younger you are when you first get the symptoms, the

more difficulty you seem to have,” he says. “Initially, Joey had a fairly rough course.” Because the boy had had so many surgeries on his vocal cords in such a short time—having tubes put down his throat, going into the operating room every few weeks, and developing some inevitable scarring—his voice was constantly in flux and never had a chance to stabilize. In effect, he lost his ability to speak.

So Joey started using his “false” vocal cords, squeezing together the tissue above his actual vocal cords.

“When you do that, the air vibrates the false vocal folds, and you get a low, husky voice,” says otolaryngologist Adam Klein. “It was a stable voice, but not one that a 5-year-old should have had. Joey subconsciously turned to this because it’s the only voice that would reliably come out.”

FINDING NORMAL

Klein and Edie Hapner, of the Emory Voice Center, were enlisted to help Joey regain his normal voice.

Hapner, director of speech-language pathology, vividly remembers the first time she met Joey—this adorable little boy who had the croaking voice of an 80-year-old man.

“We got a normal voice out of Joey the first time we saw him,” Hapner says. “He is so smart, it was just a matter of teaching him the difference between what it sounded like and felt like to use his actual vocal cords.”

But Joey didn’t embrace the change immediately, choosing instead to switch back and forth for a while.

“He would say, ‘I have two voices, my NV [new voice] and OV [old voice].’” Hapner says. “He didn’t want one to be called better than the other.”

She used fun, silly exercises such as blowing raspberries and lip trills to encourage Joey, all the while applying the physics of tube resonance to strengthen and exercise his voice.

“Tubas and clarinets use tube resonance,” she says. “We are just playing with the instrument inside our bodies.”

Vocal folds, or cords, are vibrating valves that come together several hundred times a second to create pulses of sound with the rush of air from the lungs. Larynx muscles adjust the tension to create an individual voice’s pitch and tone: women’s voices are higher at 200 to 230 hertz while men’s are lower at 100 to 120 hertz.

Young boys have even faster moving cords and higher pitches, resulting in the angelic tones that comprise the Vienna Boys Choir.

By using video stroboscopy—taking pictures of the voice box with a camera attached to an endoscope hooked to a strobe light—Hapner and Klein were able to see Joey’s vocal cords at work. They were also able to see the BB-shaped papillomas that were interfering with his ability to speak.

GOODBYE, FROGS

Luckily for Joey, his disease has slowed down considerably in the past few years. He still has to have scopes, but his last surgery to remove a papilloma was in December 2008. “He went from having them removed every few weeks to going a year and a half,” says Finley-Ellis. “Joey calls them frogs and tells Dr. Hapner that she took his frogs away.”

The first time Joey got in trouble for talking too much in school, Finley-Ellis called Hapner, and they both started crying.

“His whole personality changed when he got his voice,” Hapner says. “He always had that cute little face, but in terms of being a social creature, he wasn’t. Once he got his voice, he started singing in music class, playing with friends, doing gymnastics.”

Hapner’s office at the Voice Center is filled with frogs—stuffed frogs, plastic frogs, ceramic frogs.

“Joey and his mom bring me a frog

every time they visit,” she says. “Thank God for small children who heal so well, good surgeons, and dedicated mothers. He can’t even do the Old Voice anymore. He doesn’t remember how.”

What Joey can do is play, and sing, and laugh, and talk too much to the boy who sits at the table next to him in class. He cheers on his favorite driver at the Atlanta Motor Speedway. He pesters his 6-year-old sister, Keri, and plays ball with his dad, Mark. And he makes up strange mathematical formulas about dogs and cats.

“We have four cats: Radar, Lola, Monster, and Iggy,” he says, taking a break at a picnic table under a tree on the playground, sweat dripping down his flushed face. “Having four cats is equal to having one dog.”

Then he’s off, an 8-year-old boy with an 8-year-old voice, part of the glorious symphony, raising a joyful noise into the bright blue sky. ☀️

WEB CONNECTION To hear Joey Finley using his OV, visit whsc.emory.edu/r_voice.html. For appointments, call 404-778-7777 or visit emoryhealthcare.org/departments/voice_center/index.html. To see a video about the experiences of Karon Schindler, another patient of the Emory Voice Center, visit whsc.emory.edu/r_voicetest.html.

A troubling virus, a promising vaccine

The human papillomavirus (HPV), which causes recurrent respiratory papillomatosis (RRP), is surprisingly widespread: about 20 million Americans are currently infected with HPV, according to the CDC, and another 6.2 million people become newly infected each year. At least half of sexually active men and women acquire HPV at some point in their lives. The virus, which can lie dormant for years, is a primary cause of cervical

cancer. The CDC now routinely recommends the HPV vaccine Gardasil for 11- and 12-year-old girls, as well as anyone under age 26 who has not had the series of shots. “By giving the vaccine to adolescent girls, there is the hope of creating a herd immunity as we go into the next generation,” says Adam Klein, an otolaryngologist at the Emory Voice Center. “We expect this will greatly diminish cervical cancer and cases of RRP.”

The Emory Voice Center

Autographed CDs from Peter Gabriel, Lauryn Hill, and Coldplay line the walls of the waiting room of the Emory Voice Center at Emory University Hospital Midtown—all high-profile patients who have received help here since the center opened in 2003. Directed by Michael Johns III, the center treats patients with ailments including voice strain, vocal cord nodules and polyps, Parkinson’s disease, swallowing disorders, and throat and neck cancers.

A dimly lit room with marbled walls and a Zen rock fountain is designed for patients, such as those with spasmodic dysphonia, who receive regular Botox injections. With more than 450 Botox patients who have shots in their necks every three months, “we thought a calm room was the least we could provide,” says speech language pathologist Edie Hapner.

The center also has offered head and neck cancer screenings at the Atlanta Motor Speedway and a vocal health seminar at the Atlanta Opera Center in honor of World Voice Day.

Can suppressing
a little molecule
known as {PD-1} slow
HIV from going to
full-blown AIDS?

A caution light for AIDS

By Quinn Eastman

Andrew Lipschitz was one of the first doctors to become infected with HIV through a needle stick. In the early 1990s, he nearly died of AIDS-related lymphoma. Although relatively healthy now, he takes seven drugs every day to stave off HIV, a regimen that costs thousands of dollars a year. Lipschitz knows firsthand that a treatment that would allow someone living with the virus to go off medication for long periods of time would be extremely valuable. He's helping support just such an effort as medical director of Concerned Parents for AIDS Research, a New York-based charity organized by parents who have all been touched by AIDS.

Last year, the group contributed \$250,000 to the Emory Vaccine Center, a seed grant that supported collaboration between the lab of Georgia Research Alliance Eminent Scholar Rafi Ahmed, who directs the center, and researchers at Harvard. That work has blossomed into a \$13 million NIH-funded collaboration among several universities aimed at understanding how the immune system is tricked by chronic infections such as HIV/AIDS and hepatitis C.

A green light for balanced immunity

The researchers believe that a boost to the immune system, combined with medication, could send a strong holding signal to HIV for years.

In December 2008 in *Nature*, they described what appears to be an attractive target for HIV therapy: the molecule known as programmed death-1. PD-1 is an immune system receptor that is able to hamper immune responses during chronic infections. Treating monkeys infected by HIV's cousin, SIV, with an antibody against PD-1 allowed the animals to fend off the virus for several months.

"I didn't think that the results from primates would be so strong," says Rama Amara, an Emory researcher at the Yerkes National Primate Research Center who works with Ahmed and performed the monkey studies. "They really blew me away."

A potential clue as to why these results were so strong lies in the way HIV attacks the immune system, Amara says. HIV attaches to CD4+ or "helper" T cells, the white blood cells that initiate the body's response to invading micro-organisms.

Previous experimental therapies focused on raising the levels of CD4+ T cells in infected people because patients appear to become more vulnerable to opportunistic infections when levels of the cells drop. But there's a catch. "If you do something to make CD4+ T cells healthier, you could also be giving the virus more targets," says Amara.

Blocking PD-1 may turn out to be a more balanced approach because PD-1 dampens more than one arm of the immune system,

Amara says. In SIV-infected monkeys, blocking PD-1 did temporarily increase levels of the target CD4+ cells and HIV in the blood. But antibody-producing B cells and "killer" T cells (which clear virus-infected cells from the body) then pushed HIV levels down in a sustained way for months in some animals.

"We're finding that having enough antibodies to resist other opportunistic infections plays an important role in preventing viral infection from progressing to full AIDS," he says.

A red light for autoimmunity

PD-1 apparently plays a role in keeping immune responses from getting out of control. Part of a complex network of regulatory molecules, PD-1 inhibits the ability of T cells to recognize foreign invaders and respond to them. Without PD-1's constraints, the immune system tends toward autoimmunity,

with antibodies attacking the body's own tissues indiscriminately.

Mice genetically engineered to lack PD-1 tend to develop either a lupus-like condition or a weakened heart. In people, variations in the gene have been linked with autoimmune diseases such as lupus, rheumatoid arthritis, and type I diabetes.

Ahmed and his colleagues were the first to discern the role of PD-1 in chronic infections. They compared T cells from mice infected with two strains of an encephalitis-causing virus. One strain causes an acute infection that eventually clears, while the other causes a long-lasting infection.

Levels of PD-1 rise in T cells as the immune system fights a chronic infection. Ahmed says that viruses involved in chronic conditions are taking advantage of limits imposed by molecules like PD-1. Viruses such as HIV and hepatitis C can wait for T cells and other immune cells to become

"exhausted" and then establish themselves for the long term. After enough time goes by, the T cells act as if the viruses are no longer threats and cease their attack.

"It's as if they're hypnotized," he says. "They don't see the enemy."

Driving change agents

With an eye to minimizing side effects as well as keeping costs low, Amara envisions a "short and sweet" period of immune system therapy. Working with SIV-infected monkeys, he is combining PD-1 antibody treatments with antiretroviral drugs, either simultaneously or in tandem, to determine what works best.

With the new federal funding, Ahmed is steering a broad effort to explore PD-1 biology that includes scientists from Emory, Harvard, New York University, and the uni-

versities of Montreal and Pennsylvania. The NIH support will enable them to explore several questions. Which is the most important molecule to partner with PD-1 when developing therapies? How is the PD-1 gene turned on and off? How do different pairings of PD-1 with other molecules relate to its ability to withstand HIV's onslaught for an extended period?

Because PD-1 has a common role in the response to several chronic infections, blocking it could help shape therapies for not only HIV but also hepatitis B and C. Already a study in chimps at Children's Hospital in Columbus, Ohio, is testing whether blocking PD-1 could work against hepatitis C. In addition, an independent biotechnology firm is examining PD-1 antibodies as a potential therapy for advanced forms of cancer.

Meanwhile, Lipschitz finds it satisfying to see how far the seed money from Concerned Parents has grown into a powerful potential signal to control HIV. □

Rama Amara was surprised at how well monkeys were able to fend off AIDS with the help of an antibody against the molecule known as PD-1.



The comforts of home in the hospital



One patient, one doctor, and one vision came together in 1996 to create a place unlike any that had come before at Emory University Hospital.

The patient wasn't just any patient. He was John Rollins, a self-made North Georgia businessman who owned and operated 12 businesses by the time he was 35. The doctor wasn't just any doctor. He was Paul Seavey, known as "the doctor that all doctors wanted to have as a doctor." And the vision was a large one: to develop a hospital environment where comfort matched world-class care, where patients could heal in a place more like home.

Today, the John W. Rollins Pavilion ranks first in patient satisfaction out of 1,080 hospital units in the nation, according to Press Ganey. And the pavilion has served more than 5,000 patients, from a U.S. president and celebrities to ordinary families.

Reminiscent of rooms in a deluxe hotel, the pavilion's 11 V.I.P. suites provide guests

with meticulous care and elegant surroundings. Each suite features a patient room and separate sitting room with cherry wood furniture, dining table, sleeper sofa, and an entertainment center. While being near loved ones, families of patients can continue to transact business from the suite with wireless internet access, an in-room fax machine, and daily delivery of the *Wall Street Journal* and the *Atlanta Journal-Constitution*. A concierge takes care of special requests, and chefs cook up personalized meals.

"The facilities are nice," says Emory internist Dave Roberts, who trained under Seavey, "but what really makes the Rollins Pavilion distinct is the nursing care."

One of those nurses, Trish Archer, often worked alongside Seavey and now manages the pavilion. An Emory veteran of 26 years, her experience is typical of that of the RNs in the unit. Half have critical care experience, and all have worked in surgical and post-op areas.

"Emory Healthcare has launched new initiatives in patient- and family-centered care," says Irene Wheeler, an Emory nurse for 30 years and unit director of the pavilion, "but we've been leading the way on that for 10 years. We're experts on it." That care comes through staff readily available for families, a space that offers more privacy than a typical hospital room, and a low ratio of 1 nurse for every 3 patients.

Michele Rollins, John's widow, has taken

an active part in the pavilion, most recently donating cabinetry to update the original wing. Other family members, Randall and Peggy Rollins, have contributed toward decorating and refurbishing. And Molly Candler, wife of the late C. Howard "Buddy" Candler III, recently bought new high-tech patient beds, which readjust air automatically when a patient moves to help prevent bedsores.

Recently, generations of the Rollins and Seavey families gathered for the unveiling of a commemorative plaque to Rollins and Seavey, men with vision for generations of Emory patients and families to come.

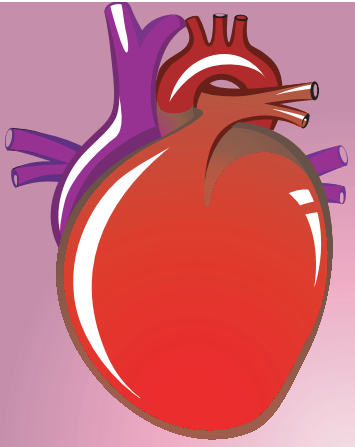
—Rhonda Mullen



WEB CONNECTION For more info about the Rollins Pavilion, contact Trish Archer at 404-712-0650 or visit emoryhealthcare.org/departments/rollins/index.html.

Did you know? In *Atlanta Magazine's* new ranking of Top Doctors, 44% in Georgia come from Emory. To see the list, visit atlantamagazine.com. To make an appointment with one of these docs, visit emoryhealthcare.org.

For a heart attack in Atlanta, take me to Emory



You don't feel like yourself. There's an uncomfortable pressure in your chest, a tingle down your left arm, and you just can't seem to get your breath. Would you know you were having a heart attack? And if so, would you know what to do?

Start by calling 9-1-1, says Kate Heilpern, chair of Emergency Medicine at Emory. "Seconds and minutes absolutely matter, and by recognizing the signals of a heart attack and calling 9-1-1, you will have a fighting chance to get yourself or a loved one to a center able to handle such emergencies."

And if you live in Atlanta, when EMS arrives, ask them to take you to Emory. Why? Emory University Hospital and EUH Midtown are the only chest pain centers in the metro area to be accredited for angioplasty by the Society of Chest Pain Centers (SCPC). The designation indicates a higher level of emergency cardiac services. (Coronary angioplasty is a procedure to treat narrowed arteries of the heart. During the procedure, a balloon is used to open a blockage in a coronary artery, improving blood flow to the heart.)

A goal of the SCPC is to reduce mortality from heart attack (about 600,000 Americans die of heart disease annually). The society is teaching the public to recognize and react to early symptoms of a possible heart attack, reducing the time it takes to receive treatment, and increasing accuracy and effectiveness of treatment.

According to a study by Emory emergency medicine doctor Michael Ross in the *American Journal of Cardiology* (July 2008), accredited hospitals performed better in heart attack core measures established by the Centers for Medicare and Medicaid Services than nonaccredited hospitals. If all hospitals performed core measures at levels reported by accredited chest pain centers, more heart attack patients would be treated with aspirin and beta blockers, Ross says. That "might lead to more heart attack patients receiving emergency angioplasty within 120 minutes—the so-called 'door to balloon' benchmark."

At Emory, the chain of survival from the 9-1-1 call to the ER to the cath lab is available 24/7. **"When EMS suspects a heart attack, getting the patient to the right place at the right time with the right providers to do the right thing definitely optimizes patient care and enhances quality and outcome,"** says Heilpern.

Emory participates in the Metro Atlanta Cardiology Consortium's TIME (timely intervention for myocardial emergencies) program, which has developed a rapid response to cardiac emergency by improving every step of care. As a part of TIME, full 12-lead EKG units are in all the ambulances that respond to 9-1-1 calls in Fulton County. They are able to transmit the EKG to participating hospitals, where a physician reads the EKG and activates the emergency cath team even before the patient arrives, shortening time between onset of the heart attack and the opening of the artery.

You may be having a heart attack if you experience

- Chest discomfort—from an uncomfortable pressure to squeezing or pain
- Discomfort in other areas of the upper body—including in one or both arms, the back, neck, jaw, or stomach
- Shortness of breath
- Cold sweat, nausea, or feeling lightheaded

If you are experiencing these symptoms, call 911

How do chest pain centers receive accreditation?

- Integrate the emergency department with local emergency medical systems
- Assess, diagnose, and treat patients quickly
- Effectively treat patients with low risk for acute coronary syndrome and no assignable cause for symptoms
- Continually improve processes and procedures
- Support personnel competency and training
- Maintain an organizational structure and commitment
- Have a functional design that promotes optimal patient care
- Support community outreach programs that educate the public to seek medical care promptly when presented with symptoms of a heart attack

A Rapid ARC to recovery

Linwood Holeman thought he was taking good care of himself. He'd been a vegan for 10 years, eating no meat, cheese,



or animal by-products. He didn't smoke or use drugs. He exercised regularly. Still at age 67, he got a dreaded diagnosis: prostate cancer. It was the disease that already had taken a heavy toll in his family. His grandfather, dad, and uncles on his dad's side of the family all had died of prostate cancer. But unlike his father, whose cancer had spread before it was diagnosed, Holeman was keeping close watch for signs of the disease. He saw his internist twice a year for check-ups, and in one 6-month period, his vigilance paid off. A blood test for early detection of prostate cancer showed his prostate specific antigen score shot from 0 to 4 in less than 6 months, indicating that something was amiss.

Holeman, who had his own accounting software business for 26 years, has another advantage: access to the newest radiation oncology treatment system in Georgia. Each weekday, he receives radiation therapy at Emory University Hospital (EUH) Midtown via a new delivery system. RapidArc is a faster and more accurate method of aiming radiation at prostate cancer cells and leaving healthy cells unharmed. EUH and EUH Midtown are the first facilities in the state to offer the system.

Even when a person is lying still, internal organs continue to move in response to breathing and other normal functions, such as digestion. For cancer patients undergo-

ing radiation therapy, these movements, however slight, can affect the accuracy and effectiveness of the treatment. For prostate cancer patients in particular, movement during radiation treatments can have tough consequences—damage to the bladder, rectum, or seminal vessels, which in turn can lead to incontinence or impotence.



This summer, Linwood Holeman received radiation therapy at Emory University Hospital Midtown, overseen by oncologist Karen Goddette. Emory's new system is quicker and more precise than traditional radiation therapy.

RapidArc, which matches or exceeds the precision of conventional radiation therapy, is available also for patients with head and neck cancers or brain tumors.

"The main advantages of this system are speed and precision," says Walter Curran, radiation oncology chair and chief medical officer of the Emory Winship Cancer Institute, the only NCI-designated comprehensive cancer center in Georgia. "This new system helps minimize the chance of movement, which affects accuracy during treatment."

RapidArc enables physicians to deliver

a complete dose with a single rotation of the treatment machine around the patient. Treatments that once took up to 15 minutes can now be completed in less than 5. For patients like Holeman who get radiation daily over the course of several weeks, those extra minutes make a significant difference.

"It feels like you're having an x-ray,"

Holeman says. "There's nothing invasive. It doesn't hurt, and it's fast and easy."

Once he completes this course of radiation therapy, Holeman will receive a radioactive seed implant in the prostate, and he'll follow radiation safety precautions for eight weeks. After that, he hopes to get back to his favorite hobby—traveling. So far, he's trekked to Israel, Egypt, Ghana, Kenya, and Mt. Kilimanjaro. Another trip to Africa may be on the horizon.—Rhonda Mullen

WEB CONNECTION To learn more about RapidArc treatments, contact 404-778-7777 or visit emoryhealthcare.org.

From the Starlight to the Towers



Eleanor Norton

Although her high school teachers encouraged her to apply for the Rockettes because of her flexibility and dance moves, Eleanor Norton was neither tall enough (5 ft.) nor big enough (97 pounds) to meet the height and weight requirements. So instead she turned to other career paths that helped her use her flair for entertaining.

One of her all-time favorite jobs was guiding tours at the upscale Cherry Hill Inn, across from Garden State Park, a grand horseracing venue built in the 1940s in New Jersey. For Norton, the best part was show-

ing visitors the Starlight Room, a ballroom for weddings and other celebrations. With an office right down the hall, she often got cake and flowers after the ceremonies.

These many years later, Norton is still giving tours several times a week at Wesley Woods Towers, a retirement living community at Emory. She takes visitors through a newly renovated lobby and past a bulletin board where residents sign up for transportation to the grocery store or doctor's appointments. She shows off a library with well-stocked shelves, a gallery that features the art of the people who live and work there, a computer room, a beauty shop, and a foot care clinic.

Usually, she has just one or two people in tow who are looking for a home for an elderly parent, but sometimes she gets a group of 15 or more Emory University students. "It's hard to get them all in here," she says, gesturing around her efficiency apartment on the sixth floor, decorated with photos of her late husband (a "cracker-jack" salesman), three children, five grandchildren, and one great-grandbaby.

In the decade that Norton has lived at Wesley Woods Towers, she has run an on-site thrift store, worked at the front desk, been active in the residents association, and served as a floor representative. "They keep me busy, and that's why I like it," she says. In fact, she recently turned down an invitation to join a regular group that plays Rummikub, a popular game at the Towers, because it would interfere with her other activities.

Norton admits that getting old is not easy. It helps to have family nearby—all three of her children have settled in Georgia, and she frequently entertains her grandson ("over 6 ft. tall," she points toward the ceiling) and other family members. Still, she's lost some friends at Wesley Woods, and recently, she herself experienced a transient ischemic attack.

After a few days in the hospital and recovery, Norton feels back to normal. Just in case, she's taking it easy now and cutting back to only two tours a week. But she can still show you the flower planters that the residents association installed from money made in the thrift store or where to play a round of Rummikub or to find a good read.—Rhonda Mullen

A community for the young at heart



Wesley Woods Center offers comprehensive geriatric care to aging seniors and their families. The Towers, which offer independent living for seniors, assisted-living services, and a full meal plan, are next door to Wesley Woods Clinic, Wesley Woods Hospital, and a health building with dental services. Specialty services on the 64-acre wooded campus include rehabilitation therapy, inpatient geriatric psychiatry, medical acute care, and dental care. Researchers at Wesley Woods study Alzheimer's, late-life depression, Parkinson's, sleep disorders, and age-related conditions, with the goal of improving the lives of the young at heart.

To schedule a personal tour of Wesley Woods Towers, call 404-728-6663. Virtual tours of the entire campus are available at emoryhealthcare.org/hospitals/wesleywoods/vw-virtualtours.html.

Experiential math

The 4-year-old was a handful, to say the least. His birth mother had abused alcohol during pregnancy, leaving her son with a host of behavioral and learning problems. He couldn't sit still for more than 30 seconds. Cochlear implants allowed him to process sounds, but a short attention span made learning or following directions challenging. When his foster mother brought him to Marcus Autism Center (an affiliate of Children's Healthcare of Atlanta), she told a therapist she was unsure whether she could adopt him.

But during a six-week program designed to improve math skills and behavior, the boy made remarkable progress. His attention span went from mere seconds to 10 minutes. He made dramatic gains in math, and his performance also improved on tasks of general cognitive functioning. With the improvements, he and his foster mother were able to better connect, and she did adopt him.

Developed by faculty members at Emory School of Medicine, the Math Interactive Learning Experience (MILE) program offers a comprehensive math intervention for children with fetal alcohol syndrome (FAS) or fetal alcohol spectrum disorders (FASDs). The program also includes education workshops for parents and guardians of children exposed to alcohol prenatally.

The umbrella term for the range of disorders that can result from prenatal alcohol exposure is FASD. The most severe of these disorders, FAS, is a lifelong condition that causes physical and mental disabilities. Abnormal facial features, growth deficiencies, and central nervous system problems may characterize FAS.

Historically, children with FASD were described as "unteachable," and therefore little attention was paid to helping them. The MILE program is one of just a few programs ever developed to improve educational and behavioral outcomes for alcohol-affected children.

"When FAS was first identified, there was a debate about whether alcohol really caused developmental problems," says Julie Kable, a pediatric psychologist at Emory and Marcus, who helped develop

MILE. "Since then, 25 years have passed, and we know that alcohol abuse during pregnancy really does cause long-term problems."

Children with FAS have difficulty regulating their behavior, says Claire Coles, a pediatric psychologist in Emory's psychiatry department who leads an FAS clinic at Marcus. "They have trouble organizing themselves and difficulties with impulse control. They also have visual and spatial deficiencies, which affect their ability to learn math," says Coles, a co-creator of MILE.

In one study, more than 55% of children who participated in MILE significantly improved in math performance. All parents in the program reported an improvement in their children's behavior, so much so that many of the children's teachers requested a briefing on MILE. After six months, the participants were tested again, and more than 68% of them showed persistent improvement in learning and behavior.

Specifically MILE teaches math to children using the FAR technique—focus and plan, act, and reflect. The children solve math problems while using a timer so they can see the passage of time—an important component, says Coles, because "alcohol-affected children often have no concept of time."

The program focuses on presenting math through experiential learning that involves manipulation of items. "They need to see it, feel it, experience it," Coles says.

For parents, the educators provide behavior management techniques that help prevent children's temper tantrums and other negative behaviors. Parents also learn to use everyday situations to reinforce math skills—for example, helping their children count creamers or sugar packets when eating out. Drilling math facts, however, is a "no-no" in the MILE curriculum.

More important, say Coles and Kable, is that MILE children experience success in a learning environment, become more open to learning, and achieve improved relationships with their parents.

The team currently is taking the MILE techniques to a broader audience of Atlanta schoolteachers.—Kay Torrance



Prevention trumps treatment

Those born outside the Southeast who didn't move to the region until after they were 21 have much better odds of avoiding a stroke than their Southeastern born-and-bred counterparts. That news came at the fourth annual Emory/Georgia Tech symposium on predictive health.

"If you were not born in the Southeast, but you're living here, you have a protective factor," said Daniel Lackland, a cardiovascular epidemiologist at the Medical University of South Carolina, who spoke at the conference. "There's something that's happening in early life that seems to make the difference."

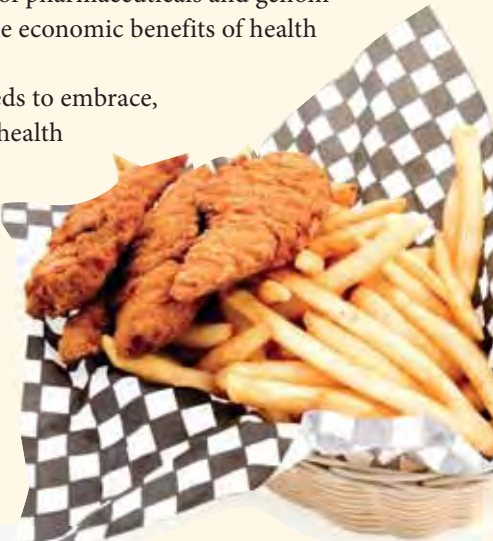
Epidemiologists have long pegged the region as the Stroke Belt, but just what may be happening when it comes to stroke and disease has become of increasing interest in the relatively new field of predictive health. Predictive health draws on a new paradigm to define unique characteristics that predict disease risks for individuals and populations. It uses new discoveries in biomedicine to emphasize health maintenance and recovery rather than treatment of disease.

With an emphasis on quality of life through disease prevention and health maintenance, predictive health also promises to bolster the economic fitness and quality of U.S. health care. "We can all agree that the past few months mark the beginning of a new economic and political era in the United States, said Fred Sanfilippo, Emory's executive vice president for health affairs, who kicked off the symposium. "The time is right for some new solutions to our broken health care delivery system, and it's becoming increasingly clear that the predictive, personalized health approach is one of the innovative answers to our current crisis."

The recent symposium focused on biomedical factors that integrate biology, behavior, and the environment. Presenters examined new ways to define and measure health, the role of pharmaceuticals and genomics in personalized medicine, and the economic benefits of health promotion and disease prevention.

What the United States truly needs to embrace, according to presenter Kim Rask, a health policy expert at Emory's Rollins School of Public Health, are the economic benefits of health promotion. Not only do we pay much more for our health care than other countries, says Rask, we also perform relatively poorly compared with other industrialized countries in rates of mortality.—Robin Tricoles

WEB CONNECTION Presentations are available at predictivehealth.emory.edu/symposium_video2008.cfm.



Technology for mental health

Each year, unknown numbers of people with severe mental health disorders get lost in the health care system. They may find themselves on a Ferris wheel of rotating doctors and nurse practitioners and unable to relay important information about their health history to providers.

An electronic personal health record (PHR) may be able to bridge the information gap for those people, says Benjamin Druss. PHRs are available to anyone through the Internet.

"PHRs are on the cutting edge now, but 10 years from now everyone will have one," says Druss, the Rosalynn Carter Chair of Mental Health at Emory's Rollins School of Public Health.

He is leading a pilot study to evaluate the use of a PHR tailored for mental health care among at-risk populations. Such patients typically exhaust private health insurance benefits or cannot work. They are commonly treated at community health clinics or public hospitals, leading to multiple providers and paper records that are lost or incomplete.

Druss has altered a PHR widely used in Seattle to allow for entry of more medication information and an advanced mental health directive identifying the person the patient wants to make treatment decisions if he or she is unable to do so. Patients carry a card to alert clinicians about their disorder and existence of the PHR. A clinical care specialist helps them complete a password-protected PHR and teaches them how to find and use computers in the community. The PHR also sends reminders about upcoming appointments.

The goal, Druss says, is to make the mental health PHR as user-friendly as possible for people with a serious mental disorder.—KT

WEB CONNECTION To set up your own PHR at Emory Healthcare, visit emoryhealthcare.org/patient_info/health_record_intro.html.



GENERATION M2M

Emory wants to breed a new kind of scientist.

The university has started a new PhD program, “Human Health: Molecules to Mankind,” or M2M, designed to educate graduate students in both lab and population sciences. Students will enroll in one of four tracks: predictive health, population processes and dynamics of infectious diseases, biomarkers and development of acute and chronic diseases, and genetic environmental determinants of health. They will work with mentors in Emory’s medical school and its Rollins School of Public Health.

“Traditionally, graduate education has been along disciplinary lines,” says Kenneth Brigham, director of the Emory/Georgia Tech Predictive Health Institute, who will co-direct the M2M program with Emory epidemiologist Michele Marcus. “People who get a PhD in biochemistry, for example, tend to have their education and efforts focused on that subject without the broader view, without the implications in populations. On the other hand, public health students learn epidemiology and population behavior often without an in-depth understanding of the basic science behind them.

“We want to create this new generation of scientists that move comfortably across the gulf,” Brigham says. “We want to create the bridge and then populate the bridge with people who can move comfortably across it.”

The doctorate is funded by a five-year \$2.5 million grant from the Burroughs Wellcome Fund.—KT

Cultivating and nursing a collective voice

Doctors and nurses at Children’s Hospital of Philadelphia were seeing pediatric patients with gunshots wounds at an alarming frequency. The hospital’s trauma doctors had mobilized and spoken to the media about the issue. The mayor’s office was getting involved. But where were the nurses?

Nursing professor Linda McCauley presented that question to her undergraduate students in a community health course at the University of Pennsylvania. “Where is nursing’s collective voice in stopping the shooting of children? It’s okay to patch and heal them, but why is nursing silent in the other areas?”

McCauley wants to see nurses speaking up and out in a collective voice. “Nursing is the most trusted profession and the largest in health care,” she says, “but we don’t go to the table. And we don’t teach nursing students to join collectively to have a voice.”

McCauley has a chance to rectify that as the new dean of Emory’s Nell Hodgson Woodruff School of Nursing. Nationally known for her research on the effects of pesticides on migrant farm workers, she is a member of the Institute of Medicine.

Since she became dean in May, McCauley already has made a long to-do list. She wants to bring more researchers on board, and faculty recruitment is top priority. Programs can’t grow without faculty, she says. In addition to the school’s core areas of research in symptom management and chronic disease and midwifery and maternal health, she would like to explore the addition of research in palliative care or mental health.

In turn, stronger research programs should help grow the PhD candidate base, McCauley says. She wants to make sure

undergraduates know that research doesn’t always entail working with test tubes or sitting in front of a computer. “Students get mesmerized by clinical care,” she says, “but research is fascinating and rewarding too.”

McCauley wants to interest at least two students each year to pursue doctoral studies. To do so, she wants to introduce students to nursing science earlier in their education, in freshman and sophomore years. “By the junior or senior year, schedules have become so tight that students don’t even want to think about staying in school longer,” she says.

McCauley’s own venture into environmental health developed in the mid-1990s. She was studying Gulf War veterans while at Oregon Health & Science

University when she met Juanita Santana, director of a Head Start program for children of migrant farm workers.

Together the two undertook a five-year study on pesticide exposure. McCauley formulated the study parameters, and Santana provided a gateway into a population that often fears outsiders. Although the study raised the ire of some growers, the researchers were able to bring them on board by appointing the farmers to an advisory committee. Soon the growers wanted their own children and homes tested for exposure.

“The study was successful because Linda was responsive to issues in the community rather than coming in and saying this is what I want to work on,” Santana says. “She listened to the people and cared about them.”

McCauley says community-based research is one of the hardest types of research to do, but the rewards are immense. She hopes to pass along her fervor to Emory’s nursing faculty and students.—KT



Nursing is the most trusted profession in health care, but nurses still lack a group voice, says the new dean.



A call for change in residents’ hours

Health care facilities can create safer conditions within the existing 80-hour limit by providing residents regular opportunities for sleep and limiting extended periods of work without rest.

— Michael Johns, Emory Chancellor and IOM committee chair

On an October evening in 1984, Libby Zion came to the New York Hospital in Manhattan. The 18-year-old college freshman arrived in an agitated state with a fever and jerking movements. She was admitted for observation and hydration and then given medication to mitigate her movements. However, she grew increasingly agitated, was placed in restraints, and eventually given more sedation—all with the approval of an off-site attending physician. The two physicians who

treated Zion were first- and second-year residents.

Zion finally calmed down but was not visually re-evaluated by either resident. The first-year resident was taking care of dozens of other patients. The second-year resident was trying to get some sleep. Toward morning, Zion’s temperature climbed to 107°F. Before long, her heart stopped. Attempts to resuscitate her failed.

Although the exact cause of Libby Zion’s death remains unknown, her case served as a catalyst for a series of reforms in medical education. Twenty-five years after her death, reforms in medical education are still ongoing. Last October, the Institute of Medicine (IOM) issued a report calling for a revision in residents’ hours, duties, and workload. The goal is to decrease the chances of fatigue-related medical errors and enhance the learning environment for doctors-in-training.

“Fatigue, spotty supervision, and excessive workloads all create conditions that can put patients at risk and undermine residents’ ability to learn,” says IOM committee chair Michael Johns, chancellor of Emory University.

The Accreditation Council for Graduate Medical Education set the maximum average hours that residents should work at 80 per week in 2003. Rather than further reducing residents’ overall hours, the IOM report recommends reducing the maximum number of hours that residents can work without sleep to 16. It also suggests increasing the number of days that residents must have off and restricting moonlighting activities during off-hours.

“Health care facilities can create safer conditions within the existing 80-hour limit by providing residents regular opportunities for sleep and limiting extended periods of work without rest,” says Johns.

However, the report cites financial costs and an insufficient health care workforce as major barriers to revising resident hours, and it calls for additional funding for teaching hospitals. Funding additional costs associated with shifting some work from residents to other health care personnel or additional residents could cost medical centers a total of \$1.7 billion per year.

The committee, composed of medical and scientific experts from across the nation, also calls for greater supervision of residents by experienced physicians, limits on patient caseloads based on residents’ levels of experience in a specialty, and overlaps in schedules during shift changes to reduce the chance of errors during the transfer of patients from one doctor to the next.—RT

WEB CONNECTION To read the complete IOM report, visit <http://www.iom.edu/residenthours>.

Do you need a house call? Emory neurosurgeon Sanjay Gupta is on call to answer your questions on a new health website from CNN. Ask the experts, including Emory oncologist Otis Brawley and Emory psychiatrist Charles Raison at cnn.com/HEALTH/expert.q.a/archive/

Relocating central vision

The patients that Emory low vision specialist Susan Primo sees have already exhausted most of their treatment options. They’ve completed medication regimens or had surgery to slow advanced age-related macular degeneration (AMD), a leading cause of blindness in the elderly. But still they don’t see well.

That’s where Primo comes in. She is studying whether behavioral modifications can lead to a change in brain activity to maximize use of remaining vision. “I work with these patients to see what they’d like to do to regain some independence,” says Primo, director of Vision and Optical Services, Low Vision at the Emory Eye Center. “Is it reading the mail or the *Wall Street Journal*? Or maybe, it’s driving.”

In macular degeneration, the macula—a layer of tissue on the inside back wall of the eyeball—gradually deteriorates. That delicate tissue is responsible for visual acuity, particularly in the center of the retina. Central vision is needed for seeing small and vivid details such as words on a page or the color of a traffic light, which means it is vital for common daily tasks such as reading or driving.

In more than two decades of working with patients who are visually impaired, Primo realized that people typically use their peripheral vision to compensate for loss in central vision. Studies have shown that people with progressive central vision loss compensate by spontaneously adopting a preferred retinal location (PRL) that takes over responsibility for visual clarity.

But what Primo, along with Georgia Tech psychologist Eric Schumacher, wanted to know was whether using these peripheral regions caused a change in how the brain is organized. Armed with Schumacher’s expertise in functional magnetic resonance imaging and Primo’s clinical experiences, the researchers did indeed discover continued activity in the part of the brain that maps to the macula. The brain scans of people with AMD who had developed their



peripheral vision showed substantially more activity than those of people who had not developed a PRL. Their study appeared in the December 2008 edition of *Restorative Neurology and Neuroscience*.

In a current study, Primo and Schumacher are exploring whether occupational training and biofeedback can help people with AMD focus on using good retinal cells and in turn speed up the brain’s reorganization. “Although others have tried to study this reorganization of macular degeneration before, no one, to our knowledge, has tried to influence it,” says Primo. “Yet it’s important to begin to come up with therapies, treatments, and technology to help patients begin to use their residual vision faster and better than they could before.” —RT

WEB CONNECTION To view a video of how macular degeneration affects vision, see whsc.emory.edu/r_macular.html.



JAMES CURRAN HAS SERVED AS DEAN OF EMORY’S ROLLINS SCHOOL OF PUBLIC HEALTH (RSPH) SINCE 1995, but recently he received new recognition: Emory’s first endowed chair in honor of a sitting dean. Endowed chairs allow the university to recruit and recognize faculty who are leaders in teaching and scholarship. Curran is such a leader. Under his stewardship, the RSPH has grown from 30 faculty members and \$5 million in research grants on its founding in 1990 to nearly 200 faculty, 900 graduate and doctoral students, and more than \$55 million in annually funded research. Curran, who is principal investigator and co-director of the Emory Center for AIDS Research, formerly led the HIV/AIDS Division at CDC, attaining the rank of assistant surgeon general. The chair is made possible by Emory’s long-time friends Lawrence P. and Ann Estes Klamon, who serve as co-chairs of the RSPH’s \$150 million fundraising initiative as part of Emory’s \$1.6 billion campaign.

Hannah’s hope

“Someone has to be the first to be cured.”

Those are the words Matt Sames expressed to his wife, Lori, in the wake of their daughter Hannah’s diagnosis with giant axonal neuropathy. Their daughter was just 4 years old at the time. Giant axonal neuropathy (GAN) is a rare genetic disorder that damages the nerve pathways that carry signals from the brain. The symptoms begin in the extremities: a dropped foot, awkward gait, tripping. Eventually victims have no ability to move, eat, or breathe. The disease is terminal in young adulthood.

It took 18 months for doctors to diagnose the uncommon disorder in Hannah. The first symptoms surfaced when she was 2 and family members noticed the arches on her feet rolled inward when she walked. Refusing to accept the lack of treatment options and minimal research being conducted on GAN, Matt and Lori Sames established Hannah’s Hope, a public charity dedicated to funding research for a treatment and eventually a cure for GAN. “In our first seven months, we raised about \$400,000 for research,” says Lori Sames.

The latest recipient of a gift from Hannah’s Hope is Emory University neurosurgeon Nicholas Boulis. Boulis, who also is a gene therapist, received \$30,000 to bolster his research on neuro-gene therapy. His research focuses on finding the best way to deliver an altered gene to the nervous system of patients suffering from GAN. He is currently working to develop a surgical device to allow the delivery of spinal cord therapeutics including drugs, viral vectors, and stem cells. Boulis and his team are collaborating with virologist Jude Samulski and his team at the University of North Carolina’s Gene Therapy Center to use preliminary data to apply for an NIH exploratory/developmental research grant.

Lori Sames says she knew she found the right researcher when Boulis told her he “gives a lot of credit to parents who refuse

to take no for an answer.” Sames has made refusing to accept “no” part of her mission since Hannah’s diagnosis.

Indeed, Emory and organizations like Hannah’s Hope are changing the research landscape through their consistent promotion of collaborative and coordinated research.

“Hannah’s Hope is a parent-driven organization devoted to therapy development. We know exactly what causes GAN—mutations in a specific gene—and now we need a treatment,” Sames says.

The timing seems to be right for giving Hannah hope.

“GAN involves a defect in the gene for gigaxonin, an important protein for maintaining the health of axons. We think this disease may provide insights that will guide the application of neuro-gene therapy to neurodegenerative disease,” says Boulis. In other words, if Boulis and his colleagues can devise a treatment mechanism for GAN, they will take a major step in the treatment of other neurodegenerative diseases like amyotrophic lateral sclerosis (Lou Gehrig’s disease) and Alzheimer’s disease, which lack such a clearly defined genetic culprit.

In the meantime, Hannah and other children affected by GAN will continue to live their lives while they wait for a treatment. Hannah celebrates her 5th birthday this year.

She will go to Chuck E. Cheese with her friends, and she’s hoping her grandfather will get her the cell phone she has been wanting. And, while Hannah maintains the innocence so typical of a young child when it comes to her prognosis, her parents and Boulis

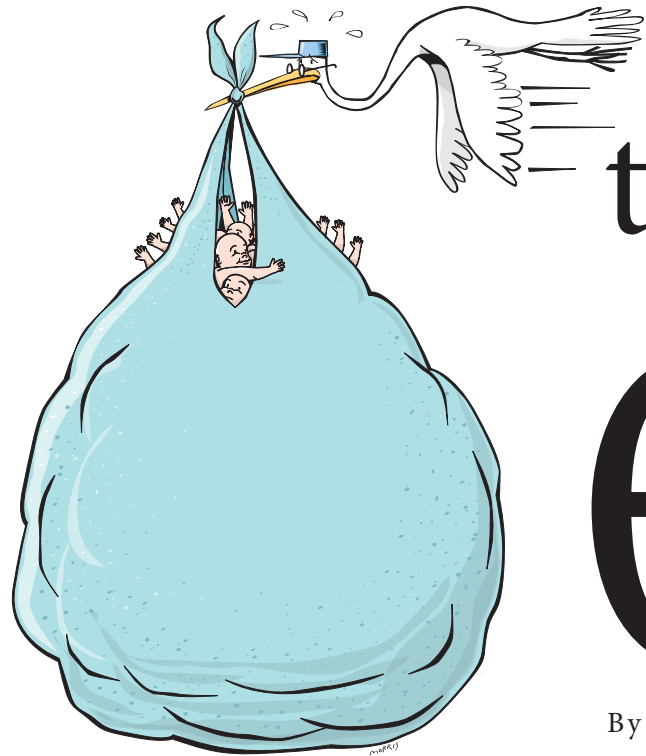


Emory and organizations like Hannah’s Hope are changing the research landscape through their consistent promotion of collaborative and coordinated research.

know they need to move as quickly as possible if they are to save Hannah from the ravaging effects of GAN. Her central nervous system will be affected within the next 3 to 4 years.

“We could not let another family receive the news we did and hear that nothing could be done,” Lori Sames says. “Our efforts will bring gene therapy to a new level, and Dr. Boulis is just the man to be on this mission with us.” —Carrie Paine

WEB CONNECTION If you would like more information on supporting the research of Nicholas Boulis, please contact Brook Brown, Director of Development for the School of Medicine at (404) 727-3989. For more information on Hannah’s Hope, see hannahshope-fund.org.



then there were eight

By Kathy Kinlaw

Illustration by Don Morris

An Emory ethicist examines decisions surrounding the Suleman octuplets.

Not since Terri Schiavo has the public's attention and passion been so galvanized around an issue of clinical ethics—and its social implications. When the news broke in January 2009 that Nadya Suleman had given birth to octuplets, initial amazement that all 8 infants were to survive (a first in the United States) turned to speculation and controversy around the medical and social circumstances surrounding their birth. As a health care ethicist who began my clinical training working with health care professionals, patients, and families making decisions about pregnancy, birth, and

the care of children, I followed the Suleman octuplets with particular interest.

As the story has continued to evolve, it has been marked by great speculation and difficulty in identifying the facts. Most of the information has come through the media, including some “direct reports” such as interviews with Nadya and press conferences with physicians caring for the infants. The speculative nature of the information has actually inflamed and thus changed the story, including the public dialogue and sentiment. We learned that Suleman had six other children, including a set of twins, all who were conceived through previous in vitro fertilization (IVF) treatments. Questions swirled around how many embryos were transferred in past and current IVF cycles, whether the sperm donor was aware of these multiple births, and how a non-working, single mother was

able to afford numerous IVF treatments and support the children.

The narrative of Nadya Suleman and her children raises fundamental questions about the rights and responsibilities of parents, obligations to protect the welfare of children, and the professional role of physicians involved in reproductive medicine.

Suleman states that growing up as a single child, she has always had a strong desire to have many children. Do women (or couples) have the right to make their own decisions about having a large family? Though there is debate about whether there is a clear constitutional right to have and rear children, our society generally supports the ability of a woman to make decisions about her own reproductive health and guards against assumptions about what characteristics are necessary to be a “good mother.”

Should there be limits to such reproductive freedom?

The welfare of the child, or of a potential child, must be carefully considered, along with the freedom of choice of the woman. In addition to assessing the health of the woman and the likelihood of success, IVF programs routinely have a counselor assess an individual or couple for evidence of concern about parenting, such as a history of violence or of psychiatric illness that would present a risk to the child. The American Society for Reproductive Medicine (ASRM) indicates that fertility programs may withhold services based on “well-substantiated judgments that those patients will be unable to provide or have others provide adequate child-rearing.” ASRM also indicates that programs may provide services “except in clear cases of significant harm to offspring.” The lack of agreed-upon criteria for when a practice or the state may withhold fertility services needs to be addressed with written policies and procedures, both to support consistent, just decision making and to protect the health and welfare of both the woman and potential children. The potential future harm is not, of course, just from the transfer procedure itself but also from the potential of implanting multiple embryos. Multiple gestation presents a health challenge to the pregnant woman and is significantly correlated with premature birth and associated health problems for infants.

In Nadya Suleman's story, the decision by the fertility specialist to transfer six embryos in one cycle also raises significant ethical questions. In fact, it is reported that she may have had multiple embryos transferred in each of her other five pregnancies, and that the six transferred most recently were fertilized embryos left over from a previous IVF cycle. Given the tremendous improvements in the success of IVF and especially the success of prior procedures with Suleman, the transfer of six embryos is hard to justify medically and ethically. The 2006 ASRM

embryo transfer guidelines clearly recommend that no more than two embryos be transferred in IVF for a patient with Suleman's reproductive history. Transferring six embryos placed both Suleman and the resulting implanted embryos at great risk. The fertility specialist has been reported to the California Medical Board for further investigation.

Even a strongly held belief in the sanctity of life does not support the decision to transfer six frozen embryos at one time. If one's goal is to maximize the chance that these embryos will implant and lead to live births, then single births best support this

each of the 14 children in this family be protected and promoted? It is unclear whether Suleman has adequate financial and people resources available to provide care. Public outcry has raised concern about publicly funded support for these children—with estimated costs to raise eight children for 18 years at a minimum of \$1.5 million, not including any special medical treatments. Psychological support also may be a concern. Product advertising and entertainment as a potential source of financial support has not been forthcoming yet, with even the potential for this funding plan leaving many feeling deeply unsettled about the long-term welfare of the children.

If this story is disquieting for many, we could ask state governments to set limits on the conditions under which women or couples can have multiple children—whether by assisted reproduction or naturally. Would we prefer such governmental intervention on private choices? Balancing the interests of individual adults, children, and society is not straightforward.

Despite the wonder of the birth of octuplets, most would agree that we should be working to avoid high-order multiple births. The risk to the potential mother and children is simply too great. Women (couples) should be fully informed, and professional

standards that limit the number of embryos transferred—and perhaps the number of eggs fertilized in the first place—should be taken seriously.

The very public nature of the Suleman story will once again play a role in this social debate as we follow the course of these children in coming weeks and months. ☐



Kathy Kinlaw, associate director of the Emory Center for Ethics, is a senior associate in pediatrics at Emory School of Medicine.

goal. Multiple gestation pregnancy actually increases the risk that some or all of the fetuses will not survive—thus the rarity of living octuplets and other high-order multiple births, and the mother is at greater risk, too.

Now that the octuplets have beaten the odds, the long-term welfare of these children remains a concern. How will the interests of

Additional Resources:

- For more information on the Emory Center for Ethics, visit ethics.emory.edu.
- The American Society for Reproductive Medicine (ASRM) has established guidelines on the number of embryos transferred, asrm.org/Media/Practice/Guidelines_on_number_of_embryos.pdf, and on child-rearing ability and the provision of fertility services, asrm.org/Media/Ethics/childrearing.pdf.

Call for a commonsense study on vaccines and autism

I am the proud grandfather of a lovable 9-year-old, nonverbal boy, who “regressed” and was diagnosed autistic just prior to 3 years of age. Admittedly, our family has no scientific evidence to prove our little guy’s “regression” was “caused” by the numerous vaccines he received, most of which contained thimerosal, a mercury-based preservative then commonly found in childhood vaccines. Unfortunately, in the six-plus years since he “regressed,” public health officials have given us no scientific evidence that would rule out that possibility. Instead, they have given us a carefully constructed statement there is “no evidence of a link between vaccines and autism,” which is not as scientifically certain as a statement declaring they have found the “cause” of autism and that cause is not vaccines.

In any event, public health officials have resisted pending federal legislation that seeks to fund an independent, scientific study of vaccinated vs. unvaccinated populations to ascertain, once and for all, if BOTH populations have suffered the same, inexplicable increase in childhood chronic autoimmune diseases, which CDC reports, affect one in every six American children. Perhaps you know why public health officials would refuse to conduct such a commonsense study?

After all, parents have every right to expect public health officials to explain why this generation of children, arguably the most heavily vaccinated generation in our nation’s history, suffer chronic autoimmune diseases, such as autism, allergies, asthma, juvenile type 1 diabetes, juvenile rheumatoid arthritis, and ADHD, which were far less common in all previous generations.

My friend’s parents have reported the exact same experience of taking their perfectly healthy child to a pediatrician and having the child receive numerous vaccines, then watching helplessly as their child’s health deteriorates—extraordinarily high temperatures, seizures, convulsions, chronic diarrhea, bizarre behaviors, sleepless nights for weeks on end, withdrawal, and an eventual diagnosis of autism. Obviously, public health officials have taken the position the child’s sudden deteriorating health is merely coincidental to, not caused by the vaccines. Perhaps this explanation would suffice were it only a few hundred or even thousand parents who reported this experience. But when literally tens of thousands of parents make the same report, common sense suggests more than mere coincidence may be responsible.

I did appreciate Dr. Pakula’s thoughtful comments on vaccines and her willingness to at least accept there is much research to be done, research that should be funded and conducted by independent sources outside the public health agencies responsible for both regulating vaccines as well as recommending them.

Bob Moffitt

*Proud grandpa of Bobby Moffitt, “regressed” 6-plus years
Sloatsburg, New York*

Editor’s note: You obviously are one of the people of whom Joseph Cubells was speaking when he said involvement of families is vital for the care of people with autism (*Emory Health*, spring 2009). Your concerns about the effects of vaccines containing thimerosol were heard at the national level by those involved with vaccines, which were changed to contain no thimerosol despite a lack of evidence of a relationship between thimerosol and autism. Although U.S. manufacturers removed the agent from vaccines by the end of 2001, no decrease in the incidence of autism has occurred. Sadly, removing thimerosol from vaccines has not helped prevent autism. Regarding the larger question of whether vaccines elevate risk for autism, scientists have not undertaken the study you suggest, comparing the health and outcomes of children who were vaccinated with those who did not receive suggested vaccinations. However, there are epidemiologic data that do not support an autism-immunization link. As Amy Pakula’s essay mentioned, our clinicians sometimes see negative outcomes for children who were not vaccinated even today, and an Emory epidemiologist collaborated on a recent study that suggested the health of the community at large is at elevated risk when a high proportion of children are not vaccinated. As our article indicated, strong evidence supports the importance of genetic

causes of autism, and Emory scientists are hard at work in the search for related genes, including susceptibility genes that might offer new clues as to what happened to your grandson and whether it was related to vaccines, the environment, or a host of other factors. We share your wish that scientists will one day be able to find all the causes of autism and what to do about them.



ask Helen

Need an appointment for an Emory doctor quick? Interested in registering for a prenatal class? Want to learn about cardiac CT scans at Emory? Helen Smith can help you with that and more.

Smith is one of the 14 registered nurses who answer 16 phone lines at Emory Healthcare’s HealthConnection. A one-stop shop for patients and referring physicians, HealthConnection is available 7a.m. to 7p.m. each weekday. **What would you like to know?**

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**Emory University Hospital
Midtown HealthConnection,**
404-778-2000

**Wesley Woods Senior
Resource Line,** 404-778-7710

For physicians
Emory Consultation Line,
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GENE AND ROSE GANGAROSA believe access to safe water is a human right. An international expert on waterborne diseases, Gene is a professor emeritus at the Rollins School of Public Health. Rose has traveled with him to developing nations and seen the devastation caused by contaminated water.

Determined to ease suffering, the Gangaros are funding research. Through estate gifts, including a charitable remainder trust, the Rose Salamone Gangarosa Chair in Environmental Health will further studies in the Center for Global Safe Water. The couple also has created the Eugene J. Gangarosa Chair in Global Safe Water.

“We know that our contributions represent only a few drops of water in an ocean of need,” Gene Gangarosa says. “So we look to others to help.”

Learn how you can support the health sciences at Emory with a planned gift. Call 404.727.8875 or visit www.emory.edu/giftplanning.

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