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SUMMER 2012

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THE WOODRUFF HEALTH SCIENCES CENTER



Surviving Alzheimer's⁸

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We know the economic burden of Alzheimer's disease on our country. The Alzheimer's Association puts the price tag at \$200 billion for this year alone.

FROM THE EXECUTIVE VP

Alzheimer's disease progress

WE ALL KNOW SOMEONE WITH ALZHEIMER'S DISEASE

(AD), WHETHER A BELOVED MOTHER, A LIFELONG

FRIEND, A FAVORITE TEACHER, OR THE NEIGHBOR ACROSS

THE STREET.

We also know the toll that AD exacts from caregivers as they struggle to support their family and friends as the loved ones lose more and more parts of themselves before the caregivers' very eyes.

And we know the economic burden of AD on our country. The Alzheimer's Association puts the price tag at \$200 billion for this year alone. That figure is bound to grow.

What we don't know about AD is how to prevent or cure it. Yet.

However at a few places across our country—like Emory's Alzheimer's Disease Research Center (ADRC)—we are getting closer to finding some answers. The Emory ADRC currently is pursuing research in gene therapy, new drugs, and a vaccine to prevent or reverse the process. It is training caregivers to stimulate the brains of their loved ones with activities that may alter the course of the disease. And it is supporting programs to educate the community about AD research and how to get involved.

You'll read about some of those efforts in this issue of *Emory Health*. I hope that they give you hope, as they do me.

Wright Caughman

Please share your feedback at evphafeedback@emory.edu.

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

SUMMER 2012



NEW AND NOTEWORTHY

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Recovering hearts. Reconnecting soldiers and families. A game changer for acute liver disease. Atlanta Ballet's first resident psychologist. New drugs and treatment for a rare lung disease. Teaching America's children about health. A critical time for critical care. And more.

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Federal funding for Alzheimer's has not kept pace with that for other diseases. Philanthropy is helping to fill the gap.



Risk and recovery



RETURNING HEALTH WITH A SERVE:
Emory Heartwise participant Don Baldwin (left) plays ping pong three times a week as a way to battle coronary artery disease.

ANN BORDEN

Stanley Wagner can once again wear the silver ring inset with green and red stones that his wife of 44 years bought for him on a Navajo reservation in 1994. That's after losing 31 pounds since starting the HeartWiseSM Risk Reduction Program at Emory.

The weight loss is intentional, part of a strategy to improve the coronary health of the 80-year-old, who had a heart attack six years ago. His wife, Elaine, also has had her share of heart trouble, having a stent placed in her heart 19 years ago.

Both the Wagners participate in HeartWise, which helps reduce the risk of a heart incident or to recover after one. The program also emphasizes primary prevention by identifying and addressing those at risk to prevent cardiovascular problems.

"There's a certain amount of security here," Elaine Wagner says, while working out in a monitored session at Emory's Blomeyer Health Fitness Center. Every five minutes, exercise physiologists check on her and the other program members to make sure they are exercising within safe bounds and showing no signs of stress.

Supervised by physicians with case management by nurses, the HeartWise program is designed to optimize appropriate lifestyle therapies. Medical therapy is included as needed. The program emphasizes regular monitored exercise, consultations with registered dietitians, a lecture series on reducing heart

risks, and education on cholesterol and blood pressure management, medications, and healthy habits.

"A program like HeartWise is the core of a comprehensive treatment plan for fighting heart disease," says Laurence Sperling, founder of preventive cardiology at Emory and himself a veteran marathon runner. "Cardiac rehab and prevention programs are essential standards for heart health care."

The program helps address patients' concerns, which Sperling acknowledges are often different from those of their physicians. "As a doctor, you want to know what medications patients need, when their follow-up appointments are," he says. "But what patients really want to know is, how is this going to impact my quality of life, when can I go back to work, when can I take up my hobbies, when can I have sex."

HeartWise also fosters community among patients to reinforce healthy habits after a heart incident. For example, Don Baldwin, 65, plays ping pong three times a week with other HeartWise participants. A retired computer specialist for the Department of Labor, Baldwin has coronary artery disease. He enjoys the camaraderie among patients and the close engagement of Emory's exercise physiologists. "They ask, how are ya feelin', and it's not a casual thing," Baldwin says.

This concern reaches beyond the walls of the exercise room. On several occasions when Baldwin began feeling slight twinges of chest pain, he phoned the HeartWise team, who was able to get him an appointment with a doctor quickly.

Including a patient's family is another important component of cardiac rehabilitation, says HeartWise Director Kathy Lee Bishop. She encourages family members to attend monthly meetings with the program's dietitian, which promote better eating habits among entire families. That is good not only for the patient who has healthy habits reinforced by a support system but also for family members who decrease their own risks of ever having a cardiac event. —Stone Irvin



want more?

For more information on the HeartWise program, call 404-778-2850 or visit hr.emory.edu/blomeyer/resources/HeartWise.html



Parkinson's finding: Half of the nearly 1 million Americans with Parkinson's disease (PD) suffer from depression. A recent study in *Neurology* reports that certain antidepressants appear to decrease depression in people with PD without worsening motor problems. The study offers hope for PD patients, says William McDonald, co-principal investigator and J.B. Fuqua Chair for Late-Life Depression at Emory, showing that "we can now safely treat depression without exacerbating other symptoms." More than 45 scientists at Emory are working to understand the causes of PD and developing more effective treatments.

The Callaway Homecoming Initiative helps returning soldiers reconnect with their families. "Decisions related to parenting, finances, and all the routine daily tasks have been the sole responsibility of the spouse, who suddenly is expected to give up control when the soldier returns," says Emory psychiatrist Doug Bremner. "Additionally, the soldiers have missed seeing their children grow and mature, and being involved in their activities. They may feel like strangers in their own homes." The program—set in the foothills of the Appalachians and supported by Callaway Gardens, Fort Benning's Maneuver Operations Center for Excellence, and Emory—helps soldiers return to family life.

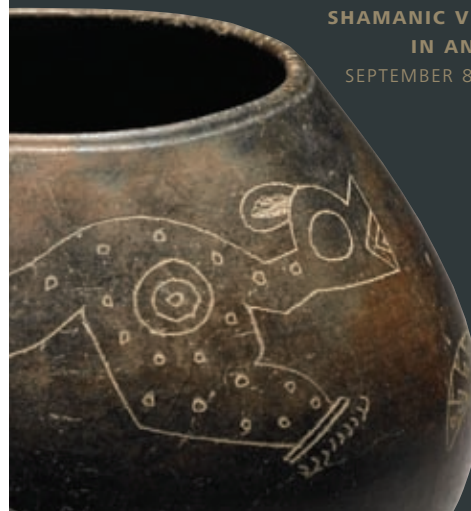


A new liver dialysis system—the Molecular Adsorbents Recirculating System (MARS)—is a potential game changer for patients in acute liver failure who either fail to qualify for a transplant or who are running out of time while waiting for a donor organ. Emory now offers MARS, which has FDA approval, to treat select patients with acute liver failure due to drugs or toxins. For more information, call 404-778-7777 or visit emoryhealthcare.org/connecting/healthconnection.html.

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Healthy business practices:

Current ongoing debates leave little doubt of the need for more people who understand the business of health care. To meet that need, Emory's Goizueta Business School now offers a new health care focus for students pursuing an MBA. The program allows students the flexibility to take a single health care-oriented class or pursue a degree combining health policy and business management. It offers courses on how to treat patients responsibly while taking into consideration good business practices, such as a class on hospice care and taking care of patients at the end of life. It also gives business students hands-on experiences with local health partners such as the CDC or Emory Healthcare, where they work with administrators to learn how to integrate business and health care practices.

Living with LAM



Patients like Teresa Stoker have driven a surge of interest in LAM, a rare lung disease, says Srihari Veeraraghavan, who co-directs the only LAM clinic in Georgia.

ANN BORDEN

More than a decade ago, Teresa Stoker was told that she had only a few years to live.

Today, she has advice for other women with the same disease that she has: "Don't pick out funeral music yet."

In 2001, Stoker experienced a painful collapsed lung, or pneumothorax, which required surgery to correct. Her doctors initially thought the cause was physical trauma, then asthma. She eventually learned that she had lymphangioliomyomatosis, or LAM—a rare, progressive lung disease that appears to affect women almost exclusively.

At the time, only a few options were available to treat the condition: oxygen, then as the disease advanced, a lung transplant. Stoker sought treatment at the NIH and later regularly flew to Cincinnati to participate in a clinical trial.

In the past decade, a surge of interest in LAM has led to studies of promising drugs and establishment of a network of LAM clinics across the country. In 2011, Emory joined the network, sponsored by the LAM Foundation, and to date offers the only LAM clinic in Georgia.

"I think the push has come from patients themselves," says pulmonologist

Srihari Veeraraghavan, co-director of the Emory LAM clinic along with Gerald Staton. "The idea for the specialized clinics is to aggregate a critical mass of services." That includes a full spectrum of care, latest information on LAM, access to clinical trials, and peer support."

In LAM,

smooth muscle cells grow uncontrollably and enter the airways, forming clusters and cysts in the lungs. This growth damages the lungs, leading to shortness of breath and pneumothorax. In addition, 40% of LAM patients have benign kidney tumors. Some cases appear to be genetic. The skew toward women may point to a role for estrogen in driving the growth of the smooth muscle cells.

LAM can be mistaken for asthma, bronchitis, or emphysema and is often misdiagnosed, since a pulmonologist typically might see only one or two cases in a lifetime. A high-resolution CT scan or biopsy is usually required for diagnosis.

Stoker, who leads a nonprofit LAM organization in Atlanta, has become an informal adviser to other Georgia women with a LAM diagnosis. Although she has had to curtail some outdoor activities, she says that so far, "it's a part of my life. It does not run my life." —Quinn Eastman

➤ **want more?**

If you would like more information about Emory's LAM Clinic or to support LAM research, contact Alicia Kanjira at 404-727-3989 or Alicia.kanjira@emory.edu.

A dancer's orientation

For years, Nadine Kaslow kept her dancing a secret from professors and academic colleagues, fearful they would take her less seriously as a scholar if they knew.

As a fast-track science student at the University of Pennsylvania, she took daily ballet classes and taught in the university's dance program. During her doctoral studies at the University of Houston, she was invited to join the Houston Ballet. No audition necessary, the director said—he had seen her dance—but she had to lose 15 pounds, a loss that would have left her, at almost 5' tall, more than 30 pounds lighter than ideal body weight. Later while building her psychology career on the faculty at Yale, she continued ballet classes. And later still as a professor of psychiatry and behavioral sciences at Emory—where she directs the postdoctoral fellowship program in professional psychology and serves as chief psychologist at Grady Hospital—she enrolled in demanding classes at the Atlanta Ballet's Centre for Dance Education.

There she met Centre Director Sharon Story and Atlanta Ballet Artistic Director John McFall. Soon after, Kaslow was named the Atlanta Ballet's first resident psychologist. There is no job description. But in consultations and therapy sessions, Kaslow tackles psychological issues faced by the dancers. She also works with parents of younger students and with McFall and Story on employment issues that involve psychological factors. It's a broad turf that she understands well.

"Dancers are incredible athletes," says Kaslow, "and they face many of the same psychological issues that can interfere with any athlete's performance—for example, anxiety, injury, or excess competitiveness."

But ballet has its special demons, in part because it is an art in which the dancer's body is the instrument, finely tuned and incredibly visible.

"Ballet breeds perfectionism," says Kaslow. A little can be good; too much and dancers become so focused on technique,

expectations, and mistakes that they can't enter the flow of the dance itself. Kaslow tries to lead dancers away from a quest for perfectionism toward one for excellence.

For many, perfectionism involves fretting about the body. The classic, streamlined ballet body is long-limbed, flat-chested, and lean. Very lean. The Atlanta Ballet's nutritionist, Emily Harrison, also a former dancer, helps members of the troupe understand nutrition and deal with their sometimes love/hate relationship with food. For her part, Kaslow helps the dancers deal with guilt associated with food.

Body image issues, prevalent in the larger society, start early in ballet, so Kaslow frequently discusses the subject with parents of pre-professional students. Another issue that begins at an early age: balancing dance with friendships and activities off stage. And a big issue that football players don't have to face? Many young male dancers have to decide either how to come out to family and friends if they are gay or, even more challenging, how to deal with the constant assumption that they are gay when they aren't.

The tight-knit ballet company members in Atlanta and elsewhere have their share of romantic entanglements, too, all with the usual potential for psychological fallout but with an extra twist. How do you dance an intimate, highly sexualized

pas de deux with a former romantic partner with whom you don't want to exchange glances, much less publically intertwine?

Professional dancers also have to think about life after ballet—and soon. Most ballet careers end when dancers approach their late 30s. What makes it worse emotionally as well as practically, says Kaslow, is how little most dancers make, how hard even successful dance companies struggle financially.

Today, Kaslow no longer worries how others see her dual life of psychologist and ballerina. She encourages friends and patients alike to find a way to keep their passions alive in their lives. —Sylvia Wrobel



Teach health for America



Erika Rees (center) and Scot Seitz are handing out gloves and goggles to sixth-grade students at a charter school in the Atlanta neighborhood of Kirkwood, where Seitz teaches earth science. The students, buzzing with excitement, are about to observe the effect of a weak sulfuric acid on common building materials. It's part of a lesson on acid rain designed by Rees, who is an MPH student at the Rollins School of Public Health (RSPH).

Briefly, a playful rebellion sets in among the ranks—idle complaints quickly placated by assurances from the leaders that, yes, it is necessary to wear safety equipment while handling even weak acids. The students settle back down with an “I’m-only-doing-this-because-I-like-you” sort of smirk.

At the end of the lesson, after the acid is poured and the observations are logged, Rees gives the students permission to remove the goggles. Most of them keep them on as they answer questions about the chemical reactions involved in acid rain, discussing the carbon emissions of cars and factories. Seitz takes some time to give a shout out to Rees, explaining to the class that she created the lesson and supplied the materials for the day’s activity. One student gives Rees a hug on the way out.

“We really don’t do things like this normally,” says Shannon

Davis. “We usually take a lot of notes and stuff.”

Rees’ experiment and working relationship with Seitz during the spring semester was the result of a new educational partnership between the RSPH and Teach for America (TFA) called Classroom to Community.

The idea for the initiative came from a discussion between MPH student Sahar Salek, who was looking for applied, practical experience, and Ariela Freedman, a research professor at the RSPH and a TFA alumna. The

possibility of a program grant from Emory’s Office of University-Community Partnerships gave birth to a grant proposal to put RSPH students in classrooms with TFA corps members as mentors to help them learn to teach health lessons to Pre-K-12 students across metro Atlanta.

“The partnership is a launch pad for using schools as a vehicle to teach critical health skills to the next generation,” Freedman says. “We give our MPH students the tools to become effective teachers through the hands-on experience they get partnering with a TFA teacher in an under-resourced Atlanta public school.”

Although it offered no course credit, the newly minted program drew in a landslide of nearly 40 applicants. Of those, 15 RSPH students were chosen to be mentored by TFA teachers and hone their teaching and leadership skills. They are teaching everything from lessons in mental health to health careers.

Audra Williams, a joint MD/MPH student at Emory and TFA alumna who co-taught the course, says the program helps RSPH students, TFA corps members, and their students alike. “We all need to take on that responsibility to learn what’s going on in our schools and in our community. This course provides the real-world experience that puts a human face on the statistics about kids and health.” —Stone Irvin



Critical care steps forward

Tim Buchman arrived at Emory in 2009, charged with one big mission: revamp critical care and standardize it across the system. As part of an academic tertiary care center, Emory University Hospital (EUH) and EUH Midtown treat large numbers of patients with highly complex medical conditions. Coupled with the fact that Atlanta metro's population is graying, critical care needed to take center stage.

Buchman directs the Emory Center for Critical Care, which integrates all of Emory's critical care units and staff to achieve better patient outcomes at lower costs. One of the cornerstones of his plan was a brand new ICU at EUH Midtown, which opened on 11-South in late May.

The design of the new unit sets the standard for all critical care in Emory Healthcare. It incorporates feedback from families of former patients and technology that make care teams more efficient. For example, after consultation with Emory patient family advisers, Buchman's team outfitted each room with a sofa, armoire, and computer desk. The advisers also told the team that they didn't want to be separated from their loved ones, so there are no curtains that draw around the beds.

The ICU also features quiet care. "Go into the average ICU today, and the first thing you are assaulted by is noise," says Buchman. "Of course, it is important to receive and respond to alerts. But instead of putting the alerts next to the patient, let's send them directly to the caregiver." Monitors in the new ICU send alerts to workstations or a "voice badge" that nurses wear on lanyards to help them monitor patients as they move about the unit. Even the flooring throughout the unit and in patient rooms is soft and mutes the clicking of hard-soled shoes.

Nursing workstations are located between every two rooms, with wide windows into the rooms. Each room has a camera to

send images to a team theater where health care providers can gather for team meetings to assess patients' progress.

The design ideas also will be incorporated in a new bed tower planned for EUH—where more than half of the 210 beds will be devoted to critical care. EUH Midtown also built a ramp to connect its operating suites to the ICU so that postoperative patients can travel from one to the other without needing an elevator.

The Center for Critical Care also is extending its reach beyond Atlanta. In early May, it was awarded a \$10.7 million grant from the federal Centers for Medicare and Medicaid Services to support telemedicine ICU services in rural north Georgia hospitals. Emory—along with Saint Joseph's Health

System, Northeast Georgia Health System, Southern Regional Medical Center, and telemedicine provider Philips Healthcare—will bring more than 40 critical care providers, including 20 nurse practitioners and physician assistants, from local hospitals to Emory for six months of advanced training. The rural hospitals also will be supported by audiovisual equipment that will allow critical care providers to consult with an ICU


physician and critical care nurse. The telemedicine system is expected to save more than \$18 million over three years.

Redesigning critical care now is of particular importance since Georgia's population is growing older. According to the U.S. Bureau of the Census, Georgia is among the top 10 states expected to have larger than average growth in residents aged 65 and older by 2030. That

growth translates into one in five Georgia residents older than 60 by 2030, yet demand for critical care physicians will outstrip supply as early as this year, says Buchman. —Kay Torrance



THE UNIT SETS THE STANDARD FOR ALL CRITICAL CARE IN EMORY HEALTHCARE. IT **INCORPORATES FEEDBACK FROM FAMILIES OF FORMER PATIENTS AND TECHNOLOGY** THAT MAKE CARE TEAMS MORE EFFICIENT.



Louise Turner, 70, and her mother Anne Eighmie, 100, on their daily mile-long walk. Eighmie has Alzheimer's disease.

Surviving Alzheimer's

Go ahead. Admit it.
The prospect scares
the **c#@p** out of you.

By MIKE KING • Photography JACK KEARSE

Just as the parents of the Baby Boom generation were terrified years ago by what they assumed was a death-for-certain diagnosis of cancer, their middle-aged children worry today about something they believe is even worse—living long enough to develop Alzheimer's disease (AD). Only now, the worry is as much for themselves as their parents.

The disease—and its assault on the circuitry of the brain that controls memory—has supplanted cancer as the most feared medical condition among those 60 years of age and older.

With good reason: In the past decade, the death rate from stroke, heart disease, and HIV/AIDS in the United States decreased in each category by double digits, while that from AD rose by more than 33%. Then there's this: Among the top 10 causes of death, AD (now number six) is the only one that cannot be cured, prevented, or even significantly slowed.

THE *take-away*

Emory researchers
work with patients
and families to
tame the fear of
America's most
dreaded disease.

No wonder we're terrified.

Still, this often-repeated narrative masks what's happening on the frontlines of the battle at places like Emory, one of about 30 research and clinical care centers for AD designated by the NIH. Here, knowledge about the disease is increasing exponentially, and new approaches to diagnosis and treatment reveal themselves routinely. Renewed experiments have begun

with gene therapy and a vaccine, both of which might slow the process and even reverse it. Moreover, caregivers and patients are being trained to stimulate the brain's plasticity—with good nutrition, exercise, playing music, working on computer puzzles, keeping a daily memory diary—that could alter the disease's course. With advancements in these areas, there is even talk about prevention.

And finally, advocates say, there is hope that the government-funded research establishment may be getting the message: AD and related dementias need significantly more investment to deal with the anticipated three-fold increase in patients as the population ages over the next 40 years.

All this leads to a more hopeful observation: There is now a very real prospect that AD—like cancer before it—is not quite the unyielding foe we all fear, especially when confronted by advancements in neuroscience

and the indomitable spirit of patients and the ones who care for them.

TWO PATIENTS AND TWO CAREGIVERS

Anne Eighmie reached the century mark last year, her sixth year since being diagnosed with AD. Her daughter, Louise Turner, 70, takes care of her mom in her Decatur home.

Turner vows never to put “mommy” in a nursing home. “I’m luckier than most caregivers,” she says, explaining that her mom remains mobile. They walk about a mile a day and often go out for lunch. Her daily routine includes giving her mother a foot massage just before bed. “I sleep in a room next to her, like a new mother. When she gets up, I get up,” Turner says. “Every day, I’m exhausted.”

Three years ago Cecile Bazaz, an accountant and executive with SunTrust, started noticing forgetfulness on the job—missed deadlines, trouble remembering passwords—

diseases, a population that is consistent with the overall population of Atlanta.”

Her first stops were to the sisters of Delta Sigma Theta and Alpha Kappa Alpha, Atlanta chapters of

expanding pool of African Americans deeply involved in AD research at Emory.

One result has been the creation of a Registry for Remembrance, a community/academic partnership that cultivates a cohort of African Americans in Atlanta for participation in neurologic research. The group, now numbering more than 125, has been meeting and providing data to researchers for about four years.

Among the suggestions for improving public screenings are to structure them in the context of an educational event. The participants also expressed a preference and more trust for researchers who share similar ethnicity. Several of the registry participants have enrolled in

clinical trials for new drugs and treatments at Emory.

Louise Turner and her mother, Anne Eighmie, were among the first to join. Turner remembers that when she volunteered to undergo a spinal tap for research into biomarkers to identify AD, she was only the eighth minority person out of more than 800 people studied so far.

But perhaps the greatest service the registry provides is the ability for participants to share concerns about how the disease progresses and how to cope with the daily aspects of caregiving, Turner says. “This is exactly the kind of outreach to minority communities that researchers must make if everyone is to share the benefits.”



Reaching out to African Americans

Emory's **Monica Parker** (*right*) wanted to reach beyond traditional sources of churches and hospitals to expand the number of African Americans participating in Alzheimer's disease (AD) research. The physician was looking for those “who are educated and less likely to suffer from chronic



the nation's largest sororities of college-educated African American women. Both chapters signed on to raise money and awareness. Their advocacy has led to an



Cecile Bazaz, 54, had to quit her job after symptoms of Alzheimer's disease worsened. Her husband now works from home so that he can care for her, and they enjoy frequent visits from their daughter.

which she attributed to menopause. But when the problems worsened, her husband, Alister, thought something else might be the cause.

Tests determined that Bazaz, then 51, had early-onset AD. She quit her job and went on long-term disability. Her husband found ways to work from home to be close to her. Now she is unable to read, drive a car, or perform other daily functions.

"We're in this for the long haul," Alister

Bazaz says. "We don't accept that there is nothing to be done. We will do whatever is necessary."

Eighmie and Bazaz illustrate the scope of the AD challenge. Eighmie's longevity represents the highest risk for the disease—almost a 50/50 chance you will get it if you live long enough. Bazaz is among the 5% to 10% of patients who are diagnosed with AD before they turn 65.

In the space between are 5.4 million Americans who now live with AD or related dementias and the 15.2 million friends and family members who provide unpaid care for them valued at more than \$210 billion a year.

Both patients and their caregivers are actively involved in programs at the Emory Alzheimer's Disease Research Center (ADRC)—one of only 28 such centers in the country funded by the National Institute on

Aging that combine clinical care and research.

At Emory, clinicians who see patients are deeply involved in research, and scientists working to develop new methods of testing and drugs for AD often know patients by name. These patients are surrounded by a team of physicians and advanced practice nurses who work closely with families, as well as social workers, neuropsychologists, and primary care physicians attempting to expand the pool of participants in ongoing research.

FIGHTING MISCONCEPTIONS

The prevailing narrative that the relentless course of AD can't be stopped is woefully outdated. Yet it is deeply rooted in public consciousness, according to Allan Levey, director of Emory's ADRC. It developed because the ability to test for the disease was limited until recently. In fact, for many years, the only conclusive diagnosis was to examine the brains of patients thought to have died of AD.

That's far from the case today. At Emory and elsewhere, more sophisticated imaging techniques and relatively simple tests, such as examining spinal fluid, are able to reveal changes in the brain that can be precursors of AD. Scientists now understand that the course of the disease is not as compressed as once thought—that instead of a few years, there may be two or three decades of changes to the brain before the worst symptoms of full-blown AD begin to show.

Similar discoveries in the 1960s and 1970s about coronary artery disease—showing that cholesterol buildup on the interior walls of blood vessels commences years before symptoms—led to development of drugs to slow the process. Combined with better diet and exercise, these interventions have significantly reduced both morbidity and mortality for heart disease.

The prospect for doing the same for AD

is very real, Levey says. More sophisticated testing and earlier intervention with drugs and behavior therapy could alter its trajectory. More than 500 research volunteers enrolled at Emory believe the same thing.

INVOLVING FAMILIES

The on-again, off-again efforts to find a vaccine for AD were dealt a major blow 12 years ago when a small number of patients developed encephalitis during experiments with a promising vaccine. Animal studies showed that the vaccine blocked the production of beta-amyloid, a protein that is supercharged in the brains of patients with AD, causing plaque buildup in the neuropathways. The

AN ESTIMATED 800,000 AMERICANS WITH DEMENTIA LIVE ALONE—MOST OF THEM WOMEN OVER 80—AND UP TO HALF HAVE NO IDENTIFIABLE CAREGIVER. THEY ARE THE MOST VULNERABLE OF PATIENTS.

threat to patients was considered too risky so experiments were halted in 2001.

But vaccine proponents were encouraged because in the patients who didn't develop encephalitis, the vaccine—as it did in animal trials—slowed down, and in some cases, even reversed the buildup of plaque that causes cell death within the brain.

In the latest round of trials, Emory neurologist James Lah and others are using preformed antibodies rather than a live version of the virus that was thought to carry the risk. "It's called passive immunity because you're not triggering the immune reaction in your own body," says Lah. "Instead you are delivering antibodies that are made elsewhere and using that as a tool to clear out something you don't want to be there."

Cecile Bazaz comes to the clinic every six weeks for lab work and scans of her brain to detect any signs of inflammation. Every three months she returns for an infusion of the vaccine.

Although he doesn't know whether his wife's treatment is working, Alister Bazaz says that the knowledge gained makes it worth it. "If you don't participate in something like this, you feel detached," he says. "And that's not the way to fight this disease."

Emory also is one of a dozen centers nationwide experimenting with gene therapy with a nerve growth factor protein called CERE-110 that is injected directly into areas of the brain damaged by AD. The goal is for the growth factor to nourish brain cells that produce acetylcholine, an essential player in memory and cognitive function. If CERE-110 can keep these brain cells healthy, then acetylcholine levels may not drop so rapidly and the deterioration associated with AD will be slowed—perhaps even halted.

At Emory, clinician-scientists are testing a drug originally developed to treat attention deficit and hyperactivity disorder (ADHD) as a potential treatment for mild cognitive impairment (a precursor to AD). The medication, Strattera, is one of the few used to treat



ADHD that is not a controlled substance, and it has been under study for a host of neurologic conditions, including autism. The theory—based on Emory scientist David Weinshenker’s studies in animals—is that it may reduce inflammation and other brain pathology that are involved in progressive degeneration, slowing the disease progression.

GETTING AN EARLIER START

These trials are focused on a therapeutic response to changes in the brain—important, Lah says, but “they are getting to the party too late.” That’s why the Emory ADRC concentrates on early detection and intervention.

New developments in proteomics—identifying the molecular signature of proteins that trigger reactions within cells—offers real hope of identifying novel elements besides amyloids that play a role in cognitive impairment, Lah says. Identifying these biomarkers would allow physicians to use a simple blood test to detect their presence in the same way that prostate specific antigen tests can signal the potential for prostate cancer.

Emory researcher William Hu has developed a tool to detect biomarkers using spinal fluid. The simple, 15-minute test should “very soon” become a standard screening method for AD, the way colonoscopies are now routinely used in patients over 50 to detect the possibility of colon cancer, Lah says.

“The great promise of biomarkers is that they allow us a way to identify the disease in its pre-symptomatic stage,” he says. “No one who works on this disease likes the idea of waiting around until someone shows advanced disease before starting treatment.”

Among other advancements, Lah and his colleagues have developed a screening test that primary care physicians and neurologists can use to identify mild cognitive impairment that is simpler and less time-consuming than the traditional, hour-long series of memory and cognition tests. The test, dubbed the MC-FAQ, takes less than five minutes with the patient and includes a functional-activities questionnaire that is filled out by a family member or someone close to the patient. It is much more effective at picking up mild cog-



Allan Levey (left) believes that more sophisticated testing and earlier intervention with drugs and behavior therapy could alter the Alzheimer’s trajectory. **James Lah** has developed such a screening test to identify mild cognitive impairment in patients.

nitive impairment and undiagnosed dementia than previous screening methods.

TREAT THE CAREGIVERS TOO

Louise Turner knew some of the signs of AD to look for in her mother. More than 10 years ago, she and her brother had noticed that their mom often repeated stories she had just told. Turner remembered that several cousins had been diagnosed with AD.

Then in 2004 while her husband was being treated at Emory for a diabetic ulcer on his foot, Turner met Monica Parker, a primary care physician who is a member of the AD team. Turner introduced Parker to her mom, and the doctor helped both mother and daughter come to grips with what was ahead.

Research shows that the risk of developing AD doubles every five years beyond the age of 65. About a third to 40% of Americans living beyond the age of 85 will develop it. For these elderly Americans, whose sons and daughters are dealing with their own health issues, a big question is, who will take care of them?

According to the Alzheimer’s Association, an estimated 800,000 Americans with dementia live alone—most of them women over 80—and up to half have no identifiable caregiver. They are the most vulnerable of patients—financially, physically, and psychologically. When family members step up to care for them, Parker says, clinicians must be ready to support the caregivers.

Among other things, Parker asked if Turner and her mom would be interested in enrolling in an outpatient services program for patients with AD at Emory. Since then, Eighmie has been involved in several ADRC projects, making her daughter something of

a lay expert on AD. Turner has become a valuable resource in helping train the caregivers of patients seen by ADRC physicians.

While caring for her mother has been difficult at times, it has been worth it, Turner says. Eighmie has lived long and well enough that her grandchildren and great-grandchildren know her as someone unafraid to face the future. That wouldn’t have happened, Turner says, “without a strong commitment within the AD team at Emory to work with the families of patients.”

Alister Bazaz feels the same way. He agrees with Levey’s approach that once a loved one is diagnosed with AD, no matter the age, the treatment plan must be comprehensive. Rather than shy away from their circle of friends after Cecile’s diagnosis, the Bazazes talked openly about her condition and helped demystify AD.

Recently, they attended a new museum moments program for patients with dementia and families at Emory’s Michael C. Carlos Museum. Developed by Emily Lu, a freshly minted Emory doctor, the program uses specially trained tour guides who help cognitively impaired visitors connect to art. “Living in the moment,” Bazaz describes it.

“It was a wonderful experience to be among patients and families, to see their minds light up through their eyes,” he says. ☐

➤ **want more?**

If you would like more information about the Emory Alzheimer’s Disease Research Center, visit med.emory.edu/ADRC.

TRADING PLACES

By SYLVIA WROBEL

Just Lucky

When he was alone in an Orlando hotel room, a piece of atherosclerotic plaque broke free in Lucky Jain's blood vessel, perhaps while he slept or dressed. As he strode to the conference room where he was to give the opening lecture of the annual neonatology board review, a clot began to form. It traveled silently, painlessly, toward his heart. When he climbed to the podium to address his colleagues, as he had done for 20 years, the clot suddenly and without warning blocked his left anterior descending artery. He was waving to a former resident when he fell wordlessly to the floor, pale, without a pulse, not breathing.

A videographer instinctively yelled, "Is there a doctor in the house?" momentarily forgetting the hundreds already moving toward Jain. Chest compressions brought him back, at least part of the way. He remembers the EMT's standard question, "What's your name, doc? What's your name?" And he remembers the smile he got when he whispered a response.

Lucky. Only one in 20 people survive such severe cardiac arrest. Of those who do, many suffer irreversible brain damage. Time is key. An hour after Jain's collapse, Emory-trained Mark Steiner, director of cardiology at a nearby hospital, had removed the clot and put in a stent, restoring blood supply to Jain's heart and brain.

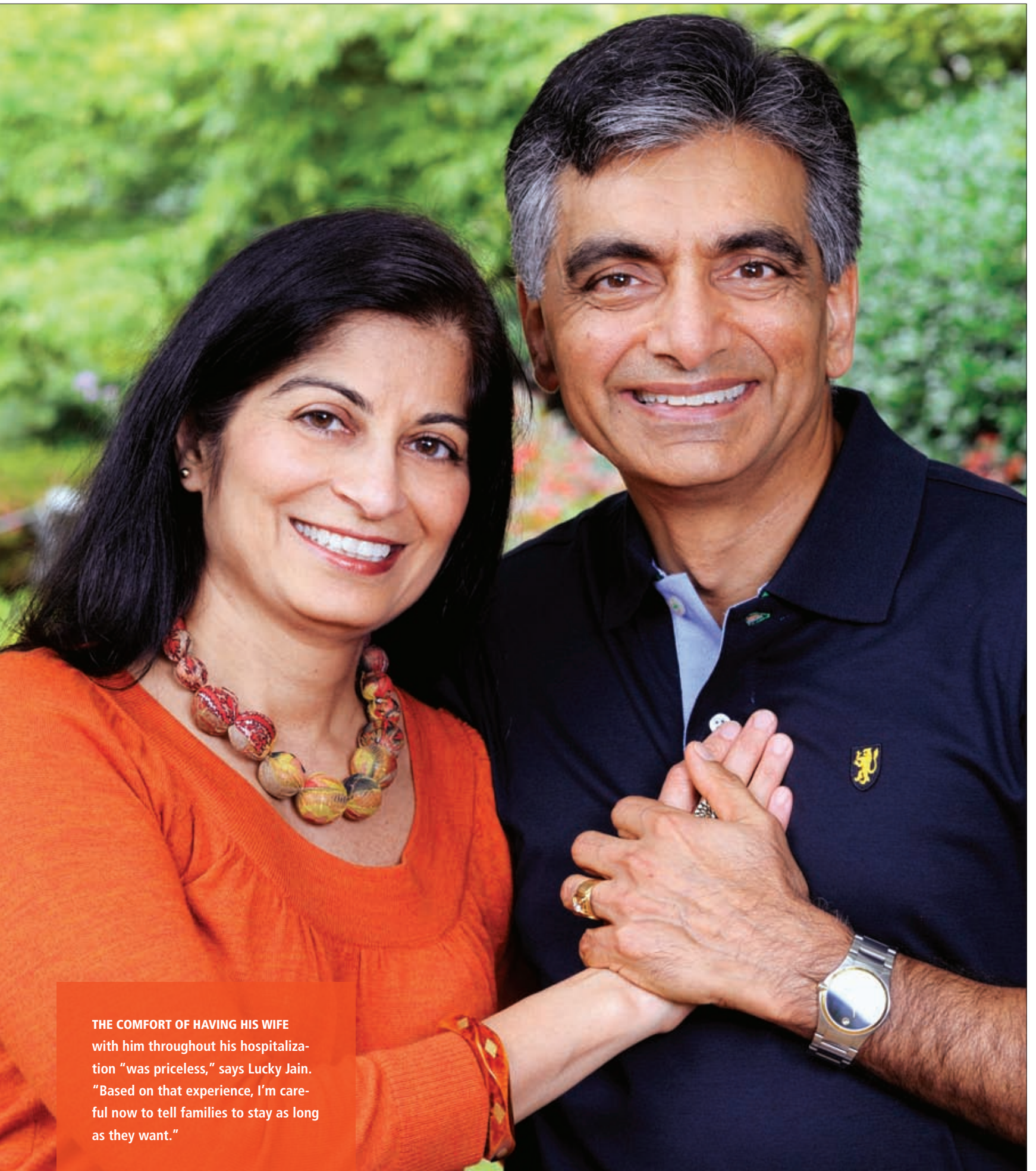
Jain—Richard W. Blumberg Professor of Pediatrics and one of Emory's busiest neonatologists—had become a patient. Physically fit, a serious tennis player still at his college weight, he hadn't seen it coming despite a family history of heart disease.

The first week was touch and go. A ventricular-assist device kept Jain's heart pumping. Back home, under the care of Emory colleagues led by Douglas Morris, he wore a defibrillator, ready to shock his sluggish heart back into action if it stopped. He spent three months in the cardiac rehabilitation program.

Did the patient experience change him? You bet, he says.

THE *take-away*

When clinicians
find themselves
as patients, they
bring lessons
learned back to
their practices.



THE COMFORT OF HAVING HIS WIFE with him throughout his hospitalization "was priceless," says Lucky Jain. "Based on that experience, I'm careful now to tell families to stay as long as they want."



NURSE PRACTITIONER AND MARATHONER
JESSICA THOMAS works with bone marrow transplant patients and is a cancer survivor herself. She helps patients learn how to live life in the face of a cancer diagnosis. "I'm one of you," she says.

On a personal level, he slowed down to a somewhat less superhuman pace. “I had done so many things on the assumption that only I could do them,” he says, “but when I looked around, I saw talent everywhere.” He delegated more. He began to meditate. Instead of eating on the run, he now savors each bite. He spends more time with those he loves. He smiles more, says thank you more often, hugs more people.

And as a clinician, he emphasizes the personal, emotional, and spiritual aspects of patient care more.

Jain’s wife Shabnam, an Emory pediatric emergency medicine physician, had refused to leave her husband’s side while he was a patient in the ICU. His awareness of her presence gave him a new appreciation of the role that families play in “keeping their loved ones going.” And not just families. Jain still tears up when speaking of the strength he gained from the concern of friends and colleagues.

Like most clinicians, he always had been careful to be as honest as possible when discussing possible outcomes. Now, having been at the opposite end of those difficult discussions, he tries to “keep the door of hope open” as wide as possible.

In Orlando, a young nurse gave him a small stone statue of an angel, promising to pray for him. Not a formally religious man, Jain nonetheless clung to the angel for days. He now encourages patients and families to draw on any available spiritual resources, without too much concern for what they are, “since they all lead to the same Almighty and all provide strength,” he says.

And finally, Jain says that his faith in the U.S. health system, already high, went up many notches in light of his recent experience. “I am so proud of what we have here,” he says. “If one of the conference center waiters had collapsed instead of me, the response of the physicians, EMT, ambulances, the hospital, would have been the same.”

Living life

Winship Cancer Institute nurse practitioner Jessica Thomas doesn’t mention her bouts with the disease to her patients, but sometimes when she is sitting in a Winship waiting room, one of them sees her and looks quizzically. “Oh yes,” she says then. “I’m one of you.”

Thomas was 20, a University of Georgia student preparing to transfer to Emory’s Nell Hodgson Woodruff School of Nursing, when her doctor discovered a melanoma on her back. She did a quick web search on melanoma, and her heart sank. Referred to Emory, she had the tumor and surrounding tissue removed. “Thank goodness

He believes that his life-threatening diagnosis made him more understanding of patients’ perceptions. **“If something worries patients enough to make an appointment and get to my office, I take their experience very seriously.”**

that’s over,” Thomas thought, but the profound experience pointed her toward oncology. After graduation from nursing school, she joined Emory’s bone marrow transplant unit.

Then, when Thomas was 24, another Emory dermatologist found a second melanoma, which she also had removed. She began to see medical oncologist Dave Lawson regularly. The following year, a third melanoma appeared. Now 28, Thomas has had at least 20 biopsies—“you lose count,” she says—and she jokingly describes her scarred back as a Picasso painting.

Although Thomas is selective about sharing her experience with patients, she always practices the lessons learned. As her Emory doctors have been with her, she is deliberately unhurried with her own patients. She knows how important her family and friends have been to her and how essential that they are included in discussions and plans. And, most of all, because she was so young when she realized that cancer would be a recurring theme in her life, she tells her patients that they can incorporate cancer into their lives without making it the focus. “No matter what the prognosis, live your life every

day,” she says. “Hold friends and family close. Do what you love.”

That means clinicians need to go beyond medical protocols to recognize what is important in their patients’ lives and help to make that happen. It meant the world to Thomas when oncologist Keith Delman shifted the date of one of her surgeries so she could run the Chicago marathon.

Ceiling tiles and other lessons

One reason that health professionals generally keep their own medical challenges to themselves is fear that the information will take the focus away from the patient’s needs. For example, when one physician found that several of his long-term patients learned of his diagnosis with a potentially serious chronic illness, they became less forthcoming in describing their own symptoms. “They didn’t want to worry me,” he says, “but of course I worried this made it harder for me to take care of them.”

“I like to think I was already pretty empathetic,” says another doctor. Still, he believes that his life-threatening diagnosis made him more understanding of patients’ perceptions. “If something worries patients enough to make an appointment and get to my office, I take their experience very seriously,” he says. Being told he probably would die young (he didn’t) also convinced him to live life to the fullest, knowing it could end at any moment. That meant marrying, having children,

enjoying sports, and practicing medicine full tilt. “Taking care of patients is such a privilege, such a joy,” he says, “it would be a shame to let worries over my own health spoil it.”

Sometimes the lesson is in the details. One physician found himself bothered by water stains on the ceiling tiles during the several days he spent flat on his back in an out-of-state ICU. “Who would have thought something like that would matter when you were ill?” he asked himself. Back in Atlanta, he walked through Emory University Hospital Midtown, looking up and reassured that the ceilings his own patients see were perfect.

Family care

Shen Tsun Wang—Jim to engineering colleagues at the University of Kentucky—became critically ill during a Danube River cruise and was placed on a ventilator at the largest and one of the best academic medical centers in Europe, Vienna General Hospital, where he subsequently had a stroke. Emory hospitalist Alan Wang and his brother Stephen, also a physician, flew to their father’s bedside. Although treatment was excellent, family involvement was severely restricted.

The sons had their father air-lifted to Emory University Hospital’s Neuro ICU, which emphasizes programs and spaces that tap into the

As a physician,
he often felt busy
without a moment
to spare. However, as
a family member
waiting for clinicians
or test results,
time seemed to
slow to a crawl.

powerful role of families in healing. Here, they were updated often and included in all medical decisions. Wang’s mother, Lung-chu, was allowed to stay with her husband around the clock, which visibly lowered her anxiety and accelerated their father’s recovery.

As chief medical officer at Emory Johns Creek Hospital and director of hospital medicine for Emory Healthcare, the younger Wang had helped implement patient- and family-centered medicine across all of Emory’s hospitals. Now he knew how much family involvement really meant, developing a new appreciation for the patience required of families. As a physician, he often felt busy without a moment to spare. However, as a family member waiting for clinicians or test results, time seemed to slow to a crawl.

Finally, as his father moved on to Emory’s Center for Rehabilitation Medicine, Wang began to realize that hospitalization is often only the tip of the iceberg of patient care. As a result, he now intentionally takes more time at discharge to help patients and families with expectations for their progress and prepare them to follow up on medications, referrals, and other long-term issues.

And the senior Wang? He’s back to walking several miles a day and reading prodigiously.

Giving and receiving

When Emory Healthcare nurse Kelly Brewer Shelby returned to patient care before her hair grew back, she always wore a wig. She didn’t want patient encounters to be about her, she says, “but if a patient opened the door about her own struggles and if it seemed my experience might be helpful, then I told her.” Shelby’s experience seemed especially helpful to women with or about to undergo testing for the same condition, since there are few survivors with whom they can talk. In January 2010, three months after getting married, she had been diagnosed with an ovarian cancer the size of an eggplant. She underwent surgery and a long sequence of body-wracking chemotherapy.

Lessons learned? First, Shelby says she gained new empathy for patients who, like her, are suddenly faced with something as “ominous and odious as ovarian cancer,” but who, unlike her, “have to navigate a complex health care system they may not understand well at a time that they are most frightened and vulnerable.”

Second, she saw how much it meant to her, as a patient, when her doctors and nurses recognized the anguish and worry of her new husband Kent and took time to take care of him. “Serious sickness is sometimes almost harder for family members than for the patient,” says Shelby, “because they can’t do anything. They can’t take away



KELLY SHELBY GAINED NEW EMPATHY for patients during her treatment for ovarian cancer. She especially appreciated the kindnesses that her providers showed her husband and family.




WHAT DID EMORY HOSPITALIST ALAN WANG learn when his dad was a patient? That the hospital stay is just the beginning of recovery from serious illness. He now takes more time with his own patients to prepare them for the weeks after discharge.

your nausea, your baldness, your pain, your fear. Those clinicians who talked to Kent or gave him something useful to do—telling him where he could go to buy a special sandwich for me when I was in the infusion center, for example—gave us both a great gift.”

And third, she realized that some of the most meaningful connections during her treatment came from the simplest things. A medical student on rotation with Ira Horowitz, her gynecologic oncologist, came in every morning and knelt down on the floor so that he could look her in the eyes to ask how she was. “I realized that often what a patient most wants, more than information, more than comfort, is to know that somebody really cares how they are doing. And this student, like Dr. Horowitz, really did.”

Two years after her diagnosis, Shelby regularly talks to medical and nursing students about her experiences as a patient. (Interestingly she taught Jessica Thomas—also profiled in this story—when Thomas was a nursing student.) “They ask wonderful questions,” she says, “about how to talk about difficult diagnoses, how to include family, how much information to provide (my husband could handle only

limited amounts, for example), and how to conduct themselves in the most helpful way.

“I share what I learned as a patient and as a nurse: your patients will always give you more than you can ever give them,” she says. 

 **want more?** 

To see a series of videos of doctors and nurses talking about their experiences as patients and what they learned, visit bit.ly/clinicianspatients.

Trading Places Part one: *After a sudden heart attack, Emory neonatologist Lucky Jain learned important lessons as a patient.*

Part two: *Emory nurse practitioner Kelly Shelby had just married when she was diagnosed with ovarian cancer.*

Part three: *Jessica Thomas was 20 when the first melanoma appeared. Three surgeries later, the Emory nurse practitioner shares the lessons she learned as a patient.*

A phase for life

By LYNNE ANDERSON • Photography JACK KEARSE

Carolyn Higgins is cheery-eyed with a bright smile, a package of cheese and crackers in her hands. Nearby are two small chocolates still in wrappers. She looks as happy and relaxed as if she's lying on a chaise on a sunny beach.

"I'm sorry," she says sheepishly, referring to the food. "I forgot my lunch."

But on an adjacent chair, zipped plastic bags hold her belongings. An IV is inserted in her right arm, slowly delivering an experimental drug that she has been getting for three years.

That she has advanced multiple myeloma seems to bother Higgins not at all. She also seems unconcerned that the standard, FDA-approved drugs used to treat myeloma failed to work for her. Higgins is thrilled to be alive three years into a phase 1 clinical trial that tests the safety of a drug developed at the Winship Cancer Institute for multiple myeloma.

"I'm starting my fourth year," she says, sounding like a kid who's tricked her mother into letting her stay up way past bedtime. "This drug and I are best friends."

Higgins is one of almost 200 patients who participated in phase 1 clinical trials at Winship last year. Opened in 2009, the phase 1 unit is at the heart of the institute's drug development program. It is one of only two such units in Georgia and by far the largest and busiest, with 38 trials in 2011. Already, phase 1 research at Winship has led to four drugs in the FDA approval pipeline as well as another 24 drugs still under study. Among them, a drug developed by Higgins's oncologist, Sagar Lonial, is coming up for FDA review within a few months.

Just this year, two trials led by Suresh

Ramalingam have moved into larger, multi-center phase 2 investigations that will test the efficacy of new agents to treat lung cancer. Both trials tested a combination of drugs, the first a combo of docetaxol and a newer agent known as STA9090. The second combined a PARP inhibitor (a drug that knocks out a cancer cell's repair mechanism) with chemotherapy.

And according to the *New England Journal of Medicine*, another Winship trial has shown promise against some solid tumors that have been difficult to treat in the past. Led by John Kauh, the study evaluates



THE *take-away*

The phase 1 unit at Emory's Winship Cancer Institute evaluates drugs given to cancer patients for the first time, advancing cures and bringing hope.

"We're a team," says Winship nurse Claudia Giddings of her patient Carolyn Higgins, who is helping Emory researchers test the safety of a drug for multiple myeloma.





The phase 1 unit at the Winship Cancer Institute becomes a home away from home for patients like Carolyn Higgins (above). There, patients put themselves on the front line of medical inquiry to help researchers like Donald Harvey (above and right) and John Kauh (next page, center) evaluate new cancer drugs. Supported by nurses, including Melissa Laramie and Claudia Giddings (next page, top left), the phase 1 trials determine whether a drug is safe for use in people.

an antibody that blocks the protein PD-1. Earlier Emory Vaccine Center Director Rafi Ahmed had discovered that PD-1 acts as a brake on immune cells. In the current study, the antibody has allowed tumors to regress and stabilize in patients with advanced cancer (including non-small cell lung cancer, melanoma, and renal cell cancer).

SAFETY FIRST

The phase 1 unit, tucked into a quiet but busy corner of Winship, occupies only 2,100 square feet, roughly the size of a family home. For many, it will become another sort of home—a place where a shared sense of purpose connects a disparate group of people and unites them against a common enemy, in this case, cancer.

These people also share common beliefs—not only does scientific research pay off but also life is made more meaningful by doing something for others.

Phase 1 trials are those in which drugs that have shown promise in laboratory studies are first administered to humans, alone or in combination with other drugs. Usually such a trial involves between 20 and 100 patients. Some of the drugs that are tested will go on

to gain FDA approval, curing people of cancer or extending their lives for many years. The main purpose, however, of a phase 1 trial is to determine whether a drug is safe for use in humans, and if so, at what dose and over what time.

Although most of the patients in the phase I unit have an aggressive cancer that has failed to respond to standard treatments, hope remains palpable. Each patient brings to the unit his or her own private reasons for taking the bold step of letting doctors and nurses try a first-in-human treatment. Some speak of their grandchildren, wanting to live to see them graduate. Others talk about a brother or sister in whose memory they fight. All face possible unknown side effects, and many spend long days in the unit, dozing, watching TV, laughing with nurses—and always hoping.

“When we give a new drug, we want to know, did it get to the cancer cell? Did it get to the proteins we wanted? And how long did it stay in the body?” says R. Donald Harvey, director of the phase 1 unit. But patient safety remains the priority.

Rigorous standards apply to these trials, and oversight—both internal and external—is

appropriately intense. Higgins says that she has been so closely monitored that she thinks of the unit as a VIP suite. “They don’t just attend to you, they hover,” she says.

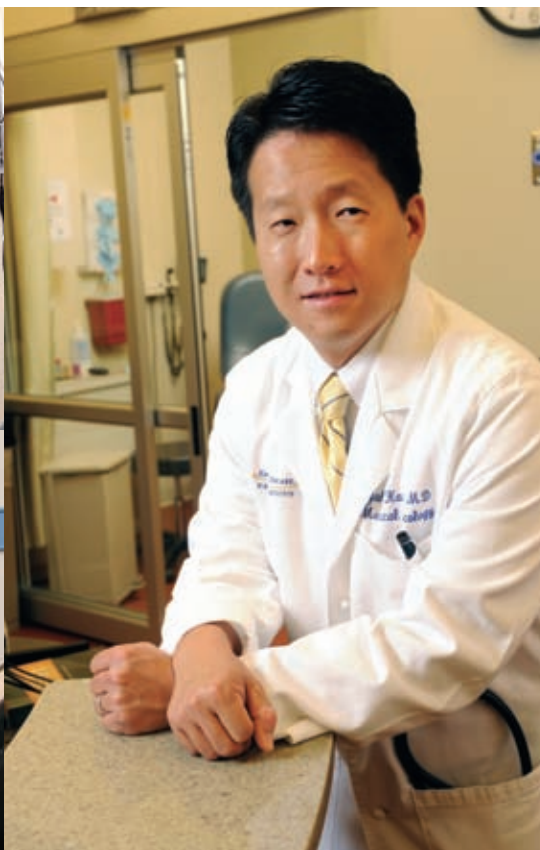
Nurses, doctors, and director alike all listen to patients attentively. Nurses draw blood or check temperatures and other vital signs as often as every 20 minutes. Patients arrive as much as two hours early for their lab work, and they typically wait at least two hours after they receive the drug, usually administered intravenously, before they are allowed to go home. For some, the treatment adds up to a 12-hour day.

The patients who enter clinical trials are pioneers, not only possibly extending their own lives but also helping unravel the mysteries of some of the most persistent diseases.

“It’s a testament to the patients we have,” says Harvey. “I’m lucky to be able to serve them, to get to know them, and to offer something they wouldn’t be able to have otherwise.”

PATIENTS AS TEACHERS

Clinical trials today are the basis of nearly all new drugs and medical devices that gain FDA approval and come to market. Basic scien-



tists often labor for years trying to find a new pathway, a new protein, or a new molecule to target to treat a disease. When an agent has proved promising in animals, investigators then evaluate it in humans.

With cancer, the drug discovery process is particularly challenging. Scientists now know about the vast complexities of cancer, the many subtypes within a broader field of cancer, and how cancer cells can and do mutate to avoid cell death.

“In most patients with cancer, there are many molecular drivers,” says Harvey. “We don’t have just a single protein or a single pathway. The challenge is in finding out in any given patient what the molecular drivers are—and that’s just the first step. The next step is finding drugs that effectively inhibit those targets and are well tolerated.” And Harvey adds, “that’s with the understanding that resistance to these targets may arise.”

Winship’s phase 1 unit goes a long way toward gaining knowledge about whether certain therapeutic agents will be well tolerated. While researchers and clinicians are careful in using the word “cure,” they all hope that the drugs being studied in phase 1 will lead to advances.

“We’re looking for successful signals that will translate to a broader community of patients and clinicians,” says Harvey.

Patients who decide to participate are brave, he notes, and the staff in the phase 1 unit do everything they can to support these pioneers.

“We all get excited when they get good scans, and we’re there for them when they don’t get good ones,” says Emory nurse Claudia Giddings, one of four full-time nurses in the unit. “We’re together. We’re a team. We’re here to celebrate more birthdays.”

Patient Martha Byrd of Canton, Ga., says that she chose to participate in a phase 1 trial to do just that—to celebrate more birthdays, not only her own but her grandchildren’s too. Originally diagnosed with breast cancer, Byrd learned in further scans that she also had unrelated pancreatic cancer. The breast tumor responded to chemotherapy, but the cancer in her pancreas did not.

Byrd pondered enrolling in the phase 1 study for some time. “I am the type of person who will get a prescription and read the side effects and say ‘no,’” she says. There was another big concern—her job. Byrd needs to work 30 hours a week to maintain her insur-

ance, and she worried about the side effects. Determined, she has worked out a way to keep her job and still receive treatment, with her boss allowing her to work from home on Wednesdays when side effects tend to be hardest for her to handle.

The thought of living to see her grandchildren graduate from high school inspired her, she says. “I’ve always had a lot of faith in my doctors,” she says. “The people here are just incredible. They answer all our questions, and they take such good care of us.”

The physicians and nurses conducting the phase 1 trials wouldn’t consider doing anything less. They view their patients as heroic and take their own roles very seriously. “It’s a tremendous responsibility,” says Ramalingam, and Kauh adds, “everyone here realizes that.”

Giddings says that the patients inspire her to give her best every day. “They’re resilient,” she says. “I figure if they’re that resilient, we’re going to be there for them however we can.”

Harvey, too, credits the patients for what they have taught him about courage and their experiences on the various drugs.

“I’m most grateful to them for the learning I’ve been able to do,” Harvey says. “Without them, we’re lost in the wilderness.”

How will we pay for Alzheimer's?

By MIKE KING

Even though the threat posed by Alzheimer's disease (AD) to government health programs continues to grow, federal funding for the disease has not kept pace.

Consider that the cost of treatment for AD this year is estimated by the Alzheimer's Association to be \$200 billion, with about \$140 billion being paid for by Medicare and Medicaid. This figure will grow exponentially as the nation's elderly population enters their retirement years and more turn to state Medicaid programs to pay for nursing home care.

Yet NIH funding for research and treatment is paltry for AD (about \$450 million this year) compared with cancer (\$5.4 billion), cardiovascular/lung disease and hypertension (\$4 billion), and HIV/AIDS (\$3.1 billion).

Advocates say it speaks to the fact that research money goes first to diseases that kill and disable at an early age. Allan Levey, director of Emory's Alzheimer's Disease Research Center (ADRC), suggests an additional reason. Funding for research often depends on public advocacy, and AD funding, in comparison with that for other diseases, has been hindered by the social stigma of AD itself. Plus there are no survivors to champion the cause. No Lance Armstrongs. No Dick Cheneys. No Magic Johnsons.

While much of Emory's ADRC funding has come through the NIH—\$12.5 million since 2005—federal dollars actually declined over the past year, according to Janet Cellar, Emory ADRC's administrative director.

But there are hopeful signs. In May, Secre-

tary for Health and Human Services Kathleen Sebelius unveiled the first national plan to address AD. Some \$50 million in the current NIH budget has been assigned to AD research considered too promising to delay. Another



\$100 million is proposed for new research funding for the 2013 fiscal year, including \$20 million for education, outreach, and support for families affected by AD. The additional spending is needed to begin implementing the National Alzheimer's Project Act, a blueprint for AD research and treatment that passed Congress with bipartisan support in 2011.

Getting the money appropriated in the extremely partisan environment is no sure thing, advocates say. That means research centers will continue to rely on private funding.

Fortunately, Emory has benefited from the resources of community members who want

to help. Last year, Atlantans Sarah and Jim Kennedy contributed \$5 million to a project aimed at increasing neurotransmitter norepinephrine levels in patients in early stages of the disease. Similar help has come from the Rich Foundation. Sylvia Dodson, who cared for her husband when he was dying of AD, has set up a \$1.3M bequest for AD research. On a community-wide scale, the ADRC benefitted from two musical events, one by the Atlanta Symphony, sponsored by the Coca-Cola Company, and a violin concert with Robert McDuffie sponsored by the family of the late Atlanta real estate developer, Mack Taylor, who died of AD in 2008.

Researchers also are turning to the states for help, says Levey. Florida, California, and several other states have set aside funds to support researchers in the battle against AD. Wisconsin spends about \$500,000 annually to help create a statewide clinical care network.

While Georgia doesn't fund AD programs directly, funds distributed through the Georgia Research Alliance are used for capital expenses, Levey says. "We're not where we need to be with funding, given what lies ahead," he says. "But as awareness and the demand for services increases, we're hopeful funding will follow. We now have many good ideas about the cause of AD. Time and money are the most important limiting factors."

By the numbers

5.4 million

Americans affected by the disease

15.2 million

Friends, family members, and loved one who care for them

17.4 billion

Hours of service provided by caregivers who are unpaid

\$183 billion

Total costs of doctor, hospital, nursing home, and hospice care for AD patients in the United States in 2011

\$1.1 trillion

Projected cost of AD services in 2050, if current trends hold

\$174,000

Average lifetime care cost for an AD patient



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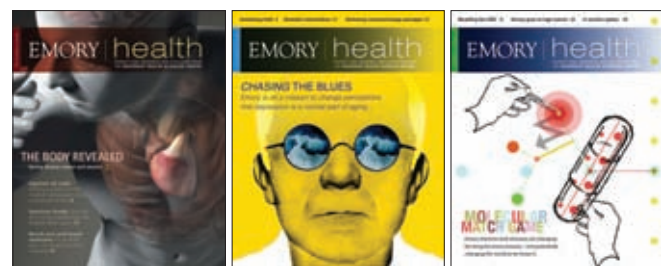
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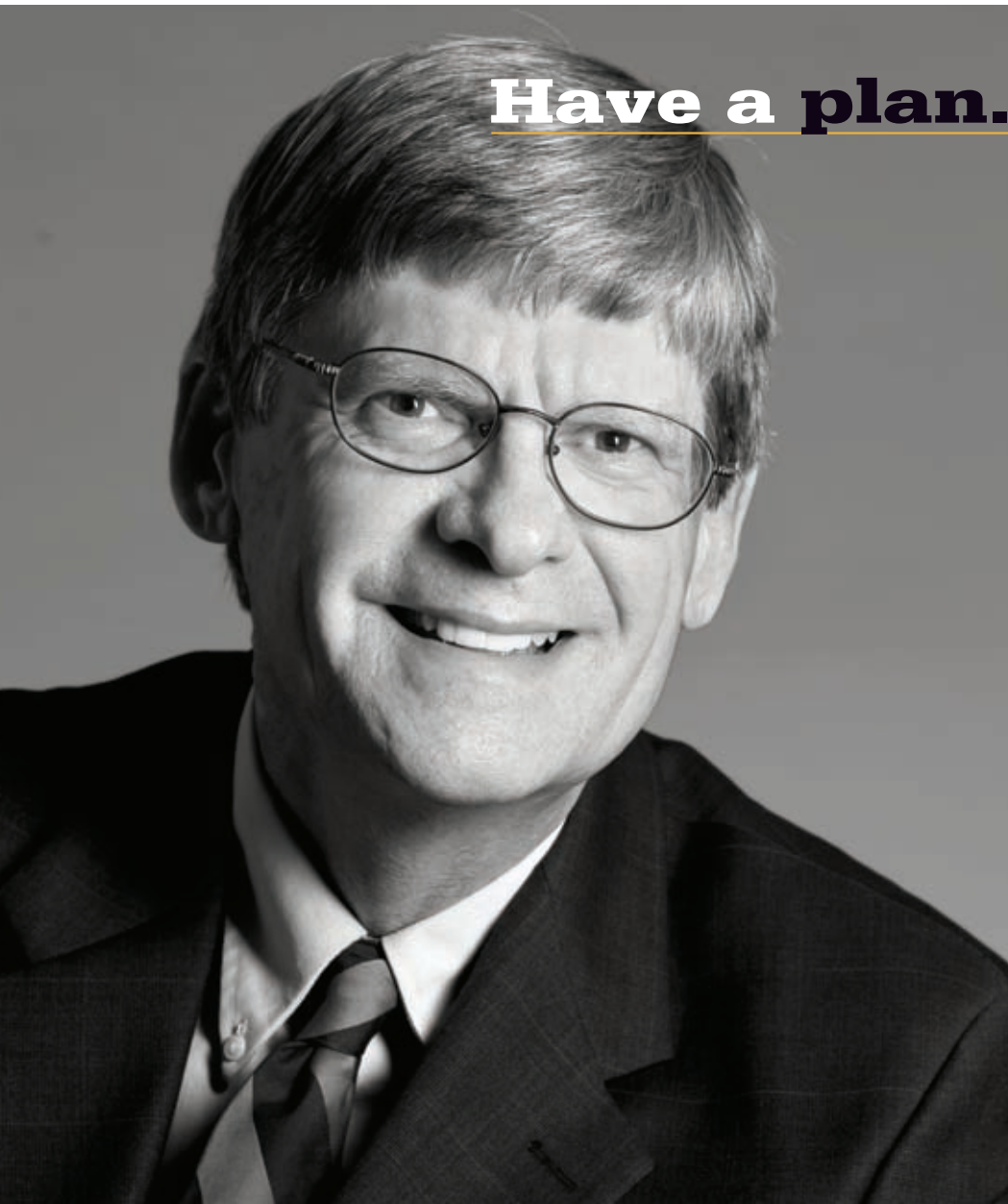
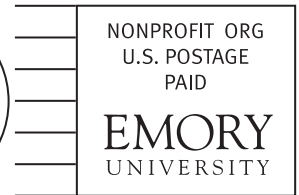
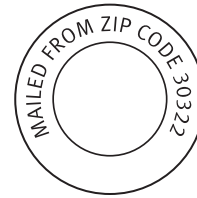
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SIX YEARS INTO THEIR MARRIAGE, George Weaver lost his wife, Allison, to breast cancer. She was only 37.

Nearly 25 years later, Weaver has made Winship Cancer Institute of Emory University the beneficiary of a life insurance policy to support breast cancer research in Allison's honor. "We learned that when breast cancer hits young women, it is often very aggressive," says Weaver, now remarried with two children. "I wanted to do something to fight this terrible disease that could take a young person in the prime of life and snatch her away."

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