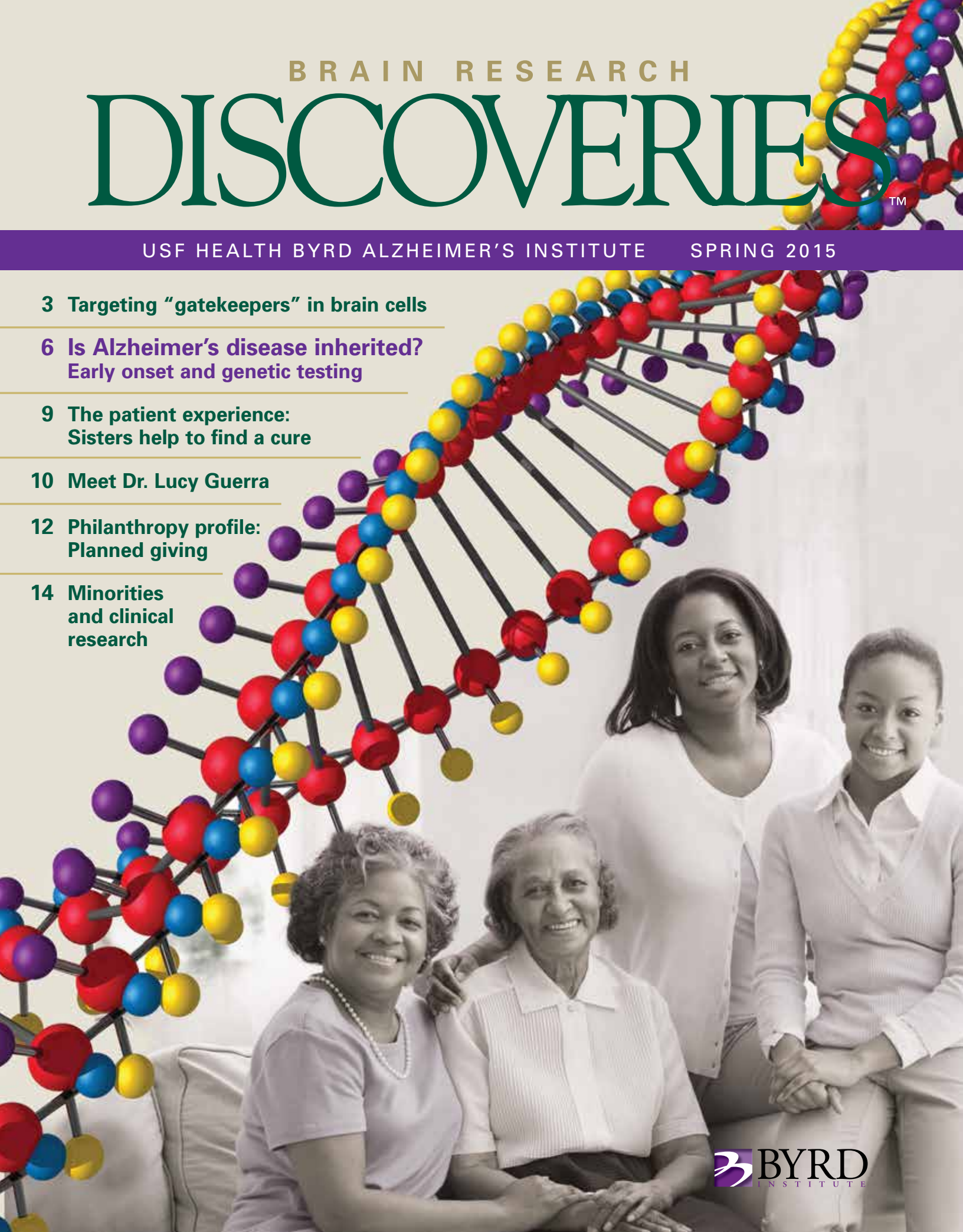
BRAIN RESEARCH

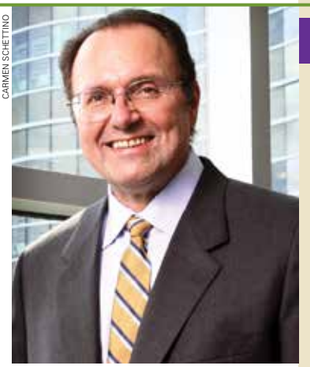
DISCOVERIES™

USF HEALTH BYRD ALZHEIMER'S INSTITUTE SPRING 2015



BYRD INSTITUTE

Ethnic diversity is critical in clinical research studies



CARMEN SCHETTINO

Increasing the diversity of participants in clinical trials is tremendously important. To date, most research volunteers are relatively affluent and predominantly European in ethnicity. This does not represent the range of ethnicities impacted by Alzheimer's disease (AD). In fact, African Americans and Hispanics have an increased risk of AD on an age-adjusted basis.

One consideration is genetics, which is discussed in this issue in my interview with Mark Zaloudek. Diminished access to health care and increased rates of other risk factors for AD, such as cardiovascular disease and diabetes, may also account for some of the disparity. However, we increasingly find that more education protects against AD. The African American and Hispanic populations reaching their 70s and 80s today have a legacy of segregated education, with many attending schools with reduced staffing and fewer days of education per school year.

Because of well-known ethnic differences in response to medications, it is critical to include ethnically diverse populations in clinical research studies, especially for AD. The USF Health Byrd Alzheimer's Institute is dedicated to this goal. We are planning a special event this summer with African Americans Against Alzheimer's to increase awareness about AD and provide more information about clinical trial opportunities. We are also developing a plan to roll out a mobile clinical trial unit to bring the research opportunities to the community rather than requiring them to come to us. I hope to tell you more about the mobile unit in an upcoming issue.

In this issue, we also introduce you to two of the Institute's rising stars. Lucy Guerra is a dynamo. Dr. Guerra provides primary care to many of our patients who are visiting the Institute's Center for Memory CARE for Alzheimer's or Parkinson's diseases. There is little that slows her down. She sees every obstacle as defeatable and finds opportunity in every challenge. USF and the Byrd Institute are fortunate to have her.

Chad Dickey is a remarkable scientist and will undoubtedly become one of the most celebrated at USF. And, he is 100% a product of Tampa. Born and raised here, he spent a scant two years in Jacksonville before returning to USF. His research success has necessitated the build-out of additional space on the fifth floor to accommodate his burgeoning research team. All of this is said with a small degree of personal pride, as I served as Chad's dissertation advisor during his time as a PhD student at USF.

I hope you enjoy this issue of Brain Research Discoveries.

...until Alzheimer's is a memory®

Dave Morgan, PhD
CHIEF EXECUTIVE OFFICER

BRAIN RESEARCH
DISCOVERIES
Spring 2015

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Targeting the "gatekeepers" in brain cells

Neuroscientist Dr. Chad Dickey is shedding light on regulating cell function in his search for ways to prevent or reverse memory loss.

As a young research scientist a decade ago, Chad Dickey could have easily been drawn into studying the causes of and cures for cancer. After all, research grants were much more plentiful in that field to help launch his career.

But a $100,000 grant back then from the Alzheimer's Association changed all that. Today, the 38-year-old Tampa-area native is determined to help shed new light on our understanding of memory loss and ways to overcome the perplexing disease that has escalated to the fifth-leading cause of death in the United States.

"My goal in going into this field was to do drug discovery and find treatments for people," says the easygoing yet scrutinizing neuroscientist at the USF Health Byrd Alzheimer's Institute in Tampa. He believes that some of his research could advance to human trials before the end of the decade.

Scientists throughout the United States and

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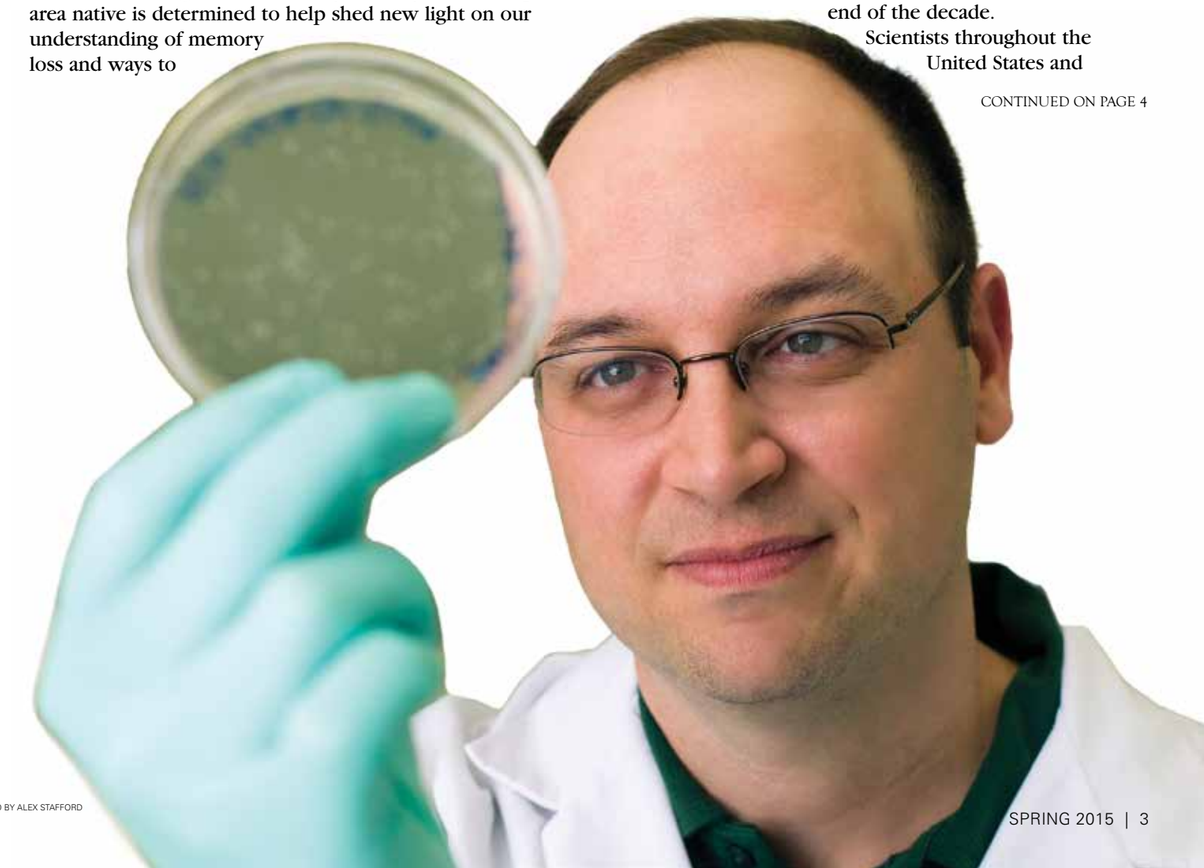

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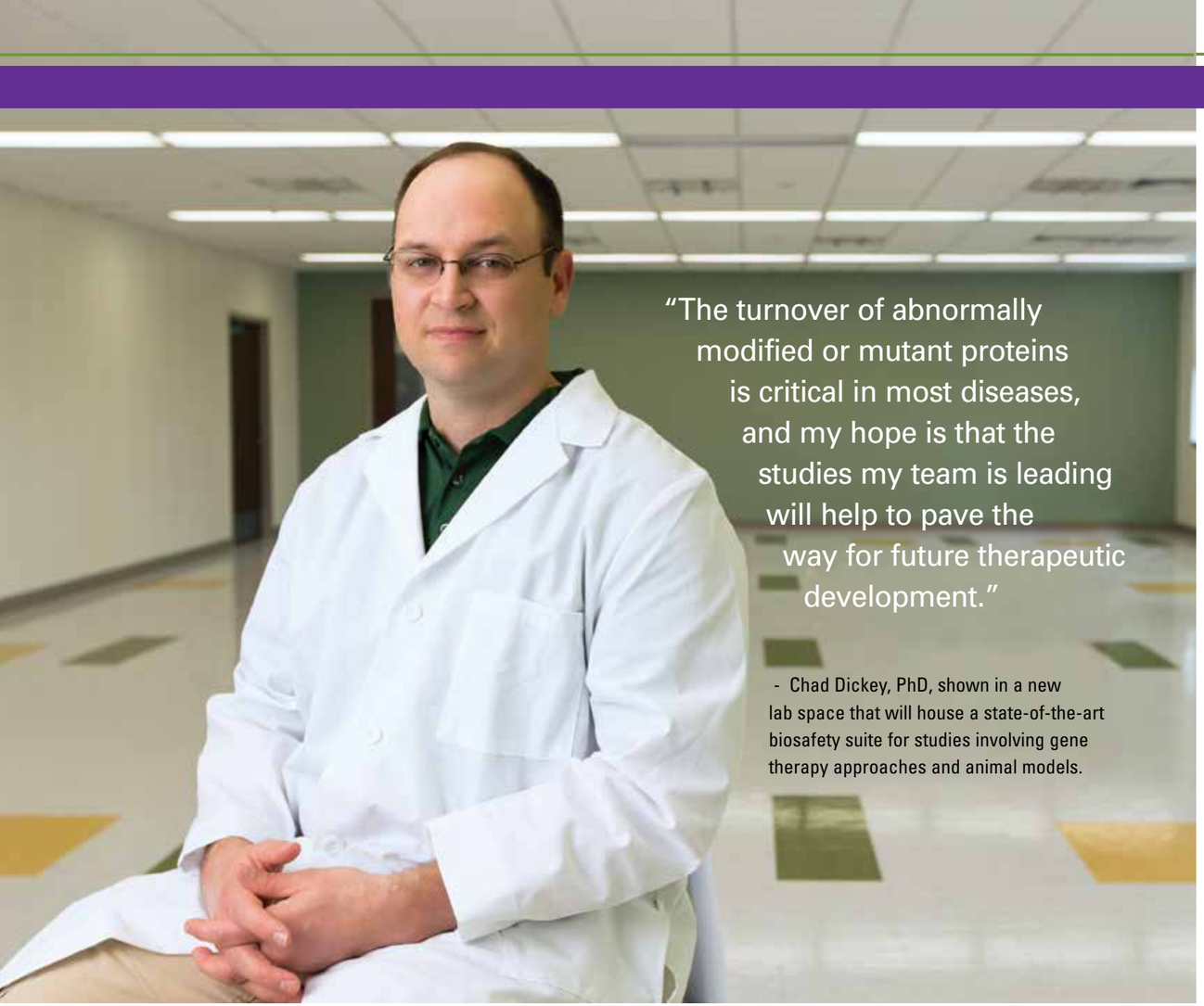


- Chad Dickey, PhD, shown in a new lab space that will house a state-of-the-art biosafety suite for studies involving gene therapy approaches and animal models.

PHOTO BY ALEX STAFFORD

Targeting the "gatekeepers" in brain cells

CONTINUED FROM PAGE 3

around the world are racing against time to better understand Alzheimer's, the only leading cause of death for which there is no known prevention or cure.

The Alzheimer's Association estimates that more than 5 million Americans have Alzheimer's or another form of dementia. That number is expected to double in 20 years as the population ages.

Alzheimer's is already the most expensive disease in the United States – exceeding the cost of treating people with cancer or heart disease – and analysts fear it could eventually bankrupt Medicare and Medicaid, short of any significant scientific breakthroughs, even though federal research dollars for Alzheimer's still lag far behind those pledged to other major diseases.

The $6 million man

The National Institutes of Health awarded Dickey more than $6 million in the past decade to build upon his promising research into so-called "protein chaperones" and how they affect brain cell function. NIH grants will allow him to continue his research for the next five years, and grants from the Veterans Administration will allow him to pursue additional laboratory research into Alzheimer's.

Dickey, who received his doctorate in pharmacology and neuroscience from USF in 2004, is trying to figure out how to activate or deactivate certain proteins in brain cells that may help prevent or reverse memory loss.

His scientific puzzle includes a buildup of harmful substances in the brain known as "tau tangles," which are linked to the progression of Alzheimer's disease by interfering with the body's intricate network of nerve cells and how they communicate with one another.

Experimenting with laboratory mice, Dickey and several of his USF colleagues want to learn more about which chaperones or combinations of chaperones within each cell could undo the damage of the tau tangles [see sidebar].

Fellow researcher Dr. Edwin Weeber admires Dickey's collaborative approach as a lead investigator. Drawing from history, Weeber equates Dickey's style of teamwork in the lab to "the smiling [Winston] Churchill type – likeable and approachable, but calculating, deliberate and always annoyingly detail-oriented," rather than the heavy-handedness of a Napoleon Bonaparte or Gen. George Patton.

"He's incredibly knowledgeable about everything brain-related, and his excitement and passion for science are infectious," added Weeber, a professor of molecular pharmacology and physiology at USF.

Making things better, not worse

For Dickey, it's all about which chaperones aren't doing their job.

Even harder to answer is what to do about them once they're identified.

He knows that researchers trying to solve one problem often create unwanted and harmful side effects.

"How do we inhibit certain protein chaperones from allowing tau to build up without screwing up the function of the rest of the cell?" he asks. "You might cure Alzheimer's, but you may cause something else. The trick right now is trying to identify whether there are chaperones that are specifically regulating tau without affecting a lot of other proteins in a cell."

Dickey thinks he may be onto something with a stress-related protein named FKBP51. By altering the presence or function of that protein, it may be possible to reverse the problem of tau buildup in the brain, he says.

In 2013, Dickey published his finding that FKBP51 partners with a beneficial protein chaperone known as Hsp90, and as the levels of FKBP51 increase with age, they somehow overtake Hsp90's ability to regulate tau in brain neurons. The result is that they speed up the progression of Alzheimer's disease by preventing the removal of excessive tau in the brain.

He wants to know more about how to regulate the FKBP51 protein to allow the brain to do a better job of maintaining a healthy level of tau.

"By harnessing these chaperones, it could possibly destroy or fix tau…in a way that makes it less toxic to the brain," he says.

A key to solving other diseases?

Dickey, who is also an associate professor of molecular medicine at USF, believes that getting a better handle on manipulating protein chaperones to improve cell health not only holds promise for treating Alzheimer's, but may provide new ways to treat more than a dozen other diseases, including Parkinson's, that also involve the abnormal buildup of tau.

That's why the NIH is also funding Dickey's work on the role chaperones play in glaucoma and depression.

For someone who initially considered becoming a cancer researcher, Dickey hopes his work may one day lead to cancer breakthroughs as well.

"With collaborators, we've been exploring the role of chaperones in cancer biology and have been developing compounds that can selectively target cancer cells through the inhibition of the chaperone Hsp70," he says.

The married father of two (his wife is an elder law attorney and their sons are ages 9 and 7) believes that learning how to make protein chaperones more effective may be the "skeleton key" to treating many human disorders.

"The turnover of abnormally modified or mutant proteins is critical in most diseases, and my hope is that the studies my team is leading will help to pave the way for future therapeutic development." ■

The key role of 'protein chaperones'

Dr. Chad Dickey believes protein chaperones may hold the key to advancing our understanding and treatment of Alzheimer's and other diseases.

So what exactly are they?

This array of more than 150 proteins found in every cell perform a variety of tasks. Together they enable us to walk, talk and think, by allowing our nerve cells to communicate with each other in ways we take for granted until something goes wrong.

As their name implies, these "chaperones" in each cell "make sure that other proteins arrive safely and are functional at their destination within the cell," according to the National Institutes of Health.

However, they also "ensure that proteins deemed to be 'ill-behaved' or abnormal are destroyed."

The chaperones' roles give them important access to other proteins in cells, leading scientists to believe that when the chaperones don't function properly, it may contribute to the cellular damage and neurological breakdowns found in Alzheimer's, Parkinson's and other diseases.

Is Alzheimer's disease inherited?

Dr. Dave Morgan, a leader in the fight against Alzheimer's disease, answers some frequently asked questions about whether genetics, ethnicity, lifestyle choices and other factors may increase your odds of developing the disease.

Today more than 5 million Americans and their families struggle with Alzheimer's disease. Experts say millions more will be diagnosed with the debilitating disease in coming decades, if there are no significant medical breakthroughs.

As head of one of Florida's leading Alzheimer's research facilities, Dave Morgan, PhD, has become a tireless advocate for investing more in scientific research to head off what he describes as the looming "tsunami" of new cases that analysts predict could bankrupt the nation's health care system.

Alzheimer's has already become the costliest medical problem in the United States, eclipsing heart disease and cancer in recent years. And unlike all other major diseases, there is still no prevention, treatment or cure for the memory-robbing disease.

Morgan, who has spent more than 30 years in Alzheimer's research and advocacy, is CEO of the University of South Florida's Byrd Alzheimer's Institute. He is a founding member of the national ResearchersAgainstAlzheimers and a member of the Florida Alzheimer's Disease Advocacy Committee, and he holds several other national and regional posts to champion the urgency to find answers to this vexing disease. Our writer, Mark Zaloudek, reached out to Dr. Morgan and asked him to share the latest scientific knowledge regarding who is at greater risk of developing the disease.

MZ: I'm sure this is a question you get asked a lot: Is Alzheimer's inherited?

DM: The answer is yes and no. Some cases are inherited. In some cases, inheritance plays a role. And in the remainder, there is no known genetic basis.

MZ: How much more likely is it that someone will develop Alzheimer's if one or both parents had it?

DM: The key here is when a parent developed the disease. In some rare instances, 1-2 percent, a parent has a mutation that causes the disease. These cases tend to occur in the 40s or 50s. In these situations, a child will have a 50:50 chance of inheriting the disease from an affected parent. This "familial" form of Alzheimer's is what was portrayed in the Oscar winning film "*Still Alice.*"

If the onset is in the 60s or even early 70s, it could be associated with a form of the gene called Apolipoprotein E. There are three normal variants of this gene (E2, E3 and E4) in humans. About 15 percent of people carry one copy of E4, but 50 percent of Alzheimer's cases have the E4 variant. Thus having this genetic variant triples the risk of developing Alzheimer's.

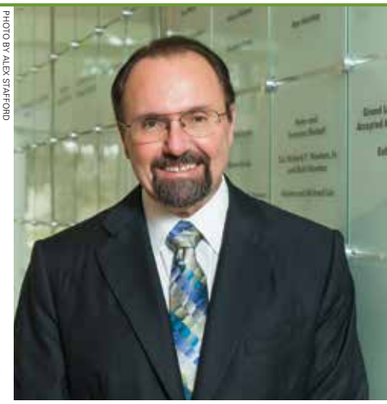
If you have two copies of E4, one from each parent, it increases the risk tenfold. Still, some people with an E4 gene live to 90 without dementia, thus it is a risk factor.

MZ: Like some genetic traits, can Alzheimer's skip a generation?

DM: It's feasible that the form associated with the E4 variant could. There are a few other genes that increase risk, but the number of people affected are far fewer than those with Alipoprotein E.

MZ: More women in the United States develop Alzheimer's than men. But we all know that this is a disease that increases with age, and women generally live longer than men. So do more women develop Alzheimer's than men of the same age?

PHOTO BY ALEX STAFFORD



Byrd Alzheimer's Institute CEO Dave Morgan, PhD

DM: Yes, even correcting for differences in longevity, women appear to have a slightly greater risk for Alzheimer's than men.

MZ: Are some ethnic groups more likely, or less likely, to develop Alzheimer's?

DM: The Alzheimer's Association reports that in the United States, African-Americans and Hispanics have almost twice the risk of developing Alzheimer's at a given age as whites.

MZ: What's the difference between Alzheimer's and senility?

DM: At one time, only cases occurring before age 65 were called Alzheimer's disease, or "pre-senile dementia." It was thought that dementia after 65 was part of the aging process, called "senility." Around 1990, we noted that not everyone reaching 100 had dementia, and those with dementia had brain changes very similar to those causing the pre-senile form, or Alzheimer's disease. Hence, once we recognized dementia as a disease irrespective of the age of onset, we started using the term Alzheimer's if the changes in the brain resembled those described by [German physician] Dr. Alois Alzheimer. About two-thirds of all dementia cases are found to have Alzheimer's; the remainder have another cause of dementia.

MZ: There are so-called "genetic markers" that predispose a person to developing Alzheimer's, but that's only half the story. Will some people with this abnormal chromosome never develop Alzheimer's, while others who don't have this genetic marker come down with the disease?

DM: Perhaps 40-50 percent of Alzheimer's cases do not have a known genetic risk factor, at least that we can identify. These "sporadic" cases likely result from wear and tear and lifestyle choices that people have made.

MZ: What does this tell us about placing too much faith in genetic testing at this point?

DM: Genetic testing only identifies risk. Sometimes there are methods to reduce the risk, and the genetic testing is useful. At least for now, there is nothing proven yet to reduce the risk in people who have genetic markers. However, there are four clinical trials in individuals with genetic risk factors that are testing treatments right now.

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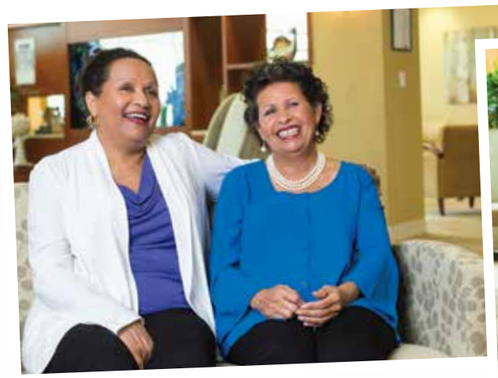
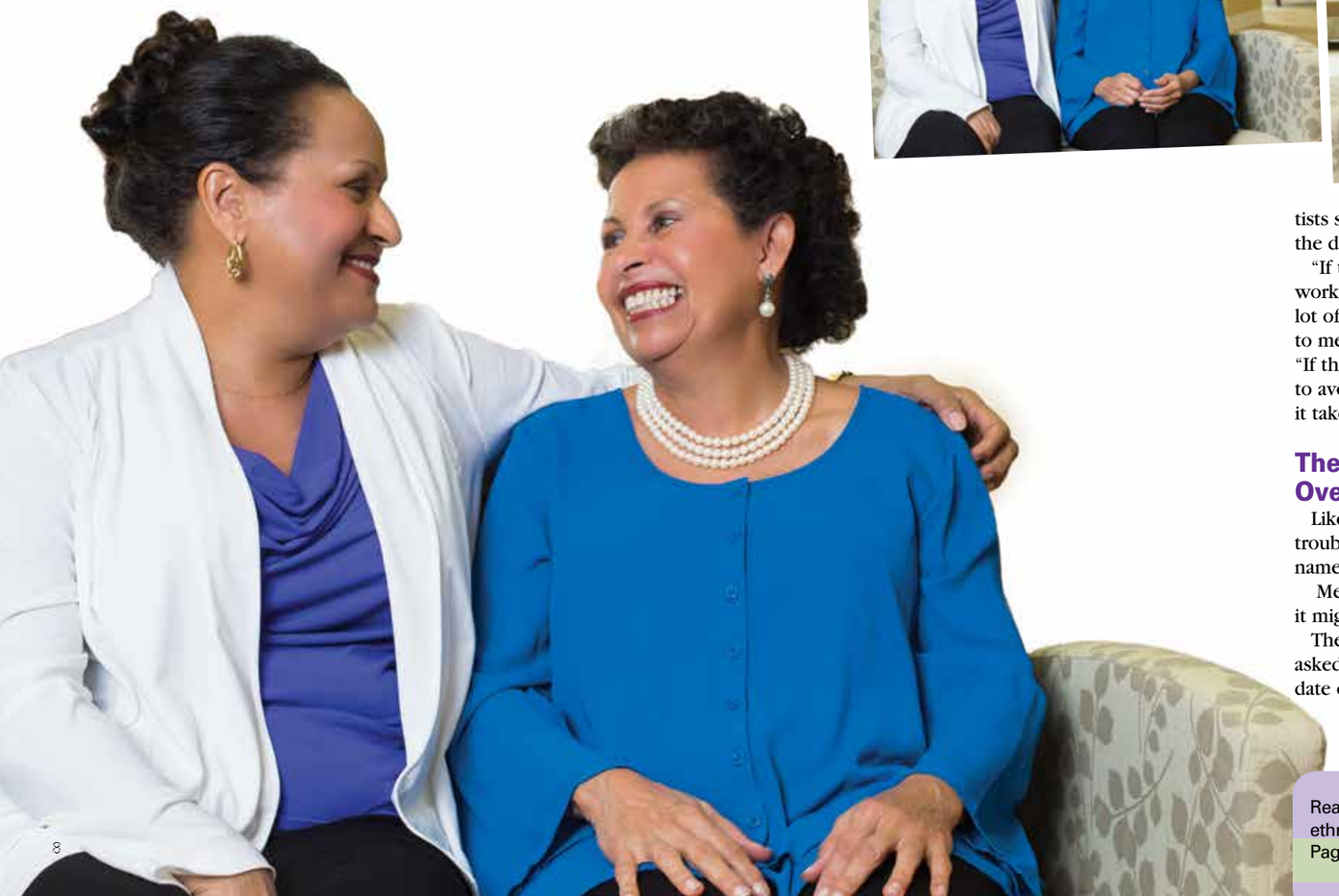
Happy together

Two sisters, ages 75 and 70, share memories and laughter as one helps the Byrd Alzheimer's Institute search for a cure.



PHOTOS BY ALEX STAFFORD



Going to a medical facility for periodic checkups can be a drag, but not for Olga Stergion, 75, and her 70-year-old sister, Ada Santana.

The two women, who live about half an hour apart in the Tampa Bay area, look forward to their outings to the University of South Florida's Byrd Alzheimer's Institute as an opportunity to share stories and laughs, as they've done throughout their lives.

"One of the reasons we do this is we are together, and we have fun and are always laughing and making jokes," Stergion says with her infectious chuckle. "It's a fun outing whenever we go to the Byrd Institute."

She also knows that accompanying her younger sister to the research facility may help scientists get one step closer to finding a cure for the memory-robbing disease with debilitating consequences. Santana is in the early stages of the disease.

Stergion is proud of her sister, not only for seeking answers about her condition, but also for enrolling in a program at the Institute testing the effectiveness of an experimental drug, to help scientists search for ways to halt or reverse the disease.

"If this [experimental] medication will work, not only will she be helped, but a lot of other people will be helped, and to me that's important," Stergion says. "If there's something that could be done to avoid this illness, I would do whatever it takes."

The first step: Overcoming denial

Like many people, Santana thought her trouble remembering certain words or names was just part of getting older.

Members of her family were afraid it might be something worse.

Then one day her grown daughter asked her point-blank: "Mom, what's my date of birth?"

Santana recalls that she "had to stop and think" about her only child's birthday. That's when she knew she might be among the growing ranks of Americans with memory loss.

That wake-up call took place about three years ago. By then, Santana's daughter and sister were among the family members who felt they needed to address the gradual changes they began noticing in Santana.

Santana's family took her to the Byrd Institute, one of the state's leading research centers, for a memory assessment. Unlike many people unwilling to confront their memory loss, Santana says she wanted to get checked out "because I want to do whatever might help me."

Medical and memory-based screenings confirmed that she was in the early stages of Alzheimer's.

Read more about the importance of ethnic diversity in clinical trials on Page 14.

> "If this [experimental] medication will work, not only will she be helped but a lot of other people will be helped, and to me that's important. If there's something that could be done to avoid this illness, I would do whatever it takes." Olga Stergion

Stergion knew all too well about the psychological and economic toll of Alzheimer's, having cared for her husband at home for 10 years before he passed away from the disease in 2005.

"Don't be afraid to get help, and don't be afraid to get tested to find out what's wrong," says Stergion. "Especially the family needs to know how to deal with it, because caring for people with this illness falls on the family. And it's not the person's fault that they have this illness."

Clinical trials offer hope

Since her diagnosis, Santana has enrolled in one of several clinical trials underway at the Institute, to see if she – and some of the more than 5 million other Americans with Alzheimer's disease – could benefit from an experimental drug before it can receive FDA approval.

CONTINUED ON PAGE 15

In her father's footsteps

By the age of 6, few of us could accurately predict what we'd be doing when we "grew up" – which makes Lucy Guerra's insight at that age even more impressive.

Simply put, she admired her father, whom she describes as an old-fashioned "country doctor."

She was still too young to understand the sacrifices her parents made some 15 years earlier, fleeing the Cuban Revolution in 1959, or the fact that her dad, an aspiring doctor, had to learn English before he could retake all of his medical boards in the United States to launch his career in his adopted homeland, while his wife supported them both.

Nor did she fully grasp the hardships that followed when, after he completed his medical residency in New York City, his first job would be in a small farming community in Kansas, because the state was actively recruiting doctors to work in rural areas. The closest Spanish-speaking family lived 100 miles away.

"My father – who was a Cuban immigrant and had a thick accent – was a 'country doctor,' believe it or not, for a community of 1,500 people with one red light in the entire county," she says with a mixture of pride and disbelief. Guerra was barely 5 years old and her sister was 3 when her parents left Queens, N.Y.

"When I was a kid living in Kansas, I thought that what my dad was doing was great. You felt like you were really a part of the community. He made house calls and sometimes my sister and I would go with him. The farmers would pay him when they could, after they had their harvest," she recalls.

"Even back then I thought 'This is what I want to do.' I saw that my father was always happy doing it."

Twenty-five years after Tomas Guerra completed his medical residency at what's known today as the Icahn School of Medicine at Mount Sinai in New York, his older daughter received her medical degree from the same school.

A challenging, multifaceted career

Today, Dr. Lucy Guerra practices medicine in ways that carry on many of the lessons she learned at her father's side.

As the division director of General Internal Medicine and an associate professor at the University of South Florida in Tampa, she juggles responsibilities serving patients and training the next generation of doctors.

She sees patients at USF Health's Morsani College of Medicine's outpatient clinic and the Byrd Alzheimer's Institute, as well as at the James A. Haley Veterans' Hospital in Tampa. Her philosophy is that doctors do their best work when they take a broader view of their role. Caring for patients should take into account the role of their family and caregivers, she says, and physicians need to work more closely with nurses, therapists, social workers, pharmacists and other health care providers to optimize each patient's care.

And she's not alone. The growing trend in the medical field is known as "personalized medicine."

"The patient is at the center, and you try to provide the best care possible by drawing upon all of these different skill sets," says Guerra, who joined the faculty at USF Health more than 10 years ago and teamed up with its Byrd Institute last summer.

A team approach is especially important when working with people suffering memory loss who come to the Byrd Institute for diagnosis or to participate in clinical trials that involve experimental drugs.

"At the Byrd Institute, you're not just working with the patients, you're also working with the family and others who are around them all the time," she says. "As a physician, you need help from all of these other people who know the patient well."

Giving back is in her DNA

In her spare time, Guerra makes sure that some of Tampa's residents who can least afford health care aren't overlooked.

She has helped guide a community outreach program known as the USF Bridge Clinic since it was established in 2007 to help under-insured adults in Tampa get the medical care they need but can't afford. And last year she became the faculty adviser to a new initiative known as Tampa Bay Street Medicine that provides medical care to the homeless.

Guerra says her parents, devout Catholics, instilled in their children "a sense of social justice" and a responsibility "to help others that have not had the opportunities that we had."

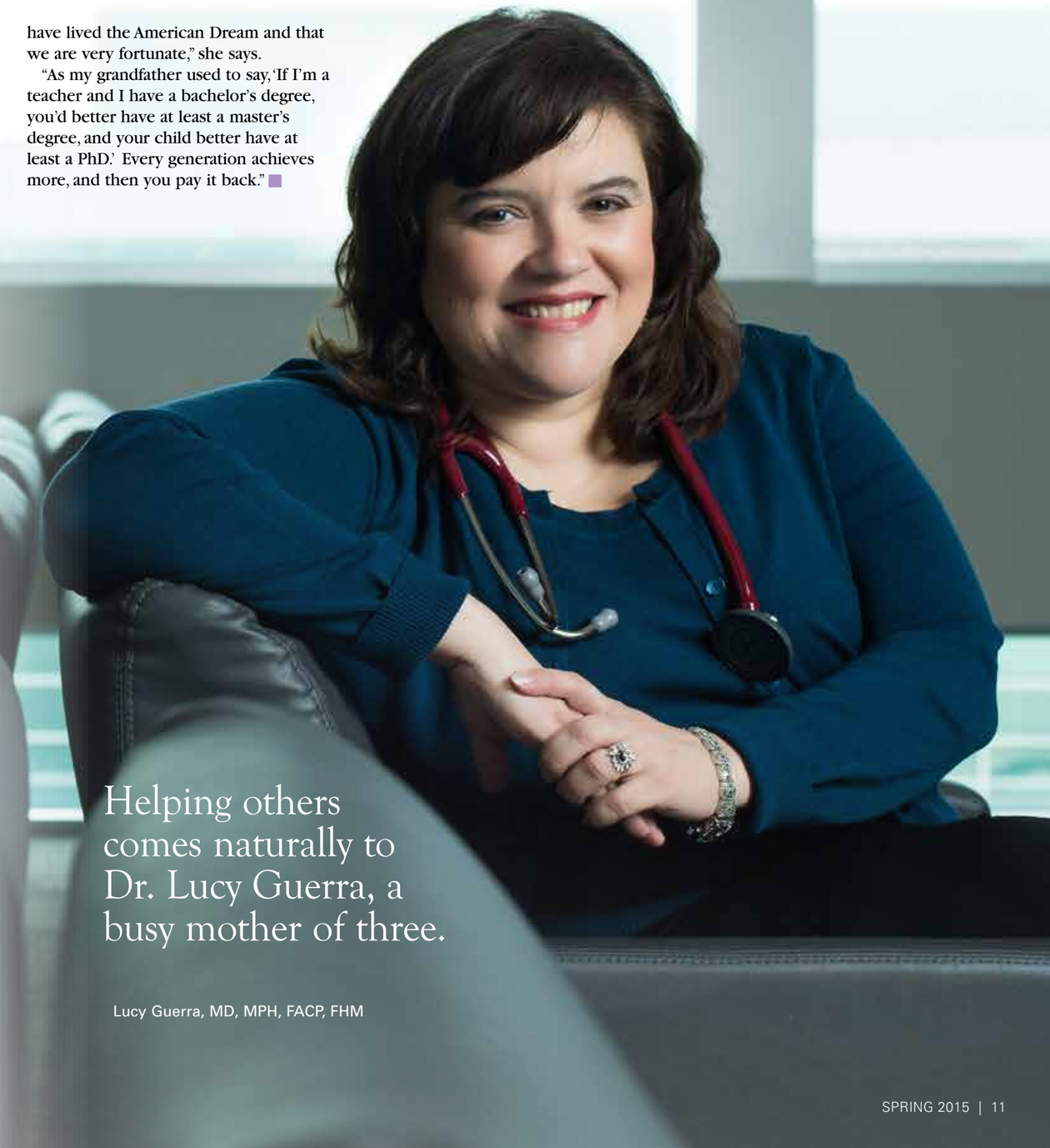
"That's what we're here to do, to pay back and serve others," she says.

Spending time with her family is also a priority. Guerra's husband, Dr. Francisco Machado, is also a physician (his practice is in Plant City, east of Tampa). Despite their demanding careers, they make time to attend baseball games and other outings with their 12-year-old sons and 10-year-old daughter.

Guerra's father, who is winding down his medical practice in Miami at the remarkable age of 81, is understandably proud of his daughter the doctor (as well as his other daughter, a professor of Latin American History at the University of Florida).

"He always reminds my sister and me that as first-generation Americans, we have lived the American Dream and that we are very fortunate," she says.

"As my grandfather used to say, 'If I'm a teacher and I have a bachelor's degree, you'd better have at least a master's degree, and your child better have at least a PhD.' Every generation achieves more, and then you pay it back." ■



Helping others comes naturally to Dr. Lucy Guerra, a busy mother of three.

Lucy Guerra, MD, MPH, FACP, FHM

PHOTO BY ALEX STAFFORD

There are many ways to join the fight against Alzheimer's

During or after their lifetime, donors are helping researchers at the USF Health Byrd Alzheimer's Institute look for ways to halt or reverse memory loss, which has become the most costly disease in the United States.

Some donors are gratified to see their gifts put to use immediately. Others know that through their estate planning, their bequests of stocks, life insurance policies, real estate or other assets will help scientists advance important research in years to come or help equip families to care for a loved one with the disease.

Their charitable acts often carry one or more ancillary benefits as well. Some arrangements may reduce a donor's income taxes, state taxes or estate taxes.

Talking with your financial planner may be the first step in supporting the Byrd Institute's mission to find a cure. Staff at the USF Foundation can also help ensure that every gift honors the donor's wishes.

The following table offers several ways to join the fight against Alzheimer's.

For more information about charitable giving, contact the USF Foundation Office of Gift Planning at (813) 974-8761, or visit the Foundation's gift planning page at usffoundation.planmylegacy.org. ■

WAYS TO GIVE	Description	Tax Benefits	Additional Benefits	Contribution Limits	Impact on Institute
Gift During Lifetime	Gifts of cash or donation of publicly traded securities.	Immediate income tax deduction. Avoid capital gains tax on donated shares of stock.	You can target current funding opportunities and see your gift in action.	None, although income tax deduction may be subject to limits.	Immediate.
Charitable Bequest	Name USF in your will or living trust to receive a portion of your estate.	Estate tax deduction for all funds left to charity.	You have full access to your funds for the rest of your life.	None.	At the end of the donor's life and after probate or trust administration (may be 9-15 months).
Retirement Plan	You can name USF as a beneficiary of your retirement plan (IRA, 401(k), 403(b), etc.).	Estate tax deduction for all funds left to charity. Charity receives all proceeds tax-free. Non-charity beneficiaries pay income tax.	Bypasses probate. You have full access to your funds for the rest of your life.	None.	Within weeks after death of last income beneficiary.
Charitable Gift Annuity	You agree to make a donation of cash or securities to USF. In return, you (and someone else, if you choose) receive a fixed amount each for the rest of your lifetime.	The initial gift is partially income tax-deductible. The annuity payments are partially income tax-free. Reduction of capital gains tax if appreciated securities are used.	Guaranteed income for you (and someone else, if you choose) for the rest of your lifetime.	None.	At the end of the annuitant(s) life.
Beneficiary Designation	You can name USF as a beneficiary of your life insurance policy, annuity, bank account or investment account.	Estate tax deduction for cash value amount. Removes asset from taxable estate.	Bypasses probate. You have full access to your funds for the rest of your life.	None.	Within weeks after your death.
Life Insurance	You make USF owner and beneficiary in an insurance policy.	Income tax deduction for cash value amount. Removes asset from taxable estate.	Bypasses probate. Arrange and fund a large future gift now.	None, but based on your ability to qualify for life insurance.	At the end of your life, or when the policy is surrendered.
Charitable Remainder Trust	Donate cash, stock or real estate to an irrevocable trust. Trust pays you for life, then the balance goes to USF.	Immediate tax deduction for a portion of the donation. Trust assets are not subject to estate tax. Estate tax (or gift tax) deduction based on value of charitable payouts.	Payouts to you (and others, if you choose) from the trust for life.	None.	Within weeks after your death.
Charitable Lead Trust	Donate cash, stock or real estate to an irrevocable trust that makes annual gifts to USF, then the balance goes to your heirs.	Income tax, estate tax, state tax or gift tax deduction based on value of charitable payouts.	Pass assets to heirs and avoid some or all of the estate tax.	None.	USF receives annual payouts until trust terminates.

Making sure everyone's included

Racial diversity is a prerequisite in the search for Alzheimer's drug breakthroughs.

Researchers testing the effectiveness of experimental drugs have to overcome several hurdles. They must carefully screen volunteers to make sure they qualify for the medical study, and they have to include a diverse sample of their community members in order for any conclusions to be valid.

No one knows that better than Jill Smith, who has been helping researchers test potential drugs to treat Alzheimer's disease and other dementias for nearly a decade.

Smith, the assistant director for clinical research at the USF Health Byrd Alzheimer's Institute in Tampa, frequently meets with community groups throughout the Tampa Bay area to boost minority participation in evaluating new drugs.

"I tell them that everybody could respond to treatments and medications differently depending on their age, their gender and possibly their ethnicity. Some studies even look at particular genes as a potential cause of differences in a participant's responses to treatment. So, as we're looking for new treatments and new options for Alzheimer's, we want to be sure that we're finding things that could help everyone," she says.

Four out of 10 Floridians are either African-American or Hispanic, and fewer than 3 percent are Asian, based on 2013 Census data. In a six-county region of the Tampa Bay area, the percentages of minorities are slightly lower.

Non-Hispanic whites have traditionally shown the greatest interest in participating in clinical trials at the Institute.

Alyssa Gamaldo, PhD, assistant professor at USF's School of Aging Studies, says there could be several reasons why minorities have been less likely to take part, including limited awareness of the research studies, being too busy to participate, and lacking convenient transportation to get to the research facility. Other factors may include being in denial about their failing memory, being fearful of the test procedures, and having an overall distrust of medical research stemming from previous studies which have mistreated minority participants, such as the Tuskegee syphilis experiment.

"The scientific research community has not been very successful in clearly communicating to minority populations from diverse religious, educational and income levels the purpose of the research and how their participation could improve our understanding of health issues," Gamaldo says.

Having too few of any group can delay experimental drug studies at any research facility, Smith explains. The National Institutes of Health, which funds many of the Alzheimer's studies nationwide, often requires the Byrd Institute to include 20 to 25 percent of racial minority participants in its clinical trials.

"If we're not meeting these recruitment efforts in a study, it has to stop enrolling until we can fulfill that requirement – and that just makes the research take that much longer," Smith says.

So Byrd officials are redoubling their efforts to include a cross-section of the communities they serve.

"It's not just that you're a minority and we want to include you," Smith says. "We want to include you the same way we want to include both men and women, people with different career and education backgrounds, and approximately equal numbers of people in their 60s and 70s and 80s."

The Institute is spreading the word through additional health fairs in minority communities and memory screenings in traditionally African-American churches. It also hopes to launch a traveling mobile unit later this year, "so that more people can access many of the same services offered at our clinic in the parking lot of their local hospital or a Wal-Mart," she says.

"Alzheimer's is a health care problem that is not going to go away," she adds. "We just want to find a cure as quickly as we can, and if one of the holdups is that we're not meeting these recruitment goals that are required as part of our research, we feel that's certainly something that can be overcome. And in the end, everyone benefits. We find new medications, and people find better access to care and treatment options." ■

Happy Together

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With her sister's help, Santana continues to visit the Institute periodically to be monitored while she takes part in the 18-month study to see if it improves her memory. Stergion, who lives in New Port Richey, northwest of Tampa, drives to her sister's house northeast of Tampa in San Antonio, then takes her to the research center about half an hour from Santana's home.

Participants in the investigational study don't know the name of the drug or whether they're getting the real thing or a placebo, but Santana is OK with that.

"It's a test and if it helps me, then it will help a lot of people," says the retired hairdresser and school bus aide from New York who moved to Florida nearly 10 years ago.

Santana says she has already benefited from the diagnosis, because she's begun using Exelon® patches that she feels make her more calm in situations that once made her upset or agitated.

Helping researchers find answers

Santana's participation is especially important to Byrd researchers because of her Puerto Rican heritage, as they strive to include more racially and ethnically diverse volunteers when testing drugs that appear to have potential benefits. The overwhelming percentage of study volunteers have traditionally been non-Hispanic whites.

"We want to be able to help everyone, not just people of a certain racial background or economic class," says Jill Smith, assistant director of clinical research at the Institute.

Alzheimer's researchers also face another uphill battle: Overcoming lagging financial support. The federal government has historically invested far more research dollars in cancer, AIDS and heart disease, even though the national cost of caring for Alzheimer's patients now outpaces costs associated with any other disease.

Santana and her sister have another important reason to help scientists unlock the mysteries of Alzheimer's. Their 73-year-old brother also has the disease, and they fear it may run in their family.

"May the Lord keep me, but who knows if I'll be one of those patients in the future," Stergion says.

She knows that Alzheimer's cuts across all races and income levels.

"I hope and pray that they [researchers] can do something to either heal the people or to help them in some other way," she says. "There are a lot of people out there who don't even know they have the beginning of this disease. That breaks my heart." ■

Is Alzheimer's Inherited?

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MZ: Are there situations where you would recommend genetic testing?

DM: It's an individual decision. Some people want to know. Others wish to remain ignorant. Right now I think it doesn't matter, and there is no real benefit to learning you are positive – other than perhaps accelerating your bucket list.

MZ: Aren't scientists finding that several other genes or genetic mutations may also play a role in developing Alzheimer's?

DM: A recent study that included over 20,000 DNA samples and surveyed the entire human DNA sequence identified about 20 genetic variants that seem to be associated with increased or decreased risk. While the "familial" genes all increase production of a material, known as amyloid, that accumulates in Alzheimer's patients, many of the other genes appear to increase inflammation in the brain.

MZ: Apart from heredity, what other factors are believed to play a role in Alzheimer's or other forms of dementia? Are there environmental or lifestyle factors as well?

DM: Two stand out consistently. Head injury increases risk. This can be a single severe event or frequent less-severe events. Boxing with an E4 variant in your DNA pretty much assures developing "dementia pugilistica."

Also, education level – the higher a person's education, the less likely he or she will develop Alzheimer's – appears to be protective, possibly because it increases reserve capacity in the brain.

Most important is a healthy lifestyle: diet, exercise and control of risk factors for other diseases, such as heart disease and diabetes. Healthy lifestyles reduce risk for many age-associated diseases, most likely because they slow the rate at which you age. They reduce heart disease, cancer, diabetes and Alzheimer's.

MZ: With more than 5 million Americans currently with Alzheimer's and those numbers expected to skyrocket in coming decades, which could bankrupt Medicare and Medicaid, why has identifying its causes and developing ways to cure or prevent it been so elusive?

DM: Part of the reason is the United States has not recognized the size of the problem and funded research adequately. Caring for Alzheimer's patients costs 30 percent more than cancer patients and the disease kills almost as many annually. Currently about 500,000 deaths each year are attributed to Alzheimer's, compared with 570,000 cancer-related deaths. Yet we spend $5 billion on cancer research and nearly 10 times less – $0.6 billion – on Alzheimer's. Heart disease receives about $3 billion in National Institutes of Health research dollars, as does HIV/AIDS.

Fewer than 10 percent of grants submitted for Alzheimer's research receive funding. Young scientists are leaving the field to go to work on other diseases. ■

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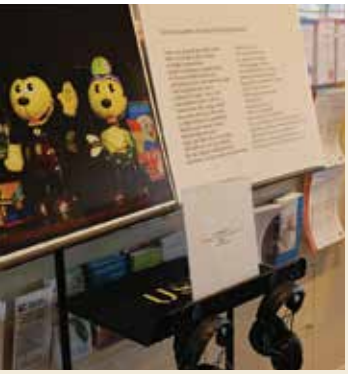

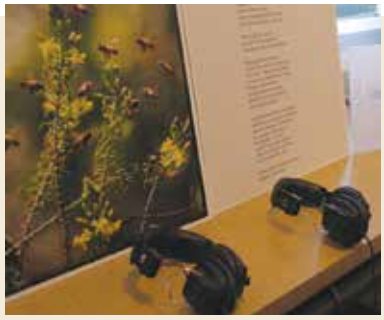

Multi-Media Exhibit Tells Story of Lost Memories

The Byrd Institute collaborated with local musicians from La Lucha jazz band to display SEE.HEAR.FEEL, a multi-media arts gallery-style exhibit featuring visual arts, poetry and music working together to tell the story of memories lost to Alzheimer's disease. The exhibit was available throughout December for patients and caregivers to enjoy during their visits to USF Health Byrd Alzheimer's CARE Center.

The exhibit presented eight collaborative art installations, which included photographs from Rossie Newson, poems by Gloria Muñoz and music by La Lucha, all aimed at bringing awareness to Alzheimer's disease. Attendees were provided with headphones at each station to enjoy the featured music.

NARFE Members Tour Byrd Institute

Members of the National Association of Retired Federal Employees (NARFE) District 6 toured the Byrd Alzheimer's Institute to learn about advancements in research and treatment for Alzheimer's disease and related disorders. Dr. Morgan presented information to 50 NARFE guests about current research and the importance of NARFE advocacy to federal legislators on the need for increased research funding for Alzheimer's disease. Founded in 1921, NARFE is dedicated to protecting and enhancing the benefits of federal employees and retirees.

World Alzheimer's Day

On World Alzheimer's Day, the faculty and staff at the USF Health Byrd Alzheimer's Institute wear purple to recognize millions of patients and caregivers affected by Alzheimer's disease. World Alzheimer's Day, recognized on September 21 of each year, was initiated by Alzheimer's Disease International in 1994.

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