

Alzheimer's

D I S E A S E C E N T E R N E W S

Volunteer couple pitches in on Alzheimer's



PHOTO BY JUNEBUG CLARK

Bill and Samra Bufkins

Literally hundreds of charitable institutions have benefitted from Bill and Samra Bufkins' generosity.

But Alzheimer's disease-related causes came to the top of the Denton couple's list two years ago when Bill was diagnosed with early onset Alzheimer's disease.

Bill, 65, formerly a human resources professional, has served as a docent at the Houston Museum of Fine Arts, been involved in the Knights of Columbus, and worked with the United Way in Houston and Dallas. Samra ("Sam"), a lecturer in Public Relations at the University of North Texas, has volunteered at the Houston and Fort Worth Zoos, is a member of the Citizen's Advisory Panel for the Denton County Transportation Authority, and assigns her public relations students to take on a project with charitable

organizations, at least 300 groups in total to date. Both volunteer at their church and sing in the choir, and have many other volunteer achievements, including working in an expatriate theater troupe while living in Saudi Arabia.

Like many spouses and family members, Sam saw the signs of Alzheimer's disease years ago. But she blamed the forgetfulness, lack of concentration, and other symptoms on side effects from other prescribed medications.

The shock came when she returned from a volunteer mission trip to Guatemala. Bill was supposed to pick her up at the airport upon arrival; he was late, and blamed it on forgetting his cell phone. Sam fell asleep on the ride from Dallas/Fort Worth International Airport to their home in Denton, and was shocked

to wake up in a shopping center parking lot in Frisco, nowhere on the planned route.

When Bill went in for a physical, he forgot to tell Dr. Elizabeth Seymour, their family physician, about getting lost and his forgetfulness, so Sam emailed her, and got a reply within the hour. Dr. Seymour referred Bill to Dr. Mary Quiceno, Assistant Professor of Neurology and Neurotherapeutics at UT Southwestern Medical Center. The diagnosis: mild to moderate cognitive impairment, and early onset Alzheimer's disease.

Sam praised the outstanding care Dr. Quiceno has given Bill, but was quick to note Dr. Robert Ruchinkas, Associate Professor, Psychiatry, Neurology & Neurotherapeutics, for the way he helped her accept the role of caregiver and all it implies.

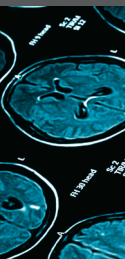
Bill and Samra continue to volunteer.

"Volunteer work has been our life's work for 30 years or more," said Samra. "It has enhanced our

Continued on page 3 »

WHAT'S INSIDE

- Spring Forum March 25
page 2
- Meet Sarah Losinger
page 7



SPRING FORUM:

The prion principle: possibilities in the next decade

Dr. Marc Diamond, Professor of Neurology & Neurotherapeutics, is UT Southwestern Medical Center's newest research gem.

Recruited to UT Southwestern last year to head the new Center for Alzheimer's and Neurodegenerative Diseases, Dr. Diamond will address the Spring Public Forum, March 25. The presentation begins at 7 p.m. in the Simmons/Hamon Biomedical Research Building, 6000 Harry Hines Blvd. Reservations are available by emailing rsvp.utsouthwestern.edu or by calling 214-648-2344.

His idea about the way accumulations of tau and other proteins spread pathology in the brain and throughout the nervous system is considered by many to be the future of neurodegenerative disease research, and hopefully will lead to new therapies to treat or prevent Alzheimer's disease.

Dr. Diamond's big idea is that toxic proteins that accumulate in neurodegenerative diseases move from cell to cell through the brain, leaving destruction in their wake. This is also thought to be how prions cause disease.

"I started wondering about a simple question: Why are these diseases progressive? Why don't they just stop with one part of your brain? That was spurred by knowledge I had about Lou Gehrig's disease, in which progressive pathology has a clear anatomical relationship. Motor neurons begin to degenerate in part of your spinal cord to start the process, but the next neurons to go are the ones that are right nearby, geographically very close to the original sick cells, or connected to them

by synapses," said Dr. Diamond.

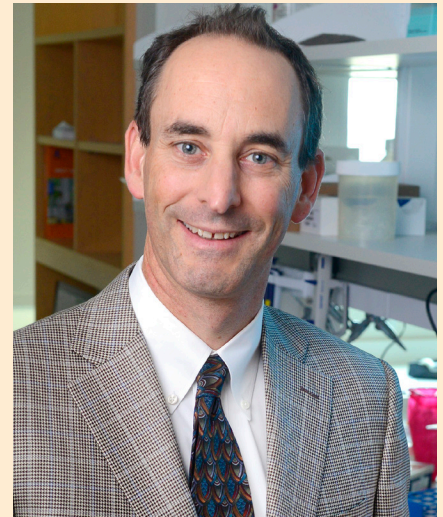
"In prion diseases, we think pathology begins in one cell with the formation of a toxic assembly, or clump of proteins. Then it moves to another cell and triggers more toxic assemblies. These clumps act something like crystal seeds, causing more protein to pile on and become abnormal," Dr. Diamond said.

Dr. Diamond realized that the pattern of disease spread throughout the brain in prion diseases looked strikingly similar to the pattern of disease spread in common neurodegenerative diseases like Alzheimer's and Parkinson's, making him wonder if they had the same underlying mechanism.

"I wasn't the first one to think of this, but what we did that other people hadn't done was start testing this idea directly in a simple, well-controlled way. In parallel with one other group, which at the same time published studies in mice, we did a series of very straightforward cell experiments that started this whole avenue of investigation that we've been working on for the last 10 years. The idea has caught on and since then a lot of people have replicated our basic experiments," he said.

Dr. Diamond's lab worked primarily with the protein tau, which accumulates in Alzheimer's disease. Others have studied synuclein, a protein that accumulates in Parkinson's disease, and still others have studied proteins that accumulate in ALS and frontotemporal dementia.

"All of a sudden now we can start to unify how we think about all of these different disorders based



Dr. Marc Diamond

on the simple idea that toxic protein aggregates, or seeds, are moving from cell to cell in the brain," said Dr. Diamond.

Perhaps even more important, this idea suggests approaches to halting the progression of Alzheimer's disease, using drugs such as antibodies or small molecules that will attack the protein seeds while they are between cells. It also suggests that detection of the seeds could lead to very early diagnosis.

"My dream, actually, where I'm hoping we'll go with all this, is that you or I will come into a doctor's office when we're 35 or 40 and they'll take a drop of blood or a little spinal fluid and run a test on it for seeds for all these different proteins that cause all the common diseases. Then the doctor will tell you whether or not you have them. And if you do, a treatment will be started before you even show any signs of disease. I don't think that's unreasonable. I think we could get there in the next 10 to 15 years," said Dr. Diamond. *

FROM THE DIRECTOR |

Roger N. Rosenberg, M.D.

At the UT Southwestern Alzheimer's Disease Center, we so greatly rely on your help and financial assistance, but it's heartening to note that others in our state and nation are recognizing the need to pick up the pace of research to end this dreaded disease.

First, the Darrel K Royal Research Fund for Alzheimer's Disease has recognized the work of three of our doctors here at UT Southwestern with significant financial support. Dr. Murat Durakoglugil, Assistant Professor of Molecular Genetics; Dr. Steven Patrie, Assistant Professor of Pathology and John L. Roach Scholar in Biomedical Research; and Dr. Florian Plattner, Instructor in the Department of Psychiatry were recipients of grants from the DKR Fund to support their work on Alzheimer's disease here at UT Southwestern. (Dr. Patrie and Dr. Plattner were recipients of your 2013 and 2014 research grants respectively.)

Rita Hortenstine, one of our friends' steering committee members, also is deeply involved with the DKR Fund, and we deeply appreciate her work with both organizations.

On a local level, I'm thrilled to tell you about a generous commitment of \$1.25 million from the Presbyterian Village North Founda-

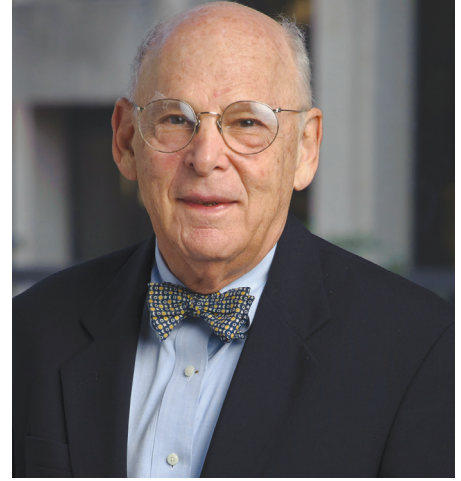
tion to further UT Southwestern's work into Alzheimer's disease. Their generous gift will support research on the development of the DNA A beta 42 vaccine to delay or prevent Alzheimer's disease, as well as establish the Presbyterian Village North Foundation Distinguished Chair in Alzheimer's Disease Therapeutic Research. We truly appreciate their support.

Meanwhile, on a national level, in a bi-partisan effort, Congress passed the Alzheimer's Accountability Act. This legislation is an extension of the National Alzheimer's Project Act, passed earlier last year.

The National Institutes of Health (NIH) has established a goal of eliminating Alzheimer's disease by 2025. To reach that goal, the NIH has established research milestones and timelines. But what the NIH has not established is the level of funding necessary to reach them.

The Alzheimer's Accountability Act requires the scientists at the NIH to submit an annual Alzheimer's research budget proposal directly to Congress, specifying the resources needed. That way, Congress will know what the scientists need.

Each year, the budget should include expected outcomes, as well as recommendations for what holds the highest priority and how to coordinate all funding for research,



education, and Alzheimer's services. Congress has acknowledged that it will trust scientific judgment over political needs to help make these decisions.

We pledge to do our best to find cures and preventatives to Alzheimer's disease, but we must ask you for your continuing help in reaching this goal. Today, some 5 million Americans suffer from Alzheimer's disease, and if we don't succeed in our quest, the Alzheimer's Association predicts that by 2050 that number will grow to 16 million.

In addition to the human toll of the disease, care for patients with Alzheimer's disease, the country's most expensive condition, cost the nation \$214 billion in 2014 with projections reaching \$1.2 trillion by 2050. Nearly one in five dollars spent by Medicare is on someone with Alzheimer's or another dementia.

This is a national priority both financially and on a very personal level.

Thank you for your continued support. *

BUFKINS

Continued from page 1

work life and our social life as much as it's helped others. I started volunteering with the Alzheimer's Association because of how much they've helped me deal with the upheaval this disease has caused in our life. I can't give them money, but I can give them time.

"I'm particularly interested in seeing more attention given to those with younger-onset Alzheimer's disease, because it's overlooked in so many cases. I now realize these symptoms were coming on at least eight years ago, and maybe if we'd have had a clue then we'd be in

better financial shape now. People need to plan when this disease takes over their lives."

The Bufkins have modified their lives. Both wear Safe Return bracelets, Bill in case he should get lost (he's given up driving,) and Sam in the event that an accident should happen and prevent her from caring for Bill.

But they haven't given up physical exercise and volunteering. While they have done 10 MS Bike Tours, including the one from Houston to Austin, they plan to buy a tandem bike and resume touring this spring.

The tandem bike and their love will help keep them together. *

Fall Friends Forum

FALL SPEAKER TELLS HEART-RENDING STORY OF GRANDFATHER'S DISEASE



Dr. Roger Rosenberg and Dr. Randall Bateman

Dr. Randall Bateman told a story at the Fall Forum that the Friends of the Alzheimer's Disease Center didn't expect: a love story.

Dr. Bateman, Professor of Neurology at Washington University School of Medicine in St. Louis and one of the leading Alzheimer's disease researchers in the nation, told his own heartbreaking tale of his grandfather's Alzheimer's disease.

"Grandad was the most amazing man I ever met," said Dr. Bateman with deep affection. Dr. Bateman described him as a vibrant, hard-working oil field worker from Texas, a dedicated WWII veteran, and eventually a successful real estate developer in Oklahoma who worked seven days a week for decades.

"I often called him for advice in my personal life, social life, and professional life," recalled Dr. Bateman. "He always steered me right. When he was going to be

80 years old, he called me up, and said, 'Grandson, I want to go skydiving. And you're going with me.'

"Grandad, you're 80 years old, and your life expectancy is not the same as mine,' I said. 'I've got a little more to lose.' It turned out he was right, jumping out of an airplane is not certain death, and we had a great time."

For years thereafter, Dr. Bateman and his grandfather celebrated Grandad's birthday by going skydiving together, and clearly, they relished every minute.

But as he aged into his mid-80s, his grandfather began complaining of a failing memory, and was diagnosed with the early stages of Alzheimer's disease.

"For the first time in my life I saw him get depressed," said Dr. Bateman. "It was shocking. He wasn't positive, he wasn't proactive, he wasn't looking forward to life."

But one thing he did do was to

dedicate himself to participating in Alzheimer's research.

"Grandad hated doctors, he never went to see doctors," Dr. Bateman mused. "He only put up with me because I was his grandson. But he was convinced that this was a disease that had to be beaten, and the only way to beat it was with research, and he regularly came in to participate in the various studies we were doing."

Dr. Bateman had already begun his career in researching Alzheimer's disease, and his grandfather's challenges and efforts sustained his professional quest.

Dr. Bateman reported on the progress of the Dominantly Inherited Alzheimer Network, which is studying a rare, dominantly inherited genetic mutation. Children of individuals who carry one of these genetic mutations have a 50 percent chance of inheriting the mutation and subsequently developing Alzheimer's disease. Carriers of this mutation have a young-onset version of the disease, with symptoms beginning as early as the 30s.

The Network is currently launching the first clinical trial aimed at preventing onset of memory impairment and dementia.

The focus of the trial is to treat the disease at its earlier stages, sometimes even before symptoms start.

"We hope to demonstrate that we are able to prevent Alzheimer's disease in the people who have the highest risk, which may pave the way for future prevention trials," said Dr. Bateman. ❄

Friends get a peek at ADC labs

Friends of the Alzheimer’s Disease Center recently took the opportunity to tour the laboratories of Dr. Ryan Hibbs, Assistant Professor of Neuroscience and Biophysics, Dr. Ryan Huebinger, Instructor in the Department of Surgery, and Dr. Florian Plattner, Instructor in the Department of Psychiatry. Each of these researchers received a \$65,000 grant from the Friends. The researchers showed the Friends early results of their work, and took questions from the guests. ❄



Dr. Florian Plattner



Dr. Ryan Hibbs

Dr. Rosenberg, Dr. Pascual produce landmark volume

Dr. Roger Rosenberg and Dr. Juan Pascual have completed three years of work in editing and revising *Rosenberg’s Molecular and Genetic Basis of Neurologic and Psychiatric Disease*.

Initiated 20 years ago by Dr. Rosenberg, the work has become a hallmark in the field of neurogenetics. This marks the fifth edition of the volume. Dr. Rosenberg is the Director of the Alzheimer’s Disease Center and Professor of Neurology & Neurotherapeutics, and Physiology, and Dr. Pascual, who joins him as co-editor of this edition, is the Director of the Rare Brain Disorders Program and Associate Professor of Neurology & Neurotherapeutics, Physiology, and Pediatrics, and is also at the Eugene McDermott Center for Human Growth & Development.

At nearly 1,500 pages, and written by 250 experts from around the world, *Rosenberg’s Molecular and Genetic Basis of Neurologic and Psychiatric Disease* provides a comprehensive introduction and reference to the foundations and key practical aspects relevant to the majority of neurologic and psychiatric disease.

The work has received kudos from the field.

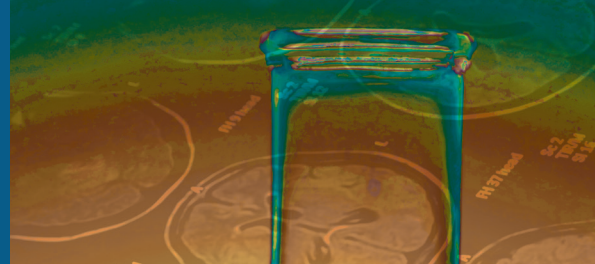
“Genetics and genomics have changed the practice of neurology and will continue to have huge impact on every discipline of medicine,” wrote Dr. Daniel Geschwind, Professor of Neurology, Psychiatry and Biobehavioral Sciences, and Director of the Center for Autism Research and Treatment, Semel Institute, University of California, Los Angeles. “In this fifth edition of the “bible” of Neurogenetics, Dr. Rosenberg and Dr. Pascual have done a remarkable job in leading the assembly of a volume that is truly representative of this rapidly advancing field. More than half of the chapters are new since the last edition.”

Publisher Academic Press calls it “a favorite of over three generations of students, clinicians and scholars” and “an essential reference for general medical practitioners, neurologists, psychiatrists, geneticists, and related professionals, and for the neuroscience and neurology research community.” ❄

Dr. Rosenberg holds The Abe (Brunky), Morris and William Zale Distinguished Chair in Neurology.

Dr. Pascual holds The Once Upon a Time Foundation Professorship in Pediatric Neurologic Diseases.

Research Studies



OBSERVATIONAL AND BIOMARKER DEVELOPMENT

While these studies do not require or offer a new treatment, they are the foundation for future research and therapeutic trials.

CORE AND TARCC RESEARCH STUDIES

People with no memory complaint, mild cognitive impairment, or early Alzheimer's disease are needed for observational studies. The studies usually involve one visit a year for neuropsychological testing, neurological exams, brain imaging, and blood sampling. The data collected from these visits are used by many investigators studying the aging brain and disorders of cognitive function. These visits may involve financial compensation. Call Sarah Brisebois, 214-648-0563, for more information.

LOAD (LATE-ONSET ALZHEIMER'S DISEASE) GENETICS INITIATIVE

The LOAD study began enrolling subjects in 2002. A new grant, based on previous findings from that study, is facilitating a phone follow-up for subjects from the first study as well as enrolling new subjects.

The goal of this national study is to expand upon the scope of data gathered from subjects already enrolled in the first phase of LOAD, as well as to enroll new large families (with three

or more living siblings age 60 or older) diagnosed with Alzheimer's disease. The focus is to learn more about the genetic, environmental, and health risks that may contribute to the development of Alzheimer's. For all subjects previously enrolled in the LOAD study, the coordinator will call each person for phone follow-up only. New subjects from previously participating families who are now age 60 or older may also enroll in this study. Call Barb Davis, 214-648-9367, for more information. ✱

CLINICAL TRIALS

EFFECT OF PASSIVE IMMUNIZATION ON THE PROGRESSION OF MILD ALZHEIMER'S DISEASE – SOLANEZUMAB VERSUS PLACEBO

This clinical trial is for individuals aged 55–90 with mild Alzheimer's disease (AD) and will examine the investigational drug Solanezumab. Solanezumab is being studied as a neuroprotective agent for persons with Alzheimer's; this trial aims to test whether Solanezumab will slow the cognitive and functional decline of AD as compared with placebo. The study will last for 18 months, and participants will be assigned at random to receive the investigational drug or a placebo and will be monitored over that period. Contact Kathy Koch, 214-648-9343, for more information.

A4 – ANTI-AMYLOID TREATMENT IN ASYMPTOMATIC AD

The A4 study is for individuals aged 65–85 who have normal thinking and memory function but who have evidence of amyloid plaque build-up in their brains

and who may be at risk for developing Alzheimer's-related memory loss in the future. A4 is a ground-breaking trial that will test an anti-amyloid investigational drug in older individuals who do not yet show symptoms of Alzheimer's disease cognitive impairment or dementia with the aim of delaying or preventing memory and cognitive decline. Please call Kathy Koch, 214-648-9343, for more details.

COGNITIVE TRAINING FOR MILD MEMORY COMPLAINTS

People age 60 or older who are in overall good health but who are noticing more “senior moments” or have been diagnosed with mild cognitive impairment are needed for a study evaluating the effects of cognitive training on brain function. A brief cognitive screening will be given to determine eligibility for the study. Those who qualify will receive eight cognitive training sessions, study-related assessments, an electroencephalogram to measure brain waves, and follow-up testing. For more information,

call Audette Rackley, 214-905-3007.

COMING SOON

SNIFF – STUDY OF NASAL INSULIN TO FIGHT FORGETFULNESS

The SNIFF Study, or Study of Nasal Insulin to Fight Forgetfulness, will be a clinical study for participants aged 55–85 with amnesic-MCI or mild Alzheimer's disease who do not take drugs for diabetes (type I or II). The purpose of the SNIFF study will be to find out whether a type of insulin, when administered as a nasal spray, improves memory in adults with a mild memory impairment or Alzheimer's disease. Growing evidence suggests that insulin carries out multiple functions in the brain and that poor regulation of insulin may contribute to the development of Alzheimer's disease. Insulin resistance, reduced cerebrospinal fluid insulin levels, and reduced brain insulin signals have been found in Alzheimer's

Continued on page 7

MEET A FRIEND | Sarah Losinger

Q: Why did you join the Friends of the Alzheimer's Disease Center?

A: My mother had Alzheimer's disease and I wanted to learn everything I could about the disease. I wanted to hear the latest developments being made toward understanding the disease and toward a cure. The Friends' forums host top Alzheimer's researchers from all over the country, so the Friends group has the opportunity to hear the latest from the research world.

Q: What achievement of the Friends has made you most proud?

A: I am impressed that the Friends' membership dues go to promising research that has been vetted by peers and committees at UTSW. I'm proud that the number of grants funded has been increasing over the past years.

Q: What would you say to inspire others to join the Friends?

A: I would say that being a part of the Friends is a great way to fund research in a more personal way. The forums that happen twice a year often have a Friends-funded researcher discussing his or her project. The research ideas are so interesting and educational. It's a very up close and personal way to learn about what's happening in Alzheimer's research and to be an essential part of each of the research projects. The more members that we have, the more projects can be funded.

Q: Outside of finding a cure for Alzheimer's disease, what are your interests and passions?

A: I have a special heart for children and I love being out in the community visiting non-profits that are addressing needs and helping those in our city. I also like to take long walks and spend time with my family. ❄



Sarah Losinger

BvB Dallas tackles Alzheimer's disease



BvB Dallas, a powder-puff football game held last fall at the Dallas Cotton Bowl, benefitted the UT Southwestern Alzheimer's Disease Center and the Center for BrainHealth at the University of Texas at Dallas. ❄

From left: Kimber Hartmann, Development Director for the Center for BrainHealth; Greer Fulton, 2014 BvB Dallas event chair; Jennifer Bergman, BvB co-chair; Dr. Mark Goldberg, UT Southwestern's Chairman of Neurology & Neurotherapeutics, and Linda and Mitch Hart Distinguished Chair in Neurology; and Carol Hall, UT Southwestern Director of Development.

CLINICAL TRIALS

Continued from page 6

patients, suggesting that a therapy aimed at correcting these deficiencies may be beneficial. Although this study

is not open to enrollment yet, please check our website for updates (www.utsouthwestern.edu/adc), as well as

www.clinicaltrials.gov (search identifier NCT01767909) or call Zohre German, 214-648-2952, for more information. ❄

NEW studies are being considered for 2015, please check our website (www.utsouthwestern.edu/adc) for updates on current studies available or call 214-648-0563 for more information.

Join Us

SUPPORT THE QUEST FOR
PREVENTION, TREATMENT,
AND A CURE



JOIN THE FRIENDS OF THE ALZHEIMER'S DISEASE CENTER

The Friends of the Alzheimer's Disease Center provide crucial support to UT Southwestern Medical Center's most promising and passionate researchers working to unlock the mysteries of Alzheimer's disease.

In addition to funding research through generous annual grants, the Friends sponsor a community-wide public forum every fall and spring, where the latest breakthroughs and best information on Alzheimer's disease are presented by leading experts from UT Southwestern and major medical centers nationwide.

Membership begins at \$500 per year, per individual or couple. Your donation is tax deductible and truly makes a difference in the fight against Alzheimer's disease.

To join the Friends of the Alzheimer's Disease Center, call 214-648-2344. Your support safeguards vital research into enhancing quality of life through early detection and improving the lives of patients and their families who live courageously each day with Alzheimer's disease.

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